Whānau experiences and persistence of healthy lifestyle change in a family-based, multidisciplinary programme for children and adolescents

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in Health Sciences, the University of Auckland, 2020.

Abstract

Aim: Family-based multidisciplinary interventions are recommended as best practice for addressing obesity in children/adolescents. However, engagement and retention in intervention programmes is challenging, and there is a lack of long-term follow-up to assess persistence of healthy lifestyle changes in real-world settings. The aim of this thesis was firstly, to understand the barriers and facilitators for participants and their families to engagement in Whānau Pakari, a family-based multidisciplinary healthy lifestyle programme in New Zealand, and secondly, to assess the persistence of healthy lifestyle change five years post-intervention.

Methods: A multiple-methods approach was undertaken, underpinned by Kaupapa Māori theory principles and a critical application of the biomedical scientific method. Past participants of Whānau Pakari were surveyed to determine initial factors that served as barriers or facilitators of attendance. In-depth interviews were conducted with past participants and their families, with varying levels of attendance. A follow-up study post-randomised clinical trial of past participants in Whānau Pakari was undertaken at five years post-initiation to determine the persistence of change over time.

Results: The interviews indicated that engagement with Whānau Pakari was affected by barriers including adverse life stressors and socioeconomic deprivation, societal norms of weight and body size and historical experiences of healthcare, including weight stigma and racism. Compassionate, respectful care mitigated these negative experiences and facilitated further engagement. The health system itself presented further barriers to access. Longitudinal outcome data to five years showed that the BMI SDS reduction observed at 12 months was not retained at five years. There were sustained improvements in secondary outcomes such as water intake and health-related quality of life.

Conclusions: Multiple upstream factors external to the service affect participants' ability to engage with the programme. The health system's relative inaccessibility also impedes health outcomes for those most affected by childhood obesity. While Whānau Pakari achieved improvements on multiple outcome measures, more intensive intervention may be required for persistent long-term improvements in health outcomes, alongside coordinated prevention efforts to minimise the effect of the obesogenic environment. Evaluation of multidisciplinary healthy lifestyle programmes needs to consider more than efficacy trials predominantly focused on BMI SDS to determine success.

Acknowledgements

This thesis represents a journey walked with many colleagues, friends and family. Undertaking this PhD in Taranaki has been challenging at times, but immensely rewarding. I am grateful to have had the opportunity to be taught and inspired by exceptional and kind people.

Dr Yvonne Anderson, primary supervisor: Thank you for challenging me, believing in me and inspiring me with your vision. I am so grateful for your constant support, kindness, encouragement and confidence. Thank you for supporting me as a researcher and friend.

Professor Paul Hofman, co-supervisor: Thank you for your patience and support throughout this journey, for being so open to new ideas and for keeping me focused on what is most important. Your wisdom and humour are always appreciated!

Dr Esther Willing, co-supervisor: Thank you for your advice, guidance and support, especially as we navigated the interview process. I have really appreciated your constant enthusiasm and insights into the ups and downs of the PhD process.

Dr Donna Cormack, co-supervisor: I have learned so much from you and really cherish my time in your classes. Thank you for being so willing to step in and support this research. I am very grateful for your expertise and for challenging me to think critically.

Dr José Derraik, advisor: thank you always for your statistical support, but more importantly your patience and kindness. I have really enjoyed working with you.

There are many other people who contributed to this work and research journey. Thank you especially to Ngauru Rawiri, for pouring so much time and energy into this research journey with me. I am grateful for your friendship, partnership, and trust during the research process and the valuable perspective and contributions you brought to this work. Tami Cave: Thank you for teaching me so much from the very beginning! I am so grateful to have worked with you over the years and to have shared your passion and commitment. Dr Arier Lee, Associate Professor Trecia Wouldes and Professor Chris Triggs: Thank you for your statistical support and guidance at various stages of the research process. Also, many thanks to Professor Cameron Grant: I am grateful for your ongoing support, encouragement and guidance over the past few years.

The Whānau Pakari clinical team: Lisa Wynter, Kate Treves, Kayla Jones, Niamh McCormack (née O'Sullivan). Thank you for sharing your time, expertise and guidance. Thank you also to the Liggins Institute professional staff in Auckland who have assisted behind the scenes so patiently, and to Jane Burnett for your assistance in the final stages with proofreading. Thank you also to Andrew Lynch, Stephanie Garratt, Jason Zhou, Carl Webber, and Cecilia Wong, for your friendship and solidarity through the writing journey!

Thank-you to the funders of this work, who are listed on page ix. I am especially grateful for being a recipient of the Agnes Paykel PhD Scholarship which allowed me financial support over the past three years.

I am part of a community that is curious about the world and values kindness and compassion, and I am grateful for the support of all my family and friends. Special thanks always to Fraser, Pauline, Richard, Cavaan, and Marilyn for your patience, encouragement, and love.

Finally, thank you to the Whānau Pakari participants and their families for sharing their time and stories so generously. I am extremely privileged to be able to contribute to child health research in Taranaki.

Publications and presentations

Publications

Wild CEK, O'Sullivan NA, Lee AC, et al. Survey of Barriers and Facilitators to Engagement in a Multidisciplinary Healthy Lifestyles Program for Children. Journal of Nutrition Education and Behavior. 2019;In Press.

Wild CE, Rawiri N, Willing EJ, et al. Determining barriers and facilitators to engagement for families in a family-based multidisciplinary healthy lifestyles intervention for children and adolescents. Submitted paper. Forthcoming 2020.

Wild CEK, Rawiri NT, Willing EJ, et al. What affects programme engagement for Māori families? A qualitative study of a family-based, multidisciplinary healthy lifestyle programme for children and adolescents. Submitted paper. Forthcoming 2020.

Wild CEK, Rawiri NT, Willing EJ, et al. Health system barriers to accessing care for children with weight issues in New Zealand. Submitted paper. Forthcoming 2020.

Wild CEK, Rawiri NT, Willing EJ, et al. Challenges of making healthy lifestyle changes for families in Aotearoa/New Zealand. Submitted paper. Forthcoming 2020.

Wild CEK, Rawiri NT, Cormack DM, et al. A collaborative Indigenous – non-Indigenous partnership approach to understanding participant experiences of a community-based healthy lifestyles programme. Submitted paper. Forthcoming 2020.

Wild CEK, Wynter LE, Triggs CM, et al. Five-year follow-up of a family-based multidisciplinary assessment and intervention for children and adolescents with weight issues – a post-RCT analysis. Submitted paper. Forthcoming 2020.

Presentations

Only includes peer-reviewed conference presentations.

Understanding barriers and facilitators to engagement in a multidisciplinary service for childhood obesity. Oral presentation, Best Abstract award. 11th Health Services and Policy Research Conference, December 4-6, 2019. Auckland, New Zealand.

Understanding barriers and facilitators to engagement in a multidisciplinary paediatric intervention programme for obesity. Oral presentation, ECR Public Health award. ANZOS-ASLM-ICCR conference, October 16-18, 2019. Sydney, Australia.

Understanding facilitators and barriers to engagement in Whānau Pakari: a family-based, multidisciplinary programme for children and adolescents. Oral presentation. Activity and Nutrition Aotearoa conference, May 22-23, 2019. Auckland, New Zealand.

Understanding facilitators and barriers to engagement in Whānau Pakari: a family-based, multidisciplinary programme for children and adolescents. Oral presentation. 23rd IUHPE World Conference on Health Promotion, April 7-11, 2019. Rotorua, New Zealand.

Understanding facilitators and barriers to engagement in Whānau Pakari: a family-based, multidisciplinary programme for children and adolescents. Oral presentation. New Investigator Award nominee, Paediatric Society of New Zealand ASM, November 6-8, 2018. Nelson, New Zealand.

Barriers and facilitators to attendance, retention and engagement in Whānau Pakari: a multidisciplinary intervention programme for children and adolescents with obesity. Poster. ANZOS-MDO Joint Conference, October 16-18, 2017. Melbourne, Australia.

Whānau Pakari: healthy, self-assured whānau that are fully active. 3MT competition. HSRAANZ 10th Health Services and Policy Research Conference, November 1-3, 2017. Surfers Paradise, Australia.

Funding

2016	Cure Kids project grant ($105,996.00)
	Primary Investigator: Professor Paul Hofman
2016	Maurice and Phyllis Paykel Trust project award ($12,000.00)
	Primary Investigator: Dr Yvonne Anderson
2017	Agnes Paykel PhD Scholarship ($104,000.00)
2017	A Better Start National Science Challenge/Cure Kids ($114,990.00)
	Primary Investigator: Dr Yvonne Anderson
2019	Faculty of Medical and Health Sciences Postgraduate Student Association travel grant ($250.00)
2019	Maurice and Phyllis Paykel Trust PhD travel award ($2000.00)

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Abbreviations

ALT	Alanine transaminase
AST	Aspartate aminotransferase
B4SC	Before Schools Check
BMI	Body mass index
CBCL	(Achenbach) Child Behaviour Checklist
CDQ	Children’s Dietary Questionnaire
CI	Confidence interval
C-PAQ	Children’s Physical Activity Questionnaire
CRP	C-reactive protein
DHB	District Health Board
GGT	Gamma-glutamyl transferase
GRx	Green Prescription
GRxAF	Green Prescription Active Families
HbA1c	Glycated haemoglobin
HDL-C	High-density lipoprotein-cholesterol
HRQOL	Health-related quality of life
IOTF	International Obesity Task Force

LDL-C	Low-density lipoprotein-cholesterol
MDT	Multidisciplinary team
NZ	New Zealand
NZE	New Zealand European
NZHS	New Zealand Health Survey
OECD	Organisation for Economic Cooperation and Development
PedsQL	Paediatric quality of life
RCT	Randomised clinical trial
SDS	Standard deviation score
UK	United Kingdom
US	United States
WHO	World Health Organization
YSR	Youth self-report

1 Introduction

Obesity is associated with substantial morbidity, mortality and health cost.[1, 2] The high prevalence of obesity globally and the impact on health is widely considered to be one of the greatest challenges of the 21st century. Rapid increases in the proportion of the population that is overweight and obese are now apparent in children as well as adults in both developed and developing countries.[3, 4] Obesity in adolescence is associated with a five times higher risk of mortality from coronary heart disease over the next forty years when compared with normal weight peers.[5]

The burden of obesity is not equally distributed, with significant inequities between and within countries. Rates of obesity are inequitable across different ethnicities and socioeconomic status. Indigenous peoples, in particular, experience disproportionately high rates of obesity and related comorbidities such as diabetes and cardiovascular disease.[6, 7] Additionally, there are disparities in terms of exposures to obesogenic environments, healthcare delivery due to reduced access and engagement with services, and lower retention rates in obesity management programmes.[8]

International conventions and agreements stipulate that Indigenous peoples have the same rights as other global citizens, including the right to health.[9] This is also the case in Aotearoa/New Zealand (henceforth referred to as New Zealand), where the Treaty of Waitangi guarantees equal rights for Māori, New Zealand’s Indigenous population.

New Zealand has the second-highest rate of childhood overweight and obesity in the Organisation for Economic Co-operation and Development (OECD),[10] with 11% of children experiencing obesity.[11] This has increased gradually over the past ten years, and childhood obesity rates remain highest for Māori and Pacific Peoples and those residing in the most deprived areas.[11] In addition to prevention efforts, the World Health Organization (WHO), recommends family-based, multicomponent programmes to address childhood obesity and its associated comorbidities, based on current evidence and best practice.[12]

1.1 Rationale and thesis context

Whānau Pakari is a multidisciplinary, healthy lifestyle intervention programme for children, adolescents and their families based in Taranaki, New Zealand. It is a whānau- (family) based programme which was developed to address high rates of childhood obesity in the region.[13] The results of the 12-month randomised clinical trial (RCT) showed that the programme achieved a modest body mass index (BMI) standard deviation score (SDS) reduction of approximately 0.1 in both treatment arms.[14] This reduction was doubled if participants attended at least 70% of the weekly sessions as asked, and therefore attendance was deemed key to outcome.[14] Only a small proportion of participants achieved this, however, so it became important to understand the barriers and facilitators of initial and ongoing engagement in the programme in order to enhance retention, thereby improving outcomes.[14] It is also important to ensure that clinical services within the prevailing healthcare system are able to provide services that are equally effective for Māori and non-Māori participants.

This thesis explores whether there are modifiable factors which prevent or enable families to engage in the Whānau Pakari programme. As the trial cohort reaches five years since baseline recruitment, follow-up data will be used to determine whether positive changes in weight status, nutrition, physical activity and psychological outcomes have persisted after five years. Finally, interpretation of these findings in the wider context of addressing childhood obesity will be considered.

1.2 Research aims

The aims of the research presented in this thesis are:

- To understand the barriers and facilitators to attendance, retention and engagement of children, adolescents and their families in Whānau Pakari, especially for Māori families and those who declined further input after their referral.
- To determine if positive healthy lifestyle changes achieved at 12 months persist for participants long-term, and to assess whether the multidisciplinary home-based assessment and weekly group session intervention was more or less effective long-term in achieving healthy lifestyle change, when compared with comprehensive home-based assessments only.

These aims were met by undertaking:

- A survey of past participants of Whānau Pakari to gain a preliminary understanding of the modifiable barriers and facilitators to engagement in Whānau Pakari during the RCT and post-trial.
- In-depth interviews with past participants with varying levels of engagement with the Whānau Pakari programme to determine the factors affecting initial and ongoing engagement.
- Comprehensive assessment of the persistence of healthy lifestyle changes in participants of the Whānau Pakari RCT with follow-up at five years post-baseline assessment.

1.3 Researcher standpoint

My role as the researcher in this study has been shaped by my research interests in the areas of child and family health, improving access to quality health services and addressing health inequities for underserved communities.

I feel a strong responsibility to ensure that my research contributes to the improvement of health outcomes within the New Zealand health system, especially for children, young people and their families. As a Pākehā (non-Māori) New Zealander, I am also committed to ensuring that my research works towards achieving health equity for Māori. Growing up in the Taranaki region and having access to abundant natural resources has given me a sense that all tamariki (children), rangatahi (young people) and whānau (families) should be able to live in Taranaki and New Zealand in full health and wellness. I value equity and fairness and believe we have a duty to rectify inequities in New Zealand.

I have completed a Bachelor of Health Science (Honours) and Bachelor of Arts through the University of Auckland. I chose to undertake my PhD through this University, while also returning to my hometown of New Plymouth, Taranaki, in order to serve this community. My academic training in health sciences, public health and political science have continued to develop my sense of social justice and my ability to ask critical questions about the research process. Further exposure to Kaupapa Māori theory shifted my worldview towards partnering with Māori researchers and communities in meaningful ways in order to achieve change.

Many questions in health research require an approach using multiple methods in order to find effective solutions that will be useful to improve people’s health. Asking questions from only one theoretical perspective may lead to the wrong questions being asked, and hence no improvement in health outcomes. Knowledge can be gained from multiple places, and it is important to prioritise participant voice in health research.

1.3.1 Whānau Pakari research team philosophy

This research is situated within the wider Tamariki Pakari Child Health and Wellbeing research programme. Tamariki Pakari means ‘healthy, self-assured youth that are fully active’.[15] The research programme aims to undertake research by communities, for communities, working towards achieving health equity, and continues to build on existing research excellence. The research team continues to develop and is guided by a team philosophy which acknowledges the standpoint of the researchers. Through genuine partnership relationships between prevailing healthcare systems and the Kaupapa Māori research space, Tamariki Pakari supports research using a framework of mixed methodologies and prioritising child and whānau voice. Tamariki Pakari advocates for clinical services that: are appropriate and accessible for all, meet the needs of tamariki and rangatahi, and promote compassionate healthcare provision.[15]

This thesis is based on an understanding that many findings related to ethnicity, particularly those for Indigenous groups, are not the result of biological determinism, but rather reflect inequities in access to healthcare and wider services and opportunities within New Zealand.[16] While the terms ‘inequality’ and ‘inequity’ are often used interchangeably, the term ‘inequity’ is used in this thesis to refer to differences which are unnecessary, avoidable, unfair and unjust,[17] are preventable and amenable to policy intervention.[18] Therefore, inequalities refer to disparities which are not necessarily unfair or unjust (such as the documented mean difference in birthweight between males and females).[19]

1.4 Structure of thesis

This thesis with publications consists of 14 chapters:

- Chapter 1 – presents an overview of the thesis
- Chapter 2 – provides background information on the importance of childhood obesity, its consequences, associated inequities and recommended management
- Chapter 3 – describes the evolution of the Whānau Pakari service
- Chapter 4 – discusses the known barriers and facilitators to engagement in lifestyle modification programmes and healthcare access more generally
- Chapter 5 – provides the theoretical approach to the research process
- Chapter 6 – presents and discusses the methods for undertaking each of the studies
- Chapter 7 – presents the results of the survey of past Whānau Pakari participants
- Chapter 8 – presents the results of in-depth interviews with past participants determining barriers and facilitators to engagement
- Chapter 9 – presents the results of in-depth interviews, focusing on the factors specifically affecting families with Māori children
- Chapter 10 – presents an analysis of the barriers to engagement at the health system level
- Chapter 11 – presents a secondary analysis of participant-identified challenges of healthy lifestyle change
- Chapter 12 – discusses the partnership approach taken by the research team to the interview process
- Chapter 13 – presents the five-year follow-up of the Whānau Pakari RCT
- Chapter 14 – summarises the key findings of the research, strengths and limitations, discusses the implications of this work, and outlines areas for future research.

The manuscripts included in chapters 7-13 are presented as published or as submitted for consideration for publication; however, all pages, tables, figures and references are numbered consecutively throughout the thesis for continuity. Submitted manuscripts have been formatted for consistency with the rest of the thesis. Acknowledgements, funding, abstracts and keywords are not included for each paper. Individuals and organisations are included in the thesis acknowledgements (where not included, refined acknowledgements remain with the manuscript), and funders are listed in the foreword. Thesis appendices include permissions (to include publications in thesis and use of figures) and supporting documents such as evidence of ethical approvals, information and consent forms for participants, questionnaires and interview schedule used in the studies, and coding matrices for qualitative research.

2 Background and significance

2.1 The importance of obesity in childhood and adolescence

Obesity in childhood and adolescence is one of the greatest public health challenges of the current century.[20] In 2016 there were 41 million children under five years of age experiencing overweight or obesity, and another 340 million children and adolescents affected aged five to 19 years.[21] Globally, obesity rates have tripled since 1975.[21] While rates of childhood obesity have plateaued in some high-income countries,[22] middle- and low-income countries are increasingly affected by obesity and overweight, and estimates show that these countries now have higher rates of obesity than their high-income counterparts.[22, 23] Many middle- and low-income countries are affected by a double burden of malnutrition, being affected simultaneously by both undernutrition, stunting and severe food insecurity, as well as overweight, obesity and diet-related non-communicable diseases.[24, 25]

Obesity is defined by the WHO as an abnormal or excessive fat accumulation that presents a risk to health.[26] There are multiple anthropometric measures for assessing overweight and obesity; the most common, convenient and practical of these is body mass index (BMI), which is mass (weight in kilograms) divided by the square of a person's height (metres) and expressed as units of kg/m^2.[26]

The WHO Technical report classified overweight and obesity for adults with associated comorbidities (Table 2.1).

Table 2.1: WHO Classification of BMI 2000[26]

Classification	BMI (kg/m^2)
Underweight	< 18.5
Normal weight	18.5 – 24.9
Overweight	≥ 25.0
Pre-obesity	25.0 – 29.9
Obesity class 1	30.0 – 34.9
Obesity class 2	35.0 – 39.9
Obesity class 3	≥ 40.0

In children, the overweight cut-off defined by the WHO Growth References 2007 uses the percentile curve that passes through BMI = 25 kg/m^2 in adults.[26] For obesity, the threshold is the percentile curve that passes through BMI = 30 kg/m^2 in adults.[26] Similar to other measures of adiposity using anthropometric data, BMI is unable to differentiate between fat, muscle or bone, and therefore does not take into account fat mass or percentage.[27] The WHO emphasised that recommended cut-offs and therefore the impact of overweight and obesity should be interpreted in combination with other comorbidities.[28]

While energy imbalance (where energy intake is greater than energy expenditure) is the crude postulated cause of weight gain, the causes of this physiological process range from processes at the cellular level to those at societal and environmental levels (‘proximal’ and ‘distal’ causes).[29] Overweight and obesity are major risk factors for a number of non-communicable diseases, including diabetes, cardiovascular diseases and cancer.[29] Non-communicable diseases account for 70% of deaths worldwide, and are produced in large part by poor diet, lack of physical activity, and alcohol and tobacco use.[30] Changes in food type, food security, declines in physical activity, increases in sedentary behaviour, and impact of maternal health during pregnancy on the unborn child have all contributed towards the increasing prevalence of obesity.[12] However, these changes are driven by urbanisation, globalisation of marketing and trade of health-harming products, population growth and poverty.[30] Many children today grow up in an ‘obesogenic’ (obesity-promoting) environment, where there is high availability, accessibility, acceptability and promotion of low-cost, energy-dense, nutrient-poor foods, along with a reduction in opportunity for physical activity due to increasingly sedentary lifestyles.[31]

A global nutrition transition has resulted in increased availability and consumption of energy-dense foods, fats, sweeteners, and highly processed foods, alongside significant shifts in factors that contribute towards physical activity or inactivity, such as design of cities, the density of residential land, land use mix, street connectivity, walkability, the provision of local facilities and spaces for public recreation and play, and the increasing reliance on cars.[32] This set of conditions encourages weight gain and obesity, and rates have increased dramatically as a result.[1] It has been argued that this is the body’s natural response to the obesogenic environment in the current world.[33] In addition, a child’s biological and behavioural responses to this environment can develop in utero, thus programming a child to be predisposed to developing obesity postnatally.[12]

2.2 Weight-related comorbidities

Obesity in adulthood is a known risk factor for weight-related comorbidities, and excess weight gain in childhood and adolescence is likely to lead to continued overweight and obesity in adulthood.[5, 34, 35] Additionally, children and adolescents with obesity are at increased risk of later adult comorbidities such as diabetes, cardiovascular disease, dementia, musculoskeletal disorders, obstructive sleep apnoea, some cancers and learning difficulties.[1, 36-38] These complications are illustrated below in Figure 2.1.

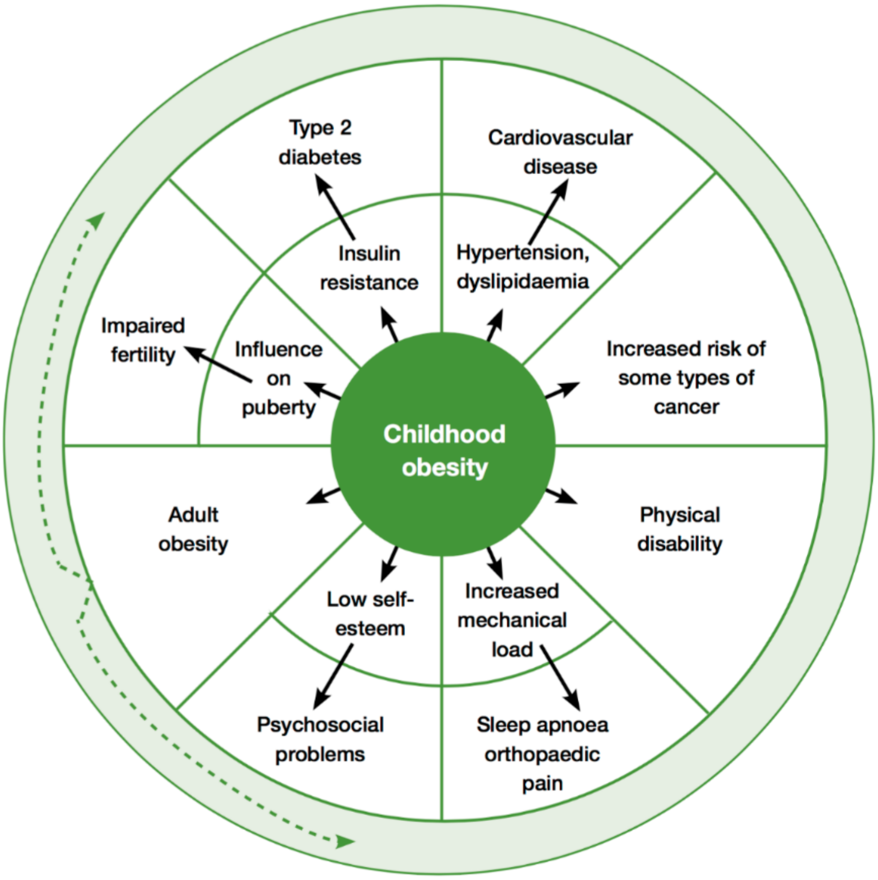


Figure 2.1: Schematic summary of the complications of childhood obesity.[29]

Childhood obesity is also associated with numerous psychological health issues, including poor health-related quality of life (HRQOL),[39] depression,[40] and low self-esteem.[41] While some of these issues could be related to the obesity itself, children and young people with obesity also face stigma and discrimination.[42] Young people with severe obesity (BMI ≥ 35 kg/m^2) are more likely to participate in unhealthy weight control behaviours, such as smoking cigarettes and vomiting after meals for weight loss, and are more likely to be bullied by their peers and family.[43]

2.3 Weight stigma

Obesity is a highly stigmatised condition and individuals with obesity face multiple forms of prejudice and discrimination.[44] The current dominant societal narrative tends to attribute overweight and obesity to personal irresponsibility and a lack of willpower, motivation and self-discipline.[45] Characterising the rise in overweight and obesity rates as a matter of personal behaviour change and couching it in the language of social responsibility focuses on individual causes of obesity without taking into account the structural determinants of health and the obesogenic environment.[46, 47] Among adults, research shows that people with overweight and obesity face social disadvantage due to marginalisation and stigmatisation in multiple domains including employment, education, healthcare, and interpersonal relationships.[48, 49] For example, a New Zealand study assessing weight bias in 344 university students found that physical education students showed strong negative prejudice toward individuals with obesity, which was greater than that displayed by their peers.[50] There is also increasing evidence of the effect of weight stigma on children and adolescents in terms of bias and stereotyping by peers, teachers, and parents.[42]

Weight bias can impact population health by increasing morbidity and mortality, through affecting mental health, interpersonal relationships, educational achievements and employment opportunities, as well as decreasing healthy behaviours and hindering weight management efforts.[44, 51, 52] Weight bias in healthcare may impede access to services. A systematic review of the effects of weight bias demonstrated that people with obesity display lower rates of healthcare utilisation, even when controlling for socioeconomic status, education, healthcare access and illness burden, due to weight bias and negative experiences in healthcare.[44] Factors contributing to the inaccessibility of health services for people with obesity included negative attitudes and disrespectful treatment from health providers, embarrassment about being weighed, and receiving unsolicited advice to lose weight.[44]

2.4 The financial burden of obesity

Estimated costs of the burden of obesity vary significantly, with large variation in methods used.[53-55] One estimate placed the annual global economic impact of obesity in 2010 at US $2.0 trillion or 2.8% of the global gross domestic product (GDP), comparable to the global impact from smoking or armed violence, war and terrorism.[56] Another estimate places the projected global cost of non-communicable diseases (cardiovascular disease, chronic respiratory disease, cancer, diabetes, and mental health) at an estimated $US 47.0 trillion from 2011-2030, or approximately 75% of global GDP in 2010.[57]

2.5 Inequities in obesity statistics

As well as the global variation between countries in obesity and overweight prevalence,[22] there are also significant inequities within countries according to various social and environmental determinants of health and illness. In many cities and regions around the world, socially disadvantaged groups are the most affected.[32] In high-income countries such as New Zealand, the risk of developing childhood obesity is greater in children living in more socioeconomically deprived households, and Māori and Pacific Island children experience higher rates of obesity than their New Zealand European peers.[11] In New Zealand, socioeconomic status and ethnicity are highly correlated characteristics, with more than 24% of Māori living in the most deprived areas of New Zealand (decile 10 of the New Zealand Deprivation Index 2013 [NZDep13]), compared with 7% of non-Māori.[58]

A social or societal determinants framework provides a foundation for taking a multi-level approach to understanding inequities in obesity prevalence and access to care.[16] The WHO defines the social determinants of health as the conditions in which people are born, grow, live, work, and age, which are influenced by wider social, economic, and political forces.[16] The WHO Commission on the Social Determinants of Health states that the marked inequities in health outcomes in non-communicable diseases such as obesity, observed within and between countries, are caused by the unequal distribution of income, goods and services, power, and agency, which manifest in poor access to healthcare and education, poor working and living conditions, and unhealthy homes, communities and cities.[16] In this model, social factors or determinants, such as ethnicity, gender, income, education, occupation, and social class, are highlighted by the Commission on the Social Determinants of Health as proxy indicators for ‘structural stratifiers’ that produce social divisions in society and define socioeconomic position.[16]

Increasing attention has been paid to the determinants of health inequities. It is likely that action on the social/societal determinants of health and wider causes will reduce the ‘social gradient’ in health and reduce inequities in health outcomes and access to care.[59]

2.6 Obesity and Indigenous peoples

There are approximately 360 million Indigenous people in 90 countries around the world.[6] They are often marginalised socially, culturally and politically due to processes of colonialism and racism related to their separate histories, languages, cultures and traditions, and there are large inequities between the world’s Indigenous and non-Indigenous populations in terms of poverty.[60] Indigenous peoples make up 5% of the world’s population, but 15% of those living in extreme poverty.[6] Globally, Indigenous peoples experience significant inequity across a range of health outcomes,[61] including mortality, morbidity, and disability.[60, 62, 63] Their health has been described as “that of the world’s very poorest”[60] and they are impacted by the ‘double burden of disease’ whereby they are affected by infectious diseases of poverty but also disproportionately from chronic ‘lifestyle’ diseases.[64] The ongoing processes of colonialism, land confiscation and cultural subjugation maintain lower levels of political power and overwhelming social deprivation for many Indigenous peoples worldwide.[6]

This thesis primarily refers to the original peoples of New Zealand, Australia and North America (Canada and the United States), and their descendants, including Māori, Aboriginal and Torres Strait Islander peoples, Native Americans, Inuit, Métis and First Nations peoples in Canada, Alaska Natives and native Hawai’ians. These Indigenous populations experienced similar processes of colonisation by European imperial powers, resulting in population decline due to land dispossession, social change and newly introduced infectious diseases, and continue to experience the contemporary effects of colonisation today, evident by significant inequality and poverty.[7]

In terms of obesity prevalence, Indigenous populations have higher rates of obesity than their non-Indigenous counterparts. For example, the prevalence of obesity in Māori children in New Zealand is 16%, compared with 11% in the total population, with greater inequities in certain regions.[11] In Canada, First Nations children have rates of obesity four times that of the Canadian population.[65] In Australia, 10% of Aboriginal and Torres Strait Islander children experienced obesity, compared with 7% of non-Indigenous Australians.[66] Food insecurity is a major contributor in sustaining health inequities between Indigenous and non-Indigenous peoples.[65]

Explanations which promote biological and genetic differences in understanding Indigenous health are limited in their ability to explain such significant inequities.[67] In fact, 5 – 10% of obesity is attributable to genetic causes.[68] Rather, it is necessary to engage with the social and political determinants of health to understand Indigenous health inequities.[69, 70] Socioeconomic disadvantage is often central to the Indigenous experience.[71] It has been proposed that there are three main pathways that contribute towards ethnic health inequities: differential access to the determinants of health or exposures to disease, differential access to healthcare, and differential quality of care.[72]

2.6.1 Aotearoa/New Zealand

Māori are the Indigenous people of New Zealand and make up approximately 17% of the population according to the 2018 New Zealand census.[73] Traditionally, Māori identified themselves within their whānau (extended family), hāpu (sub-tribe or family groups), and iwi (tribe), and view themselves as the tangata whenua (people of the land) of Aotearoa/New Zealand. Although they are collectively known as Māori today, many Māori continue to describe their identity through their genealogy to their iwi, hāpu and whānau.

Māori experience significant health inequities in mortality and morbidity when compared to the rest of the New Zealand non-Indigenous population.[74, 75] Māori also have higher levels of unmet need, especially due to cost of healthcare. In the 2018/2019 New Zealand Health Survey, 41% of Māori adults had an unmet need for primary care (compared with 30% of New Zealand Europeans) as well as 25% of Māori children (compared with 18% of New Zealand European children).[11] This unmet need included being unable to visit a general practitioner (GP) or after-hours medical centre due to cost, lack of transport, lack of childcare for other children and being unable to get an appointment at their usual provider within 24 hours.[11]

2.6.2 International statutory context

Over the past 20 years there have been significant inroads into recognising the rights of Indigenous populations globally, and this includes the right to health. The WHO recognises the right to health as an essential human right in its constitution. In September 2007 the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) was adopted by the General Assembly (107th plenary meeting on 13 September 2007). UNDRIP amalgamates 'Indigenous historical grievances, contemporary challenges, and socio-economic, political and cultural aspirations.' Notably, there were four votes against the adoption – Australia, Canada, New Zealand and the United States. These countries have now all, to some extent, changed their stance, and New Zealand endorsed the UNDRIP in 2010.[76]

In addition, the United Nations Permanent Forum on Indigenous Issues acts as an advisory body to the Economic and Social Council, and is concerned with economics, social development, culture, environment, education, health and human rights, as they pertain to Indigenous people. This Forum has called for a broader approach to health and stated that the right to health is visible through the emotional, spiritual, social and cultural wellbeing of the whole community, rather than simply the health of the individual.[77]

2.6.3 National statutory context

In New Zealand, Māori have the right to equal health outcomes with other New Zealand citizens under Te Tiriti O Waitangi (The Treaty of Waitangi). Te Tiriti was signed in 1840 between some Māori and representatives of the British Crown, which provided the constitutional foundation for establishing the New Zealand Government and guaranteed Māori sovereignty and the rights and privileges of British citizens.[78] The terms of the Treaty were not upheld by the British or subsequent New Zealand Governments, resulting in land loss and destruction of social, cultural, political and economic bases.[71]

In the present day, the Treaty provides a framework for ensuring equitable health outcomes for Māori – the same degree of health as non-Māori New Zealanders.[79] This and other human rights charters acknowledge that inequities are unfair and state that governments have a duty to provide interventions such as affirmative action and restorative justice programmes and legislative protection in order to combat inequities.

Despite this legal obligation to intervene,[79] efforts to reduce and prevent ongoing inequities in health between Māori and non-Māori have largely been limited in their success. The Waitangi Tribunal's 2019 report *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry* found that the Crown failed to address persistent Māori health inequities through the design and administration of the primary healthcare system, a breach of the Treaty of Waitangi.[80] Recommendations from this report include a renewed commitment to the Treaty and its principles, and explicit equity commitments in primary health system policy and legislative documents.[80] To date, these recommendations and others have not been acted upon by the current Government.

2.7 Child and adolescent obesity management

The WHO Commission on Ending Childhood Obesity has stated:

> ‘The greatest obstacle to effective progress on reducing childhood obesity is a lack of political commitment and a failure of governments and other actors to take ownership, leadership and necessary actions.’[12] (p. XIII)

International recommendations for addressing childhood obesity emphasise that no single intervention can address the growing obesity epidemic alone.[12] In January 2016 the WHO's Commission on Ending Childhood Obesity produced its final report with recommendations under six areas for action: promote intake of healthy foods; promote physical activity; preconception and pregnancy care; early childhood diet and physical activity; health, nutrition and physical activity for school-age children; and weight management.[12] Addressing childhood obesity is a cross-sectoral challenge, reflected in the Commission's recommendations and statements. The six recommendations span multiple areas of action, reflecting the breadth of actions required.

Both prevention and intervention efforts are required, and obesity and overweight in childhood is an important opportunity to address the health of children and their families and reduce the burden of NCDs in the future.[12] The Commission stressed the role of governments in monitoring and accountability systems in order to track rates of childhood obesity, but also identified non-state actors as critical to success, as all sectors must engage and work together in order to bring about change.

2.7.1 Multidisciplinary, family-centred, home-based approaches

One of the six recommendations of the WHO's Commission on Ending Childhood Obesity is the provision of multicomponent (including nutrition, physical activity and psychosocial support), family-based, lifestyle weight management services for children and adolescents with obesity.[12] International evidence for child and adolescent obesity management suggests that multidisciplinary lifestyle interventions are best practice.[81] A 2009 Cochrane review on interventions for treating obesity in children found that:

> ‘combined behavioural lifestyle interventions compared to standard care or self-help can produce a significant and clinically meaningful reduction in overweight in children and adolescents.’[82] (p. 2)

The review also noted the importance of parental involvement, especially with children prior to adolescence.[82] This 2009 review has since been updated and refined into age-specific reviews focusing specifically on diet, physical activity and behavioural interventions for the treatment of overweight or obesity up to the age of six years,[83] from six to 11 years,[84] and from 12 to 17 years.[85] These reviews found that multicomponent interventions were beneficial in achieving small, short-term reductions in BMI,[83-85] and that further research on sustaining intervention benefits was required.[84] In addition, the US Preventive Services Task Force has recommended intensive interventions with ≥26 contact hours for children aged six years and older for improvements in weight status for up to 12 months.[86, 87]

However, intervention programmes must be accessible and appropriate in order to address inequities and ensure that services are meeting the needs of those most affected by childhood obesity. A home-visit model may be able to address some of the issues around accessibility of healthcare.[13, 88] A systematic review of weight management interventions delivered in the home setting suggested that whilst the home visitation model was promising, it was not clear if the reductions in weight status were due to the home visit itself.[89] However, a home-visit model potentially has merit in overcoming barriers to accessing services in a hospital-based setting.

2.7.2 Clinically significant improvements in weight status

Recent meta-analyses for both children and adolescents have shown that while many lifestyle-based weight management interventions observe statistically significant changes in BMI SDS, they may not result in clinically meaningful improvements in metabolic and cardiovascular health.[84, 85] What constitutes a clinically meaningful decrease in BMI SDS in lifestyle interventions has evolved over time. A 2012 meta-analysis demonstrated that a reduction in BMI SDS of 0.1 was clinically significant, leading to improvements in metabolic indicators including low-density lipoprotein cholesterol (LDL-C), triglycerides, fasting insulin and blood pressure.[90] More recently, a 2016 observational study highlighted that a BMI SDS reduction of ≥0.25 improved the cardiovascular risk profile in children with overweight and obesity, and a reduction of ≥0.5 doubled the effects.[91] However, the same study found that in children with hypertension, dyslipidaemia or insulin resistance at baseline, smaller reductions in BMI SDS were associated with significant improvements in cardiovascular risk factors.[91] A recent meta-analysis showed that a reduction of at least 0.6 in mean BMI SDS ensured a mean reduction of percentage body fat mass.[92] A related systematic review is still in progress to establish the change in BMI required to improve metabolic and cardiovascular outcomes in children and adolescents with obesity.[93]

2.7.3 BMI SDS reduction as a primary outcome measure for multidisciplinary intervention programmes

There are challenges to BMI SDS reduction being the sole measure of efficacy in clinical trials of obesity interventions.[94] Most studies continue to report changes in BMI SDS as a measure of success in achieving improvements in weight status.[87] BMI SDS is predominantly used as a unit of measurement instead of BMI in order to provide a standardised measurement for the degree of obesity in children adjusted for age and gender, and account for both gender and age.[95] However, the use of BMI SDS has been questioned in terms of its ability to evaluate changes at the extremes of BMI percentiles.[96] Proposed options include expressing high BMI values as a percentage of the 95th percentile,[96] change in percentage overweight,[97] and the triponderance index.[98] It has been proposed that BMI SDS is not a strong predictor of percentage body fat in younger children.[99] A study of 663 children aged between four and 18 years with overweight and obesity demonstrated that BMI SDS was a weak predictor of total fat mass and percentage body fat for children under nine years of age.[99]

A lack of BMI SDS reduction should not be equated with a lack of healthy lifestyle change,[94] and there have been suggestions to focus on other markers of success of interventions including change in weight gain trajectory, improvement in obesity-associated complications, and change in markers of future complications, such as improvements in cardiovascular fitness, quality of life, and metabolic markers.[100] Recent population data highlighted that those identified as overweight or obese by the age of three years were likely to continue to increase their BMI SDS by approximately 0.1 per annum into adolescence.[101] Therefore, any halting of increase in BMI SDS trajectory may be beneficial over time, even if the ultimate goal is reduction in weight status over time. Increasingly, there are calls from Indigenous groups to focus on more culturally relevant outcomes, such as considering psychological, spiritual and wider family wellbeing, in order to improve health outcomes for these groups, due to the stigmatisation experienced with measures such as BMI.[102]

2.7.4 Long-term effectiveness of multidisciplinary interventions

It is important to determine if positive changes in weight status, dietary, physical activity and sedentary behaviours and quality of life are persistent long term. However, there is limited evidence of persistent healthy lifestyle change in multidisciplinary lifestyle interventions at two years; further, the data are difficult to interpret due to heterogeneity in baseline BMI SDS, age at entry, the types of interventions provided, location, retention rates, and follow-up period.[103-107] Reports of longer-term outcomes from these interventions are even more limited.[84] While long-term follow-up studies of obesity interventions are critical, there are a number of reasons contributing to the dearth of follow-up studies, including low retention rates, the difficulty of maintaining adherence to treatment arms over a long period of time, lack of intervention success and a reticence from funders to fund long-term follow-up studies.[108]

Reported long-term follow-up studies have had mixed success. Studies of various family-based behavioural interventions in the United States included follow-up at five and ten years, which found that changes achieved in behavioural interventions initiated in childhood could persist into young adulthood.[97, 109] However, these studies lacked comparison control groups and were relatively homogenous in terms of ethnicity and deprivation, with most families being white, middle-class and two-parent families. It is also unclear whether these interventions, conducted in the late 1970s and early 1980s, would remain effective in the present day due to the increasing influence of the obesogenic environment.[110]

More recently, a five-year follow-up of a family-centred, multidisciplinary cognitive-behavioural lifestyle programme in 2008 showed sustained improvements in BMI SDS, waist circumference and lifestyle habits, among other parameters.[111] However, the study included no participant sociodemographic information such as ethnicity and socioeconomic status, also lacked a comparison control group, and was limited by the small number of participants; 31 children were recruited and 20 completed the programme and five-year follow-up.[111] A seven-year follow-up of a lifestyle intervention for children with overweight in Germany showed sustained reductions in BMI SDS (median -0.26; interquartile range -0.87-0.23 BMI SDS), with a retention rate of 42% (n = 32) at seven years.[112]

An early childhood obesity prevention trial based on a home-visit model in socioeconomically disadvantaged areas of Sydney, Australia followed 369 children three years after the two-year trial from birth into early childhood.[113] However, at five years post-baseline the effect of this early life home-visiting intervention on child BMI and BMI SDS at age two years was not sustained.[113] In terms of future research, a study protocol for a blended in-person and web-based lifestyle intervention in Canada has been developed to meet the needs of an ethnically diverse population, including Indigenous peoples, but follow-up is planned for 18 weeks post-baseline assessment only.[114]

There is some longitudinal evidence available that lifestyle intervention can result in persistent healthy lifestyle changes in adults. A follow-up study over 20 years in China showed that those who had undertaken a diet, exercise, or combination intervention had a 43% lower incidence of diabetes.[115] However, this study included a long intervention period of six years, and baseline BMI was relatively low, in the overweight range (BMI 25.8 control and 25.2 intervention). There was also no change in BMI at the end of the intervention period.[115]

Given the associated comorbidities with childhood obesity,[116] it is important to understand whether intervention in childhood can result in persistent reductions in BMI SDS over time as well as changes in other health and wellbeing outcomes. There is a need for long-term follow up of home-based programmes, with representation from Indigenous and other marginalised groups, and assessments of interventions in real-world settings.

2.7.5 New Zealand context

In New Zealand, 90% of deaths are due to non-communicable diseases, owing to risk factors such as obesity, inadequate diet and physical activity, and tobacco and alcohol use.[30] Sixty-five percent of the New Zealand population aged over 15 years are classified as being overweight (34%) or having obesity (32%), placing the country second in the OECD rankings for overweight and obesity, behind the United States.[4, 10] This prevalence has increased three-fold from the 1970s.[117] These figures are unequally distributed throughout the population, with some groups experiencing higher rates of obesity and overweight than others. According to the 2018/2019 New Zealand Health Survey (NZHS), 48% of Māori adults and 67% of Pacific adults experience obesity.[11] In addition, those living in the most deprived areas (deciles 9 and 10 of the NZDep13) are 1.6 times more likely to have obesity than those living in the least deprived areas (deciles 1 and 2 of the NZDep13), after adjusting for age, gender and ethnicity.[11, 118]

Rates of obesity in childhood are equally concerning. The 2018/2019 NZHS reports that 11% of children aged between two and 14 years experience obesity, which is an estimated 94,000 children.[11] A further 20% of children were classified as overweight.[11] Inequities are also present in childhood, with rates of obesity being substantially higher for Māori (16%), Pacific peoples (28%) and children living in the most deprived quintile of households (20%).[11] The effect of deprivation appears to be more pronounced in children, with children living in the most deprived areas being 2.7 times more likely to experience obesity than those living in the least deprived areas, adjusting for age, gender and ethnicity.[11]

In addition, New Zealand children and adolescents who experience overweight and obesity are at increased risk of associated physical and psychological comorbidities and health risk indicators, such as dyslipidaemia, abnormal liver function, raised fasting insulin, subclinical inflammation, acanthosis nigricans, breathing pauses and elevated blood pressure.[116]

Data from 2006 estimates the cost of healthcare and lost productivity attributable to overweight and obesity in New Zealand to be between NZ$722-849 million.[119] However, there are currently no more recent estimates, and it is likely that these costs have increased over the past decade.

2.7.6 Childhood obesity management in New Zealand

Clinical guidelines for weight management in children and young people in New Zealand were first published in 2009 and reflected the multi-component ‘FAB’ (food, activity and behaviour) approach in a family-centred model of care.[120] This approach recommended dietary, physical activity and behaviour changes to support healthy lifestyle changes in a family/whānau environment. An updated version was released in 2016, which provided more current evidence-based recommendations for practitioners, especially around sleep habits.[121] The family-focused ‘FAB’ approach (including healthy sleep habits) remains recommended best practice and multidisciplinary interventions are supported.[121]

The Green Prescription Active Families (GRxAF) programme is the most widespread programme aimed at addressing childhood obesity through physical activity in New Zealand and is run through regional sports trusts. The aim of the programme is to support families to set goals for lifestyle change and physical activity levels.[122] Past research has reviewed the effectiveness of Active Families; an audit of GRxAF in Taranaki showed that, while some families achieved healthy lifestyle change, modification was required to improve recruitment and reach those groups most affected by childhood obesity.[123] Additionally, the programme is not offered nation-wide.

In 2013 the Office of the Auditor General released a report identifying the need for a national strategy to address obesity in New Zealand. The report also highlighted barriers for families accessing the various services available for managing weight-related health issues, including awareness, cost, establishing a supportive connection with service providers, and motivation.[124] In October 2015 the government released the Childhood Obesity Plan, which included 22 initiatives.[125] The Ministry of Health states that: ‘the focus is on food, the environment and being active at each life stage, starting during pregnancy and early childhood.’[125] The Plan is intended to be cross-sectoral, covering multiple government agencies, the private sector, communities, schools and families. Three broad areas of action were identified: targeted interventions for those already experiencing obesity, support for those at risk of developing obesity, and broad population-based approaches to prevent obesity.[125]

One of the targeted initiatives of the Childhood Obesity Plan was the 'Raising Healthy Kids' target, introduced on 1 July 2016, which stated: 'By December 2017, 95% of obese children identified in the B4 School Check (B4SC) programme will be offered a referral to a health professional for clinical assessment and family-based nutrition, activity and lifestyle interventions.'[126] The B4SCis a free health and development check for four-year-olds, acting as a health screen before a child starts school. It is the final Well Child Tamariki Ora check. The B4SC was selected as an assessment point for the Raising Healthy Kids target, due to stated focus on early life intervention.[126] However, the Raising Healthy Kids target measured the rate of referrals offered, rather than the proportion of families who accepted a referral and subsequently engaged in a weight management programme.[126] No data is available as to whether this target achieved better outcomes for children with weight issues and their families, given the focus was on the referral rate rather than the rate of families who actually took up the referral to further care.

The second targeted initiative of the Childhood Obesity Plan was improved access to nutrition and physical activity programmes, such as Active Families, for those families referred through the B4SC programme.[125] Despite this, few children and adolescents experiencing weight issues have access to intervention programmes. Most children and adolescents with overweight and obesity coming to the attention of medical professionals are either managed by a general practitioner or general paediatrician with minimal intervention programmes being available nationally.[123] However, the GP workforce is declining,[127] and the 2018/2019 New Zealand Health Survey identified high levels of unmet need for primary healthcare due to cost and access – 30% of the general population and 41% of Māori reported not being able to access primary care when required within the past 12 months, due to the inability to pay for GP appointment (13%) or being unable to get an appointment within 24 hours (21%).[11] In addition, there is substantial geographical variation in the types of programmes being offered (if at all), and there is no national cohesive approach for managing childhood obesity intervention, despite national clinical guidelines being available since 2009.[120]

3 Evolution of Whānau Pakari: an evidence-based child and adolescent obesity service for Taranaki

Acknowledging the heterogeneity in the provision of child and adolescent obesity services across NZ, a multi-centre audit was undertaken to determine the effectiveness of models of care for childhood obesity in New Zealand. This audit showed modest reductions in BMI SDS irrespective of the model of care, which included either standard medical follow-up in a paediatric outpatient clinic, medical follow-up with a paediatrician plus dietitian input, medical follow-up with dietitian input and GRxAF input, or a multidisciplinary intervention programme. This audit highlighted moderate value in terms of weight status in providing services for those affected by obesity.[128]

3.1 Conventional approach for addressing childhood obesity in Taranaki

In Taranaki prior to 2012, the conventional medical model for addressing childhood obesity involved a hospital-based medical appointment with possible dietitian input and/or involvement in GRxAF, run by the regional sports trust in the community. However, an audit of GRxAF programme in the region found that the programme had limited reach with those who most needed assistance, given it was not region-wide, and did not address inequities in child and adolescent obesity statistics.[123] The conventional model of care was also unsustainable if all those identified were to be offered referral to a paediatrician in a medical clinic for screening of weight-related health issues. Based on audit findings and widespread community consultation, a multidisciplinary intervention involving multiple health professionals based in the community was created, in order to achieve widespread access and enhance appropriateness of the service offered.[129]

3.2 The Whānau Pakari clinical service

Whānau Pakari is a family-based, multicomponent and multidisciplinary healthy lifestyle programme for children and adolescents experiencing weight issues. The name ‘Whānau Pakari’ means “healthy self-assured families that are fully active” in Te Reo Māori (the Māori language), and was the name gifted to the programme by a prominent Māori community representative.[13] The programme evolved through substantial and widespread community consultation and stakeholder engagement, including with the regional sports trust, the Public Health Unit and the Māori Health team at the District Health Board, key stakeholders in Māori Health Centres in the region and iwi representatives.[13] This consultation process was necessary to help build relationships in the community and provide an opportunity for contribution from community stakeholders in the creation of the programme. Community consultation is ongoing.

3.2.1 Referral pathway

Families are referred to the service through a variety of professionals, including GPs, paediatricians, dietitians, kaiawhina (community health support workers), school counsellors, and via self-referral, in order to remove any barriers to referral in the community.

Referral criteria to Whānau Pakari are children and adolescents aged between five and 16 years with a BMI ≥98th centile, or >91st centile with significant weight-related comorbidities.[13] These cut-offs are used by the New Zealand Ministry of Health for defining obesity and overweight for 0-5 years, and were modified from UK Cole data.[95, 130]

3.2.2 Model of care

Whānau Pakari is a clinical service delivered in the community in an innovative way, where healthcare is taken out of hospital walls and into the home, without compromising quality of care. The programme is a 'demedicalised' model, which removes the need for a traditional hospital appointment from paediatric or dietetic services. However, paediatrician oversight is retained through regular multidisciplinary team meetings, with input from a dietitian, physical activity specialist, and psychologist. This allows for any weight-related comorbidities to be identified and addressed, without the need for hospital appointments. A multidisciplinary team model of care is suited to the nature and complexity of childhood obesity and the wide range of weight-related comorbidities.

Participants continue to receive comprehensive medical assessments and support through home visits from a trained healthy lifestyles coordinator (a health professional trained in focused weight-related assessment, supported by a paediatrician). Home-based assessments remove travel barriers for the participants, improving access for Māori and those living in more deprived areas.

The comprehensive medical assessments include a medical history and examination for identification of weight-related comorbidities, as well as assessment of dietary intake and knowledge of healthy lifestyles, evaluation of quality of life and psychological wellbeing, and assessment of physical activity and cardiovascular fitness. Blood sampling was undertaken to assess for metabolic status. Any weight-related comorbidities identified at the assessment are managed and appropriate secondary referrals made where necessary.

Childhood obesity is a sensitive, emotionally charged issue for many families. Whānau Pakari aims to be a supportive, non-judgemental and non-stigmatising environment for families. Once involved in the programme, the concepts of obesity and weight are not discussed, and instead the focus is on improved health and wellbeing, and how to make healthy lifestyle change persistent.

3.2.3 Weekly programme sessions

Weekly programme sessions include nutrition, physical activity and psychology content, and involve not just the child referred to the programme, but their wider family members. For example, the physical activity sessions include games and introductions to new sports in order to find activities that interest each family. Nutrition sessions include practical cooking sessions and virtual supermarket tours in addition to content around portion sizes and healthy eating concepts. Psychology sessions discuss topics such as bullying, self-esteem and goal setting.[13]

3.3 The Whānau Pakari randomised clinical trial

The Whānau Pakari service commenced in 2012, and an RCT was embedded in the service. The aim of the trial was to evaluate the effectiveness of a family-centred multidisciplinary intervention for children and adolescents with weight issues in Taranaki. The community consultation during the establishment of Whānau Pakari aided in ensuring that the intended research was acceptable to the community and that barriers to participation identified previously were addressed.[13, 131]

The study design and methodology have been published previously.[13] The 12-month trial compared a high intensity ‘intervention’ arm of six-monthly home-based assessments with advice and weekly sessions with a low intensity ‘control’ arm of six-monthly assessments with advice only. A true control arm was not possible due to the ethical implications of identifying children and adolescents with obesity and not offering care. All participants were followed for a further 12 months after the trial ended, until 24 months, with consent to 60 months follow-up.

3.3.1 Results of the RCT

The results of the RCT showed increased recruitment from Māori, who comprised 47% of participants, compared with the previous GRxAF programme (39%).[13, 123] The remainder of the cohort were Pacific (3%), Asian (3%), and other ethnicities (4%) (prioritised ethnicity used). Participation of those from most deprived households was 29%, compared with 15% of the population of Taranaki.[132]

The results of the baseline assessments demonstrated that obesity should not be viewed as a singular condition; there was a concerning prevalence of comorbidities in the cohort, with clear health inequities irrespective of ethnicity.[116] There were also low levels of physical activity and high screen time,[133] a high prevalence of eating behaviours such as comfort eating, and suboptimal sweet drink intake and fruit and vegetable intake.[134] Children and adolescents in Whānau Pakari also showed high levels of emotional and behavioural difficulties and lower HRQOL.[135]

The results of the 12-month assessments showed that both the high-intensity intervention and low-intensity assessment and advice model resulted in a modest reduction in BMI SDS from baseline (0.10 [$p < 0.05$] and 0.12 respectively [$p < 0.05$]).[14] Participants also showed improvements in cardiovascular fitness and HRQOL, and the greatest improvements were found in younger participants and those from less deprived households.[14]

At two years, the reductions in BMI SDS at 12 months drifted back to baseline BMI SDS, irrespective of age, ethnicity or socioeconomic status. However, persistent changes and improvements were observed in cardiovascular fitness, reductions in sweet drink intake, increases in water intake and improvements in HRQOL.[136]

Secondary analysis of participants in the high intensity intervention group with high attendance (attending ≥70% of the intervention sessions, as asked) showed a greater reduction in BMI SDS (0.22) than those attending <70% of sessions (0.04; $p = 0.04$).[14] This persisted to 24 months, demonstrating that attendance was key to long term outcome.[136] However, males were more likely to have high attendance at intervention sessions than females ($p = 0.04$) and New Zealand European participants were more likely to have higher attendance than Māori participants ($p < 0.0001$). Age did not affect attendance.[14] Therefore, while Whānau Pakari achieved high recruitment rates for Māori and those from deprived households, understanding how to enhance retention and outcome for groups most affected by obesity was needed. It became necessary to identify the barriers and facilitators to initial and ongoing engagement in Whānau Pakari in order to optimise access to the programme.

3.3.2 Service evaluation

A multi-source evaluation of Whānau Pakari found that the programme achieved higher total referral rates for Māori, compared with referral rates to the national equivalent programme, GRxAF.[129] Referrer satisfaction was high and emphasised the positive impact of the Whānau Pakari programme in terms of raising awareness and facilitating discussions regarding childhood obesity.[129]

Focus group evaluation of the experiences of Whānau Pakari participants and their caregivers has shown the programme to be a positive and beneficial experience for those involved, emphasising the importance of connectedness, knowledge-sharing and self-determination, the collective journey alongside other families and programme deliverers, and the importance of a non-judgemental, respectful environment.[137]

An economic evaluation showed that Whānau Pakari was more efficient and cost-effective compared with the previous conventional medical care at 12 months.[138] It highlighted that a home-based model does not need to be more expensive. The removal of multiple separate hospital visits to different health professionals, including visits to paediatricians, led to gains in efficiency and societal cost, without compromising quality of care.[138]

3.4 Whānau Pakari as a service post-clinical trial

The modest improvements in weight status noted in both arms of the trial are encouraging when they are applied to a 'real-world' service provision setting, as was the case in Whānau Pakari. The improvements in HRQOL and cardiovascular fitness in both groups indicate that wider health benefits were achieved.[14] The Whānau Pakari programme is more efficient and cost-effective compared with the previous conventional model of care,[138] and has received over 1,000 referrals to date.[139] The programme provided screening for and management of weight-related comorbidities within the service model and demonstrated improved health outcomes for Māori overall, thereby contributing towards addressing health equity. Whānau Pakari also showed high stakeholder, referrer and participant satisfaction.[129] In determining the success of the Whānau Pakari real-world service, a multi-methods framework taking into account trial outcomes, service evaluation and participant feedback, while also assessing improvements in health equity, was deemed most appropriate. The benefits of the Whānau Pakari model of care in terms of cost efficiencies, scalability, and improvements in outcomes for Māori are such that this model became the ongoing model of care.[138]

The results of the research led to adaptations in the Whānau Pakari service. A rolling entry model was implemented, so that if one family withdraws from the programme, another could take their place without additional cost, which has led to increased programme capacity in weekly group sessions.[138] There is increased flexibility for families with a shorter six-month programme being introduced, given waning attendance after six months in the 12 month trial,[14] with continued 12-month follow-up and the option to continue with the programme for longer than six months if families feel they are still benefiting from the programme. This is supported by the US Preventive Services Taskforce's recommendation of ≥26 contact hours for children aged six years and older for improvements in weight status for up to 12 months.[86, 87] In addition, from 2017, age-appropriate interventions have been piloted in the form of a pre-school programme for young children and an adolescent school holiday workshop, and results are forthcoming.

Close linkages between the clinical delivery team and research team have allowed for relatively quick translation of research into practice. However, several key questions remain unanswered in terms of Whānau Pakari programme development and sustainability, including understanding the factors affecting engagement in the programme, especially for Māori whānau and families, and those who decline further input after their initial referral. In addition, the long-term outcomes of the Whānau Pakari trial are not yet known, and the natural growth trajectory of children and adolescents with obesity without any input is required in order to contextualise the success of interventions.

4 Barriers and facilitators to engagement in community-based healthy lifestyle programmes for children and adolescents

International evidence suggests that community-based healthy lifestyle programmes can be effective for weight management, but success relies on family engagement.[140] Engagement and retention remains challenging, especially when scaling up interventions from RCTs.[141, 142] In addition, many studies lack representation from Indigenous groups and other marginalised populations, which is pertinent given that Indigenous peoples show lower rates of healthcare utilisation and delayed presentation to health services,[6] and therefore may have different experiences that need to be taken into account in intervention design and implementation.

Several social and demographic characteristics such as age, gender, ethnicity and deprivation are known to be associated with social inequities and access to healthcare, [59, 143-149] and similar factors are also associated with engagement, recruitment, attendance and retention of both parents and children in weight management programmes. A systematic review of barriers and facilitators to initial and continued attendance at community-based lifestyle programmes for families experiencing childhood overweight and obesity included both socio-demographic characteristics and programme or service factors, both modifiable and non-modifiable.[141] Factors identified in this and other studies range from child age and gender, weight status and psychological distress, to family social disadvantage and deprivation, single parenting, income, parenting efficacy, parental nutrition and physical activity behaviours, readiness for change, as well as a range of service and environmental factors, such as distance to travel to the programme, timing of programme sessions, and the size of the programme.[141, 150] However, the patterning of some of these proximal determinants is shaped by more distal determinants that produce social divisions and define socioeconomic position in society.[16]

4.1 Defining barriers and facilitators

Factors affecting engagement in healthcare are often referred to as barriers (factors that prevent engagement) and facilitators (factors that enable engagement). The terms ‘participation’, ‘attendance’, and ‘engagement’ are used somewhat indiscriminately when discussing barriers and facilitators to initial and ongoing engagement with healthy lifestyle programmes. Some studies identify known barriers to the broader concept of programme ‘engagement’, such as the clinical environments of programmes, mismatched expectations, a lack of family support, scheduling conflicts, and transportation issues.[150] Other studies have differentiated between factors that affect engagement at different stages,[150] including programme enrolment (enhanced by a parent’s awareness of their child’s overweight status and desire to improve their child’s health),[151, 152] programme attendance (for example, children’s involvement in attendance decisions),[153] and programme completion (for example, a child’s development during a programme, of social groups and improvement in their self-esteem and confidence).[151, 153]

4.2 Relevance for Indigenous groups

While there is a lack of research focusing on factors affecting engagement in healthy lifestyle programmes for Indigenous groups, previous research in other areas of health services research has shown that Indigenous peoples and other ethnic minorities face additional complex barriers when accessing healthcare. These may be geographical, such as a lack of health facilities in Indigenous communities, or cultural, such as a lack of cohesion between healthcare providers and the communities they serve, in terms of language and understanding of Indigenous culture and history.[154] Although non-Indigenous people face many similar barriers to accessing healthcare, the Indigenous experience is shaped, framed and exacerbated by the ongoing effects of colonisation. This has had significant impacts on both health outcomes and access to healthcare for Māori and other Indigenous peoples,[61, 63] and has contributed to the destruction of Indigenous economic, social and cultural bases which have an impact on health and healthcare access.[63, 71] It has been proposed that socioeconomic circumstances and racial discrimination are the main barriers to healthcare access for these groups, as direct effects of colonisation.[154]

A systematic review of barriers and facilitators to Indigenous participation in RCTs in New Zealand, Australia, Canada and the United States (countries with similar histories of colonisation) identified barriers such as a distrust of research or research processes and concerns for privacy and confidentiality.[131] Additionally, Western European knowledge systems and methodologies were sometimes perceived to be in conflict with Indigenous knowledge systems, and a lack of Indigenous presence in the design and implementation of RCTs was of concern and acted as a barrier for Indigenous participation.[131] A key concern for marginalised ethnic groups in the United States, including Native American peoples was a 'mistrust of white people' and the feeling of being treated like 'guinea pigs'.[155]

It has been proposed that the relative disadvantage for Indigenous versus non-Indigenous populations may have an impact on the ability and willingness of Indigenous people to participate in research.[131] It is possible that this disadvantage also contributes towards a general mistrust of health services and acts as a barrier to participation and engagement in community programmes.[156] Many of the barriers and facilitators identified in the review appear to be plausible potential barriers and facilitators to engagement with health services, which have been identified elsewhere.[154]

The following section summarises the known factors affecting engagement in family-based healthy lifestyle programmes at the individual, programme, health system, and societal levels, with identification of potential barriers and facilitators affecting engagement for Indigenous groups. The chapter concludes with a discussion of the concept of cultural safety as it relates to facilitating engagement.

4.3 Individual-level factors

Multiple studies have identified individual-level characteristics or predictors which are associated with a family being more or less likely to engage with lifestyle intervention programmes.[141] The Parenting, Eating and Activity for Child Health (PEACH™) programme, a parent-only lifestyle intervention for children with obesity based in Queensland, Australia, found several factors associated with recruitment and attendance including marital status and socioeconomic status.[150] However, the impact of these individual or family-level factors is often exacerbated by wider determinants of health at the societal level.[16] For example, child gender has been previously identified as a non-modifiable predictor of engagement,[141] but the impact of gender on engagement is likely not due to an inherent biological characteristic but is instead a reflection of wider societal beliefs and attitudes around weight in boys and girls. The social determinants of health concept identifies individual- or family-level determinants, such as ethnicity, gender, and socioeconomic status as proxy indicators for structural stratifiers or wider factors at the societal level that produce social divisions and define socioeconomic position.[16] Therefore, it is still useful to identify potential factors at this level affecting engagement in programmes as proxy indicators for wider determinants of healthcare access.

4.3.1 Ethnicity and deprivation

There are few studies that include appropriate and adequate representation from marginalised ethnic groups; rather, the homogeneity of samples is often included as a study limitation.[141] However, it is important to understand factors that affect these groups and the nuanced relationship they have with community programme participation, given known inequities in attendance by ethnicity and socioeconomic status.[141] In a systematic review of the association between ethnicity, socioeconomic status and study dropout in paediatric weight management programmes in the United States, black participants had higher ‘dropout’ rates (65-67%) than white participants (22-27%).[157] In addition, low family income was associated with lower ‘adherence’ to the programme.[157] Another systematic review found that families of ethnic minorities, families with a lone parent, and those living in more deprived areas were more likely to drop out from weight management programmes prematurely.[141] When studies have included participants from ethnic minorities and/or low income areas, ethnicity and deprivation are often identified as non-modifiable predictors of attendance,[141] although they are better understood as markers for social processes that are modifiable such as racism and poverty. For Indigenous peoples, these processes are often highly interrelated rather than separate factors.[58]

4.3.2 Gender

Child gender may be associated with initial and continued attendance at community-based lifestyle programmes,[141] although there is no consensus in the literature. Parents of girls with overweight or obesity may be more likely to enrol their child in community weight management programmes than parents of boys,[158-160] and similarly, parents of girls may be more likely to complete a programme.[158, 160] This is corroborated by similar studies which show that parents are more likely to identify girls as being overweight than boys.[161, 162] In another study, more *self-referred* parents were seeking help for their daughter, while parents *referred by a health professional* were more likely to enrol their son.[150] Conversely, in the Whānau Pakari trial, girls were less likely to have high attendance at programme sessions compared with boys.[14] However, the PEACH™ programme evaluation found that child gender had no relationship with attendance.[150]

4.3.3 Perception of child weight status

Parental perception of child weight may also act as a barrier to attendance and engagement in weight management programmes. Awareness of a child's weight status, especially when overweight,[150-152] and concern for the child's physical and psychological health and wellbeing can increase programme enrolment.[137, 141] However, some studies have shown that many parents do not identify their child as overweight according to weight management guidelines,[163-166] which may prevent them from enrolling in weight management programmes or being inclined to engage. There are several reasons as to why this may be the case, including a distrust of weight charts and other biometric measures, fear of being blamed, unwillingness to label their child as overweight or believing they would 'grow out of it', wanting to avoid further stigmatising their child, or being reluctant to acknowledge their own weight status.[141] It is also possible that changing social norms mean that parents simply do not recognise excess weight in their children, given the prevalence of obesity worldwide.[152] However, perception of child weight is not universally identified as affecting engagement,[167] and some longitudinal studies report that the ability of parents to be able to correctly identify whether their child is overweight has no positive impact on BMI later in life. [168, 169]

4.4 Programme-level factors

Several factors at the programme or service level can affect engagement, and are potentially modifiable in order to improve initial and ongoing engagement.[141] For example, the Parenting, Eating and Activity for Child Health (PEACH™) programme evaluation identified the referral source as a determinant of attendance, with programme attendance being greater in self-referrals compared with a referral from a health professional.[150] Factors related to the accessibility of the programme or service are described below.

4.4.1 Accessibility of the lifestyle intervention programme

Accessibility has been identified previously as ‘personal and programme logistics’ which affect both initial and ongoing attendance.[141] Barriers to attendance included the location and timing of sessions, availability of transport and changing family circumstances.[141] Previous research in other areas of healthcare access has found that when transport is provided to appointments for cervical and breast screening programmes, participation in these schemes increased for Aboriginal and Torres Strait Islander women.[170] The feasibility of this type of initiative for attendance at ongoing weekly sessions in lifestyle programmes is unknown, but it has been proposed that a home-visit model may increase engagement.[88]

Similarly, geographical access is a key factor affecting engagement in health services for many Indigenous groups. Factors such as the degree of isolation or distance from the service,[171-173] ease and cost of transportation,[171, 172] as well as the costs of travelling away for extended care[171] all act as barriers to Indigenous engagement with prevailing healthcare models. In addition, the availability of health services has been consistently identified as a barrier and/or facilitator,[171] in terms of service location, availability of providers within facilities, and whether the services are known to the community.[172]

Engagement is likely to be enhanced for Indigenous groups through reflexive health services that address convenience[174] and cost,[175] and provide community-governed, family-centred health services.[131, 176] Additional facilitators of service engagement include ongoing service availability and continuity of care, an appropriate volume of services for the population served, and the provision of transport and accommodation for patients from rural and remote regions.[177]

4.4.2 Suitability and acceptability of lifestyle intervention programmes

In terms of programme suitability and acceptability, previously identified facilitators of attendance include the social interaction and support gained from programme sessions, the practical nature of the sessions, and a family-centred approach inclusive of parents and children.[141] A family-centred approach has also been identified as a key facilitator of engagement for Indigenous communities.[176] A lifestyle-focused, holistic approach, as opposed to a focus on weight loss, can facilitate initial attendance or enrolment.[141] In addition, continuity of staff and regular communication between programme staff and families is an important facilitator.[141] However, programme staff could also be a barrier to programme attendance, as staff who lack experience, enthusiasm or group management skills can hinder the effectiveness of programmes.[141]

While a previous systematic review collated a wide range of factors affecting attendance, retention and engagement in community healthy lifestyle programmes for children and their families, only one study identified cultural appropriateness as a barrier or facilitator to engagement.[178] ‘Cultural barriers’ are often identified as a reason for problematic clinical communication between practitioners and patient, but these are not well defined and cover a range of communication issues and racially-charged interactions.[171] A 2011 qualitative study in Australia investigating cultural barriers to accessing healthcare for Indigenous groups demonstrated the dissonance between patients and practitioners when discussing perceived cultural barriers.[171] Cultural barriers identified by Aboriginal and Torres Strait Islander peoples included the roles of kin and others in care, shame, respect and reciprocity, and lifestyle assumptions made by practitioners.[171] Competing cultural priorities can also influence attendance at healthcare service appointments, such as being away on ‘sorry business’ (attending a funeral or caring for sick relatives).[175] Non-Indigenous practitioners identified some of the same barriers, namely respect and reciprocity, and a lack of understanding of Aboriginal kinship structures and poor attitudes towards Aboriginal culture.[171] However, although non-Indigenous practitioners emphasised the physical environment of the practice setting was important, they were unable to elaborate on specific qualities required to make a setting culturally appropriate, other than including aboriginal artwork.[171]

Further research in Indigenous participation in research and healthcare services highlight the importance of relationships and partnership-building, as well as trust and reciprocity.[131, 176] Reciprocal trust and shared decision-making in patient care can enable participants and allows for interventions to be delivered more effectively and reduce health disparities.[176] The communication between provider and patient within this partnership is key and the unequal power dynamic often present in these interactions directly affects communication in care for Indigenous peoples.[177]

4.5 Health system-level factors

Very few factors at the health system-level are identified in the literature as affecting engagement in lifestyle modification programmes. However, this is possibly due to a research focus on individuals rather than structures.[179] A recent WHO report from the Regional Office for Europe recognised that there were a number of barriers to health system preparedness and responsiveness to addressing childhood obesity, including inadequate workforce education, insufficient financing of childhood obesity management, fragmented care and a lack of integration in service delivery, and poor governance.[180] A 2004 stocktake of obesity services in NZ showed a lack of a national coordinated approach intervention and prevention.[181] There is a lack of programmes for addressing childhood obesity internationally, which is perhaps the greatest barrier at the health system level to obesity intervention.

Structural barriers have been identified as affecting engagement in other areas of health services research, particularly for Indigenous groups.[171, 182] A review of access to cancer services for Māori identified health system barriers including the cost, configuration and location of services, and service funding and resource constraints.[182] An Australian study of barriers perceived by both Indigenous peoples and non-Indigenous practitioners found that perceived structural barriers by non-Indigenous practitioners included non-adherence with appointment systems by Indigenous patients, a lack of understanding of the health system and related social services, lack of health literacy and the need for centralised services in one location.[171] By contrast, Indigenous patients cited a lack of flexibility in services, lack of communication and understanding barriers between patients and providers,[173] bureaucracy in health and social support systems creating navigation difficulties,[177] confusing duplication in services offered by different providers, and the expectation that Indigenous communities can and will keep up with changes in medical systems.[171] This has invariably led to disillusionment in prevailing healthcare models, and at times, an active decision to disconnect from engaging with the healthcare system at large.[156]

4.5.1 Models of health and approach to healthcare provision

The values and assumed beliefs that are common in biomedical models of health and health systems may themselves be barriers,[131, 172] such as:

- Patients who do not practice healthy behaviours 'don't care about their health.'
- Personal health is the most important priority for each family member.
- Everyone understands the concept of 'chronic illness'
- Adherence failure is the patient's problem.
- Healthcare is available and accessible to all.[172]

A key facilitator of Indigenous engagement is to use models of care that embrace Indigenous knowledge systems, such as kaupapa Māori services.[131, 176, 182, 183] A lack of consultation and genuine participation in the conception and development of acceptable health services may negatively affects access for Indigenous groups.[154]

A qualitative study of the drivers of obesity drivers in Māori men found four key determinants of obesity in Indigenous populations, which can also suggest the aspects of obesity services that serve as barriers and facilitators to engagement.[184] The factors that were conducive to health and healthy weight were relationships and social connectedness (kotahitanga) and a holistic view of health incorporating Indigenous worldviews and customs. The factors that were identified as detrimental to health were the lasting effects of historical trauma and colonisation, and the inappropriateness of the biomedical model of caloric input and output (Figure 4.1).[184] Overall, conventional medical approaches to obesity management focused on weight loss tend not to resonate with Indigenous worldviews and instead initiatives that focus on local, traditional knowledge may be more appropriate,[102, 184] and conducive to engagement with Indigenous communities.

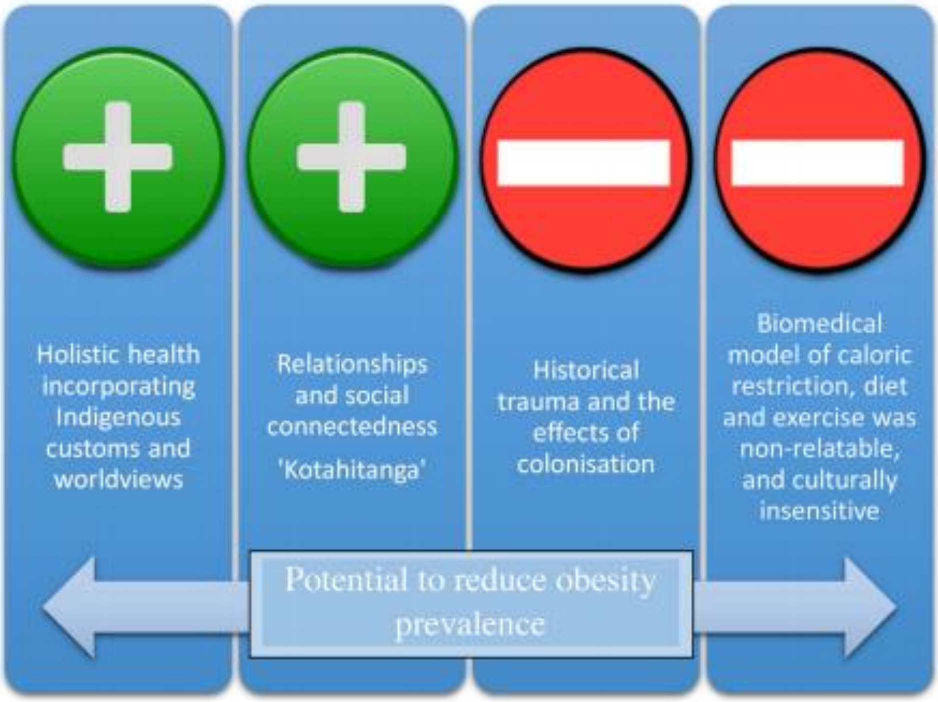


Figure 4.1: Intrinsic drivers for health potential and obesity expression in Indigenous peoples.[184]

4.6 Societal-level factors

4.6.1 Weight stigma

The stigma associated with excess weight can be a substantial barrier to initial attendance in community-based lifestyle programmes.[141] Because children with obesity are vulnerable to stigma, stereotyping and bias from multiple sources such as school, family members and their wider peer group,[44] as well as from health professionals,[50, 185, 186] some families may try to minimise or avoid this by declining care. There are associations between weight stigma and body-related shame and healthcare avoidance – a survey study of 216 women found that BMI is associated with an increase in the delay and avoidance of preventive care.[187]

It has been recommended that researchers and service deliverers consider how messages are framed in programmes aimed at addressing childhood obesity.[188] Parents may be more inclined to enrol their children in programmes that are focused on healthy lifestyles, rather than those focused on weight loss.[42, 141, 189] Additionally, the manner in which health professionals approach the topic of weight with families is important, as blame or judgement may cause families to decline care.[42, 190] The terms 'fat' and 'obese' have been identified as particularly 'undesirable, stigmatising and blaming'.[188] Therefore, a less stigmatising and judgemental approach to programme delivery may facilitate engagement and retention.

4.6.2 Differential access to services

Socioeconomic deprivation is one of the main barriers to Indigenous access of health services. Financial deprivation is associated with higher rates of comorbidities, which increases the need for healthcare services and resources.[71, 191] Approximately 24% of Māori live in the most deprived decile of New Zealand (compared with 7% of non-Māori) and only 4% live in the least deprived decile (compared with 12% of non-Māori).[58, 118, 183] Financial deprivation and the high cost of services is consistently identified by Indigenous people as a barrier to accessing healthcare.[171-173, 182, 192] Māori and Aboriginal Australians are also less likely to fill a prescription due to financial constraints.[193, 194] A lack of access to transport has been reported as an additional barrier to healthcare, through mechanisms such as the unaffordability of petrol and the unavailability of public transport.[193, 195] Additionally, socioeconomic deprivation is associated with higher levels of psychosocial stress and morbidity,[194] and in turn, those with high levels of psychosocial stress are less likely to access healthcare services and resources when they need it.[59]

This differential access to social, political and economic resources as an ongoing effect of colonisation is a form of institutional or systemic racism, and can operate without identifiable individual perpetrators.[7, 196] In terms of engagement with health services, racism impedes the equitable distribution of health resources necessary for access to adequate healthcare.[197]

4.6.3 Racism

Racism is a known determinant of health and driver of ethnic inequities, and is increasingly acknowledged as shaping healthcare interactions and outcomes.[198, 199] Interpersonal racism is personally-mediated prejudice and discrimination, that may appear in the health system in direct, explicit ways, as well as more implicitly and passively as *implicit racial/ethnic bias,* a belief or association about a racial/ethnic group that may be automatically-activated,[200] focused on the perceived cultural characteristics or behaviours associated with a particular ethnicity.[154] Self-reported racism is associated with poorer health outcomes and reduced access to, and quality of, healthcare services and resources.[74, 201] Prolonged and cumulative exposure to discrimination results in poorer health outcomes.[198] This can cause psychosocial stress for the individual, who may internalise the racism resulting in poorer relationships with health providers.[201] Psychosocial stress has consistently been associated with adverse health outcomes for Indigenous people.[202]

Power imbalances in clinical interactions may be reinforced by the dominance of the biomedical paradigm which generally holds the view that poor health outcomes for Indigenous people are caused by ‘noncompliant’ behaviours.[172, 176] This can serve as a barrier to continued access to services for Indigenous peoples, often due to the unfriendly and condescending nature of communication from both health professionals and 'gatekeepers' such as reception staff.[172, 203] A low tolerance for children accompanying adult patients unable to access childcare[174] and a lack of accommodation of extended family[182] have also been reported as barriers for Indigenous patients.

An attempt to counter implicit bias is the 'difference blindness' ethos common in Australia where practitioners treat 'all patients the same' regardless of age, gender, ethnicity or religious belief.[204] However, difference blindness has been identified as a barrier to Indigenous access rather than a facilitator.[171] While it is important not to discriminate against anyone based on ethnicity, it is also important to recognise difference to allow for more nuanced patient-provider interactions. Essentially, difference blindness is a philosophy about treating all patients equally, rather than equitably. It fails to acknowledge that Indigenous patients have needs and concerns specific to their cultural heritage, and that historically their encounters with medical systems have been different from other patients.[171] Alternatively, ensuring cultural safety in healthcare is a strengths-based approach to address some of these issues within prevailing healthcare services.

4.7 Cultural safety in healthcare

Discussions on what makes a service or programme 'acceptable' often centre around dimensions of patient comfort and satisfaction, trust, respect, and relationships.[172] The factors identified throughout this chapter demonstrate that the most important enablers of access and engagement for Indigenous groups are not necessarily concrete items that are task-based or can be check-listed.[171, 176] Stereotypical components of Indigenous cultures are not ingredients to transform services into becoming more appropriate, aware, sensitive or competent.[176] *Cultural safety* shifts the role of culture away from a checklist approach for becoming 'competent' in the culture of others, and towards a critical examination of the power imbalances in healthcare interactions between Indigenous patients and non-Indigenous healthcare providers.[176, 183, 205] This is a strengths-based approach within a healthcare organisational context as well as the individual health professional-patient interface.[205]

Cultural safety refers to delivering quality care based on the concept of 'critical consciousness' which acknowledges and is reflective of power differentials, and is linked to achieving health equity.[205]

> 'Cultural safety requires healthcare professionals and their associated healthcare organisations to examine themselves and the potential impact of their own culture on clinical interactions and healthcare service delivery. This requires individual healthcare professionals and healthcare organisations to acknowledge and address their own biases, attitudes, assumptions, stereotypes, prejudices, structures and characteristics that may affect the quality of care provided […]'[205] (p. 14)

Cultural safety is distinct from Western concepts of care that are culturally responsive, sensitive or competent.[206] The World Health Organization has also argued that notions of cultural competency are not only insufficient for Māori but are inappropriate and unsafe.[206, 207] Importantly, the provision of culturally safe services is to be defined by the 'end users' – that is, the Indigenous Māori people of New Zealand – rather than non-Māori service providers.[208, 209]

Culturally safe communication and practices[177] may include employing Indigenous people,[131, 176, 177] providing care in Indigenous spaces and by being inclusive of patient perspectives regarding healthcare, such as differing worldviews and competing demands of patients.[177] A cultural safety approach emphasises the recognition of the Treaty of Waitangi, its consequences and the effects of colonisation on contemporary health status.[205] It recognises the role of societal determinants in producing and maintaining health inequities between Māori and non-Māori through racism and discrimination and requires healthcare professionals to minimise bias and achieve equity within the workforce and working environment.[210] Curtis and colleagues recommend a comprehensive approach to cultural safety for health organisations, which includes engagement in cultural safety activities and training as part of professional development and the assessment of cultural safety through the monitoring of inequities.[210]

Greater clarity is needed in terms of how we conceptualise barriers to engagement in healthy lifestyle programmes and their causes, in order to move towards understanding facilitators of improved access to healthcare services for children and their families.[176] There are some specific barriers for Indigenous peoples which may not be captured in a universal approach to understanding access to healthcare. A past focus of the literature has tended to be on individual or community-level barriers, and less so on the role of health providers, systems and society. However, the changes required to eliminate disparities in access in New Zealand and other countries are often resisted by political, structural, social and cultural forces. There are strengths-based approaches to addressing these issues.

5 Theoretical foundation

This chapter discusses the theories which have informed the development and carrying out of this research. This thesis is comprised of two main studies, using multiple methods, both quantitative and qualitative, in order to focus on understanding the complexity of an area such as childhood obesity in New Zealand. Using multiple methods allowed for the use of the Westernised biomedical scientific method alongside a Kaupapa Māori-informed approach as appropriate and recognises the value of using a range of methods to answer the research questions.

Overall, a critical lens was applied to the research. Critical theory considers the historical, ideological and social forces and systems which produce, constrain and maintain societal power relations and structures.[211] Applying a critical lens to the studies in this thesis allowed the research to explore what may be considered opposing methods and methodologies of inquiry. Weaving together both the investigation of long-term clinical outcomes of paediatric obesity management and intervention and the lived experiences of service users of a 'demedicalised' family-based assessment and intervention programme allowed a more complete picture of long-term outcomes and participant experience.

In New Zealand, health research should be responsive to the rights and diversity of Māori, which reflects the government's view that research should contribute towards addressing health inequities, [212-216] and also reflects the obligations of researchers under the Treaty of Waitangi to ensure that research is responsive to Māori.[214] There are many ways to achieve this in health research,[214] such as including Māori as participants and following recommended ethnicity data collection standards, promoting Māori voice through appropriate sampling in both quantitative and qualitative research methods and careful data analysis, and increasing the relevance of the research for Māori through consultation, dissemination, relationship building, workforce development and engaging in the Kaupapa Māori theoretical space.[214] The methods used in both studies have been developed to meet these commitments.

5.1 Biomedical scientific method

The biomedical scientific method is the dominant methodological approach in the health and medical sciences and many social sciences. It is generally underpinned by the positivist paradigm, which emphasises the importance of objectivity, systematic and detailed observation, testing hypotheses through experimentation, and verification.[217] It is based on the assumptions that:

- the objective world has an independent reality of human thought *(realism)*
- the world is discoverable, observable, measurable and able to be studied through systematic methods *(empiricism)*
- knowledge is stable across time, culture, ideology and gender *(universal),* able to be reduced to portions which can be combined to give a full picture of the whole *(reducible),* able to retain its meaning when transferred between contexts *(transportable)* and unambiguous/univocal.[217]

These principles give rise to the scientific method of knowledge production. The 'evidence' found through these various methodologies is combined to create a 'body of knowledge' to allow people to explain, control and predict events and guide decision-making and practice. This method of conducting science also assumes that there are variables or factors which need to be controlled in order to ensure experimental validity.[217]

The biomedical scientific method has had primacy in science and academia in Westernised universities, which has often in turn rendered the knowledge produced in other worldviews and paradigms as inferior to the prevailing canon of thought.[218] However, the emphasis on objectivity (especially in relation to areas such as behaviour change in human beings) has since been challenged and subsequent methodological approaches have been developed to address the limits of a purely positivist approach.[217] A critical approach to the scientific method adopts a post-positivist or critical realist view, which argues that there are multiple competing views of science as well as multiple truths.[219] This approach recognises that researchers and research are not completely objective and value-free, but are influenced by their social, cultural and political contexts. This gave rise to multi-methods research which allows for the incorporation of participant experience through the integration of quantitative and qualitative methods.

In this thesis, the biomedical scientific method has been applied with a critical lens, being cognisant of the wider historical and contemporary milieu. In doing so, this methodological approach is able to better contextualise the clinical outcomes of participants involved in a multidisciplinary healthy lifestyle intervention. This critical application of the biomedical scientific method has also been developed to help meet commitments to responsiveness to Māori,[214] and remain conscious of the methodological limitations. This approach informed how recruitment, data collection and data analysis were undertaken in order to include appropriate numbers of Māori participants, produce meaningful results, and contribute towards achieving health equity.

5.2 Kaupapa Māori theory

Established first in educational research,[220] Kaupapa Māori theory and research emerged partially as a response to prevailing Westernised methodologies in science and social science. These reproduced deficit explanations (i.e. attributing inequities to factors inherent to a cultural group) of Indigenous outcomes in health and other outcomes within multiple facets of New Zealand society and failed to provide genuine benefits from the research process.[189, 221] Kaupapa Māori theory recognises that research is often viewed with suspicion by Māori and is implicated in the process of colonisation.[222] It acknowledges the complexity of Māori historical and contemporary realities, with Māori worldviews and realities at the centre.[223]

Kaupapa Māori research refers to Māori-led research with several philosophical and practical aims. These may include:

> ‘promoting Māori at the centre of the inquiry, developing research questions that Māori partners have signalled are important, appropriate sampling, utilising Māori processes where appropriate, resisting ‘victim-blame’ analyses, partnering with Māori with aligned objectives, Māori health research workforce development and contributing to the elimination of ethnic inequities’ (p. 98).[214]

There is considerable debate around whether non-Māori researchers can participate in Kaupapa Māori research,[224-226] because Kaupapa Māori theory by definition necessitates Māori ownership and control of the research process.[224] Previous research led by non-Māori researchers but aligned with Kaupapa Māori theory is characterised as being ‘consistent with’ or ‘informed by’ Kaupapa Māori theory.[214, 223, 227, 228] Therefore, this research draws on Kaupapa Māori principles, with engagement from the outset with leading Māori health researchers and representation throughout the research process. The research process is aligned with Kaupapa Māori principles,[214, 227] such as aiming to be transformative and beneficial to Māori, aligned with a structural determinants of health approach, rejecting of victim blaming, cultural deficit theories, and cultural essentialism, emancipatory, and exemplary of research excellence.[223]

Inherent to Kaupapa Māori theory is a critique of power structures and societal inequities, as well as a requirement for self-reflection and evaluation of all stages of the research process, from research team formation and study design to future policy implications of the research.[229] A process of ongoing reflection, critique and re-adjustment was an assumed part of this research approach.

In addition, the values underpinning this research were informed by Smith[229] and Cram's[230] work on 'Community-Up' research practices.[231] 'Community-Up' research values are developed from Māori cultural practices that seek to uphold the mana (dignity) of those involved in research.[231] They are useful for guiding Indigenous and non-Indigenous researchers working with Indigenous communities, and can also guide how transdisciplinary researchers might collaborate with one another.[231] These values allowed the methods employed to be reflexive to the research participants and their contexts, and included (p. 40-41):

- Aroha ki te tangata – respect for people, allowing people to define the research space and context (e.g. where to meet), and respect for data
- He kanohi kitea – be a face that is seen and known by the community
- Titiro, whakarongo... kōrero – look, listen… then speak.
- Manaaki ki te tangata – take care of people through sharing, hosting and being generous with time, expertise, and relationships
- Kia tupato – be cautious, politically astute, culturally safe, and reflexive
- Kaua e takahia te mana o te tangata – do not trample on the mana (dignity) of people. People are often the experts on their own lives, including their challenges, needs and aspirations. Look for ways to collaborate on research reports, as well as research agendas.
- Kia mahaki – be humble. [231]

These values informed both how the research process was undertaken with participants, and how the interdisciplinary research team collaborated with each other. A specific discussion of how these values informed the process of undertaking interview research with whānau is presented in Chapter 12. Overall, adopting an approach informed by Kaupapa Māori theory allowed the research to more fully consider the experience of participants involved in the Whānau Pakari service, using a variety of methods and approaches. Where a specific theory has underpinned the method development of a particular study, this has been identified in the respective chapter. For example, the development of the questionnaire used in the survey-based study in Chapter 7 was informed by eco-social theory,[232] which applies a broad ecological approach to understanding the distribution of disease and inequities in health. The survey study in Chapter 7 applies these broad principles to patterns of healthcare engagement, rather than patterns of disease. However, this approach did not specifically inform phase two of the research.

6 Methods

This chapter outlines the methodology of the research and provides a detailed overview of each stage of the research process. The variety of methods chosen facilitated increased breadth and range of study findings; both the quantitative and qualitative studies addressed different aspects of childhood obesity in New Zealand. This was a pragmatic approach to research that does not subscribe to one particular methodological tradition over another, but instead focused on the research question, utility of the research and finding answers using the most appropriate methods possible from a wide range of approaches.[222, 229, 233]

This thesis includes two main studies. Study one was a qualitative-based study using survey and interview methods to understand the factors affecting engagement in the Whānau Pakari programme. Study two was a longitudinal follow-up of participants from the original Whānau Pakari trial at five years.

6.1 Study one: Understanding barriers and facilitators to attendance, retention and engagement in Whānau Pakari

The Whānau Pakari trial found that, whilst there were modest reductions in BMI SDS overall at 12 months, there was a doubling of reduction in weight status in participants who attended ≥70% of intervention sessions.[234] Given the more favourable outcomes for those with high attendance, it was important to understand the drivers of lower engagement and conversely, reasons for high attendance. The aim of the Whānau Pakari barriers and facilitators study was to understand barriers and facilitators to participation, retention and engagement in Whānau Pakari. It was anticipated that these may be factors preventing (barriers) or enabling (facilitators) engagement at the service, sector and societal level, due to the multiple facets of accessing a community-based obesity intervention service in New Zealand. The study was conducted in two phases, using both a survey and in-depth interviews to understand the experiences of Whānau Pakari service-users with varying levels of attendance.

Ethical approval for the Whānau Pakari Barriers and Facilitators study was granted by Central Health and Disability Ethics Committee (New Zealand) (17/CEN/158/AM01). Locality approval was obtained from the Taranaki District Health Board. Written informed consent was obtained from all study participants.

6.2 Phase One: Online survey of past Whānau Pakari service users/past participants

This survey gathered initial data about aspects of the service which enabled participation and those factors which deterred people from taking part.

6.2.1 Participants

Participants included parents/caregivers and children over 11 years of age from the Whānau Pakari service from a sample of participants with a contact phone number on record from January 2012 to January 2017. This included both the original randomised clinical trial participants and post-trial service users (as the programme content and delivery did not change post-trial), as well as those who were offered a referral to the service but declined further input.

Exclusion criteria were participants who repeated the programme more than once during the time period, due to anticipated inaccuracies in attendance reporting.

6.2.2 Questionnaire development

The survey questionnaire development was informed by Kaupapa Māori theoretical principles and eco-social theory (an ecological approach to understanding the distribution of disease and inequities in health),[232] which provided a framework for the survey to understand organisational and structural barriers to healthcare access, rather than focusing on narrow individual characteristics which may reproduce deficit understandings of healthcare engagement. The survey questions were developed in consultation with a range of Māori and non-Māori stakeholders and researchers, including the Taranaki District Health Board Public Health Unit, and collected data about the factors which enabled and prevented participation in Whānau Pakari. The online survey was developed using Qualtrics software (Qualtrics, Provo, UT, USA, 2018). Both the computer and mobile versions were beta-tested to ensure face validity and comprehension prior to release and were verified to ensure webpage responsiveness. The full set of survey questions are in *Appendix D. Questionnaire and interview schedule*. Each survey comprised 37 questions in total, but the actual number of questions answered by respondents varied due to the survey's branching design.

Both quantitative and qualitative data (open-text answers) were collected. Quantitative data collected included demographic information, yes or no questions and five-point Likert scales assessing agreement with key statements. Ethnicity was collected as per the New Zealand Ministry of Health Ethnicity Data protocols, whereby multiple ethnicities were possible.[235] As the online survey was anonymous, and the phone and post versions were confidential, it was not possible to compare self-reported estimates of attendance rates with actual attendance rates of participants.

6.2.3 Recruitment

Participants were invited to take part in a brief online survey about their experiences with Whānau Pakari. Recruitment for the survey was by e-text with an invitation to participate in the anonymous survey. The text contained a hyperlink to complete the survey online, as well as the option to take the survey via phone or post, and this was followed by three reminder texts over the following weeks. An option to opt out of the survey was also included. One invitation to participate was sent per family, so that families with more than one child involved in the service did not receive the invitation twice.

6.2.4 Data collection

Written consent for the online version of the survey was obtained through clicking a button stating agreement with the consent statement. Telephone surveys were scheduled at a time convenient for the participant and conducted by the candidate/researcher. The researcher obtained verbal informed consent and recorded the participants' responses in written form. Postal surveys, along with participant information sheets and consent forms, were sent to the preferred address provided by the participant, with a return envelope with paid postage included. Survey participants were offered the chance to win a prize for a sporting goods voucher as incentivisation to take the survey.

6.2.5 Data analysis

Quantitative data were analysed using SAS v.9.4 (SAS Institute, Cary, NC, USA, 2016), using non-parametric tests due to the non-normal data distribution. Qualitative data collected using open text comment fields was coded and analysed in MAXQDA Standard 2018 (version 18.2.0, VERBI GmbH Software, Berlin, Germany, 2018)[236] using a process of thematic analysis. Thematic analysis is a method for identifying, analysing, reporting and interpreting patterns within qualitative data, with results reported as 'themes' which represent aspects of participant experience.[237]

The analysis included entire survey responses due to the brevity of the open text comments. A coding matrix was developed which allowed consistency within and between survey responses. This was tested and developed using a reflective process of expanding the matrix through adding new codes, as well as refining the matrix by collapsing multiple codes together and renaming them.[237] Given the brevity of responses and discreteness of the data, many changes had to be made during the first ten test survey responses. As this process continued, fewer changes had to be made. This process was overseen by members of the research team who have experience in both qualitative research methods and Indigenous health research. A final copy of the coding matrix is in *Appendix E. Coding matrices.*

Codes were amalgamated into related areas which formed common themes present in the data.[237]. These themes were appraised and refined by the wider research team. While this data did not include detailed descriptions of participant experience, the results of the survey were used to prepare and refine the interview schedule in phase two in order to ensure areas of importance were included.

6.2.6 Dissemination

Dissemination directly to participants was not possible due to the anonymous and confidential nature of the survey, but the results are available via Open Access publication (Chapter 7).

6.3 Phase Two: In-depth interviews

The in-depth interviews focused on collecting detailed information on participant experience with Whānau Pakari, as well as wider experiences of the health system. It was important to understand barriers and facilitators to participation, retention and engagement at varying levels of engagement in Whānau Pakari, including those who declined their referral and had no further contact with the programme. Interviews were conducted across a six-month period from mid-June to November 2018. The interview process was undertaken by the candidate and an interview facilitator, who identifies as Māori and who has iwi affiliations to Ngāti Mutunga, Ngāti Tama, Ngāti Rāhiri o Te Ati Awa me Ngai Tūhoe.

6.3.1 Interview schedule development

The results of the survey (phase one) acted as an initial indicator of the families' experiences and ensured that the subsequent interview schedule covered key areas of interest. As with the survey, the interview questions were developed in consultation with a range of stakeholders and researchers, including the Taranaki District Health Board Public Health Unit. The questions were also informed by current health policy.[125] The interview schedule is included in *Appendix D. Questionnaire and interview schedule.*

6.3.2 Participants

Interview participants were primarily parents or caregivers of children and adolescents who had been referred to Whānau Pakari from service inception in January 2012 to January 2017. Children and adolescents, if over 11 years of age, were also able to participate.

The sample included families who were involved with either the original Whānau Pakari randomised clinical trial (January 2012 to August 2015) or the subsequent Whānau Pakari clinical service (from trial end until January 2017). The referral timeframe ended in January 2017 because this was when several service changes took place (see Chapter 3).

Participants were recruited from four different groups of Whānau Pakari service users who had varying levels of engagement (Table 6.1).

Table 6.1: Participant interview groups

Participant group	Description
≥70% attendance	Attended more than 70% of weekly sessions, as recommended by the service team
<30% attendance	Attended fewer than 30% of weekly sessions
Discontinued after first assessment	Had one assessment with the healthy lifestyle coordinator, then discontinued
Referred, did not proceed	Referred to Whānau Pakari but declined further contact

This sample was chosen to allow conclusions to be made about the acceptability of the service at different levels of attendance and allow a sample with maximum variation to account for a range of experiences and social contexts. We aimed to interview equal numbers of families with Māori and non-Māori children, in order to ensure an appropriate level of Māori voice within the data.[214] Rather than recruiting participants in proportion to Whānau Pakari participation rates (47% for Māori), we intended to recruit Māori participants to 50% of the cohort. Therefore, the sample contained roughly equal numbers of families with Māori and non-Māori children involved in Whānau Pakari to ensure that appropriate representation was attained to make recommendations to improve programme engagement with Māori participants.[238]

6.3.3 Recruitment

Eligible participants who had been referred to Whānau Pakari during the period of interest were invited to participate via phone call and follow-up text messages. Recruitment was undertaken by the PhD candidate and the interview facilitator, primarily through contact details on the Whānau Pakari database. Where contact details had changed, recruitment was also undertaken via whanaungatanga (kinship or relationships linked by whakapapa [genealogy]) relationship networks and contacts.[239] This approach has increasingly been utilised as a recruitment methodology in Kaupapa Māori-based research,[240] and in large-scale studies seeking to ensure appropriate representation of Māori participants.[241]

Appropriate koha (gift, donation or contribution) in the form of a fruit bag and voucher were offered to participants to thank them for their time and as a sign of reciprocity, acknowledging the gift of participant experiences that was shared with the interview team.[242]

6.3.4 Data collection and interview process

Given that those who had limited engagement and who declined involvement in the original Whānau Pakari trial and service were key groups to include as participants, several steps were taken to remove barriers to participation in this study. The interviews took place in the participant home (or in another location acceptable to the family) in order to minimise inconvenience and travel barriers. Other interview locations included participant workplaces and Taranaki Base Hospital. This was informed by a key value of Community-Up Research Practice, 'kaua e takahia te mana o te tangata' – do not trample on the mana (dignity) of people.[229, 230] Conducting interviews in the home values participants as key informants and experts on their own lives, challenges, needs and aspirations, in their own environment. Sixty-four interviews were conducted from a possible pool of 74 potential participants. Interviews were approximately 30 – 60 minutes duration, but interview timing was flexible to ensure interview closure was not premature.[219]

The interviews were conducted by the PhD candidate and the interview facilitator as a team where possible; however, the Māori interview facilitator led these interviews when appropriate. The candidate and interview facilitator asked clarifying questions and stated back summaries of participants' stories to check their understanding, and regular debrief sessions were held with the wider research team. These steps helped ensure *credibility* of the data collected during interviews, according to Lincoln and Guba's criteria for establishing trustworthiness and rigour in qualitative research.[219] A full description of this partnership interviewing process and the steps taken to ensure a high participation rate, engagement and a strength-based interviewing process, informed by Kaupapa Māori principles, is included in Chapter 12.

Participant information sheets were explained, and informed consent obtained to audio-record and transcribe the interviews. All participant information was anonymised, via a unique number from 001 – 074. Participant ethnicity for both the parent/caregiver and child was confirmed at the time of the interview by using the Statistics New Zealand ethnicity question, which allows for multiple ethnicity responses, as is recommended best practice for collecting ethnicity data in New Zealand.[235] The participant information sheets and consent forms are included in *Appendix C. Evidence of ethical approval, patient information sheets and consent forms.*

All interviews were recorded using a digital voice recorder, with the participants' consent. Each recording was transcribed verbatim by an independent transcriber. Transcripts were then checked by the PhD candidate for accuracy, to remove any identifying information, and to familiarise the candidate with the data.[243] Participants were offered their transcripts for review and comment, which helped establish credibility of the data through verification of participant responses.[219] The transcribed interviews were then stored and managed using MAXQDA,[236] a qualitative analysis software package.

6.3.5 Analysis

While qualitative data analysis is a systematic process, it is also dynamic, evolving and reflective,[244] and ‘involves a constant moving back and forward between the entire data set, the coded extracts of data that you are analysing, and the analysis of the data that you are producing’ (p. 86).[237]

As with phase one of the study, a coding matrix was developed by the candidate under guidance from the supervision team using MAXQDA software, based on research aims, objectives and questions. The coding matrix allowed for consistency within and between interviews. Two interviews from each category of participants were chosen to develop the coding matrix and ensure consistency across the range of participants (eight interview transcripts in total).[237] The interviews with these participants had detailed answers to almost all of the interview questions, and therefore covered almost all of the themes that would need to be coded across all of the interviews. The coding matrix was tested and developed using a reflective process of expanding the matrix through adding new codes, as well as refining the matrix by collapsing multiple codes together and renaming them.[237]

Many changes were made to the coding matrix through this process due to the breadth of interviews. The coding matrix was then peer reviewed by senior members of the research team with extensive experience in qualitative research. The final coding matrix was then used to code all of the interviews, including the eight test interviews, which were recoded to ensure consistency. A copy of the final coding matrix is provided in *Appendix E. Coding matrices.*

The candidate coded all the interviews within the group of interviews before moving on to the next group. This enabled the researcher to develop a detailed understanding of each group of participants and the contextual factors that influenced and shaped their engagement with Whānau Pakari.

Interview data were analysed using an inductive thematic analysis approach,[237] which also drew on the literature and the researcher's understanding of the topic. Thematic analysis is a method for identifying, analysing, reporting and interpreting patterns within data, and it allows the researcher to explore the 'experiences, meanings and the reality of participants' (p. 81).[237] It aligns well with a pragmatic approach to research as it is theoretically flexible and can allow for sophisticated and complex interrogation of the latent (underlying) meanings in datasets.[237] Thematic analysis was chosen because of its flexibility and its ability to capture and contrast aspects of the participants' experience across different interviews within and between groups of participants with varying levels of engagement. It can also explore and assess differences across characteristics such as ethnicity and gender.

The process of identifying themes essentially began during data collection phase, as the candidate and interview facilitator used the return car trip from interviews to debrief, reflect and share thoughts on the interview experiences. The candidate actively read each interview transcript to identify patterns and themes within the data that related to the research question and objectives. During the coding phase the candidate was able to compare these developing themes across interviews within each group of participants. After coding all of the interviews in each of the four groups of participants, the candidate had developed an understanding of both the themes that were common across a group of participants (e.g. participants who were referred but declined further contact with the service), and those that applied to a specific interview, or subgroup of participants. The sample size was large enough for both corroboration between participant accounts and variation within the sample. This triangulation between participant stories allowed for a high degree of *dependability* (reliability).[219]

The candidate then combined data within related codes into themes that applied across participants in a particular group. Additional themes or sub-themes that applied to a specific interview or sub-group of participants were also identified as these contributed to the researcher's understanding of the experiences of not only Whānau Pakari service users and their whānau, but also the wider experiences of children and families affected by obesity. The candidate then re-read the interviews to determine whether the identified themes accurately reflected the dataset as a whole.[237] These themes were appraised by the wider research group, which included the interview facilitator, Māori researchers and supervisors, for refinement and interpretation.

Throughout this process it was acknowledged that researcher positionality and values would influence data analysis, as values shape the way each researcher perceives and interprets the world. The researcher positionality has been stated in Chapter 1. Acknowledgement of researcher standpoints allowed the research team to debate, challenge, and refine interpretations of the data. It was agreed that the 'Give-Way' rule would be applied routinely if there was disagreement over the interpretation of the data concerning Māori participants, and the final decision involving cultural interpretation of Māori participants' experiences would pass to a Māori project team member.[210, 223, 245] Therefore, the final themes were developed in partnership with the wider research group, and continued to be refined during the writing up of results. While qualitative research involves a degree of subjectivity by nature, this process of establishing authenticity of data interpretation and fairness allowed for *confirmability* (comparable to the concept of objectivity in quantitative research).[219]

The final results included detailed description from participant data, so that the reader could ascertain the degree of *transferability* to other contexts.[219]

6.3.6 Secondary analysis

After the initial analysis, it became apparent that further analysis was required to adequately reflect participant experiences. Although it was not a focus of the interviews, a secondary analysis of a subgroup of participants was undertaken to understand the challenges of implementing healthy lifestyle changes. Analysis was as above. The code ‘Challenges of Healthy Lifestyle Change’ from the original coding matrix was used to focus the analysis of key themes. Participant transcripts were included in the analysis if they had discussed the challenges of healthy lifestyle change in their interview.

6.3.7 Dissemination

Dissemination to participants was via a short feedback video, created by the candidate and interview facilitator. The video contained an explanation of the key themes and outcomes of the interview research and thanked the participants for their time and contribution. This feedback video was created in response to requests from participants who preferred this dissemination medium to gathering for a feedback hui (meeting) due to reported time constraints. The feedback video was distributed to participants via email and text message.

The results of the study will be disseminated via publication in Open Access scientific journals.

6.4 Study 2: Five-year outcomes of Whānau Pakari

The Whānau Pakari five-year outcomes study assessed whether reductions at 12 months in BMI SDS from baseline,[234] and improvements in secondary outcome measures such as dietary outcomes, physical activity and quality of life, were persistent at five years post-baseline assessment. At 12 months, BMI SDS reductions were greatest in participants who attended ≥70% of intervention sessions.[14] By 24 months post-baseline, the BMI SDS reduction at 12 months was not sustained – however, ≥70% attendance in the high-intensity intervention resulted in a persistent BMI reduction after 24 months, with a reduction in sweet drink intake, increases in water intake and improvements in cardiovascular fitness in the high-intensity intervention group.[136] Given that this was a follow-up study, the original randomised clinical trial methodology was adopted to maintain consistency. Therefore, the following methodology arises from the Whānau Pakari randomised clinical trial study protocol.[13]

6.4.1 Study design

The Whānau Pakari randomised clinical trial (RCT) was granted ethics approval by the Central Health and Disability Ethics Committee (HDEC) (New Zealand) (CEN/11/09/054),[13] with approval for follow-up to five years (CEN/11/09/054/AM10). Trial registration was with the Australian New Zealand Clinical Trials Registry (ANZCTR: 12611000862943).

6.4.2 Participants

Children and adolescents aged between five and 16 years in Taranaki with a body mass index (BMI) ≥98th centile, or those >91st centile with weight-related comorbidities, were offered participation in the original randomised clinical trial if referred to Whānau Pakari.[13] These cut-offs were chosen as they are nationally accepted for use by the Ministry of Health for defining obesity and overweight respectively for 0–5 years, (modified UK Cole data).[95, 130] All randomised participants (n = 203) from the original RCT were eligible for the follow-up at five years. At initial conception, 20 of the earliest recruited participants were contacted to ensure most were willing to undertake an assessment. Positive responses were received by 16 participants (80%). This was the estimated maximum recruitment rate for the five-year outcome project.

6.4.3 Recruitment

Recruitment was undertaken by the same trained Healthy Lifestyle Coordinator (HLC) that undertook the assessments at baseline, 6 months, 12 months, 18 months and 24 months. This ensured continuity of relationship between the HLC and participants and their families, in an attempt to increase engagement with participants.[13] Participants from the original Whānau Pakari randomised clinical trial were contacted via phone call and text and invited to undertake an assessment at five years post-baseline assessment. Incentivisation for completion of an assessment was provided. Ethics only allowed for direct contact with participants and their families, so participants who had moved out of the region were lost to follow-up as it was not possible to approach other healthcare providers for assessment information.

6.4.4 Assessments

Assessments for the five-year outcomes project were undertaken by the HLC in the family home or in another appropriate location preferred by the participants.[13] The assessments included a comprehensive medical history and examination, focusing on the presence of weight-related comorbidities. The assessment data (Table 6.2) was entered into the specific purpose-built Whānau Pakari database. Accompanying adults' heights and weights were also collected but are not reported in this study.

Table 6.2: Assessment information for all participants,[13] showing the additional data collected in the five-year outcome project.

Key assessments	**Baseline**	**6 months**	**12 months**	**18 months**	**24 months**	**5 years**
Resting heart rate	✓	✓	✓	✓	✓	✓
Blood pressure[a]	✓	✓	✓	✓	✓	✓
Height[b]	✓	✓	✓	✓	✓	✓
Weight[c]	✓	✓	✓	✓	✓	✓
Waist circumference[d]	✓	✓	✓	✓	✓	✓
Hip circumference[e]	✓	✓	✓	✓	✓	✓
Acanthosis nigricans screen	✓	✓	✓	✓	✓	✓
Ear, nose & throat examination[f]	✓	✓	✓	✓	✓	✓
Questionnaires	✓	✓	✓	✓	✓	✓
Blood sampling[j]	✓	-	✓	-	✓	✓

Technical/procedural information: [a]using Welch Allyn portable sphygmomanometer with flexiport reusable blood pressure cuffs of appropriate size, [b]to 0.1 cm using average of three readings on Seca 213 portable stadiometer, [c]to 0.1 kg using Seca 813 digital scales, [d]Seca 201 standard measuring tape (at mid-point between the lower margins of the rib and the top of the iliac crest to 0.1 cm at end of normal expiration),[246] [f]using Welch Allyn portable auroscope, [g]fasting insulin, fasting glucose, liver function tests, C-reactive protein, glycated Haemoglobin (HbA1c), and fasting lipids.[13]

6.4.4.1 Calculations

Calculations were body mass index (BMI), BMI percentile, and BMI standard deviation score (SDS) using UK Cole normative data,[247] uploadable on the KIGS auxology software (Pfizer Endocrine Care^{TM}). Further calculations were undertaken, including height percentile, blood pressure SDS, waist hip ratio, and waist height ratio. Table 6.3 shows a summary of the methodology for these calculations; the full methodology for these have been previously reported.[13]

Table 6.3: Summary of calculations undertaken during five-year follow-up assessment

Calculations	Methodology
BMI, BMI percentile, BMI SDS	UK Cole normative data on KIGS auxology software (Pfizer Endocrine Care TM).[247]
Height percentile	Gender-specific growth charts for 2–18 years recommended by Australasian Paediatric Endocrine Group for Australian and New Zealand use.[248]
Blood pressure SDS, BP percentile	Age-based paediatric blood pressure reference chart calculator based on data from The Fourth Report for consistency with historical data.[249, 250]

6.4.4.2 Questionnaires

Questionnaires included dietary, psychology and physical activity questionnaires. Dietary intake was assessed using the modified children's dietary questionnaire for New Zealand use[251] and 24-hour food recall.[13] A knowledge of healthy lifestyles questionnaire (modified from the 2008 Nutrition Survey)[252] was also administered; however, the results are beyond the scope of this thesis and are not reported.

The Paediatric Quality of Life inventory (PedsQL^{TM})[253-258] is an extensively validated model designed to evaluate quality of life (QOL) in children and adolescents, with both parent and child self-report versions. The Achenbach Child Behaviour Checklist (CBCL)[135] measures psychological wellbeing with parent and self-report for children (Child Behaviour Checklist for Ages 1½ - 5: 7-28-00 Edition-601 and Child Behaviour Checklist for Ages 6-18: 6-1-01, Edition-201) and self-report for young people (Youth Self-report for Ages 11-18: 6-1-01, Edition-501).

For assessment of self-reported physical activity, the Children's Physical Activity Questionnaire (C-PAQ) was used, which includes sedentary time such as screen time,[259] and assessment of cardiovascular fitness included a 550m walk/run.[260] The study intended to assess actual physical activity in the cohort with five days of ActiGraph sGT3X-BT (ActiGraph Pensacola, Florida, USA) accelerometer wear (three weekdays and two weekend days), but the resulting number of participants with adequate data was too low for analysis.

6.4.4.3 Blood sampling

Venous blood sampling was undertaken to assess for metabolic status, and identify the biochemical comorbidities associated with obesity.[29] This included tests for fasting insulin, fasting glucose, liver function tests, C-reactive protein, glycated Haemoglobin (HbA1c), and fasting lipids.[13] Incentivisation for these samples was provided. All testing was undertaken in New Zealand and samples were stored and destroyed after approximately seven days.

6.4.5 Primary and secondary outcomes

The primary outcome measure was the change in BMI SDS at five years post-enrolment. Secondary outcome measures included changes in dietary intake and behaviour, HRQOL, physical activity and sedentary behaviour, cardiovascular and metabolic profile (resting heart rate, blood pressure, waist circumference and waist-height ratio) and fasting insulin, lipids and glycaemic control (fasting glucose and HbA1c). It was important to examine a wide range of health and health behaviour indicators at five-year follow-up to determine persistence of healthy lifestyle change.

6.4.6 Analysis

Statistical analyses were undertaken using SPSS v25 (IBM Corp, Armonk, NY, USA). A general linear mixed model was used to assess change from baseline and five years after initiating the intervention, adjusting for the baseline value of each respective parameter and including a family code as a random factor to account for siblings in the cohort. An additional model was run based on repeated measures of BMI SDS over the five-year period from baseline, using the same covariates as above, as well as a random participant effect. Multivariate models were run to assess the effect of variables such as age, gender, ethnicity and socioeconomic status. Secondary outcomes were also analysed in the whole cohort using paired McNemar’s tests and paired t-tests. Means and standard deviations of changes from baseline in outcomes of interest, for both the raw and modelled data, were used. See Chapter 13 for a complete discussion of analysis process.

6.4.6.1 Exclusions

At five years, one participant was excluded from analysis due to being pregnant at the time of the assessment. Participants with type 1 diabetes (n = 2) or type 2 diabetes (n = 1) were excluded from analyses related to glycaemic control, liver function tests and C-reactive protein.[13]

6.4.6.2 Ethnicity comparisons

The Whānau Pakari RCT incorporated a high recruitment rate of Māori and families from the most deprived households,[14] so it was important to assess whether there were equitable outcomes for Māori and non-Māori participants at five years.

6.4.7 Dissemination

Results of the individual assessments at five years were discussed with participants following their assessment. Results of the five-year follow-up study will be via publication in an Open Access scientific journal.

7 Results: Survey of barriers and facilitators to engagement

It was important to discern whether there were programme factors which could be modified in order to improve engagement with Whānau Pakari. A survey of past participants of the programme and their parents/caregivers was undertaken to provide initial data about aspects of the service which enabled participation and those factors which deterred people from taking part. This study was undertaken as phase one of the wider investigation into the accessibility and appropriateness of the programme and served as a precursor to in-depth interviews. Where updated data and information has since become available, this has been noted at the end of the chapter in an addendum.

Published

Wild CEK, O'Sullivan NA, Lee AC, Cave TL, Willing EJ, Cormack DM, Hofman PL & Anderson YC. Survey of Barriers and Facilitators to Engagement in a Multidisciplinary Healthy Lifestyles Program for Children. Journal of Nutrition Education and Behavior. 2019;In Press. doi: 10.1016/j.jneb.2019.10.010

7.1 Introduction

One of the key recommendations of the World Health Organization's Report of the Commission on Ending Childhood Obesity is to 'provide family-based, multicomponent lifestyle weight-management services for children and young people who are obese.'[12]

Improving access to nutrition and physical activity programmes for families in Aotearoa, also known as New Zealand, is a targeted initiative of the current national Childhood Obesity Strategy.[125] Childhood obesity now affects 11% of children aged 2−14 years in New Zealand.[261] New Zealand children and adolescents with obesity have a concerning prevalence of weight-related comorbidities, suboptimal eating behaviours, low physical activity, and psychological difficulties, irrespective of ethnicity.[116, 133-135] However, Māori, New Zealand's Indigenous population, are 1.6 times more likely to experience obesity than their non-Māori counterparts.[261] In addition, children living in households in the most socioeconomically deprived areas are two times more likely to have obesity than children living in the least deprived areas.[261] Therefore, multidisciplinary interventions must be able to engage with these groups to produce equitable outcomes.

The success of childhood obesity management programmes depends on both initial recruitment and ongoing retention.[140] Ethnicity and socioeconomic status are associated with adherence within paediatric weight management programmes — a systematic review highlighted that black participants showed higher dropout rates in weight-management interventions than white participants, and low family income was associated with lower attendance in weight-management programmes in the United States.[157] Previous studies have identified that specific factors may enable (described as facilitators) or inhibit (described as barriers) engagement in terms of recruitment and retention.[141, 167] These may be internal to the service, such as a family-focused programme design and effective programme staff, or external to the service, such as personal logistics, time pressures, and parental acknowledgement of weight.[141, 167] Indigenous groups, such as Māori, face additional barriers to healthcare access and use due to significant socioeconomic disadvantage, racial discrimination, and social marginalisation,[262] largely due to the lasting effects of colonisation.[154] However, previous studies have not specifically explored barriers for Indigenous groups in accessing community-based healthy lifestyle programmes for children and their families.[141] Therefore, it is necessary to understand which factors act as barriers and facilitators to attendance, retention, and engagement in weight-management programmes, especially for groups most likely to experience obesity.

Whānau Pakari is a multidisciplinary assessment and intervention programme for children and adolescents based in Taranaki, a semirural region of New Zealand.[13] The family-centred service assesses individuals in their homes, essentially "demedicalising" care by removing paediatrician and dietitian hospital appointments. Whānau Pakari is a community-based intervention programme replacing the conventional secondary care clinical service and is unique because it incorporates a home-based medical assessment and intervention into one programme. Weekly sessions of approximately one-hour duration took place at community sporting venues and incorporated dietary sessions, including the concept of healthy food, portion size, cooking sessions, virtual supermarket tours; family physical activity sessions, including a variety of sports and games to find participants' interests; and psychology sessions, covering topics such as self-esteem and how to make healthy lifestyle changes.[13] Participants and accompanying family members signed a commitment contract, in which it was explained that participants were expected to attend ≥70% of programme sessions.[13, 107] The programme included a 6- and 12-month option, with further follow-up.[14] The service was established in 2012, and eligibility criteria are children aged 4−16 years, assessed as either falling in the obese (body mass index [BMI] ≥98th percentile), or overweight (BMI >91st percentile) categories with associated weight-related comorbidities, according to UK Cole cut-offs for BMI based on age and gender.[13, 95]

A randomised clinical trial embedded within the healthy lifestyles programme showed increased reach with equal engagement of Māori and New Zealand European participants (comprising 47% and 43% of trial participants, respectively) and with 29% of participants from the most deprived quintile of household deprivation compared with 15% of the overall population.[116, 263] Overall, all participants, irrespective of being in the high-intensity intervention or low-intensity control group, achieved a BMI SDS reduction of 0.1 at 12 months.[14] However, when participants attended ≥70% of intense intervention sessions (the number recommended before onset of the study), the change in BMI SD score was -0.22 compared with -0.04 for those attending <70% ($p = 0.04$).[14] Improvements were also seen in health-related quality of life and cardiovascular fitness in both the intervention and control groups.[14]

The aim of this study was to assess the barriers and facilitators to attendance, retention, and engagement in Whānau Pakari, particularly for Māori, by surveying past participants of the programme as part of ongoing programme efforts to address equity and retention. Second, to examine the association between ethnicity and perceived accessibility and acceptability of the programme. It was anticipated that programme factors such as location and timing of assessments and sessions would have an impact on participant engagement. This survey was an initial process preceding in-depth interviews with families.

7.2 Methods

Ethical approval for the Whānau Pakari Barriers and Facilitators study was granted by the Central Health and Disability Ethics Committee (New Zealand) (17/CEN/158/AM01). Electronic written consents were obtained from all participants.

7.2.1 Participants

Participants were from a convenience sample of past Whānau Pakari service users who had a current contact phone number on record. Inclusion criteria were parents and caregivers (or children if over 11 years of age) from the original randomised clinical trial and post-trial service users and those who were offered a referral to the service but declined further input, from establishment of the service in January 2012 to January 2017 (programme content and delivery did not change post-trial). Participants who repeated the programme twice back-to-back were excluded because of expected inaccuracies in attendance reporting.

7.2.2 Data Collection

Qualtrics software (Qualtrics, Provo, UT, 2018) was used to build the online survey, where written consent was obtained through clicking a button stating agreement with the consent statement. The survey development was informed by the theoretical framework of the broader study, which drew from Kaupapa Māori theory[229, 264] and eco-social theory.[232] This guided the identification and development of survey questions to capture structural and organisational barriers and facilitators, rather than a narrow focus on characteristics of individuals or families. The survey questions gathered data about the variables that enabled participation and those factors which deterred people from taking part. The questions were developed in consultation with a range of Māori and non-Māori researchers and stakeholders, including the Public Health Unit at Taranaki District Health Board, and were beta-tested to assess comprehension and face validity. Both the computer and mobile versions were verified for Web page responsiveness. The survey included both quantitative (demographics, yes or no questions, and Likert scales assessing agreement with statements) and qualitative (open-text comment) questions. As the survey was confidential, and the online version was anonymous, self-reported estimates of attendance rates were unable to be compared with actual attendance rates of participants. Ethnicity was collected as per the New Zealand Ministry of Health Ethnicity Data Protocols.[235]

Participants were asked to participate in a brief online survey about their experiences with Whānau Pakari. A multimodal strategy was used for both recruitment and response to allow for maximum recruitment into the study. Recruitment for the survey was by e-text with an invitation to participate in the confidential survey. The text contained a hyperlink to complete the survey online and the option to take the survey via phone or post. This was followed by three reminder texts over the following weeks. The capacity to 'opt out' of the survey was also included. One invitation to participate was sent per family, so that families with more than one child involved in the service did not receive the invitation twice. Postal surveys were sent to the address provided by the participant, and telephone surveys were scheduled at a time convenient for the participant. Survey participants were offered the chance to win a voucher for sporting goods as an incentive to take the survey.

7.2.3 Data Analysis

Quantitative data were analysed using SAS version 9.4 (SAS Institute, Cary, NC, 2016). Wilcoxon signed rank test and Spearman correlation coefficient were used because of the non-normal distribution of the data to compare the statement variables about the assessment and sessions between Māori and non-Māori and to assess the correlation with level of attendance. Logistic regression was used to assess the association of dichotomised attendance outcome variable with ethnicity and length of programme. Qualitative data collected using open-text comment fields were coded and thematically analysed in MAXQDA Standard 2018 (version 18.2.0, VERBI GmbH Software, Berlin, Germany, 2018). One researcher (CEKW) developed the coding matrix with training in development, application, and refinement from EJW and DMC, who have experience in both qualitative research and Indigenous health research. This was peer reviewed over several meetings with the wider research team for consistency within and between survey responses and to ensure overall rigour,[265] before CEKW coded the remainder of the dataset under supervision. Codes were amalgamated into related areas, which formed common themes present in the data. The research team was comprised of both Indigenous Māori and non-Māori researchers. In the event of disagreement over the interpretation of the data concerning Māori participants, it was agreed to use the "Give Way" rule, whereby each researcher's contribution and standpoint are acknowledged, and the final decision involving cultural interpretation of Māori participants' experiences passes to a Māori research team member.[245]

7.3 Results

7.3.1 Demographics

A total of 344 potential respondents were asked to participate, of which 71 completed the survey, with a response rate of 21% (71/344), which is comparable to similar surveys of patient experience (Table 7.1).[266, 267] Ninety-two percent (n = 65) completed the survey online, 3% (n = 2) completed by telephone, and 6% (n = 4) completed by post; 45% identified as Māori, and 89% of respondents were female. Eighty-two percent (n = 58) were an accompanying adult (parents or caregivers) of a child involved in Whānau Pakari. Average time to complete the online survey was approximately 12 minutes. All respondents had accepted their referral to Whānau Pakari (i.e. no families who were referred and declined further input responded to the survey).

Table 7.1: Socio-demographic And Input Level Data Of Survey Respondents (N = 71).

Participants	Description	N (%)
Accompanying adult as respondent		58 (82)
Child as respondent		13 (18)
Female		63 (89)
Ethnicity†	Māori	32 (45)
	New Zealand European	37 (52)
	Asian	2 (3)
Accepted referral		71 (100)
Level of input	Home-based assessment and weekly sessions (high-intensity)	39 (55)
	Home-based assessment only (low-intensity)	14 (20)
	One assessment then decided not to be involved in the programme	3 (4)
	Started on home-based assessments only, then moved to weekly sessions	15 (21)

†Prioritised ethnicity. Total ethnicity output is included in Supplementary Table 1 for information.

Table 7.2 shows the level of agreement across a range of statements about the assessments and programme sessions. Overall, the assessments and sessions were perceived to be convenient in terms of location and time. The programme was perceived to be both appropriate and beneficial for families. There was more variation in the level of agreement with the statement, “Other things were more important at the time.” Most participants agreed that the programme was culturally appropriate.

Table 7.2: Level of Participant Agreement Across Statements Relating to Assessments and Programme Sessions

Statement	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
The assessments were in a convenient location.	44 (62)	13 (18)	6 (8)	5 (7)	3 (4)
The assessments were at a convenient time.	37 (52)	20 (28)	5 (7)	8 (11)	1 (1)
We had the time to attend assessments.	34 (48)	23 (32)	8 (11)	6 (8)	0 (0)
The sessions were in a convenient location.	24 (44)	17 (32)	6 (11)	6 (11)	1 (2)
The sessions were at a convenient time.	23 (43)	18 (33)	5 (9)	8 (15)	0 (0)
We had the time to attend sessions.	22 (41)	19 (35)	9 (17)	4 (7)	0 (0)
We had transport to get to sessions.	37 (69)	7 (13)	5 (9)	2 (4)	3 (6)
The programme seemed appropriate for my family.	30 (56)	15 (28)	4 (7)	4 (7)	1 (2)
I felt the programme could work for my family.	31 (57)	16 (30)	4 (7)	2 (4)	1 (2)

I felt my family would benefit from the programme.	33 (61)	16 (30)	3 (6)	2 (4)	0 (0)
Other things were more important for my family at the time.	5 (9)	11 (20)	17 (32)	11 (20)	10 (19)
Previous experiences with healthcare made me not want my family to attend.	1 (2)	8 (15)	10 (19)	8 (15)	27 (50)
I thought other people might judge me and my family for attending.	5 (9)	8 (15)	8 (15)	9 (17)	24 (44)
I felt that the programme was culturally appropriate.	24 (44)	11 (20)	13 (24)	2 (4)	4 (7)

Statements concerning assessments were answered by n = 71, and statements concerning sessions were answered by n = 54, due to the survey’s branching design.

Note: Data are presented as n (%)

Regarding attendance, self-reported higher attendance levels had a weak positive but significant association with respondents reporting the sessions to be conveniently located (r_s = 0.29, p = 0.03). Attendance levels were lower when respondents reported other priorities to be more important for their family (r_s= -0.32, p = 0.02). Ethnicity was not associated with participant agreement with the statement, “I felt the programme was culturally appropriate.” However, Māori more frequently reported that past experiences of healthcare influenced their willingness to attend Whānau Pakari (p = 0.03) (Wilcoxon signed rank test).

7.3.2 Thematic Analysis of Barriers and Facilitators

Thematic analysis of open-text comments highlighted six key themes that demonstrate the barriers and facilitators to engagement in the programme experienced by participants (Table 7.3).

Facilitators identified included a concern for the child’s or family’s health, the perceived ease of accessibility of the programme, and the ongoing support received once engaged in the programme (Table 7.3). There was an indication that families are aware of the health issues and concerns and were looking for support, suggesting that this was an initial facilitator to attendance. Findings indicated that families did not believe they would achieve healthy lifestyle change on their own without support. The perceived accessibility of the service was identified as a facilitator of both the ability of the service to be convenient, accommodating and flexible, and the ability of the respondent to have access to personal resources to get to sessions, such as the availability of family support and transport. The ongoing support from the programme received by participants, once they were involved in Whānau Pakari, was another facilitator to ongoing attendance. Key terms that respondents used were “non-judgemental,” “encouraging,” “supportive,” “fun,” and that the programme built confidence and self-esteem.

Table 7.3: Participant-Identified Barriers and Facilitators to Engagement in the Whānau Pakari Programme From Open-Text Comments†

Domain	Theme identified	Example feedback
Facilitators	Motivation to improve health of child and/or family	“We needed support and help and we could not do it on our own.”
	Perceived accessibility	“Based at home […] no cost, petrol, don't have to find care for other children, flexible.”
	Ongoing support from programme	“The lady I spoke with each time was lovely, and spoke to you like a friend and made you feel comfortable.”
Barriers	Perceived suitability	“Great programme for those that need help with eating right food but we knew and was doing all the stuff we was learning about so for me it was not appropriate.”
	Perceived accessibility	“Had to stop attending as we ended up having no car to travel from [town] to [town] each week.”
	Other priorities/activities	“I admit when we were getting worn out from all the busyness, it would be Whānau Pakari that we chose not to go to.”

†Questions to elicit qualitative data included: (1) What were the factors that helped you attend Whānau Pakari sessions/assessments, if any? (2) What things prevented you from attending Whānau Pakari sessions/assessments, if any? (3) How could Whānau Pakari better meet your needs/the needs of your whānau/family? (4) Do you have any other comments about your experience with Whānau Pakari?

Barriers identified included perceived suitability, perceived accessibility, and other priorities or activities (Table 7.3). The perceived suitability or appropriateness of the programme for the child or family was a barrier for some respondents because of the wide age range of the children attending the programme, from ages 5−16 years. For others, the programme material was perceived to not be relevant for their family. In addition to being identified as a facilitator, the perceived accessibility of the programme was also identified as a potential barrier to attendance. This likely reflected the need to travel to the weekly group sessions, rather than the home-based assessment aspect of the programme. Lastly, respondents identified that attending Whānau Pakari was not a priority over other activities or work.

7.4 Discussion

In this study of New Zealand caregivers and participants referred to a community-based multidisciplinary assessment and intervention service for children and adolescents with obesity, the key findings were that concern for family health and the ongoing support provided by the team were key facilitators to initial and ongoing attendance. Perceived suitability of the programme and the importance of other family priorities were found to be key barriers. Perceived accessibility of the programme emerged as a key facilitator and barrier, depending on individual family circumstances. Second, although the programme was considered culturally appropriate, past experiences of healthcare were reported to influence willingness to attend for Māori, but these experiences were not elaborated on in the qualitative comments.

Kelleher and colleagues[141] identified personal and programme logistics as barriers to initial and continued attendance. In this survey, the identification of programme accessibility as both a facilitator and a barrier highlights the limitations of healthcare services in a fiscally-constrained environment to have capacity for programme delivery in more locations around the region.

Whereas the Whānau Pakari home-visit assessment model has removed the barrier of accessing a hospital appointment and overcome transport barriers, accessing weekly sessions is still highly dependent upon personal logistics such as service users having time and their own transportation. In addition, both the quantitative and qualitative data suggest that attendance is diminished when the programme is considered a lower priority in comparison with other family activities or considerations, which is also reflected in the literature.[141]

The strong agreement with the statement that the programme was culturally appropriate is encouraging as Whānau Pakari endeavoured to be more responsive and appropriate for Māori participants than the previous model of care. However, Māori respondents reported that past experiences of healthcare affected their willingness to attend Whānau Pakari. This suggests that further understanding of the relationship between past experiences of healthcare is required to understand how to improve engagement for Māori. While this has not been explored in the context of community-based healthy lifestyle programmes, this finding has been explored in other areas of healthcare use, such as the association of negative health experiences with lower rates of cancer screening for Māori women[262] and the impact of past experiences on healthcare use among Aboriginal cardiac patients in Australia.[268]

The findings of this study were generally consistent with a previous systematic review of barriers and facilitators to initial and continued attendance in community-based lifestyle programmes, which showed that parental concern for child health and wellbeing was a driving factor to attendance, and over time, positive programme experiences fostered continued attendance.[141] In this survey, the collection of open-text comments alongside the quantitative data provided valuable insight into participant experiences, and the ongoing support received from the programme deliverers was identified by respondents as a facilitator of ongoing engagement. The New Zealand Health Survey highlighted that Māori and those from the most deprived levels of household deprivation experience the greatest levels of unmet need owing to cost or transportation.[261] Given these groups are over-represented in child obesity statistics, the continuity of care provided by a multidisciplinary team undertaking an assessment and intervention is likely to favourably address equity in this area.

A strength of the study was the wide representation by ethnicity with 45% of respondents identifying as Māori. This is comparable to the recruitment rate in the Whānau Pakari randomised clinical trial[13] and higher than the underlying proportion of Māori in Taranaki, which is 19%.[263] Limitations included the unavoidable level of sample bias due in part to response rate, which may have affected validity, and the potential recall bias for some participants whose time period between programme participation and survey response was up to five years. This study tried to attain the greatest response rate possible by offering multiple modes for responses and sending two-weekly or fortnightly reminder texts during the study. Despite the low response rate, there was good representation from Indigenous respondents, which suggests that the findings are still useful.[269] This study also included respondents who had the option to be involved in a 6-month or 12-month programme, the latter of which had two more opportunities for contact via assessments, which may have resulted in differences in programme experience. However, this survey is a representation of the real-world experience of a clinical service of this nature, which is why it was opted to include this group within the study.

7.5 Implications for research and practice

Given that only participants who had accepted their referral responded to the survey, there is a need to determine the barriers to initial engagement for the group who declined further contact with the service after being referred. In-depth interviews are underway to understand the barriers for this group and the relationship between past experiences with healthcare and subsequent engagement with services such as Whānau Pakari, particularly for Māori. It is hoped that understanding the barriers and facilitators to engagement in Whānau Pakari can contribute toward the improvement of prevailing healthcare models and help work toward health equity.

Supplementary Table 7.1: Total ethnicity of respondents: multiple responses per respondent possible.

n		71
Ethnicity	Māori	32
	New Zealand European	56
	Asian	3
	Pacific Peoples	1
	Other	3

7.6 Addendum

Since publication, the following data and information has been updated:

- The Childhood Obesity Strategy is under review by the current Government, and no longer formally in place (see 7.1).

8 Results: Interviews – Determining barriers and facilitators to engagement for families

Phase two of the barriers and facilitators project focused on understanding the experiences of families involved in Whānau Pakari. This was to determine the barriers and facilitators to participation, especially for families with varying levels of engagement. Building on the survey study in Chapter 7, it was important to understand if there were factors that could be modified to facilitate engagement. The manuscript in this chapter explores the experiences of participants accessing both Whānau Pakari and the wider health system and includes participants who declined their referral and had no further contact with the programme.

Submitted for consideration of publication to *BMJ Open.*

Wild CE, Rawiri N, Willing EJ, Hofman PL & Anderson YC. Determining barriers and facilitators to engagement for families in a family-based multidisciplinary healthy lifestyles intervention for children and adolescents. Submitted paper. Forthcoming 2020.

8.1 Introduction

Excess weight in childhood and adolescence affects physical, psychological and social health and well-being, and is a known risk factor for comorbidities both in childhood and adulthood.[29] Children with weight issues in Aotearoa/New Zealand (henceforth referred to as New Zealand) demonstrate a high prevalence of weight-related comorbidities, as well as low physical activity, suboptimal eating behaviours, and low health-related quality of life.[116, 133-135] One of the key recommendations of the World Health Organization's Report of the Commission on Ending Childhood Obesity is to "provide family-based, multicomponent lifestyle weight management services for children and young people who are obese".[12] A systematic review and meta-analysis found that a minimum of 26 hours of contact time in lifestyle interventions is associated with improvements in weight status in children and adolescents.[87] However, as with any service attempting to facilitate lifestyle change, success relies on continued family engagement.[140] It is also important that such multidisciplinary services – and other health professionals addressing childhood obesity in a primary care setting – are able to engage with groups most affected by obesity, namely those living in the most deprived areas and ethnic minorities.[33]

Improving *engagement* with childhood obesity services requires addressing both initial recruitment and ongoing retention.[140] Service, system and society-related factors may *enable* or *inhibit* initial and ongoing engagement; factors which are also referred to as facilitators and barriers.[141, 167] A review of the factors affecting attendance at community-based lifestyle programmes found that weight stigma, parental reluctance to identify overweight and logistical challenges were key barriers to initial and ongoing attendance.[141] Under-represented in the literature are those who declined treatment altogether, as many past studies had low recruitment from these families. Therefore, it is important to understand the experiences of families experiencing childhood obesity in order to improve initial recruitment and ongoing retention in healthy lifestyle services, particularly for groups most affected.[141]

Whānau Pakari is a family-centred, community-based assessment and intervention programme for children and their families, based in Taranaki, a mixed urban-rural region of New Zealand (NZ). The name means 'healthy, self-assured families that are fully active'. The focus of the programme is on healthy lifestyle change rather than weight loss or obesity, in order to minimise judgement and weight-related stigma. The multidisciplinary service involves a home-based medical assessment with advice, removing the hospital appointment in order to *demedicalise* care, and includes weekly nutrition, physical activity and psychology sessions. This approach takes healthcare outside hospital walls and into the community, without compromising quality of care. A randomised clinical trial of the Whānau Pakari model of care demonstrated modest reductions in body mass index (BMI) standard deviation score (SDS) and improvements in cardiovascular fitness and health-related quality of life.[13, 14] Greatest improvements in BMI SDS were found in those who attended the recommended ≥70% of intense intervention sessions.[14] However, Māori (NZ's Indigenous population) and females were less likely to attend ≥70% of sessions, with sustained retention in the programme favouring males and NZ Europeans.[14]

Previous evaluation of the experiences of Whānau Pakari participants and their caregivers has shown the programme to be a positive and beneficial experience for those involved, emphasising the importance of connectedness, knowledge-sharing and self-determination, the collective journey alongside other families and programme deliverers, and the importance of a non-judgemental, respectful environment.[137] However, a survey of past participants of Whānau Pakari indicated that previous experiences of healthcare may influence subsequent engagement with health services, particularly for Māori.[270] Therefore, the objective of this study was to understand barriers and facilitators to initial attendance and ongoing retention in the Whānau Pakari programme.

8.2 Methods

8.2.1 Design

In NZ, health research is required to be responsive to the needs and diversity of Māori.[214] The study design and research approach was informed by Kaupapa Māori theory, which resists persistent power imbalances and the continued use of cultural deficit theory (attributing poor health to something inherent to a 'culture') to explain inequities between Māori and non-Māori.[214, 221] Kaupapa Māori research is an approach which centres Māori voice and experience and is aligned with a social and structural determinants of health framework.[223] Subsequently, priority was given to ensuring that the voices and experiences of Māori participants were understood in this study. In-depth interviews, centring on participant experience with Whānau Pakari and wider experiences of the health system, were undertaken. A specific focus was to understand the barriers to attendance and retention at varying levels of engagement in Whānau Pakari, including those who declined their referral and had no further contact with the programme. Factors which facilitated both initial and ongoing engagement were explored.

Ethical approval for the Whānau Pakari Barriers and Facilitators study was granted by Central Health and Disability Ethics Committee (NZ) (17/CEN/158/AM01). Written informed consent was obtained from all study participants.

8.2.2 Participants

Eligible participants were parents and/or caregivers of children and adolescents who had been referred to the service from January 2012 to January 2017. Children and adolescents over 11 years of age were also invited to participate. The eligibility criteria for referral to the service are children aged five to 16 years, identified as having obesity [body mass index (BMI) ≥98th centile], or overweight (BMI >91st centile) with associated weight-related comorbidities.[13, 95]

Participants were recruited from four different groups of Whānau Pakari service users who had varying levels of engagement (≥70% attendance at sessions, <70% attendance at sessions, dropped out after one assessment, and referred but declined further input) using stratified random sampling. Recruitment was via telephone call and text message. The sample contained equal numbers of families with Māori and non-Māori children to ensure appropriate representation of Indigenous children's experiences.

The interviews were conducted by CW and NR together where possible. NR led the interviews with Māori families when appropriate. Interviews took place in the participant home or alternative locations chosen by the participant (including a hospital, participant workplaces, and a community library) in order to minimise inconvenience and travel barriers. A *koha* (gift, donation or contribution) was offered to participants in acknowledgement of their time and as a sign of reciprocity for the information shared.

8.2.3 Data collection

Informed consent was obtained to record, transcribe and analyse participant data. All participant information was anonymised. Participant ethnicity for both the parent/caregiver and child was confirmed at the time of the interview by using the NZ Census 2006 ethnicity question.[235] All interviews were audio-recorded and independently transcribed. Participants were offered their transcripts to review for accuracy and acceptability.

8.2.4 Analysis

Interview transcripts were coded and analysed thematically in MAXQDA.[236] CW developed the coding matrix with peer review from EW, coded the interview data, and identified the initial themes. The authors collaborated to finalise the themes and develop the framework. The acknowledgement of different researcher standpoints allowed the authors to debate, challenge, and refine interpretations of the data. Specifically, the researchers agreed to apply the ‘Give-Way’ rule if there was disagreement over the interpretation of the data concerning Māori participants, with the final decision involving cultural interpretation of Māori participants’ experiences passing to a Māori researcher.[210, 223, 245]

8.2.5 Patient and Public Involvement statement

Participants were first involved in the research at the recruitment stage, although some participants had been involved in an earlier related randomised clinical trial.[13] The research questions were informed by the experiences of participants voiced during clinical assessment and in previous focus group research.[137] The design of the research drew from Kaupapa Māori theory, which informed the research process in order to prioritise the experiences and preferences of participants. The dissemination process to participants was altered as a result of participant preference to receive feedback via a summary video, rather than at a group meeting. Participants were not asked to assess the burden of the time required to participate in the research.

8.3 Results

Sixty-four interviews were conducted (out of a potential cohort of 74) with families who had varying levels of engagement, across a six-month period from June to November 2018 (76 participants in total) (Table 8.1). Half of the interviews were with Māori families (families with a Māori child who had been referred to the service), including interviews with non-Māori parents of a Māori child.

8.3.1 Demographics

Table 8.1: Participant demographics

Interview participants N		76*
Female participant *n*		65
Ethnicity %†	Māori	32
	NZ European	75
	Asian	7
	Other European	5
Level of engagement *n*	Attended ≥70% of programme sessions	18
	Attended <30% of programme sessions	19
	Had one assessment, then discontinued with the programme	7
	Referred, but chose not to engage	20

*64 interviews total, 11 interviews involved 2+ family members.

†Total ethnicity output (more than one ethnicity selected)

Three major domains and subthemes affecting participant engagement are described in Table 8.2 in participants' own words. A fourth domain of respectful, compassionate care was identified as a mediator, which was able to mitigate the effect of the first three themes.

8.3.2 Domain 1: Obesity sits within the context of multiple other complex stressors for families in NZ

Participation in the Whānau Pakari service was affected by the multiple complex stressors of living in contemporary New Zealand. These were acute, one-off adverse events, such as a death in the family, and chronic, ongoing challenges, such as financial insecurity. Childhood obesity and overweight as a health concern sat within the context of multiple other important concerns for families. Participants were often living in 'crisis mode' or dealing with multiple challenges at once, including: financial and food insecurity, suicide, abusive relationships, deaths in the family, mental health issues, disability, relocation, marriage and family break-ups, fostering children, children being raised by other caregivers, drug use and significant other illnesses.

For parents of children with multiple health conditions, especially mental health concerns or autism spectrum disorder, addressing weight was often not perceived to be as important compared with other competing family health concerns. Parents and caregivers also reported the challenges of balancing multiple demands such as long work hours, shift work and extracurricular activities alongside attending Whānau Pakari.

> 'I think he had one of his sporting things on and I was doing 50 hours a week at that time and I was like 'oh, my God, I can't do it', I couldn't do it. I mean, if he needed, if I felt like he needed to be there, I would get him there, like, it's, my work's not that important. Weeds and shit can wait, you know, like, people can wait um if it was a, if I felt like it was serious. I would have got him there, but I just yeah.'

Similarly, socioeconomic deprivation and food insecurity were perceived to be more immediate and pressing concerns than childhood overweight or obesity. Both initial attendance and ongoing retention were affected by a lack of participant resources, even if participants expressed a desire to attend. Participants who engaged with Whānau Pakari and other services despite the impact of adverse stressors appeared to have more resources.

Table 8.2: Key determinants of engagement and retention in Whānau Pakari

Domain and subthemes	Example participant quotation
Adverse life stressors & socioeconomic deprivation	‘I wouldn’t say it was, like, you guys as such – it was just the history behind what she had um, but we come from, so um I came from an abusive marriage, which had split up because of abuse... So this was really hard at the time.’
	‘Once she lost her father, well that was pretty much the end of it. She just didn’t want to do nothing. As much as I tried to encourage her to, you know, get with the programme, no she just didn’t want to know about it.’
Competing health priorities	‘…[DAUGHTER] was under [child and adolescent mental health services] for suicide watch and stuff like that… so for us there was that added stuff as well.’
Financial insecurity/socioeconomic status	‘I didn’t have a house and lived in that camper. Yeah, so it just didn’t work out, otherwise she would have gone.’
Societal norms of weight and body size	
Age	‘Like, a weight problem, like, at the time he was only six years or seven years.’
	‘… we were kind of shocked because they said that [SON] was, like, obese or something … I don’t think he’s overweight at all… Because he’s really tall… so I don’t understand, like, what sort of weight should he have been because he was, he’s just like a, he was like a normal kid. So I don’t understand what is overweight and underweight. Because I’ve seen some, not being mean, but overweight kids, and he wasn’t overweight.’

Gender	‘She might develop an eating disorder and I don’t want that. I’d rather, you know, it’s weird, but I’d rather she be overweight than underweight, you know what I mean? I’d hate to deal with an anorexic daughter because that’s hard work.’
Genetic Disposition	‘You know… it’s just the way it is sometimes. Some people get good genes, some people get other genes and it means it doesn’t work out.’
Historical experiences of healthcare	
Weight stigma and discrimination	‘… having visited for something else entirely different and then being told kind of ‘your child’s obese and we are going to refer you’ and just doing it front of him […] it was just even in the way that it was delivered and I was kind of not expecting it. I mean, I can see that he’s, he’s a bit chunky, but I just, I don’t know […] [the referral] was a bit off-putting.
Racism	‘…people will judge you for what and where, what colour you are or whatever… [it] just made me more determined to get in there and do what I had to do.’
Respectful, compassionate care mitigated past experiences	‘It was not just the families, but also the, what do you call them, the workers… Very supportive, non-judgemental. I think that made a big difference and ‘yes we are going to go’ because they are not judging you… the staff was very supportive.’

8.3.3 Domain 2: Societal norms of weight and body size affect how people experience seeking care for weight

8.3.3.1 Age

The age of the child involved in the service affected the degree to which families chose to engage, due to a perception that children were too young to have weight problems, which was a key reason for both dropping out of the service early or declining input altogether. Children who were clinically overweight or had obesity were perceived to be a normal weight in early childhood and increasingly beyond. Some participants felt that while their child might not fit into a set of assessment criteria, this did not necessarily equate to their child being unhealthy.

> ‘When he got put in the […] ‘oh, he’s overweight’ box. And when you’re, like, ‘he’s not that overweight’, because it was just he wasn’t in their little boxes. I think that more annoyed me, is that they’ve got these sort of, like, ‘this is the normal weight for a five year old’. Well, there’s all sorts of different five year olds. He’s now ten years and he is my height […] he’s a big guy.’

There was a strong belief that if children were ‘big but active’, then their weight was not a concern.

> ‘…he’s always been big, but he’s really active. Like he wins the triathlons and the cross-country and he bikes and swims… it’s not like he can’t exercise or is held up, you know what I mean? And so we just thought well, and it’s not like he wasn’t healthy eating.’

8.3.3.2 Gender

Families appeared more reluctant to engage their female children in services that are characterised as weight-related, both at initial recruitment and throughout the programme, for fear of their child developing self-esteem issues. Parents also reported their daughters were often reluctant to attend themselves.

> ‘To me it’s like you don’t need to involve her because she’s already self-conscious, soft-hearted, already upset about it sort of thing and, like, to me it was like more of a trigger. So, I was, like, no. I will do it my way. So I pulled back because it wasn’t worth it for her, you know what I mean? Like, her self-esteem and stuff is worth more than, you know, going to a dietitian where at home I can just stop giving her all that stuff to make her healthier. So that’s where it comes across wrong.’

8.3.3.3 Genetics

Overweight and obesity was often associated with genetics by participants. This was sometimes specifically linked to ethnicity, and specifically the perception that Māori and Pacific peoples are ‘naturally big’. A familial propensity towards overweight resulted in participants reportedly acting in two ways: either they did not want to engage because they felt that there was no point, given their weight was genetic (Table 8.2), or they were compelled to engage more in order to counteract their genetics:

> ‘My side of the family is really obese so weight has always been an issue, so if you are trying to diet everyone gets behind you because they know what the challenge and the battle is. No, we don’t really care what other people say, we just get on with it.’

8.3.4 Domain 3: Historical experiences of healthcare affect future perception and engagement with services

Past experiences of healthcare influenced participants' opinions, perceptions and behaviour in relation to seeking care again. This was a multidimensional phenomenon, acting across both weight and ethnicity. If participants had had negative experiences in the health system in relation to their weight or ethnicity, then they were less willing to engage with Whānau Pakari and other health services. This was especially important if the referral experience to Whānau Pakari was negative, given that this may have been the first instance of being confronted about their child's weight.

> 'Basically they told her she was obese [at the B4 School Check] … Yeah, that she was obese for her age and they said this in front of her, and she was like "what is obese"? And they said, "you're bigger than any other child your age" but she's not the only one […] So they say it in front of a child, it sort of knocks their self-esteem and their confidence right back.'

While weight stigma was experienced across all groups of participants, there were few feelings of stigma about attending Whānau Pakari for those participants who engaged highly (≥70% of sessions):

> 'There was nothing to be embarrassed about. You know, like secretive about it. It was something that I was doing for my kid, to help her get better in herself and if someone else had a problem then that was their problem, not mine. At the end of the day it is about her. Not about what anyone else thought.'

Experiences of racism in the healthcare system and in wider society affected how participants reengaged with health services. This included a wide range of race-related experiences from interpersonal to institutionalised racism. Likewise, participants recounted a variety of responses to these experiences from renewal of engagement and wanting to 'prove them wrong', to disengagement with outside entities and organisations, to internalised racism.

> '…we have been through so much stigmatisation that nothing more than one thing matters […] because for us it's about the betterment of our children and our whānau [family] as a unit.'

8.3.5 Mediator 1: Respectful, compassionate care mitigated past experiences

Conversely, positive and respectful care received in both the Whānau Pakari programme and in other areas of the health system mitigated the effect of the first three determinants, particularly against the impact of past negative experiences of healthcare. A positive referral experience generally set a positive tone for interacting with the Whānau Pakari service itself.

> 'So we decided yes, this would be an awesome programme for our daughter, because we wanted her to just have some stability at the time because she was just starting High School, going into a phase where people were judging and things like that, you know, building her self-esteem […] It's helped her with her confidence and just building a life that's easy for her, you know. So, yeah, I thank [referrer] for that and for putting us onto that programme too because it was really awesome. We, as a whānau, we enjoyed it, and just being able to support her in that programme.'

Participants who did engage with Whānau Pakari reported that the care received in the programme was 'different' from previous care received and that the programme deliverers were 'like a family'. For these families, the respectful and compassionate care countered some of the negative effects of past experiences.

> ‘It was just the people, that’s all it was. It was just the approach of the people to be honest um and that made us comfortable, and I go by my children a lot because if they’re uncomfortable well then they’re not the right people to be around for us. And they were comfortable.’

The social and team aspects of Whānau Pakari were beneficial for families, as well as the perceived extra care received

> ‘I liked it. I didn’t think I was going to. I thought ‘oh, this is going to be stupid’, but no it wasn’t. It was actually a bit of an eye opener. I actually learnt something. And then we just recently got her blood tests and all that done again because through the doctors they didn’t do no diabetic tests or anything like that. Through Whānau [Pakari] they did. They did heaps more than the doctors did. So I think that’s pretty much why we stayed with them, it was like ‘aha, we can get some serious help here’.

Figure 8.1 summarises the interacting and mitigating domains affecting participant engagement.

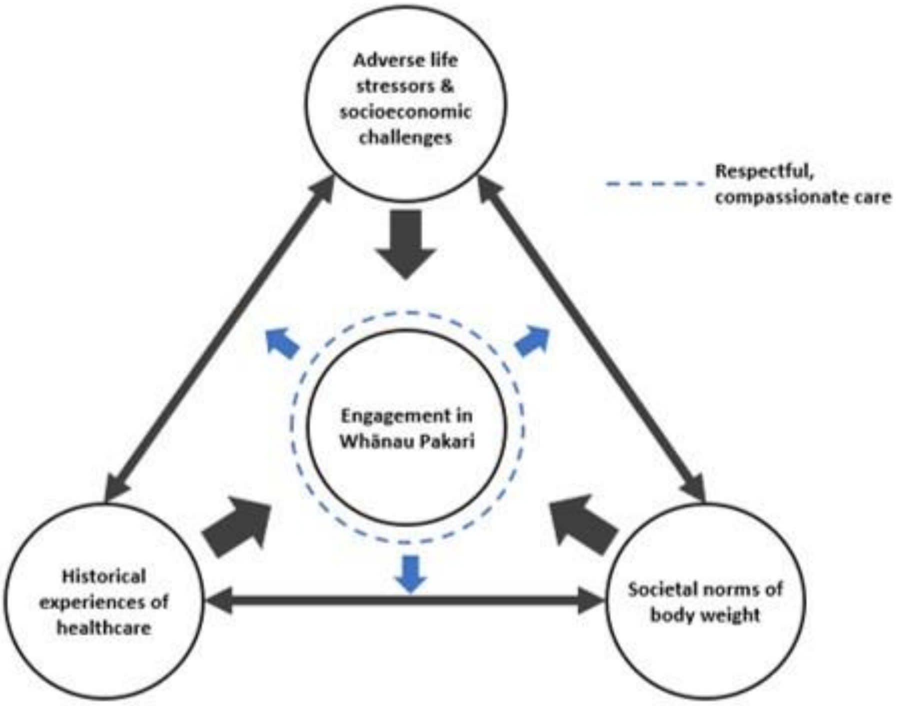


Figure 8.1: The three interacting factors that influence participant engagement in Whānau Pakari. Respectful, compassionate care can partially mitigate the effects of these determinants.

Discussion

This study found that engagement in Whānau Pakari was determined by the degree to which participants were affected by three interactive domains: complex adverse life stressors, societal norms of weight and body size, and past experiences of healthcare. These complex mechanisms operated at multiple levels including at the service, health system and wider societal levels, so that experiences at the seemingly distal societal level could still have an impact on participant engagement at the service level. While the impact of these factors was evident across all four groups, some participants appeared to be resilient to the impact of these determinants. Additionally, respectful and compassionate care appeared to act as a positive mediator. Conversely, participants who declined further input after their referral were more likely to be experiencing greater life stressors without the resources to overcome them. Participants also appeared to be affected by societal norms of weight with regards to age, gender and the perceived impact of genetics, and negative experiences of healthcare often resulted in complete disengagement.

We were surprised that clear recommendations for specific changes to internal programme aspects were not forthcoming from participants across all levels of attendance, as this was a specific intent of the project. Although factors such as the difficulty of attending programme sessions with shift work and other stressors were identified as a barrier by some participants, there was no clear consensus on factors such as timing and location. While forces external to the service affected engagement, our study indicates that there are opportunities at the service level to facilitate initial and continued engagement in Whānau Pakari, and potentially other services. Despite the negative experiences of participants in the health system (both weight and non-weight related), the care received in Whānau Pakari by deliverers was generally seen as ‘different’, and a key reason for wanting to continue with the service.

In our study, many participants who declined further engagement after their referral were reluctant to identify their young children as having weight issues and requiring assistance. Past research has identified multiple reasons for parental reluctance to identify overweight in their children,[165] including not recognising obesity as a ‘disease’ and, therefore, not warranting the same attention as other health concerns, and wanting to avoid further stigmatising their child. Our data suggests that families are especially concerned with the mental health of their children, which was often perceived to be more important than identifying and addressing overweight and was a key reason for declining referrals. There appears to be a disconnect between the focus on early life intervention due to the growth trajectories of young children with overweight or obesity into adolescence and adulthood,[101, 125] and the concerns and priorities of parents with young children.

Research indicates that parents of girls with overweight or obesity are more likely to enrol them in healthy lifestyles programmes than families with boys with overweight or obesity.[141] The contrasting findings of our study, which also included participants who declined their referral, show clear parental concern for the mental health and self-esteem of their daughters, which may reflect a desire to focus on positive body image, self-esteem and mental health and avoid increasing body dissatisfaction.[48] The findings of this study would suggest that the differences in how males and females experience weight in NZ society contributes towards the differing retention rates between male and female participants at the service level. It is concerning that two important health issues – overweight and mental health – are pitted against each other as perceived incongruent concerns, given that both are significant causes of ill-health among children and adolescents, and suboptimal health-related quality of life was identified in a previous cohort with weight issues.[135]

It has been argued that message framing with regards to terminology is vital in childhood obesity programmes, in order to prevent further stigmatisation of families seeking help for weight.[42] While the Whānau Pakari *programme* aims to be non-judgemental and non-stigmatising, it is equally important that the *referral* to the service is perceived to be non-stigmatising by families in order to encourage engagement. Given the impact of the referral experience on Whānau Pakari in relation to initial and continued engagement with the service, the referral process must be respectful and compassionate, with an acknowledgement of past instances of stigma and discrimination. The sensitivity of weight as a discussion topic requires non-judgemental language, compassion, and an acknowledgement of the wider context and potential pressures on the family.[42]

As in previous studies,[189] many participants in this study had experienced weight stigma, blame and judgement from health professionals as well as a societal culture of weight bias. Indigenous participants often experienced this in addition to varying forms of racism. The impact of racial discrimination on healthcare use in NZ is well-documented,[198, 271] and the compounding impact of multiple stigmas is likely to contribute towards differential attendance rates between Māori and NZ Europeans. Previous weight bias and racism which occurs outside the service may play a role in participant reluctance to engage with Whānau Pakari. Further research should investigate the role of racism and weight stigma in engagement with healthcare for weight issues among ethnic minorities.[272]

The strengths of this study include the large sample size across participants with varying levels of engagement which allowed for in-depth and broad analysis. In addition, this study included data from a targeted group of participants (those who declined further contact after referral) whose lack of contact with the service limits the power of quantitative methods in drawing conclusions, and who are typically difficult to recruit, as recognised in previous studies.[141] Finally, there was good representation from families with Māori children who comprised approximately half of the interviews, allowing us to draw conclusions for a group whose voice is historically absent from obesity research.

The main limitation of this study was the lack of child and adolescent voice with regards to their experiences with Whānau Pakari. While it was intended to conduct interviews with families, many parents at recruitment were reluctant to involve their children due to the sensitivity of material discussed or were unable to involve them due to timing issues. This meant that children's experiences have only been explored through their parents' accounts, rather than through their own voice. It is possible that participants were discretionary in what they chose to share; however, the disclosure of extremely personal and sensitive experiences suggests that any researcher – participant power dynamics were overcome by steps the interviewers took to mitigate this difference.

8.4 Conclusions

In conclusion, this study found that much of the difference between Whānau Pakari participants who engaged highly and those who did not engage appeared to be due to the degree to which participants were affected by the impact of factors at the system and societal levels. Focusing purely on weight in multicomponent interventions does not acknowledge the complexity of contemporary family life. However, family-based multidisciplinary intervention programmes such as Whānau Pakari are an opportunity to acknowledge the wider societal challenges affecting achievement of healthy lifestyle change. Health professionals and providers can engage in respectful and compassionate care to help counteract past negative experiences of healthcare. Referral pathways for healthy lifestyle change programmes need to be as flexible as possible to remove any barriers to engagement, and referrers need to develop a deeper understanding of the importance of the referral conversation in relation to weight. Respectful, compassionate care is critical to enhanced retention in programmes, and ongoing engagement in healthcare services overall.

9 Results: Interviews – What affects programme engagement for Māori families?

It was important to understand the specific experiences of Indigenous families in order to provide family-based, multidisciplinary healthy lifestyle programmes that are culturally appropriate. This chapter contains the manuscript reporting factors affecting engagement for Māori families in order to understand inequities in attendance rates in Whānau Pakari. It also considers whether Whānau Pakari was perceived to be culturally appropriate for Māori families.

Submitted for consideration of publication to *Journal of Paediatrics and Child Health.*

Wild CEK, Rawiri NT, Willing EJ, Hofman PL & Anderson YC. What affects programme engagement for Māori families? A qualitative study of a family-based, multidisciplinary healthy lifestyle programme for children and adolescents. Submitted paper. Forthcoming 2020.

9.1 Introduction

Indigenous peoples face increased barriers to accessing healthcare.[154] Racism is a known determinant of health and driver of ethnic inequities, and is increasingly acknowledged as shaping healthcare interactions and outcomes.[198, 199] *Institutional or systemic racism*, as a lasting effect of the colonisation of Indigenous peoples worldwide, is reflected in differential access to social, political and economic resources, as well as poorer health and social outcomes, and can operate without identifiable individual perpetrators.[7, 196] *Interpersonal racism* refers to personally-mediated prejudice and discrimination, and may appear in the health system in a more covert and passive form, manifesting as *implicit racial bias*, a belief or association about a racial/ethnic group that may be automatic.[200] Lastly, *internalised racism* refers to the acceptance and internalisation of racial assumptions and stereotypes by the groups themselves in society.[196, 198-200] In Aotearoa/New Zealand (henceforth referred to as New Zealand [NZ]), Māori (the Indigenous people of NZ) report a higher prevalence of racial discrimination and are also more likely to experience multiple forms of discrimination compared with NZ Europeans.[273] Racism is known to be associated with both poorer health outcomes and reduced access to healthcare and resources.[201]

Under the Treaty of Waitangi/Te Tiriti o Waitangi[215] and reinforced by commitments to international conventions such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and the United Nations Convention on the Rights of the Child (UNCROC),[274] health professionals and researchers in NZ have an obligation to address health inequities for Māori. One of the key guiding principles of the NZ Health Strategy is equitable access to health services,[212] in order to improve health outcomes for those most affected by conditions such as obesity. Furthermore, the Waitangi Tribunal's Health Services and Outcomes Kaupapa Inquiry recently recommended that the NZ Public Health and Disability Act 2000 be amended to include a health sector objective to achieve equitable health outcomes for Māori.[80]

While high prevalence rates of obesity are an issue for all groups,[22] inequalities persist globally in both prevalence and access to healthcare, across ethnicity, gender, and socioeconomic status.[65] Multidisciplinary intervention programmes remain internationally recommended best practice in terms of addressing childhood obesity.[12, 87] The retention of families in community-based healthy lifestyle programmes is key to positive health outcomes.[14, 141] However, previous research also demonstrates inequities in attendance between different ethnic groups – a systematic review of ‘barriers’ and ‘facilitators’ to participation within paediatric weight management programmes showed higher dropout rates among Black participants and those on a low family income than White participants in the USA.[157] However, few studies have explored the underlying reasons for differences in attendance among Indigenous groups and other marginalised ethnic groups, or have cited ‘cultural inappropriateness’ of the programme as the reason for disengagement.[178]

In NZ, obesity prevalence rates are 1.6 times higher in Māori children and three times higher in Pacific children compared with the overall population of children aged 2-14 years (11%).[11] Inequities in socioeconomic position also exist, with children living in the most socioeconomically deprived areas being twice as likely to experience obesity than those living in the least deprived areas.[11] These findings are consistent with inequities between Indigenous and non-Indigenous populations in international statistics.[65]

Whānau Pakari is a family-based assessment and intervention programme for children and adolescents with weight issues, with a multidisciplinary team including a paediatrician, physical activity specialist, dietitian, healthy lifestyles coordinator, and psychologist.[13] It aims to be non-stigmatising, with a focus on healthy lifestyle change rather than weight or obesity. The programme has replaced the conventional hospital-based model of care within the prevailing healthcare model in Taranaki, NZ, in order to provide more accessible, appropriate healthcare. The results of a randomised clinical trial embedded in the service found that participants achieved a modest reduction in body mass index standard deviation score (BMI SDS), as well as achieving positive changes in health-related quality of life and cardiovascular fitness. Greater reductions in BMI SDS were achieved if participants attended ≥70% of programme sessions [14] While service recruitment included approximately equal numbers of Māori and NZ European (NZE) participants, Māori and females were less likely to attend the recommended number of sessions.[14]

A concurrent paper describes the results of 64 interviews with Whānau Pakari participants with varying levels of attendance in order understand the barriers and facilitators to engagement in Whānau Pakari.[275] The aim of this paper was to specifically explore the experience of Māori families in order to understand why there were inequities in programme attendance for Māori participants and their families in terms of long-term retention. Given these inequities, we also sought to determine whether Whānau Pakari was perceived to be culturally appropriate for Māori.

9.2 Methods

In NZ, health research should be responsive to the needs and diversity of Māori.[214] The approach of this research team was developed with the aim of contributing towards the elimination of health inequities for Māori, and resisting both persistent power imbalances and the continued use of cultural deficit theory to explain inequities between Māori and non-Māori, which attributes poor Māori health to Māori 'culture' or something inherent to Māori as a social group.[221]

Ethical approval for the Whānau Pakari Barriers and Facilitators study was obtained from the Central Health and Disability Ethics Committee (NZ) (17/CEN/158/AM01) and all study participants gave written consent to participate.

The method for conducting the interviews has been described previously.[275] In brief, CW and NR undertook 64 in-depth interviews in the home with past participants of Whānau Pakari with varying levels of engagement, with equal numbers of interviews with families with Māori and non-Māori children. Interview participants were mainly parents and/or caregivers of children involved in Whānau Pakari, and several children also participated. Interview recordings were independently transcribed and participants were offered their transcripts to check for accuracy and acceptability. The interview transcripts were coded and analysed in MAXQDA software using thematic analysis, identifying common patterns across participants as well as differences between groups with regards to the level of engagement, gender, ethnicity and age. The authors collaborated to finalise the themes and develop the framework, with agreed respectful parameters allowing the authors to debate, challenge, and refine interpretations of the data. Specifically, the researchers agreed to apply the 'Give-Way' rule if there was disagreement over the interpretation of the data concerning Māori participants, and the final decision involving cultural interpretation of Māori participants' experiences would pass to a Māori researcher.[223] Results of the interviews with Māori whānau (families) are described.

9.3 Results

This study's findings aligned with Camara Jones' framework for understanding racism and its impact on health service engagement.[196] The core themes identified in the results were therefore categorised utilising this framework and have been grouped accordingly: Institutional Racism; Interpersonal Racism; and Internalised Racism, although it is important to acknowledge these are not discrete categories. This study also identified what was considered culturally appropriate care for participants (Table 9.1).

Table 9.1: What affects engagement for Māori families?†

Theme	Example participant quotation
Institutional or Systemic racism: substantial structural barriers & socioeconomic deprivation	‘And that’s what I said at the family group conference [a meeting coordinated by child youth and family services]– ‘I disagree with that because they were being fed’. It might not be healthy to some people. But at least they were eating.’
Interpersonal racism: cumulative effect of weight stigma and racism	‘…so firstly what I think happens for families who are vulnerable, and we sit in that category because we have disability in our family and I’m a single parent, and you layer that and all sorts of things that go with that and especially with [SON 1] because he’s Māori and he’s carrying weight so you add that on top of that… so there’s a big huge vulnerability that sits in around that…’ ‘… [my husband is] dark, he dresses like the rest of the [suburb] boys, which doesn’t always come across to professionals as… they assume things that aren’t necessarily true, but they put him in that basket a lot, into the sense that at times he wouldn’t be able to pick up our own son’s medication from the chemist. Yeah, and that used to piss me off. It was like ‘what?’ But, yeah they just put you in that category. And it’s, yeah, not fair.’
Internalised racism & biological determinism: perception that ancestry determines outcome	‘ [referring to Māori ancestry] That’s why he’s built like he is.’ ‘… he was a bigger boy and I mean, you know, I’m big, his father’s bigger than me so it’s just in his [blood].’

Appropriate care: respectful, compassionate, positive relationship-building	'… we left them to talk by themselves, you know, in our whare [home], which was great because they came out to our house… you could just see the change, you know, just having a conversation with her about what the programme was about and how it could benefit her wellbeing, more so than anything else, but um just seeing her flourish from that conversation was huge. It was just huge. And for us to see her, oh she's starting to smile a little bit more, you know, and being talkative… Well, she wouldn't talk to me in some places, but yeah once we put her on the programme she was open to anything after that.'

†Data are from interviews with Māori whānau (families)

9.3.1 Institutional or Systemic racism: substantial structural barriers and socioeconomic deprivation

Systemic or institutionalised racism was evident through the wide range of adverse events affecting many Māori participants and their families, which affected their capacity to engage with the service and the wider health system. Māori participants and their families frequently reported both acute and chronic life stressors and difficult socioeconomic conditions.

> ‘We didn’t have a vehicle. And we were going to car-pool with my aunty who had to take her son as well. And, um, she didn’t have enough for all of us, you know. I just felt shit that I couldn’t take him […] Unless I hitch hike with all of them.’

Systemic racism was demonstrated through the range of experiences evident within single families. For example, Māori or Pacific participants who were socially assigned by other people as NZ European experienced racism differently in the health system and wider society. Participants acknowledged that they were accorded societal advantage or disadvantage depending on how they were socially assigned by others.

> ‘I mean, she doesn’t look like no Islander, she looks like a white girl. She’s so fair.’

> ‘Um, when the two boys were going to school, cause one was dark and one was white, they used to get teased quite a bit because they didn’t think they were brothers and that’s really upsetting because why should they be different because one’s dark and one’s white, you know, because [SON 2] actually identifies with his culture just as much as [SON 1] does, and it’s almost like he’s worked twice as hard whereas [SON 1]’s dark and he doesn’t care, you know […] I know a lot of people who name their children, um European names so they get ahead, and they are still do that today and it’s really upsetting if that happens and disappointing.’

9.3.2 Interpersonal racism: cumulative effect of weight stigma and racism

While weight stigma was experienced by both Māori and non-Māori participants, Māori participants reported compounding effects of weight and race stigma in their interactions with health professionals and felt targeted because of their weight and being Māori. When asked about discrimination, one participant emotionally recounted her reaction to being stereotyped by a health professional:

> ‘I’m like ‘mmm, that makes you not want to go back to you… [tearful] it’s probably true, but like you don’t, oh I don’t know, yeah, I don’t know. She’s trying to do her job, but it’s just how she said it. I don’t know. Yeah. I can still see her face now. I didn’t like her. We didn’t like her.’

Much of the interpersonal racism experienced by participants both within and outside the health system was centred around implicit bias and stereotyping, as a result of systemic racism. In some cases, participants were reluctant to articulate this as racism and instead described experiences of being judged or treated unfairly in the community, such as the participant below who described their son’s experience at school:

> ‘… he said “Mum, I’m the only brown boy at school.” I said “no you’re not. I’m sure there’s another one.” […] he said “oh no, Mahia is brown too, that’s right,” and I said “see, you’re not the only one,” but there’s some kids there, white kids, who, I’m just assuming are a little bit racial. That might be because of the way their family, you know, obviously it’s how their parents kind of probably are, and I know that their parents possibly don’t have brown associations.’

However, participants also identified more explicit instances of racism occurring within and outside the health system, resulting in suspicion of a range of government-provided services in addition to the health system (Table 9.2).

> ‘Cops [police] may judge us, but they won’t even know that they’re judging us. Like, really in their intentions or hidden agendas, they judge us because of what I look like. They’re driving, but really they’re going to pull you over. ‘Oh, we’re just doing a random check’. I’ve done it, sort of driven past cops with this [hat and hooded jumper] on and then when you drive back past them with no hat and they don’t even look at us. Yeah, my mate… I was driving with him and he, he saw a cop coming and he goes ‘bro, take your hat off, take your hat off’ and I go ‘aye, why is that’? ‘Coz some cops are coming, take it off’, and he took it off and then it made a difference – cop didn’t look at us.’

Table 9.2: Participant responses to experiences of racism in terms of engagement with health services*

Participant response	Example participant quotation
Distrust of health services	'I don't trust the healthcare system. Definitely don't. I record everything, I investigate everything, make sure that I'm happy with everything, and yeah.' 'I think that's why I, in the end, I don't know if I could trust them [hospital service] with any help so I don't go to them anymore.'
Renewed determination to engage with health services	'I know there's people around that may, you know, everyone is judgemental, and they may be stereotyping or whatever, if they saw us maybe behave… I just think let people do that if they want, that's their shallow lives, they have no idea what we're about and it's not going to worry us what other people think.'
Disengagement with health services	'I probably did need the referral, but because, part of it because I didn't know what they did or who they were. I wasn't keen on an outsider coming in, if you know what I mean. Um, an outside entity coming in. Like, um yeah and it had nothing to do with who was in it or anything like that. It was just yeah my kid needed some tough love.'

* +/- other government services

9.3.3 Internalised racism & biological determinism: perception that ancestry determines outcome

Many Māori participants, and NZ European participants with Māori children, self-attributed overweight and obesity to family genetics, or more broadly to their ancestry (Table 9.1). There was a perception that Māori and Pacific peoples are 'naturally big' but that this was not necessarily a concern. This perception of children being ‘born big’ or ‘solidly built’ was evident across both Māori and non-Māori families, but it was specifically linked to ethnicity by Māori participants and parents of Māori children.

> ‘I’m from, um my mother was a [family name] and they’re a big family – she’s one of 18 – and so, I mean if you know any of the [family name]’s, some of them are built like big brick shit houses, so we’re used to it. We’re used to having family members and other people around us that are, have got, you know, big kids and little kids. I mean, I’ve got four kids and he’s the only one that’s built big. The others are all like little bean poles… so, you know, it’s like you look at him and go ‘he’s a throwback’ sort of thing.’

These internalised ideas shaped attitudes about genetic propensity towards overweight and obesity, the perceived potential effectiveness of healthy lifestyle change, and therefore the perceived value of engaging with healthy lifestyle services.

Additionally, the internalisation of racist stereotypes was concerning and highlights the relationship between external racism and internalised identity.

> ‘…There are a lot of us that, yeah, there are a lot of bad people that are brown and that too so the good ones that are brown will actually have it all too because that’s what happens I suppose. But we do get judged, but I don’t let that beat us though […]

Although not directly linked to health system use, the experiences of these participants are the result of the ongoing effects of both believing and challenging internalised racism, which often led to a distrust of and disengagement with services (Table 9.2).

9.3.4 What is appropriate care?

Despite the past negative incidents of care many participants had experienced, participants were clear about what constituted ‘good care’ (Table 9.1). Care that was respectful, compassionate and dignified appeared to overcome some of the past negative experiences. Many participants reported receiving this type of care in Whānau Pakari, as well as in other areas of healthcare. When asked directly, participants reported that Whānau Pakari was culturally appropriate, and responses tended to be centred around the positive relationships developed with the delivery team rather than any tangible aspect of the service itself.

> ‘Do you mean culturally? Yeah of course or I wouldn’t have been… we would have opted out otherwise. Yeah, we wouldn’t have been going, we’d have been making up all these excuses, well I know I would. You would have been ‘hey, oh just don’t worry about going today, I’ll say something’, that sort of thing. Yeah, nah, I did, I really enjoyed it. Like I say, the staff, they were awesome… Our experience with you guys was awesome, and with everyone else. Those are pretty straight up answers.’

Participants also spoke of respectful care they had received elsewhere in the health system. Likewise, it centred around the compassion and kindness of healthcare professionals, irrespective of their ethnicity.

> ‘Yeah, no, the Māori lady… get another Māori to approach another Māori aye… yeah she kind of became someone that we could turn to if we needed anything, which was awesome, but she’d also throw some of it back in our face as well, where it got to the point where I was ‘I don’t think I need you actually’. Aye, I think I might go to this side of the fence where I’ve got an awesome um white lady who is prepared to sit there, listen and help, you know, help me and my daughter big time.’

These participants demonstrate some positive experiences with relationship building in the health system and are examples of how respect and compassion are critical components of culturally appropriate care.

9.4 Discussion

This study found that the engagement of Māori families in Whānau Pakari was influenced by the effects of institutional racism, manifesting as socioeconomic deprivation and other differential barriers to access, as well as interpersonal and internalised racism and stigma experienced throughout the health system and wider society. Participants demonstrated a range of responses to these experiences including disengagement from Whānau Pakari, regardless of where the experience occurred. However, respectful and culturally appropriate care with an emphasis on positive relationship-building may be a way to partially mitigate and resist past experiences of racism and weight stigma. Our data suggest that at the system and service level, healthcare that practices *manaakitanga* (the process of showing respect, support, and care for others) and *aroha* (love, compassion, empathy, kindness) as guiding principles can promote engagement, although it is acknowledged this is not always sufficient for families who are dealing with multiple complex challenges.

This study's findings are consistent with the limited previous literature on barriers to engagement in lifestyle interventions for Indigenous groups and other marginalised ethnic groups, as well as literature on healthcare access more generally which commonly identifies socioeconomic factors and racial discrimination as key barriers for Indigenous peoples.[154, 171] The high rates of socioeconomic deprivation for Māori as a result of institutionalised racism are likely to contribute towards differential rates of access to health services such as Whānau Pakari between Māori and NZE. While 'personal circumstances' are frequently identified as factors influencing attendance in multiple studies,[141] a study of participant retention in a family-led weight management programme for Pacific children with obesity specifically identified unpredictable life events such as deaths, illnesses and employment changes as key barriers which affected momentum and participation.[178] Although some of these stressors are unpredictable, many are the result of household deprivation in participant communities. For example, it is difficult to address weight issues when food insecurity is a bigger threat to health and wellbeing due to the social conditions in which children and their families live. In NZ, almost one in five children live in households experiencing moderate to severe food insecurity.[276] These factors are external to a healthy lifestyle service but were consistently identified as determinants of non-participation and attrition as families' priorities are forcibly and understandably changed.

Our study demonstrates that previous occurrences of racism have an enduring ability to influence seemingly unrelated interactions within the health system. Racism in NZ has previously been identified as a key determinant of health, contributing towards health loss and inequities between Māori and NZ Europeans.[277] A 2018 study of multiple forms of discrimination in NZ showed that discrimination was associated with a number of negative health impacts for Māori including poorer self-rated health, poorer mental health and greater life dissatisfaction. There was a dose-response relationship between the number of forms of discrimination experienced and negative health impacts.[273] Racism need not be explicit to have negative health effects – Crengle and colleagues' study in 2012 showed that being 'unsure' about having experienced ethnic discrimination is associated with a range of adverse health outcomes.[278] Our study suggests that for some Māori participants, various experiences of racism and weight stigma – regardless of where they occurred – affected subsequent engagement with the health system. Practically, this has important implications for clinical care – if participants have had stigmatising or discriminatory experiences elsewhere, this may affect engagement with other unrelated services.[262]

Ensuring that prevailing healthcare services are culturally appropriate is important to mitigate inequities, alongside supporting Indigenous-led services. Past evaluations of the service[270] and participant interview data suggest the service is considered culturally appropriate. In this study, the accounts of what made the service appealing or acceptable to all, but particularly to Māori, centred around 'the people' (programme deliverers). When participants chose to engage with Whānau Pakari despite historical experiences of weight stigma and racism, they cited the relationships developed with programme deliverers as the reason this engagement was successful. Previous studies have identified relationships and social connectedness as essential for culturally appropriate services and enabling engagement with Indigenous groups,[171, 184] especially in community-based healthy lifestyle programmes.[141] The programme emphasis on general health and wellbeing rather than obesity is also likely to contribute towards the acceptability of the programme for Māori, given the questioning of the utility and relevance of weight as an outcome measure for Indigenous groups in favour of other outcomes of physical, psychological, spiritual and familial health and wellbeing.[184]

A strength of this study is the strong representation from Māori participants, as well as those who chose not to engage with the service altogether. Our high recruitment rate was due to a concerted effort to overcome common barriers to research participation, which included text reminders, home-based interviews, a mixed Māori-NZ European interview and research team, taking the time to establish rapport with the participant before commencing the interview, and a *koha* (gift) which recognised the time and effort given by participants as a sign of reciprocity. The principles which guided the research process included interviews designed to be positive, respectful encounters, being mindful of the past historical experiences of research for Indigenous peoples. The analysis was undertaken with Māori and non-Māori researchers who had agreed parameters for respectful contributions.[223]

The research was not designed to be generalisable to other ethnic groups in NZ and globally to other Indigenous populations; however, it does identify a number of issues that have commonalities in the experiences of Indigenous peoples globally. A limitation is the ability of this study to capture the heterogeneity of Māori experience. Half of the interviews were with participants who had Māori children involved in Whānau Pakari, and this also included interviews with NZ European parents and caregivers of Māori children. While this perhaps influenced how participants perceived their experiences, it also reflects the lived realities of Māori children growing up in contemporary NZ.

In conclusion, the experience of racism at institutional, interpersonal and internalised levels affects engagement at a programme level for Māori families. Past negative experiences in the healthcare system had an impact on engagement with the service. While participation in the programme itself was identified as a positive experience for most participants, this was insufficient to achieve sustained engagement for some families due to external competing priorities. Racism that occurs elsewhere in the health system or in wider society may have ongoing effects with regards to subsequent engagement with other health services, and until these issues are addressed, inequities in service engagement between Indigenous and non-Indigenous groups are likely to persist. While it may not be enough to address the effects of racial discrimination more generally, compassionate, respectful, appropriate care focusing on positive relationship-building can help mitigate some of the impact of racism on engagement in prevailing healthcare services.

10 Results: Interviews – Health system barriers to accessing care for children with weight issues in New Zealand

While barriers at the programme level should be minimised to improve engagement in family-based, multidisciplinary programmes, it is also important to evaluate barriers to access at the health system level. This chapter contains the manuscript investigating the health system-level barriers affecting engagement and retention in both Whānau Pakari and other health services from the in-depth interviews.

Submitted for consideration of publication to *Journal of Health Services Research and Policy.*

Wild CEK, Rawiri NT, Willing EJ, Hofman PL & Anderson YC. Health system barriers to accessing care for children with weight issues in New Zealand. Submitted paper. Forthcoming 2020.

10.1 Introduction

In addition to population-level prevention efforts, it is important that children and youth affected by obesity and their families have access to appropriate programmes focusing on healthy lifestyle change, and care for weight-related comorbidities. The World Health Organization (WHO) Report of the Commission on Ending Childhood Obesity recommends family-based, multicomponent interventions as best practice for addressing childhood obesity.[12] However, a 2019 WHO report from the Regional Office for Europe highlighted that health system responses to childhood obesity in the European region were insufficient, due to a number of system factors including a lack of governance, lack of integrated service delivery and fragmented care, inadequate financing of childhood obesity management and poor workforce education.[180] Both the New Zealand Health Strategy[212] and He Korowai Oranga: Māori Health Strategy[279] offer guiding policy at the strategic level for responding to the increasing pressures on the health system, including achieving equitable outcomes for Māori (Aotearoa/New Zealand's [NZ] Indigenous population). However, while both strategies include implementation plans, there are a lack of mechanisms to achieve accountability and ensure these high-level aspirations are realised.

NZ has the second highest prevalence of overweight in childhood in the Organisation for Economic Cp-operation and Development at 39%, second only to the United States.[10] In 2016, the NZ Government introduced the Raising Healthy Kids target, as a targeted initiative of the Childhood Obesity Plan, to be incorporated into the B4 School Check (B4SC), an existing free health and development check that aims to identify and address any health, behavioural, social, or developmental concerns before starting school.[125] Health targets are designed to improve health service performance for key public and government priorities. The Raising Healthy Kids target stated that by December 2017, 95% of children with obesity identified in the B4SC programme would be offered a *referral* to a health professional for clinical assessment and family-based nutrition, activity and lifestyle interventions.[125] The second key initiative of the Childhood Obesity Plan was that the families referred through the B4SC would have improved access to nutrition and physical activity programmes.[125] However, while there is some national guidance on the recommended composition of these programmes,[121] there is national variability in terms of the types of programmes offered, little indication of how access to the programmes would be improved, and it is not clear whether the health system is equipped to manage the additional referrals to programmes. No research on the readiness of the NZ health system to implement WHO or indeed NZ government recommendations for addressing childhood obesity has been conducted to the authors' knowledge.

The most widespread programme for addressing weight issues for children and their families in NZ is Green Prescription (GRx) Active Families (AF), a free community-based health programme run through regional sports trusts that aims to increase physical activity. However, an audit of the GRxAF programme in Taranaki (a mixed urban-rural region of NZ) showed that the programme needed modification to improve accessibility and appropriateness for population groups most affected by childhood obesity, such as Māori and those living in the most deprived areas.[123] In response to these findings, Whānau Pakari was established in 2012 in Taranaki.[13] The key aspects of the programme are that it is a family-based multidisciplinary assessment-and-intervention programme that is based in the community. It takes a 'demedicalised' approach, whereby the medical assessments are based in the home as part of a wider assessment, removing the need for a traditional clinical hospital appointment, yet retaining the ability to address weight-related comorbidities. The multidisciplinary team includes a dietitian, physical activity specialist, and psychologist who facilitate weekly sessions, with clinical oversight from a paediatrician. Previous focus group research showed that participants and their caregivers valued the sense of connectedness, knowledge-sharing, the experience of the collective journey and the respectful, non-judgemental environment in the family-based programme.[137] The programme is cost-effective compared with conventional standard of care in paediatric clinics.[138] It is also more accessible than the GRxAF model, with a higher recruitment rate for groups overrepresented in obesity statistics.[13]

A randomised clinical trial embedded in the service showed that the greatest improvements in weight status were found in participants who attended ≥70% of programme sessions, so it was important to understand the barriers and facilitators of engagement in Whānau Pakari to enhance retention. Initial engagement and ongoing retention are challenges for many community-based programmes.[141] In order to understand the factors affecting engagement in Whānau Pakari, the Whānau Pakari Barriers and Facilitators study involved a brief initial survey and 64 home-based interviews with families who had been referred to the programme, including those who declined further input after their referral. The survey showed that attendance was affected by the perceived convenience of the programme.[270]

The key findings of the interviews have already been presented,[272, 275] which took an inductive approach to identifying key themes at the societal level, namely the effect of adverse life stressors and socioeconomic deprivation, societal norms of body weight and historical experiences of healthcare. During this process it became clear that there were additional barriers at the health system level which made it difficult to engage with not only Whānau Pakari, but with the wider health system as well. Therefore, the objective of this study was to deductively analyse the interview data to identify barriers created and maintained by the health system, which affected engagement in both Whānau Pakari and the broader health system.

10.2 Methods

The full methods for the Whānau Pakari Barriers and Facilitators study have been previously presented.[275] In brief, we conducted 64 interviews with families who had been referred to the Whānau Pakari programme in order to understand the barriers and facilitators to initial and ongoing engagement in the programme.

The study was informed by Kaupapa Māori theory which, among other philosophical aims, rejects cultural deficit explanations of health inequities (attributing inequities to something inherent to a cultural group) and is aligned with a structural determinants of health approach.[229] The interview schedule included questions about participants’ experiences accessing the health system, and especially any barriers they faced to accessing care. For this analysis, we were particularly focused on system-level barriers to engagement with health services in general, including but not limited to engagement with the Whānau Pakari programme. This allowed us to focus on how access to the service operates in the context of the wider health system and policy environment in NZ.

Ethical approval for the Whānau Pakari Barriers and Facilitators study was obtained from Health and Disability Ethics Committee NZ. Written informed consent was obtained from all study participants.

10.2.1 Participants

Parents and/or caregivers of children and adolescents who had been referred to the service between January 2012 and January 2017, and children if aged over 11 years were invited to participate. Purposive recruitment was from four different groupings of families who had been referred to the service and engaged to varying degrees to gain a range of participant experiences: participants who attended ≥70% of programme sessions, those who attended <30% of sessions, those who had their initial assessment and then discontinued with the programme, and those who declined any further contact after their referral. Half of the interviews were with families with Māori children who had been referred to Whānau Pakari to ensure appropriate representation. Participant demographics are shown in Table 10.1.

Table 10.1: Interview participant demographics (parents of caregivers of children and adolescents referred to the Whānau Pakari service).

Interview participants (N)		76*
Female participant *n*		65
Ethnicity %†	Māori	32
	NZ European	75
	Asian	7
	Other European	5
Level of engagement *n*	Attended ≥70% of programme sessions	18
	Attended <30% of programme sessions	19
	Had one assessment, then discontinued with the programme	7
	Referred, but chose not to engage	20

*64 interviews total, 11 interviews involved 2+ family members.

†Total ethnicity output (people are counted once in each ethnic group if more than one ethnicity reported)

The interviews were conducted jointly by Author 1 and Author 2, and Author 2 led the interviews with Māori families when appropriate. Interviews took place between June and December 2018 in participant homes, workplaces, the hospital or community locations, as chosen by the participant for convenience. Participants were gifted a *koha* (gift, donation or contribution) in reciprocation for their information and time.

10.2.2 Data collection

Written informed consent was obtained and all participant information was anonymised. Participant ethnicity for both the parent/caregiver and child was confirmed at the time of the interview by using the NZ Census 2018 ethnicity question. Interviews were audio-recorded and independently transcribed and participants were offered their transcripts to review for accuracy and acceptability.

10.2.3 Analysis

MAXQDA software was used to code and thematically analyse the finalised transcripts.[236] Thematic analysis is a flexible method for identifying, analysing, and interpreting patterns within qualitative data, and it allows the researcher to explore deeply the experiences of participants.[237] The code 'System-related experience' was used to identify participant experiences related to the health system which presented as barriers to engagement.

The research team agreed to apply the 'Give-Way' rule if there was disagreement over the interpretation of the data concerning Māori participants, with the final decision involving cultural interpretation of Māori participants' experiences passing to a Māori researcher.[223] This allowed for respectful acknowledgement of different researcher standpoints.

10.3 Results

Five key system-level factors were identified that affected participants' abilities to access both the community-based programme and the wider health system: the national policy environment, funding constraints, lack of coordination between services, difficulty navigating the system, and the cost of primary healthcare (Table 10.2). The first two were discussed in the context of engaging specifically with Whānau Pakari as a programme within the health system, and the latter three were discussed in the context of engaging with the health system more generally. Each factor is explained in the following sections.

National Policy Environment

Many families who had been referred to Whānau Pakari at the B4SC for their preschool-aged child believed that the referrers felt obliged to refer even when it was not warranted, which in turn made families feel like the referral was a ‘tick box exercise’.

> ‘So the Nurse who did all of our B4 school checks said that, you know, ‘because you’re in this percentile um I need to refer you’. I said ‘okay then’. And she was kind of reluctant um, but I said ‘if that’s what you’ve got to do, then that’s what you’ve got to do and that’s fine’. […] she was quite… not apologetic, but, yeah, about having to refer me. Because obviously they’ve got some matrix there that if it’s this and this then we have to refer people.’

There was frustration that the Raising Healthy Kids target’s referral criteria was based solely on the weight criteria of ≥98th percentile which was perceived as an insufficient benchmark for a referral by some parents. Parents reported being reluctant to engage with the Whānau Pakari programme after this referral experience, which was considered off-putting.

Table 10.2: Health system-level factors preventing engagement in Whānau Pakari with participant quotations to illustrate examples.

Health system-level factor	Representative comments from participants
National Policy Environment	'…I mean that's not that welcoming either is it? Well, you know, 'I have to refer you'. So that was weird. […] And that's and that's when I think, well, you know, if you're kind of reluctant and probably there's other people that, you know, you want to be encouraging to go or if you do want to be encouraging them to go then you need to be a bit more encouraging.' 'I just felt that she felt bad […] kind of apologetic that 'I have to refer you' because you're here, but it's because that was the only assessment she was using. I mean she may have picked up other things during the visit that she thought, you know, that my parenting was okay, but regardless she still had that matrix that she was using and so she had to.' 'There's not really a lot about the nutrition and healthy stuff and then so it's really only height and weight and whatever, I mean I guess that's part of it, it's just based on that. Whereas if there was more around examining diets and exercise and things, you could also get that feedback then and "that's another reason why we are referring you".'
Funding constraints	'I've seen a lot of groups and organisations that are 'we're going to do this, we're going to do this' and they get halfway through and for whatever reason, whether it be funding, administration, the board not liking how things are said or done, um all is lost because you don't, this doesn't fit into this little square or this round circle here, it's working for these families, can you not see the difference? You know, and yet you are going to pull funding from this one because, okay, instead of helping twenty families like we wanted you to, you only helped five. Oh, sorry about you five […] not saying that every programme or everything is going to

	work for every family, but you've got to keep trying to figure out what works. […] Without those resources these families fall through the gaps.'
	'I just would have liked a bit more one-on-one. Yeah, not just in a group session, you know. Like, yeah, one-on-one so that you are able to sort of be able to talk about your own child, you know. Not just be in the group and then, 'what do you think'? and then. I wanted to say sort of sometimes some things, but you know, I just prefer, to just be on my own. So that's what I would have liked a bit more, was the one-on-one there. […] I'm one of those ones I just don't like all and sundry knowing my business. I've always been like that.
Lack of coordination across the health system	'Yeah, because they just asked the same question over and over again after we'd already gone through it […] I think the end they were like 'oh, so, why didn't you come to us in the first place?' I remember that question because I was like, do you not read the file? I said to her 'have you not read the file'? Yeah, I said that. But that's not just this service though. Like, I say that to CYFS [child youth and family services] all the time, 'do you not read the fucking files'? Yeah, um, lots of services, they just don't… repeating shit it's horrible. Especially when it's dwelling, sad reasons, you know what I mean? So that makes it hard.'
	'The problem now is that she's passed 18 years and she doesn't fit into the criteria of being with [child and adolescent mental health services]. But, she's only young so she's too young to go onto the mental health system. So, yeah, so it's like, where's the in-between? You know, there's no in-between for things like that. I mean, God, I don't want her in the mental health system if I can help it.'

Difficulty navigating the health system	‘Sometimes you get frustrated because you just think someone should help you, it did, it felt like we never got anywhere, it felt like we never got anywhere, we went around in circles and never got anywhere, around in circles.’
	‘But yeah, just, you’ve got to fight the system. You’ve got to fight [for] what’s right and I’m trying to get her to have the confidence to stand up.’
	‘…the people who get this are not necessarily the ones that always need it, it’s the ones who are organised enough to get it. I used the system effectively, but I know of a lot of people who don’t.’
Cost of primary healthcare	‘It’s, like, I need to save up or I need to be, there needs to be a good reason to travel to the Doctor and cause it’s a two week wait as well.’
	‘…they don’t always let you tick it up and pay it off […] just her inhalers now cost me $20 something. You know, back in the day it was $3. $3 and that was your repeats as well. Now it’s, like, $20 for that thing and then you’ve got to go back and pay for those repeats as well […] the health system is not cheap. You know, that’s why I thought we had a community services card, but even that’s all gone up.’
	‘Just sometimes, you know, I just feel the doctors are, certain ones, you know, just want your money and you’re just in and out. You know, and you’re like ‘I’m just paying you that much for, like, not even five minutes’.

	‘Especially if you know someone who has been through it, it makes it really easy… especially now that you’ve got to pay for them to go to the doctor. Make the most of this age range [under 13 years], it’s free, but yeah just I’d rather ask someone before I pay the $30 or $40 odd dollars to go to the doctor. Especially if you are, like I say, you know someone who has been through something or similar it’s, you know, you can’t pay $30 or $40 just to go ‘oh, just do this’ and your mate could have told you that. And some doctors, they’re not that helpful.’

Funding constraints

Specific suggestions of service improvement largely centred around increased service delivery in more locations and at more times, especially for those located rurally, or for shift workers. Participants expressed frustration at the lack of funding available for services which they perceived to be necessary, valuable and in high demand.

> '…I know even in the health system, although it's really hard, it comes down [to the fact that] they don't have funding, they don't have enough people and yep there's holes in their system so I don't hold it against them either, I just think that they need to fight for more funding and try and fill those holes, you know.'

Among those parents/caregivers who engaged with the programme, there was also demand for more intensive one-on-one psychology support for their children. Parents spoke openly about the mental health challenges their children experienced and the desire for professional support.

Lack of coordination across the health system

Participants experienced a lack of coordination and information-sharing across the health system, particularly when dealing with complex cases. Families who accessed the system at multiple points of care reported that they experienced a lack of communication between services and found themselves frequently repeating their family and social histories to providers. This extended past the health system across to other social services involved in child and family health and wellbeing:

> '…from my perspective, our family has probably cost the government quite a lot of money because we've had so much engagement in a whole lot of services when really we could have just sat in under one umbrella and being probably better monitored in through that over the years.'

Families found it difficult to engage with multiple services at once, and felt that dealing with multiple family concerns comprehensively at one point of entry would be more effective:

> ‘And so what we ended up with was a whole lot of services in and around our family because, because this service would say ‘well we deal with this here, but we can’t look at that so we’re going to refer you to that’, and they will refer you to this and refer to that, and as a vulnerable person you just want to help your child, help your situation, so you take on that along with a whole lot of information and advice from other professionals […] How do you make sense of that on top of living in a state of high adrenalin? […] you’re just running to kind of fix everything and not really getting much ahead, well getting ahead, but not really, you know, it’s been really hard.’

Participants also encountered difficulties when their children were transferred from paediatrics to adult care, especially in the case of children accessing mental health services. There was a general perception that mental healthcare/services for young people were in high demand and under-resourced:

> ‘They don’t cover all age groups, you know like, you’re covered from this person until this age and then there is a little bit of a hole in their system where no one covers.’

Difficulty navigating the health system

Participants frequently stated that the health system was complex and difficult to navigate and expressed frustration at their inability to access the care they needed, despite being referred to multiple health and social services:

> ‘…the Police would come in and say this is a mental health problem, mental health would say well this is a health problem, health would say mental health… [who] would say it’s an education problem […] I’m not the most unintelligent person in the world. Now if I’ve found that this system really difficult to navigate, and my God I have, how

> does the rest of the world manage this? And you guys are wondering why you are not getting engagement. This is why you're not getting engagement – because it's too friggin hard.'

> 'We'd go from referral, referral, referral, referral, referral, referral. It felt like we never got anywhere.'

Effective navigation of the health system and access to care required parents/caregivers to be organised and persistent, and participants acknowledged that this was not always possible for some families:

> 'As a parent you just learn to be more persistent in getting the results. You know, you stamp your feet until you get things done.'

However, participants acknowledged that these issues were system-wide rather than service or programme-specific and acknowledged the constraints on healthcare service delivery.

> 'It's being realistic, you know […] it's difficult 'cause I know that some families would see one negative experience and go 'oh fuck that, I don't want to be involved with DHB [district health board]', but the reality is there's so many facets of it and they are not all joined, and they don't all communicate and one person isn't in charge of everything.'

Cost of primary healthcare

Cost was frequently cited as a major barrier for families accessing primary healthcare. The participant quotes below demonstrate the multiple factors involved in the financial output for accessing primary healthcare, even with government subsidies – from the actual cost of the appointment to petrol and travelling costs, waiting times, and prescription and equipment costs.

> ‘[DAUGHTER, 16] sprained her ankle last week and I had to go to the GP [general practitioner/primary care physician], you know, and $110 later just because she sprained her ankle. X-ray. We had to buy crutches, can you believe – you can’t hire them these days. You know, so it’s like, so the cost. We’re a family that’s, you know, can afford it just, you know. I think for other families it must be like “wow”.’

> ‘They said ‘oh, we need you to um we need to come in, we’ve got a non-urgent matter’ and I thought oh no, another $16, you know, and a trip into [town].’

However, for some participants it was not necessarily the cost of the appointment that was the biggest barrier, but rather the perceived lack of care for the financial cost. Many participants felt they would rather address their health concerns themselves, rather than pay for a short appointment.

> ‘It’s about forking out $50 every time for 15mins of ‘here you go, here’s some’, something, you know, that you can… I don’t know.’

10.4 Discussion

Our key findings were that engagement in a community-based multidisciplinary programme for children and adolescents with weight issues was affected by five factors at the system level – the impact of national-level policy, system coordination, health system navigation, funding constraints, and the cost of primary healthcare. The first two factors directly influenced participant engagement in the Whānau Pakari programme, and the latter three factors were discussed by participants as persistent barriers to accessing care in the healthcare system in general, especially for families dealing with multiple complex health concerns. These findings are not solely isolated to one DHB, or NZ, and are supported by the WHO Europe 2019 report based on questionnaires, literature review and interviews, which cited fragmented service delivery and inadequate funding as system-level factors impeding health system response to childhood obesity management.[180] Our results suggest that even an effective, well-designed intervention programme that is acceptable to the community will struggle with participant engagement in the context of a health system that poses challenges to engagement.

Previous research has shown that there were few programme-level factors that could be easily addressed to improve retention in Whānau Pakari.[275] Clearly, recruitment and retention in the service would be enhanced by more locations and times for service delivery, yet the fiscal constraints of the health system impede this. Currently the health system is not equipped to respond to the needs of its population, especially with families dealing with multiple health issues.[181]

The Health and Disability System Review interim report highlighted the complexity and fragmentation of the current health system, making it difficult for people to navigate and leading to dissatisfaction and a lack of confidence and trust in the system.[280] Our data supports this finding, especially for families dealing with multiple health concerns at once. Addressing weight issues in children in isolation is insufficient – previous research in NZ has highlighted the complexity of children experiencing overweight, including various weight-related comorbidities,[116] dietary behaviours,[134] physical and sedentary behaviour,[133] and psychological difficulties.[135] Multidisciplinary teams are best suited to the coordination and management of complex care for health concerns such as weight issues and weight-related comorbidities.[12] A multidisciplinary assessment and intervention service such as Whānau Pakari is better placed to provide care in a more holistic way, while being able to address multiple comorbidities through the home-based, comprehensive assessment which allows families to deal with multiple concerns at once – including being cognisant of wider issues affecting the family.

The NZ Childhood Obesity Plan's key initiatives focused on the Raising Healthy Kids target, with a referral for clinical assessment from a health professional for family-based nutrition, activity and lifestyle intervention.[125] Our study suggests that the Raising Healthy Kids target's pursuit of meeting a *referral rate* target was palpably felt by parents/caregivers at the B4SC, which discouraged some families from pursuing the referral. However, mitigating this through more holistic discussion of nutrition and physical activity in relation to weight would be challenging for public health nurses to cover in the short timeframe of the appointment, which covers a number of childhood health and development domains, including oral health, vision, hearing and emotional and physical development, as well as height and weight.[281] Importantly, there is no consistent data available on the proportion of families who actually take up the referral to healthy lifestyle programmes in general nationally. It is possible that this initiative of the Childhood Obesity Plan may not achieve better outcomes for children with weight issues and their families, given the focus was on the *referral rate* rather than availability of multidisciplinary family-based programmes.

As primary care is the first point of contact for most people seeking health services in NZ, general practice may seem like the ideal setting for management of weight-related issues. However, the costs associated with accessing primary healthcare cited by families suggests that addressing weight issues in children and adolescents within general practice in NZ is not ideal, especially given the declining GP workforce,[127] and the high levels of unmet need for primary healthcare due to cost, as suggested by this study's participants and national data.[11] In the 2018/2019 NZ Health Survey, 30% of the general population and 41% of Māori reported not being able to access primary care when required within the past 12 months, due to the inability to pay for GP appointment (13%) or being unable to get an appointment within 24 hours (21%).[11] The introduction of free GP appointments for children aged 0 – 13 from December 2018 partially addresses the high cost of primary care for children;[282] however, the intergenerational and complex nature of weight issues supports a family-centred multidisciplinary model that can support the ongoing journey through the life course in primary care. Leaving this care solely to general practice is likely to overburden an already stretched system, and not likely to achieve comprehensive screening of weight-related comorbidities due to limited time in general practice. Finding innovative solutions in primary care to these issues may lend itself to a workable solution in the future.

A strength of this study was the strong representation across Māori and non-Māori families who had been referred to the service, as well as from non-service users, which provided a variety of perspectives. While this study provided a useful understanding of the challenges faced by families accessing care for child and adolescent weight issues, it may be limited in its ability to generalise to other health system users. However, the study did include participants who had declined further input after their referral to Whānau Pakari. Additionally, this study did not include the perspectives of public health nurses who administer the B4SC – it was clear from the interviews that many felt uncomfortable making target-driven referrals for weight in this setting.

In conclusion, our study suggests that, despite the innovative steps the Whānau Pakari programme has taken to improve accessibility and acceptability, it is still difficult to engage in a health system that creates and maintains substantial barriers to accessing services. Policymakers need to account for these factors when considering the future direction of care for children and adolescents with weight issues and associated comorbidities in NZ. However, providing community-based multidisciplinary intervention programmes is important for those affected. Intentions from government, such as those expressed in the Childhood Obesity Plan, must be accompanied by clear implementation systems and coordination across sectors. There are already policies in place to guide health system coordination such as He Korowai Oranga and the NZ Health Strategy.[213, 279] However, the reality of accessing the health system for complex issues such as weight for many children, adolescents and their families in New Zealand does not reflect the strategic vision outlined in these documents. Well-designed, acceptable intervention programmes, which address child and adolescent weight issues and associated comorbidities, are likely to continue to struggle with retention without addressing key health system-level determinants of engagement.

11 Results: Interviews – Challenges of making healthy lifestyle changes for families in New Zealand

Maintaining healthy lifestyle changes is key to successful long-term outcomes in multidisciplinary healthy lifestyle programmes. This chapter contains the manuscript presenting a secondary analysis of the in-depth interview data focusing on the challenges of healthy lifestyle change for families in New Zealand today.

Submitted for consideration of publication to *Public Health Nutrition.*

Wild CEK, Rawiri NT, Willing EJ, Hofman PL & Anderson YC. Challenges of making healthy lifestyle changes for families in Aotearoa/New Zealand. Submitted paper. Forthcoming 2020.

11.1 Introduction

An estimated 32% of adults and 11% of children aged 2–14 years in Aotearoa/New Zealand (henceforth referred to as New Zealand [NZ]) are affected by obesity, and a further 20% of children are classified as overweight.[11] Additionally, children living in the most deprived areas are twice as likely to experience obesity as those living in the least deprived areas.[11] In addition to population-level prevention efforts, it is important that children and youth experiencing weight issues are offered support to make healthy lifestyle changes; international recommendations for the management of childhood obesity include family-based healthy lifestyle programmes that incorporate nutrition, physical activity and psychosocial components.[12, 90] NZ children with obesity show high rates of weight-related comorbidities, as well as suboptimal dietary behaviours and low levels of physical activity, irrespective of ethnicity.[116, 133, 134] At a national level, only 50% of NZ children (2–14 years) meet the Ministry of Health's fruit and vegetable intake guidelines.[261] Additionally, 89% of children (6 months–14 years) exceed screen time recommendations for their age group, and 23% (0–14 years) have insufficient sleep.[261] However, there is currently fragmented provision of multicomponent healthy lifestyle programmes for children and adolescents in NZ, which means access to these services remains limited.

Implementing and sustaining healthy lifestyle changes can be challenging due to a wide range of individual, social and environmental factors – a 2017 review of barriers and enablers to healthy nutrition, physical activity, sedentary activity and sleep habits found that most barriers were identified at individual and interpersonal levels, and there is a knowledge gap around environmental and policy-level influences.[283] A multi-centre qualitative study in Canada of barriers and enablers of healthy lifestyle behaviours in adolescents with obesity found that physical and mental health, self-efficacy (in terms of self-regulation, controllability and competence beliefs), social relationships and accessibility of opportunities for lifestyle change all affected adolescents' abilities to make changes.[284]

Previous research in NZ into the challenges of making healthy lifestyle changes has largely focused on the cost of eating healthily in an obesogenic [obesity-promoting] environment.[285, 286] A qualitative study of the facilitators and barriers to achieving a healthy weight in children among focus groups with Māori (the Indigenous peoples of NZ) parents and caregivers demonstrated that a key barrier to making healthy food choices was cost, but this was closely related to lack of time, the number of people to feed, and individual preferences.[287] In addition, food provisioning decisions were complex and involved weighing up the relative importance of ensuring both child health and happiness.[287]

One family-based multidisciplinary programme focused on supporting families to make healthy lifestyle changes is Whānau Pakari, which means ‘self-assured whānau [families] who are fully active’. The programme is more accessible than previous models,[123] with a ‘demedicalised’ approach, removing hospital visits. Medical assessments occur in the home, which is more acceptable to the community. Focus groups with past Whānau Pakari participants showed that participants and their caregivers valued the sense of connectedness, knowledge-sharing, the experience of the collective journey and the respectful, non-judgemental environment in the family-based programme.[129] Whānau Pakari has demonstrated effectiveness in a randomised clinical trial, which showed improvements in physical activity, psychological outcomes and body mass index (BMI) standard deviation score (SDS) at 12 months.[14] Whilst the BMI SDS reductions did not persist at 24 months, reductions in sweet drink intake, increases in water intake, and improvements in cardiovascular fitness and health-related quality of life were present,[14, 136] as well as qualitative evidence of a range of health and wellbeing benefits [129, 270]

This paper presents a secondary analysis of data from the Whānau Pakari Barriers and Facilitators study, which involved understanding the factors influencing engagement and retention in Whānau Pakari through a survey and in-depth, semi-structured interviews with past participants who had been referred to the programme.[270] The content of the interviews was broad, ranging from participants’ experiences in the Whānau Pakari programme itself to wider experiences in the healthcare system. While it was not solicited by the interviewers, over half of participants volunteered information about the challenges of healthy lifestyle change. This was not a focus of the interview and the information was not requested by the interviewers, but it was clearly an important topic for participants, and part of their experience of engaging in a healthy lifestyle programme. Although it was not part of the primary analysis of the interview data, it was important that participant voice was reflected in the wider research project. The research team considered the challenges discussed by participants to be an element to explore in the context of addressing childhood obesity in NZ. Therefore, the objective of this secondary analysis was to identify the challenges of making and sustaining healthy lifestyle changes for families with children and adolescents who were referred to a multidisciplinary healthy lifestyle programme.

11.2 Methods

Ethical approval was obtained from Central Health and Disability Ethics Committee (NZ) (17/CEN/158/AM01) and written informed consent was obtained from all study participants. In brief, in-depth, home-based interviews were undertaken with parents, caregivers and past participants of Whānau Pakari who had engaged with Whānau Pakari to varying degrees. Whānau Pakari eligibility criteria were children and adolescents aged five to 16 years with a BMI ≥98th centile, or those >91st centile with weight-related comorbidities. The sample of interview participants included those who had been referred to the service and then declined further input, as well as both Māori and non-Māori families. Author 1 and Author 2 conducted the interviews jointly, and Author 2 led the interviews with Māori families when appropriate. Participant ethnicity for the parent/caregiver and child was confirmed during the interview using the NZ Census 2018 ethnicity question. A koha (gift, donation or contribution) was offered in reciprocity for participants' time. The interviews were audio recorded, independently transcribed and returned to participants for accuracy and acceptability checks.

Interview transcripts were coded and analysed in MAXQDA software using thematic analysis. The code 'Challenges of Healthy Lifestyle Change' used to focus the secondary analysis of key themes identified from participant-initiated accounts. Participant transcripts were included in the analysis if they had discussed the challenges of healthy lifestyle change in their interview (n = 38 of the original 64 interviews). Author 1 conducted the initial analysis with supervision from Author 3. The research team collaborated to finalise the themes, with previously agreed respectful parameters allowing the authors to debate, challenge, and refine interpretations of the data. It was agreed to apply the 'Give-Way' rule throughout the wider study if there was disagreement over the interpretation of the data concerning Māori participants.[210, 223, 245]

The demographic characteristics of the n = 38 participants included in the secondary analysis are presented in Table 11.1. Seventeen interviews were with families with Māori children (Māori or non-Māori parent/caregiver). No interviews included children or adolescents as participants.

Table 11.1: Interview participant demographics (parents or caregivers of children and adolescents referred to the Whānau Pakari service) included in secondary analysis

Interview participants (n)		**42**
Female *n* %		36 (86)
Ethnicity *n* %†	Māori	14 (33)
	NZ European	27 (64)
	Other European	1 (2)
Level of engagement *n* % ‡	Attended ≥70% of programme sessions	11 (29)
	Attended <30% of programme sessions	11 (29)
	Had one assessment, then discontinued with the programme	4 (11)
	Referred, but chose not to engage	12 (32)

n = 38 interviews included in secondary analysis.

†Total ethnicity output (more than one ethnicity selected, total adds to >100)

‡ Refers to number and percentage of interviews. Four interviews involved two family members

11.3 Results

Participants described a range of factors that influenced their ability to both implement and maintain positive healthy lifestyle changes, identified and supported by example participant quotations in Table 11.2.

Overall, participants had a sense that a wide range of factors contributed towards someone experiencing weight issues, and therefore a range of factors contributed towards their ability to make healthy lifestyle changes:

> ‘You’ve got the economic one, you’ve got the social one, you’ve got the individual one, you’ve got the monetary one, and all those factors contribute into why someone is overweight.’

Table 11.2: Participant-identified challenges of healthy lifestyle change.

Factors	Quotations to illustrate identified challenges
Financial cost	‘Fruit and veggies, they encourage you to eat them, but I can spend $40 odd, $50 just on fruit and veggies a week out of my groceries, and then, you know, you’ve still got your meat and everything else on that it’s not cheap to live […] there’s people worse off than me that really struggle. So you look at your food and then your health system, like, doctors and then your medicines, it all adds up.’
Food environment	‘…you sit there and you’re not hungry, after about five minutes of ads about food and junk food then you think ‘oh I might go have a biscuit or a cup of tea’
Time pressures	‘I mean, when you’re in a busy life you haven’t got time to go reading everything on the box in the supermarket have you?’
Stress	‘I always have to watch my weight and I am trying to be a mother and I might have to go to work as well and I’m trying to figure what everybody is going to eat every day and it’s exhausting. How do I keep everybody on track and not fall over?’
Consistency across households	‘I had to knuckle down on my partner with my daughter because he’d be like ‘I’m allowed to give her a treat’ and I’m like ‘yeah, and then she goes down to Nanny’s and Nanny has made her cupcakes and then she goes over to Koro’s and he’s done all these things, and her aunties will give her all these things’. It all adds up to lots of sugar.’
Independence in adolescence	‘So when I controlled everything, she was younger, we got her weight down […] I could control it, but as she’s got to teenage years, we have our license now, we have a job. We can’t control it. We’re our own identity so now she’s her own, she is her own weight and I can’t do anything about it.’

Concern for mental health	‘I just don’t want him to have any issues about it. We try our best to make sure he eats good stuff.’
Frustration when not seeing change	‘[DAUGHTER]’s always been big. She’s still a big girl now. But whatever she tries to do, nothing works. She would eat nothing, she could just drink water, and still gain weight. She’s just one of those people. The more exercise she does, it does nothing.’

11.3.1 Financial cost of healthy eating

Participants stated that the cost of healthy food was off-putting, impacting their ability to make healthier choices. This cost was an extra burden on the family when they did choose to purchase it, especially with larger families. Buying in bulk was cheaper but put pressure on families due to the upfront cost.

> ‘So when you think of meat, fruit, vegetables, it is quite a costly thing, and we lived in a house of essentially nine people, so it was a massive meal to make and money was extremely tight because there was seven kids and, you know, two adults, so it was quite hectic.’

> ‘Food’s not cheap and especially when you take them off formula and put them on normal cow’s milk […] we go through 6+ litres of milk a week. I buy the three litres ’cause it works out a little bit cheaper, but three litres is still $5 something so, you know, in your groceries so there’s $10 – $15 just for milk.’

Many families on one income struggled to make healthier choices, and due to the cost of changing to healthy food for the whole family, some families made the choice to prepare healthy meals for the child who needed it most.

> ‘The cost of changing the food and, you know, for one particular person when you’ve got like two or three kids and stuff like that does make it a lot. When you’ve got one child it’s not too bad if you’ve got two incomes, but when you’ve got, say like a solo parent and you’ve got three or four kids, trying to give that other kid extra decent stuff that they need. I mean, they all should have it, but, you know, when you’re doing one you can afford it, but when you’ve got two or three that you are trying to get to eat healthy as well [it] does put a big toll on it. I mean, we tried it, I tried it quite a while

> with [SON] and it was just like, it was getting costly and then I was only part-time working then and it was a big struggle.'

In addition, for families struggling with ongoing food insecurity, it was more important that the family had some food than no food:

> 'We went to a family group conference [a meeting coordinated by child yourth and family services] […] she said oh they didn't have very good lunches, and I said, "I beg your pardon?" Because I had been there a lot of times when she'd made their lunches and taken them up to school. On a pay day she would go to the supermarket in the morning and then take their lunches to them so that she had, they had lunches, and if they didn't have lunches, she didn't send them to school.'

One participant stated, 'they may not have been the healthiest of lunches, but there was plenty of it', demonstrating the variation in identified priorities relating to food for families.

11.3.2 Effect of the food environment

The food environment contributed towards food provisioning decisions and physical activity, such as the types of food outlets available and food advertising. Another participant recognised the effects of food advertising on her family's ability to make healthy choices. One participant stated that the introduction of a fruit shop to their small town (population of <2000 people) had changed residents' eating habits:

> '…until the past two months we couldn't afford the fruit and veggies. Now we've got a fruit shop in town that sells seconds and local produce, you know […] So people in this town, that fruit shop has given hundreds of people on no incomes, you know, it changed our diet and it's making a difference.'

Participants recognised that a change in environment affected their abilities to make healthy lifestyle changes:

> ‘I visit my country and we eat more vegetables and more walk because my mum not drive, and she’s just skinny, skinny and skinny. When we come back she start again [to] eat.’

11.3.3 Time available to make healthy meals

Many families stated it was the time cost involved that was a barrier to eating healthily – this included planning, buying, preparing, cooking and cleaning up. This was often difficult or unrealistic for families working long hours or with only one parent available to prepare meals.

> ‘And with how our lifestyles worked, it just wasn’t realistic […] by the time we all get home the last thing any of us wanted to do was dick around with a long-term meal. They just wanted food on the table ’cause they’re starving and I didn’t want to do anything so, you know, we do fall back on things like macaroni cheese and sausages and things like that because it was easy.’

11.3.4 Stress of implementing healthy lifestyle changes

Similarly, the stress of trying to implement healthy lifestyle changes was often perceived to be too much for families depending on the time available, work hours, family size, and competing priorities.

> ‘It’s small changes in small periods of time because otherwise you have rip roaring arguments at home and children are detoxing off sugar over here and mum’s over in

> the corner wanting a drink going ‘oh my God’, feeling, the screaming, the fighting over it. It just wasn’t worth it.’

Making healthy lifestyle changes around nutrition was also difficult compared with other lifestyle factors such as smoking, due to the necessity of food in everyday life:

> ‘It’s like people who smoke and people who drink – they know that they shouldn’t, but they still do. *Laughing.* The thing is, you can’t just quit food. Oh, I’ll just quit eating. *Laughing.* I’ll just quit, I’ll just go cold turkey and I won’t eat any more ever. It doesn’t work.’

In many cases, parents and caregivers simply wanted to keep their children happy, which often equated to them being full. Some participants spoke of how difficult it was to consistently make healthy lifestyle changes when families were dealing with other complex issues:

> Participant 1: ‘It did affect our kids though, I must notice, when that happened [imprisonment]. Our kids started getting judged from our actions, aye.’
>
> Participant 2: ‘Yeah, that’s when I let them eat whatever they wanted, gave them whatever they wanted. They were crying, “I was missing Dad”, so here eat whatever you want. Lost control of them.’

11.3.5 Consistency across family

It was difficult to maintain consistent healthy lifestyle changes across families with parents living in separate households.

> ‘[DAUGHTER, 17], at home her diet, we didn’t have that stuff in the house so her diet, she ate the same as what the other two girls ate. The other two girls weren’t overweight.

> It was when she went to the other house, there was access to Coke and so she binged on it.’

Participants also expressed frustration when other family members fed their children what they wanted rather than trying to maintain changes.

> ‘Nannies and Grandads man – they’re shocking. Like, I tried to get to my parents onboard and I’m like ‘look, we need to watch what she eats, you know, don’t give her any lollies and all this stuff and fizzies’ and oh yeah, no. ‘No, we’re grandparents, we’re allowed to do that’. Well, you’re affecting her then, aren’t they? […] They’re like ‘they’re my moko [grandchildren], they’re alright’. […] When everybody else gives them treats, aye, it all adds up.’

11.3.6 Balancing healthy lifestyle changes with concern for mental health

There was concern from some families about the risk of stigmatising children based on their size, and strong concerns about child and adolescent mental health. For some families this was considered more important than implementing healthy lifestyle changes relating to weight. For other families trying to make healthy lifestyle changes relating to weight, this was a delicate balance between encouraging healthy choices and protecting self-esteem.

> ‘Having had conversations with friends who have had daughters who have suffered from eating disorders, and having had a sister who did, my kind of feeling is that the best approach is the fairly low-key relaxed. Just let her kind of figure it out, try and be there, not ask her lots of questions and not do the whole, “what are you eating?” “How long did you exercise for?” I just think you just have to keep it a little bit light and yeah, trust that she’ll figure it out.’

11.3.7 Independence in adolescence

It was difficult for parents/caregivers to help their older children to make or maintain changes as they moved into adolescence. Many adolescents started working and gained more financial independence. Parents expressed how difficult it was to continue to support their teenage children to make healthy lifestyle changes. The introduction to alcohol in adolescence was another challenge due to the social pressure to drink alcohol with their peers:

> ‘Now they all drink so it’s like “grrr, do you realise how much sugar those fucking crap drinks have in them [DAUGHTER]?” Bloody RTD [ready to drink alcohol mixes] thingies, KGBs [alcohol brand]…’

11.3.8 Frustration when not seeing change / maintaining motivation

A key challenge for maintaining healthy lifestyle changes was frustration when participants did not see changes in their health or body weight. Many participants stated how difficult it was to continue with the lifestyle changes they had made because it did not seem to make a difference. This was discouraging for many families who may have made positive healthy lifestyle changes but felt like they had still ‘failed’. One participant speculated that this was why many people did not continue with their lifestyle:

> ‘It’s a mystery to me why he didn’t [lose weight] … All I can think of is that I feel like I’m still big, I’m still, overweight, and he’s still overweight […] It’s reflecting on me – “look, I’m still the same, I’m not doing it properly, people are going to say to me, ‘you’re not doing it properly’”.’

Making lifestyle changes in the hope of losing weight was considered a futile endeavour by some participants, which was a key barrier for maintaining healthy lifestyle changes.

11.4 Discussion

This study shows that families in NZ face a range of challenges when attempting to make healthy lifestyle changes in current environments. Participant-identified challenges were the financial and time cost of eating healthily, the stress of making healthy lifestyle changes, the effect of the food environment, maintaining changes across split households, concern for child mental health, increased independence in adolescence, and frustration when not seeing changes. Implementing healthy lifestyle changes is challenging even with the support of a healthy lifestyle intervention due to a range of external socio-environmental factors.

Previous research in NZ has shown that food provisioning decisions are affected by a wide range of factors such as cost, tiredness, stress, lack of help, time, food preferences, and access to food, many of which can be mitigated by the economic determinants of food insecurity.[287] Our study supports this finding and similarly identified the multiple facets of the cost of healthy eating, which includes not only the financial cost of purchasing healthy food,[285, 286] but also the time cost and additional stress of preparing healthy meals.[287] The range of stressors on families is mentally taxing and families may be less able to make healthy lifestyle changes when dealing with multiple other concerns, especially in the context of the obesogenic environment and entrenched socioeconomic inequities.

Family- and community-based multidisciplinary interventions are needed given the prevalence of weight-related comorbidities in NZ children.[116] The identification by participants of the clear effect of the food environment on peoples' ability to make healthy choices further reinforces the need to make healthy choices easier through addressing food environments at a policy level,[288] as well as addressing income and socioeconomic inequity.[16] Community-based interventions need to be provided within the context of wider preventative efforts.[33] The effectiveness of intervention programmes and families' abilities to sustain healthy lifestyle changes are likely to be enhanced by policies that focus on improving the food environment and decreasing the cost of healthy food. Given children and adolescents live in families, and families live in communities, it remains difficult for persistent healthy lifestyle change to be achieved when the surrounding environment remains obesogenic.

The frustration and shame experienced by families if they did not see weight changes despite the adoption of many healthy habits reinforces the need for a range of health and wellbeing goals and indicators of success in multidisciplinary interventions. The utility of BMI as a sole measure of intervention success has previously been questioned,[94] particularly as a relevant measure for Indigenous groups.[102] A lack of reduction in BMI should not be equated with failing to adopt healthy lifestyle changes, and an over-focus on weight in childhood obesity interventions is a missed opportunity for many families who have made positive dietary and physical activity changes.[94] However, it is acknowledged that improvements in weight status are key in addressing weight-related comorbidities long-term.

The Whānau Pakari programme takes a non-stigmatising, non-judgemental approach, with a focus on healthy lifestyle change rather than using terms such as weight loss, diet or obesity. However, participants are still inundated with messages from wider society that reinforce the idea that 'success' is solely weight loss over a set period of time, while trying to make changes in an obesogenic environment, which may be discouraging for participants. In addition to policies that focus on reducing the effect of the obesogenic environment, a societal shift to address the stigma associated with weight is also required.

A strength of this study is that the data is likely to be reliable and not influenced by social desirability bias, as it was freely offered by participants and not a focus of the interview. However, a limitation of the secondary analysis is that it was not possible to ask further explanatory questions that might have further clarified the data. For example, many of the participant accounts focused on challenges around healthy food, and notably missing from the data is discussion of the challenges of making changes in physical activity, sedentary activity and sleep hygiene behaviour. Also missing are factors that enable families to make healthy lifestyle changes, in addition to the barriers. Given the low numbers of NZ children meeting national recommendations in these areas,[261, 289] this is an important element in understanding the effectiveness of interventions in NZ. Parental and caregiver identification of adolescence as a difficult period for healthy lifestyle change reflects the need to prioritise child and adolescent voice, which this study was unable to do, and should be a focus of future research in this area. Previous qualitative research has recommended that lifestyle interventions for adolescents should emphasise a broader range of outcomes than weight, particularly focusing on mental health as an outcome. [284]

In conclusion, families in NZ face a range of challenges at both the individual and interpersonal to socioenvironmental levels that impede their ability to make and sustain healthy lifestyle changes. Implementing healthy lifestyle changes is challenging even with the support of a healthy lifestyle programme due to a range of external socio-environmental factors. The effectiveness of intervention programmes in a real-world setting, and the ability of families to achieve persistent healthy lifestyle changes would be enhanced by aligned coordinated policies which focus on improving the food environment in order to make it easier for families to make persistent healthy lifestyle changes.

12 A collaborative Indigenous – non-Indigenous partnership approach to the research process

This chapter contains the manuscript discussing the partnership approach undertaken by the researchers who contributed to the interview study, which allowed for rich data collection and analysis and respectful engagement in the research process.

Submitted for consideration of publication to *BMC Public Health.*

Wild CEK, Rawiri NT, Cormack DM, Willing EJ, Hofman PL & Anderson YC. A collaborative Indigenous – non-Indigenous partnership approach to understanding participant experiences of a community-based healthy lifestyles programme. Submitted paper. Forthcoming 2020.

12.1 Background

Ko koe ki tēnā, ko ahau ki tēnei kiwai o te kete.

You at that and I at this handle of the basket.

This article describes the collaborative research approach undertaken by a team of Māori (the Indigenous people of Aotearoa/New Zealand) and non-Indigenous researchers involved in exploring the barriers and facilitators to engagement in Whānau Pakari, a home-based, family-centred healthy lifestyles programme established to address weight management issues among children and adolescents. It will explore the partnership undertaken by the two researchers directly involved in interviews with programme participants, whose working relationship was critical to the success of the research, as well as the wider approach taken by the research team. The use of Community-Up research principles[229, 290] provided values to guide the research team in respectful research practice and was an essential part of the reflective process required to navigate and negotiate the challenges and opportunities that emerged during the research.

Increasing obesity rates among adults and children are concerning. Indigenous peoples experience consistently inequitable health outcomes, including in rates of childhood obesity.[7] The high rates of children and adolescents experiencing obesity worldwide are reflected in Aotearoa/New Zealand (henceforth referred to as New Zealand), where 12% of children aged 2–14 years are affected. Māori are 1.6 times more likely to experience obesity than non-Māori.[261] The World Health Organization has recommended family-based, multi-component lifestyle programmes as the model of care for addressing childhood obesity.[12] Equitable access to health services is a key guiding principle of the New Zealand Health Strategy,[212] and therefore healthy lifestyles programmes addressing childhood obesity must be accessible and acceptable to the communities they serve.

12.1.1 Whānau Pakari

Whānau Pakari is a family-centred healthy lifestyles assessment and intervention programme based in Taranaki, New Zealand. It is unique in that it provides a comprehensive medical assessment in the home, allowing participants to have any underlying weight-related comorbidities addressed without a hospital appointment.[13] It also provides weekly sessions focusing on nutrition, physical activity and psychology in a community setting in a positive, non-judgemental format. The focus is on healthy lifestyles rather than weight. The programme is run by a multidisciplinary team, with physical activity specialist, dietitian, and psychologist input, and clinical oversight from a paediatrician. The programme achieved high initial recruitment with Māori (47%, compared with the background rate in Taranaki of 17%)[291] with comparable recruitment as New Zealand European families (43%), as well as high representation from those residing in the most deprived areas (28%, compared with the background rate in Taranaki of 15%).[14, 292] The greatest outcomes were found in participants who attended ≥70% of programme sessions; however, these participants were more likely to be of New Zealand European ethnicity.[14]

A key part of the research programme discussed in this paper was understanding barriers (factors that prevent or limit engagement) and facilitators (factors that enable engagement) for participants accessing Whānau Pakari, in order to be able to understand how to improve ongoing engagement in the programme with Māori in particular. While we anticipated that there might be some barriers unique to being referred to an obesity intervention programme, it was likely that many of the barriers experienced by whānau and families were also applicable and relevant for understanding healthcare service use across a range of primary and community-based services. We undertook a qualitative research project involving 64 home-based, in-depth interviews with families who had been referred to the Whānau Pakari service, with equal numbers of whānau and families with Māori and non-Māori children to ensure appropriate representation.[293] This included participants who attended weekly sessions to varying degrees, those who had one assessment and decided not to continue, as well as those who declined further input from the service after their initial referral, in order to ensure representation from those who did not engage.

12.2 Methods

12.2.1 Kaupapa Māori informed research

In New Zealand, all research involving Māori should be responsive to Māori under the Treaty of Waitangi,[215] establishing a strong impetus to work towards health equity for Māori.[214] Before undertaking this project, the research team agreed that this research would take an approach informed by Kaupapa Māori research principles and objectives.[214, 227] There is considerable debate around the degree to which non-Māori can participate in Kaupapa Māori research.[224] By definition, Kaupapa Māori research necessitates Māori ownership and control of the research process.[294] Given the lead researcher and PhD student in this case were non-Māori, the approach of this research was considered 'Kaupapa Māori informed', as it centred whānau in the interview process and paid attention to broader contexts, considering power and structural issues.[227] This methodological approach was appropriate to the aim of the research, as there is a strong commitment in the research team to achieve health equity and reduce barriers to engagement within prevailing healthcare services by providing robust outcome data, in order to complement Kaupapa Māori service provision and research. We believed that this approach to the research would enable interview participants to positively engage in the research, and would reduce many of the common barriers to research participation for Indigenous peoples.[131]

12.2.2 'Community-Up' research process

The research process was informed by the 'Community-Up' approach to research conduct developed by Smith[229] and Cram,[290] which provides guiding principles for entering into respectful research processes with whānau, in ways which uphold their mana (status, dignity).

These values included: *aroha ki te tangata* (respect for people, allow people to define their own space and meet on their own terms), *he kanohi kitea* (meeting face to face and being a face that is known and seen in the community), *titiro, whakarongo… korero* (looking and listening to develop an understanding before speaking), *manaaki ki te tangata* (sharing, hosting, being generous), *kia tūpato* (be cautious, politically astute, reflexive about insider-outsider status), *kaua e takahia te mana o te tangata* (not trampling on the mana or dignity of a person), and *kia māhaki* (being humble, not flaunting knowledge). These values were important for the research team for guiding interactions with participants and with each other, and several key principles implemented in our research process are discussed in depth below.

12.2.3 An Indigenous – non-Indigenous research team

The research team was comprised of both Māori and non-Māori researchers. Throughout this process it was acknowledged that researcher positionality and values would influence the research process.[295] Acknowledgement of our researcher standpoints and specific skills allowed us to debate, challenge, and refine interpretations of the data with respect and openness. This was particularly important for CW (non-Māori) and NR (of Ngāti Mutunga, Ngāti Tama, Ngāti Rahiri o Te Ati Awa, and Ngāti Tūhoe descent) who formed a partnership as facilitators for the interviews. The interview process required us to actively 'work the hyphen', bringing the Indigenous – non-Indigenous relationship to the fore and requiring us to acknowledge our differences.[226] Jones argues that the 'us' of the Indigenous – non-Indigenous research team must not replace the hyphen between the two worlds – rather, it identifies a relationship which is conditional, fluid and constantly negotiated.[226] Additionally, as a wider Indigenous – non-Indigenous research team we worked collaboratively, acknowledging our diversity within the research team and embraced the 'productive tension of difference'.[226] This allowed space for different realities and knowledge, and the view was taken that the collaboration *should* be a contested, negotiated process, which was ultimately reassuring.

In addition to the constant personal reflexivity required as a mark of researcher integrity,[211] further layers of interpersonal collective reflexivity were required to deal with the complexities and 'messiness' of this collaborative research. This involved constant self-audit, as well as a reflexive approach to the dynamics of the relationships within the research team. Jones notes that to engage with a methodology as an outsider calls for a constant restless uncomfortable reflexivity.[226] As both intermittent insiders and outsiders, we frequently questioned ourselves and each other, and the power dynamics at work within our relationship and in our interactions with interview participants.

12.3 Results

The application of 'Community-Up' research principles allowed for a respectful research process which upheld the *mana* (status, dignity) of the interview participants and the research team. Three key 'Community-Up' research principles which shaped our research process are discussed below, as well as the challenges we encountered.

12.3.1 Aroha ki te tangata – respect for people

The interview participants were past Whānau Pakari programme users, including those who had not had any further contact with the programme aside from the initial referral. The non-Māori coordinating researcher took responsibility for recruitment of non-Māori participants, and the Māori researcher took responsibility for recruitment of Māori participants. Given that we were interested in talking with families who had not engaged highly with the service, especially non-service users, we were flexible in our approach and used a variety of recruitment strategies, including telephone calls, text messages, emails, and making use of whānaungatanga connections. Whānaungatanga is the process of establishing meaningful, reciprocal and familial relationships through culturally appropriate ways, establishing connectedness and engagement and, therefore, a deeper commitment to other people.[296] For example, the interview encounter began with making connections between the researchers and research participants, which built rapport and relationships based on shared experiences other than the research at hand. As well as being used to establish linkages and rapport in the interview encounter, whānaungatanga was also used as a recruitment methodology, whereby it was possible to contact and recruit some participants via existing relationships and networks. This allowed connections to be established early in the interview process. In the interview, the researcher who had made the initial contact with the participant led the interview, with the other researcher contributing to the interview as appropriate. Interview times and locations were chosen by the participant, in order to overcome travel and timing barriers, and frequently took place in the participant's home. Other whānau and family members were sometimes present, which was accepted as part of the participant terms of the research process.

12.3.2 Kia tupato – be cautious, politically astute, reflexive about insider-outsider status

We agreed to apply the 'Give-Way' rule throughout this research if there was disagreement over the interpretation of the data concerning Māori participants, and the final decision involving cultural interpretation of Māori participants' experiences would pass to a Māori project team member.[210, 223, 245] This allowed for a systematic and practical way of navigating differential interpretations within a diverse research team, with agreed parameters from the beginning.

We also found the underlying principle of the Give-Way rule to be a useful tool during data collection. CW and NR worked together to establish rapport with the interview participants and develop a comfortable environment for the sharing of experiences and stories. Practically, this meant that, in some cases, CW as the non-Māori researcher and doctoral student ‘gave way’ to the relationship already established between the NR and the participant – the interview was led and conducted primarily by NR, with CW there to assist and contribute when appropriate. This was an instinctive, dynamic process which evolved as the interview progressed and involved a constant negotiation of the multiple and subtle ways in which we were both insiders and outsiders to participants.[229] We were aware that we both held multidimensional identities, allowing us varying levels of insider-outsider status, depending on the interview participant and the context.[297, 298] Conducting the interviews as a partnership gave us a greater shared ability to connect with and position ourselves alongside the interview participants according to shared identities, backgrounds, relationships and experiences.

12.3.3 Titoro, whakarongo… korero – look, listen… then speak

The time spent travelling to and from interviews unexpectedly became a significant and vital part of the data collection and analysis process. CW and NR travelled to and from interviews together, and the time spent in these car trips became a place for collective knowledge-building, sharing, discussion, reflection, debrief, debate and challenge. This was invaluable for the success of the partnership and the research. It facilitated us knowing ourselves and each other in the context of the research project, allowing us to develop an instinctive knowledge of our dynamic insider-outsider status with participants. We were also able to immediately peer debrief if an interview experience was surprising or unplanned, or if sensitive material was raised. The success of the interviews was highly dependent on this partnership between CW and NR, which required time and effort to cultivate.

12.3.4 Challenges

Our interview recruitment strategy was based on obtaining equal numbers of interviews with Māori and non-Māori whānau and families, in order to ensure adequate representation from Māori whānau. However, we occasionally found that ethnicities on hospital records did not align with how participants identified at the interview. This meant that sometimes we only became aware of how a participant currently self-identified when meeting them face to face, requiring a flexible interview strategy in order to allow the best interview experience for the participant. As well as flexibility in our conceptions of ethnicity, this process required us to question our assumptions and understandings of what it meant to be a Māori whānau, rejecting notions of cultural essentialism.[223] We subsequently broadened our inclusion criteria to respect the preferences of participants and allow for diversity, which resulted in interviews with grandparents, caregivers, extended whānau and non-Māori parents and/or caregivers of Māori children. While this added complexity and challenged our original research protocol, the research team agreed that this simply reflected the complexities and fluidity of whānau in New Zealand today.[235]

12.4 Conclusion

Our research team which comprised both Indigenous and non-Indigenous researchers adopted a collaborative partnership approach for the interview process, based on principles informed by a Kaupapa Māori approach, which resulted in rich research findings and professional growth as researchers. The research team held a strong unifying belief in the importance of the work, a commitment to health equity, and mutual respect, as well as a willingness to be intellectually challenged, to learn from one another, with humility demonstrated from all parties. A partnership approach to interviewing effectively enabled the researchers to engage with a diverse participant group, while prioritising Māori voice through intensive recruitment efforts and a thoughtful interview process which was responsive to Māori participants. The Community-Up principles provided a solid foundation that guided the interview process and decision-making, and ultimately allowed us to effectively navigate any challenges that emerged. While there is not one ‘best practice’ for respectful, effective Indigenous – non-Indigenous health research, our team was committed to ongoing communication, awareness and attention to the relationships that formed the basis of our research partnership.

13 Results: Five-year follow-up of Whānau Pakari – a post-RCT analysis

Long-term outcomes of multidisciplinary programmes addressing childhood obesity are limited; however, it is important to assess whether interventions are effective long-term. This chapter contains the manuscript reporting the five-year follow-up of participants after the Whānau Pakari randomised clinical trial.

Submitted for consideration of publication to *JAMA Pediatrics.*

Wild CEK, Wynter LE, Triggs CM, Derraik JGB, Hofman PL & Anderson YC. Five-year follow-up of a family-based multidisciplinary assessment and intervention for children and adolescents with weight issues – a post-RCT analysis. Submitted paper. Forthcoming 2020.

The Quality of Life study described in this paper was carried out using the PedsQL™, developed by Dr James W. Varni.

13.1 Introduction

Family-based, multidisciplinary lifestyle interventions are recommended best practice for addressing childhood obesity;[12, 82] however, long-term follow-up studies assessing the outcome are limited, especially past two years. The US Preventative taskforce identified that a minimum of 26 contact hours is required to achieve reductions in body mass index (BMI) standard deviation score (SDS).[299] While 0.1 was originally considered a clinically meaningful BMI SDS reduction,[90, 91] a prospective observation study found a 0.25 to 0.50 reduction in BMI SDS was required to achieve improvements in cardiovascular and metabolic outcomes.[91] It has been suggested that a lack of reduction in BMI SDS should not be equated with failure to make healthy lifestyle changes,[94] and there is growing debate around the sole use of BMI SDS as a relevant health indicator,[102] especially when determining programme success. However, in light of recent findings highlighting that 90% of those identified as experiencing obesity at three years will continue along this trajectory into adolescence,[101] and the prevalence of weight-related comorbidities in those children and youth with obesity,[116] the importance of addressing weight and its associated comorbidities cannot be ignored.

Retention rates and long-term outcomes of multidisciplinary lifestyle interventions are variable. Retention rates of 42% to 89% have been reported with modest sustained reductions in weight in five to ten years post-intervention.[97, 109, 111, 112] However, these studies were limited by a lack of comparison control groups,[97, 109, 111] were homogenous in terms of ethnicity and socioeconomic deprivation,[97, 109] and/or did not report sociodemographic information.[111] A home visit trial to prevent early childhood obesity in socioeconomically disadvantaged areas of Australia showed reductions in BMI SDS at two years were not sustained at five years post-baseline (74% retention rate).[113] There is limited long-term follow-up of home-based intervention programs, low representation from Indigenous and other marginalised groups, and assessments of interventions in real-world settings.

The Whānau Pakari randomised clinical trial (RCT) assessed a novel community-based multidisciplinary healthy lifestyle service for children/adolescents and their families in Taranaki, Aotearoa/New Zealand (henceforth referred to as New Zealand [NZ]).[13] Its development was based on widespread community consultation and audit findings of a previous programme, which had limited engagement with groups most affected by obesity (namely Māori, the Indigenous people of NZ, and those living in the most deprived areas).[13, 123] Whānau Pakari is a family-centred, home-based programme with a comprehensive medical assessment/intervention programme in one 'demedicalised' model (replacing conventional hospital-based care), which was cost-effective at 12 months.[138] The programme is committed to addressing inequities in the prevailing healthcare service and was evaluated within the real-world context of a clinical service. Given the disproportionate rates of obesity internationally among Indigenous groups and those who are most deprived, Whānau Pakari specifically addressed accessibility and appropriateness of service for these groups.[17–19]

Twelve-month data demonstrated reductions in BMI SDS from baseline in the low-intensity assessment-and-advice and the high-intensity intervention groups, and improvements in cardiovascular fitness and health-related quality of life (HRQOL).[20] At two years, participants reverted back to their baseline BMI SDS, irrespective of age, ethnicity and socioeconomic status.[136] Persistent improvements in cardiovascular fitness, reductions in sweet drink intake, increases in water intake and improvements in HRQOL were found.[136] As was observed at 12 months, high attendance in the high-intensity intervention resulted in BMI SDS reductions at 24 months, demonstrating that attendance is key to outcome.[136]

The purpose of this longitudinal study was to determine BMI SDS at five years in Whānau Pakari participants. Given this was a service focused on healthy lifestyle change, secondary outcomes were also assessed.

13.2 Methods

The methodology for the Whānau Pakari trial has previously been reported,[13] as well as outcomes at 12[14] and 24 months.[136] The unblinded RCT involved a high-intensity intervention including a home-based medical assessment with advice and weekly group sessions compared with a low-intensity control group receiving home-based assessments/advice only.[13] Both groups received six-monthly follow-up for another 12 months. The trial was embedded in a community-based clinical service, which was family-based and ‘demedicalised’, removing the hospital appointment without compromising quality of care. The trial aimed to recruit high numbers of Māori participants and those living in more deprived areas of Taranaki, where approximately 24,684 children aged 0-15 years reside, of whom 83% identify as NZ European (NZE), 32% as Māori, and 12% as other ethnic grouping (total ethnicity output used where multiple ethnic groupings possible; therefore, total is greater than 100%).[73]

The Whānau Pakari RCT and the five-year follow-up was granted ethical approval by the Central Health and Disability Ethics Committee (NZ) (CEN/11/09/054/AM10). Written and verbal informed consents were obtained from all participants and/or guardians. Trial registration was with the Australian NZ Clinical Trials Registry (ANZCTR: 12611000862943).

13.2.1 Participants

Eligible participants were children/adolescents aged 5–16 years in Taranaki with a BMI ≥98th centile, or those >91st centile with weight related comorbidities, using UK Cole normative data[95] and calculated using KIGS auxology software (Pfizer Endocrine Care TM). Referral to the original Whānau Pakari trial was between January 2012 and August 2014.[13] Exclusion criteria included medical or psychological conditions affecting the individual’s ability to undertake physical activity or participate in group sessions, medical conditions likely to influence primary outcome, a lack of “readiness” to make lifestyle changes based on a quantitative and qualitative assessment, and the absence of a committed family member/caregiver, required to support the program's family-based approach.[13] Families agreed to attend ≥70% of weekly sessions if randomly assigned to the high-intensity intervention.

The high-intensity intervention group participated in a 12-month multidisciplinary programme with weekly sessions, with input from a physical activity specialist, a dietitian and a psychologist. Sessions took place at community sporting venues, incorporating activity sessions (including games and introduction to various sports), dietary sessions (including portion size, cooking sessions and virtual supermarket tours), and psychology sessions (including discussions around making healthy lifestyle changes and self-esteem).[13] The programme aimed to be non-judgmental and non-stigmatising, and obesity and weight were not concepts discussed with participants once in the program; rather, the focus was on healthy lifestyle change. Both arms received six-monthly follow-ups with home-based assessments and advice, and the multidisciplinary clinical team undertook case reviews with paediatrician oversight to address any identified weight-related comorbidities.

13.2.2 Data collection

Five-year follow-up assessments were completed in the family home, or at another location preferred by the participant, by a health professional trained in focused weight-related assessment, with clinical oversight from a paediatrician. This included medical and dietary history and examination, including resting heart rate, blood pressure (based on the Fourth Report percentiles[249] to maintain consistency with previous data collection) and waist-height ratio, identification of weight-related comorbidities,[116] and physical activity and psychological assessment. Perceived and actual physical activity were assessed by the children's physical activity questionnaire (C-PAQ) including assessment of sedentary time and five days of ActiGraph wGT3XBT (ActiGraph LLC, Pensacola, Florida) accelerometer wear. Cardiovascular fitness was assessed by a 550m walk/run.[260] Changes in HRQOL were assessed using the Pediatric Quality of Life [PedsQL^{TM}][253] questionnaire (a 4.4-point and 4.5-point change in total score on the PedsQL^{TM} questionnaire for child self-report and parent proxy report, respectively, are considered clinically meaningful[255]) and Achenbach Child Behavior Checklist [CBCL].[300] Fasting blood tests were assessed, and cut-offs for liver function, lipids, low-sensitivity CRP, fasting insulin, and glycated haemoglobin have been described previously.[13]

13.2.3 Data analysis

Demographic characteristics were compared using χ^2 or Fisher's exact tests for categorical variables, and one-way analysis of variance (ANOVA) for continuous variables. Study outcomes were compared between trial arms (intervention vs control) and between intervention groups stratified by attendance at 12 months (≥70% vs <70%) using generalised linear models, including the baseline value of the respective parameter as a covariate, and family code as a random factor to account for siblings. Change in water intake was also adjusted for participant's age (due to the described increase in water intake with age).[301, 302] An additional model was run based on repeated measures of BMI SDS over the five-year period from baseline, using the same covariates as above, as well as a random participant effect. Across the whole cohort non-parametric McNemar's tests were used to compare the rates of adverse clinical and behavioural outcomes.

A generalised linear model was run to examine the associations between key demographic parameters and the change in BMI SDS from baseline to five years, namely age (<10 vs ≥10 years), sex, ethnicity (Māori vs non-Māori), and socioeconomic status, as well as family code as a random factor. Data were analysed in SPSS v25 (IBM Corp, Armonk, NY, USA) and SAS v9.4 (SAS Institute, Cary, North Carolina, USA). All statistical tests were two-tailed with the significance level maintained at $p < 0.05$.

13.3 Results

13.3.1 Study participants/Demographics

Overall retention from baseline at the five-year assessment was 43% (86 from the 199 participants at baseline) and 62% from 12 months ($n = 138$ at 12 months). Reasons for drop-out at five years included moving out of the region ($n = 19$), lack of time or disinterest ($n = 21$), not attending the scheduled appointment ($n = 2$) or being uncontactable ($n = 71$). One participant was excluded from the analysis as they were pregnant at the time of the assessment, and 16 participants were excluded as they subsequently engaged in the Whānau Pakari clinical service for further lifestyle intervention post-trial after 24 months (Figure 13.1). Therefore, five-year follow-up included 28 control participants and 41 intervention participants (Figure 13.1).

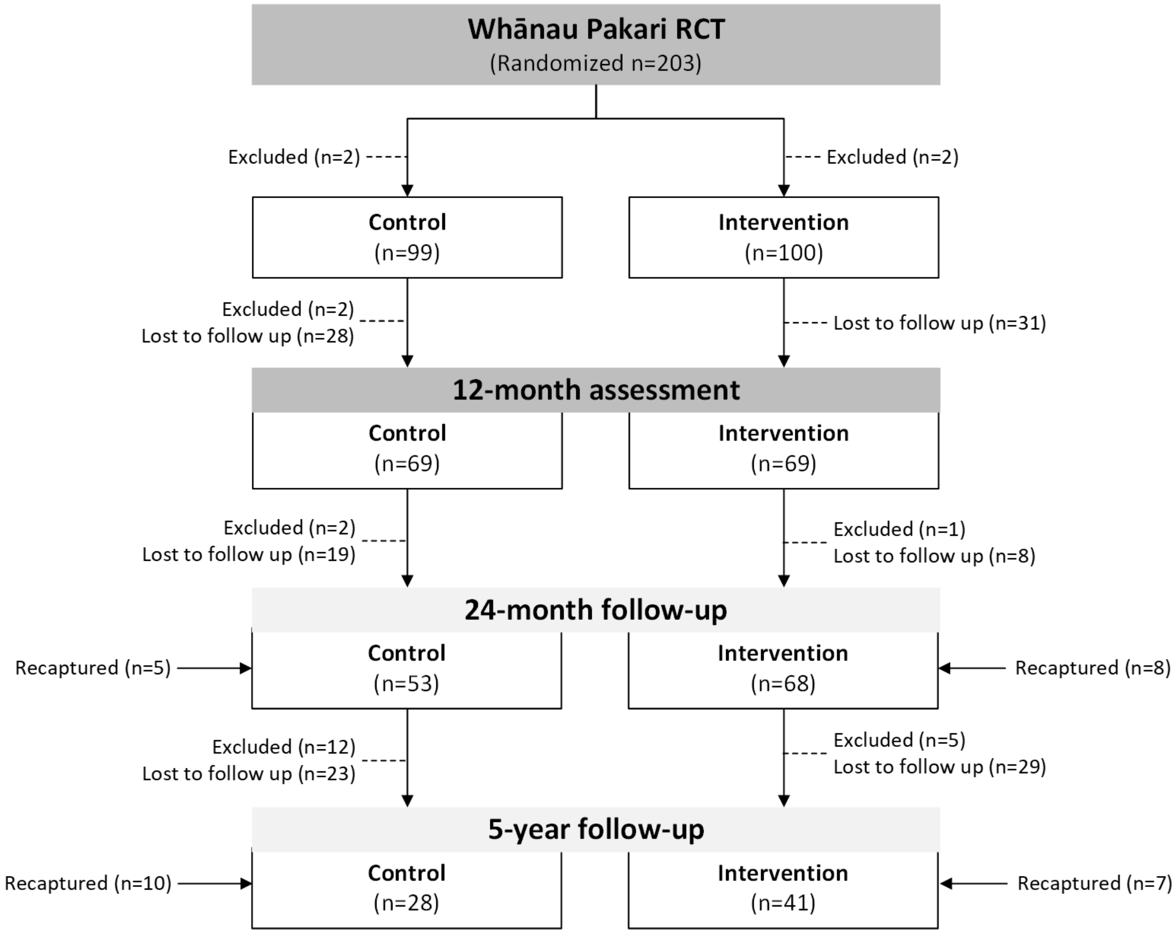


Figure 13.1: Flow of participants from the original Whānau Pakari trial to five-year follow-up.

The baseline characteristics of participants who completed the five-year assessment compared with those who were not retained at five years are provided in Supplementary Table 13.1. In the control group, baseline BMI SDS was lower for participants who had a five-year assessment ($p < 0.001$), and there were fewer males than females at five years compared with non-participants ($p = 0.006$) (Supplementary Table 13.1). In the intervention group, the BMI SDS of accompanying adults was higher on entry ($p = 0.029$) and the proportion of accompanying adults with obesity was higher in five-year participants compared with those lost to follow-up ($p = 0.040$). However, there were no differences in the change in BMI SDS at the 12-month or 24-month assessments between those who were retained at five years and those who were not (Supplementary Table 13.2). Neither ethnic group nor socioeconomic status was associated with participation in assessments at five years (Supplementary Table 13.1).

13.3.2 Low-intensity control vs high-intensity intervention

The low-intensity control and high-intensity intervention groups (n = 69) had similar demographic and baseline characteristics, although there were more females than males in the control group (p = 0.007) (Table 13.1). There was no difference in change in BMI SDS between participants in the high-intensity intervention and low-intensity control group, with both groups displaying a similar drift back to baseline at five years (Table 13.2, Figure 13.2, A). Overall, 41% (n = 28) of participants had a reduction in BMI SDS at five years from baseline.

For secondary outcomes, compared with the control group, the high-intensity intervention group showed increases in reported screen time and fasting insulin, the latter most likely due to increased age (Table 13.2). There was a decrease in sweet drink intake (140 ml/day) and an increase in water intake (400 ml/day) in the intervention group compared to baseline (Table 13.2). Clinically meaningful improvements[255] persisted from baseline in HRQOL (total child generic scaled scores for both the intervention and control groups, and improvements in total parent generic scaled scores in the intervention group) (Table 13.2). Improvements in CBCL internalising, externalising and total raw scores (i.e. decrease) in both groups from baseline were observed (Table 13.2). Participant numbers who had completed the 550m walk/run and with sufficient accelerometer wear were too small to report on objective measures of physical activity.

Table 13.1: Baseline characteristics of the 69 participants from the Whānau Pakari randomised clinical trial who completed the five-year assessment.

		Control	**Intervention**
n		28	41
Age (years)		10.2 ± 3.6	10.5 ± 3.1
Female		22 (79%)	19 (46%)
Ethnic group [a]	Māori	12 (43%)	21 (50%)
	Pacific Peoples	–	–
	European (total)	16 (57%)	19 (46%)
	New Zealand European	15 (54%)	17 (42%)
	Asian (total)	–	1 (2%)
	Indian	–	1 (2%)
	Asian (other)	–	–
Anthropometry	BMI (kg/m^2)	27.16 ± 5.88	28.14 ± 4.09
	BMI SDS	2.79 ± 0.6	3.00 ± 0.5
Socioeconomic status	Quintile one (least deprived) [b]	1 (4%)	6 (15%)
	Quintile two	5 (18%)	7 (17%)
	Quintile three	6 (21%)	7 (17%)
	Quintile four	8 (29%)	9 (22%)
	Quintile five (most deprived)	8 (29%)	12 (29%)
Accompanying adult	BMI (kg/m^2) [c]	33.45 ± 7.04	34.80 ± 6.94
	BMI ≥30 kg/m^2 [d]	20 (71%)	29 (74%)
Living arrangements	Two-parent household	14 (52%)	19 (49%)
	One-parent household	12 (44%)	19 (49%)
	Other	1 (4%)	1 (2%)

Continuous variables are presented as means ± standard deviations, while categorical variables are n (%).

BMI, body mass index; SDS, standard deviation score.

[a] Prioritised ethnic group (self-allocated into a single ethnic group).

[b] Quintiles of level of household deprivation based on the New Zealand Deprivation Index 2006.[29]

[c] Parameter was measured where consented to (n = 28 and n = 39), otherwise not included.

[d] Adult cut-off for obesity

Table 13.2: Changes from baseline at the five-year assessment among participants in the Control and Intervention groups from the Whanau Pakari randomised clinical trial.

	Control	Intervention	p-value
n	28	41	
Primary outcome			
BMI SDS	-0.003 (-0.22, 0.21)	0.17 (-0.01, 0.34)	0.230
Secondary outcomes			
Waist-to-height ratio	0.014 (-0.007, 0.035)	0.035 (0.018, 0.052)***	0.124
Sweet drink intake per day (ml)	-14 (-113, 85)	-140 (-223, -57)**	0.056
Water intake per day (ml)	206 (-191, 604)	400 (54, 746)*	0.947
Reported screen time per day (minutes)	-20 (-86, 46)	96 (43, 149)***	**0.009**
Total generic scaled score – child [a]	5.7 (0.8, 10.5)*	7.3 (3.4, 11.2)***	0.598
Total generic scaled score – parent [a]	5.7 (-0.7, 12.2)	5.4 (0.1, 10.6)*	0.931
CBCL internalising raw score [b]	-43 (-46, -40)****	-45 (-48, -43)****	0.258
CBCL externalising raw score [b]	-46 (-49, -44)****	-45 (-47, -43)****	0.267
CBCL total raw score [b]	-13 (-21, -5)**	-16 (-23, -9)****	0.615
Total reported activity per day (minutes)	-1 (-39, 37)	17 (-13, 47)	0.464
HbA1c (mmol/mol)	-0.9 (-2.4, 0.7)	-0.5 (-1.6, 0.5)	0.727
Fasting insulin (pmol/L)	-6 (-50, 38)	56 (26, 85)***	**0.024**

Data are means and 95% confidence intervals adjusted for the value of respective parameter at baseline, except for water intake where age at the five-year assessment was also added as a covariate.

Stated p-values are between-groups. P-values that are statistically significant at $p < 0.05$ are shown in bold.

*p < 0.05, **p < 0.01, ***p < 0.001, and ****p < 0.0001 for within-group differences from baseline.

BMI SDS, body mass index standard deviation score; CBCL, Achenbach Child Behavior Checklist; HbA1c, glycated haemoglobin.

[a] Total overall HRQOL score out of 100 for PedsQL questionnaire.[24] A 4.4-point and 4.5-point change in total score on the PedsQL™ questionnaire for child self-report and parent proxy report, respectively, are considered clinically meaningful.[255]

[b] CBCL raw scores were used for a continuous measure. A decrease in CBCL scores is an improvement.

13.3.3 Whole cohort analyses

For the 69 participants who completed an assessment at five years, multivariable models showed change in BMI SDS from baseline was +0.35 SDS greater in females than males (0.21 [95% CI 0.05, 0.37] vs -0.14 [95% CI -0.35, 0.07]; p = 0.013). In addition, participants aged <10 years at baseline (n=34) displayed an improved BMI SDS compared with those aged ≥10 years (n=35) (-0.15 [95% -0.33, 0.03] vs 0.21 [95% CI 0.03, 0.40]; p = 0.008), although there was no within-group difference among those aged <10 years. There was no association of ethnicity or socioeconomic status with change in BMI SDS (data not shown).

Supplementary Table 13.3 summarises changes in medical history, examination findings, and metabolic markers (where available) of the cohort. There were reductions in the rate of reported hyperphagia (40% at five years vs 66% at baseline; p = 0.005), but an increase in the proportion of participants with elevated fasting insulin (from 67% to 90%; p = 0.022) (Supplementary Table 13.3).

13.3.4 Subgroup analysis of attendance

Supplementary Figure 13.1 shows variation in attendance levels over the 12 months within the high-intensity intervention group for those assessed at five years, with a median attendance of 48% [Q1 = 21%, Q3 = 74%].

Subgroup analysis of the high-intensity intervention over five-year period follow-up demonstrated that BMI trajectories of the two attendance groups were different (p = 0.013), where participants who attended ≥70% of the weekly sessions maintained a BMI SDS reduction until at least 24 months (Figure 13.2, B). However, by five years both trajectories had converged towards baseline BMI SDS and were no longer different (p = 0.17; Table 13.3; Figure 13.2, B).

These two groups were demographically similar, although the high-attendance group contained a higher proportion of NZE participants (p = 0.025; Table 13.3). In the high-attendance group, there were greater improvements in total parent generic scaled scores (PedsQL^{TM}) compared to the low-attendance group (Table 13.3). Fasting insulin levels increased in the low-attendance group but were unchanged in the high-attendance group Table 13.3).

Table 13.3: Demographic characteristics at baseline and changes from baseline to the five-year assessment among the 46 participants in the intervention group who completed the trial and had valid attendance data, according to their level of attendance (<70% vs ≥70%, expressed as proportion of available sessions attended).

	≥70%	**<70%**	**p-value**
n	12	29	
Demographic characteristics			
Age at baseline (years)	11.6 ± 2.3	10.1 ± 3.4	0.150
Baseline BMI SDS	2.84 ± 0.39	3.06 ± 0.56	0.216
Baseline BMI accompanying adult (kg/m^2)	33.02 ± 6.06	35.60 ± 7.26	0.291
Accompanying adult BMI ≥30 kg/m^2 [a]	9 (75%)	20 (75%)	0.999
Socioeconomic status (most deprived quintile) [b]	2 (17%)	10 (35%)	0.268
Two-parent household	6 (50%)	13 (48%)	0.796
Sex ratio (female)	3 (25%)	16 (55%)	0.078
Ethnic group (NZ European) [c]	9 (75%)	8 (28%)	**0.025**
Change from baseline at five years			
BMI SDS	-0.03 (-0.35, 0.28)	0.20 (0.00, 0.40)*	0.214
Waist-to-height ratio	0.032 (-0.001, 0.066)	0.035 (0.013, 0.057)**	0.909
Sweet drink intake per day (ml)	-124 (-274, 25)	-171 (-269, -74)**	0.597
Water intake per day (ml)	443 (-280, 1166)	376 (-137, 888)	0.467
Reported screen time per day (minutes)	149 (30, 267)	45 (-33, 124)	0.161
Total generic scaled score – child [d]	7.6 (-0.1, 15.2)	8.7 (3.7, 13.6)**	0.807
Total generic scaled score – parent [d]	13.2 (4.7, 21.8)**	2.1 (-4.0, 8.2)	**0.039**
CBCL internalising raw score [c]	-46 (-50, -43)	-47 (-49, -45)	0.649
CBCL externalising raw score [c]	-44 (-47, -40)****	-45 (-48, -43)****	0.435
CBCL total raw score [c]	-15 (-27, -3)*	-16 (-24, -8)***	0.865
Total reported activity per day (minutes)	64 (4, 123)*	-2 (-41, 38)	0.072
HbA1c (mmol/mol)	-1.9 (-4.0, 0.2)	-0.2 (-1.5, 1.2)	0.164
Fasting insulin (pmol/L)	-1 (-54, 52)	73 (38, 107)***	**0.026**

Demographic data are means ± standard deviations or n (%); outcome data are means and 95% confidence intervals adjusted for the value of respective parameter at baseline, except for water intake where age at the five-year assessment was added as a covariate.

P-values that are statistically significant at $p < 0.05$ are shown in bold.

*p < 0.05, **p < 0.01, ***p < 0.001, and ****p < 0.0001 for within-group differences from baseline.

BMI SDS, body mass index standard deviation score; CBCL, Achenbach Child Behavior Checklist; HbA1c, glycated haemoglobin.

[a] Adult cut-off for obesity.

[b] Quintiles of level of household deprivation based on the NZ Deprivation Index 2006.[29]

[c] Prioritised ethnic group (self-allocated into a single ethnic group).

[d] Total overall HRQOL score out of 100 for PedsQL questionnaire.[24] An increase in the HRQOL score is an improvement.
[c] CBCL raw scores were used for a continuous measure. A decrease in CBCL scores is an improvement.

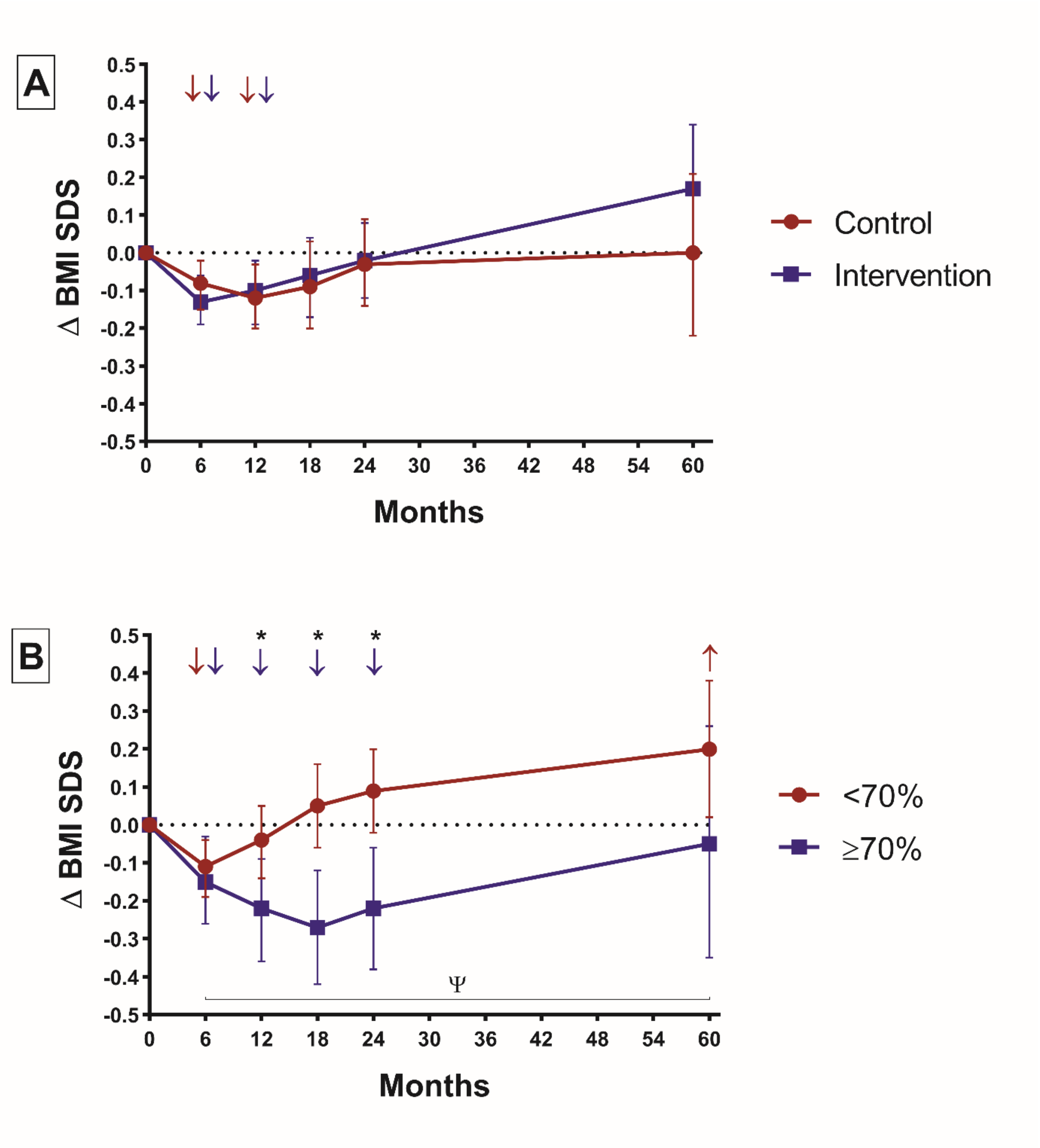


Figure 13.2: Changes in body mass index standard deviation scores (Δ BMI SDS) from baseline.

(A) In control (red) vs intervention (blue) groups; (B) Among participants in the intervention arm according to levels of attendance at prescribed sessions, i.e. <70% (red) vs ≥70% (blue). The baseline level is represented by the dotted line. * indicates a statistically significant difference at $p < 0.05$ between groups at a given time point, while Ψ indicates a difference in BMI SDS trajectory from baseline ($p = 0.013$). Any within-group difference (at $p < 0.05$) is indicated by an arrow, whose orientation provides the direction of the change and its colour the respective group.

13.4 Discussion

In this five-year follow-up of children/adolescents with obesity, the improvements in BMI SDS seen at 12 months after trial commencement were no longer observed. Both the high-intensity and low-intensity groups drifted back to their baseline BMI SDS, irrespective of age, ethnicity or socioeconomic status. The lack of difference in terms of ethnicity and socioeconomic deprivation in primary outcome was encouraging, despite negative overall findings. Early intervention appears more beneficial, which has been supported by previous international findings.[12]

Subgroup analysis of the high-intensity intervention group comparing participants with high attendance and low attendance previously showed a significant reduction in BMI SDS in the high attendance group at 12 months and 24 months.[14, 136] It is possible that the lack of a detectable difference at five years might have resulted from the relatively small sample size in the group with high attendance. Attendance is key to outcome to two years, and BMI trajectory remained more favourable in the high attendance group at five years.

Mild differences in insulin levels between the high-intensity intervention and low-intensity control group are likely due to differences in pubertal onset and growth,[303] due to similar changes in waist-to-height ratios of the two groups. Increases in screen time in the whole cohort and between the high-intensity intervention and low-intensity control group are also likely to be attributable to general increases in screen time levels with age.[304]

It has been proposed that effectiveness of interventions is likely to be affected by the obesogenic environment.[110] Although a 1990 study of a behavioural family-based intervention appeared to have sustained effects at five years,[109] there is an acknowledgement that, in the present day, the increasing influence of the obesogenic environment may impact the effectiveness of these interventions.[110]

Long-term observational data of children with obesity is required to assess natural growth trajectories, in order to contextualise the effectiveness of multidisciplinary healthy lifestyle interventions in a real-world setting. A population-based longitudinal study of 34,196 German children examining annual change in BMI SDS showed that, for adolescents with overweight or obesity, there was rapid weight gain in early childhood (two to six years) with continued weight gain throughout childhood and into adolescence resulting in ongoing increases in per annum BMI SDS.[101] Considering these findings, the halt of annual increases in BMI SDS in this study is encouraging. Data for those not accepting referral to the programme is currently being collected to further understand the present findings in the wider context.

Previous research showed that the Whānau Pakari framework was acceptable to participants,[137] improved access for Māori and those living in the most deprived areas and enabled far more assessments and participant contact than previous models of care.[14, 138] Concepts of obesity and weight are not discussed with participants once in the programme; rather, the focus is on healthy lifestyle change with the aim of being non-judgmental and non-stigmatising.[136] In this study, sustained improvements in sweet drink intake, water intake (albeit self-report), HRQOL and psychological outcomes were seen. This is encouraging as previous studies showed no change or a lack of sustained improvement in HRQOL.[104] However, this study suggests that the high-intensity intervention may require greater intensity or further age-appropriate offerings in order to ensure that clinically meaningful BMI SDS reductions are achieved. The latter is already occurring in the ongoing service model, which has continued due to its increased efficiencies and ability to address health equity in terms of access and appropriateness of service.

A strength of this study was the strong representation from Māori and those living in the most deprived households, which is encouraging given the lower rates of Indigenous groups in

RCTs globally, and the need to make programs culturally acceptable. The study followed participants to five years, where there is a lack of data assessing home-based assessments and multidisciplinary interventions in general and has also allowed for analysis over a range of secondary outcome measures. To our knowledge, this is the first long-term assessment of a home-based healthy lifestyle intervention in a ‘real-world’ setting, including a high proportion of Indigenous participants.

Limitations included the small sample size at five years which may have created potential bias. The retention rate was comparable with one previous study,[112] and lower than others.[97, 109, 111, 113] However, we attempted to minimise potential response bias by comparing the 12-month and 24-month outcomes of five-year participants with the outcomes of those who were lost to follow up. It was also not possible to include actual physical activity outcomes due to the small amount of data collected using accelerometer wear. Prioritised ethnicity output was used, so this will not represent all the ethnicities with which participants identified.

13.5 Conclusion

In conclusion, a home-visit multidisciplinary assessment/intervention that achieved high engagement from those most affected by obesity did not achieve long-term improvements in primary outcome. Ethnicity and socioeconomic deprivation were not associated with outcomes. Attendance and age remain important considerations in healthy lifestyle programs, and assessment of these programs against multiple outcome measures including wider programme effectiveness is important. The model has proved more effective than previous care on multiple outcome measures, improving health equity, addressing weight-related comorbidities, and increasing reach. Early intervention and flexibility of intervention offerings to increase long-term BMI SDS reductions should be considered.

Supplementary Table 13.1: Baseline demographic characteristics of the Whānau Pakari randomised clinical trial five-year participants and non-participants.

		Control		Intervention	
		Participants	**Non-participants**	**Participants**	**Non-participants**
n		28	71	41	59
Age (years)		10.2 ± 3.6	10.7 ± 3.2	10.5 ± 3.1	10.9 ± 3.0
Female		22 (48%)	34 (79%)**	19 (46%)	31 (52.5%)
Ethnic group [a]	Māori	12 (43%)	35 (49%)	21 (50%)	26 (44%)
	Pacific	–	3 (4%)	–	2 (3%)
	European (total)	16 (57%)	30 (42%)	19 (46%)	26 (44%)
	New Zealand European	15 (54%)	28 (39%)	17 (42%)	26 (44%)
	Asian (total)	–	3 (4%)	1 (2%)	5 (8%)
	Indian	–	1 (1%)	1 (2%)	4 (7%)
	Asian (other)	–	2 (3%)	–	1 (2%)
Auxology	BMI SDS	2.80 ± 0.63	3.25 ± 0.50*	3.00 ± 0.52	3.20 ± 0.63
	BMI SDS range	1.52–3.72	2.22–4.97	2.10–4.58	1.8–5.34
Socioeconomic status [b]	Quintile one (least deprived)	1 (4%)	4 (6%)	6 (15%)	8 (14%)
	Quintile two	5 (18%)	7 (10%)	7 (17%)	12 (20%)
	Quintile three	6 (21%)	16 (23%)	7 (17%)	11 (19%)
	Quintile four	8 (29%)	22 (31%)	9 (22%)	15 (25%)
	Quintile five (most deprived)	8 (29%)	22 (31%)	12 (29%)	13 (22%)
Accompanying adult	BMI (kg/m^2) [c]	33.45 ± 7.04	35.55 ± 7.95	34.80 ± 6.948	31.39 ± 7.6*
	BMI ≥30 kg/m^2 [d]	20 (71%)	51 (76%)	29 (74%)	30 (54%)*
Living arrangements	Two-parent household	14 (52%)	34 (48%)	19 (49%)	34 (59%)
	One-parent household	12 (44%)	31 (44%)	19 (49%)	21 (36%)
	Other	1 (4%)	6 (9%)	1 (2%)	3 (5%)

Data are means ± standard deviations or n (%), as appropriate.

BMI: body mass index; NZ: New Zealand; SDS: standard deviation score.

[a] Prioritised ethnic group (self-allocated into a single ethnic group).

[b] Quintiles of level of household deprivation based on the NZ Deprivation Index 2006.[292]

[c] Parameter was measured where consented to (n = 28, 67, 39 and 56, respectively), otherwise not included.

[d] Adult cut-off for obesity.

* P-value < 0.05; ** P-value < 0.001.

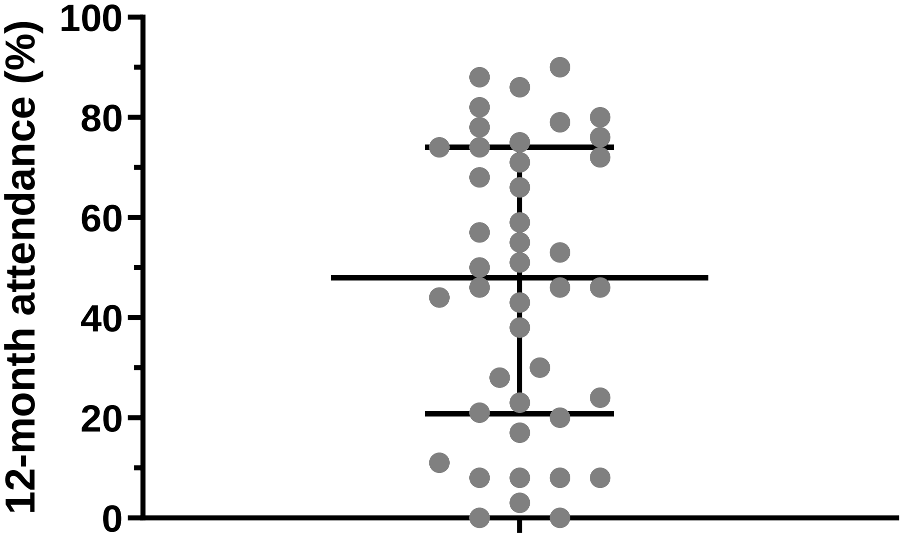
Supplementary Table 13.2: Primary outcome at 12- and 24-months in the Whānau Pakari randomised clinical trial among five-year participants and non-participants.

		Low-intensity Control			High-intensity Intervention		
		Five-year Participants	**Non-participants**	**p-value**	**Five-year Participants**	**Non-participants**	**p-value**
12 months	n	24	45		35	34	
	Δ BMI SDS	-0.12 (-0.29, 0.04)	-0.10 (-0.22, 0.02)	0.86	-0.17 (-0.27, -0.07)	-0.03 (-0.13, 0.07)	0.053
24 months	n	20	33		35	33	
	Δ BMI SDS	-0.14 (-0.34, 0.05)	0.02 (-0.12, 0.17)	0.19	-0.07 (-0.20, 0.06)	0.05 (-0.08, 0.18)	0.19

Data are means (95% confidence intervals).

Δ: change

BMI SDS: body mass index standard deviation score.



Supplementary Figure 13.1: Distribution of attendance over the 12-month duration of the Whānau Pakari randomised clinical trial among participants in the high-intensity intervention group (n = 41) who were assessed at the five-year follow-up.

Horizontal bars represent the median, quartile 1, and quartile 3.

Supplementary Table 13.3: Rates of adverse outcomes amongst the entire cohort (n = 69) at baseline at the Whānau Pakari randomised clinical trial and at the five-year follow-up.

		n	Baseline	5 years	p-value
History [a]	Hyperphagia	68	45 (66%)	27 (40%)	**0.005**
	Night waking for food	68	5 (7%)	9 (13%)	0.289
	Satiated after food	68	38 (56%)	39 (57%)	0.999
	Comfort eating	68	37 (54%)	39 (57%)	0.845
	Rapid eating	68	34 (50%)	28 (41%)	0.345
	Headaches	68	24 (35%)	22 (32%)	0.839
	Visual disturbance	68	18 (27%)	20 (29%)	0.815
	Difficulty getting to sleep	68	16 (24%)	26 (38%)	0.078
	Insufficient sleep [b]	66	2 (3%)	5 (8%)	0.453
	Television/computer in bedroom	68	34 (50%)	38 (56%)	0.571
	Snoring	68	37 (54%)	29 (43%)	0.170
	Breathing pauses	68	12 (18%)	6 (9%)	0.146
	Reported asthma	68	16 (24%)	10 (15%)	0.070
Examination	Waist height ratio >0.5	69	65 (94%)	62 (90%)	0.508
	Acanthosis nigricans	69	27 (39%)	22 (32%)	0.359
	Pre-hypertension [b]	69	3 (4%)	5 (7%)	0.727
	Hypertension	69	1 (1%)	2 (3%)	0.999
Laboratory markers	**Inflammatory marker** [b]				
	ls-CRP 3.0–15.0mg/L	39	11 (28%)	13 (33%)	0.754
	Glycaemic control [b]				
	HbA1c >42mmol/mol	40	0 (0%)	1 (3%)	0.999
	Fasting insulin >80pmol/L	39	26 (67%)	35 (90%)	**0.022**
	Serum lipids [b]				
	≥1 abnormal lipid	38	20 (53%)	22 (58%)	0.774
	Cholesterol >5.2mmol/L	38	7 (18%)	8 (21%)	0.999
	HDL-C <1.0mmol/L	38	5 (13%)	7 (18%)	0.754
	LDL-C >3.4mmol/L	37	3 (8%)	9 (24%)	0.109
	Elevated triglycerides	38	14 (37%)	14 (37%)	0.999
Laboratory markers	**Liver function tests** [b]				
	≥1 abnormal test	34	15 (44%)	20 (56%)	0.267
	AST	30	3 (10%)	8 (27%)	0.063
	ALT	40	10 (25%)	14 (35%)	0.344
	GGT	40	10 (25%)	17 (43%)	0.118

Data are n (%); p-values were derived from non-parametric McNemar's tests comparing paired data from baseline and the five-year follow-up, with statistically significant differences at $p < 0.05$ shown in bold.

ALT, alanine transaminase; AST, aspartate aminotransferase; ls-CRP, low-sensitivity C-reactive protein; GGT, gamma-glutamyl transferase; HDL-C, high-density lipoprotein cholesterol; HbA1c, glycated haemoglobin; LDL-C, low-density lipoprotein cholesterol.

[a] Proxy and self-report of eating behaviour, symptoms, and other health behaviours.

[b] Abnormal findings based on upper limits of normal and cut-points from the appropriate guidelines as previously described.[13]

14 Discussion

14.1 Overview

This chapter provides an overview of the research, its strengths and limitations, key implications for clinical practice and policy, and the implications of this work for future research.

The aims of this thesis were:

- To understand the barriers and facilitators to attendance, retention and engagement of children, adolescents and their families in Whānau Pakari, especially for Māori families and those who declined further input after their referral.
- To determine if positive healthy lifestyle changes achieved at 12 months persist for participants long-term, and to assess whether the multidisciplinary home-based assessment and weekly group session intervention was more or less effective long-term in achieving healthy lifestyle change, when compared with comprehensive home-based assessments only.

These aims were met by undertaking:

- A survey of past participants of Whānau Pakari to gain a preliminary understanding of the modifiable barriers and facilitators to engagement in Whānau Pakari during the RCT and post-trial.
- In-depth interviews with past participants with varying levels of engagement with the Whānau Pakari programme to determine the factors affecting initial and ongoing engagement.

- Comprehensive assessment of the persistence of healthy lifestyle changes in participants of the Whānau Pakari randomised clinical trial with follow-up at five years post-baseline assessment.

Comparisons with previous literature have been discussed in previous chapters and have not been extensively revisited in this chapter. Whilst this thesis focuses predominantly on addressing equity for NZ’s Indigenous population, and those from most deprived households, as these were the groups most overrepresented in childhood obesity statistics where this research was undertaken, it is acknowledged that inequities exist for Pacific peoples, and minority ethnic groups across the country.

14.2 Summary of key findings

14.2.1 Upstream barriers prevent engagement in Whānau Pakari, producing inequities at the service level

Addressing barriers to engagement and retention in intervention programmes is important in order to improve long-term outcomes for children and adolescents with obesity.[141] Most factors affecting engagement and retention in community-based lifestyle modification programmes have previously been identified at the level of the individual, resulting in victim-blaming explanations for poor retention or engagement, or at the programme level (Chapter 4).[141] However, the results of the survey of past participants of the Whānau Pakari programme (Chapter 7) identified that while programme convenience was key to self-reported engagement, there were few suggestions and little consensus on improvements to the programme itself to facilitate this, due to differing family circumstances.[275] Similarly, the findings of the interviews with past participants, including those who declined input after their referral, demonstrated that the identified barriers affecting engagement for the cohort were predominantly ‘upstream’ (Chapter 8). Specific recommendations for programme changes to improve engagement were not forthcoming from the interviews.[275] The Whānau Pakari model appeared to be accessible and acceptable to the community overall; however, there were several distal factors which influenced the degree to which participants were able to engage with the programme (highlighted in Chapter 8, Figure 8.1):

(1) Societal beliefs and social norms around weight and body size contributed to a reluctance to discuss healthy weight with health professionals or engage with programmes such as Whānau Pakari. Overall, among participants who did not engage, there was a reluctance to identify children as being overweight due to the negative social consequences for people with overweight and obesity reflecting widespread weight stigma.[165] Further, some participants identified their child as overweight, but wanted to avoid stigmatising their child or ‘making a big deal’ of their weight so did not want to intervene. These societal beliefs and social norms varied according to factors such as age, gender and participants’ beliefs about the role of genetic background, providing the impetus to engage or disengage.

Obesity is a highly stigmatised issue,[44] which is reflected in the parental concern for their children’s mental health evident in the interviews. At the same time, previous research has shown that the Whānau Pakari RCT cohort of children and adolescents showed a high prevalence of weight-related comorbidities and risk factors,[116, 135] which, if not addressed, could lead to further complications in adulthood.[29] In the Whānau Pakari programme, the concepts of obesity and weight were not discussed with participants once in the programme; rather, the focus was on healthy lifestyle change with the aim of being non-judgemental and non-stigmatising.[129] Of note, a 2019 systematic review and meta-analysis showed that intervention including a dietary component in children with obesity was not associated with an increased risk of depression or anxiety over a 16-month follow-up period.[305] Additionally, in the five-year follow-up of the Whānau Pakari RCT, clinically meaningful improvements in quality of life and psychological scores were demonstrated with this non-stigmatising approach (Chapter 13). It is important that non-judgemental, non-stigmatising care for weight-related comorbidities is available and accessible. However, the results of the interviews with past participants suggest that weight stigma in the health system and at a wider societal level is hindering intervention efforts by impacting on initial engagement.

(2) The stress of family life in NZ makes it difficult to engage when families are managing multiple other complex priorities, and this is exacerbated by socioeconomic inequities in NZ. A key reason for inequities in retention between Māori and non-Māori participants was differences in socioeconomic deprivation and associated stressors. Much of the previous literature on programme engagement has characterised these factors at the individual level as 'personal circumstances',[141, 178] and in doing so, renders them unmodifiable and the responsibility of the participant. However, retention in programmes such as Whānau Pakari would, in part, be improved with basic improvements in social conditions. For example, in NZ nearly 20% of children experience moderate-severe food insecurity, making it difficult for the healthy choice to be the easy choice.[276, 288]

While factors such as food security were external to the programme, they were consistently identified as determinants of non-participation and attrition in Whānau Pakari as families' priorities changed.[270, 272, 275] The stressors associated with engaging with a weekly intervention and trying to implement healthy lifestyle changes would be partially mitigated by addressing social determinants such as socioeconomic inequity.[16, 287] The Child and Youth Wellbeing Strategy launched by the NZ Government in August 2019 aims to directly address many of these wider socioeconomic determinants with indicators including material wellbeing, child poverty and food insecurity,[306] which, if acted upon, could in time translate into both improved health outcomes and improved engagement in programmes such as Whānau Pakari.

(3) Historical experiences of weight stigma and racism in healthcare have ongoing, lasting effects which can make it difficult to reengage with the health system. Many participants experienced weight stigma, blame and judgement from health professionals, consistent with previous studies.[189] These experiences contributed to a reluctance to commence or continue healthy lifestyles intervention and disengagement from other parts of the health system, such as primary care for unrelated issues. The experiences of participants emphasise the importance of training health professionals in terms of healthy weight conversations, in the context of wider issues relevant to the family. This has been reinforced by the Royal Australasian College of Physician’s position statement on obesity, which acknowledges that the health sector has a key role to play in reducing weight stigma and bias, and that health professionals should have access to training opportunities to understand weight bias and to develop the skills needed to have sensitive conversations with patients.[307] Chapter 8 of this thesis emphasises that the experience of the referral to a healthy lifestyles programme such as Whānau Pakari is vital for continued engagement.[275]

In addition to weight stigma, Māori participants experienced multiple and compounding forms of racism, which contribute to the varying experiences and therefore differential engagement between Māori and non-Māori families. The survey of past participants in Chapter 7 indicated that previous experiences of healthcare were associated with self-reported lower attendance for Māori and this was reinforced in the in-depth interviews. The effect of racism on healthcare use in NZ is well-documented.[198, 271] The experiences of participants in this study indicate that racism that occurs externally may still contribute to disengagement in the programme of interest. While the Whānau Pakari programme has endeavoured to be acceptable to the community,[13, 129, 137] and interview participants stated that the framework was culturally appropriate for their families,[275] wider structural changes will be required to address racism in the health system, and at a societal level in order to enhance engagement at a programme level.

Part of the Child Health and Wellbeing Strategy includes developing a work programme to address racism and discrimination through policy and legislative processes, such as ensuring that the Treaty of Waitangi and anti-racism and anti-discrimination considerations are built into advice to Ministers, Cabinet, and Parliamentary processes.[306] This programme is being led by the Education and Justice ministries,[306] and it is not clear if this will translate to structural change in the health system. The enduring nature of racism and discrimination has the potential to affect engagement with seemingly unrelated services in other sectors;[272] therefore, a cultural and structural shift will take time.

More explicit recommendations for structural changes have been made by the Waitangi Tribunal report, *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry* (Wai 2575), as part of an ongoing investigation into the compliance of the New Zealand primary healthcare system with the Treaty of Waitangi.[80] The report recommended that a commitment to the Treaty of Waitangi and its principles should be stated explicitly in all documents that make up the policy framework of the primary health system, with renewed commitment to principles such as tino rangatiratanga (self-determination or sovereignty), equity, and active protection (to act to achieve equitable health outcomes for Māori), and a commitment to both culturally appropriate primary healthcare and options for Kaupapa Māori primary health services.[80] The principle of partnership also requires the New Zealand Government and Māori to work together to govern, design, deliver and monitor primary health services. Previous Tribunal reports have emphasised how co-governance in social service design and delivery upholds the Treaty relationship and is essential for improving socioeconomic status for Māori.[80]

Finally, there are immediate opportunities at the programme level to mitigate the effects of racism that occurs in other settings. Respectful, compassionate care can help mitigate past negative experiences in the health system and facilitate continued engagement with services.[275]

In particular, referral experiences which are respectful, discreet, caring, fully informed, and acknowledge past experiences of stigma within the health system may be more favourable for engagement (see section 14.4.1).

(4) Initial barriers to accessing the health system

Once a family is referred to the programme, the Whānau Pakari model of care overcomes many health system level barriers identified in Chapter 10. However, substantial barriers to engagement in intervention programmes *prior* to referral are still evident, which means that care is not available to those who may need it most (Chapter 10).[308] The findings outlined in Chapter 10 demonstrated a number of barriers to health system preparedness and responsiveness to address childhood obesity, which reflected the same barriers identified by the World Health Organization in other parts of the world, including insufficient financing of childhood obesity management and fragmented and uncoordinated care.[180] The fragmented health system is difficult to navigate,[280] and participants reported having to repeat their story multiple times, with a sense that different parts of the system did not talk to each other. A lack of coordination leads to poor continuity of care. In addition, the policy environment with a national level preschool referral target encourages indiscriminate referrals without room for professional judgement, due to the perceived mandatory nature of the target. Well-designed, acceptable intervention programmes that address child and adolescent weight issues and associated comorbidities across the paediatric life course, while minimising programme-level barriers, are likely to continue to struggle with retention without addressing key determinants of engagement at the health system level. The health system's relative inaccessibility is an impediment to improved health outcomes for children and their families experiencing childhood obesity.

Chapter 10 has reinforced that the strategies outlined in high-level policy documents such as He Korowai Oranga and the New Zealand Health Strategy have not been translated into everyday health system access for NZ families.[213, 279] Similarly, the Health and Disability System Review interim report identified a lack of consistent implementation across the health sector,[280] and the 2019 *Hauora* report highlighted a lack of accountability measures and mechanisms in the primary healthcare sector and that these strategies and the Primary Health Care Strategy needed more explicit explanations of how recommendations would be integrated into practice.[80]

14.2.2 BMI SDS trajectory is affected by attendance

In the Whānau Pakari trial, participants in the high-intensity intervention who attended ≥70% of intervention sessions achieved a significant reduction in BMI SDS at 12 months, which was sustained to 24 months.[14] The association between retention in obesity intervention and outcome has previously been documented.[107] The results of the Whānau Pakari five-year follow-up suggest that attendance is still important for BMI SDS reduction (Figure 13.2, B). Chapter 13 shows a distinct difference in BMI SDS trajectory over five years between participants with ≥70% versus <70% session attendance. By five years there was no longer a detectable difference between attendance groups, likely due to the small number of participants assessed at five years who attended ≥70% of sessions. However, the trend indicates that retention in intervention sessions remains important due to the clear difference in BMI SDS trajectory over time.

14.2.3 Flexibility of high-intensity intervention may be required for persistent healthy lifestyle changes

The findings of the five-year follow-up of the Whānau Pakari RCT indicate that earlier intervention appears beneficial in terms of long-term outcomes (Chapter 13), and this is supported by previous international findings.[12] While there was no detectable within-group difference in those aged <10 years, potentially due to low numbers of participants, there was a difference in change in BMI SDS between children aged <10 years and those aged ≥10 years. Early intervention offerings, however, are best embedded within a paediatric life course approach, as there is beneficial impact on wider outcome measures at any age.

In addition, more intensive intervention should be considered in order to sustain BMI SDS reduction in the long term (Chapter 13). This may require increased offerings within the model and consideration of ways to further support families in achieving healthy lifestyle change, without compromising the acceptability and effectiveness of the current framework of care.

In the interviews, many families expressed frustration and were discouraged if they did not see weight changes despite the adoption of many healthy lifestyle changes (Chapter 11).[309] This was despite the explicit avoidance of weight loss as a goal in the programme, highlighting the prevailing societal pressures to lose weight. It is possible that greater reductions in BMI SDS that are clinically meaningful, and therefore presumably reductions of weight-related comorbidities, would be more motivating for families and encourage sustained healthy lifestyle change over time. Part of the discouragement identified by participants stemmed from attempting to make changes in a highly obesogenic environment (Chapter 11). Currently, the healthy choice is not the easy choice in NZ society. An intervention option that was more intensive (even just in the initial phase) might be able to produce more motivating changes for participants and their families and may be able to overcome the effects of the obesogenic environment as a mitigating strategy (section 14.2.5). Alternatively, continued contact with the service via ongoing maintenance options may produce more favourable outcomes, although this may be difficult in a fiscally constrained health system environment. Further exploration as to how this could be achieved is warranted.

While flexibility in the offerings within the intervention programme should be considered, such as the age-appropriate weekly sessions already implemented (Chapter 3), a more intensive intervention will not be appropriate for everyone. The Whānau Pakari model of care is currently widely accepted by the community,[137] but participants still face substantial barriers relating to retention and ongoing engagement, and the programme will never work for all that are referred. Improving or amending the content of the intervention would not address the barriers to attendance in the health system and in wider society. Importantly, in the Whānau Pakari RCT and the five-year follow-up, the *efficacy* of the intervention was not dependent on socioeconomic status or ethnicity, but ongoing *attendance* at the high-intensity intervention sessions was associated with ethnicity. While a more intensive intervention could be tailored to a subset of participants, it is important that any future intervention options do not increase inequities and are co-designed.

While reductions in BMI SDS did not persist to five years in either arm of the trial, it could be argued that both the low-intensity control arm and the subgroup of participants in the high-intensity intervention arm who attended ≥70% of sessions achieved a similar outcome long-term (Figure 14.1). The subgroup of intervention participants with lower attendance, however, surpassed their baseline BMI SDS by 18 months. These findings are limited by the small number of participants at five years.

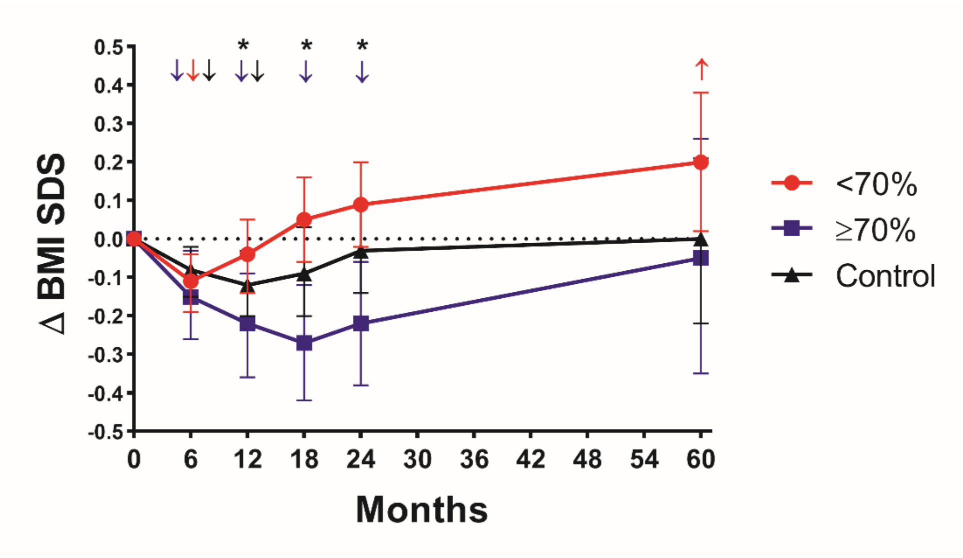


Figure 14.1: Changes in body mass index standard deviation scores (Δ BMI SDS) from baseline in the control group (black) and in the intervention group according to levels of attendance at prescribed sessions, <70% (red) and ≥70% (blue).

The baseline BMI SDS is represented by the dotted line. Asterisks (*) indicate statistically significant differences in change from baseline at $p < 0.05$ between the attendance groups at a given time point, while within-group differences are indicated by colour-matched arrows whose orientation provide the direction of the change.

Previous research has identified that participant ‘readiness for change’ was not a predictor of BMI SDS change in the Whānau Pakari RCT.[310] It is possible that the greater reductions in BMI SDS observed in the control group and high attendance intervention group were reflective of a participant’s ‘capacity for change’, whereby the commitment required was achievable and matched to participant choice and family needs, which is reflective of a real-world service setting. The Whānau Pakari RCT treatment arms were determined for participants through randomisation. It would follow that participants who were randomised to the intervention arm but who could not attend at least 70% of sessions may have achieved more favourable BMI SDS outcomes if they were able to choose the level of intervention intensity that best suited their family context, which is how the current service post RCT operates. Research to understand BMI SDS outcome within this environment is currently underway.

14.2.4 Natural trajectory data is required to contextualise the success of multidisciplinary intervention programmes

Life course data of children with obesity without intervention is required to contextualise the success of multidisciplinary interventions. There is no natural BMI trajectory data available for children in New Zealand. The Growing Up In New Zealand longitudinal study, which tracks approximately 7,000 children from before birth to young adulthood,[311] is a future opportunity to obtain this data for New Zealand children. International data suggests that any ‘clamping’ of BMI trajectory is beneficial compared with no intervention. Figure 14.2 depicts the incremental change in BMI SDS in children and adolescents with obesity from a longitudinal study of children in Germany (n = 34,196).[101] This study found that children experiencing obesity had an increased BMI SDS in infancy, and this increased steadily throughout childhood.

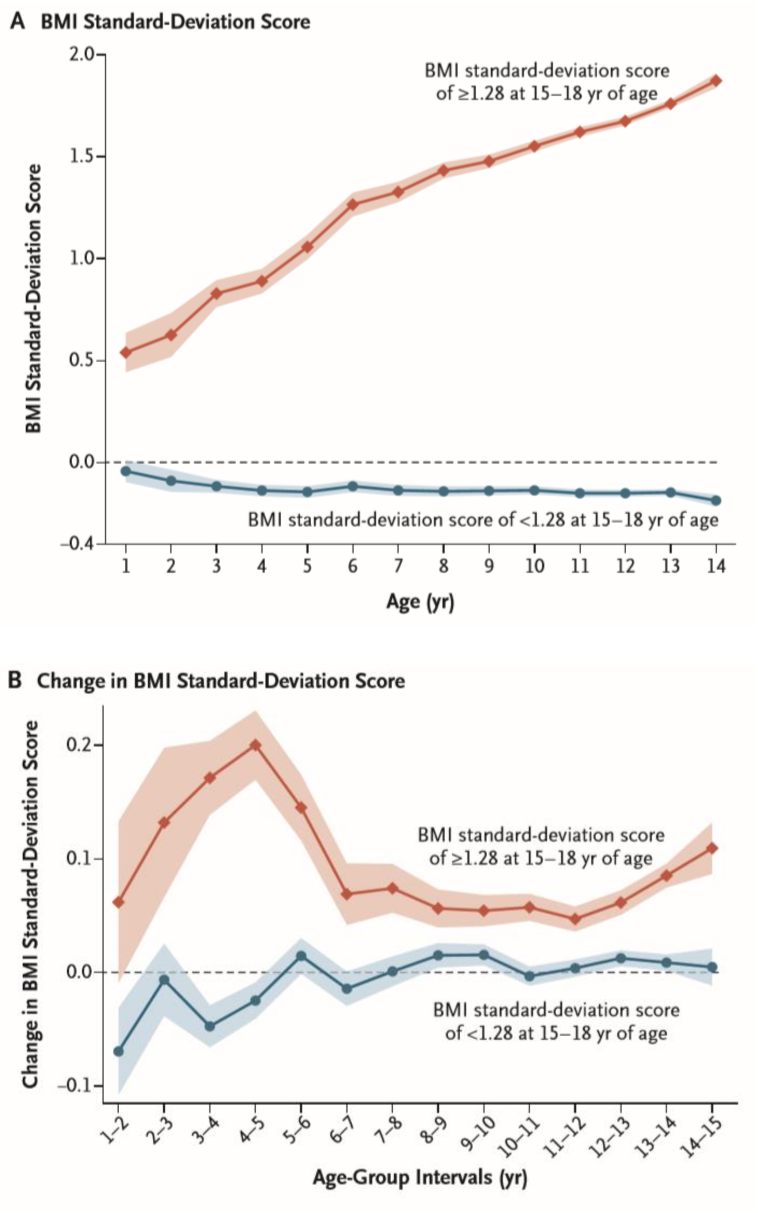


Figure 14.2: Dynamics of BMI Changes during Childhood.

Shown are the BMI standard-deviation score (Panel A) and the change in BMI standard-deviation score in 1-year age-group intervals (e.g., 1 to 2 represents the change from the 1-year age group to the 2-year age group) (Panel B), according to adolescent weight categories of underweight or normal weight (BMI standard-deviation score of <1.28; 26,883 adolescents) and overweight or obesity (BMI standard-deviation score ≥1.28; 7313 adolescents). Values are shown as means; shaded areas indicate 95% confidence intervals. Beginning at 1 year of age, the mean BMI standard-deviation score of the adolescents who were overweight or obese was already significantly higher than that of the adolescents who were underweight or had a normal weight, and the score continued to increase with increasing age (Panel A). Adolescents with overweight

or obesity had the greatest annual increases in the BMI standard-deviation score between 2 and 6 years of age (Panel B).

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Figure 14.2 demonstrates a positive annual BMI SDS increment of approximately 0.1.[101] Extrapolating this to the Whānau Pakari five-year outcome data would suggest that the ‘clamping’ effect of the Whānau Pakari model prevented an approximate BMI SDS increase of 0.33 for the high-intensity intervention, and 0.55 for those who attended ≥70% of intervention sessions, despite not moving participants out of the obese range when compared with baseline. However, these are approximations and should be interpreted with caution. In the German longitudinal study of acceleration of BMI, 90% of the children with obesity identified at three years of age had obesity in adolescence. Given that obesity in adolescence is associated with a five-fold increase in the risk of dying from coronary heart disease in forty years,[5] appropriate and acceptable forms of intervention in childhood appear valuable and should be considered, irrespective of long-term BMI SDS reduction. However, local and national data is required to provide relevant estimates for the New Zealand context and population.

14.2.5 The obesogenic environment impedes intervention efforts

The effectiveness of interventions is likely to be limited by the obesogenic environment.[110, 312] While not specifically solicited in the interviews, many families shared their experiences of attempting to make healthy lifestyle changes in current environments. Implementing healthy lifestyle changes is challenging, even with the support of a healthy lifestyle programme, due to a range of external socio-environmental factors. Intervention programmes aimed at addressing obesity and weight-related comorbidities in children are crucial; however, if the wider environment continues to be obesogenic in nature, then intervention programmes will continue to have a limited effect. The clear effect of the food environment on peoples' ability to make healthy choices highlights the need to address food environments at a policy level.[288, 313] Community-based interventions need to be provided alongside a coordinated prevention approach in order for families to be able to make persistent long-term healthy lifestyle changes.[33]

14.2.6 Evaluation of multicomponent healthy lifestyle programmes needs to move beyond clinical efficacy trials solely focused on BMI SDS

Although the Whānau Pakari programme did not achieve BMI SDS reduction at five years, the programme achieved improvements on multiple outcome measures including HRQOL and water intake, has improved health equity in terms of initial engagement and appropriateness of the service, and has outperformed past conventional models of care in terms of reach. Previous research indicates that the Whānau Pakari framework is cost-effective at 12 months[138] and acceptable to participants,[137] with improved access for Māori and those living in the most deprived areas.[14] At five years, retention was not affected by ethnicity or socioeconomic deprivation, with strong representation from Māori participants, suggesting that the model of care continues to be acceptable for the community, which is supported by the interview findings. Participant experiences in Chapter 8 reiterate that the model of care is appropriate and acceptable, primarily due to the approach of the programme deliverers and reinforced by the wrap-around support of the multidisciplinary model which provides coordinated access to care for weight-related comorbidities.

Engagement with the Whānau Pakari framework had positive effects on HRQOL (Chapter 13). The sustained improvements in HRQOL at five years is encouraging given that a previous study of a Finnish lifestyle intervention programme showed no change or a lack of persistent improvement in HRQOL at two years.[104] While there were no between-group differences in HRQOL or CBCL scores in the five-year follow-up, there were improvements in multiple outcome measures in both the low-intensity control and high-intensity intervention arms, and similarly in the total cohort analysis. This suggests that engaging with the Whānau Pakari framework, regardless of intervention intensity, is positive for participants' quality of life and any identified behavioural difficulties.

The perceived value of the programme for participants goes beyond what can be captured by a single outcome measure. Whānau focus groups with parents/caregivers and children involved in the programme and a survey of past participants highlighted a range of health and wellbeing benefits beyond weight loss or BMI SDS reduction.[137, 270] The utility of BMI as the sole measure of intervention success has previously been questioned,[94] particularly as a relevant measure for Indigenous groups.[102] A lack of reduction in BMI should not be equated with failing to adopt healthy lifestyle changes, and a strong focus on weight in childhood obesity interventions is off-putting for many families who have made positive dietary and physical activity changes.[94] In addition to weight status, outcome measures should include a wide range of relevant indicators of health and wellbeing in determining overall programme success. The Whānau Pakari RCT and five-year follow-up study included dietary, physical activity and psychological measures (Chapter 13).[13] Evaluation of multicomponent healthy lifestyle programmes needs to move wider than clinical efficacy trials solely focused on BMI SDS in order to determine success.

14.3 Strengths and limitations

Strengths of this research include:

1. The use of multiple methods, both quantitative and qualitative, to understand family experiences in Whānau Pakari. The research approach was informed by Kaupapa Māori theory and the critical application of the scientific method in an attempt to facilitate a positive research experience for participants and minimise barriers to participation.
2. The first long-term assessment to date of a home-based healthy lifestyle multidisciplinary assessment/intervention programme in a ‘real-world’ setting, including a high proportion of Māori participants and those from most deprived households.
3. High participation from Māori in all aspects of the research. This allowed for analysis that captured the diverse realities of participants involved in Whānau Pakari.
4. The high number of interviews undertaken with participants with varying levels of engagement, including those who declined further input after their referral to Whānau Pakari. Non-service users are typically difficult to recruit, and their perspectives have historically been missing from health services research.

Limitations of this research include:

1. The inability to generalise findings beyond the study population to other population groups, including Pacific peoples and other ethnicities, and geographic regions in New Zealand and internationally. However, it is encouraging that a programme specifically designed to address equity and focus on the needs of those most affected in the region was effective for all ethnicities and socioeconomic groups.

2. Low response rate in the survey, including no respondents among those who declined their referral to Whānau Pakari, which may have affected findings. This was mitigated by interviewing non-service users in the interviews.
3. The inability to explore the facilitators of implementing healthy lifestyle change in further detail in the secondary analysis of the interview data.
4. The lack of a true control group in the RCT and subsequent five-year follow-up study, which may affect the conclusions drawn from the data.
5. Although comparable to previous studies, the low retention rate in the five-year follow-up may have affected outcomes, and the inability to comment on aspects of cardiovascular fitness due to a lack of accelerometer wear data was disappointing.
6. The lack of national natural BMI SDS trajectory data to contextualise the success of the intervention compared with those without intervention.

14.4 Implications for clinical practice and policy

14.4.1 Respectful, compassionate clinical care facilitates engagement

While future interactions with health professionals cannot undo past experiences, the interview data indicates that positive interactions can help mitigate the effects of past experiences by providing compassionate, respectful care. Multidisciplinary healthy lifestyle programmes should aim to be non-judgemental and non-stigmatising. Message framing with regards to terminology is also important in childhood obesity programmes, in order to prevent further stigmatisation of families seeking help for weight.[42] It is equally important that referrals to such programmes are perceived to be non-stigmatising by families to facilitate initial engagement. An ideal referral process would be mana-enhancing (mana = status, dignity), respectful and compassionate, guided by the principles of manaakitanga (the process of showing respect, support, and care for others) and aroha (love, compassion, empathy, kindness) with an acknowledgement of the wider context and potential pressures on the family, and past instances of stigma and discrimination.

14.4.2 Success in multidisciplinary healthy lifestyle programmes requires addressing upstream determinants

Retention in multidisciplinary programmes and, therefore, health outcomes would be improved with action on the societal determinants of health in order to improve the conditions in which NZ families live. The Royal Australasian College of Physicians argues that the societal determinants of health underpin obesogenic environments.[314] Addressing these determinants would not only contribute towards obesity prevention, but would also improve intervention outcomes by facilitating ongoing engagement in multidisciplinary programmes.

For intervention to be successful, the food and physical environment needs to be more conducive to change. Policy and regulation are likely to be most effective in helping families make healthier choices by decreasing the impact of the obesogenic environment.[314] Policies that focus on improving the food environment and decreasing the cost of healthy food may improve the effectiveness of intervention programmes and families' abilities to maintain healthy lifestyle changes. Key areas for action include: marketing to children, fiscal policies, such as a tax on sugar sweetened beverages, food literacy and food labelling, healthy food service policies, community food retail environments, access to green spaces (urban spaces where people can be less sedentary, engagement of people in recreational play and exercise, taking advantage of natural surroundings) and transport systems.[25, 314, 315]

14.4.3 A coordinated approach to intervention and prevention is needed

Both intervention and prevention initiatives are required in order to address childhood obesity in NZ and beyond. A lack of a national coordinated approach to intervention and prevention has been identified previously by the Ministry of Health in 2004.[181] The Childhood Obesity Plan released in 2015 had the broad goals of creating opportunities to make healthy choices easier and targeting those with obesity and those at risk of developing obesity.[315] However, the Plan was criticised for its lack of truly new initiatives, with most prevention initiatives being 'business as usual' policies focused on education, with a lack of meaningful regulation.[315] The Plan also lacked a national coordinated approach to intervention. The Raising Healthy Kids health target was introduced in 2016 as a key initiative of the Plan. The focus, however, was on reaching the target's required proportion of pre-schoolers identified as having obesity at the B4SC, and them being offered a referral to further clinical assessment and intervention, rather than the availability of family-based multidisciplinary programmes and uptake of these programmes by those referred (see Chapter 8).

Although the Childhood Obesity Plan has ceased to be an official Government strategy, many of its initiatives are still operational, with a focus on creating supportive environments.[125] The GRxAF programme currently operates in most (but not all) regions in New Zealand. However, it has previously been shown to be inaccessible for those who need it most,[123] and it is unable to offer comprehensive medical assessments to address weight-related comorbidities. It therefore misses a key opportunity to provide a "one-stop shop" model that would provide continuity of care in an area which is often emotive and stigmatised. A multidisciplinary team model with central coordination of comprehensive medical care for weight-related comorbidities for children and adolescents is recommended;[129] however, this model of care is not available nationally. It is unlikely that this level of care can be provided currently in general practice and primary care, given the pressures on the workforce and time constraints. However, in addition to family-based multidisciplinary programmes being available nationally, the health system itself must be permeable for families accessing support, and this includes primary care services.

14.5 Ongoing and future research

After the RCT ended recruitment in August 2014, a six-month programme with rolling entry was introduced due to waning attendance in the latter six months of the 12-month programme. This decision was supported by the findings of the US Preventative Taskforce, which identified a dose effect of 26 weeks minimum for improvements in BMI SDS.[86] The ongoing clinical service offers both a low-intensity assessment-and-advice option (similar to the low-intensity control arm of the RCT) and a high-intensity option including assessments with weekly activity sessions (as per the high-intensity intervention arm of the RCT). The international literature still supports high intensity programmes,[91] especially when compared with standard care. Providing choice within the Whānau Pakari programme allows families to choose the method of delivery that will be most suitable for their family, whilst also ensuring weight-related comorbidities are screened. Further age-specific intervention models have also been developed following participant feedback:[137] a programme for pre-school aged children (currently under evaluation) and an adolescent two-day workshop model, within the Whānau Pakari multidisciplinary framework of care.

Future research regarding Whānau Pakari should focus on:

- Analysis of the Whānau Pakari clinical service post-RCT to determine the effectiveness of ‘business as usual’ service provision.
- Consideration of ways to intensify offerings within the high-intensity intervention model in order to enhance long-term outcomes.

- Determining the BMI SDS trajectory over time of children and adolescents who were referred to Whānau Pakari but declined further input by auditing incidental heights and weights from chart reviews.
- Mapping the food and physical activity environment of Whānau Pakari participants using global information systems data, in order to further understand and address the food and physical activity environment for these children and adolescents.
- Understanding whether the Whānau Pakari framework is generalisable within existing intervention models in other regions of New Zealand and beyond.

14.6 Conclusion

Although the Whānau Pakari programme appears to have minimised programme-level barriers, with positive feedback from the participants and families who engaged, there are multiple upstream factors that hinder their ability to engage with the programme, both at initial enrolment and in terms of long-term retention. These upstream factors are largely responsible for differences in retention rates between Māori and non-Māori participants. The health system's relative inaccessibility also impedes health outcomes for those most affected by childhood and adolescent obesity. The Whānau Pakari programme achieved improvements on multiple outcome measures, has begun to address health equity, and has outperformed past conventional models of lifestyle-focused care in terms of reach and initial engagement. However, findings from international outcome data for children and adolescents affected by obesity indicate the ultimate goal remains weight loss for those affected by obesity to ensure reduction in weight-related comorbidities over time. More intensive and/or increasingly flexible interventions may be required for better and more persistent changes in health outcomes long term. A coordinated approach between prevention and intervention team to diminish the effect of the obesogenic environment and address upstream societal determinants is also needed.

The Whānau Pakari based approach considers the child within the context of the family. In order to improve retention, engagement, and ultimately outcomes in multidisciplinary healthy lifestyle programmes, the family needs to be viewed within the context of the community, environment and wider society. It is important that multidisciplinary intervention programmes are welcoming, health professionals are respectful and compassionate, and society and policy appreciate the complex relationships at play between the societal determinants of health and the development of obesity in children and adolescents. Reductions in BMI SDS are important to minimise weight-related comorbidities, yet wider service-level outcomes and addressing health equity in terms of accessibility and appropriateness of any interventions are also critical for engagement and retention, and therefore improved health outcomes.

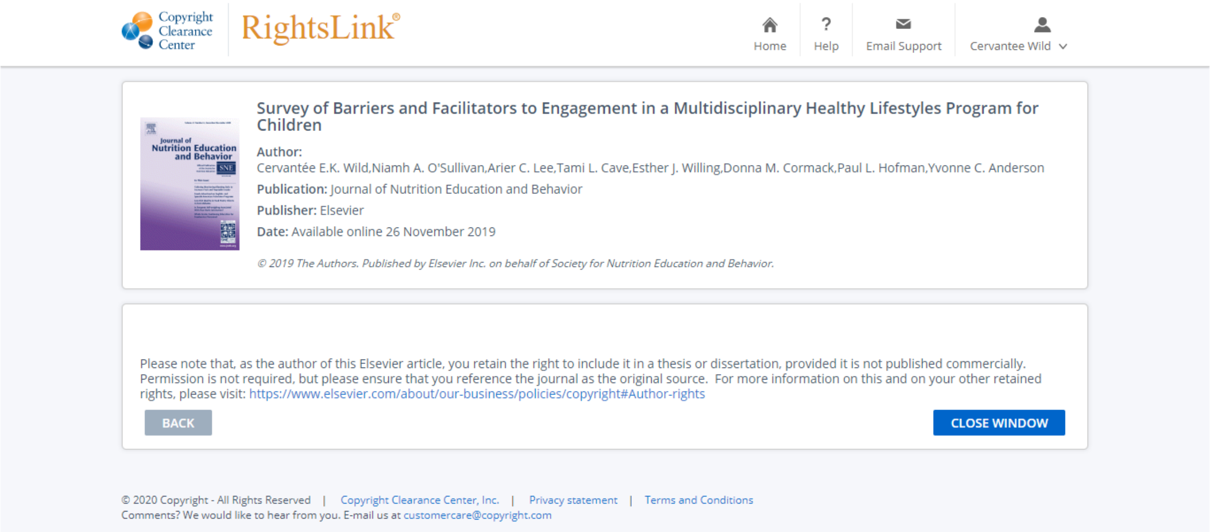
There remains a tension between the responsibility of health professionals to address weight-related health indicators and achieve reductions of weight status over time, and the need for a non-judgemental, non-stigmatising approach to enhance engagement with participants and their families at varying levels of acceptance of weight issues. For multidisciplinary assessment and intervention programmes for children and adolescents to be successful, both of these aspects need to be reconciled within service development and policy planning moving forward. Whānau Pakari has achieved this, despite not achieving significant BMI SDS reductions over time, and could be used as a framework for other regions whilst working to improve outcomes over multiple measures of effectiveness. BMI SDS remains an important outcome measure in terms of the effectiveness of healthy lifestyle programmes; however, evaluation of multidisciplinary healthy lifestyle programmes needs to move wider than clinical efficacy trials solely focused on BMI SDS in order to determine success. A national coordinated approach that acknowledges the need for multidisciplinary team working in a non-stigmatised model of care will be critical to achieving access and appropriateness of services for all.

Appendices

Appendix A. Permissions to include manuscript in thesis

Wild CEK, O'Sullivan NA, Lee AC, et al. Survey of Barriers and Facilitators to Engagement in a Multidisciplinary Healthy Lifestyles Program for Children. Journal of Nutrition Education and Behavior. 2019;In Press.

Cervantée Wild designed and managed the study, undertook data analysis, and wrote the manuscript. Niamh O’Sullivan assisted with study management and data collection. Arier Lee undertook data analysis. Tami Cave contributed to study design. Esther Willing contributed to study design, oversaw data analysis of qualitative component and provided critical appraisal of the manuscript. Donna Cormack contributed to study design, oversaw data analysis of qualitative component and provided critical appraisal of the manuscript. Paul Hofman contributed to study design and provided critical appraisal of the manuscript. Yvonne Anderson contributed to study design and data analysis and provided critical appraisal of the manuscript.



Survey of Barriers and Facilitators to Engagement in a Multidisciplinary Healthy Lifestyles Program for Children

Author:
Cervantée E.K. Wild,Niamh A. O'Sullivan,Arier C. Lee,Tami L. Cave,Esther J. Willing,Donna M. Cormack,Paul L. Hofman,Yvonne C. Anderson

Publication: Journal of Nutrition Education and Behavior

Publisher: Elsevier

Date: Available online 26 November 2019

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Wild CE, Rawiri N, Willing EJ, et al. Determining barriers and facilitators to engagement for families in a family-based multidisciplinary healthy lifestyles intervention for children and adolescents. Submitted paper. Forthcoming 2020.

This paper has been submitted for consideration to *BMJ Open*.

Cervantée Wild co-designed the study, and undertook recruitment, data collection, data analysis, and writing of the manuscript. Ngauru Rawiri undertook recruitment and data collection and contributed to data analysis and interpretation. Esther Willing contributed to study design, oversaw data analysis and interpretation and provided critical appraisal of the manuscript. Paul Hofman contributed to study design and provided critical appraisal of the manuscript. Yvonne Anderson contributed to study design and data interpretation and provided critical appraisal of the manuscript.

Wild CEK, Rawiri NT, Willing EJ, et al. What affects programme engagement for Māori families? A qualitative study of a family-based, multi-component healthy lifestyle programme for children and adolescents. Submitted paper. Forthcoming 2020.

This paper has been submitted for consideration to *Journal of Paediatrics and Child Health.*

Cervantée Wild co-designed the study, and undertook recruitment, data collection, data analysis, and writing of the manuscript. Ngauru Rawiri undertook recruitment and data collection and contributed to data analysis and interpretation. Esther Willing contributed to study design, oversaw data analysis and interpretation and provided critical appraisal of the manuscript. Paul Hofman contributed to study design and provided critical appraisal of the manuscript. Yvonne Anderson contributed to study design and data interpretation and provided critical appraisal of the manuscript.

Wild CEK, Rawiri NT, Willing EJ, et al. Health system barriers to accessing care for children with weight issues in New Zealand. Submitted paper. Forthcoming 2020.

This paper has been submitted for consideration to *Journal of Health Services Research and Policy*.

Cervantée Wild co-designed the study, and undertook recruitment, data collection, data analysis, and writing of the manuscript. Ngauru Rawiri undertook recruitment and data collection and contributed to data analysis and interpretation. Esther Willing contributed to study design, oversaw data analysis and interpretation and provided critical appraisal of the manuscript. Paul Hofman contributed to study design and provided critical appraisal of the manuscript. Yvonne Anderson contributed to study design and data interpretation and provided critical appraisal of the manuscript.

Wild CEK, Rawiri NT, Willing EJ, et al. Challenges of making healthy lifestyle changes for families in Aotearoa/New Zealand. Submitted paper. Forthcoming 2020.

This paper has been submitted for consideration to *Public Health Nutrition.*

Cervantée Wild co-designed the study, and undertook recruitment, data collection, data analysis, and writing of the manuscript. Ngauru Rawiri undertook recruitment and data collection and contributed to data analysis and interpretation. Esther Willing contributed to study design, oversaw data analysis and interpretation and provided critical appraisal of the manuscript. Paul Hofman contributed to study design and provided critical appraisal of the manuscript. Yvonne Anderson contributed to study design and data interpretation and provided critical appraisal of the manuscript.

Wild CEK, Rawiri NT, Cormack DM, et al. A collaborative Indigenous – non-Indigenous partnership approach to understanding participant experiences of a community-based healthy lifestyles programme. Submitted paper. Forthcoming 2020.

This paper has been submitted for consideration to *BMC Public Health.*

Cervantée Wild co-designed the study and wrote the manuscript. Ngauru Rawiri contributed to research process design. Donna Cormack contributed to study design and critical appraisal of the manuscript. Esther Willing contributed to study design and provided critical appraisal of the manuscript. Paul Hofman contributed to study design and provided critical appraisal of the manuscript. Yvonne Anderson contributed to study design and provided critical appraisal of the manuscript.

Wild CEK, Wynter LE, Triggs CM, et al. Five-year follow-up of a family-based multidisciplinary assessment and intervention for children and adolescents with weight issues – a post-RCT analysis. Submitted paper. Forthcoming 2020.

This paper has been submitted for consideration to *JAMA Pediatrics.*

Cervantée Wild oversaw data collection, completed data cleaning, was involved in analysis and interpretation and wrote the manuscript. Lisa Wynter undertook clinical assessments/data collection and data entry. Christopher Triggs provided statistical oversight and critical appraisal of the manuscript. José Derraik undertook data analysis and provided critical appraisal of the manuscript. Paul Hofman contributed to study design, data interpretation and critical appraisal of the manuscript. Yvonne Anderson designed and supervised the study, contributed to data interpretation and provided critical appraisal of the manuscript

Appendix B. Permission to include figures in thesis

Lakshman R, Elks CE, Ong KK. Childhood obesity. Circulation. 2012;126(14):1770-9.

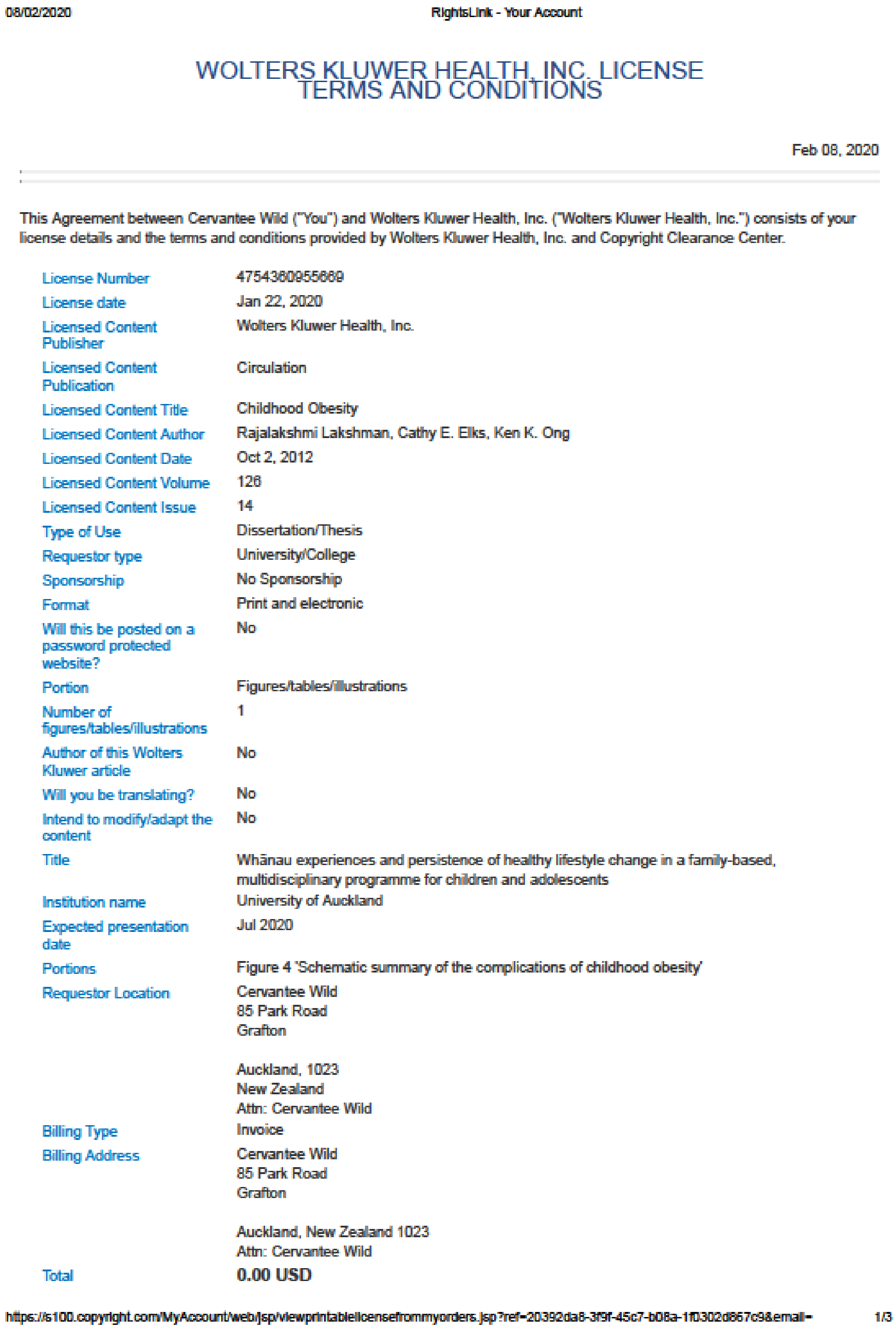

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Figure 14.2: Dynamics of BMI Changes during Childhood.

Shown are the BMI standard-deviation score (Panel A) and the change in BMI standard-deviation score in 1-year age-group intervals (e.g., 1 to 2 represents the change from the 1-year age group to the 2-year age group) (Panel B), according to adolescent weight categories of underweight or normal weight (BMI standard-deviation score of <1.28; 26,883 adolescents) and overweight or obesity (BMI standard-deviation score ≥1.28; 7313 adolescents). Values are shown as means; shaded areas indicate 95% confidence intervals. Beginning at 1 year of age, the mean BMI standard-deviation score of the adolescents who were overweight or obese was already significantly higher than that of the adolescents who were underweight or had a normal weight, and the score continued to increase with increasing age (Panel A). Adolescents with overweight or obesity had the greatest annual increases in the BMI standard-deviation score between 2 and 6 years of age (Panel B).

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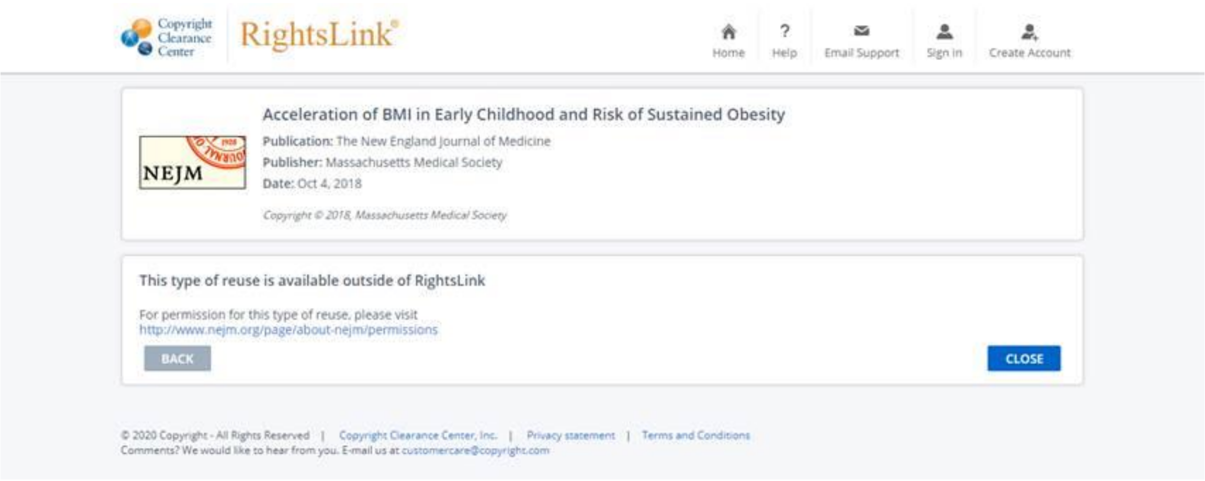

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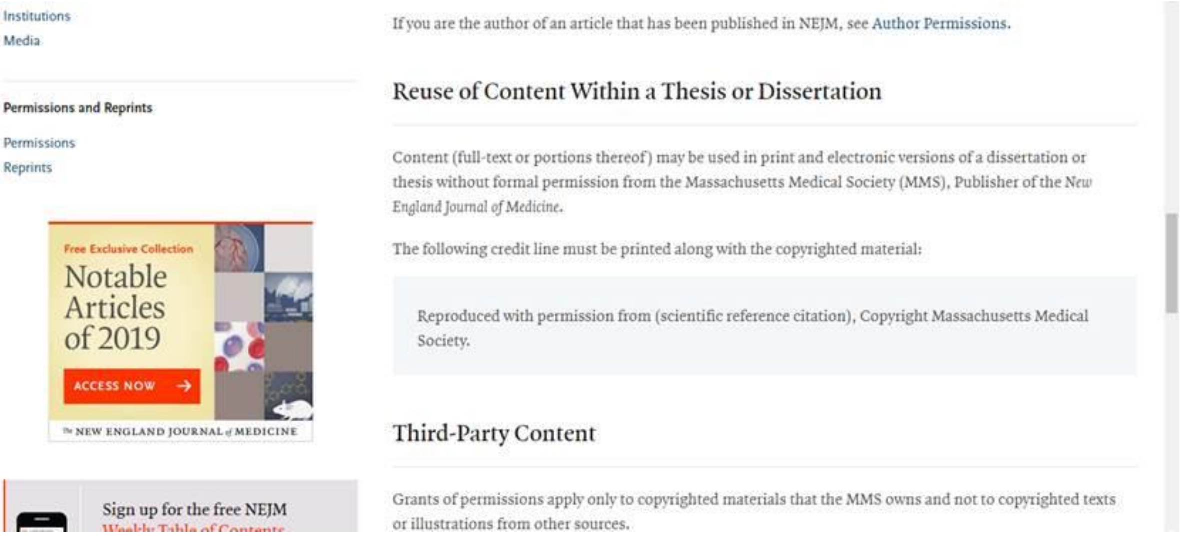

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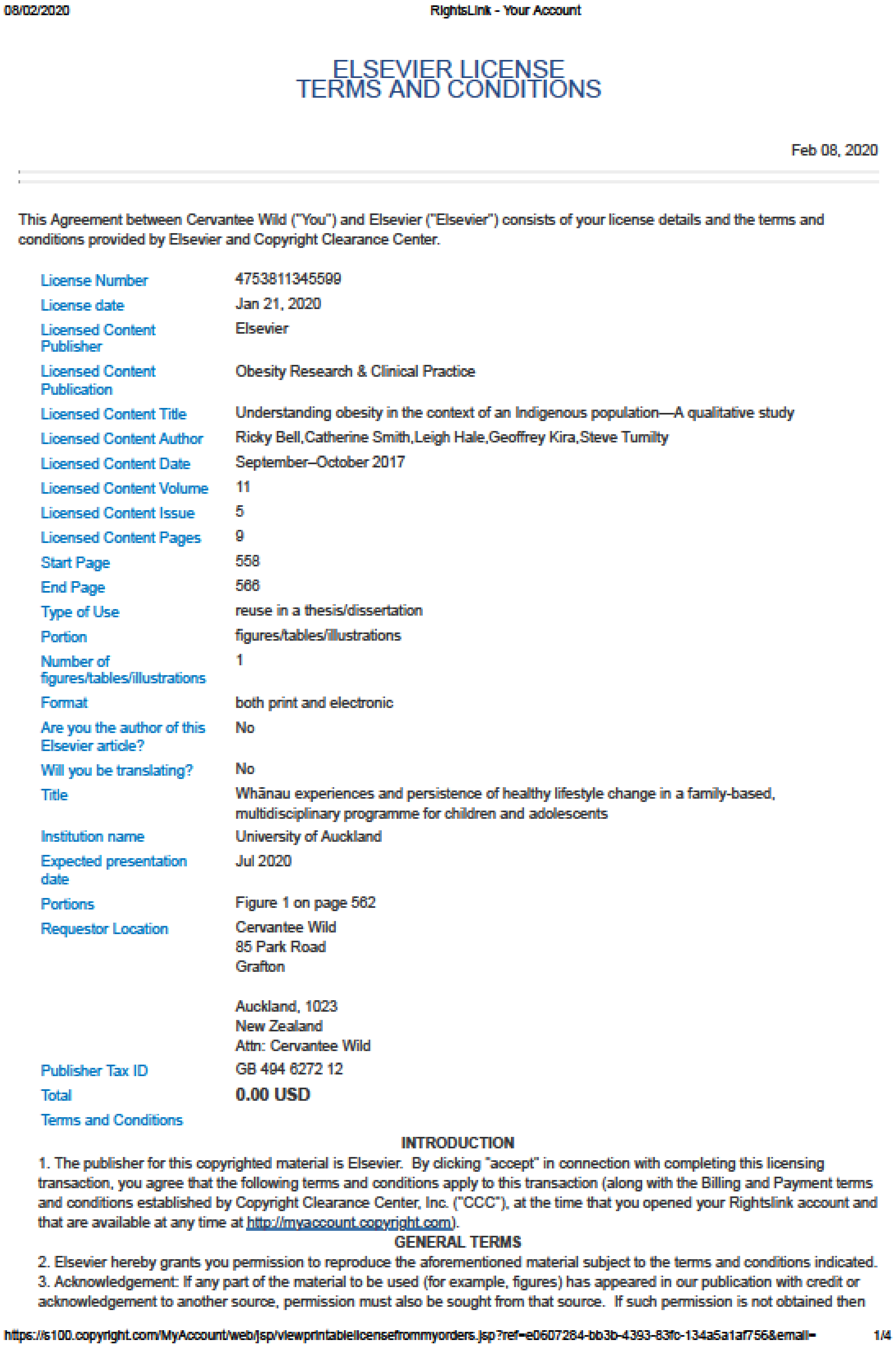
Figure 4.1: Intrinsic drivers for health potential and obesity expression in Indigenous peoples.[184]



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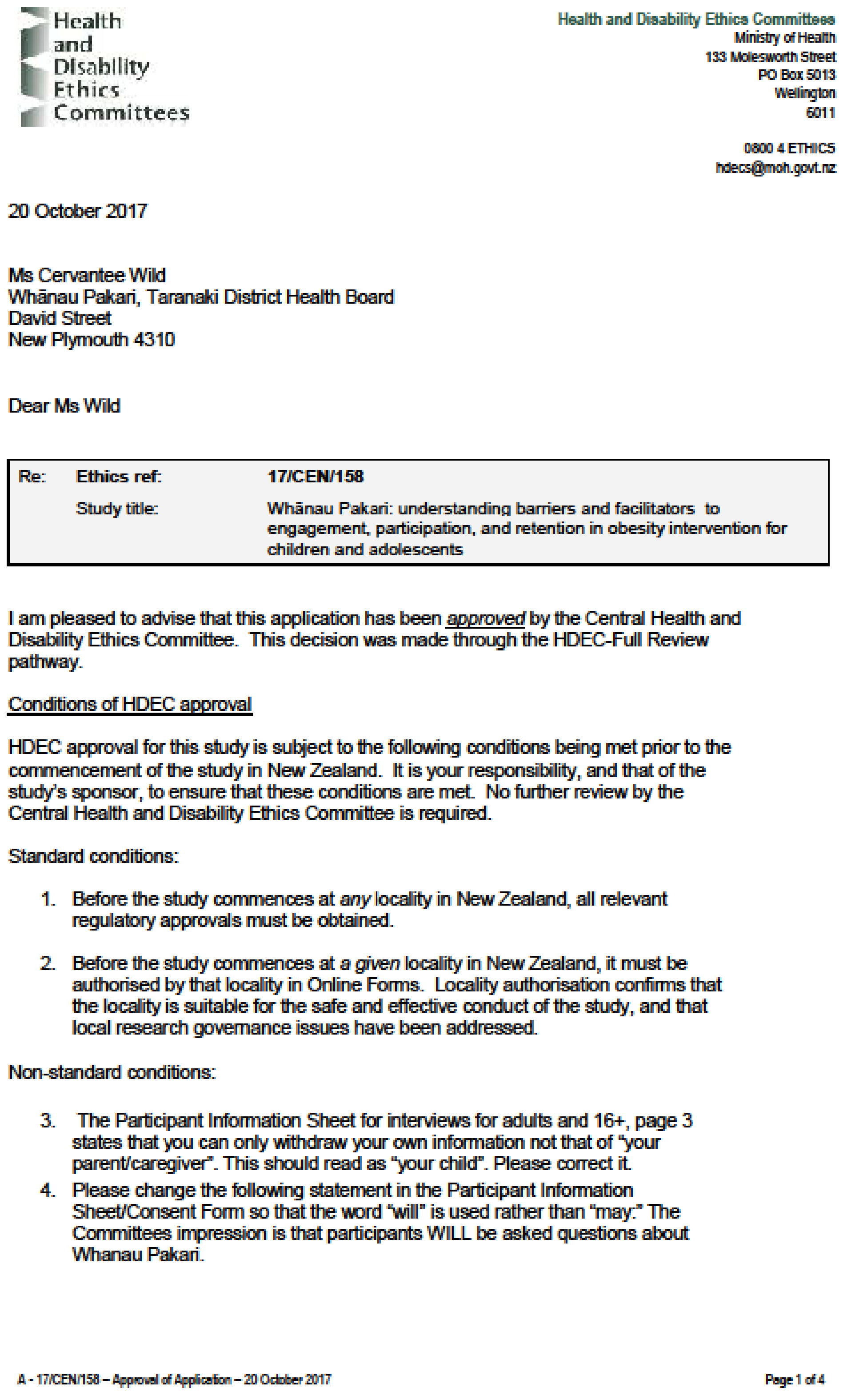
Appendix C. Evidence of ethical approval, patient information sheets and consent forms



Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

20 October 2017

Ms Cervantee Wild
Whānau Pakari, Taranaki District Health Board
David Street
New Plymouth 4310

Dear Ms Wild

Re:	**Ethics ref:**	**17/CEN/158**
	Study title:	Whānau Pakari: understanding barriers and facilitators to engagement, participation, and retention in obesity intervention for children and adolescents

I am pleased to advise that this application has been *approved* by the Central Health and Disability Ethics Committee. This decision was made through the HDEC-Full Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

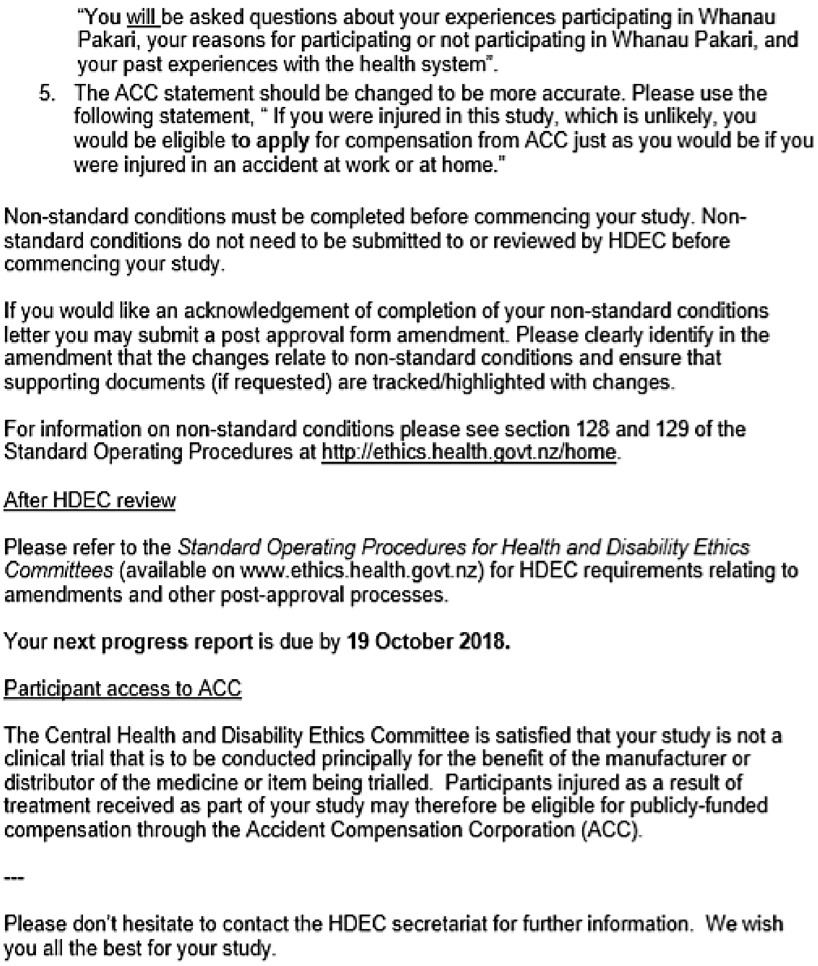
Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.

2. Before the study commences at *a given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

Non-standard conditions:

3. The Participant Information Sheet for interviews for adults and 16+, page 3 states that you can only withdraw your own information not that of "your parent/caregiver". This should read as "your child". Please correct it.
4. Please change the following statement in the Participant Information Sheet/Consent Form so that the word "will" is used rather than "may:" The Committees impression is that participants WILL be asked questions about Whanau Pakari.



"You will be asked questions about your experiences participating in Whanau Pakari, your reasons for participating or not participating in Whanau Pakari, and your past experiences with the health system".

5. The ACC statement should be changed to be more accurate. Please use the following statement, " If you were injured in this study, which is unlikely, you would be eligible **to apply** for compensation from ACC just as you would be if you were injured in an accident at work or at home."

Non-standard conditions must be completed before commencing your study. Non-standard conditions do not need to be submitted to or reviewed by HDEC before commencing your study.

If you would like an acknowledgement of completion of your non-standard conditions letter you may submit a post approval form amendment. Please clearly identify in the amendment that the changes relate to non-standard conditions and ensure that supporting documents (if requested) are tracked/highlighted with changes.

For information on non-standard conditions please see section 128 and 129 of the Standard Operating Procedures at http://ethics.health.govt.nz/home.

After HDEC review

Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your next progress report is due by 19 October 2018.

Participant access to ACC

The Central Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

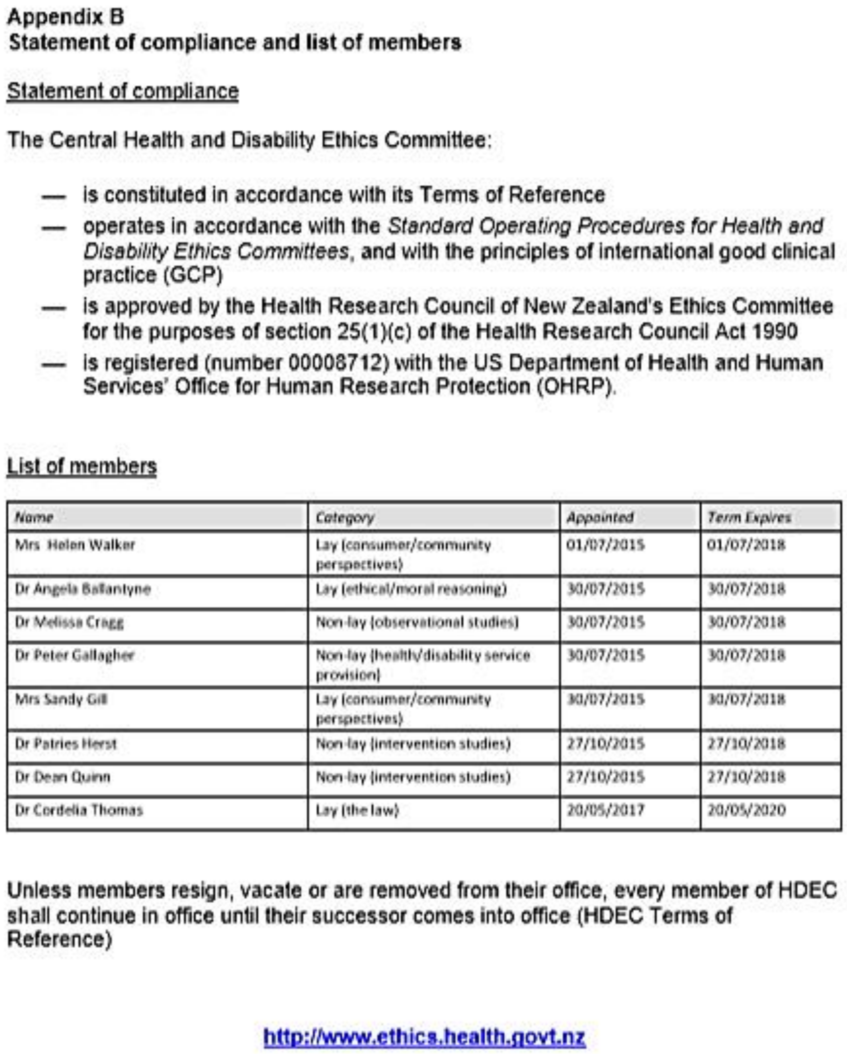
Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A
Documents submitted

Document	*Version*	*Date*
CVs for other Investigators: Curriculum vitae for Dr Yvonne Anderson (principal investigator)	1	08 August 2017
Evidence of scientific review: Evidence of favourable peer review for Whanau Pakari (also see separately uploaded award invitation)	1	09 August 2017
Evidence of scientific review: Invitation to A Better Start National Science Challenge Cure kids 2017 funding round award function	1	09 August 2017
Covering Letter: Covering letter	1	09 August 2017
Protocol: Study protocol	1	09 August 2017
PIS/CF: Whanau Pakari information sheet and consent form for adults (16+) for interviews	1	09 August 2017
PIS/CF: Whanau Pakari Information sheet and assent form for children (5-16 years) for interview	1	09 August 2017
PIS/CF: Whanau Pakari information sheet and consent form for adults (16+ years) and teens (11-16 years)for online survey	1	09 August 2017
PIS/CF for persons interested in welfare of non-consenting participant: Whanau Pakari information sheet and consent form for parents/caregivers of children (5-16 years) for interview	1	09 August 2017
Survey/questionnaire: Online survey questions	1	09 August 2017
Head of Department (Liggins Institute) approval	1	09 August 2017
CV for CI: CV for Cervantee Wild (CI)	1	09 August 2017
Application		
Survey/questionnaire: Updated Online Survey questions with clearer direction, tracked changes	2	02 October 2017
Protocol: Updated study protocol containing details for dealing with participants who disclose any concerning information	2	02 October 2017
PIS/CF: Amended Whanau Pakari information sheet and consent form for adults (16+) for interviews	2	02 October 2017
PIS/CF: Amended Whanau Pakari Information sheet and assent form for children (5-16 years) for interview	2	02 October 2017
PIS/CF: Amended Whanau Pakari information sheet and consent form for adults (16+ years) and teens (11-16 years)for online survey	2	02 October 2017
PIS/CF for persons interested in welfare of non-consenting participant: Amended Whanau Pakari information sheet and consent form for parents/caregivers of children (5-16 years) for interview	2	02 October 2017
Evidence of scientific review: Peer review from A Better Start National Science Challenge funding round with researcher responses	1	02 October 2017
Survey/questionnaire: Interview schedule	1	02 October 2017
Response to Request for Further Information		
Covering Letter: informing of possible change of interview schedule_02Oct2017.pdf		



Appendix B
Statement of compliance and list of members

Statement of compliance

The Central Health and Disability Ethics Committee:

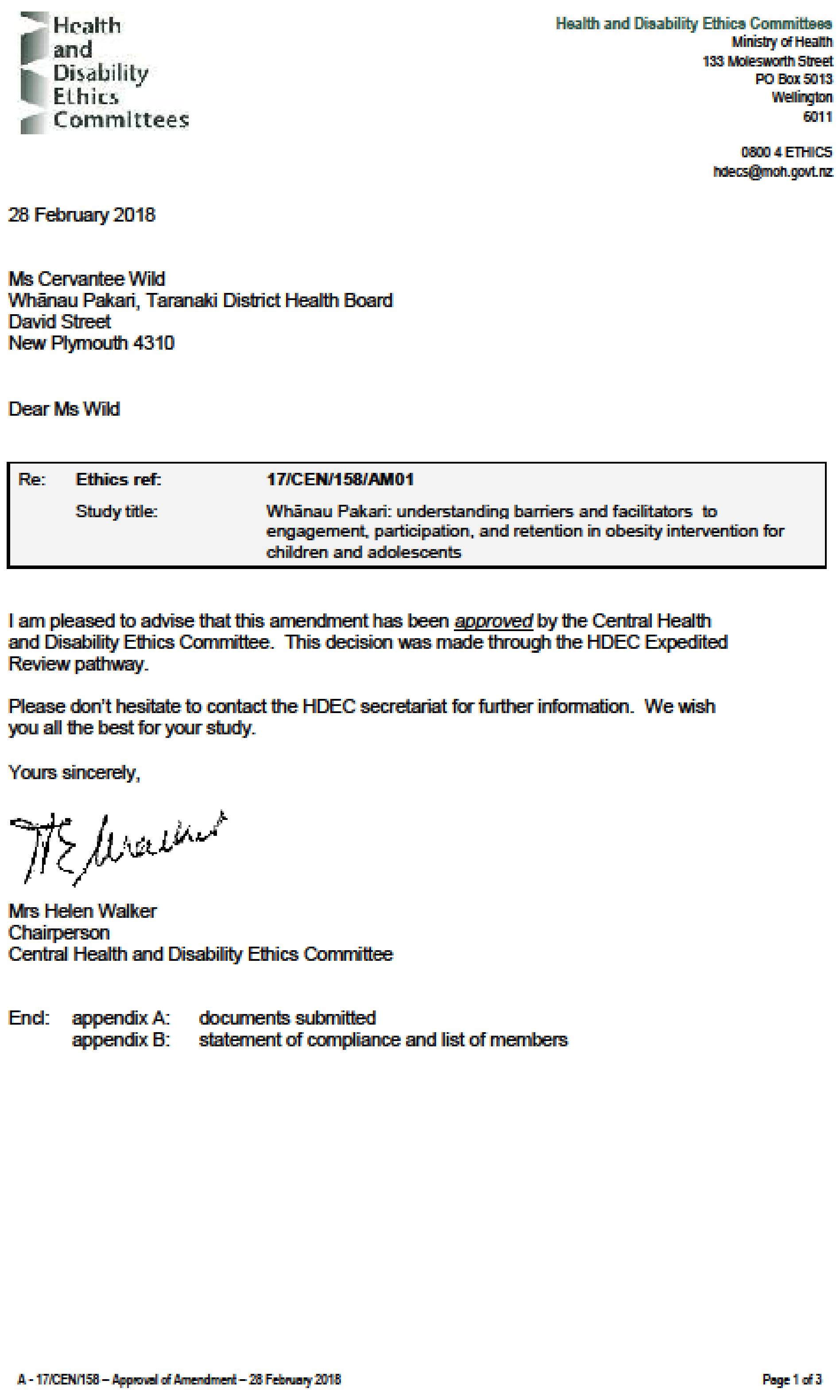
- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008712) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

Name	*Category*	*Appointed*	*Term Expires*
Mrs Helen Walker	Lay (consumer/community perspectives)	01/07/2015	01/07/2018
Dr Angela Ballantyne	Lay (ethical/moral reasoning)	30/07/2015	30/07/2018
Dr Melissa Cragg	Non-lay (observational studies)	30/07/2015	30/07/2018
Dr Peter Gallagher	Non-lay (health/disability service provision)	30/07/2015	30/07/2018
Mrs Sandy Gill	Lay (consumer/community perspectives)	30/07/2015	30/07/2018
Dr Patries Herst	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Dean Quinn	Non-lay (intervention studies)	27/10/2015	27/10/2018
Dr Cordelia Thomas	Lay (the law)	20/05/2017	20/05/2020

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

http://www.ethics.health.govt.nz



Health and Disability Ethics Committees

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecs@moh.govt.nz

28 February 2018

Ms Cervantee Wild
Whānau Pakari, Taranaki District Health Board
David Street
New Plymouth 4310

Dear Ms Wild

Re:	**Ethics ref:**	**17/CEN/158/AM01**
	Study title:	Whānau Pakari: understanding barriers and facilitators to engagement, participation, and retention in obesity intervention for children and adolescents

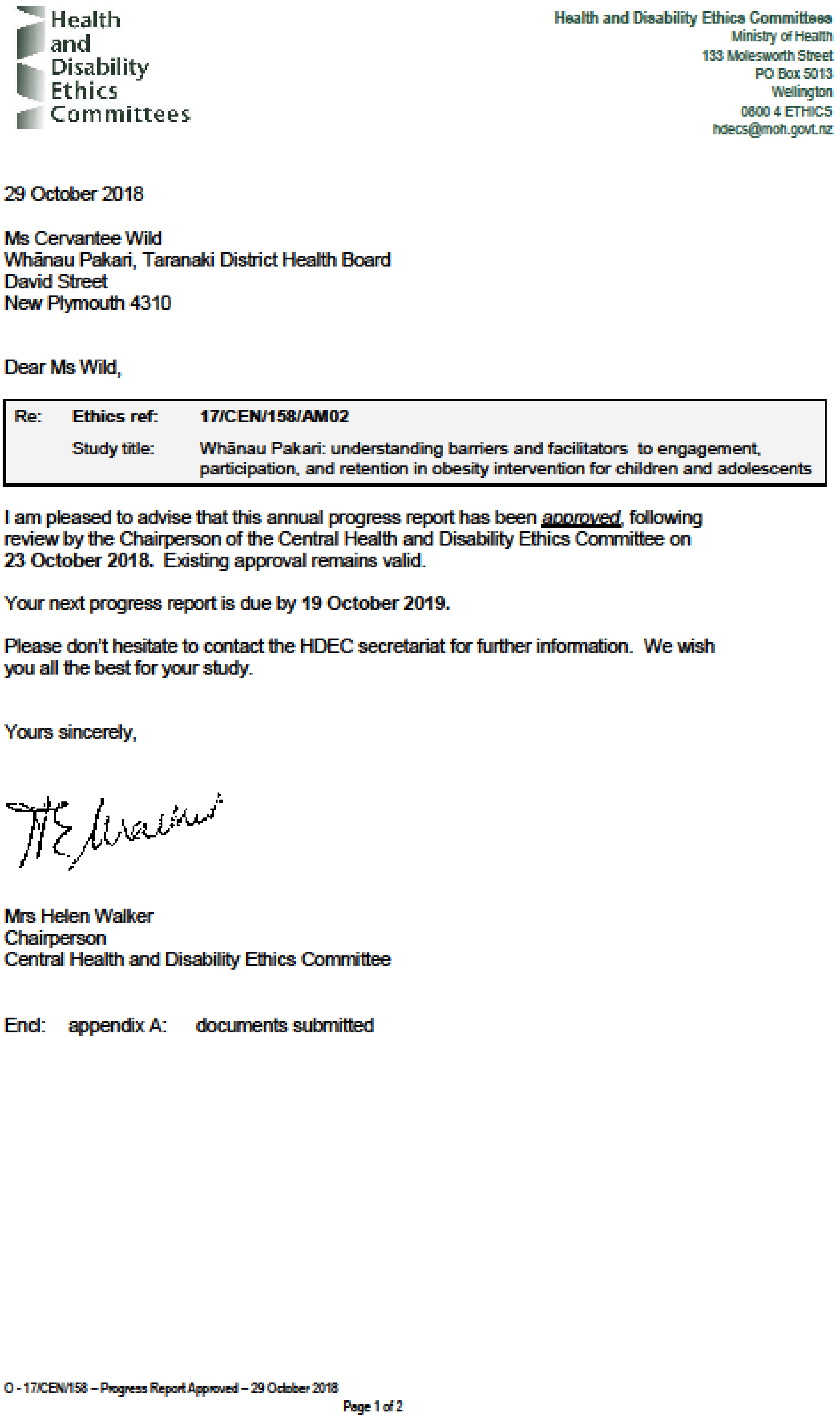
I am pleased to advise that this amendment has been *approved* by the Central Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members



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29 October 2018

Ms Cervantee Wild
Whānau Pakari, Taranaki District Health Board
David Street
New Plymouth 4310

Dear Ms Wild,

Re: **Ethics ref:** **17/CEN/158/AM02**
Study title: Whānau Pakari: understanding barriers and facilitators to engagement, participation, and retention in obesity intervention for children and adolescents

I am pleased to advise that this annual progress report has been *approved*, following review by the Chairperson of the Central Health and Disability Ethics Committee on **23 October 2018.** Existing approval remains valid.

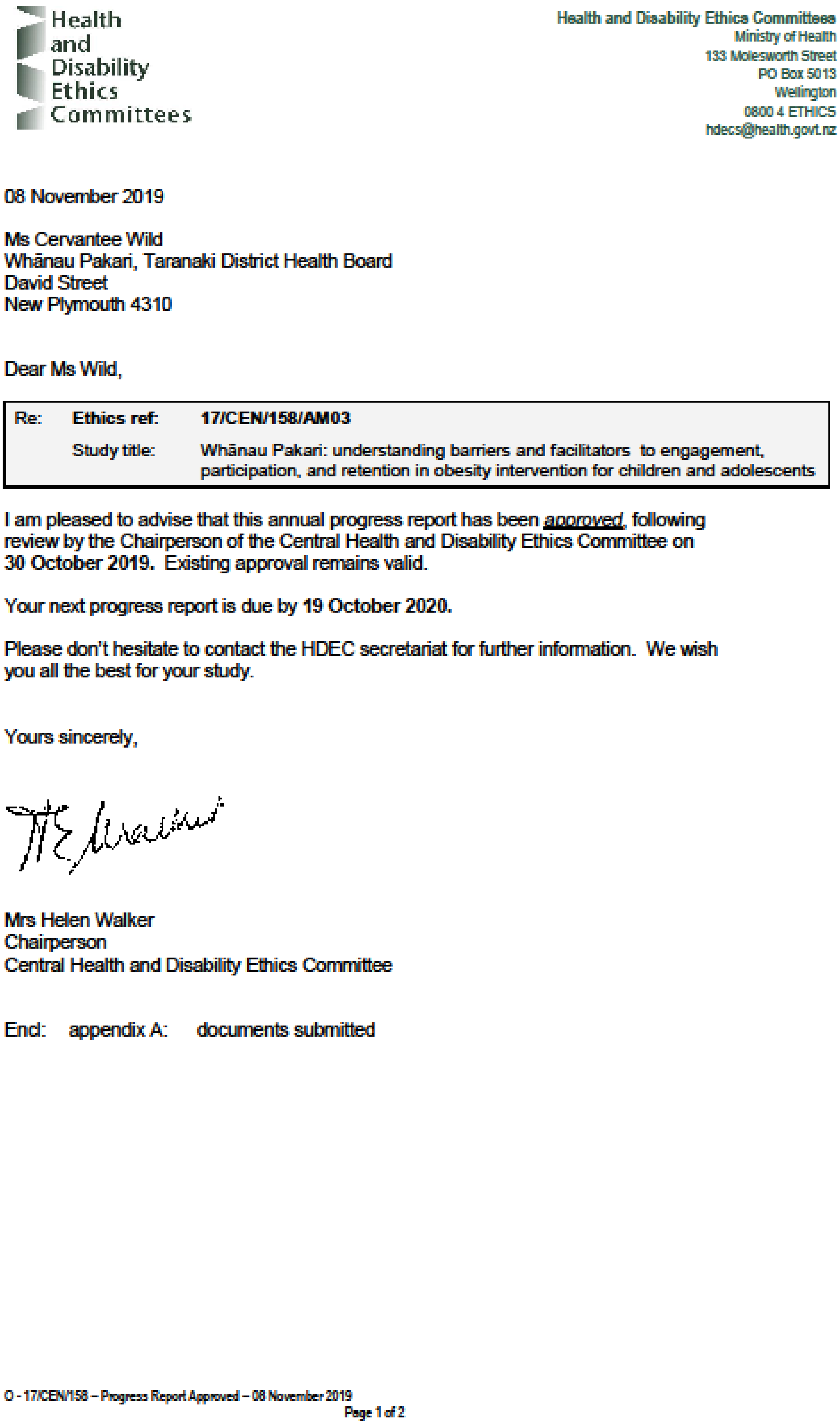
Your next progress report is due by **19 October 2019.**

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted



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0800 4 ETHICS
hdecs@health.govt.nz

08 November 2019

Ms Cervantee Wild
Whānau Pakari, Taranaki District Health Board
David Street
New Plymouth 4310

Dear Ms Wild,

Re: **Ethics ref:** **17/CEN/158/AM03**
Study title: Whānau Pakari: understanding barriers and facilitators to engagement, participation, and retention in obesity intervention for children and adolescents

I am pleased to advise that this annual progress report has been *approved*, following review by the Chairperson of the Central Health and Disability Ethics Committee on **30 October 2019.** Existing approval remains valid.

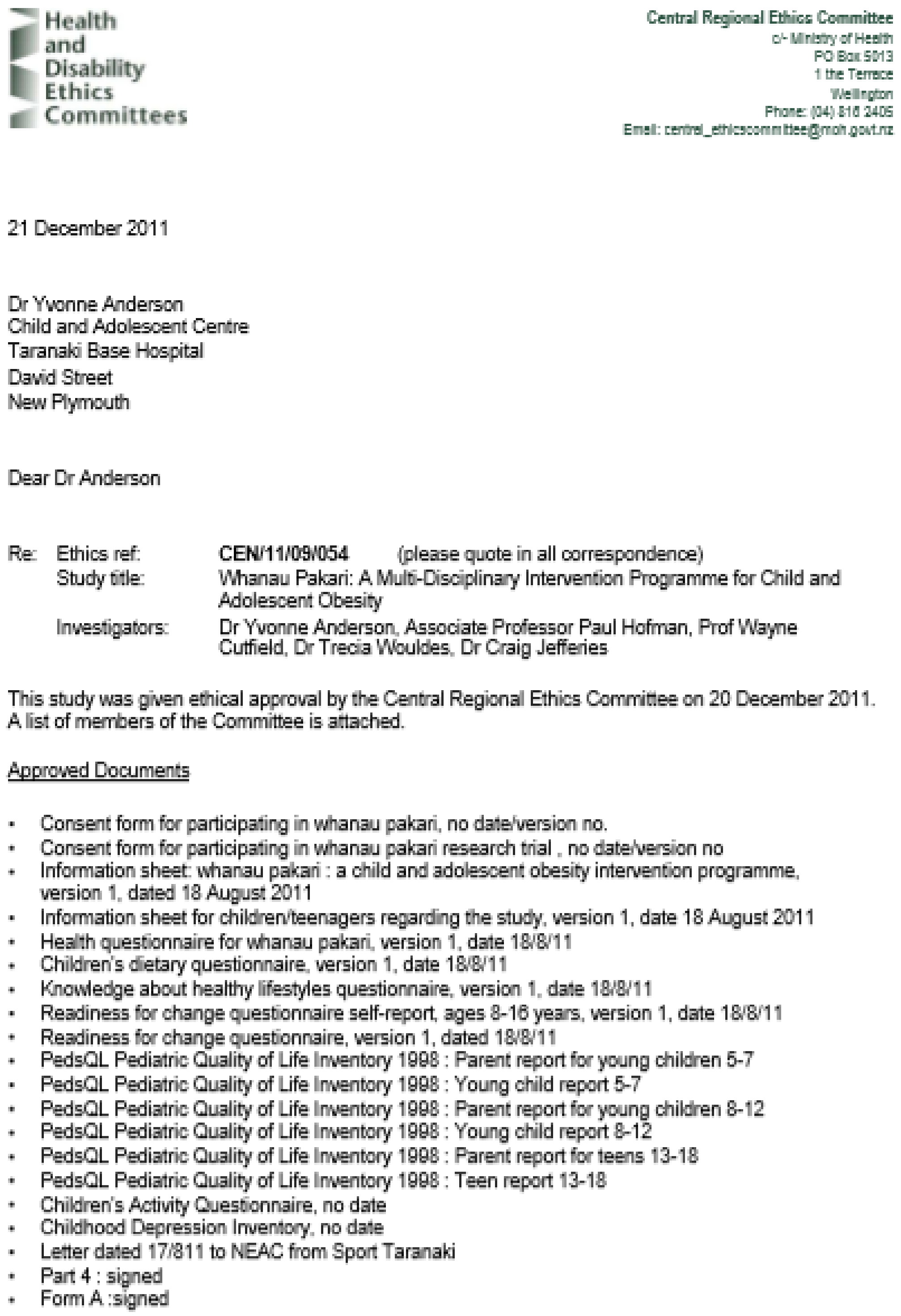
Your next progress report is due by **19 October 2020.**

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted



Health
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Committees

Central Regional Ethics Committee
c/- Ministry of Health
PO Box 5013
1 the Terrace
Wellington
Phone: (04) 816 2405
Email: central_ethicscommittee@moh.govt.nz

21 December 2011

Dr Yvonne Anderson
Child and Adolescent Centre
Taranaki Base Hospital
David Street
New Plymouth

Dear Dr Anderson

Re: Ethics ref: **CEN/11/09/054** (please quote in all correspondence)
Study title: Whanau Pakari: A Multi-Disciplinary Intervention Programme for Child and Adolescent Obesity
Investigators: Dr Yvonne Anderson, Associate Professor Paul Hofman, Prof Wayne Cutfield, Dr Trecia Wouldes, Dr Craig Jefferies

This study was given ethical approval by the Central Regional Ethics Committee on 20 December 2011. A list of members of the Committee is attached.

Approved Documents

- Consent form for participating in whanau pakari, no date/version no.
- Consent form for participating in whanau pakari research trial , no date/version no
- Information sheet: whanau pakari : a child and adolescent obesity intervention programme, version 1, dated 18 August 2011
- Information sheet for children/teenagers regarding the study, version 1, date 18 August 2011
- Health questionnaire for whanau pakari, version 1, date 18/8/11
- Children's dietary questionnaire, version 1, date 18/8/11
- Knowledge about healthy lifestyles questionnaire, version 1, date 18/8/11
- Readiness for change questionnaire self-report, ages 8-16 years, version 1, date 18/8/11
- Readiness for change questionnaire, version 1, dated 18/8/11
- PedsQL Pediatric Quality of Life Inventory 1998 : Parent report for young children 5-7
- PedsQL Pediatric Quality of Life Inventory 1998 : Young child report 5-7
- PedsQL Pediatric Quality of Life Inventory 1998 : Parent report for young children 8-12
- PedsQL Pediatric Quality of Life Inventory 1998 : Young child report 8-12
- PedsQL Pediatric Quality of Life Inventory 1998 : Parent report for teens 13-18
- PedsQL Pediatric Quality of Life Inventory 1998 : Teen report 13-18
- Children's Activity Questionnaire, no date
- Childhood Depression Inventory, no date
- Letter dated 17/811 to NEAC from Sport Taranaki
- Part 4 : signed
- Form A :signed

Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
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hdecs@moh.govt.nz

27 January 2017

Dr Yvonne Anderson
Child and Adolescent Centre
David Street
New Plymouth 4310

Dear Dr Anderson

Re:	**Ethics ref:**	**CEN/11/09/054/AM09**
	Study title:	Whanau Pakari: A Multi-Disciplinary Intervention Programme for Child and Adolescent Obesity

This letter is to confirm approval of the annual progress report for this study, reviewed by the Chairperson of the Central Health and Disability Ethics Committee on 24 January 2017. Existing approval remains valid.

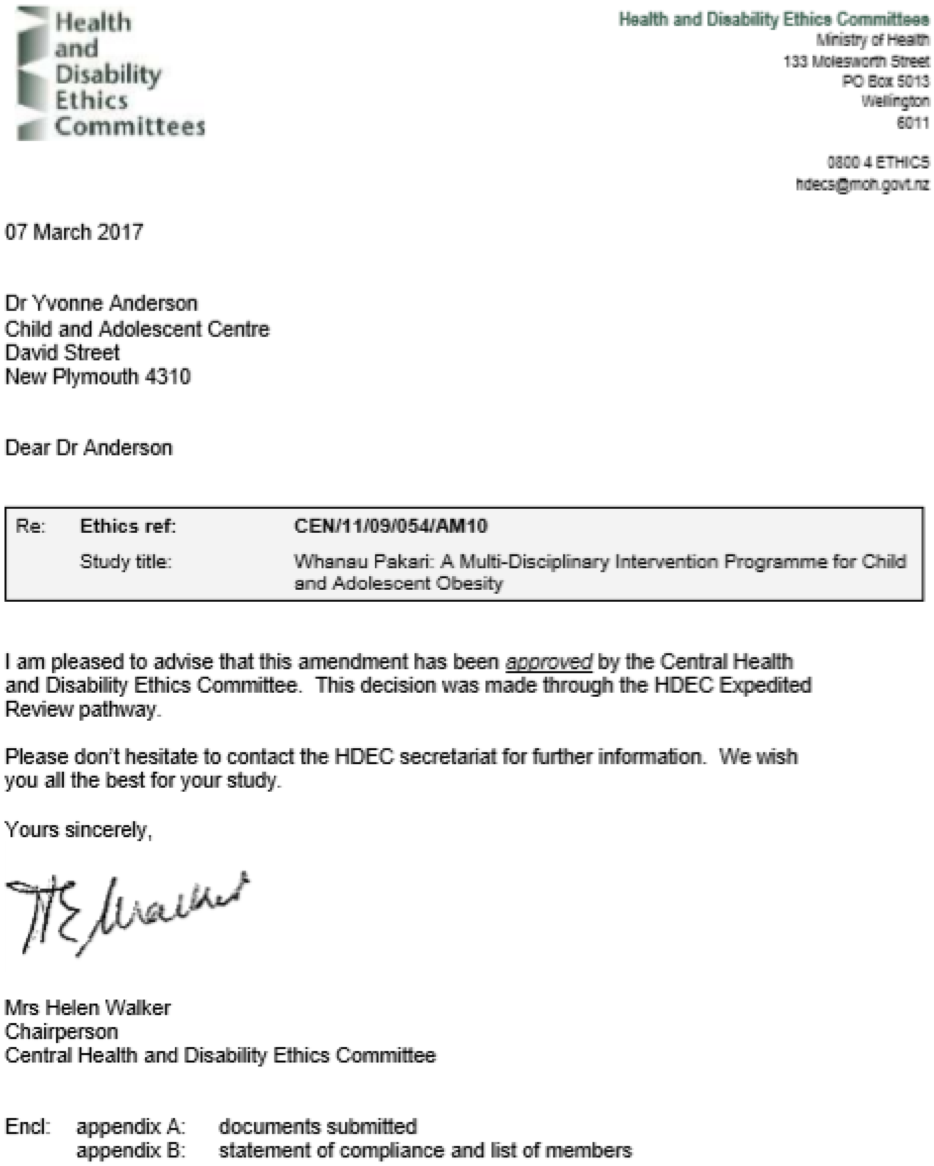
Your **next progress report** is due by **20 December 2017.**

Please don't hesitate to contact us for further information.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted



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07 March 2017

Dr Yvonne Anderson
Child and Adolescent Centre
David Street
New Plymouth 4310

Dear Dr Anderson

Re:	**Ethics ref:**	**CEN/11/09/054/AM10**
	Study title:	Whanau Pakari: A Multi-Disciplinary Intervention Programme for Child and Adolescent Obesity

I am pleased to advise that this amendment has been *approved* by the Central Health and Disability Ethics Committee. This decision was made through the HDEC Expedited Review pathway.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

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18 December 2017

Dr Yvonne Anderson
Child and Adolescent Centre
David Street
New Plymouth 4310

Dear Dr Anderson

Re:	**Ethics ref:**	**CEN/11/09/054/AM11**
	Study title:	Whanau Pakari: A Multi-Disciplinary Intervention Programme for Child and Adolescent Obesity

This letter is to confirm approval of the annual progress report for this study, reviewed by the Chairperson of the Central Health and Disability Ethics Committee on 16 December 2017. Existing approval remains valid.

Your next progress report is due by 20 December 2018.

Please don't hesitate to contact us for further information.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted

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23 April 2019

Dr Yvonne Anderson
Child and Adolescent Centre
David Street
New Plymouth 4310

Dear Dr Anderson,

Re:	**Ethics ref:**	**CEN/11/09/054/AM12**
	Study title:	Whanau Pakari: A Multi-Disciplinary Intervention Programme for Child and Adolescent Obesity

I am pleased to advise that this annual progress report has been *approved*, following review by the Chairperson of the Central Health and Disability Ethics Committee on 10 April 2019. Existing approval remains valid.

Your next progress report is due by 21 December 2019.

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,

Mrs Helen Walker
Chairperson
Central Health and Disability Ethics Committee

Encl: appendix A: documents submitted

Information Sheet for participants regarding the online survey

Study title:	**Whānau Pakari: understanding barriers and facilitators to engagement, participation and retention in healthy lifestyle programme for children and teens**	
Locality:	**Taranaki**	Ethics committee ref: 17/CEN/158
Lead investigator:	**Dr Yvonne Anderson**	Contact phone number: **(06)7536139**

We invite you to take part in this study. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Information Sheet for participants will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. We expect this will take about 10 minutes. You may also want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to click the 'I accept' button at the bottom of the screen.

Why are we doing the study?

Over the past few years, you may have participated in a healthy lifestyle programme called Whānau Pakari – or you may have been referred to the programme, but not taken part. We want to know the reasons why some people participated in Whānau Pakari and why some people did not.

There is a lack of research looking at interventions for weight issues with long-term follow-up, especially in New Zealand. In Taranaki, a programme called 'Whānau Pakari' has been running since 2012 to help tamariki (children) with weight issues and their whānau to make healthy lifestyle changes. Research findings from this programme have shown that Whānau Pakari has managed to achieve a high rate of engagement with Māori children, and those from the most deprived households of Taranaki. We also found that those that attended more programme sessions achieved greater health benefits. It's important to find out the reasons why families did or did not engage with Whānau Pakari, so that the programme can be improved for the future.

This study has been funded through the acquisition of grant money from the following sources: A Better Start National Science Challenge Curekids 2017 funding round.

The study is supported by the Liggins Institute, University of Auckland and the Taranaki District Health Board. The principal researcher is Dr Yvonne Anderson, who works at the Taranaki District Health Board. If you have any questions regarding the study, please see the contact details of the principal researcher at the end of this information sheet. The study has current approval from an ethics committee.

What would your participation involve?

There are two parts to this study: an online survey, and an interview. If you have taken part in the Whānau Pakari programme, you will be asked for your consent to participate in the study. The online survey will take approximately 10 minutes. Your responses will be anonymous. You will be asked questions about your experiences participating in Whānau Pakari, your reasons for participating or not participating in Whānau Pakari, and your past experiences with the health system.

You and your family may also be invited to participate in an interview to talk about your experiences with Whānau Pakari in more detail. This would take 30-60 minutes, and would be held at your home or another place of your choosing. Our conversation would be recorded with your consent and you would be anonymous if you wish. You may choose to have whānau members with you.

What are the possible benefits and risks to you in participating?

There are no risks to you participating in the study. If you choose not to take part in the study, this will not impact on your care. The investigator has oversight and overall responsibility to ensure that care is provided to all participants in this study.

What are the rights of participants in the study?

Please do not hesitate to ask us any questions that you may have. Please be aware that you can withdraw your consent for your participation at any time, and participation is entirely voluntary. If you choose not to participate, your medical care will not be affected. The Whanau Pakari clinical service team do not know who is involved with this research project.

We respect the confidentiality of all participants and we are committed to ensuring the privacy of all information gathered as part of the study.

What would happen if you were injured in the study?

If you were injured in this study, which is unlikely, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

What will happen after the study ends, or if you pull out?

Because the survey will be anonymous, it will not be possible to withdraw your answers after you have entered them.

Data from the study will be stored securely in locked filing cabinets at Taranaki Base Hospital for ten years. All electronic data will be stored on Qualtrics servers, and then transferred to hospital servers (password protected). Any data used in research publications will be anonymised.

The findings of the study will be communicated to the tamariki (children) and adults involved in the programme at feedback hui (group meetings) at the completion of the study.

Where can you go for more information about the study, or to raise concerns or complaints?

Full name of principal researcher:	Dr Yvonne Anderson
Contact phone number:	(06) 7536139

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

You can also contact a Māori support person familiar with the study:

Tami Cave, (06) 753 7777 ext 8729

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone:	0800 4 38442
Email:	hdecs@moh.govt.nz

Thank-you for reading this information sheet

CONSENT FORM

WHĀNAU PAKARI: UNDERSTANDING BARRIERS AND FACILITATORS TO ENGAGEMENT, PARTICIPATION AND RETENTION IN A HEALTHY LIFESTYLE PROGRAMME FOR CHILDREN AND TEENS

I hereby consent to participate in the above study. I have had the opportunity to read the Information sheet and have asked any questions I have.

I understand that this part of the study is a short online survey.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my future healthcare. I will not be able to withdraw data once I have started the survey.

I have read and I understand the Information sheet for volunteers taking part in the study designed to understand reasons for participation in Whānau Pakari. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the information given.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study. However, I do understand that anonymous data may be shared with the research team.

I have had time to consider whether to take part in the study.

I know who to contact if I have any questions about the study in general.

Full name of principal researcher:	Dr Yvonne Anderson
Contact phone number:	(06) 7536139

I ACCEPT **I DO NOT ACCEPT**

Information Sheet for Adults (aged 16+) regarding the interviews

Study title:	**Whānau Pakari: understanding barriers and facilitators to engagement, participation and retention in a healthy lifestyle programme for children and teens**	
Locality:	**Taranaki**	Ethics committee ref: 17/CEN/158
Lead investigator:	**Dr Yvonne Anderson**	Contact phone number: **(06)7536139**

We invite you to take part in this study. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Information Sheet for Adults will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what will happen after the study ends. We will go through this information with you and answer any questions you may have. We expect this will take about 10 minutes. You may also want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Adult Consent Form on the last page of this document. You will be given a copy of both the Information Sheet for Adults, and the Adult Consent Form to keep.

This document is 4 pages long, including the Adult Consent Form. Please make sure you have all the pages.

Why are we doing the study?

Over the past few years, you may have participated in a healthy lifestyle programme called Whānau Pakari – or you may have been referred to the programme, but not taken part. We want to know the reasons why some people participated in Whānau Pakari and why some people did not.

There is a lack of research looking at interventions for weight issues with long-term follow-up, especially in New Zealand. In Taranaki, a programme called 'Whānau Pakari' has been running since 2012 to help tamariki (children) with weight issues and their whānau make healthy lifestyle changes. Research findings from this programme have shown that Whānau

Pakari has managed to achieve a high rate of initial engagement with Māori children, and those from the most deprived households of Taranaki. We also found that those that attended more programme sessions achieved greater health benefits. It's important to find out the reasons why families participated in Whānau Pakari, so that the programme can be improved for the future.

This study has been funded through the acquisition of grant money from the following sources: A Better Start National Science Challenge Curekids 2017 funding round.

The study is supported by the Liggins Institute, University of Auckland and the Taranaki District Health Board. The principal researcher is Dr Yvonne Anderson, who works at the Taranaki District Health Board. If you have any questions regarding the study, please see the contact details of the principal researcher at the end of this information sheet. The study has current approval from an ethics committee.

What would your participation involve?

There are two parts to this study: an online survey, and an interview. If you have taken part in the Whānau Pakari programme, you will be asked for your consent to participate in the study. The online survey will take approximately 10 minutes. Your responses will be anonymous.

You and your family may also be invited to participate in an interview to talk about your experiences with Whānau Pakari in more detail. This would take 30-60 minutes, and would be held at your home or another place of your choosing. Our conversation would be recorded with your consent and you would be anonymous if you wish. You may choose to have whānau members with you.

You will be asked questions about your experiences participating in Whānau Pakari, your reasons for participating or not participating in Whānau Pakari, and your past experiences with the health system.

What are the possible benefits and risks to you in participating?

There are no risks to you participating in the study. If you choose not to take part in the study, this will not impact on your care. The investigator has oversight and overall responsibility to ensure that care is provided to all participants in this study.

What would happen if you were injured in the study?

If you were injured in this study, which is unlikely, you would be eligible to apply for compensation from ACC just as you would be if you were injured in an accident at home. This does not mean that your claim will automatically be accepted. You will have to lodge a claim with ACC, which may take some time to assess. If your claim is accepted, you will receive funding to assist in your recovery. If you have private health or life insurance, you may wish to check with your insurer that taking part in this study won't affect your cover.

What are the rights of participants in the study?

Please do not hesitate to ask us any questions that you may have. Please be aware that you can withdraw your consent for your participation at any time, and participation is entirely voluntary. If you choose not to participate, your medical care will not be affected. The Whānau Pakari clinical team do not know who is involved with this research project.

We respect the confidentiality of all participants and we are committed to ensuring the privacy of all information gathered as part of the study.

What will happen after the study ends, or if you pull out?

You may withdraw your answers up to one month from your interview. You are only able to withdraw your own data, not your parent/caregiver's data if they participated as well.

Data from the study will be stored securely in locked filing cabinets at Taranaki Base Hospital for ten years. All electronic health data will be password protected, on databases held on hospital servers. Any data used in research publications will be anonymised.

The findings of the study will be communicated to the tamariki (children) and adults involved in the programme at feedback hui (group meetings) at the completion of the study.

Where can you go for more information about the study, or to raise concerns or complaints?

Full name of principal researcher:	Dr Yvonne Anderson
Contact phone number:	(06) 7536139

If you have any queries or concerns regarding your rights as a participant in this study, you may wish to contact an independent health and disability advocate:

Free phone: 0800 555 050

Free fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

You can also contact a Māori support person familiar with the study:

Tami Cave, (06) 753 7777 ext 8729

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone:	0800 4 38442
Email:	hdecs@moh.govt.nz

Thank-you for reading this information sheet.

WHĀNAU PAKARI: UNDERSTANDING BARRIERS TO ENGAGEMENT, PARTICIPATION AND RETENTION IN A HEALTHY LIFESTYLE PROGRAMME FOR CHILDREN AND TEENS

ADULT CONSENT FORM FOR PARTICIPATION IN STUDY (INTERVIEW)

I, ______________________ hereby consent to participate in the above study. I have had the opportunity to read the Information sheet for adults, and had my questions answered after discussion with ______________________.

I understand that this part of the study is a commitment to one 30-60 minute recorded interview.

I understand that taking part in this study is voluntary (my choice), and that I may withdraw from the study at any time, and this will in no way affect my future healthcare.

I have received the Information sheet for Adults and I understand that I will receive copies of the Adult consent form. I have read and I understand the Information sheet for Adults, dated_____________, for volunteers taking part in the study designed to understand reasons for participation in Whānau Pakari. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I have had the opportunity to use whānau support or a friend to help me ask questions and understand the information given.

I understand that my participation in this study is confidential and that no material that could identify me will be used in any reports on this study. However, I do understand that anonymous data may be shared for the purpose of research.

I have had time to consider whether to take part in the study.

I know who to contact if I have any questions about the study in general.

I would like to receive a summary of my interview answers for my review.

Yes ☐ **No** ☐

Email/postal address:

Full name of principal researcher:	Dr Yvonne Anderson
Contact phone number:	(06) 7536139
Project explained by:	

Project role:

Signed: ___________________ **Name:** _______________________ **Date:** _____________

Appendix D. Questionnaire and interview schedule

Survey questionnaire

NB. The survey was formatted appropriately for completing on paper and online via a computer or mobile phone.

Whānau Pakari: understanding barriers and facilitators to engagement, participation and retention in a healthy lifestyle programme for children and teens

Tick the option that applies to you:

1. I am a:

   ☐ Past Whānau Pakari participant aged 11+ years (child or teen)
   ☐ Past Whānau Pakari accompanying adult (parent/caregiver)

Questions for parents/caregivers	**Questions for Whānau Pakari children or teens**
2. Did you accept your child's referral to Whānau Pakari?	2. Did your parent/caregiver accept your referral to Whānau Pakari?
○ Yes ○ No	○ Yes ○ No
2a. Please give a reason for declining your child's referral to Whānau Pakari:	2a. Please give a reason for your parent/caregiver declining your referral to Whānau Pakari.

3. What level of input did you choose (or were allocated to)? *Tick the option that applies to you*

☐ Home-based assessments only
☐ Home-based assessments and weekly sessions
☐ I started on home-based assessments only, then moved to assessments and weekly sessions
☐ I had one assessment but then decided not to be involved in the programme

4. If you had weekly sessions…

a. Were they offered for 6 months or 12 months?

☐ 6
☐ 12

b. If you can recall, how many of the weekly sessions did you and your whānau/family attend?

☐ None
☐ Less than half
☐ About half
☐ More than half
☐ All

5. To what extent do you agree with the following statements about the **assessments?** *Tick the option that applies to you*

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
The assessments were in a convenient location	☐	☐	☐	☐	☐
The assessments were at a convenient time	☐	☐	☐	☐	☐
We had the time to attend assessments	☐	☐	☐	☐	☐

6. To what extent do you agree with the following statements about the **sessions?** *Tick the option that applies to you*

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
The sessions were in a convenient location	☐	☐	☐	☐	☐
The sessions were at a convenient time	☐	☐	☐	☐	☐
We had the time to attend sessions	☐	☐	☐	☐	☐
We had transport to get to sessions	☐	☐	☐	☐	☐
The programme seemed appropriate for my family	☐	☐	☐	☐	☐

	Strongly disagree	Somewhat disagree	Neither agree nor disagree	Somewhat agree	Strongly agree
I felt the programme could work for my family	☐	☐	☐	☐	☐
I felt my family would benefit from this programme	☐	☐	☐	☐	☐
Other things were more important for my family at the time	☐	☐	☐	☐	☐
Previous experiences with healthcare made me not want my family to attend	☐	☐	☐	☐	☐
I thought other people might judge me and my family for attending	☐	☐	☐	☐	☐
I felt that the programme was culturally appropriate	☐	☐	☐	☐	☐

7. What were the factors that helped you attend Whānau Pakari sessions/assessments, if any?

8. What things prevented you from attending Whānau Pakari sessions/assessments, if any?

9. How could Whānau Pakari better meet your needs/the needs of your whānau/family?

10. Do you have any other comments about your experience with Whānau Pakari?

11. Which ethnic group do you belong to? *Mark the space or spaces which apply to you.*

    ☐ New Zealand European
    ☐ Māori
    ☐ Samoan
    ☐ Cook Islands Māori
    ☐ Tongan
    ☐ Niuean
    ☐ Chinese
    ☐ Indian
    ☐ Other (Please state: e.g. Dutch, Japanese, Tokelauan)
    ____

12. What is your gender?
    ☐ Male / Tāne
    ☐ Female / Wahine
    ☐ Gender diverse

    a. If you are gender diverse, are you...
    ☐ Gender diverse not further defined / Ira tāngata kōwhiri kore
    ☐ Transgender male to female / Whakawahine
    ☐ Transgender female to male / Tangata ira tāne
    ☐ Gender diverse not elsewhere classified / Ira tāngata kōwhiri kore

If you are a parent/caregiver:

13. How many children did you have referred to Whānau Pakari?

14. Which ethnic group does your child belong to? *Mark the space or spaces which apply to your child. Answer for each child involved in Whānau Pakari.*

CHILD 1

Ethnicity	**Gender**
Mark the space or spaces which apply to your child ☐ New Zealand European ☐ Māori ☐ Samoan ☐ Cook Islands Māori ☐ Tongan ☐ Niuean ☐ Chinese ☐ Indian ☐ Other (Please state: e.g. Dutch, Japanese, Tokelauan)	☐ Male / Tāne ☐ Female / Wahine ☐ Gender diverse *If your child is gender diverse, are they…* ☐ Gender diverse not further defined / Ira tāngata kōwhiri kore ☐ Transgender male to female / Whakawahine ☐ Transgender female to male / Tangata ira tāne ☐ Gender diverse not elsewhere classified / Ira tāngata kōwhiri kore

CHILD 2 (if required)

Ethnicity	**Gender**
Mark the space or spaces which apply to your child ☐ New Zealand European ☐ Māori ☐ Samoan ☐ Cook Islands Māori ☐ Tongan ☐ Niuean ☐ Chinese ☐ Indian ☐ Other (Please state: e.g. Dutch, Japanese, Tokelauan)	☐ Male / Tāne ☐ Female / Wahine ☐ Gender diverse *If your child is gender diverse, are they…* ☐ Gender diverse not further defined / Ira tāngata kōwhiri kore ☐ Transgender male to female / Whakawahine ☐ Transgender female to male / Tangata ira tāne ☐ Gender diverse not elsewhere classified / Ira tāngata kōwhiri kore

CHILD 3 (if required)

Ethnicity *Mark the space or spaces which apply to your child* ☐ New Zealand European ☐ Māori ☐ Samoan ☐ Cook Islands Māori ☐ Tongan ☐ Niuean ☐ Chinese ☐ Indian ☐ Other (Please state: e.g. Dutch, Japanese, Tokelauan)	**Gender** ☐ Male / Tāne ☐ Female / Wahine ☐ Gender diverse *If your child is gender diverse, are they…* ☐ Gender diverse not further defined / Ira tāngata kōwhiri kore ☐ Transgender male to female / Whakawahine ☐ Transgender female to male / Tangata ira tāne ☐ Gender diverse not elsewhere classified / Ira tāngata kōwhiri kore

Thank you for completing this survey! Fill in your email address or phone number to go in the draw to win one of three $400 Rebel Sport vouchers (optional – your responses will still be anonymous)

Interview schedule

Introduction:

- Purpose of interview
- Why the participant has been chosen
- Expected duration of interview
- Seek informed consent
    - Talk through information sheet
    - Explain how information is confidential
    - Use of note-taking and tape recorder
    - Written or/and documented oral consent

Interviewer administered ethnicity question

The interviewer states: please use this card to tell me which ethnic group or groups you belong to.

Show card
O New Zealand European
O Māori
O Samoan
O Cook Islands Māori
O Tongan
O Niuean
O Chinese
O Indian
O Other (such as Dutch, Japanese, Tokelauan). Please state.
The interviewer ticks all that apply.

Referral & initial thoughts

- Tell me about your experience of Whānau Pakari.
- Who referred you to Whānau Pakari?
- Do you remember how they told you about the programme? (if not self-referral)
- Did they talk with you and your tamariki/rangatahi?
- How did you feel about being referred? How did you talk to your tamariki/rangatahi about the programme and referral?

- Why did you decide to:
    - Accept the referral?
    - Decline the referral?

Direct interview based on answer, i.e. omit questions pertaining to attending Whānau Pakari if they did not accept referral

- How did you feel about starting the programme? [Prompt: Excited, nervous, reluctant, annoyed, etc.]
- Which part of the programme (if any) were you more interested in, or seemed more relevant for you and/or your family/whānau?
- Were you worried about what other people might think about you and your whānau attending Whānau Pakari?
    - Prompt: If yes, can you tell me what you were worried about?
    - [If weight stigma identified: Have you ever been treated unfairly or discriminated against because of your weight or your child's weight? If yes, can you tell me a bit more about this?]

Overall experience

- Which parts of the programme were the most helpful? [Prompt: what was helpful about them/why was it helpful?]
- Which parts of the programme did you find were more difficult? [Prompt: what was difficult /why was it difficult?]
- Did Whānau Pakari meet your needs in supporting you to make healthy lifestyle changes as a whānau? Why/Why not?
- Did Whānau Pakari meet your expectations in terms of what you thought the team would provide? How did/didn't they do this?
- Would you recommend Whānau Pakari to other whānau, and why/why not?

Barriers and facilitators

- Can you think of things that might have motivated you or your whānau to participate (or things that kept you from participating)?
- What were the things that helped you to or made you want to continue to attend Whānau Pakari sessions, if any?
- What were the things that made it hard for you to continue to attend Whānau Pakari, if any?
- Did you experience any travel barriers to get to the sessions?

  - Distance to sessions
  - Access to a car
  - Petrol/current registration or WOF
  - Cost of parking

- The Healthy Lifestyles Coordinator came to you for the assessments. What were the good things about a home visit? What were the negative things?
- Do you prefer home-based assessments rather than coming to the hospital? [Can you tell me why/why not?]
- Please describe how you were able to involve the rest of your tamariki and whānau.
- How much of a priority was Whānau Pakari in relation to your other whānau demands?
- How did other competing demands, obligations or choices impact on your decision to attend Whānau Pakari?
- Can you please describe how Whānau Pakari was or wasn't appropriate for you culturally? How could it be made more appropriate?
- Can you please describe how Whānau Pakari was (or wasn't) suitable for whānau like yours?
- Can you please describe how Whānau Pakari was (or wasn't) whānau-friendly, inviting, comfortable? What could be done to improve this?
- Can you please tell me how costs may or may not have been barriers to participation in Whānau Pakari? How?
- Can you tell me about any other barriers to participation in Whānau Pakari that you experienced?

Beliefs and feelings around healthy lifestyle programmes

- What do you think about healthy lifestyle programmes in general?

Previous experiences with health system

- In general, can you describe what your experiences with the health system have been like prior to the Whānau Pakari programme?
- Have you ever felt that you or your family have been treated unfairly in the health system? [Prompt: could include not being treated with respect and dignity, not listened to etc.] If yes, why do you think that this happened? [Prompt: what do you think the reason was?]

- If discrimination not identified above: In your experiences with the health system, have you ever been treated unfairly or discriminated against? If yes, can you tell me a bit more about this? Why do you think this happened?
- Have you had any previous negative experiences with health providers? If yes, can you tell me a bit more about this?
- Have any of you or your whānau's previous experiences with the health system influenced your decision to attend Whānau Pakari? If yes, can you please describe how.
- Have you had any previous negative experiences with health providers that made you choose not to attend Whānau Pakari sessions? [Prompt: E.g. Experiences with doctors around your child's weight or other health concerns]

Previous experiences with societal stigma

- In your day-to-day life, have you ever been treated unfairly or discriminated against? If yes, can you tell me a bit more about this? Why do you think this happened?
- Have you ever witnessed or heard about other members of your whānau being treated unfairly or discriminated against for any reason? If yes, can you tell me a bit more about this?
- Do you think any of these experiences influenced your decisions or ability to attend, engage, participate or continue participation in Whānau Pakari?

Appendix E. Coding matrices

Survey coding matrix

Main code	Sub-code
Barriers	Age appropriate
	Suitability for family
	Sick family member
	Lack of time
	Lack of family support
	Other priorities
	Work
	Lack of transport
	Relocation out of region
	Distance to sessions
	Location
Facilitators	Family support
	Convenient
	Home-based
	Family-centred
	Child health / own health
	Transport available
	Location
	Programme deliverers
	Fun / social
	Non-judgemental/supportive/encouraging

Interview coding matrix

Main code	**Sub-code**
Ethnicity & ancestry	
Experience in society	
Experience in health system	Relationship with doctor
Discrimination/stigma	Weight
	Ethnicity/race
	Solo parent
Weight beliefs & terminology	
Appropriateness/suitability	Age appropriateness
Type of referral	CAMHS
	Paediatrician
	Hospital/secondary care referral
	B4 Schools Check
	GP
	School
	Other
Experience of referral	Positive
	Negative
	Neutral
Stigma of referral/attending Whānau Pakari	
Child or family health and wellbeing	
Mental health	
Challenges of healthy lifestyle change	
Logistics	
Personal/family factors	Income/cost
Whānau Pakari service/programme	Family focus
	Social aspects
	Location
	Home visits
	Service team/programme deliverers
	Perception of programme/service
	Programme content

References

1. Lobstein T, Baur L, Uauy R. Obesity in children and young people: a crisis in public health. Obes Rev. 2004;5 Suppl 1:4-104.

2. Han JC, Lawlor DA, Kimm SY. Childhood obesity. Lancet. 2010;375(9727):1737-48.

3. Baur LA, Hazelton B, Shrewsbury VA. Assessment and management of obesity in childhood and adolescence. Nat Rev Gastroenterol Hepatol. 2011;8(11):635-45.

4. OECD. OECD Factbook 2015-2016: Economic, environmental and social statistics. Paris (FR); 2016.

5. Twig G, Yaniv G, Levine H, Leiba A, Goldberger N, Derazne E, et al. Body-mass index in 2.3 million adolescents and cardiovascular death in adulthood. N Engl J Med. 2016;374(25):2430-40.

6. United Nations. State of the world's indigenous peoples. New York (US): United Nations Department of Economic and Social Affairs, Division for Social Policy and Development, Secretariat of the Permanent Forum on Indigenous Issues; 2009.

7. Anderson I, Robson B, Connolly M, Al-Yaman F, Bjertness E, King A, et al. Indigenous and tribal peoples' health (The Lancet-Lowitja Institute Global Collaboration): a population study. Lancet. 2016;388(10040):131-57.

8. Lovasi GS, Hutson MA, Guerra M, Neckerman KM. Built environments and obesity in disadvantaged populations. Epidemiol Rev. 2009;31(1):7-20.

9. UN General Assembly. United Nations Declaration on the Rights of Indigenous Peoples: resolution / adopted by the General Assembly New York (NY): United Nations; 2007 [updated 2007 October 02; cited 2020 February 26]. Available from: https://undocs.org/A/RES/61/295.

10. UNICEF. The State of the World's Children 2019. Children, Food and Nutrition: Growing well in a changing world. New York: UNICEF; 2019.

11. Ministry of Health. Tier 1 statistics 2018/2019: New Zealand Health Survey [Internet]. Wellington (NZ): Ministry of Health; 2019 [updated 2019 November; cited 2020 February 20]. Available from: https://minhealthnz.shinyapps.io/nz-health-survey-2018-19-annual-data-explorer/_w_104ecbf8/#!/home.

12. World Health Organization. Report of the Commission on Ending Childhood Obesity. Geneva (CH): World Health Organization; 2016.

13. Anderson YC, Wynter LE, Moller KR, Cave TL, Dolan GM, Grant CC, et al. The effect of a multi-disciplinary obesity intervention compared to usual practice in those ready to make lifestyle changes: design and rationale of Whanau Pakari. BMC Obes. 2015;2:41.

14. Anderson Y, Wynter L, Grant C, Cave T, Derraik J, Cutfield W, et al. A novel home-based intervention for child and adolescent obesity: the results of the Whānau Pakari randomized controlled trial. Obesity. 2017;25(11):1965-73.

15. Tamariki Pakari Child Health and Wellbeing Trust. Tamariki Pakari [Internet]. New Plymouth (NZ): Tamariki Pakari Child Health and Wellbeing Trust; 2019 [cited 2020 February 21]. Available from: https://www.tamarikipakari.org/.

16. Commission on Social Determinants of Health. Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health. Geneva (CH): World Health Organization; 2008.

17. Dahlgren G, Whitehead M. Policies and strategies to promote social equity in health. Stockholm (SE): Institute for Future Studies; 1991.

18. Mills C, Reid P, Vaithianathan R. The cost of child health inequalities in Aotearoa New Zealand: a preliminary scoping study. BMC Public Health. 2012;12(1):384.

19. Braveman P, Gruskin S. Defining equity in health. J Epidemiol Community Health. 2003;57(4):254-8.

20. Gluckman P, Nishtar S, Armstrong T. Ending childhood obesity: a multidimensional challenge. Lancet. 2015;385(9973):1048-50.

21. World Health Organization. Obesity and overweight [Internet]. 2018 [updated 2018 February 16; cited 2019 December 19]. Available from: https://www.who.int/en/news-room/fact-sheets/detail/obesity-and-overweight.

22. Abarca-Gómez L, Abdeen ZA, Hamid ZA, Abu-Rmeileh NM, Acosta-Cazares B, Acuin C, et al. Worldwide trends in body-mass index, underweight, overweight, and obesity from 1975 to 2016: a pooled analysis of 2416 population-based measurement studies in 128.9 million children, adolescents, and adults. Lancet. 2017;390(10113):2627-42.

23. World Health Organization. Global status report on noncommunicable diseases 2014. Geneva (CH): World Health Organization; 2014.

24. de Onis M, Blossner M, Borghi E. Global prevalence and trends of overweight and obesity among preschool children. Am J Clin Nutr. 2010;92(5):1257-64.

25. Swinburn BA, Kraak VI, Allender S, Atkins VJ, Baker PI, Bogard JR, et al. The Global Syndemic of Obesity, Undernutrition, and Climate Change: The Lancet Commission report. Lancet. 2019;393(10173):791-846.

26. World Health Organization Technical Consultation. Obesity: preventing and managing the global epidemic. Report of a WHO consultation 2000. Geneva (CH): World Health Organization; 2000.

27. Nambiar S, Hughes I, Davies PS. Developing waist-to-height ratio cut-offs to define overweight and obesity in children and adolescents. Public Health Nutr. 2010;13(10):1566-74.

28. World Health Organization. Physical status: The use of and interpretation of anthropometry, Report of a WHO Expert Committee. Geneva (CH): World Health Organization; 1995.

29. Lakshman R, Elks CE, Ong KK. Childhood obesity. Circulation. 2012;126(14):1770-9.

30. World Health Organization. Noncommunicable Diseases Progress Monitor, 2017. Geneva (CH): World Health Organization; 2017.

31. Dixon J, Omwega AM, Friel S, Burns C, Donati K, Carlisle R. The Health Equity Dimensions of Urban Food Systems. J Urban Health. 2007;84(Suppl 1):118-29.

32. Friel S, Chopra M, Satcher D. Unequal weight: equity oriented policy responses to the global obesity epidemic. BMJ. 2007;335(7632):1241-3.

33. Swinburn BA, Sacks G, Hall KD, McPherson K, Finegood DT, Moodie ML, et al. The global obesity pandemic: shaped by global drivers and local environments. Lancet. 2011;378(9793):804-14.

34. Singh AS, Mulder C, Twisk JW, van Mechelen W, Chinapaw MJ. Tracking of childhood overweight into adulthood: a systematic review of the literature. Obes Rev. 2008;9(5):474-88.

35. Serdula MK, Ivery D, Coates RJ, Freedman DS, Williamson DF, Byers T. Do obese children become obese adults? A review of the literature. Prev Med. 1993;22(2):167-77.

36. World Health Organization. Consideration of the evidence on childhood obesity for the Commission on Ending Childhood Obesity: report of the Ad hoc Working Group on Science and Evidence for Ending Childhood Obesity. Geneva (CH): World Health Organization; 2016.

37. Must A, Jacques PF, Dallal GE, Bajema CJ, Dietz WH. Long-term morbidity and mortality of overweight adolescents. A follow-up of the Harvard Growth Study of 1922 to 1935. N Engl J Med. 1992;327(19):1350-5.

38. Choudhary AK, Donnelly LF, Racadio JM, Strife JL. Diseases associated with childhood obesity. AJR Am J Roentgenol. 2007;188(4):1118-30.

39. Williams J, Wake M, Hesketh K, Maher E, Waters E. Health-related quality of life of overweight and obese children. JAMA. 2005;293(1):70-6.

40. Quek YH, Tam WWS, Zhang MWB, Ho RCM. Exploring the association between childhood and adolescent obesity and depression: a meta-analysis. Obes Rev. 2017;18(7):742-54.

41. Griffiths L, Parsons T, Hill A. Self-esteem and quality of life in obese children and adolescents: a systematic review. Int J Pediatr Obes. 2010;5(4):282-304.

42. Puhl RM, Latner JD. Stigma, obesity, and the health of the nation's children. Psychol Bull. 2007;133(4):557-80.

43. Farrant B, Utter J, Ameratunga S, Clark T, Fleming T, Denny S. Prevalence of Severe Obesity among New Zealand Adolescents and Associations with Health Risk Behaviors and Emotional Well-Being. J Pediatr. 2013;163(1):143-9.

44. Puhl RM, Heuer CA. The Stigma of Obesity: A Review and Update. Obesity. 2009;17(5):941-64.

45. Kirk SF, Price SL, Penney TL, Rehman L, Lyons RF, Piccinini-Vallis H, et al. Blame, shame, and lack of support: a multilevel study on obesity management. Qual Health Res. 2014;24(6):790-800.

46. Kim SH, Willis LA. Talking about obesity: news framing of who is responsible for causing and fixing the problem. J Health Commun. 2007;12(4):359-76.

47. Lawrence RG. Framing obesity: the evolution of news discourse on a public health issue. Harvard International Journal of Press/Politics. 2004;9(3):56-75.

48. Puhl R, Brownell KD. Bias, discrimination, and obesity. Obes Res. 2001;9(12):788-805.

49. Brownell KD, Puhl RM, Schwartz MB, Rudd L, editors. Weight bias: nature, consequences, and remedies. New York (US): Guilford Publications; 2005.

50. O'Brien KS, Hunter JA, Banks M. Implicit anti-fat bias in physical educators: physical attributes, ideology and socialization. Int J Obes. 2007;31:308.

51. Ramos Salas X, Forhan M, Caulfield T, Sharma AM, Raine K. A critical analysis of obesity prevention policies and strategies. Can J Public Health. 2018;108(5-6):e598-e608.

52. Sutin AR, Stephan Y, Terracciano A. Weight discrimination and risk of mortality. Psychol Sci. 2015;26(11):1803-11.

53. Tremmel M, Gerdtham UG, Nilsson PM, Saha S. Economic burden of obesity: a systematic literature review. Int J Environ Res Public Health. 2017;14(4).

54. Specchia ML, Veneziano MA, Cadeddu C, Ferriero AM, Mancuso A, Ianuale C, et al. Economic impact of adult obesity on health systems: a systematic review. Eur J Public Health. 2015;25(2):255-62.

55. Dee A, Kearns K, O'Neill C, Sharp L, Staines A, O'Dwyer V, et al. The direct and indirect costs of both overweight and obesity: a systematic review. BMC Res Notes. 2014;7:242.

56. Dobbs R, Sawers, C., Thompson, F., Manyika, J., Woetzel, J.R., Child, P., McKenna, S., Spatharou, A. Overcoming obesity: an initial economic analysis. Jakarta (ID): McKinsey Global Institute; 2014.

57. Bloom D, Cafiero E, Jane-Llopis E, Abrahams-Gessel S, Bloom L, Fathima S, et al. The Global Economic Burden of Noncommunicable Diseases. Geneva (CH): World Economic Forum; 2011.

58. Ministry of Health. Neighbourhood deprivation [Internet]. Wellington (NZ): Ministry of Health; 2018 [updated 2018 August 02; cited 2020 February 19]. Available from: https://www.health.govt.nz/our-work/populations/maori-health/tatau-kahukura-maori-health-statistics/nga-awe-o-te-hauora-socioeconomic-determinants-health/neighbourhood-deprivation.

59. Marmot M. Social determinants of health inequalities. Lancet. 2005;365(9464):1099-104.

60. Stephens C, Nettleton C, Porter J, Willis R, Clark S. Indigenous peoples' health—why are they behind everyone, everywhere? Lancet. 2005;366(9479):10-3.

61. Anderson I, Crengle S, Kamaka M, Chen T-H, Palafox N, Jackson-Pulver L. Indigenous health in Australia, New Zealand, and the Pacific. Lancet. 2002;367(9524):1775-85.

62. Bramley D, Hebert P, Tuzzio L, Chassin M. Disparities in Indigenous health: a cross-country comparison between New Zealand and the United States. Am J Public Health. 2005;95(5):844-50.

63. Gracey M, King M. Indigenous health part 1: determinants and disease patterns. Lancet. 2009;374(9683):65-75.

64. Indigenous Peoples and Poverty: An International Perspective. London: Zed Books; 2005.

65. Smylie J, Adomako P. Indigenous Children's Health Report: Health Assessment in Action. Toronto (ON): St. Michael’s Hospital; 2009.

66. Australian Institute of Health and Welfare. A picture of overweight and obesity in Australia 2017. Canberra (AU): AIHW; 2017.

67. Pearce N, Foliaki S, Sporle A, Cunningham C. Genetics, race, ethnicity, and health. BMJ. 2004;328(7447):1070-2.

68. PHG Foundation. Genomics of Obesity: The Application of Public Health Genomics to the Prevention and Management of Obesity in the UK. Cambridge (UK): PHG Foundation; 2013.

69. Krieger N. Epidemiology and the web of causation: Has anyone seen the spider? Soc Sci Med. 1994;39(7):887-903.

70. King M, Smith A, Gracey M. Indigenous health part 2: the underlying causes of the health gap. Lancet. 2009;374(9683):76-85.

71. Durie MH. The health of indigenous peoples. BMJ. 2003;326(7388):510-1.

72. Jones CP. Invited commentary: “race,” racism, and the practice of epidemiology. Am J Epidemiol. 2001;154(4):299-304.

73. Statistics New Zealand. Census 2018: Ethnic group (detailed single and combination) by age and sex, for the census usually resident population count, 2013 and 2018 Censuses (RC, TA, SA2, DHB) [Internet]. Wellington (NZ): Statistics New Zealand; 2018 [cited 2020 February 13]. Available from: http://nzdotstat.stats.govt.nz/wbos/Index.aspx?DataSetCode=TABLECODE8277&_ga=2.92833245.1767426386.1581458380-841211100.1581458380#.

74. Robson B, Harris R. Hauora: Māori Standards of Health IV: A study of the years 2000–2005. Wellington (NZ): Te Rōpū Rangahau Hauora a Eru Pōmare; 2007. Report No.: 978-0-9583608-1-4.

75. Ministry of Health. Wai 2575 Māori health trends report. Wellington (NZ): Ministry of Health; 2019.

76. Key J. National Govt to support UN rights declaration. Beehiveorgnz2010.

77. UN Permanent Forum on Indigenous Issues. Report on the twelfth session (20-31 May 2013) [Internet]. New York (NY): United Nations; 2013 [cited 2020 February 28]. Available from: https://undocs.org/E/C.19/2013/25.

78. Orange C. The Treaty of Waitangi. Wellington (NZ): Bridget Williams Books; 1987.

79. Kingi TK. The Treaty of Waitangi: a framework for Maori health development. New Zealand Journal of Occupational Therapy. 2007;54(1):4-10.

80. Waitangi Tribunal. Hauora: report on stage one of the Health Services and Outcomes Kaupapa Inquiry. Wellington (NZ): Waitangi Tribunal; 2019.

81. Janicke DM, Steele RG, Gayes LA, Lim CS, Clifford LM, Schneider EM, et al. Systematic review and meta-analysis of comprehensive behavioral family lifestyle interventions addressing pediatric obesity. J Pediatr Psychol. 2014;39(8):809-25.

82. Oude Luttikhuis H, Baur L, Jansen H, Shrewsbury VA, O'Malley C, Stolk RP, et al. Interventions for treating obesity in children. Cochrane Database Syst Rev. 2009(1):Cd001872.

83. Colquitt JL, Loveman E, O'Malley C, Azevedo LB, Mead E, Al-Khudairy L, et al. Diet, physical activity, and behavioural interventions for the treatment of overweight or obesity in preschool children up to the age of 6 years. Cochrane Database Syst Rev. 2016(3):Cd012105.

84. Mead E, Brown T, Rees K, Azevedo LB, Whittaker V, Jones D, et al. Diet, physical activity and behavioural interventions for the treatment of overweight or obese children from the age of 6 to 11 years. Cochrane Database Syst Rev. 2017;6:Cd012651.

85. Al-Khudairy L, Loveman E, Colquitt JL, Mead E, Johnson RE, Fraser H, et al. Diet, physical activity and behavioural interventions for the treatment of overweight or obese adolescents aged 12 to 17 years. Cochrane Database Syst Rev. 2017;6:Cd012691.

86. Grossman DC, Bibbins-Domingo K, Curry SJ, Barry MJ, Davidson KW, Doubeni CA, et al. Screening for obesity in children and adolescents: US Preventive Services Task Force recommendation statement. JAMA. 2017;317(23):2417-26.

87. O'Connor EA, Evans CV, Burda BU, Walsh ES, Eder M, Lozano P. Screening for obesity and intervention for weight management in children and adolescents: evidence report and systematic review for the US Preventive Services Task Force. JAMA. 2017;317(23):2427-44.

88. Salvy SJ, de la Haye K, Galama T, Goran MI. Home visitation programs: an untapped opportunity for the delivery of early childhood obesity prevention. Obes Rev. 2017;18(2):149-63.

89. Appelhans BM, Moss OA, Cerwinske LA. Systematic review of paediatric weight management interventions delivered in the home setting. Obes Rev. 2016;17(10):977-88.

90. Ho M, Garnett SP, Baur L, Burrows T, Stewart L, Neve M, et al. Effectiveness of lifestyle interventions in child obesity: systematic review with meta-analysis. Pediatrics. 2012;130(6):e1647-71.

91. Reinehr T, Lass N, Toschke C, Rothermel J, Lanzinger S, Holl RW. Which amount of BMI-SDS reduction is necessary to improve cardiovascular risk factors in overweight children? J Clin Endocrinol Metab. 2016;101(8):3171-9.

92. Birch L, Perry R, Hunt LP, Matson R, Chong A, Beynon R, et al. What change in body mass index is associated with improvement in percentage body fat in childhood obesity? A meta-regression. BMJ Open. 2019;9(8):e028231.

93. Birch L, Perry R, Penfold C, Beynon R, Hamilton-Shield J. What change in body mass index is needed to improve metabolic health status in childhood obesity: protocol for a systematic review. Systematic reviews. 2016;5(1):120-.

94. Armstrong SC, Skinner AC. Defining “success” in childhood obesity interventions in primary care. Pediatrics. 2016;138(4):e20162497.

95. Cole TJ. A chart to link child centiles of body mass index, weight and height. Eur J Clin Nutr. 2002;56(12):1194-9.

96. Flegal KM, Wei R, Ogden CL, Freedman DS, Johnson CL, Curtin LR. Characterizing extreme values of body mass index-for-age by using the 2000 Centers for Disease Control and Prevention growth charts. Am J Clin Nutr. 2009;90(5):1314-20.

97. Epstein LH, Valoski A, Wing RR, McCurley J. Ten-year outcomes of behavioral family-based treatment for childhood obesity. Health Psychol. 1994;13(5):373-83.

98. Peterson CM, Su H, Thomas DM, Heo M, Golnabi AH, Pietrobelli A, et al. Tri-ponderal mass index vs body mass index in estimating body fat during adolescence. JAMA Pediatr. 2017;171(7):629-36.

99. Vanderwall C, Randall Clark R, Eickhoff J, Carrel AL. BMI is a poor predictor of adiposity in young overweight and obese children. BMC Pediatr. 2017;17(1):135.

100. Steinbeck KS, Lister NB, Gow ML, Baur LA. Treatment of adolescent obesity. Nat Rev Endocrinol. 2018;14(6):331-44.

101. Geserick M, Vogel M, Gausche R, Lipek T, Spielau U, Keller E, et al. Acceleration of BMI in early childhood and risk of sustained obesity. N Engl J Med. 2018;379(14):1303-12.

102. Warbrick I, Came H, Dickson A. The shame of fat shaming in public health: moving past racism to embrace indigenous solutions. Public Health. 2018;176:128-32.

103. Savoye M, Nowicka P, Shaw M, Yu S, Dziura J, Chavent G, et al. Long-term results of an obesity program in an ethnically diverse pediatric population. Pediatrics. 2011;127(3):402-10.

104. Kokkvoll A, Grimsgaard S, Steinsbekk S, Flægstad T, Njølstad I. Health in overweight children: 2-year follow-up of Finnmark Activity School - a randomised trial. Arch Dis Child. 2015;100(5):441-8.

105. Jiang JX, Xia XL, Greiner T, Lian GL, Rosenqvist U. A two year family based behaviour treatment for obese children. Arch Dis Child. 2005;90(12):1235-8.

106. Taylor RW, Cox A, Knight L, Brown DA, Meredith-Jones K, Haszard JJ, et al. A tailored family-based obesity intervention: a randomized trial. Pediatrics. 2015;136(2):281-9.

107. Kalarchian MA, Levine MD, Arslanian SA, Ewing LJ, Houck PR, Cheng Y, et al. Family-based treatment of severe pediatric obesity: randomized, controlled trial. Pediatrics. 2009;124(4):1060-8.

108. Jones RA, Sinn N, Campbell KJ, Hesketh K, Denney-Wilson E, Morgan PJ, et al. The importance of long-term follow-up in child and adolescent obesity prevention interventions. Int J Pediatr Obes. 2011;6(3-4):178-81.

109. Epstein LH, McCurley J, Wing RR, Valoski A. Five-year follow-up of family-based behavioral treatments for childhood obesity. J Consult Clin Psychol. 1990;58(5):661-4.

110. Epstein LH, Paluch RA, Roemmich JN, Beecher MD. Family-based obesity treatment, then and now: twenty-five years of pediatric obesity treatment. Health Psychol. 2007;26(4):381-91.

111. Vignolo M, Rossi F, Bardazza G, Pistorio A, Parodi A, Spigno S, et al. Five-year follow-up of a cognitive-behavioural lifestyle multidisciplinary programme for childhood obesity outpatient treatment. Eur J Clin Nutr. 2008;62(9):1047-57.

112. Reinehr T, Bucksch J, Muller A, Finne E, Kolip P. 7-Year follow-up of a lifestyle intervention in overweight children: Comparison to an untreated control group. Clin Nutr. 2018;37(5):1558-62.

113. Wen LM, Baur LA, Simpson JM, Xu H, Hayes AJ, Hardy LL, et al. Sustainability of effects of an early childhood obesity prevention trial over time: a further 3-year follow-up of the Healthy Beginnings Trial. JAMA Pediatr. 2015;169(6):543-51.

114. Liu S, Marques IG, Perdew MA, Strange K, Hartrick T, Weismiller J, et al. Family-based, healthy living intervention for children with overweight and obesity and their families: a ‘real world’ trial protocol using a randomised wait list control design. BMJ Open. 2019;9(10):e027183.

115. Li G, Zhang P, Wang J, Gregg EW, Yang W, Gong Q, et al. The long-term effect of lifestyle interventions to prevent diabetes in the China Da Qing Diabetes Prevention Study: a 20-year follow-up study. Lancet. 2008;371(9626):1783-9.

116. Anderson YC, Wynter LE, Treves KF, Grant CC, Stewart JM, Cave TL, et al. Prevalence of comorbidities in obese New Zealand children and adolescents at enrolment in a community-based obesity programme. J Paediatr Child Health. 2016;52(12):1099-105.

117. Ministry of Health. Understanding excess body weight: New Zealand Health Survey. Wellington (NZ): Ministry of Health; 2015.

118. Atkinson J, Salmond C, Crampton P. NZDep2013 Index of Deprivation. Wellington (NZ): Department of Public Health, University of Otago; 2014.

119. Lal A, Moodie M, Ashton T, Siahpush M, Swinburn B. Health care and lost productivity costs of overweight and obesity in New Zealand. Aust N Z J Public Health. 2012;36(6):550-6.

120. Ministry of Health and Clinical Trials Research Unit. Guidelines for weight management in New Zealand children and young people. Wellington (NZ): Ministry of Health; 2009.

121. Ministry of Health. Clinical guidelines for weight management in New Zealand children and young people. Wellington (NZ): Ministry of Health; 2016.

122. Ministry of Health. Active Families [Internet]. 2020 [updated 2020 February 14; cited 2020 February 25]. Available from: https://www.health.govt.nz/your-health/healthy-living/food-activity-and-sleep/green-prescriptions/active-families.

123. Anderson YC, Taylor GM, Grant CC, Fulton RB, Hofman PL. The Green Prescription Active Families programme in Taranaki, New Zealand 2007-2009: Did it reach children in need? J Prim Health Care. 2015;7(3):192-7.

124. Controller and Auditor-General. Evolving approach to combating child obesity. Wellington (NZ): Office of the Auditor-General; 2013.

125. Ministry of Health. Childhood Obesity Plan [Internet]. Wellington (NZ): Ministry of Health; 2015 [updated 2019 April 24; cited 2019 November 12]. Available from: https://www.health.govt.nz/our-work/diseases-and-conditions/obesity/childhood-obesity-plan.

126. Ministry of Health. Health targets: Raising healthy kids [Internet]. Wellington (NZ): Ministry of Health; 2016 [updated 2018 August 10; cited 2019 December 21]. Available from: https://www.health.govt.nz/new-zealand-health-system/health-targets/about-health-targets/health-targets-raising-healthy-kids.

127. The Royal New Zealand College of General Practitioners. The Royal New Zealand College of General Practitioners 2018 general practice workforce survey. Wellington (NZ): The Royal New Zealand College of General Practitioners; 2019.

128. Anderson YC, Cave TL, Cunningham VJ, Pereira NM, Woolerton DM, Grant CC, et al. Effectiveness of current interventions in obese New Zealand children and adolescents. N Z Med J. 2015;128(1417):8-15.

129. Anderson Y. Whānau Pakari: a multi-disciplinary intervention for children and adolescents with weight issues [PhD thesis]. Auckland (NZ): University of Auckland; 2018.

130. Ministry of Health. Fact Sheet 6: Plotting and assessing infants and toddlers up to age five years. Wellington (NZ): Ministry of Health; 2010.

131. Glover M, Kira A, Johnston V, Walker N, Thomas D, Chang AB, et al. A systematic review of barriers and facilitators to participation in randomized controlled trials by Indigenous people from New Zealand, Australia, Canada and the United States. Glob Health Promot. 2014;0(0):1757.

132. Statistics New Zealand. 2013 Census QuickStats about a place: Taranaki Region [Internet]. Wellington (NZ): Statistics New Zealand; 2014 [cited 2017 June 20]. Available from: http://archive.stats.govt.nz/Census/2013-census/profile-and-summary-reports/quickstats-about-a-place.aspx?request_value=14110&tabname=#.

133. Anderson YC, Wynter LE, Grant CC, Stewart JM, Cave TL, Wild CEK, et al. Physical activity is low in obese New Zealand children and adolescents. Sci Rep. 2017;7:41822.

134. Anderson YC, Wynter LE, Butler MS, Grant CC, Stewart JM, Cave TL, et al. Dietary intake and eating behaviours of obese New Zealand children and adolescents enrolled in a community-based intervention programme. PLoS ONE. 2016;11(11):e0166996.

135. Anderson YC, Wynter LE, Treves KF, Grant CC, Stewart JM, Cave TL, et al. Assessment of health-related quality of life and psychological well-being of children and adolescents with obesity enrolled in a New Zealand community-based intervention programme: an observational study. BMJ Open. 2017;7(8):e015776.

136. Anderson Y, Wynter L, O'Sullivan N, Wild C, Grant C, Cave T, et al. Two-year outcomes of Whānau Pakari: a novel home-based intervention for child and adolescent obesity. Horm Res Paediatr. 2019;91(suppl 1):152.

137. Anderson Y, Wild C, Hofman P, Cave T, Dommett T, Derraik J, et al. Participant and caregivers' experiences of a multi-disciplinary programme for healthy lifestyle change in Aotearoa/New Zealand. Health Promotion International. 2019;In Review.

138. Anderson YC, Leung W, Grant CC, Cave TL, Derraik JGB, Cutfield WS, et al. Economic evaluation of a multi-disciplinary community-based intervention programme for New Zealand children and adolescents with obesity. Obes Res Clin Pract. 2018;12(3):293-8.

139. Taranaki District Health Board. Whānau Pakari programme attracts international speakers [Internet]. New Plymouth (NZ): Taranaki District Health Board; 2019 [updated 2019 December 12; cited 2020 February 28]. Available from: https://www.tdhb.org.nz/news/documents/media_release_2019_12_12.shtml.

140. Skelton JA, Beech BM. Attrition in paediatric weight management: a review of the literature and new directions. Obes Rev. 2011;12(5):e273-81.

141. Kelleher E, Davoren MP, Harrington JM, Shiely F, Perry IJ, McHugh SM. Barriers and facilitators to initial and continued attendance at community-based lifestyle programmes among families of overweight and obese children: a systematic review. Obes Rev. 2017;18(2):183-94.

142. Kelleher E, McHugh SM, Harrington JM, Perry IJ, Shiely F. Understanding engagement in a family-focused, multicomponent, childhood weight management programme delivered in the community setting. Public Health Nutr. 2019;22(8):1471-82.

143. Marmot M. Social determinants and the health of Indigenous Australians. Med J Aust. 2011;194(10):512-3.

144. Waters E, de Silva-Sanigorski A, Burford BJ, Brown T, Campbell KJ, Gao Y, et al. Interventions for preventing obesity in children. Cochrane Database Syst Rev. 2011(12).

145. Fleary SA, Freund KM. Social disparities in obesogenic behaviors in adolescents. J Racial Ethn Health Disparities. 2018;5(1):24-33.

146. Ebbeling CB, Feldman HA, Chomitz VR, Antonelli TA, Gortmaker SL, Osganian SK, et al. A randomized trial of sugar-sweetened beverages and adolescent body weight. N Engl J Med. 2012;367(15):1407-16.

147. Gortmaker SL, Peterson K, Wiecha J, Sobol AM, Dixit S, Fox MK, et al. Reducing obesity via a school-based interdisciplinary intervention among youth: Planet Health. Arch Pediatr Adolesc Med. 1999;153(4):409-18.

148. Plachta-Danielzik S, Pust S, Asbeck I, Czerwinski-Mast M, Langnase K, Fischer C, et al. Four-year follow-up of school-based intervention on overweight children: the KOPS study. Obesity (Silver Spring). 2007;15(12):3159-69.

149. Webber LS, Catellier DJ, Lytle LA, Murray DM, Pratt CA, Young DR, et al. Promoting physical activity in middle school girls: trial of activity for adolescent girls. Am J Prev Med. 2008;34(3):173-84.

150. Williams SL, Van Lippevelde W, Magarey A, Moores CJ, Croyden D, Esdaile E, et al. Parent engagement and attendance in PEACH™ QLD – an up-scaled parent-led childhood obesity program. BMC Public Health. 2017;17:559.

151. Moore KG, Bailey JH. Parental perspectives of a childhood obesity intervention in Mississippi: a phenomenological study. The Qualitative Report. 2013;18(48).

152. Newson L, Povey R, Casson A, Grogan S. The experiences and understandings of obesity: families' decisions to attend a childhood obesity intervention. Psychol Health. 2013;28(11):1287-305.

153. Banks J, Cramer H, Sharp DJ, Shield JP, Turner KM. Identifying families' reasons for engaging or not engaging with childhood obesity services: A qualitative study. J Child Health Care. 2014;18(2):101-10.

154. Zambas SI, Wright J. Impact of colonialism on Maori and Aboriginal healthcare access: a discussion paper. Contemp Nurse. 2016;52(4):398-409.

155. Roberson NL. Clinical trial participation. Viewpoints from racial/ethnic groups. Cancer. 1994;74(9 Suppl):2687-91.

156. Jansen P, Bacal K, Crengle S. He Ritenga Whakaaro: Māori experiences of health services. Auckland (NZ): Mauri Ora Associates; 2008.

157. Ligthart KAM, Buitendijk L, Koes BW, van Middelkoop M. The association between ethnicity, socioeconomic status and compliance to pediatric weight-management interventions - A systematic review. Obes Res Clin Pract. 2017;11(5s1):1-51.

158. Fagg J, Cole TJ, Cummins S, Goldstein H, Morris S, Radley D, et al. After the RCT: who comes to a family-based intervention for childhood overweight or obesity when it is implemented at scale in the community? J Epidemiol Community Health. 2015;69(2):142-8.

159. O'Connor TM, Hilmers A, Watson K, Baranowski T, Giardino AP. Feasibility of an obesity intervention for paediatric primary care targeting parenting and children: Helping HAND. Child Care Health Dev. 2013;39(1):141-9.

160. Welsby D, Nguyen B, O'Hara BJ, Innes-Hughes C, Bauman A, Hardy LL. Process evaluation of an up-scaled community based child obesity treatment program: NSW Go4Fun®. BMC Public Health. 2014;14:140.

161. Jeffery AN, Voss LD, Metcalf BS, Alba S, Wilkin TJ. Parents' awareness of overweight in themselves and their children: cross sectional study within a cohort (EarlyBird 21). BMJ. 2004;330(7481):23-4.

162. Campbell MW, Williams J, Hampton A, Wake M. Maternal concern and perceptions of overweight in Australian preschool-aged children. Med J Aust. 2006;184(6):274-7.

163. Rietmeijer-Mentink M, Paulis WD, van Middelkoop M, Bindels PJ, van der Wouden JC. Difference between parental perception and actual weight status of children: a systematic review. Matern Child Nutr. 2013;9(1):3-22.

164. Doolen J, Alpert PT, Miller SK. Parental disconnect between perceived and actual weight status of children: a metasynthesis of the current research. J Am Acad Nurse Pract. 2009;21(3):160-6.

165. Towns N, D'Auria J. Parental perceptions of their child's overweight: an integrative review of the literature. J Pediatr Nurs. 2009;24(2):115-30.

166. Parry LL, Netuveli G, Parry J, Saxena S. A systematic review of parental perception of overweight status in children. J Ambul Care Manage. 2008;31(3):253-68.

167. Perry RA, Daniels LA, Bell L, Magarey AM. Facilitators and barriers to the achievement of healthy lifestyle goals: qualitative findings from Australian parents enrolled in the PEACH Child Weight Management Program. J Nutr Educ Behav. 2017;49(1):43-52.e1.

168. Parkinson KN, Reilly JJ, Basterfield L, Reilly JK, Janssen X, Jones AR, et al. Mothers' perceptions of child weight status and the subsequent weight gain of their children: a population-based longitudinal study. Int J Obes. 2017;41(5):801-6.

169. Jeffery AN, Metcalf BS, Hosking J, Mostazir MB, Voss LD, Wilkin TJ. Awareness of body weight by mothers and their children: repeated measures in a single cohort (EarlyBird 64). Child Care Health Dev. 2015;41(3):434-42.

170. Reath J, Carey M. Breast and cervical cancer in indigenous women-overcoming barriers to early detection. Aust Fam Physician. 2008;37(3):178-82.

171. McBain-Rigg KE, Veitch C. Cultural barriers to health care for Aboriginal and Torres Strait Islanders in Mount Isa. Aust J Rural Health. 2011;19(2):70-4.

172. Tripp-Reimer T, Choi E, Kelley LS, Enslein JC. Cultural barriers to care: inverting the problem. Diabetes Spectr. 2001;14(1):13-22.

173. Marrone S. Understanding barriers to health care: a review of disparities in health care services among indigenous populations. Int J Circumpolar Health. 2007;66(3):188-98.

174. Hayman NE, White NE, Spurling GK. Improving Indigenous patients' access to mainstream health services: the Inala experience. Med J Aust. 2009;190(10):604-6.

175. Sushames A, Engelberg T, Gebel K. Perceived barriers and enablers to participation in a community-tailored physical activity program with Indigenous Australians in a regional and rural setting: a qualitative study. Int J Equity Health. 2017;16(1):172.

176. Peiris D, Brown A, Cass A. Addressing inequities in access to quality health care for indigenous people. CMAJ. 2008;179(10):985-6.

177. Gibson O, Lisy K, Davy C, Aromataris E, Kite E, Lockwood C, et al. Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: a systematic review. Implement Sci. 2015.

178. Teevale T, Taufa S, Percival T. Acceptability and non-compliance in a family-led weight-management programme for obese Pacific children. Public Health Nutr. 2015;18(14):2625-33.

179. Nelson AR. Unequal treatment: report of the Institute of Medicine on racial and ethnic disparities in healthcare. Ann Thorac Surg. 2003;76(4):S1377-81.

180. World Health Organization. Mapping the health system response to childhood obesity in the WHO European Region: An overview and country perspectives. Copenhagen (DK): World Health Organization; 2019.

181. Blair N. A stock-take of interventions and programmes aimed at childhood obesity prevention and management in New Zealand. Wellington (NZ): Ministry of Health; 2004.

182. Cormack D, Robson B, Purdie G, Ratima M, Brown R. Access to cancer services for Māori: a report prepared for the Ministry of Health. Wellington (NZ): Wellington School of Medicine and Health Sciences; 2005.

183. Ellison-Loschmann L, Pearce N. Improving access to health care among New Zealand's Maori population. Am J Public Health. 2006;96(4):612-7.

184. Bell R, Smith C, Hale L, Kira G, Tumilty S. Understanding obesity in the context of an Indigenous population — a qualitative study. Obes Res Clin Pract. 2017;11(5):558-66.

185. Sabin JA, Marini M, Nosek BA. Implicit and explicit anti-fat bias among a large sample of medical doctors by BMI, race/ethnicity and gender. PLoS ONE. 2012;7(11):e48448.

186. Sabin JA, Moore K, Noonan C, Lallemand O, Buchwald D. Clinicians' implicit and explicit attitudes about weight and race and treatment approaches to overweight for American Indian children. Childhood obesity (Print). 2015;11(4):456-65.

187. Drury CA, Louis M. Exploring the association between body weight, stigma of obesity, and health care avoidance. J Am Acad Nurse Pract. 2002;14(12):554-61.

188. Puhl RM, Peterson JL, Luedicke J. Parental perceptions of weight terminology that providers use with youth. Pediatrics. 2011;128(4):e786-93.

189. Smith KL, Straker LM, McManus A, Fenner AA. Barriers and enablers for participation in healthy lifestyle programs by adolescents who are overweight: a qualitative study of the opinions of adolescents, their parents and community stakeholders. BMC Pediatr. 2014;14(1):53.

190. Grimes-Robison C, Evans RR. Benefits and barriers to medically supervised pediatric weight-management programs. J Child Health Care. 2008;12(4):329-43.

191. Booth AL, Carroll N. Economic status and the Indigenous/non-Indigenous health gap. Economics Letters. 2008;99(3):604-6.

192. Schoen C, Doty MM. Inequities in access to medical care in five countries: findings from the 2001 Commonwealth Fund International Health Policy Survey. Health Policy. 2004;67(3):309-22.

193. Bolitho S, Huntington A. Experiences of Maori families accessing health care for their unwell children: a pilot study. Nurs Prax N Z. 2006;22(1):23-32.

194. Jatrana S, Crampton P. Primary health care in New Zealand: who has access? Health Policy. 2009;93(1):1-10.

195. Shahid S, Finn L, Bessarab D, Thompson SC. 'Nowhere to room ... nobody told them': logistical and cultural impediments to Aboriginal peoples' participation in cancer treatment. Aust Health Rev. 2011;35(2):235-41.

196. Jones CP. Levels of racism: a theoretic framework and a gardener's tale. Am J Public Health. 2000;90(8):1212-5.

197. Kritharides L, Brown A, Brieger D, Ridell T, Zeitz C, Jeremy R, et al. Overview and determinants of cardiovascular disease in indigenous populations. Heart Lung Circ. 2010;19(5-6):337-43.

198. Harris R, Cormack D, Tobias M, Yeh LC, Talamaivao N, Minster J, et al. The pervasive effects of racism: experiences of racial discrimination in New Zealand over time and associations with multiple health domains. Soc Sci Med. 2012;74(3):408-15.

199. Paradies Y, Ben J, Denson N, Elias A, Priest N, Pieterse A, et al. Racism as a determinant of health: a systematic review and meta-analysis. PLoS ONE. 2015;10(9):e0138511.

200. Clair M, Denis JS. Sociology of Racism. In: Wright JD, editor. International encyclopedia of the social & behavioral sciences. 2nd ed. Oxford: Elsevier; 2015. p. 857-63.

201. Ziersch A, Gallaher G, Baum F, Bentley M. Racism, social resources and mental health for Aboriginal people living in Adelaide. Aust N Z J Public Health. 2011;35(3):231-7.

202. Paradies Y. A review of psychosocial stress and chronic disease for 4th world indigenous peoples and African Americans. Ethn Dis. 2006;16(1):295-308.

203. Manhire-Heath R, Cormack D, Wyeth E. '…but I just prefer to treat everyone the same…': general practice receptionists talking about health inequities. Aust J Prim Health. 2019;25(5):430-4.

204. National Health and Medical Research Council. Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research. Canberra (AU): Commonwealth of Australia; 2003.

205. Curtis E, Jones R, Tipene-Leach D, Walker C, Loring B, Paine S-J, et al. Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. Int J Equity Health. 2019;18(1):174.

206. Coup A. Cultural safety and culturally congruent care: a comparative analysis of Irihapeti Ramsden's and Madeleine Leininger's educational projects for practice. Nurs Prax N Z. 1996;11(1):4-11.

207. Leininger M. Leininger's critique response to Coup's article on cultural safety (Ramsden) and culturally congruent care (Leininger) for practice. Nurs Prax N Z. 1997;12(1):17-23.

208. Clarke M. Preface. In: Wepa D, editor. Cultural safety in Aotearoa New Zealand Auckland (NZ): Pearson Education New Zealand; 2005. p. v-vii.

209. Papps E. Cultural safety: Daring to be different. In: Wepa D, editor. Cultural Safety in Aotearoa New Zealand. Auckland: Pearson Education New Zealand; 2005. p. 20-8.

210. Airini DB, Curtis E, Johnson O, Luatua F, O'Shea M, Rakena TO, et al. Success for all: improving Māori and Pasifika student success in degree-level studies. Auckland (NZ): University of Auckland; 2009.

211. Nicholls R. Research and Indigenous participation: critical reflexive methods. Int J Soc Res Methodol. 2009;12(2):117-26.

212. Minister of Health. New Zealand Health Strategy: Future direction. Wellington (NZ): Ministry of Health; 2016.

213. Ministry of Business, Innovation, and Employment and Ministry of Health. New Zealand Health Research Strategy: 2017-2027. Wellington (NZ): Ministry of Business, Innovation and Employment and Ministry of Health; 2017.

214. Reid P, Paine SJ, Curtis E, Jones R, Anderson A, Willing E, et al. Achieving health equity in Aotearoa: strengthening responsiveness to Māori in health research. N Z Med J. 2017;130(1465):96-103.

215. Health Research Council of New Zealand. Guidelines for Researchers on Health Research Involving Māori. Auckland (NZ): Health Research Council of New Zealand; 2010.

216. Health Research Council of New Zealand. Māori Health Advancement Guidelines. Auckland (NZ): Health Research Council of New Zealand; 2019.

217. Grant BM, Giddings LS. Making sense of methodologies: a paradigm framework for the novice researcher. Contemp Nurse. 2002;13(1):10-28.

218. Grosfoguel R. The structure of knowledge in Westernized universities: epistemic racism/sexism and the four genocides/epistemicides of the long 16th century. Human Architecture: Journal of the Sociology of Self-Knowledge. 2013;11(1):73-91.

219. Lincoln YS, Guba EG. Naturalistic inquiry. Beverly Hills (CA): SAGE Publications, Inc; 1985.

220. Smith G. Kaupapa Māori: Theory and praxis [PhD dissertation]. Auckland (NZ): University of Auckland; 1997.

221. Valencia RR, editor. The Evolution of Deficit Thinking: Educational Thought and Practice. London (UK): Routledge; 1997.

222. Barnes HM. Kaupapa Maori: explaining the ordinary. Pac Health Dialog. 2000;7(1):13-6.

223. Curtis E. Indigenous positioning in health research: the importance of Kaupapa Māori theory-informed practice. AlterNative. 2016;12(4):396-410.

224. Smith G, Hoskins T, Jones A. Interview: Kaupapa Māori: the dangers of domestication. New Zealand Journal of Educational Studies. 2012;47(2):10-20.

225. Barnes A. What can Pākehā learn from engaging in kaupapa Māori educational research? Wellington (NZ): Te Wāhanga Mātau He Whānau Ora. New Zealand Council for Educational Research; 2013.

226. Jones A. Dangerous liaisons: Pākehā, kaupapa Māori, and educational research. New Zealand Journal of Educational Studies. 2012;47(2):100-12.

227. Malpas P, Anderson A, Wade J, Wharemate R, Paul D, Jacobs P, et al. A critical exploration of a collaborative Kaupapa Maori consistent research project on physician-assisted dying. N Z Med J. 2017;130(1454):47-54.

228. Naepi S. Navigating the currents of kaupapa Māori and Pan-Pacific research methodologies in Aotearoa New Zealand. MAI Journal. 2015;4(1):71-84.

229. Smith LT. Decolonizing methodologies: research and Indigenous peoples. London: Zed Books; 1999.

230. Cram F. Maintaining Indigenous voices. In: Mertens DM, Ginsberg PE, editors. The Handbook of Social Research Ethics. Thousand Oaks (CA): SAGE Publications, Inc; 2009.

231. Cram F, Phillips H. Claiming interstitial space for multicultural, transdisciplinary research through community-up values. International Journal of Critical Indigenous Studies. 2012;5(2):36-49.

232. Krieger N. Methods for the scientific study of discrimination and health: an ecosocial approach. Am J Public Health. 2012;102(5):936-44.

233. Cram F. Developing partnerships in research: Pākehā researchers and Māori research. Sites: A Journal for South Pacific Cultural Studies. 1997;35:44-63.

234. Anderson Y, Wynter L, Grant C, Cave T, Derraik J, Cutfield W, et al. A novel home-based intervention for child and adolescent obesity: the results of Whānau Pakari randomised controlled trial. Obesity. 2017;25(11):1965-73.

235. Ministry of Health. HISO 10001:2017 Ethnicity Data Protocols. Wellington (NZ); 2017.

236. MAXQDA 2018. Berlin, Germany: VERBI Software; 2018.

237. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77-101.

238. Robson B. Mana Whakamārama - equal explanatory power: Māori and non-Māori sample size in national health surveys. Wellington (NZ): Te Rōpū Rangahau Hauora a Eru Pōmare, Wellington School of Medicine and Health Sciences, University of Otago for Public Health Intelligence, Ministry of Health, New Zealand; 2002.

239. Bishop R. Collaborative research stories: Whakawhanaungatanga. Palmerston North (NZ): Dunmore Press; 1996.

240. Rewi T. Utilising Kaupapa Māori approaches to initiate research. MAI Journal. 2014;3(3):242-54.

241. Dyall L, Kepa M, Hayman K, Teh R, Moyes S, Broad JB, et al. Engagement and recruitment of Māori and non-Māori people of advanced age to LiLACS NZ. Aust N Z J Public Health. 2013;37(2):124-31.

242. Jones R, Crengle S, McCreanor T. How Tikanga guides and protects the research process: insights from the Hauora Tane project. Social Policy Journal of New Zealand. 2006(29):60-77.

243. Denzin NK, Lincoln YS. The SAGE handbook of qualitative research. 5th ed. Los Angeles (CA): SAGE Publications, Inc; 2018.

244. Liamputtong P. Qualitative research methods. 4th ed. Melbourne (AU): Oxford University Press; 2013.

245. Curtis ET, Wikaire E, Lualua-Aati T, Kool B, Nepia W, Ruka M, et al. Tātou tātou/success for all: improving Māori student success. Wellington (NZ): Ako Aotearoa National Centre for Tertiary Teaching Excellence; 2012.

246. World Health Organization. Waist circumference and waist-hip ratio: report of a WHO expert consultation. Geneva (CH): World Health Organization; 2011.

247. Freeman JV, Cole TJ, Chinn S, Jones PR, White EM, Preece MA. Cross sectional stature and weight reference curves for the UK, 1990. Arch Dis Child. 1995;73(1):17-24.

248. Australian and New Zealand Growth Charts [Internet]. Morrisset (AU): Australasian Paediatric Endocrine Group; 2018 [updated 2018 September 11; cited 2020 February 24]. Available from: https://apeg.org.au/clinical-resources-links/growth-growth-charts/.

249. National High Blood Pressure Education Program Working Group on High Blood Pressure in Children and Adolescents. The fourth report on the diagnosis, evaluation, and treatment of high blood pressure in children and adolescents. Pediatrics. 2004;114(2 Suppl 4th Report):555-76.

250. Medicine BCo. Age-based pediatric blood pressure reference charts [Internet]. Houston (TX): Baylor College of Medicine, USDA/ARS Children's Nutrition Research Center; 2017 [cited 2019 December 09]. Available from: https://www.bcm.edu/bodycomplab/Flashapps/BPVAgeChartpage.html.

251. Magarey A, Golley R, Spurrier N, Goodwin E, Ong F. Reliability and validity of the Children's Dietary Questionnaire: A new tool to measure children's dietary patterns. Int J Pediatr Obes. 2009;4(4):257-65.

252. Clinical Trials Research Unit Synovate. A national survey of children and young people's physical activity and dietary behaviours in New Zealand: 2008/09. Wellington (NZ); 2010.

253. Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. Med Care. 1999;37(2):126-39.

254. Varni JW, Limbers CA. The Pediatric Quality of Life Inventory: Measuring Pediatric Health-Related Quality of Life from the Perspective of Children and Their Parents. Pediatr Clin N Am. 2009;56(4):843-63.

255. Varni JW, Burwinkle TM, Seid M, Skarr D. The PedsQL 4.0 as a pediatric population health measure: feasibility, reliability, and validity. Ambul Pediatr. 2003;3(6):329-41.

256. Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. Med Care. 2001;39(8):800-12.

257. Chan KS, Mangione-Smith R, Burwinkle TM, Rosen M, Varni JW. The PedsQL: reliability and validity of the short-form generic core scales and Asthma Module. Med Care. 2005;43(3):256-65.

258. Varni JW, Seid M, Knight TS, Uzark K, Szer IS. The PedsQL™ 4.0 Generic Core Scales: sensitivity, responsiveness, and impact on clinical decision-making. J Behav Med. 2002;25(2):175-93.

259. Corder K, van Sluijs EM, Wright A, Whincup P, Wareham NJ, Ekelund U. Is it possible to assess free-living physical activity and energy expenditure in young people by self-report? Am J Clin Nutr. 2009;89(3):862-70.

260. Hamlin MJ, Fraser M, Lizamore CA, Draper N, Shearman JP, Kimber NE. Measurement of cardiorespiratory fitness in children from two commonly used field tests after accounting for body fatness and maturity. J Hum Kinet. 2014;40(1):83-92.

261. Ministry of Health. Tier 1 statistics 2016/17: New Zealand Health Survey [Internet]. Wellington (NZ): Ministry of Health; 2017 [cited 2019 March 22]. Available from: https://minhealthnz.shinyapps.io/nz-health-survey-2016-17-tier-1/.

262. Harris R, Cormack D, Tobias M, Yeh L-C, Talamaivao N, Minster J, et al. Self-reported experience of racial discrimination and health care use in New Zealand: results from the 2006/07 New Zealand Health Survey. Am J Public Health. 2012;102(5):1012-9.

263. Ministry of Health. Population of Taranaki DHB Wellington (NZ): Ministry of Health; 2019 [updated 2019 January 08; cited 2019 February 20]. Available from:

https://www.health.govt.nz/new-zealand-health-system/my-dhb/taranaki-dhb/population-taranaki-dhb.

264. Pihama L. Kaupapa Maori theory: transforming theory in Aotearoa. He Pukenga. 2010;9(2):5-15.

265. Chilisa B. Indigenous research methodologies. California: SAGE Publications, Inc; 2012.

266. Health Quality & Safety Commission New Zealand. Patient experience survey: results for patients treated in February 2018. Wellington (NZ); 2018.

267. Safdar N, Abbo LM, Knobloch MJ, Seo SK. Research methods in healthcare epidemiology: survey and qualitative research. Infect Control Hosp Epidemiol. 2016;37(11):1272-7.

268. Artuso S, Cargo M, Brown A, Daniel M. Factors influencing health care utilisation among Aboriginal cardiac patients in central Australia: a qualitative study. BMC Health Serv Res. 2013;13(1):83.

269. Morton SM, Bandara DK, Robinson EM, Carr PE. In the 21st century, what is an acceptable response rate? Aust N Z J Public Health. 2012;36(2):106-8.

270. Wild CEK, O'Sullivan NA, Lee AC, Cave TL, Willing EJ, Cormack DM, et al. Survey of barriers and facilitators to engagement in a multidisciplinary healthy lifestyles program for children. J Nutr Educ Behav. 2019;In Press.

271. Harris RB, Cormack DM, Stanley J. Experience of racism and associations with unmet need and healthcare satisfaction: the 2011/12 adult New Zealand Health Survey. Aust N Z J Public Health. 2019;43(1):75-80.

272. Wild CE, Rawiri N, Willing EJ, Hofman PL, Anderson YC. What affects programme engagement for Māori families? A qualitative study of a family-based, multidisciplinary healthy lifestyle programme for children and adolescents. Forthcoming 2020.

273. Cormack D, Stanley J, Harris R. Multiple forms of discrimination and relationships with health and wellbeing: findings from national cross-sectional surveys in Aotearoa/New Zealand. Int J Equity Health. 2018;17(1):26.

274. Ministry of Social Development. United Nations Convention on the Rights of the Child (UNCROC) [Internet]. Wellington (NZ): Ministry of Social Development; 2014 [updated 2014 September 29; cited 2019 July 29]. Available from: https://www.msd.govt.nz/about-msd-and-our-work/publications-resources/monitoring/uncroc/.

275. Wild CE, Rawiri N, Willing EJ, Hofman PL, Anderson YC. Determining barriers and facilitators to engagement for families in a family-based multidisciplinary healthy lifestyles intervention for children and adolescents. Forthcoming 2020.

276. Ministry of Health. Household Food Insecurity Among Children in New Zealand. Wellington (NZ): Ministry of Health; 2019.

277. Harris R, Tobias M, Jeffreys M, Waldegrave K, Karlsen S, Nazroo J. Effects of self-reported racial discrimination and deprivation on Māori health and inequalities in New Zealand: cross-sectional study. Lancet. 2006;367(9527):2005-9.

278. Crengle S, Robinson E, Ameratunga S, Clark T, Raphael D. Ethnic discrimination prevalence and associations with health outcomes: data from a nationally representative cross-sectional survey of secondary school students in New Zealand. BMC Public Health. 2012;12(45).

279. Minister of Health. The Guide to He Korowai Oranga: Māori Health Strategy 2014. Wellington (NZ); 2014.

280. Health and Disability System Review. Health and Disability System Review – Interim Report. Hauora Manaaki ki Aotearoa Whānui – Pūrongo mō Tēnei Wā. Wellington (NZ): ; 2019.

281. Ministry of Health. Well Child / Tamariki Ora Programme Practitioner Handbook: Supporting families and whānau to promote their child’s health and development – Revised 2014. Wellington (NZ): Ministry of Health; 2013.

282. Ministry of Health. Bulletin updates for extending access to primary care services [Internet]. Ministry of Health; 2018 [updated 2019 December 13; cited 2020 January 8]. Available from: https://www.health.govt.nz/our-work/primary-health-care/primary-health-care-subsidies-and-services/bulletin-updates-extending-access-primary-care-services.

283. Kebbe M, Damanhoury S, Browne N, Dyson MP, McHugh TF, Ball GDC. Barriers to and enablers of healthy lifestyle behaviours in adolescents with obesity: a scoping review and stakeholder consultation. Obes Rev. 2017;18(12):1439-53.

284. Kebbe M, Perez A, Buchholz A, McHugh TF, Scott SS, Richard C, et al. Barriers and enablers for adopting lifestyle behavior changes in adolescents with obesity: A multi-centre, qualitative study. PLoS ONE. 2018;13(12):e0209219.

285. Wang J, Williams M, Rush E, Crook N, Forouhi NG, Simmons D. Mapping the availability and accessibility of healthy food in rural and urban New Zealand - Te Wai o Rona: Diabetes Prevention Strategy. Public Health Nutr. 2010;13(7):1049-55.

286. Mackay S, Vandevijvere S, Xie P, Lee A, Swinburn B. Paying for convenience: comparing the cost of takeaway meals with their healthier home-cooked counterparts in New Zealand. Public Health Nutr. 2017;20(13):2269-76.

287. Glover M, Wong SF, Taylor RW, Derraik JGB, Fa’alili-Fidow J, Morton SM, et al. The complexity of food provisioning decisions by Māori caregivers to ensure the happiness and health of their children. Nutrients. 2019;11(5):994.

288. New Zealand Medical Association. Tackling obesity. Policy Briefing. Wellington (NZ); 2014.

289. Guthold R, Stevens GA, Riley LM, Bull FC. Global trends in insufficient physical activity among adolescents: a pooled analysis of 298 population-based surveys with 1·6 million participants. Lancet Child Adolesc Health. 2020;4(1):23-35.

290. Cram F. Rangahau Māori: Tona tika, tona pono – the validity and integrity of Māori research. In: Tolich M, editor. Research Ethics in Aotearoa. Auckland (NZ): Longman; 2001. p. 35-52.

291. Statistics New Zealand. Census 2013: Ethnic group by age group and sex [Internet]. Wellington (NZ): Statistics New Zealand; 2013 [cited 2020 January 20]. Available from: http://nzdotstat.stats.govt.nz/wbos/Index.aspx?DataSetCode=TABLECODE8021#.

292. Salmond C, Crampton P, Atkinson J. NZDep2006 Index of Deprivation. Wellington (NZ): Department of Public Health, University of Otago; 2007.

293. Paine S-J, Priston M, Signal TL, Sweeney B, Muller D. Developing new approaches for the recruitment and retention of Indigenous participants in longitudinal research: lessons from E Moe, Mama: Maternal Sleep and Health in Aotearoa/New Zealand. MAI Journal. 2013;2(2):121-32.

294. Walker S, Eketone A, Gibbs A. An exploration of kaupapa Maori research, its principles, processes and applications. Int J Soc Res Methodol. 2006;9(4):331-44.

295. Walter M, Anderson C. Indigenous statistics: a quantitative research methodology. California: Left Coast Press; 2013.

296. Bishop R, Glynn T. Culture counts: Changing power relations in education. Palmerston North: Dunmore Press; 1999.

297. Dwyer SC, Buckle JL. The space between: on being an insider-outsider in qualitative research. Int J Qual Methods. 2009;8(1):54-63.

298. Serrant-Green L. Black on black: methodological issues for black researchers working in minority ethnic communities. Nurse Res. 2002;9(4):30-44.

299. Whitlock EP, O'Conner EA, Williams SB, Beil TL, Lutz KW. Effectiveness of primary care interventions for weight management in children and adolescents: an updated, targeted systematic review for the USPSTF. Rockville (MD): Agency for Healthcare Research and Quality (US); 2010. Report No.: 10-05144-EF-1.

300. Achenbach TM, Ruffle TM. The Child Behavior Checklist and related forms for assessing behavioral/emotional problems and competencies. Pediatr Rev. 2000;21(8):265-71.

301. Kant AK, Graubard BI. Contributors of water intake in US children and adolescents: associations with dietary and meal characteristics - National Health and Nutrition Examination Survey 2005-2006. Am J Clin Nutr. 2010;92(4):887-96.

302. Sichert-Hellert W, Kersting M, Manz F. Fifteen year trends in water intake in German children and adolescents: results of the DONALD Study. Dortmund Nutritional and Anthropometric Longitudinally Designed Study. Acta Paediatr. 2001;90(7):732-7.

303. Levy-Marchal C, Arslanian S, Cutfield W, Sinaiko A, Druet C, Marcovecchio ML, et al. Insulin resistance in children: consensus, perspective, and future directions. J Clin Endocrinol Metab. 2010;95(12):5189-98.

304. Rhodes A. Screen time and kids: What's happening in our homes? Melbourne (AU): The Royal Children's Hospital Melbourne; 2017.

305. Jebeile H, Gow ML, Baur LA, Garnett SP, Paxton SJ, Lister NB. Association of Pediatric Obesity Treatment, including a dietary component, with change in depression and anxiety: a systematic review and meta-analysis. JAMA Pediatr. 2019:e192841.

306. Child Wellbeing & Poverty Reduction Group. Child and Youth Wellbeing [Internet]. Wellington (NZ): New Zealand Government; 2019 [updated 2019 December 12; cited 2020 January 29]. Available from: https://childyouthwellbeing.govt.nz/.

307. RACP Position Statement: Action to prevent obesity and reduce its impact across the life course [press release]. Sydney (AU): Royal Australasian College of Physicians, May 2018.

308. Wild CE, Rawiri N, Willing EJ, Hofman PL, Anderson YC. Health system barriers to accessing care for children with weight issues in New Zealand. Forthcoming 2020.

309. Wild CE, Rawiri N, Willing EJ, Hofman PL, Anderson YC. Challenges of making healthy lifestyle changes for families in Aotearoa/New Zealand. Forthcoming 2020.

310. Anderson YC, Dolan GMS, Wynter LE, Treves KF, Wouldes TA, Grant CC, et al. Caregiver's readiness for change as a predictor of outcome and attendance in an intervention programme for children and adolescents with obesity: a secondary data analysis. BMJ Open. 2019;9(3):e023195.

311. Growing Up In New Zealand. Welcome to Growing Up in New Zealand [Internet]. Auckland (NZ): University of Auckland; n.d. [updated 2019 December 17; cited 2020 January 26]. Available from: http://www.growingup.co.nz/en.html.

312. Egger G, Swinburn B. An "ecological" approach to the obesity pandemic. BMJ. 1997;315(7106):477-80.

313. Osei-Assibey G, Dick S, Macdiarmid J, Semple S, Reilly JJ, Ellaway A, et al. The influence of the food environment on overweight and obesity in young children: a systematic review. BMJ Open. 2012;2(6):1-12.

314. Royal Australasian College of Physicians. Action to prevent obesity and reduce its impact across the life course: evidence review. Sydney (AU); 2018.

315. Sundborn G, Thornley S, Lang B, Beaglehole R. Better health or better business: a critique of the childhood obesity plan. N Z Med J. 2016;129(1440):145-8.