Participants’ and caregivers’ experiences of a multidisciplinary programme for healthy lifestyle change in Aotearoa/New Zealand: a qualitative, focus group study

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ABSTRACT

Objective Child and adolescent obesity continues to be a major health issue internationally. This study aims to understand the views and experiences of caregivers and participants in a child and adolescent multidisciplinary programme for healthy lifestyle change.

Design Qualitative focus group study.

Setting Community-based healthy lifestyle intervention programme in a mixed urban–rural region of Aotearoa/New Zealand.

Participants Parents/caregivers (n=6) and children/adolescents (n=8) who participated in at least 6 months of an assessment and weekly session, family-based community intervention programme for children and adolescents affected by obesity.

Results Findings covered participant experiences, healthy lifestyle changes due to participating in the programme, the delivery team, barriers to engagement and improvements. Across these domains, four key themes emerged from the focus groups for participants and their caregivers relating to their experience: knowledge-sharing, enabling a family to become self-determining in their process to achieve healthy lifestyle change; the importance of connectedness and a family-based programme; the sense of a collective journey and the importance of a nonjudgemental, respectful welcoming environment. Logistical challenges and recommendations for improvement were also identified.

Conclusions Policymakers need to consider the experiences of participants alongside qualitative outcomes when informing multidisciplinary intervention programmes for children and adolescents affected by obesity.

Trial registration number Australian New Zealand Clinical Trials Registry (ANZCTR):12611000862943; Post-results.

INTRODUCTION

In Aotearoa/New Zealand (NZ) (henceforth referred to as NZ), obesity is considered the leading risk factor causing health loss, having now surpassed tobacco.1 Children currently experience an obesity prevalence rate of 9.4% in NZ.2 Creation of any multidisciplinary interventions for addressing childhood obesity should consider the needs of those most over-represented in obesity statistics, namely, Māori and Pacific peoples, and those from the most deprived households.3 Achieving equity is a stated priority of the New Zealand Health Strategy.3

The concept of ensuring access to healthcare services for all is not new.4 A systematic review of barriers and facilitators to participation by Indigenous People in randomised controlled trials (RCT) highlighted a key barrier was lack of access to participation due to disadvantage or social exclusion, and a common facilitator was culturally appropriate study design.5 Issues of access and appropriateness also hold true for healthcare services. Understanding from participants of healthcare services their experiences, and prioritising their voice is critical if healthcare professionals are to understand how to minimise barriers to engagement, thereby achieving equity of service provision and uptake.

In a response to audit findings of the pre-existing intervention programme in the
region for children affected by obesity, Whānau Pakari was created. The Whānau Pakari programme commenced in 2012 in Taranaki, a mixed urban–rural region of NZ. Whānau Pakari means healthy, self-assured families that are fully active. The objectives of the Whānau Pakari team (clinical and research) were: (1) to create and assess a multidisciplinary intervention for children and adolescents with obesity in Taranaki that provided comprehensive assessment and intervention in one model, (2) to improve access and appropriateness of the clinical and community service, especially for Māori and those from the most deprived households and (3) to assess whether those who participated in the 12-month intense intervention programme showed significant improvements in health and quality of life indices compared with those receiving a minimal intensity intervention of assessment, follow-up and advice. The key elements of the Whānau Pakari programme were: (1) a service that was family-based, with a requirement that at least one adult member of the family had to be actively involved, (2) a wide referral base where anyone in the community could refer, (3) a commitment to groups over-represented in obesity statistics with a more appropriate, equitable and acceptable model of care and (4) a ‘demedicalised’ approach to the participant’s journey through the service, with all medical assessments being undertaken as part of a wider assessment in the home, avoiding medical/hospital appointments. To ensure robust outcome data were available, a RCT was embedded within the service. Findings of the RCT have been reported elsewhere.

The Whānau Pakari programme was a collaboration between the regional sports trust and the district health board. The service included not only the intervention but also an assessment to ensure that all weight-related comorbidities were identified and addressed in all participants. The 12-month intervention included baseline, 6-month and 12-month home-based assessments for all participants with the healthy lifestyle coordinator, one home visit by the dietitian and physical activity coordinator, and weekly intervention sessions during school term time for 12 months. Assessments included medical history and examination, dietetic and physical activity history and psychology screening. Intervention components included dietitian sessions (including virtual supermarket tours, cooking sessions, how to grow vegetables, portion size, label reading), psychology sessions (including self-esteem, parenting, family dynamics and sleep) and physical activity (various games and sporting activities).

This paper presents research findings from two focus groups that were held with parents/caregivers and children involved in the Whānau Pakari programme. These focus groups were part of a wider evaluation that was conducted by Cogo Consulting (Auckland, New Zealand) who were engaged as external evaluators to conduct a limited process evaluation, focusing on the acceptability of the model of service delivery to project partners and stakeholders. The evaluation findings can be found elsewhere. The purpose of this paper is to provide insight into the development of the Whānau Pakari programme, based on the thoughts, perspectives and experiences of programme participants and their whānau (family, or wider family group).

METHODS

The research was qualitative and was guided by principles of a Kaupapa Māori approach (one which respects Māori philosophy, world-view and cultural principles). Data collection consisted of two focus groups to determine and report on participant thoughts, perspectives and experiences of the Whānau Pakari programme. Focus groups were chosen as the programme participants were used to working in a group setting, and this was the first study of wider qualitative research to understand barriers and facilitators to engagement for participants in the programme. Eligibility criteria were all participants of the Whānau Pakari healthy lifestyle programme, who had been attending assessments and weekly group sessions in North Taranaki for more than 6 months at time of recruitment (September 2016), resulting in 16 eligible participants (ages 4.5–12 years) and 14 committed family members. Participants had affiliations to varying ethnicities (Māori, Pacific, NZ European, Asian and other). Due to limited funding, focus groups in North Taranaki only were able to be offered. One focus group was conducted with the Whānau Pakari programme participants, and another focus group was conducted with at least one of their committed family members. Committed family members were either parents, grandparents or appointed carers of the participants.

In total, eight children (aged 4.5–12 years, six NZ European and two Māori) participated in the participant focus group (three siblings), and six committed family members (four NZ European and two Māori, four parents and two grandparents) participated in the adult focus group, with both focus groups held on 15 September 2016. 50% (n=3) of the cohort resided in the most deprived quintile of household deprivation. Average weekly session attendance for children was 14 (range 3–16) and 15 (range 10–21) for committed family members. Those who did not participate from those invited either had other commitments, transport issues or declined the invitation without reason.

The focus groups were led by a Taranaki-based Māori researcher using interview guides, participant information sheets and consent forms developed by Cogo Consulting in consultation with the research team. Participants were asked about their overall experiences with the Whānau Pakari programme (interview guide in online supplemental material). Both positive and negative views were sought from participants and caregivers. Written and verbal informed consents were obtained from all participants or their guardians.

Focus groups were conducted over 90 min. These were audio-recorded and independently transcribed. Data

were then analysed by Author 10 using a thematic analysis approach. Analysis and interpretation were underpinned by Kaupapa Māori Theory principles, which take a strength-based approach, avoiding victim-blaming and deficit explanations to understand participant experience in order to align with the overall aims of Whānau Pakari. First, the focus group transcripts were read repeatedly and methodically by Author 10 to become familiar with the content (familiarisation). Author 10 did not participate in data collection and was independent of the Whānau Pakari programme. Labels were then generated to code-specific sections of the data relevant to understanding the experiences of focus group participants. The data set was coded and a coding matrix was developed through the collation of like codes and refinement. The entire data set was then recoded using this final matrix. Author 10 then identified patterns across the data set and generated initial themes. These were then reviewed, defined and refined recursively for consensus in collaboration with the wider research team to ensure trustworthiness and credibility. The final analysis was reported by Authors 1 and 10.

**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. Participants were not involved in the design or conduct of the study. They were not asked to assess the burden of the time required to participate in the research.

**RESULTS**

Participant responses converged across five distinct domains: participant experiences, healthy lifestyle changes achieved due to being part of the programme, perspectives on the programme delivery team, barriers to engagement and improvements. Across these domains, four key themes emerged: knowledge-sharing; enabling a family to become self-determining in their process to achieve healthy lifestyle changes; the importance of connectedness and a family-based programme; the sense of a collective journey and a nonjudgemental, respectful, welcoming environment. These themes are presented below, along with an initial general assessment of the programme and a fifth theme of logistical challenges and participant-generated recommendations for improvement.

Half the children said that they liked being part of the programme while the other children initially stated that they did not like being part of Whānau Pakari. When asked why they liked being part of Whānau Pakari, the children responded that they liked making new friends and the activities and games.

Because we meet new friends (Child M).

Most of the children stated that they had fun at Whānau Pakari and enjoyed learning about their health and how to make healthier decisions.

Child B: I’ve had fun like learning about my health and stuff.

Child M: Same.

Child B: And like learning how to control myself more.

Child M: And cook.

Opportunities for increasing awareness and capability building were well received. In particular, these children liked the variety of sessions involved in Whānau Pakari, with sports and cooking lessons highlighted as popular activities within the intervention.

You learn like lots of different sports, learn how to cook some of the food, you also learn portion sizes and habits (Child I2).

The three children who stated that they did not like attending Whānau Pakari said that they found certain aspects of the programme boring.

It’s boring when like when (the dietitian) is talking about food at the Whānau Pakari place (Child D).

Despite some stated feelings of boredom, participants also suggested which activities they would have preferred. In the excerpt below, the child talks about wanting more sports sessions within Whānau Pakari as these were the aspects of the intervention that they enjoyed the most.

I would rather more sports sessions (Child B).

Other children stated that they enjoyed the psychology sessions and wanted to learn more in this area, as Child I recalls:

every second week we have got YMCA [community centre where sport sessions were held] … probably every third week so then we get to learn more about the other side of it… the psychology (Child I).

Overall, the children were positive about their experiences with the intervention throughout the focus group. As it progressed it became apparent, this was true even for the children who had initially stated that they did not like it, with later comments such as ‘[my] favourite thing I like to do is go to the boxing arena, and the YMCA’ (Child D). This was evident to the point of stating they would tell their friends about the programme:

Because they could, so they could like get healthier and get stronger and get faster. (Child D).

Parents and caregivers were overwhelmingly positive about their engagement with Whānau Pakari, stating that participating in the intervention had many positive outcomes for their children. Although some of the parents and caregivers were apprehensive about their
involvement in the intervention, once they attended, they thought it was a positive experience for their family.

It was for us, I mean, being grandparents and M living with us, it was for us, we weren’t sure how we were going to take the programme but no, it’s been really good (Parent F).

Knowledge-sharing, enabling a family to become self-determining in their process to achieve healthy lifestyle change

Parents and caregivers felt supported by the Whānau Pakari team when encouraging their children to change their habits.

It was eye opening, eye opening for me and for my daughter ‘cause I’ve tried to say stuff to her, to guide her and stuff, and then having someone else sort of like when she had to write down how many days she watches TV and screen time and stuff like that, it was quite a good eye opener for her. Because I can say to her, ‘oh you watch too much TV’, but then to have someone else point that out that maybe it was a little bit too much, it was quite an eye opener (Parent R).

Children were not asked in the focus group whether or not they had lost weight, as the focus of the Whānau Pakari programme is healthy lifestyle change, not weight loss. When asked by the facilitator what had changed since they had been on the programme, not one child mentioned losing weight, and spoke instead about increased knowledge relating to portion sizes, nutrition and being more self-determining of their health.

Well I basically learnt how to portion size and stuff from like all the nutrition sessions and stuff (Child B).

For others, self-determination was about being more confident and having the knowledge and skills to make healthy decisions each day.

My thoughts have changed … like just on eating healthier. Because before I joined Whānau Pakari, I would probably drink a cup of juice a day, now I would have like barely even one a week (Child B).

Participants in the focus group with parents and caregivers supported the comments made by their children. They talked about their children having more confidence and being more outgoing after their involvement with Whānau Pakari.

Her self-esteem was so low that coming into this programme it’s so high now, she came from a really shy kid, not talking to anybody apart from me and maybe my mum, and now she just talks to everybody now and she knows how to eat healthy, she knows good things, bad things, she’s just taking it all in now and for a kid who’s 6 she has done so well through this programme (Parent R).

Parents and caregivers also talked about the changes in their own behaviour due to their involvement in Whānau Pakari and having increased access to knowledge alongside their children. They were more confident in setting boundaries with their children.

You tell him that’s enough screen time now and he can understand why. And we don’t get as many tantrums or anything like that out of it like we used to so that’s good (Parent M).

All of the parents and caregivers involved in the focus group said that they had learnt to limit their children’s food choices and portion sizes.

I have learnt how to put my foot down more a little bit – like if she’s wanting to eat more, I just put my foot down (Parent R).

Through being exposed to the programme, families were making healthier decisions both at home and when eating takeaway food.

I think that’s the key of it, it’s the eating better side of it. Even if we have takeaways, it’s now ’what should we have?’, ‘oh we can pick a healthy option in the takeaway menu’. Yeah D’s like Subway, ‘where do you want to go for takeaways, I want to go to Subway (Parent M).

They also commented on the skills and knowledge that their children had acquired and that this had created opportunities for new activities for them to do as a family.

They are so much more aware of food than what they used to be, and different ways too, like the girls are quite keen now to get a little vege garden going so they can start watching food and that way they can go from, there’s no way, the two girls are not outdoor kids at all and for them to go ’look it would be real cool if we grew lettuce and carrots (Parent V).

A couple of the parents talked about the way in which Whānau Pakari prepared their children to make health decisions as adults and that their involvement with the intervention had given them skills that would remain with them once they had left home. As parent V outlines below, this was the basis for positive behaviour change:

And getting them prepared for like the real world, when they leave home what you teach them is what they are going to learn, they can go right ‘I’m on a budget… I can make a really healthy vegetarian stir fry for the same price that I am going to get me a Big Mac’. Think about what they have learnt over the process and go well actually I am better off doing that, not only am I cooking, I am doing it for myself, I may have grown those vegetables (Parent V).
The importance of connectedness and a family-based programme

One of the key elements of Whānau Pakari is that the activities involve the wider family, not just the child who is referred to the intervention. The children were positive in terms of the ability of their wider whānau to get involved, along with the levels of buy-in within their whānau:

Child M: My nana does it... and wait, poppa watches it and my nana joins in.
Child B: Well, my mum just comes down and joins with us.
Child J: She sometimes stays up and helps, plays with us sometimes.

All of the parents and caregivers stated that they felt their ability to participate with their children was a positive aspect in terms of their involvement with Whānau Pakari.

You sort of felt that you were joining a family rather than just like with my doctor it was very one on one, like my doctor could say, you know, as non-harshly as she thought it was that my daughter was overweight and we needed to do something about it, whereas here it was all these families going through the same sort of stuff so you were just joining a bigger family to all sort of help one another and like I can talk to one of the other parents about what they are going through and they may have advice on what I needed, so it’s very much a welcoming environment from the start (Parent V).

Rather than their child learning and developing on their own, their family was able to walk with them along this experience and this had positive outcomes for their family as a collective:

I just think this programme is just so good for us and as a family we are working at things together and not just as singly... it’s just together and it’s just so nice and it’s brought us all together and just to love each other a lot more and that (Parent R).

A nonjudgemental, respectful, welcoming environment

Parents and caregivers commented on the lack of stigma around their child’s weight and involvement in Whānau Pakari. This contrasted to their experiences with other health professionals. For parent M, the absence of judgement and other deficit-framing was appreciated:

There was no judgement or anything like that which you felt quite often with other medical people. They tended to be you know ‘what do you do’, ‘oh well do you think you should be doing this’, whereas there was none of that, it was more like you spoke to other people and you heard other people’s things and thought, yeah I could try that (Parent M).

In the past, some of the parents and caregivers had felt judged by the health professionals that they were engaging with as if they were blamed for their child’s weight and health issues. This made them reluctant to seek help from health professionals.

I mean you always have that fear of judgement, because you’ve had judgement previously like from my doctor and stuff like and then it becomes my fault that my daughter’s this way, it’s not just yes there is things I have contributed to it or I haven’t done but she also is part of it as well so that’s what I mean by the time management thing she needs to figure out things as well (Parent V).

One aspect of this welcoming environment for children and their family was due to the focus on healthy lifestyles rather than weight loss. All of the parents agreed that this was an important part of the intervention. For parent
V, the respect shown to them and their whānau was an enabling aspect of the programme:

[The Healthy Lifestyle Coordinator] was very welcoming, very caring, made the kids feel at ease, not that it was ‘you’re here cause you’re overweight’, it became more of a ‘we’re trying to do things in a healthier way’, it’s not just about you losing weight, it’s about everything, about you feeling good about yourself, getting them more active, helping you learn different ways, contributing and cooking yourself, it was a big family situation, not just a ‘you’re here because you’re too fat, lose weight’, it was everything (Parent V).

Parents and caregivers indicated that this respect was also felt in the way the staff involved in Whānau Pakari focused on developing relationships with the children and tailoring their advice to the needs of each child.

And the other thing is they know the kids as well. Cause I’ve sort of said something about D and it was like I got told something totally different than what one of the other parents got told about their kid and I thought that would definitely work with D but probably might not work with anybody else (Parent M).

Logistical challenges and recommendations for improvement

Logistical challenges were a barrier to parent and caregiver involvement in the programme. For some parents, attending the afternoon sessions each week was a challenge due to work commitments or extra-curricular activities, as parent M explains:

I have occasional problems with getting away from work so that’s the only barrier that I really have (Parent M).

This was a concern for these parents as often these extra-curricular activities were team sports that their children were part of and that being part of these sports teams was an important aspect of increasing their physical activity levels.

My daughter plays netball on a Thursday so we were doing the 3.30 sessions till netball season started, then we swapped, and now netball season is finished, it’s not so bad, but she was missing out of half of netball practice to come here and I am in two minds because obviously netball is helping her but then so is this, so the timing thing is a big thing as well (Parent V).

For another parent, their child did not want to attend the sessions, in particular, psychology sessions, when they conflicted with their rugby practice.

I found the Thursday was an issue because D had rugby practice on Thursday night at the same time and it was like, and D would say ‘psychology I’m not going to that, I’m going to practice’. (Parent M).

When parents and caregivers were asked how they thought Whānau Pakari might be improved, a number of them did not think that any changes needed to be made. They felt that the intervention already provided the support and education that they needed as a whānau to make healthy lifestyle changes.

No, I don’t either, they cover everything, they monitor your progress like from the start, and then the six month, and then obviously the yearly like check out and if we have questions, we can ask, we can email, we can call, we can text, we’re still very included, even if they are physically not there, they are still there. So I think that is really important, but everything just falls into place really, aside with the odd occasion with the timing, just juggling stuff but other than that, everything’s just worked well, everybody has worked well together, and we all seem to get along really well. As parents obviously we have been put in situations where we are all in the room together and stuff and we all still can confer stories with everybody else and go ‘oh crap I’ve had to deal with this, what about you?’ sort of thing, so nah I can’t say that there is anything they need to change at all (Parent V).

Two of the parents and caregivers stated that they believed the intervention should be provided to children and their family across the country as well as being implemented within a school setting to increase the scope of the intervention.

Parent F: Is this actually national wide this programme? I think it should be.

Parent V: I think it should be, it should be introduced into the school situation where you can go through school to go further because there is a lot of lower decile schools and things like that that could benefit from having this being introduced to encourage them, because a lot of people are on budgets and things as well so it is really hard to be healthy and on a budget at the same time especially if you are a big family, so I think it would help in a lot of ways to be introduced into schools, not just going through Child and Adolescents or your doctor or Barnados [family support charity], it would benefit a lot of families going into schools.

DISCUSSION

This study found that overall, participants’ and caregivers’ experiences of Whānau Pakari were positive. Four key themes were identified as central to participant experience: the importance of connectedness and a family-based programme; knowledge-sharing, enabling a family to become self-determining in their process to achieve healthy lifestyle change, the sense of a collective journey and a nonjudgemental, respectful welcoming environment. These themes highlighted the importance of respect of the participant and their family through their
journey through the programme. An additional theme of logistical challenges and recommendations for change emphasised that the barriers to engagement with the programme were largely logistical and due to competing priorities.

Multidisciplinary intervention programmes continue to be recommended as the optimal approach for addressing childhood obesity.18,19 Given the intergenerational nature of obesity,18 programmes that involve the whole family are important to achieving long-term healthy lifestyle change. In terms of cost-effectiveness, ‘treating’ the parent/caregiver or child alone is almost five times more expensive per unit of weight loss than a family-based approach.20 These findings provide scope and context on the importance of family-based programmes for participants. By drawing on Kaupapa Māori principles, participants were free to express the importance of self-determination in relation to achieving healthy lifestyle change, the value of a collective journey, and the importance of a space where cultural aspirations and identity were respected.12

When determining why intervention programmes for child obesity may or may not be successful, the importance of a mixed methods approach, with qualitative research methods alongside quantitative methods, has been highlighted previously.21 Factors external to an intervention but central to the participants are key factors in determining whether participants are successful and engage with any programme.21 Consistent ‘facilitator’ and ‘barrier’ themes in an intervention programme undertaken in 5–9-year olds affected by moderate obesity in Australia were: internal locus of parental control (eg, increased self-efficacy); external locus of parental control (eg, food provided at school) and child factors (eg, child’s attitude to eating).21 The experiences of these participants indicate that Whānau Pakari was positive in terms of engagement. A wider awareness of the acceptability of interventions for participants and their families is key to determining overall success of a programme outside of a clinical research setting.

With the move to a more agentic (individualistic) approach in healthcare services, a risk exists that the result is an increase socioeconomic inequalities in obesity,22 especially if population targeting of services is seen as inappropriate by recipients. Judgemental approaches, or fat-shaming, particularly affects Indigenous groups, perpetuating discourses of Indigenous failure.23 Programmes that embrace cultural principles such as manaakitanga (the capacity to care and reciprocate care) and whakamana (enabling of individuals and families)23 are critical to addressing these issues, and these principles will likely resonate with all people, not just Māori participants and their whānau.

‘Treating’ obesity in children as a single condition is arguably a misguided approach.24 Research to date in NZ has highlighted the complexity of the participants presenting, not only in terms of weight-related comorbidities25 but also varied dietary behaviour,26 physical and sedentary behaviour27 and psychological challenges.28 Public policy and health service deliverers of such programmes need to take into account not only clinical outcomes but also the voice of referral stakeholders and, most importantly, the participants themselves.

Strengths of this study were the ability to prioritise both caregiver and child voice, alongside previously reported qualitative outcome data.8,9,29 Limitations include the inability to conduct further focus groups in South Taranaki due to funding constraints, and small participant and adult focus groups with minimal Māori representation on the day. This potentiated the inability to reach data saturation as well as triangulate with other qualitative data sources. However, it is acknowledged that data saturation is a concept that is being increasingly challenged, and meaning is able to be generated through interpretation of captured data.30 Wider qualitative research is warranted to understand barriers and facilitators to engagement in more detail to inform the programme. Despite these limitations, this paper makes a valuable contribution by providing space for the voices and perspectives of children and adolescents alongside their caregivers.

CONCLUSION

In conclusion, this study found that caregivers and participants identified the importance of connectedness in a family-based programme, knowledge sharing, the ‘collective journey’ and a nonjudgemental, respectful environment as key factors in their experience of this multidisciplinary intervention programme for healthy lifestyle change. Policymakers need to fund multidisciplinary programmes addressing weight in children and adolescents more widely, and consider these findings in programme and wider healthcare service development, prioritising child and caregiver voice wherever possible.

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Acknowledgements The authors thank the participants of Whānau Pakari. We also thank the Taranaki District Health Board and Sport Taranaki for funding the clinical service and for support of the trial.

Contributors YCA was involved in study design, analysis, interpretation and wrote the manuscript. CEKW, PLH and TLC were involved in study design and critical appraisal of the manuscript. KJT undertook the focus groups and critically appraised the manuscript. TD was contracted to undertake the focus group evaluation and critically appraised the manuscript. JGBD, WSC and CCZ were involved in study design and critical appraisal of the manuscript. EJW was involved in study analysis, interpretation and writing of the manuscript.

Funding YCA reports grants from the Health Research Council of NZ, grants from the Royal Australasian College of Physicians, grants from the Maurice and Phyllis Paykel Trust, grants from the Taranaki Medical Foundation, and grants from Cure Kids during the conduct of the study; TLC and CEKW report grants from the Taranaki
Medical Foundation, grants from the Maurice and Phyllis Paykel Trust, grants from Lotteries Health Research during the conduct of the study; PLH reports grants from Lotteries Health Research and Cure Kids during the conduct of the study; CGG reports grants from the Maurice and Phyllis Paykel Trust, the Health Research Council, the Starship Foundation, A Better Start National Science Challenge & Cure Kids, the US National Institutes of Health, Glaxo Smith Kline and the University of Auckland. Ms. Dornett was contracted in her capacity at Cogo Consulting to undertake the stakeholder and participant/family focus group evaluations. The funders had no role in the conduct of the research, study design, collection, analysis and interpretation of data, in the writing of the manuscript and in the decision to submit the article for publication. The researchers are independent of the funders and all had full access to all of the data in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

Competing interests  None declared.

Patient consent for publication  Not required.

Ethics approval  Full ethics review for this process evaluation was not required under the regulations of the National Ethics Advisory Committee 2012 for programme evaluation and audit. The wider Whānau Pakari randomised clinical trial was granted ethics approval by the Central Health and Disability Ethics Committee (New Zealand) (CEN/11/09/054).

Provenance and peer review  Not commissioned; externally peer reviewed.

Data availability statement  No additional data available.

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