



Co-designing health research in Aotearoa New Zealand

// A short guide

Te hoahoa tahi i te rangahau hauora i Aotearoa

// He aratohu poto

Debbie Goodwin & Amohia Boulton

February 2024

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Dr Debbie Goodwin

DBZ Consultancy Ltd.





Kupu Whakataki

Introduction

Co-design of research and health services by academic researchers, community-based health providers and communities has the potential to enhance equity of health outcomes. Working together in partnerships that support shared power and decision-making not only acknowledges the mana (importance) of all those involved but leads to more enduring solutions. This is particularly relevant for Aotearoa New Zealand¹ where the Government's 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 and reducing health inequities between Māori and non-Māori.

The term "co-design" is often used in a broad sense to describe an approach to working collectively. This can encompass many different methods and a variety of collective arrangements, processes and impacts. Increased use of co-design in Aotearoa New Zealand over recent years has seen a range in the quality of practice.

To help address a lack of guidance around co-design practice, and to further understand the potential benefits of co-design as a methodology, the Healthier Lives–He Oranga Hauora National Science Challenge commissioned a kaupapa Māori evaluation of five of our co-designed research projects². While Pacific evaluation frameworks were not used in this study, a number of Pacific community representatives and researchers who participated in it felt that the study design aligned well with Pacific aspirations.

Independent researcher Dr Debbie Goodwin undertook this evaluation, which assessed how the co-designed projects were conceptualised and implemented, and analysed the challenges, solutions and lessons learnt for future co-designed research. The study participants were academic and community-based members of the five research teams, including leaders and staff of the Māori and Pacific health providers who partnered in the research, as well as the community researchers employed by these organisations.

This short guide presents some of the key lessons distilled from the evaluation. The full report of the evaluation is available at <https://healthierlives.co.nz/resources/> or via https://en.wikipedia.org/wiki/Healthier_Lives

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.

² Three of these projects were co-funded by the Health Research Council of New Zealand and the Ministry of Health through the Long-term Conditions Partnership.







Ngā whakaaro o te tāngata mō te hoahoa tahi

Perceptions of co-design

There are different perceptions about what co-design entails. Community organisations have told us that the term “co-design” is at risk of becoming a catchphrase and losing meaning through overuse.

Clarifying the model of co-design being used is therefore important at the start of any project: what will happen, who will make decisions, how will resources be shared, and which areas of decision-making are up for discussion?

Other terms that are often used alongside co-design research also need to be clearly defined, for example “equal partnership”, “community-centred”, “whānau-led”. Creating shared understandings and expectations helps to avoid confusion and later frustration for everyone involved.

There is no single way to approach co-design but clear communication about what you are seeking to achieve and how you plan to go about it is essential if the process is to have integrity and the outcomes are to be worthwhile.

Ngā painga o te hoahoa tahi

Benefits of co-design

There are multiple benefits of co-designing health research. Perhaps the main one is developing culturally engaged programmes and resources that are likely to be successful and long lasting because they meet the needs of communities.

However, there are also benefits to those involved. Healthier Lives' community partners have reported increased confidence about being involved in future research as a result of a positive co-design experience. It offered them capacity building, learning opportunities, and enhanced academic credibility through conference presentations and joint authorship of research papers.

Healthier Lives' researchers have reported that listening closely to community needs, challenges and aspirations helped them gain insights into the barriers that Māori and Pacific communities face in accessing healthcare. It helped re-shape non-Māori researchers' perspectives and built their knowledge of the influence of cultural factors. Co-designing projects supported better community buy-in and participation in research, and communities were able to identify 'out of the box' solutions, resulting in programmes and resources that may not have been created without their involvement.



Te hoahoa tahi me te ao Māori, Te Moana-nui-a-Kiwa hoki

Co-design with Māori and Pacific

From the perspectives of Healthier Lives' Māori and Pacific community partners, good co-design processes depend upon nine elements. Six of the elements (Hononga, Mahitahi, Tikanga me ngā Kawa, Ngā Pūkenga, Ngā Hua and Tino Rangatiratanga) were identified by Dr Debbie Goodwin and Toi Tangata as key Māori principles that reflect good co-design research with, and as, Māori³. Three other elements (Te mātauranga o tētahi hapori, Te kōtuitanga taurite and Kaitiakitanga), together with Rangatiratanga, were identified through Dr Goodwin's evaluation of co-design within Healthier Lives projects.

³ As outlined in the full evaluation report, these elements are captured in the Te Whetū Evaluation Matrix developed by Dr Goodwin as part of her doctoral studies.

Hononga Connection and trust

Good co-design relies on trusting relationships, whanaungatanga, strong bonds and transparency between co-design partners.



Mahitahi Working together

Good co-design involves working together as one in a partnership with agreed purposes, values, roles and processes.





Tikanga me ngā kawa **Values and practices**

Good co-design demonstrates respect for all participants' tikanga and kawa (values, contexts and processes) and prioritises alignment with the tikanga and kawa of communities and less powerful partners.



Ngā pūkenga **Expertise and skills**

Good co-design shares expertise and develops the skills needed for design, co-design and working with communities.

Ngā hua **Outcomes**

Good co-design produces outcomes and benefits that are equitable for those participating in the co-design and those using its results.



Te mātauranga o tētahi hapori Cultural framing

Good co-design incorporates cultural knowledge and ways of being and doing in community contexts.



Rangatiratanga Leadership and authority

Good co-design supports and prioritises community aspirations and facilitates Māori and Pacific-led research and research leadership.

Kaitiakitanga Guardianship

Good co-design addresses and protects intellectual and cultural property rights, including data sovereignty, particularly where different knowledge bases, e.g., mātauranga Māori and Western research, are shared as part of the project.



Te kōtuitanga taurite Equal partnership

Good co-design starts at the “front-end” together, with co-governance and joint decision making throughout the project.





“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

“...[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 [the academic researchers] valued too, because they didn't know or didn't have a full understanding of [our cultures and communities].”

Community partner

“The conversations with Māori and Pacific need to happen at the initiation phase of any of the projects.”

Community partner

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

Community partner

Ngā mea i ākona e mātou

What we have learnt

Through Healthier Lives' experience of co-designing research, we have learnt practical lessons:

1. Relationship-building

Trusting relationships and shared understanding are critical to successful co-design. Co-design with communities is not a 'once over lightly' research approach. It needs to be well thought through and the partnerships well-defined.

2. Accountability

Co-design must recognise the existing accountability relationships that community organisations have with their communities, and not compromise these. These relationships are developed on trust and have accountabilities that must navigate cultural responsibilities.

3. Time

Co-design requires considerably more time investment, both on the part of researchers and the community, than is usually allocated in a standard research process. It requires going at the pace of each partner while being aware that community partners can be busy with other priorities.

4. Flexibility

Co-design requires flexibility and can be challenging for both partners and funders, as there is often uncertainty about what will be designed, how long it will take, and the pace at which community partners can contribute. Flexibility is required in both research and research funding processes.

5. Transparency

Being clear and transparent about the different frameworks and methodologies being used, as well as creating shared understandings of the processes involved, is important for effective co-design and collective problem-solving. Clearly explaining any academic and technical language is important for meaningful communication between researchers and communities.

6. Capacity building

Reciprocal capacity building is both a necessary part of the co-design process and is also an outcome of co-design. This enables all partners to grow and change and facilitates improvements in future co-design research projects.

7. The right people

Ethnically and culturally appropriate staffing, and culturally competent researchers, are essential for successful co-design. It is important that researchers have personal attributes such as being respectful, humble, and encouraging leadership and guidance from within the community. Staff turnover in community partner organisations can impact on a project and the handover between staff therefore needs to be carefully managed.

8. Resourcing

Along with funding for the co-design process and research project, appropriate resourcing for community organisations is essential. This provides the capacity for organisations to participate in and lead research within their communities.

9. Sustainability

Ensuring the sustainability of the co-created programme or resource beyond the life of the research project is of paramount importance, given the significant time commitment by communities, community partners and researchers, their personal and cultural contributions, and the funding investment that goes into the co-design process.



“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

“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.”

Community partner

“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 of what their challenge is, their worldview is, so that we could design whatever needed to be designed.”

Community partner

“The most interesting or part of what 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.”

Community partner



Te tū rangatira i roto i te rangahau hoahoa tahi

Integrity in co-design research

Clarity and transparency in the way that researchers and communities conceptualise and implement a co-design process is crucial to its success. Getting this right at the start, and throughout the process, enables co-design to proceed with integrity, by giving due attention to the relationships and needs of all parties.

The Co-design Research Integrity Poutama portrays and defines three different levels of co-design as a conceptual ladder, or poutama, describing the elements that can impact on the effectiveness of the co-design process, and on the relationships between researchers and the community.

Co-design with integrity typifies the top level of the poutama, where projects are co-led, with shared governance and shared decision-making from the outset.

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

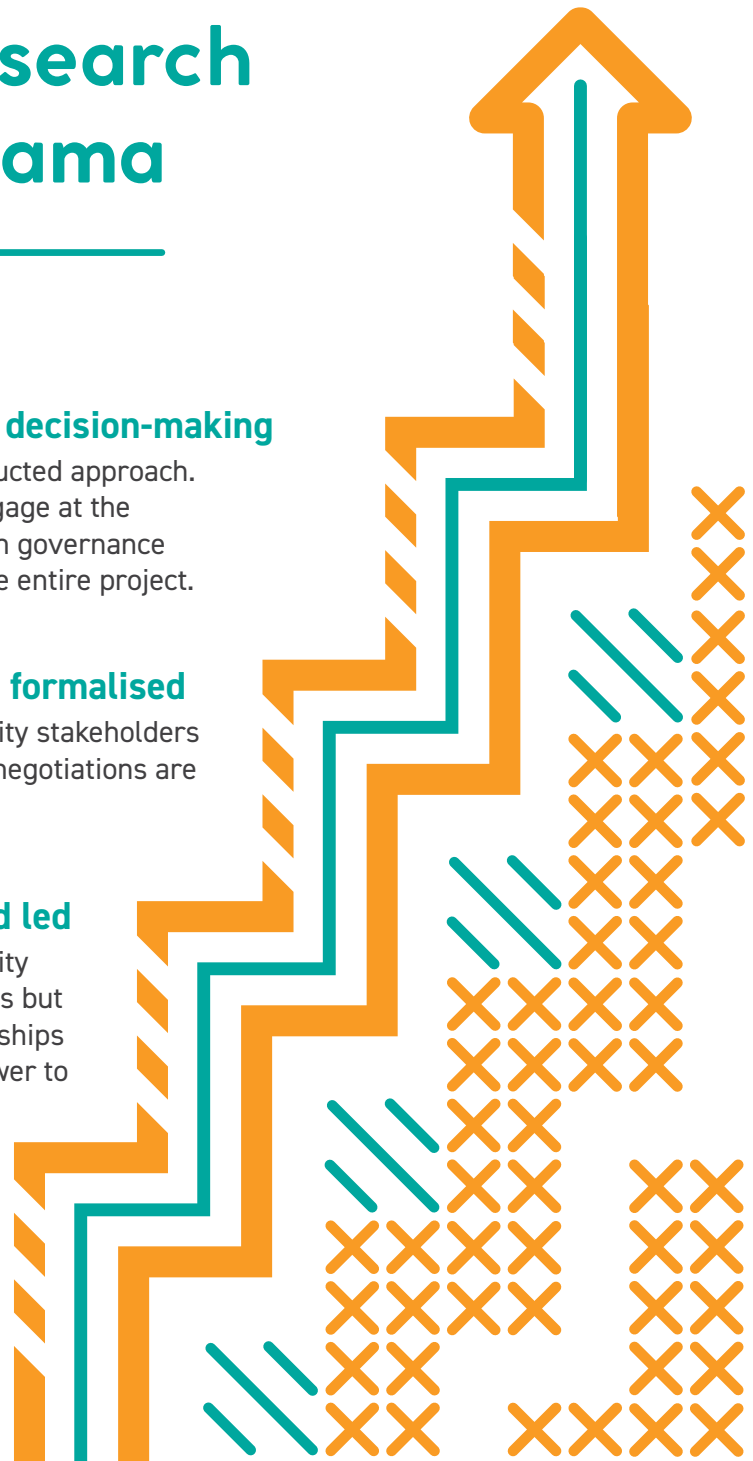
Researchers initiate the project. Community stakeholders are engaged in a formal partnership and negotiations are ongoing throughout the project.

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.



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Consultation alone is not considered to be co-design and is therefore not ascending the poutama. However, taking steps toward higher levels of co-design integrity, and aspiring towards more authentic co-design, including formalised partnerships and shared decision-making, brings integrity to a co-designed project and can result in benefits above and beyond the generation of research findings.

Kupu Whakamutunga

Conclusion

To achieve equitable health outcomes in Aotearoa New Zealand, we need to implement evidence-informed health programmes and products that are appropriate for, and acceptable to, all communities. Adopting more authentic approaches to co-design, as exemplified by the Co-design Research Integrity Poutama, will enable this.

This short guide to co-design reflects the experiences and lessons learnt by university researchers and community partners in five Healthier Lives research projects, as captured through an independent evaluation conducted by Dr Debbie Goodwin.

Those interested in finding out more can read the full evaluation report at <https://healthierlives.co.nz/resources/> or <https://ourarchive.otago.ac.nz/handle/10523/15462>

Striving towards more authentic co-design in research has the potential to improve health equity and provides greater transparency and equality in research with Indigenous and minority communities. It relies on taking the time to develop respectful and often long-term relationships, working at the pace of partners, and making a commitment to appropriate resourcing and shared decision-making, all of which can lead to greater benefits for communities.





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 pūkauranga 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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