Co-designing health research in Aotearoa New Zealand

// Lessons from the Healthier Lives National Science Challenge

Te hoahoa tahi i te rangahau hauora i Aotearoa

// He akoranga mai i He Oranga Hauora te Wero Pūtaiao ā-Motu

Debbie Goodwin & Amohia Boulton

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Ngā Mihi
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Dr Debbie Goodwin

DBZ Consultancy Ltd.

He Wāhinga Kōrero
Foreword

Co-design is becoming widely acknowledged as a crucial component of both health research and the planning and implementation of health services. It seems obvious that the involvement of health service users in research and service development is likely to lead to better research outcomes and greater uptake of services than would otherwise occur. This is especially the case when research and health service planning is aimed at redressing the inequitable health outcomes that exist for some sections of our population, including Māori, Pacific peoples, those living in rural areas and those on low incomes. Additionally, co-designing research-informed solutions to health issues with Māori, iwi, hapū and hapori is one way of honouring Treaty partnership obligations.

While the importance and relevance of co-design is now widely accepted by health researchers, policymakers and planners, and valued by communities, there appears to be no universally accepted definition of what it involves. In reality, there is a spectrum of co-design practices, ranging from consultation with the relevant communities, to full partnership and shared decision-making from the earliest stage of design and throughout the life of a project to its implementation and evaluation. Consultation alone is not considered by communities to be co-design. Various partnership practices show a range of benefits and challenges, both for researchers and community members. So how can we define which practices are effective and what elements are required for authentic co-design?

The Healthier Lives–He Oranga Hauora National Science Challenge has a vision of "Aotearoa New Zealand with equitable health outcomes and a substantially reduced burden of non-communicable diseases". When appropriate, Healthier Lives projects have included co-design methodologies as a pivotal component of their research approach. This report, based on in-depth interviews with academic researchers, community-based researchers and community partner organisations involved in Healthier Lives research, considers the strengths and limitations of the co-design approaches used and provides insights about how to undertake co-design with integrity. We hope it will make a useful contribution to health research and service planning in Aotearoa New Zealand, and more broadly as a means to help redress the inequitable health outcomes experienced by Indigenous communities worldwide.

Sir Jerry Mateparae

Chair, Governance Group and Kāhui Māori

Healthier Lives–He Oranga Hauora National Science Challenge

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1. Kupu Whakataki
Introduction

Co-design is increasingly being used in Aotearoa New Zealand[1] to develop innovative solutions, services, programmes and products, and has become more popular as a research approach in the health sector. There are many drivers for this, including the following:

i. the ambition to be more innovative and find better solutions for entrenched health, social and economic issues

ii. to create the opportunities for greater participation, partnership and input from those who use publicly funded programmes and services

iii. to enact Te Tiriti o Waitangi by involving Māori, iwi, hapū and hapori in designing solutions, and

iv. as a research or policy directive to improve outcomes.

The Healthier Lives-He Oranga Hauora National Science Challenge (Healthier Lives) is a research collaboration hosted by the University of Otago and was one of eleven National Science Challenges set up in 2014 to take a more strategic approach to the government's science investment. Healthier Lives has co-design as one of its three guiding principles. Several research projects from the first phase of Healthier Lives (2015-2019) included co-design methodologies as a core component of their research approach. The purpose of this report, therefore, is to provide a greater understanding of how co-design was conceptualised and implemented in these Healthier Lives projects, and what lessons can be learnt from researchers and their community partners to inform future efforts in co-design health research.

1.1 About Healthier Lives–He Oranga Hauora National Science Challenge

Healthier Lives–He Oranga Hauora is one of three health-focused National Science Challenges and has a vision of an "Aotearoa New Zealand with equitable health outcomes and a substantially reduced burden of non-communicable diseases (NCDs)." NCDs are the leading cause of premature death and disability worldwide. In Aotearoa New Zealand, four major non-communicable diseases—cancer, cardiovascular disease, diabetes and obesity—account for over a third of total death and disability (Healthier Lives, 2019). Furthermore, NCDs are associated with significant health inequities for Māori and Pacific peoples, and those living in remote rural areas or deprived neighbourhoods. Healthier Lives aims to find better ways to prevent and treat these four diseases and translate this knowledge into practice.

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1 For the purposes of this report, we have used Aotearoa to acknowledge the collective of islands that has come to be known as the sovereign state of New Zealand. Māori recognise that Aotearoa comprises a number of islands including, amongst others, Te Ika a Māui, Te Waipounamu, Rakiura and Wharekauri.

Its commitment to Te Tiriti o Waitangi (as outlined in the New Zealand Public Health and Disability Act 2000, (Boulton et al., 2004)) provides an impetus for strengthening partnerships with Māori, iwi, hapū and Māori communities and reducing health inequities between Māori and non-Māori.

The Healthier Lives research projects in this study had a particular focus on research with Māori and Pacific organisations and communities. Given the increasing use of co-design methodologies in research with Indigenous peoples, the Healthier Lives governance group sought to understand more about the nature and value of its commissioned co-design research, particularly including Māori and Pacific communities. Concerns have recently been raised by Indigenous peoples about the misuse of co-design as well as the burden it can place on communities (Shollum-Whaanga et al., 2020; Akama et al., 2019). Therefore, it is critical to ensure good co-design approaches are being utilised.

1.2   About this study

A kaupapa Māori evaluation[2] was undertaken, aimed at developing an understanding of:

i.   how co-design research was conceptualised and implemented within the Healthier Lives projects

ii.   the challenges that were experienced by researchers and community participants, what worked and what didn't work

iii.   what solutions could be gleaned, and

iv. what lessons could be useful for others who may be implementing future co-design research projects in health settings.

Eight university researchers and eight community partners across five Healthier Lives co-designed research projects (see Appendix 1 for brief description) were interviewed. The projects were:

- He Pikinga Waiora (HPW)

- OL@-OR@

- Pacific Prediabetes Youth Empowerment Programme (PPYEP)

- Mana Tū

- WellConnectedNZ™.

Study participants included eight academic and eight community-based members of the five research teams. The latter included leaders and staff of the Māori and Pacific health providers who partnered in the research, as well as the community researchers who were employed by these organisations. Some community researchers were funded by, and specifically employed for, the project, while others were seconded to the project from existing roles within their organisation.

An ethics application for this study was approved on 22 April 2020 by the New Zealand Ethics Committee Te Roopu Rapu i te Tika (https://www.nzethics.com/).

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2   Designed, led and implemented by Māori

1.3   What is co-design?

Defining 'co-design' can be difficult, as the term appears across a range of academic traditions, including design sciences, critical social sciences, business and public administration. Each of these traditions employs specific methods, frameworks and language that contribute to different types of co-design processes.

Further, co-design is often used in a broad sense to describe an approach to working collectively. Understanding what co-design approaches are being used and being clear about the meaning of co-design in its context is important.

1.4   Context for co-design in Aotearoa New Zealand

The rise of co-design practice in New Zealand has seen a range in the quality of approach. Improved evaluation of these practices will enable better guidance for the future use of co-design in Aotearoa.

> We have observed an increased interest and use of the term 'co-design' and participatory practices particularly by government ministries, research institutes and local government, however these are of varying quality and approaches differ widely. There is currently little resource available to measure or guide best practice and the definition of co-design is very fluid (Schollum-Whaanga, et al., 2020, p. 7).

One definition commonly used in the Aotearoa New Zealand health sector is predicated on experience-based co-design (Bate & Robert, 2006):

> True co-design... involves all stakeholders as partners through every stage of the design process—identifying a challenge, engaging people, capturing experiences, understanding experiences, planning improvements and measuring the impact of changes (Ko Awatea, 2019).

This definition purports that co-design is not solely about consulting people but involving them throughout the design, implementation and evaluation processes. Adding to this notion of participation, co-design can also be seen as involving a partnership approach. In Aotearoa New Zealand, co-design has a particular meaning when it is used in relation to Māori and Te Tiriti o Waitangi[3] . From an Aotearoa New Zealand government perspective, Te Arawhiti-The Office for Māori Crown Relations define co-design as partnership and shared decision-making:

> The Crown and Māori will partner to determine the issue/problem, to design the process and develop solutions. The Crown and Māori will make joint decisions.[4]

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3   In Aotearoa New Zealand, the Crown and Māori have a special relationship under Te Tiriti o Waitangi (the Treaty of Waitangi), a document signed in 1840 which provides the basis for Crown/ Māori partnerships. Te Tiriti o Waitangi therefore not only delineates a partnership approach but also specific Māori-led approaches to research. Co-design research thus becomes a particular vehicle for shared spaces within research and can be viewed by those participating as an opportunity for Māori to explicitly partner with researchers in academia (as a Māori partner) and vice versa (academia with Māori).
4   Te Arawhiti—The Office for Māori Crown Relations (no date), *Crown engagement with Māori*, Te Arawhiti—The Office for Māori Crown Relations, viewed 28 September 2023, <https://www. tearawhiti.govt.nz/assets/Tools-and-Resources/Crown-engagement-with-Maori-Framework.pdf>.

Indeed, the ethics of co-design in Māori contexts is an area of concern expressed by Māori design and evaluation practitioners, as the use of co-design methodology within Māori communities has increased. Practitioners have highlighted the danger of co-design being misused, of being implemented inappropriately and without due regard for the burden on communities. However, when implemented well, co-design provides the opportunity for whānau Māori and Māori communities and organisations to lead and partner with government "in governance, design and delivery, implementation and ongoing learning and evaluation of initiatives and responses" (Schollum-Whaanga et al., 2020, p. 7). Good co-design with Māori may be regarded, then, as aligning with Te Tiriti o Waitangi, that is, ensuring power-sharing between Crown agencies and Māori, and honouring mātauranga Māori and tino rangatiratanga such that Māori aspirations and equitable outcomes are realised. From a Te Ao Māori perspective, co-design as, and with, Māori should start with Te Ao Māori processes, tikanga and mātauranga Māori (Schollum-Whaanga et al., 2020) as the foundation.

The results of this study are presented in four sections that outline key findings relating to a range of co-design topics: Section 2) Co-design with Māori and Pacific peoples; Section 3) Benefits of co-design; Section 4) Perceptions of co-design; and Section 5) What we have learnt. In the final section, a new conceptual model, the Co-design Research Integrity Poutama, is presented. This can assist researchers to articulate levels of co-design implementation and move toward greater integrity in co-design research with Māori and Pacific communities.

2. Te hoahoa tahi me te ao Māori, Te Moana-nui-a-Kiwa hoki
Co-design with Māori and Pacific

2.1   Co-design with Māori

A particular benefit of applying a co-design approach to research in the Aotearoa New Zealand context is the value that is brought to research projects through authentic engagement of researchers with Māori communities. Thus, to reflect a Māori co-design perspective in the study, a kaupapa Māori evaluation framework was used.

Te Whetū Evaluation Matrix is a framework that was developed by the researcher, Debbie Goodwin, as part of her PhD work, with key input from Toi Tangata, a Māori organisation involved in a Healthier Lives-funded research project. The framework depicts six key Māori principles that are perceived as reflecting good co-design research with, and as, Māori: Hononga, Mahi Tahi, Tikanga me ngā Kawa, Ngā Pūkenga, Ngā Hua and Tino Rangatiratanga (see Table 1 for descriptors).

Interviewees were asked to retrospectively complete a short exercise rating their views about the presence of the six principles within their research co-design project. Table 1 presents the overall response ratings.[5] These data indicate that the five research projects were highly regarded (rated "reasonably good" to "very strong"), by both community representatives and researchers, and therefore were perceived as exhibiting a strong presence of key Māori principles experienced in the co-design processes. Notwithstanding these ratings, room for improvement still exists, based on the qualitative feedback received.

It should be noted that the framework was initially developed as an evaluation tool for use in discussion and sense-making by co-design teams, and to support a focus on the presence of Māori principles (via ratings and subsequent discussion) that apply to co-designing. These discussions can be used by partners to create space for collective kōrero and adaptions or improvements in the co-design research process, for current and prospective co-design partnerships. However, in this study, the more comprehensive approach was not used, and individual ratings were instead tallied for reporting purposes.

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5   Some respondents were not able to complete the table, and in one research project there were no community respondents available for this research. Several respondents chose two options.

Table 1: Te Whetū Evaluation Matrix: Presence of key Māori principles in the co-design research – ratings by university researchers and community partners

Te Whetū Evaluation Matrix — Mark relevant box with an X	This element was non-existent or **Very Unsatisfactory**. Needs urgent attention.	This element was **Just Okay** but there are some significant gaps. Significant development needed.	This element was **Reasonably Good** but there are some minor gaps that need further development.	This element was **Very Strong**. No serious weaknesses noted.
Hononga Connected and trusting relationships, strong bonds, whanaungatanga and transparency between co-design partners.			4r 3c	5r 3c
Mahi Tahi Working together as one: Agreed partnership, purposes, values, roles and processes.			3r 2c	6r 4c
Tīkanga me ngā kawa Respecting and aligning with participants' tīkanga and kawa (values, contexts and processes). Priority alignment to participant communities and less powerful partners.			4r 1c	5r 5c
Ngā Pūkenga Sharing expertise and developing skills needed for doing design and co-design, and working with communities.		1c	5r 4c	5r 2c
Ngā Hua Co-design outcomes and benefits that are equitable for those participating in the co-design and those using the results of the co-design.			3r 3c	6r 2c
Tino Rangatiratanga Self determination for ropū Māori/Pacific/communities. The co-design process supports and prioritises Māori/Pacific communities' aspirations.			4r 2c	5r 5c

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Note: The numbers in the columns refer to the number of individual responses from each project; "r" denotes university researcher responses; and "c" denotes community partner responses (including community-based researchers).

2.2   Co-design with Pacific

While Pacific evaluation frameworks were not used in this study, feedback from a number of Pacific community representatives and researchers provided insights into the usefulness of the co-design process. Overall, Pacific interviewees reflected that co-designed research was a valuable approach, and that co-design was already used within some Pacific organisations, albeit from Pacific perspectives. The connections and relationships established between Pacific community organisations and Pacific researchers were seen as crucial for supporting a shared co-design approach. This was particularly noted where community partners and academic researchers had a solid and collective understanding of the issues impacting on Pacific Peoples, and communities had the ability to make decisions and lead the approaches.

A capacity-building and empowerment approach was critical to using co-design with Pacific communities. One community representative commented that the Te Whetū principles aligned well with Pacific aspirations.

2.3   What does good co-design look like from Māori and Pacific interviewee perspectives?

Based on the feedback and experience of community partner interviewees in this study, four major elements of good co-design when working with Māori and Pacific communities were identified. These elements are discussed below, namely:te mātauranga o tētahi hapori (cultural framing), te kōtuitanga taurite (equal partnership), kaitiakitanga (guardianship), and rangatiratanga (sovereignty). These elements can be viewed alongside the six principles from Te Whetū evaluation matrix to describe what good co-design looks like with Māori and Pacific communities.

2.3.1   Te mātauranga o tētahi hapori: Good co-design incorporates cultural knowledge and ways of being and doing in community contexts

Māori and Pacific community partners described the importance of incorporating cultural perspectives, framing, concepts, and methods into the co-design research approach using a collective process that was seen to be valued by Māori and Pacific communities. The involvement of Māori, Pacific peoples, and organisations in the research projects brought cultural and community context, and experience, to the co-design research process and enabled community organisations to have greater influence in the process, programmes and services. It also enabled researchers to gain a greater understanding of community realities.

> ...[to]see another layer of humanness and realness in terms of what theory might say that we could articulate what it meant in our communities which I think they valued too, because they didn't know or didn't have a full understanding of [our cultures and communities].
>
> *Community partner*

It was important to understand the true essence and nuance of conversations and, in one case, to run focus groups in different Pacific Island languages. The nuances of the many different cultures and experiences of Pacific Peoples were valued and acknowledged in the research, and were therefore "given a platform where it would have that level of acceptance" within Pacific communities. Similarly, mātauranga Māori (Māori knowledge) was strongly reflected in a number of frameworks, programmes and products that were co-designed.

Community feedback was found to influence the research in several ways: by expanding the focus of the research, by re-languaging or by bringing a different perspective altogether. For example, having narrowly-focused research project parameters was a common experience highlighted by community representatives. The solution was further negotiation and adaption. This is a good example of how co-design can impact the research by re-orienting the research objectives, questions and definitions to be more meaningful and appropriate for community participants.

Co-designing with people from the relevant communities connected the research to the reality of people's lives, needs and challenges, and with their cultural perspectives and values. This was a real strength, as it supported greater success in design. Merit was also seen in having the whānau voice factored into the research as it was being designed and implemented. So, too, was the feeling that one's own

input (as a community representative) was valued and contributed to something. One community representative perceived the approach used as 'gold standard.'

> I hope it's an approach that can be, sort of, replicated or is used as, like, a gold standard for any future research projects or health projects as well.
>
> *Community partner*

2.3.2 Te kōtuitanga taurite: Good co-design starts at the "front-end" together

Community organisations' involvement at the proposal phase of the research was important to community leaders. Good co-design in communities was about discussing and formulating shared goals, visions, and outcomes at the concept stage of the research, as well as having input from both the community organisation (as partner) and researchers.

> The conversations with Māori and Pacific need to happen at the initiation phase of any of the projects.
>
> *Community partner*

> Going in there as research partners from day one, the communities are equal partners to this, as well.
>
> *Community partner*

Not being involved at the proposal or development phase resulted in community organisations being absent from initial discussions regarding research focus, methodologies, methods, and resource allocation. Developing the research focus together at the front end of a project was desired. Differing perceptions by partners of resource needs and appropriate methodologies and methods required further discussion.

One issue of concern raised by community organisations was the perception of not being regarded as a leading research partner, specifically because of the mana that this holds. This was seen as being about equity, ensuring Māori are involved as leaders in research that affects Māori. It was felt that the level and amount of work that community organisations contribute to the research is not recognised equitably, especially when community organisations are not named as principal investigators. A lot of the work was done by community organisations, including input into questionnaires, facilitating co-design workshops with communities, being involved in design of the intervention and eventual implementation of research programmes. It was felt that being named as community partners, rather than principal investigators, failed to truly recognise the mana held by community partners in their relationships, which played a big part in leveraging networks essential to the research.

> I mean, I think they felt that they did acknowledge us, but I think it's just that they underestimate how, because it's built on our friendships and our relationship and our linkages.
>
> *Community partner*

2.3.3 Kaitiakitanga: Good co-design addresses and protects intellectual and cultural property rights and data sovereignty

Cultural and intellectual property is an important issue for Māori and Māori organisations, particularly in co-design research where different knowledge bases, i.e., mātauranga Māori and Western research, are present and freely shared as part of the project. Cultural knowledge becomes a significant part of products and programmes that are designed as part of the research. As kaitiaki of cultural knowledge, Māori partner organisations have a role to ensure that knowledge is not misappropriated and is used for the benefit of Māori communities. For the teams and community organisations undertaking Healthier Lives-funded projects, negotiating intellectual property took time and resource. In future projects, anticipating the resource needs and joint discussion required for this important component of the research relationship at the start of the research, and throughout the design process, should become a routine part of any co-design process.

2.3.4 Rangatiratanga: Good co-design facilitates Māori-led and Pacific-led research

Māori-led research was seen by a number of Māori community representatives as an opportunity to identify, develop and drive tailored models and programmes that would result in better outcomes. Several research projects were seen as providing great examples of Māori-led research, as they involved Māori researchers and Māori communities as leaders in the projects.

Having Māori organisations lead and deliver the research programmes was viewed by some as critical because it ensures that rangatiratanga is enacted within co-designed research and is supported by the research partners.

> But the value is…like I said – designed by Māori for Māori – so we got good results from that, better outcomes.

Community partner

3. Ngā painga o te hoahoa tahi
Benefits of co-design

From informant observations, this study identified a number of overarching benefits of working together in co-design. These are listed in Appendix 2 and reveal the different perspectives of university researchers and community partners. While similar benefits can be noted across the two distinct partner groups, there were some differences. For example, a benefit for community partners was increased assertiveness and discernment around organisational involvement in future research projects and, for communities, decreased fear of being involved in research. A benefit for university researchers was gaining greater insight into the barriers to accessing healthcare experienced by Māori and Pacific communities. The diversity of community experiences and stories impacted researchers' understanding, specifically identifying the mindsets of health practitioners as posing a particular barrier. The positive effects on health practitioner practices, of listening to the experiences of patients or community members, have also been noted as a benefit in experienced-based co-design research (Bate & Robert, 2006).

> We health professionals have to get over our own barriers, assumptions, deficit attitudes and risk averse mindsets before this kind of co-design will actually work properly. The barriers are our own, not external.
>
> *University Researcher*

Both community and research partner groups emphasised the benefits resulting from the process of doing co-design research, such as capacity building and learning opportunities. These extended to relationship capital, including building new research relationships with academic and community provider organisations and developing trusted relationships.

Other valued benefits (also noted as research outcomes) included culturally cognisant co-designed programmes and products; improved programme retention rates; empowerment of programme users; enhanced credibility of community organisations through joint authorship of research papers; and the opportunity to publish evidence on the effectiveness of programmes for Māori and Pacific populations.

From an academic research perspective, the research projects demonstrate that the resulting products and programmes could not have been developed without the involvement of communities. Listening closely to communities' needs, challenges and aspirations as well as making joint design decisions supports greater community influence and voice and better community buy-in and participation in research. In addition, communities can identify solutions that are "out of the box" for some researchers. Both the benefits arising from the process and the outcomes resulting from co-designed programmes or products demonstrate what can be achieved through co-design research.

4. Ngā whakaaro o te tāngata mō te hoahoa tahi
Perceptions of co-design

One focus of this study was to understand how university researchers and community partners conceptualised co-design, given the broad nature of the term and its diverse use. Vignettes provided further detail of the various perceptions of university researchers and community partners for each of the five research projects (see Appendix 3). In general (across both groups), how co-design was perceived and undertaken varied, and this caused some concern and/or confusion for those participating. As one informant noted:

> [e]verybody has their own interpretation of what co-design looks like.
> *Community partner*

There was some agreement that the term 'co-design' was becoming a catch-phrase, particularly within government and the health sector. The understanding of co-design was sometimes unclear or ambiguous, and the term was seen as having lost meaning through overuse. This was a concern for participants, as they felt it was not being used with integrity.

> It's hard because co-design has become a little bit of a catchphrase for the government and government agencies at the moment... but then when you push them on what co-design looks like... it's still their same method but just packaged differently.
> *Community partner*

> I did go off co-design after these programmes, only because it became so saturated and diluted in every single setting that I sat in, I just got heartily sick of it because everybody has their own interpretation of what co-design looks like.
> *Community partner*

Lessons from this study suggest that assumptions about co-design—often made at the outset of a project—require clarification and negotiation as to what co-design is, what will happen, who makes the decisions and what areas of decision-making are up for discussion. Without appraisal, these assumptions may create confusion and frustration and result in unmet expectations. In addition, terms used alongside co-design research, including 'equal partnership,' 'community-centred' or 'whānau-led,' need to be expansively defined in relation to practices. Reaching agreement on such terms would preserve the integrity of the co-design research process. The following two sections outline researcher and community partner perspectives on the multiple meanings and perspectives of co-design.

4.1 What university researchers said

Co-design was regarded by university researchers as a participatory approach that involved a variety of stakeholders, and aimed to design solutions, products, and programmes to improve significant health issues. University researchers agreed co-design was not just about consultation; several teams viewed it as requiring significant involvement of partners throughout the co-design process, and this required building relationships during the entire research process.

Co-design was also perceived by a number of university researchers interviewed as partnering with communities. Community partners were involved in co-governance throughout the projects and helped make decisions on "big picture aspects of the project." For some university researchers, co-design was about "co-everything", community partners being involved in the design, data collection, analysis, and dissemination processes.

One objective of co-design, undisputed by participants in this study, was to involve end-users, those who would be using an intervention or programme, in its design. However, while people from communities were engaged in parts of the design process, they were also often represented by the community partner organisations or in advisory roles at different phases of the co-design research process. Community organisations often became the long-term partners of the research team and the mediators between the team and the community of interest. Acknowledging how and when end users, community members, and whānau are involved in co-design needs to be further thought through within a co-design process.

Although the meaning of the term 'partnership' was about ensuring the community partners were involved in key decisions about the research, decisions about the research topic and methods had largely been made prior to the community partners coming on board. This was a source of tension, as community organisations wanted to be involved in establishing the research focus, research planning and resource allocation. University researchers, however, did focus on providing funding for community partners to participate and undertake aspects of the research, and a number of research teams used formal agreements (both written and oral) that outlined everyone's responsibilities and philosophies for the project, including roles, responsibilities and resources.

Several university researchers agreed that co-design was about being community-centric and community-led, not just community-based. This meant working with the community at their pace, identifying social capital or enabling community organisations to lead the approach as much as possible.

A key part of co-designing was providing training and capacity-building activities to enable participation in, and understanding of, the co-design research. This also encourages community ownership of the programmes and enables community organisations to continue the programme in the future.

4.2 What communities said

Community partners interviewed in this study saw co-design in relation to themselves co-designing with their communities, that is, building trust and relationships with their community and then co-designing programmes, services and/or products along with them. Co-design was also seen as being "led" by the community:

> and for us that meant our clients, our whānau on the ground.
>
> *Community partner*

Co-design was viewed as being whānau-centred, bringing forward the whānau and community voice, using an ongoing cycle of iteration and development during design and implementation or testing with whānau. Thus, co-design was about empowering people, communities and whānau, and was an opportunity to do something that would improve the development of services and provision of care, as well as "inform policy changes toward better care for our community." One community partner said it is like an ongoing relationship of quality improvement.

A view held in common by community partners and university researchers was that co-design involved a capacity building approach, enabling greater participation and understanding.

> [Co-design is] an iterative and inclusive approach to capacity and capability building among Māori, kaupapa Māori organisations, groups and people.
>
> *Community partner*

Co-design with academic partners was perceived as making decisions about resources together.

> Real co-design happens when we're deciding who's getting what together.
>
> *Community partner*

5. Ngā mea i ākona e mātou
What we have learnt

The five research projects in this study provided multiple opportunities for learning about co-designing with community partners, including what is needed for these relationships and what to look out for when planning co-design research. The following section presents a summary of key lessons learnt based on the challenges and the solutions that researchers and community partners experienced. These can help inform researchers, communities and funders looking to implement co-design research. This section integrates feedback from both researchers and community organisations.

5.1   Co-design requires trusting relationships

Co-design requires relationships to be formed and maintained with the co-design partners or participants. The strength of these relationships directly impacts the co-design process and people's participation in it. Trusting in each other as partners and/or participants in co-design was seen as critical to the success of any research project adopting this approach.

Before starting the process, community partners and university researchers need to build a shared understanding of co-design research, including roles and responsibilities (who will be involved and how) and expectations for the design and implementation of co-designed programmes. This requires significant discussion with community partners at the beginning.

> I think if you establish that trust and relationship in a culturally appropriate fashion then you'll be able to look at the other elements, understanding what their challenge is, their worldview is, so that we could design whatever needed to be designed.
>
> *Community partner*

Several examples of co-design included in this study involved establishing a key relationship between an academic research team and community partner organisations, who agreed to design together and share in decisions about what was designed. In such arrangements, there is a need to clarify expectations about the participation of multiple stakeholder groups, such as community members and whānau, so that there is a collective understanding of who is co-designing with whom – at what stage of the research and at what level (e.g., governance, project management or service delivery level). Ensuring that power sharing is transparent and upheld with integrity is essential, as is clarifying roles and expectations in the research and how people will work together.

The importance of communities (not just community organisations) being involved throughout the co-design process was raised by several informants. Communities were seen to be an equal partner in the research. One of the research teams noted there was less buy-in from those who had not been involved in the design aspects of the programme and their needs differed somewhat from those provided by the

programme. Thus, a co-design partnership with a community requires a certain amount of groundwork to be carried out in advance: a 'once over lightly' approach should not be attempted.

Communities and/or community partners clearly wanted to be involved at the very beginning of co-design proposals, especially in the significant discussions around research goals and budgets. Researchers should only consider submitting proposals for co-design research if they have discussed and negotiated the proposal with community partners and there is joint commitment to the research goals.

Furthermore, continuous engagement, communication and negotiation with community organisations were required and meant moving at a slower pace than expected; however, this ensured that there was agreement on important aspects.

Strong relationships mean that realistic and honest conversations can be had, and assumptions are not being made.

> When you build that trust you have a willingness to challenge each other and a willingness to listen and respect each other with the commitment to the project and the end goal.
>
> *University researcher*

Informants emphasised an additional benefit of establishing strong relationships. Once researchers and community organisations have built up a trusting relationship, there is a solid foundation from which partners can springboard into further collaborative projects.

5.2   Co-design must take cognisance of accountability relationships in communities

University researchers need to recognise the tensions for those working in community organisations. Māori and Pacific organisations hold strong accountabilities to their communities, whānau, hapū, iwi and other community organisations who participate in the research.

Community organisations reflected that how they act in research-related activities will impact their ongoing relationships with their communities. This can create tension between what academic researchers want and what the community organisations need to do when involving communities that they know and are often a part of. Community organisations and their kaimahi (staff) are most often the 'seen faces' in the community for the research project. Managing the tensions of community organisations and their relationships with those communities who engaged in the co-design research was a significant and constant challenge for community partners.

> So, they [communities] are learning to trust us alongside that whole engagement process.
>
> *Community partner*

Thus, university researchers should understand these accountabilities and support research that is conducive to upholding the integrity of ongoing relationships (both their partners' and their own).

5.3   Co-design requires time

Co-design was seen as requiring more time than usually allocated in a standard research process, as it involves doing more steps together with the co-design partners. Pacing the research alongside the already busy community organisations was a significant challenge. Community partners are often busy with their own work and contract deliverables, as well as maintaining the community relationships through which the research is implemented. Giving communities the ability to lead the pace of the research was important, as they are often focused on implementing health services and are not necessarily set up for research.

University researcher feedback noted the significant time that it took to develop new relationships with community organisations, as well as the trust needed to work together effectively. Time is required for collective discussion around vision and values, allocation of resources, and setting and implementing collaborative ways of working. Negotiation and good communication were continued through a collective and ongoing journey of co-design, testing, implementation, and evaluation. Understanding a community organisation's way of working and the different needs and challenges that they experienced was important. It was noted by one research group that a two-year time frame for research is not long enough to engage and explore things in-depth with Māori and Pacific communities.

> So, there was all the best intentions and great willingness to work together and then there was just delays that were beyond our control as researchers, beyond their control as providers.
>
> *University researcher*

5.4   Co-design requires flexibility

Co-designed research was experienced as being very open-ended about what will be designed. This enabled community partners and communities to have a say in what was designed. It was acknowledged that because of its very nature, there is no certainty about what will be designed and, sometimes, how things will occur, and this can be challenging for both co-design partners and funders.

> But it was like you were just walking around in the dark, not knowing where you were going, if you're going to get to the other end or achieve your goal because everything was just… keep moving.
>
> *University researcher*

There was recognition of the need for flexibility in the research processes, parameters, budgets, time frames, and the co-design outcomes that were envisaged, as well as the research outputs. There were instances where research parameters were redefined, and research time frames and budgets reset. One university researcher noted that at times, it was like "crystal ball gazing" to work out the budget and "hoping that you've got enough money". Timelines and budgets are frequently "best laid plans" that need constant reviewing, reflecting the iterative and ever-changing environment that is the co-design research process.

The need for flexibility around the research focus was particularly evident because community partners often had different perspectives around what was important and how research should be undertaken in communities. Changes were made in a number of aspects of research design, including the definitions and parameters.

In some cases, unforeseen circumstances in the wider social environment required significant reviewing and adaptation of the research process. This significantly impacted on several community organisations, which meant they were unable to continue in the research and dropped out. Learning to plan for unanticipated issues will be helpful.

Significant delays to the process were experienced in several projects because of the need to respond to issues raised by community organisations. Such delays caused some anxiety for university researchers because of the need to collect data and provide results to meet deliverables and deadlines. Needing to be patient and flexible with reporting accountabilities such as dates was a key lesson and requires the funders and commissioners of the research to be on board with that.

Successful co-design requires funders to be flexible in their expectations, e.g., meeting research milestones. To better support a successful outcome, funders could consider funding in stages: a pre-research phase for relationship-building and ideas development and negotiation; a co-design research process phase including design and testing; and implementation and evaluation phases.

5.5 Co-design requires transparency in the use of frameworks and methods

Research teams in Healthier Lives-funded projects used a variety of models and frameworks in the execution of the research, including models of social change, community based participatory research, co-design approaches and frameworks used in the health and other sectors.

Traditional research methods, culturally specific methods and design science methods were used to understand end user feedback on needs and solutions. For example, design thinking tools and processes, co-design workshops, interviews, hui, wānanga and discussions, as well as other research tasks, were used with community partners, participants and other key stakeholders in designing solutions, as well as testing, delivering and evaluating solutions (interventions, products or programmes).[6] Aspects of Design Thinking (mindsets, activities, and tools) were used in some of the training and co-design facilitation with several communities, as well as Māori or Pacific models and approaches. However, utilising cultural approaches and concepts, or adapting methodologies to incorporate a cultural view, were key in engaging Māori and Pacific communities.

How these activities were undertaken, with whom, and at what stage of the process, varied across the different research projects. As stated previously, being transparent about the frameworks, approaches and methods used, as well as when and with whom they are being used, enables partners to engage actively and critically in the co-design process.

Additionally, co-design research needs to be cognisant of the language used. Academic language is specialised and often discipline-specific. Participants in this study noted that the nature of some of the discussions around models and references to literature felt unfamiliar and difficult to grasp. Examples included developing an understanding of both co-design and the technical aspects of digital products (such as apps).

6   A key proponent of Design Thinking is the Standford d. school, see:
     https://dschool.stanford.edu/resources/getting-started-with-design-thinking

> I think that had a little bit more technicality to it because it was about some digital spaces that I certainly wasn't well versed in, so as well as learning the concept of co-design, it was also being able to understand that digital view which was very new to me.

Community partner

An unfortunate consequence of the language gap between university researchers and community partners was that sometimes the latter were not as engaged as they would have liked. Bridging the gap between academic-technical language and that of the co-design situation may be needed to support those not from the academic research world. However, there were good examples of research projects incorporating the language and cultures of communities, e.g., te reo and tikanga Māori, and Pasifika language and culture, particularly in the engagement with communities.

5.6   Co-design is an opportunity for reciprocal capacity building

Aspects of co-design, design thinking, research and cultural processes were seen as new to some of the university researchers, community organisations and communities involved. Opportunities for training, upskilling, and sharing knowledge in these areas were provided in the research projects and were well-received and valued, benefiting both community and academic partners. These capacity-building activities were a key part of the co-design approach in several projects. They included educating and building understanding for co-design amongst both university researchers and community partners; supporting communities to lead co-design approaches and undertake research tasks; developing greater understanding of cultures; and building community understanding around why the research was being undertaken.

University researchers learnt more about the cultures and languages of the participating communities, while the latter became familiar with the technical language used in both research and design. It was recognised that this form of learning takes time; not factoring in adequate time can create significant barriers to full engagement and understanding.

The expertise and skills of both communities and university researchers were shared across project teams. This contributed to an understanding of community and research practices and increased cultural awareness.

> The most interesting part of what the co-design process did throughout was build relationships, build capacity and build capability and bring people along that journey, because it allowed for a continual iteration and listening and checking, versus assuming and dictating, and then potentially failing.

Community partner

In addition, resourcing community roles to support the research was a capacity-building strategy employed by a number of the research teams. This approach was well received by community organisations; discussion around resource allocation at the planning stages was seen by some partners to be a more equitable process.

5.7 Co-design must involve the right people

Having the right staff to participate in the research was seen by community partners as crucial for ensuring project success. It was evident that community partner leaders and staff were knowledgeable about, and had good relationships with, their communities. This ensured community engagement in the research. Community organisations also relied on existing staff to participate in the project, at least initially. Some projects also funded additional roles e.g., community research roles based in the organisation. Getting the right staff from the start was seen as "less fixing up later on." This included having key leaders and decision-makers available to participate in initial research discussions and the right people to introduce new staff and community researchers to the community. Those who coordinate the project, train staff and implement the research must be acceptable to the community.

> So… it's critical… the stuff that [the community researcher and others] are doing, because if you don't do it well, then all you're left with is the literature review.
>
> *Community partner*

Having Māori or Pacific staff and community researchers was seen as essential for a number of the research projects. In one case, being Pacific was critical to ensuring that Pacific communities and organisations were engaged in the research at the outset and that Pacific voices were heard throughout the design process. On the other hand, having non-Pacific and non-Māori researchers also worked well in several projects due to the attributes of the researchers, as described in the next section.

5.7.1 Researcher attributes for co-design

Important attributes of academic and community researchers that helped establish good working relationships between researchers and communities were identified by community partners as follows: being humble when meeting with communities to co-design; encouraging leadership and guidance from the community; being culturally competent and comfortable in community settings; and being respectful and using language that is understood by others in the community.

> They came across very humble - like, they knew nothing, we knew everything. Even though we know that they knew stuff, you know? So, they were willing to learn from us as much as we were wanting to learn from them. Never pushed those boundaries, never, ever, came across like they did know more…
>
> *Community partner*

Some of the negative perceptions and experiences of research in communities can be overcome when the appropriate cultural processes are used, and the appropriate community researchers are involved. Often, but not in all cases, such researchers were Māori (in Māori communities) or Pacific (in Pacific communities). Where there were non-Māori or non-Pacific people involved in a project, the attributes of humility, respect, kanohi kitea and contribution (giving and serving others) were apparent and went a long way towards establishing effective relationships. The support provided by wider Māori and Pacific teams that facilitated introductions of non-Māori or non-Pacific research team members was also seen as essential for the researchers to be effective.

5.7.2 Adaptation to organisational staff turnover

For several community organisations, a key challenge was having sufficient internal capacity to support research activities, as research is often not seen as a community organisation's core business. Additionally, filling the necessary roles when staff left was a common challenge. Several research projects experienced staff turnover, particularly those involved in representing community organisations or providing key research roles. This impacted the community organisations' participation in the project and how the research developed. For example, in one project the research was flexible enough to adapt and utilise the new staff's expertise, although this took the project in a slightly different direction. Passing on the baton to new staff was important to get right given that changes in staff can cause significant delays to the execution of any research. Ensuring good communication across the research team, as well as with staff, facilitates a more seamless approach to staff turnover.

5.8 Co-design must resource community organisations appropriately

Resourcing for co-design was an important issue raised by this study's informants in terms of ensuring communities had fair and sufficient resourcing to participate in the research project. It was found that in some cases community groups felt they did not have enough resourcing to do what was being asked of them. A number of research projects provided funding for community researchers (either full- or part-time) to be employed by community organisations. The purpose of this model was to share resourcing more directly and provide some capacity within the community partners; however, at times this was not necessarily seen as sufficient.

There was acknowledgement by university researchers and community partners alike that it was difficult to determine what the research process was going to look like because of the co-designing approach. Consequently, neither university researchers nor community organisations had a clear idea of how much resourcing and personnel involvement the research would need. In some cases, re-aligning budgets was required to provide adequate resourcing for community organisations. Thus, ongoing review of resource needs is important.

> And none of us … expected … what it was actually going to be… and [how] involved for each organisation… and actually it was really quite a big output from us so … didn't feel like [it] was remunerated as well as it could have been.
>
> *Community partner*

> And we're at the table from the beginning. Because that will help us prepare ourselves before we get into the co-design phase… and then the budget, staff resourcing… because … you'll recruit to the resource that you have.
>
> *Community partner*

5.9 Co-design requires innovative and sustainable funding approaches

Obtaining funding for co-design research through traditional funding streams is difficult. Funders tend to favour research projects linked to a specific product; the end-product of co-design is, however, unknown at the outset of the co-design process.

The sustainability of the programme or product that was co-designed was probably the single most important issue for the majority of those interviewed. While much effort went into attempts at sustaining the programmes once they had been designed and trialled, finding additional funding was difficult. A strong feeling of disappointment and dismay was noted by community organisations and university researchers alike when a programme was unable to secure continued, sustainable funding.

> It was a brilliant piece of over four years work [but] I didn't feel it had some sustainability. We always knew I think at about the third year, that we needed to start tracking and looking for some levels of sustainability. We just didn't get there.

Community partner

5.9.1 Funding for design, implementation and evaluation

Understanding partner and community expectations for implementation is important in co-design research, as often there is an expectation that the co-designed programme or product will be implemented into communities for their use, rather than just tested. Intentionally planning for life after the initial research is a vital part of the co-design process with communities and community organisations that are implementing 'live' programmes. Such planning can include consideration of the future adaption and maintenance needs of programmes/products; building in funding for implementation; identifying important data collection needs; defining the ongoing roles of partners in implementation; ensuring ongoing sustainability of research relationships; and recognising that the stakes are often higher for community partners and their relationships with communities.

Involving key funders at the outset of the co-design process can be useful insofar as their understanding of the designed programme builds over time. Testing in the real world after the initial testing phases can provide further refinement and, in the context of Healthier Lives projects, was considered critical by community organisations.

Specific and targeted research funding for further refinement and adaptation in different contexts may be a useful way to approach research and development, with already established goodwill partnerships. Equally important, however, is documenting what good co-design research can achieve. If co-design can show that it provides effective outcomes, there is a greater chance of future funding.

6. Te tū rangatira i roto i te rangahau hoahoa tahi
Integrity in co-design research

This study highlighted that a key element for success is being clear and transparent about the way university researchers and community partners conceptualise and implement co-design. The way co-design is conceived becomes a reference point for expectations of the research and design approach, how much involvement one has and who has the power in decision-making. Research and design elements can include deciding on the initial research issues, research methods, allocation of resources, design and testing of solutions (prototypes or pilots), implementation and evaluation.

There are a variety of ways university researchers and community partners conceptualise co-designed research methodologies and methods. Getting this right at the beginning will assist researchers to implement co-design with integrity and pay attention to the relationships and the needs of both communities and researchers.

The following section presents a concept model that was developed by the authors while reflecting on the different co-design implementation experiences within this study. There are nuances within co-design research implementation that require attention: how partners and communities are involved; and how the ways they are involved impact on each partner organisation and the research itself.

6.1   Co-design research integrity poutama

This study found that there were different levels of participation in co-designed research. An explanation of each level is outlined in Figure 1. The Co-design Research Integrity Poutama is informed by the traditional poutama pattern found in Māori weaving and other artforms[7] and by Hart's ladder of youth participation (Hart, 1997). This conceptual poutama drew on descriptions of co-design features within Healthier Lives research projects and the aspirations of the university researchers and communities involved. It presents the steps toward higher levels of co-design integrity, starting from the bottom step (which is NOT a co-design approach) towards more authentic co-design implementation at the top. The poutama incorporates elements of co-design that can impact on the effectiveness of the co-design process, outcomes and relationships.

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7   The poutama is a pattern found in wall panel weaving, shaped like a staircase. It represents the journey of either Tāne, or among some iwi, Tāwhaki, to the heavens to obtain the baskets of knowledge. It is a pattern which symbolises both the pursuit of knowledge and the striving for human progress. | He tauira tukutuku te poutama, he rite ki te arawhata te āhua. E tohu ana i te pikinga o Tāne, o Tāwhaki rānei ki ngā rangi ki te tiki i ngā kete o te wānanga. He tauira hei waitohu i te whāinga i te mātauranga me te ahunga whakamua o te ao tangata.

Co-design Research Integrity Poutama

Level 3: Shared governance and decision-making

A community-led, or co-led and co-constructed approach. Researchers and community partners engage at the conceptualisation stage, formally agree on governance and share decision-making throughout the entire project.

Level 2: Community partnership formalised

Researchers initiate the project. Community stakeholders are engaged in a formal partnership and negotiations are ongoing throughout the project.

Level 1: Researcher initiated and led

Researchers initiate the project. Community stakeholders are engaged at certain points but their involvement is often ad hoc, partnerships are not formalised and they have less power to make decisions.

Consultation only

Researchers inform community stakeholders about the research project and consult them about some aspects of it. Community stakeholders have some input but don't make decisions.
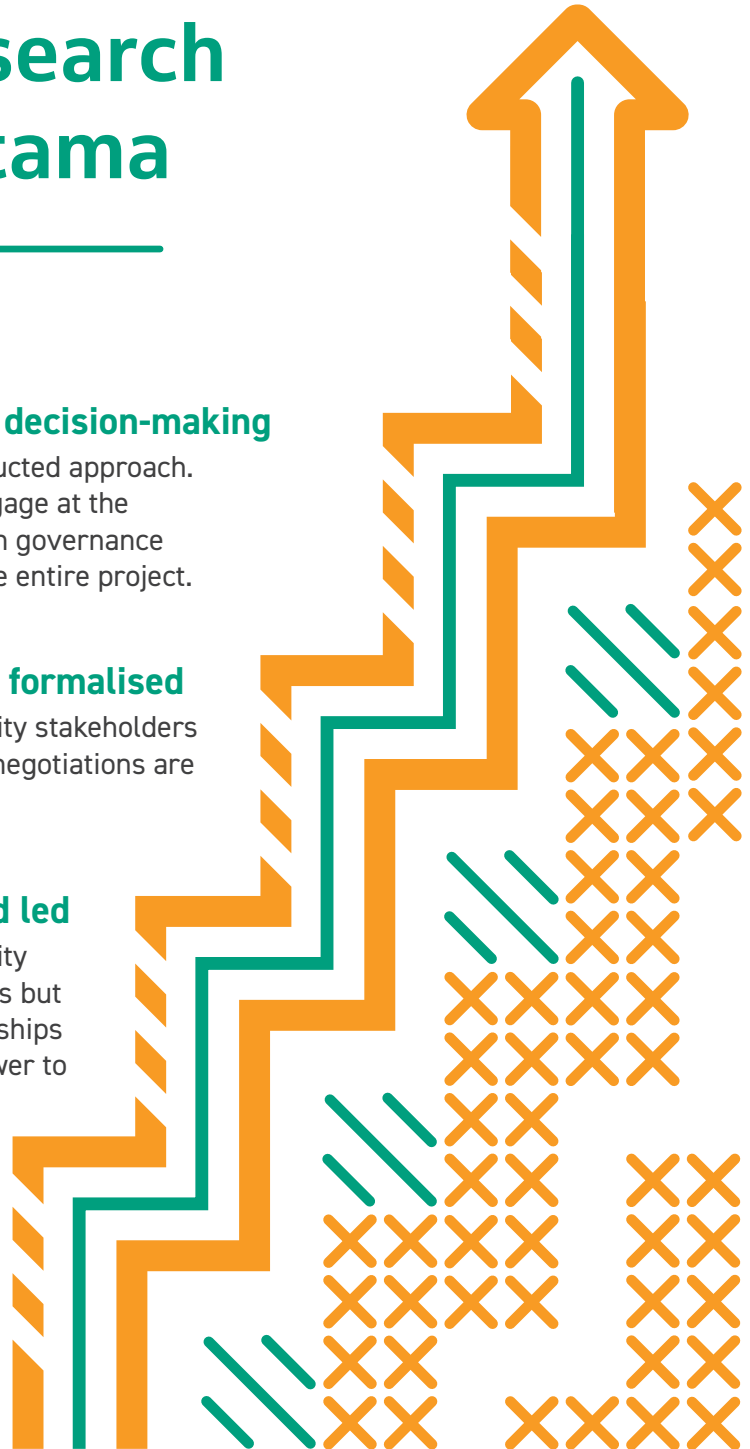
Figure 1. He poutama mō te tū rangatira hoahoa tahi | The co-design research integrity poutama.
There are different levels of participation in co-design. This conceptual poutama presents steps towards higher levels of integrity in co-design. Consultation alone is NOT a co-design approach.

6.1.1   Consultation only

In a "consultation only" process, community members and potential users, health and service providers and other key stakeholders have no decision-making power regarding the research or solutions; the locus of power in the research relationship remains with the research team. This is not considered to be co-design, as it involves consultation only rather than partnership.

While all the research projects in this study undertook some form of consultation, they also engaged more deeply with specific groups, communities and/or providers to design and, at times, test solutions.

One community representative described an often-used health research approach that entails researchers collecting narratives from stakeholders to inform design and then completing the design and delivery separately.

> It's like, we're going to take your perspectives and we're going to design something up and we'll deliver it and it's, kind of, just left at that.
>
> *Community partner*

Thus the "consultation only" level of the Poutama is not considered to be co-design and is not ascending the ladder.

6.1.2   Level 1 - Researcher-initiated and led

At Level 1, there is no formal partnership with community groups; researcher-initiated and researcher-led choices and ideas predominate. This level involves having users represented on research teams or participating as advisors. However, without a balance of community members and university researchers at the table, the degree of joint decision-making is questionable. While the outcome may still be worthwhile, the extent to which power is shared with communities is limited.

In some of the projects in this study, community participation was ad hoc and employed iterative phases involving a range of different stakeholders at any one time. This method resulted in greater reliance on researcher-led approaches for the design and solutions. But this did not mean that the process used was less extensive or comprehensive. On the contrary, some of the examples involved substantial user (and other stakeholder) feedback over several months or years.

However, ad hoc input at varying stages of a project may be seen as consultation rather than a commitment to partnering, and opens itself up to critique from communities about integrity in co-design. Based on this study's feedback, the researcher proposes that for integrity in co-design to be demonstrated by university researchers, the processes used must be in line with community perspectives on co-design. This is particularly pertinent to Māori communities because of the Crown-Māori commitment under Te Tiriti o Waitangi to partnership, and to enable Māori self-determination. Co-design as partnership requires shared decision-making at the level of governance and operations.

6.1.3 Level 2 - Community partnerships formalised

Community partnerships are formalised at Level 2 through invitation by the university researchers, with resources offered, agreements signed, and contracts established. Much effort is put into initiating, engaging, developing, and maintaining partnerships. A number of research projects engaged community organisations by spending significant amounts of time on relationship building, ongoing communication and negotiation of roles and resources throughout the research process. Joint values were set, capacity building and training provided, and community-based staff were resourced.

Community partners were involved in decisions about key elements of the design of products or programmes. Examples included decisions to: create an app[8] (as opposed to other forms of mobile-phone-delivered health products); focus on a significant and hard-to-reach population group for co-designing a programme; develop culturally relevant material; and broaden research parameters.

Working with discrete partners inspired community ownership and allowed for a greater focus on capacity and capability building and ongoing relationships. It also enabled greater user/stakeholder involvement in analysis and publication of research, as well as in testing co-designed programmes on the ground. Furthermore, the partnering process provided for greater communication and the ability to challenge university researchers on issues affecting community partners, such as negotiating boundaries around intellectual property rights, and the need for greater resourcing. There were examples of university researchers adapting processes to ensure that the realities, needs and aspirations of community organisations were included. One university researcher described maintaining the integrity of the collaborative design process by keeping to agreed values and ideals of shared decision-making throughout the process. This was a significant achievement given the stress of reporting accountabilities for the research funds.

> I think we did a brilliant job in terms of a co-designed project for what we said co-design was going to be and how it was going to look – we did that, we delivered on that.
>
> *University researcher*

These examples demonstrate that genuine negotiation in partnership relationships requires the commitment of all project partners in the project, as well as flexibility. The majority of community partners remained in the project throughout the co-design, implementation, testing and evaluation processes, and were positive about the relationships with researchers.[9]

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8   An application downloaded by a user to a mobile device.
9   Several community partner groups did not continue due to lack of capacity to participate and unforeseen circumstances around their organisation.

6.1.4 Level 3 – Shared governance and decision-making

At Level 3, the project is co-led and co-constructed. Understood as "co-design with integrity", this level involves researchers and community partners being engaged at the conceptualisation stage of the research and agreeing on shared governance and decision-making for the entire project.

Some informants viewed this as the ideal goal and definition of authentic co-design research. Although none of the projects had community partners on board at the proposal stage of the research, going forward into any future research projects in this manner was important for community partners. This would mean that discussions about the research focus, resources and other sticking points (such as intellectual property) could be negotiated early on. Being named on a research proposal as a research partner or co-investigator was also seen as important for acknowledging the skills, knowledge and deep expertise of the community and its leaders.

7. Kupu Whakamutunga
Conclusion

7.1   Co-design is a valued research approach

This study highlighted the value and benefits of co-design, particularly with Māori and Pacific community partners, as well as ways in which co-design can be improved. The lessons learnt from the shared experiences can help inform more authentic and equitable approaches to co-design in future research. To this end, the study provides guidance for planning and articulating how and when partners and communities will be engaged in co-design research and will assist in anticipating some of the issues before they arise.

7.2   Co-design with Māori and Pacific communities

This study established four key elements that should be taken into account when working with Māori and Pacific communities in co-design research: te mātauranga o tētahi hapori, te kōtuitanga taurite, kaitiakitanga, and rangatiratanga. The inclusion of these elements in any research endeavour can ensure a more equitable and considered approach to involving communities in co-design. They can be used alongside Te Whetū evaluation principles to describe what good co-design looks like for Māori and Pacific, having been drawn from both Māori and Pacific community perspectives.

7.3   Co-design with integrity has many benefits

This study proposes that formalised partnerships and shared decision-making brings integrity to co-design, resulting in benefits above and beyond the generation of research findings. These benefits include: increased community buy-in and improved recruitment and retention rates in community-based studies; "out of the box" research solutions not necessarily considered by academic researchers; more culturally cognisant solutions; the building of capacity and capability in both communities and research teams; the ability to co-publish evidence on the effectiveness of programmes in Indigenous communities; and communities being more discerning about, and less fearful of, involvement in future research.

7.4   Co-design offers opportunities for building more equitable research

While the co-design projects in this study were largely led by academic organisations, it was evident that Māori-led and Pacific-led approaches were desired by community organisations, particularly as they already knew their communities well and had a good understanding of their communities' cultures and lived experiences. Where research tasks were led by Māori/Pacific academic-based researchers, Māori/Pacific community-based researchers and Māori/Pacific community organisations, there was evidence of strong and trusting relationships, increased capacity, reciprocity of skills, networks

and knowledge within research teams and communities, and often greater connection to whānau and community participants. Non-Māori researchers and community researchers also played a part in this by supporting with humility, open minds and a willingness to serve the community.

There is more opportunity to support Māori and Pacific organisations to lead research that matters to them and their communities, while operating in a co-design relationship with academic researchers. An authentic co-design partnership combines both the necessary research expertise with local community and cultural expertise and builds greater research and cultural capacity among the partners. Ultimately, new and valued relationships can create a shared understanding and a true sense of working together or mahi tahi. More appropriate research and intervention models are therefore developed, communities and community partners have greater influence, decision-making processes are shared, and greater equity in research outcomes is achieved. Implementing good co-design research necessitates paying attention to relationships, being transparent in the use of co-design processes and ensuring appropriate resourcing.

Research projects with Māori partners and communities (and those of other Indigenous or minoritised groups) must incorporate the elements of **te kōtuitanga taurite**, **te mātauranga o tētahi hapori**, **kaitiakitanga**, and **rangatiratanga**. Those projects which actively and authentically address these elements may be regarded as aiming for, and ultimately achieving, excellence of co-design in Aotearoa New Zealand.

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Tāpiritanga 1
Appendix 1

Healthier Lives co-designed research projects, 2015-2019

Project	Type of Study	Outputs	Selected Publication
He Pikinga Waiora: making health interventions work for Māori communities	Implementation science	**He Pikinga Waiora** Implementation Framework, a kaupapa Māori framework to guide the implementation of new health programmes. Two co-designed health programmes aimed at preventing diabetes and other NCDs: o **Kimi Ora** o **Poutiri Health Challenge**	Oetzel, J., et al., Implementation framework for chronic disease intervention effectiveness in Māori and other indigenous communities. Global Health, 2017. 13(1): p. 69.
OL@-OR@: a Māori and Pasifika mHealth approach	Cluster randomised controlled study	**OL@-OR@ healthy lifestyle app** with separately tailored versions for Māori and Pacific Peoples	Ni Mhurchu, C., et al., A co-designed mHealth programme to support healthy lifestyles in Māori and Pasifika peoples in New Zealand (OL@-OR@): a cluster-randomised controlled trial. Lancet Digit Health, 2019. 1(6): p. e298–e307.
The Pasifika Prediabetes Youth Empowerment Programme (PPYEP)*	Mixed methods evaluation of two health programmes including a cluster randomised controlled trial	**Youth-led programmes** aimed at reducing the risk factors for prediabetes in Pasifika youth and young adults.	Firestone, R., et al., Pasifika Prediabetes Youth Empowerment Programme: learnings from a youth-led community-based intervention study. N Z Med J, 2021. 134(1530): p. 57–68.
Mana Tū: a whānau ora approach to long term conditions*	Mixed methods evaluation of health programme	**Evaluation of Mana Tū** programme, aimed at better management of poorly controlled diabetes in primary care.	Harwood, M., et al., Mana Tū: a whānau ora approach to type 2 diabetes. N Z Med J, 2018. 131(1485): p. 76–83.
WellConnectedNZ – Improving individuals' health by strengthening community connectedness – a proof of concept initiative*	Mixed methods evaluation of several initiatives	**Pou Ārahi** (guideposts) for empowering healthcare professionals **WellConnectedNZ™ map**, an interactive map of opportunities for social connection in Christchurch.	Wilkinson, A., et al., Maintenance and Development of Social Connection by People with Long-term Conditions: A Qualitative Study. Int J Environ Res Public Health, 2019. 16(11).

* This project was co-funded by Healthier Lives, the New Zealand Ministry of Health and the Health Research Council of New Zealand as part of the Long-term Conditions Partnership.

Tāpiritanga 2
Appendix 2

Benefits of co-designed research

The following tables summarise and provide examples of the benefits that were discussed by the different partners (academic research teams and community partner organisations) working together in the co-design research. It should be noted that some benefits reported in one column relate to perceived benefits for the other partner. In general, there was good consensus from both groups about the benefits of co-design research but some differences were noted.

University researcher perspectives	Community partner perspectives
Culturally cognisant programmes/products A number of the resulting products/programmes were seen as making a difference for participants because of the input from the community perspectives and the inclusion of culturally appropriate material. The products/programmes were seen as something tangible or meaningful to communities. **Retention rates and equitable outcomes** Other benefits included excellent retention rates, equitable outcomes and one programme also showed that those who had completed the programme had experienced much less racism. "It helps achieve equitable outcomes and benefits for whānau." It was "what the communities wanted." **Identifying further gaps** An example from one of the research projects affirmed the need for the system to be able to fund co-creation processes and "un-silo" their systems. **Short-term sustainability** There was short-term (one year) sustainability for a number of the programmes. Community partners adapted and used the models after the initial research.	**Culturally cognisant programmes/products** Increased awareness among researchers and attention to aspects of culture in the research added value. Additional research contracts for community organisations and co-development of proposals have occurred since the original research. "But I think it added value to that process for the research to be mindful of these other determinants of Pacific peoples… not determinants of health but determinants of who we are. And I really enjoyed (this project)… and they may not have understood it, but they still embraced it and I appreciate them for doing that." The support from other Pacific groups in the research around cultural connectedness or feedback on other aspects was helpful. **Retention rates and clinical results** "Great clinical results, and great retention because of the responsiveness of the programme to whānau participants." **Short-term sustainability** A key outcome was the development and short-term (one year) sustainability of new programmes. **Empowering whānau** Empowerment for whānau participating in the designed programme was valued by community organisations. The outcomes of some programmes were seen as good clinically and socially for whānau. "Empowerment, I think was a strength of and a really good outcome of the programme."
Credibility created for community organisations Community organisations developed capacity in research and were seen to aspire to setting up their own research projects. Co-authored papers and shared conference presentations also provided avenues for community organisations to participate in research dissemination.	**Credibility through involvement in research** Being named on academic papers and being involved with an academic research team was seen as very beneficial for community organisations, as it raised the credibility of the organisation.

University researcher perspectives	Community partner perspectives
Increased publications on research relevant to communities Reporting on marginalisation of Pacific populations and its impact on health and wellbeing was a key outcome of the Pacific data from the research.	**Increased opportunities for evidencing community innovations** Researchers can help raise awareness among funders at regional and national levels of the "amazing innovations" and community-driven initiatives already happening in the community. "Those amazing innovations that are actually so good are not seen." Often these initiatives just need "little tweaks" to capture the impact, and time to communicate these impacts to funders. It was noted that often provider staff are "so busy doing" they don't share the good stuff.
Community buy-in There has been some community buy-in of the intervention by the community organisation but the extent of this is yet to be seen. "I would hope the communities felt they owned the programme and see it as a resource to shape it to fit their community."	**Community buy-in** Bringing people along on the journey, listening to people and responding with continual iteration of the design was a good outcome. "Heaps of unintended benefits or consequences from that process." Young people have continued meeting after the research because of their relationships.
Relationships with community organisations Strong relationships built with community organisations – "it would be good to see more come from these relationships in terms of building on and taking that forward in some way."	**Relationships with academic organisations and other service providers** For community organisations, building relationships with academia and other organisations was seen as a core benefit. The "connecting and working with the other community partners was great, as well as connecting with the research network of academics and the overall Healthier Lives project." "And made some really good relationships and rekindled old relationships so yeah, there were lots of mutual benefits too, along the way, which don't need to add up to money, you know." "It was an enjoyable experience and enabled us as an organisation to connect with new groups and extend our reach out to others across Auckland."
Building capacity and capability Funding for community organisations provided extra resources to assist with participating in the research. Research experience and knowledge was built in community organisations. There was a focus on ensuring the reporting was meaningful and could support funding proposals for community organisations. Some of the youth involved in the project have chosen to go on and study. Increased cultural knowledge in researchers.	**Building capacity and capability** Capacity and capability were built in community organisations in co-design and research approaches; it provided additional resources and increased skills. People were able to take on learning in lots of different ways and were seen to take that into their own lives and communities. "And the most interesting part of what the co-design process did throughout was build relationships, build capacity and build capability and bring people along on that journey because it allowed for a process of continual iteration and listening and checking, versus assuming and dictating, and then potentially failing." A huge value was the involvement of young people in training, being given tools to use and then being able to design their own initiatives, research them, prepare them and implement them.

University researcher perspectives	Community partner perspectives
Learning about co-design approaches Learning for researchers about co-design methods and enthusiasm for using those approaches going forward was noted as an outcome for this research. One example supported learning about what co-design could look like from two different theoretical perspectives; a Pākehā based one and a Pacific worldview.	**Learning about co-design approaches** Organisations learning about how to co-design and implement programmes with communities was a key result of this research. One Māori organisation noted it was the first time they had been involved in co-design research, while others reported they already did this.
Internal learning for researchers and health practitioners Some researchers shared how the research provided personal and professional learning opportunities. We have to get over our own barriers "before this kind of co-creation will actually work properly." An example of the barriers talked about were the attitudes and mindsets of researchers and health professionals that look at what can go wrong, rather than what can go right, which often stops anything happening. **Researchers' personal learning and achievements** PBRF outcomes were achieved, as well as learning more about research, working in diverse teams, and working with people whose voices are not usually heard. "I found that pretty powerful, listening to those stories and working in that space, yeah."	**Learning for community organisations** Aspects of learning for community organisations included learning about research. Community leaders have broadened their views about implementing their programmes and connecting to the community, focusing more on "co-design and client-centric care." Research roles can bring different ways of thinking to a community organisation about how things are going, how things can be improved and where other potential research projects and programmes could exist. "Yeah, it's good for us to be able to get into an academic space, as a small Māori organisation, we don't get that many opportunities." "[The organisation is] looking at different ways as to how we can deliver services and different ways as to how we can connect into the community and provide better healthcare support for our whānau." **Learning from others** One community representative learnt a lot from the young people involved in the project. Community representatives felt it was great to engage with the youth who are a priority group and gaining an understanding of their worldview was very helpful. Researchers willing to learn from the community was also noted. "The [researcher] was willing to learn from us as much as we were wanting to learn from [them]." Another lesson was the importance of disseminating the research learning back into the community and the research teams staying committed to that.
	Greater assertiveness in community organisations The importance of being involved at the very beginning of the research to discuss resource and budgets has helped community organisations be more discerning and assertive regarding other research projects that have come their way since and how they will participate in them.
	Decreased fear of research in communities The community embraced the research and found it a very positive experience because of its bottom-up approach. They don't have a fear of research being: "some high-up academic thing that might be difficult to understand. Instead, they were fully engaged in the process and really wanted it to be a successful project, so they now aren't afraid."

Tāpiritanga 3
Appendix 3

Vignettes

The vignettes outlined in this section tell us more about how each project conceptualised and implemented co-design research, from the perspectives of both the community partners and the researchers who were interviewed. The vignettes were drawn directly from interviews and written by the author in an informal style to give life to the stories of co-design research experience. They were checked by interviewees and feedback was incorporated.

OL@-OR@: How co-design was conceptualised and implemented – Community partner perspectives

"Co-design research was an opportunity for equal partnership, ensuring community organisations could directly influence the research project by using Pacific and Māori cultural frameworks, concepts and methodologies. A structured process for co-design allowed time and space for talanoa/hui and acknowledged the importance of ethnic-specific perspectives and languages as well as other aspects, such as urban and rural accessibility. Co-design enabled practical improvements in terms of the development of services and provision of care, informing: "policy changes toward better care for [the] community." It was also welcomed as a refreshing change to the many research projects that had come through their organisation over the years and resulted in research fatigue.

Co-design was already an intentional part of one community organisation as what they deliver is based on co-design with their communities: "It's a community-owned organisation, that's always been our mandate." Their experience of building trust and relationships with their community and then co-designing results in the community meant that the community not only articulated the issue or the challenges but also how they wanted to receive or develop the solution.

For a number of community partners, understanding what co-design was in this particular research context took some time to grasp. However, it was felt that co-design was a lot more than consultation and that there was a whole process around it involving "creativity and storytelling." A cultural perspective was important to intertwine with the design thinking tools.

> The communities are equal partners to this.
>
> *Community partner*

> For us, knowledge of tikanga... empathy... I think its empathy and along with a knowledge of design thinking approaches and how, creatively... you can use the tools to ask some of those questions and have people participate.
>
> *Community partner*

Community partners agreed that the use of a Māori co-design facilitator brought tikanga knowledge, pūrākau knowledge and how to engage with people and use the design thinking tools with empathy and understanding.

A Pacific way of co-design was seen as talanoa and having good conversations.

Use of talanoa as the main method for co-design helped to engage the different ethnic-specific groups as well as youth. This was undertaken in their first language and translated back into English.

> We aimed to understand what the worldview of health was to these different groups, and what the challenges were, using creative methods such as art. We aimed to understand how they wanted to be communicated to which informed the OL@-OR@ app.
>
> *Community partner*

Community partners strongly advised that co-design research needs to "culturally fit our communities." Establishing trust and relationships in a culturally appropriate fashion will help with understanding the communities' challenges and worldviews and designing whatever needs to be designed. Having cultural understanding as well as an understanding of the different languages and the true essence of the conversations is important.

A key attribute of the co-design research was feeling that Pacific cultures, concepts and the nuances of the different cultures and experiences of Pacific peoples were valued and acknowledged and "given a platform where it would have that level of acceptance."

Overall, the implementation of co-design with community organisations allowed the latter to have some influence over the research and provide community context and experience. It was felt by a community partner, that this enabled researchers to:

> ...see another layer of humanness and realness in terms of what theory might say... that we could articulate what it actually meant in our communities which I think they valued too because they didn't know or didn't have a full understanding of... because you know, because I frequently would hear them say stuff like 'Yes, you know, we're really good at writing the theory but you guys tell us what that means in your community' and then we would say: 'Yeah, nah, that's not really good' and then they would adjust accordingly, so it was really valuable to have that level of respect, yeah, to acknowledge that and then be able to change it, well, not change... but maybe even influence their thought processes.
>
> *Community partner*

> The co-design research gave us an opportunity to do co-design in a structured way.
>
> *Community partner*

OL@-OR@: How co-design was conceptualised and implemented – University researcher perspectives

At the beginning of the research, getting end-user involvement in the design of a potential intervention was seen as important; a co-design methodology was suggested by a colleague. The initial conceptualisation of co-design came from its use in the health sector and a six-step framework developed by Bratteig et al (2012)[10] was then used to frame the different stages of co-design, acknowledging that all partners should be involved in all stages.

The "end user" was conceptualised by the researchers as Māori and Pacific communities and community organisations, as the intervention was intended to be useful for these populations. Community organisations involved in the research were seen as key links between the academic team and Māori and Pacific communities as well as being representatives of those communities. A slightly different perspective offered by one researcher was that co-design was about local people and communities "driving the research."

It was pointed out that researchers often state that co-design is being used when what they are actually doing is consultation. Co-design takes time, resources and the building of relationships.

> If you're really going to do true co-design, you really have to invest the time and the resources in building the relationships.
>
> *University researcher*

> Design thinking tools and mātauranga Māori perspectives of co-design were brought into the training to support the co-design facilitation with the communities through a Māori co-design facilitator. Understanding of co-design grew through this approach. The co-design facilitator (trained in design thinking) also helped "translate the framework into something practical that we could use with the communities and co-design partners"
>
> *University researcher*

> Once a common vision, objectives and values had been agreed by all researchers and community partners, the team worked really well "by providing different perspectives and listening to those perspectives really respectfully"
>
> *University researcher*

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10   Bratteig T, Bødker K, Dittrich Y, Holst Mogensen P, Simonsen J. Methods: Organising principles and general guidelines for participatory design projects. In:Simonson J, Robertson T, eds. International Handbook of Participatory Design. Abingdon-on-Thames, UK: Routledge; 2012:117–144.

From a researcher's perspective, community partner/community engagement worked really well; they were "much more engaged in the research than I've previously experienced in research projects"

University researcher

One researcher noted it is difficult for community organisations to include research as part of core business, so we asked, "what can we do to take the fire off you, and we would do it." The co-design research approach "in terms of actually being able to get input from potential end users and design an intervention... was incredible"

University researcher

I think we designed something that certainly as academics alone, we would not have designed.

University researcher

He Pikinga Waiora: How co-design was conceptualised and implemented – Community partner perspectives

Community partners saw co-design as important for working with Māori. It was an iterative, inclusive approach that should be ongoing. It was about "being community led and for us that meant our clients, our whānau on the ground." It kept participants engaged.

A strength of the co-design approach was in the connection and responsiveness to whānau – being able to iterate and change the programme within guidelines, being kaupapa Māori and whānau-centred.

> It allowed for a process of continual iteration and listening and checking, versus assuming and dictating, and then potentially failing.
>
> *Community partner*

> I think the best way to work with Māori is to be able to design programmes with them, for them... by them, even probably run by them.
>
> *Community partner*

> The concept of co-design is invaluable to addressing Māori health (and other) inequities as we are a community-focused society not an individual-focused society. It is key to have a partner agency/organisation who values the time and resource required to ensure that co-design is done properly and is ongoing.
>
> *Community partner*

Co-design was seen as not necessarily about new ideas and innovation; it might be just about reconfiguration, i.e., empowering people, communities and whānau through capacity and capability building: "[w]hen I reflected, that's the thing that held truest over everything that we did."

Learning to do co-design together was a first for one of the Māori organisations and the community involved. Co-design was an opportunity to design a programme with the community, which is something that they had wanted to do and were really excited about.

> A lot of our contracts that we have with [organisation] are given to us from the Ministry or the DHB, as opposed to us designing it, so yeah, I was really excited about that.
>
> *Community partner*

Researchers were acknowledged for being very flexible and helpful and able to adapt to the community members' needs. This was seen as quite different from what they were used to as a Māori health organisation. Humility and a willingness to learn from the community was noted — "(they've) got a very hūmārie āhua[11]."

Turning up again and again to connect with the community members during the co-design process enabled trust to be developed. Having the researchers attend and front the kōrero and be part of the projects was appreciated — "for Māori, kanohi kitea[12] is such a powerful thing."

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11 humble appearance or characteristic
12 to be seen within the community

Co-designing health research in Aotearoa New Zealand

Māori ways of doing things were naturally incorporated into the hui processes, and the research team helped to facilitate a whānau atmosphere. They got the important things right such as "having hui with kai, starting with karakia, acknowledging everyone, enabling everyone to do whakawhanaunga[13] and not taking over the space by making sure that, you know, things are running on time and to agenda sort of thing." There was a sense of ease between the research team and community team where if they needed to say something it was an open floor. They "took our lead."

> Co-design does work... our whānau need to be involved in the solutions, yeah. That was probably the biggest takeaway for me.
>
> *Community partner*

Researchers can help raise awareness among funders at regional and national levels of community-driven initiatives already happening: "[t]hose amazing innovations that are actually so good are not seen." Often these initiatives just need "little tweaks" to capture the impacts as well as time to communicate these impacts to funders. Often, provider staff are "so busy doing" that they don't share the good stuff.

He Pikinga Waiora: How co-design was conceptualised and implemented – University researcher perspectives

This study was originally conceptualised from an Indigenous participatory research approach called He Pikinga Waiora; it bears some resemblance to a community-based participatory research perspective (CBPR). The He Pikinga Waiora approach partners with community groups throughout the entire research process; co-design, co-development, co-definition, co-implementation, "co-everything" and has a commitment to benefiting the community and following the collective voice of communities to determine what will work in their community.

The researchers started with meeting with community groups to negotiate how they wanted to work and be involved in the decision-making process and the design. Building on the existing relationships was helpful but co-design still took a long time: "it's never going to work in one year." The research team had a series of conversations with community stakeholders about how each understood co-design, what the researchers and partners wanted it to look like, and what values and principles they would work with. The questions asked were "What do you want to do? Do you think you want to be involved? How might we do this?"

The research team wanted to ensure their ways of working were aligned with the tikanga and values base of the provider/community organisation. Some researchers played a negotiating role between Māori providers, while others were the "front-facing" members of the team. A key principle informing their way of working was establishing the trust that created a willingness to challenge each other, to listen and respect each other. A joint commitment to the project and the end goal was also important.

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13   to develop a relationship, get to know one another

A key aspect of implementing co-design was ensuring significant resources were provided to organisations and equally shared with both community "sites." Co-governance and shared decision-making were implemented through community organisations helping to make decisions on "big picture aspects of the project" and everyone's philosophies for the project, roles, responsibilities and resources were outlined in written agreements.

Regular informal catch-ups with the community organisations occurred, as well as a periodic process evaluation to check that researchers had done what they said they would do. Initial evaluation indicated to the team that "we weren't as good at sustainability and shared decision-making with the community as we were with relationship building: the community organisations wanted more say in how research measures were implemented; and we needed to spend more time with community staff to check the length of questionnaires - we found they were too long for participants". Changes were made in later stages to address these issues.

Co-design workshops were used initially to draw key stakeholders together and design interventions or programmes. Community researchers (funded by the research and sitting within the provider organisation) worked on the research project and contributed skills and time to other organisational projects. The community researchers were expected to be part of the organisational culture. This required an astute person who could work across multiple dynamics.

Ongoing communication through meetings, hui and wānanga with community organisations and specific staff was undertaken.

> I think we did a brilliant job in terms of a co-designed project for what we... said co-design was going to be and how it was going to look – we did that, we delivered on that.
>
> *University researcher*

Pasifika Prediabetes Youth Empowerment Programme: How co-design was conceptualised and implemented – Community partner perspectives

In our co-design, young people had ownership and responsibility for implementation. Of huge value was the training, giving young people tools to use and then design their own initiatives, from research and preparation to implementation.

Young people's involvement was a success because of the design emphasis on connections and environments, regardless of their gender, ethnicity or age. Bringing the research and training to the young people on a weekly basis over six months was seen as very important. The environment at one of the local organisations was conducive to undertaking the training with young people; they reported that it was safe and familiar and food was provided. The level of creativity of the young people was evident within the project. They developed good relationships with each other and, for that reason, continued with their projects after the research.

The community organisation felt in full control of the overall research project. They were able to be flexible with their budgets to allow different ideas from the young people to be implemented. Contributing to the young people's sense of belonging was important in the co-design context.

> Everything was under our management, and we could be as flexible as we chose to be depending on which way the young people took it.
>
> *Community partner*

The co-design methodology was guided and shaped by Pacific cultural models and frameworks like the Fonofale (Ministry of Health, 2008) so it was inclusive and powerful. There was a really strong cultural connection with the project and between researchers and community organisations: "it was really easy to communicate on a level that we both understood."

For a number of community people, a key challenge was getting them to understand what the research project was and what the process of co-design looked like. The use of the co-design concept had become so saturated, and people were using so many different interpretations of it that its meaning was diluted.

> Everybody has their own interpretation of what co-design looks like... and so now I've moved to co-development. Co-development, which means before you even write the concept on the paper, we're going to have a discussion first, and we're going to set the parameters.
>
> *Community partner*

A good example of working collaboratively was where the researcher discussed and negotiated the research at the outset.

> She'll come to me first and say, 'Look, I think this is a good concept, what do you think?' and then I can add to it and this is what I want to see happen can happen here in this community. So, she'll take it away, do the proposal, send it back and forth, so yeah, that's been, really, really a strong way that we've been able to develop, you know, particular research of interest for both of us, yeah.
>
> *Community partner*

> Overall, it was great to engage with the youth who are a priority group, and to understand their worldview was very helpful. We learnt a lot from the young people involved in the project.
>
> *Community partner*

Pasifika Prediabetes Youth Empowerment Programme: How co-design was conceptualised and implemented – University researcher perspectives

Co-design was viewed as requiring an empowerment process to first build capacity. This involved a five-month programme undertaken with young people before they participated in co-designing modules. Capacity building meant educating and building people's understanding around why the research was needed, which was important for community buy-in.

> The co-design model is embedded within the empowerment programme, so, it's probably important to note that we can't do the co-design without having, doing, the empowerment process first.
>
> *University researcher*

The co-design research was a community-centric and community-led approach, not just a community-based approach. This meant working with the community to try to identify their social capital resources, building capacity and capability, aiming for community ownership of the programmes and identifying how community organisations could continue the programme as part of a regular service through dialogue and talanoa[14].

> Our two Pacific communities undertook the training of the empowerment programme – this was open to the entire community provider, not just the key representatives of the community. It was a good opportunity of capacity development. They were involved in all aspects – with opportunities always being offered to lead the analyses or writing of the work.
>
> *University researcher*

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14   Talanoa is a Pacific concept of formal or informal conversation, sharing ideas and relating experiences and stories (Vaioleti, 2006).

Being flexible with the research parameters and protocols around including the family and community in the interventions was culturally appropriate. Timing was also dictated by the communities.

> Our communities were able to dictate when the study occurred and when it needed to pause due to commitments of the youth and their own work. We had to make changes to the logistics of the intervention to fit the extraneous needs of the community.
>
> *University researcher*

It needed to work for communities, who were already overworked. The researchers were open and flexible to what was going to work best for the community and respected that the Chief Executives were also running core business and that it was difficult to include research as part of the daily business.

Trusting the process was a key part of co-design: "you've got to go with what the community believes is best for them."

There was a strong cultural connection between the researchers and community organisational staff, which enabled a greater understanding of the nuances of culture, easier communication between the partners and an understanding of concepts related to Pacific cultural practices.

Youth took the modules and developed further programmes within their churches, so there was great knowledge transfer.

> I would hope the communities felt they owned the programme and see it as a resource to shape it to fit their community.
>
> *University researcher*

Mana Tū: How co-design was conceptualised and implemented – Community partner perspectives

Mana Tū was seen as "whānau-centred design" because whānau voice was captured in an ongoing way through the implementation phase via the Kaimanaaki. The programme continued to develop in response to the needs of whānau. Kaimanaaki shared the key issues whānau were experiencing on a monthly basis, "almost like it was their own, and so, we felt like, okay, you know, by virtue of going through the Kaimanaaki, we are capturing the whānau voice and we are doing all we can to, sort of, continuously improve or incorporate their perspective in the design."

Thus, co-design was seen as being a continuous process of quality improvement that sought feedback from stakeholders, including whānau as part of an ongoing relationship. This contrasts with a finite process whereby co-design is seen as solely gathering stakeholder narratives and perspectives at the start and therefore the design and delivery is done separately.

> It should be a continuous relationship between stakeholders and there should be that continuous, quality improvement almost, so, you're always going back and, you know, checking – 'is this programme still fit for purpose with the stakeholder groups?'
>
> *Community partner*

The Kaimanaaki role was quite diverse and very challenging. The personality of the Kaimanaaki was the key strength of the whole thing, "so getting the right people into those roles" is important.

Cultural elements worked into the programme included whakawhanaungatanga, karakia (if whānau wanted that) and supporting diverse needs of whānau, e.g., attending Rongoā classes, cultural connectedness. "Empowerment, I think was a strength of, or a really good outcome of, the programme."

> Whānau reported that having other whānau involved in consultations with them was helpful and beneficial to those whānau as well. In future "I'd like to see a whānau stakeholder or advisory group have more influence in a formal, structured way."
>
> *Community partner*

Mana Tū: How co-design was conceptualised and implemented – University researcher perspectives

The Mana Tū researchers described their co-design approach as being like building a plane while you're flying it: "It was very much learn as we go and it was just being open to that." The co-design was iterative from the start to the end of the project. All stakeholders (whānau, GP clinics and Kaimanaaki) were able to continuously give feedback on what was working well and what wasn't, so the Mana Tū team could learn and pivot their approach to better support whānau needs and outcomes.

The process of co-design included meeting with a wide range of key stakeholders over a period of 18 months to: identify gaps together; look at the local and international Indigenous evidence; deconstruct mainstream frameworks for the management of long-term health conditions; ensure whānau wellbeing determinants were being addressed; and support a pragmatic approach by sharing what was working in communities.

Ultimately, it resulted in a new kaupapa Māori model which was underpinned by Māori cultural values and upheld Māori rights to equity in decision-making and outcomes. The often-used Flinders Model[15] didn't fit with these objectives, so the team created a waka hourua to conceptualise the ideas for supporting whānau to live with long-term conditions. Instead of focusing on prevention and giving less attention to those living with diabetes, "we were saying the opposite, we need to be more engaged with them. They're [whānau] still determining the goals, but our role is to be more involved and make sure that they're getting what they need."

A case management model whereby Kaimanaaki provide "intensive self-determined management" was developed to support whānau to navigate toward self-determined goals and outcomes. Kaimanaaki worked alongside providers inside primary care clinics to provide basic health literacy education, oversee clinical management and engage/coordinate the social support needed. With whānau in the waka, primary care services were the sail, unfurling when more care was needed and then tucked away when whānau chose.

> Our role as the sail is to help them to navigate to their journey... and as tupuna used stars to navigate, whānau used the stars as indicators that they were on track.
>
> *University researcher*

Kaimanaaki workers were employed and based in GP clinics that had high numbers of Māori and Pacific people living with diabetes. The Kaimanaaki came from a range of working backgrounds and included social workers, nurses, community health workers and receptionists. All received formal training and certification before deployment and ongoing training and development opportunities over the course of the project. All but one of the Kaimanaaki were either Māori or Pacific.

The approach with whānau was solution-focused and strengths-based. The Kaimanaaki supported people through whakawhanaungatanga first to build rapport, then introduced the intervention, the research and the assessments. They supported whānau to make and prioritise goals and helped them achieve these, providing regular clinical and other feedback, including cultural and social results, along the way.

While case management wasn't a new idea, there were specific elements that made this programme successful. These included: being led by Māori (delivered by a Māori-led PHO); having largely Māori or Pacific staff who could relate well with whānau; having good infrastructure support for Kaimanaaki case management roles; and a collective team approach to ongoing quality improvement through debriefing and peer support.

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15   https://www.flindersprogram.com.au/wp-content/uploads/Flinders-Program-Information-Paper.pdf

Being well connected into the general practice team was also important, and part of the co-design process meant working closely with these teams throughout. As a result, they described feeling engaged, and thus contributed to the continuous improvement of the programme. Employing the right people, who were experienced in, or at least open to, co-design was also critical to the success of the project.

> [The Project Manager] was amazing and I have to credit the success of us getting, recruiting and being able to complete the project, down to her. So, it's just, I think that workforce is key."
>
> *University researcher*

A robust co-design process at the outset has meant that Mana Tū's impact is varied and felt by many. Not only has it improved diabetes markers for most participants, it also has improved the way people feel when visiting the clinics (with 80% of whānau saying they experienced less discrimination when engaging with the healthcare system after Mana Tū). Clinic teams felt more engaged with services addressing the wider determinants for health (i.e., housing, MSD support). Kaimanaaki were inspired to continue their own professional development, contributing to Māori and Pacific health workforce capacity and capability.

WellConnectedNZ: How co-design was conceptualised and implemented – University researcher perspectives

The focus of this research was initially on trying to improve access to rehabilitation services for people with long-term conditions. The original idea for the research project was to work with potential programme users of rehabilitation programmes from different places to design a programme and processes with which they would be happy. The research team was trying very much not to take a medical model approach in the design of rehabilitation programmes; they wanted to include a bio-psychosocial, co-design approach, drawing from kaupapa Māori frameworks. They didn't want to use the traditional approach where "models had often been created by specialists and parachuted into communities". New ways of thinking and communicating were potentially going to be the most relevant.

As a result, the project undertook a 180-degree turn to explore the concept of "social connection" and its intersections with health, wellbeing and rehabilitation. The researchers went into the project wanting to develop trusting relationships, wanting "to achieve something that was useful beyond the research arena that respected people's tikanga, their values, their concepts, their processes."

The research team learnt early on that health professionals had very different thinking processes in comparison to community stakeholders. In fact, health professionals seemed to put up barriers, used deficit-type language in their conversations and had different priorities. This led the team to alter its thinking, strategies and discussions with communities.

> We, as healthcare workers, are talking the wrong language, using deficit model speech, creating barriers that our communities don't recognise and thinking about things with different priorities than our communities do.
>
> *University researcher*

Co-design was about the project being driven by the discussions arising from within the community. At the initial stage, over 500 people were involved in interviews, chats, hui and group discussions from different stakeholder groups. We asked them different questions around health literacy, technology, social connection and healthy communities: "What do you think makes up a healthy community?"

The co-design process was one of ebb and flow. It was 'tidal' in that parts were done with the community and then brought back to consolidate the information, then taken out again to check back, asking "have we got this right?".

The research was quite unwieldy, "like stuffing an octopus into a string bag – so every time we thought we had it neatly contained, another tentacle escaped, and we had something else that we had to look at."

The researchers' initial assumption was that not much was going on in communities and they wanted to support communities to create local initiatives. However, through the many conversations with stakeholders about social connection, the researchers realised there were a lot of things already going on in the community.

> It's almost like an underground system exists, but nobody really knows about it, or if you do know about it, it's because somebody told you via word-of-mouth type thing. It became clear that that system needed to be more visible.
>
> *University researcher*

Mapping community activities and creating a digital website/app became the "next phase" in the research. So, the concept of the WellConnectedNZ map was birthed.

Pou Ārahi or key Māori concepts were distilled from the discussions and became guiding principles that others can take into their approaches. Pou Ārahi included elements such as: respectful relationships; community connections and taking time to connect; the value of face-to-face encounters; listening more and listening better; re-humanising the person-to-person interactions; and people being able to give and receive rather than being seen as a problem.

The research process resulted in a personal journey for some of the researchers. It helped them reflect on our own assumptions as Pākehā researchers and better understand Māori language and frameworks.

> We health professionals have to get over our own barriers, assumptions, deficit attitudes and risk averse mindsets before this kind of co-design will actually work properly. The barriers are our own, not external.
>
> *University researcher*

Ngā Kupu Māori
Glossary of Te Reo words

Te Reo Māori	English
āhua	disposition, nature
hapori	community
hapū	sub-tribe
hui	meeting
hūmārie	gentle
iwi	tribe
kaimahi	worker
kaimanaaki	case worker
kaitiakitanga	guardianship, custodianship
kanohi kitea	a face that is seen, a trusted person (a person known by being seen by the iwi among them)
karakia	prayer
kaupapa Māori	Māori projects
kōrero	discussion, talk
mātauranga Māori	Māori knowledge
Pākehā	New Zealander of European descent
pou ārahi	leader, guidepost
poutama	staircase pattern
pūrākau	story, legend
rangatiratanga	sovereignty
rongoā	medicine
te ao Māori	the Māori world
te mātauranga o tētahi hapori	cultural framing
te kōtuitanga taurite	equal partnership
tikanga	custom, values
tino rangatiratanga	self-determination, independence
waka hourua	double-hulled voyaging canoe
wānanga	intensive learning session
whakawhanaunga	to strengthen relationships
whakawhanaungatanga	strengthening of relationships

Te Reo Māori	English
whānau	family
whānau ora	healthy family

Whakapā Mai
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Healthier Lives – He Oranga Hauora National Science Challenge is a *national collaborative research programme in Aotearoa New Zealand, with a mission to investigate* equitable approaches to the prevention and treatment of four major non-communicable diseases – cancer, cardiovascular disease, diabetes and obesity.

Tō mātou kitenga kia noho a Aotearoa New Zealand hei whenua he ōrite ngā putanga hua hauora mō te tangata, kia iti iho hoki ngā pīkauranga o ngā māuiui kāore e taea te tuku ki te tangata kē (ngā non-communicable diseases).

Our vision is of Aotearoa New Zealand with equitable health outcomes and a substantially reduced burden of non-communicable diseases.

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