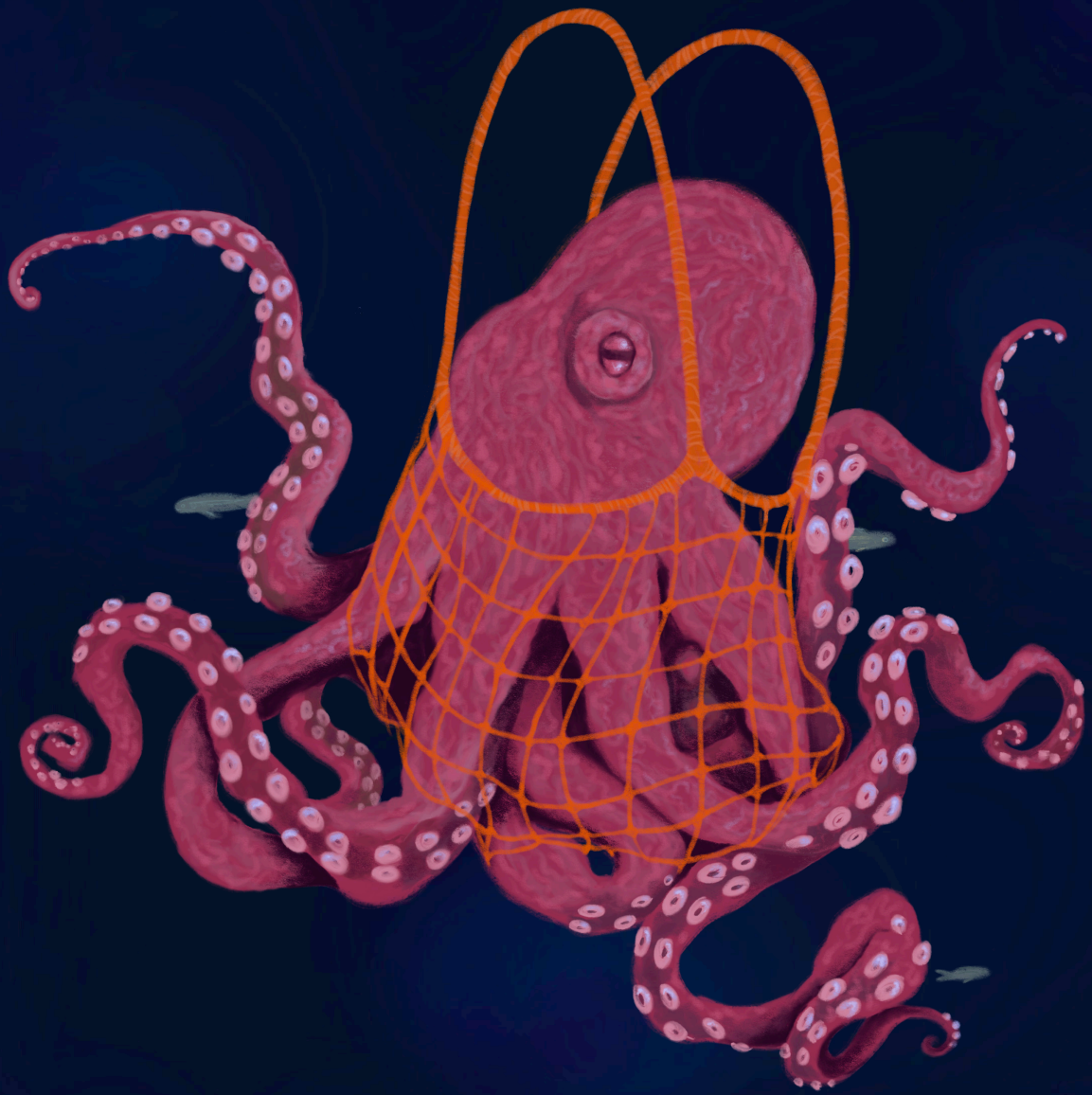
The Ethical Octopus:
Exploring care-full co-production through a participatory ethnographic feminist praxis



Anjuli Clare

The Ethical Octopus:
Exploring care-full co-production through a participatory ethnographic feminist praxis

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the requirements for the degree of

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Anjuli Clare

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Supervisors

Professor Anna Brown
Associate Professor Faith Kane
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Abstract

Co-production is a participatory design approach that is increasingly being used for relational, transdisciplinary and complex research. With a multitude of definitions, it isn't always easy to narrow down what is or isn't counted as co-production. In general, this approach aims to carry out research with the people who might benefit or be affected by the research, becoming genuine partners in all stages of the research. Through principles of sharing power, prioritising relationships, building capacity and using participatory means, co-production blurs the boundaries between academia and communities and centres people's lived experiences.

Using a case study of women's health — Care-full Co-production — this thesis explores the use of co-production within an Aotearoa New Zealand context, by collaboratively developing a library of research questions with women about women's health. Gentle conversations over a 'Cuppa & Cake' provide an opportunity for building relationships with women across the country to share experiences and build new knowledge about women's health. A participatory ethnographic feminist praxis guided the development of a nuanced understanding of co-production in action. Taking a reflexive and reflective perspective on the micro and macro aspects of the case study, this process-focussed research is a detailed and descriptive explanation of theory and practice.

Through a metaphor about an octopus, a set of provocations guides the structure of this thesis. Responses to these provocations, along with examples from Care-full Co-production, provide a deeper understanding of the key considerations for carrying out co-production embedded with an ethics of care. By exploring the head and arms of *The Ethical Octopus*, this thesis positions co-production as an ethico-onto-epistemology, with a focus on the core principles that are vital to co-production. The provocations and principles discussed in this thesis provide researchers and practitioners with an accessible approach to applying co-production in other contexts.

Keywords

Design, co-production, participatory design approaches, feminist praxis, participatory ethnography, women's health, ethics of care, ethico-onto-epistomology, co-design

Preface

Some aspects of the research in this thesis have been shared elsewhere, including:

- *Lightning Talk*, Te Pūnaha Matatini Annual Hui, June 2022, Hamilton
- *The Co-Production Project — an action research project*, New Zealand Geographical Society Biennial Conference, 2022, Christchurch (with Anna Brown)
- *Poster,* Te Pūnaha Matatini Annual Hui, October 2024, Hamilton
- *Sifting through the unknown with recipe free research,* Te Pūnaha Matatini Blog, 2024 https://www.tepunahamatatini.ac.nz/2024/03/14/sifting-through-the-unknown-with-recipe-free-research/
- *'Wrestling an octopus into a string bag' — the many tentacles of co-producing research,* AD/REC Limit/No Limit Conference, 2024, Paris (with Anna Brown).
- *More Than a Name Tag workshop,* AD/REC Limit/No Limit Conference, 2024, Paris (with Anna Brown).
- *Head and heart — An ethical tightrope,* DRS2024 Biennial Conference, 2024, Boston.
- *More Than a Name Tag workshop,* DRS2024 Biennial Conference, 2024, Boston.
- *Co-producing with Care and Cake*, International Society of Critical Health Psychology Blog, 2024, https://ischp.net/2025/03/26/co-producing-with-care-and-cake/
- *Interview,* TuneFM, University of New England, March 2025, Armidale, Australia https://omny.fm/shows/tunefm/including-more-women-in-medical-research-will-bene
- *Untangling co-producing research through a case study of women's health,* Menstruation Research Network Monthly Seminar, 2025, online (with Sabrina Wester)
- *Untangling co-producing research through a case study of women's health (V2),* Co-production in Practice Symposium, 2025, Wellington (with Cyndi Miller, Jean Donaldson & Hanna Breurkes)
- *The Hand Book — shared as part of a wider project on Emergent Engagement*, Public Communication of Science and Technology Conference, 2025, Scotland (shared by Anna Brown and Jonathon Burgess)

Acknowledgements

It's a bit surreal to be at the point, when it still constantly surprises me that *I* have completed a PhD! This project has been amazing, inspiring and has challenged me in entirely new ways — and I could not have reached this moment without the support of many others.

Ngā mihi nui to my supervisors — Anna, Faith and Siouxsie — for choosing to work with me and all the support along the way. I've really appreciated your guidance, generosity and continual encouragement. Your willingness to sit with me in the uncertainty of carrying out research differently made the experience all the better. I will treasure the memories of shared meals, cuppas, conversations, travel and friendship.

Thank you to Te Pūnaha Matatini, for not only funding this PhD and the wider project but also providing me with a place to belong. To everyone who makes up Te Pūnaha Matatini, and especially Te Tira Maurikura — your inspiring, supportive and welcoming ways of being truly add to the whole PhD experience.

To the people of Toi Rauwhārangi Massey College of Creative Arts, thank you for accepting my research with all of its uncertainty, and for being so welcoming.

Thank you to all the academics and critical friends I met along the way (online and offline) — your generosity of knowledge sharing and support was invaluable. Additionally, thank you in advance to my examiners — for your time, energy and expertise — without which, it wouldn't be possible to complete this qualification.

I am very grateful for my many friends, both offline and online, many of whom are my 'chosen family'. Thank you all for cheering me on, encouraging me when I was struggling, listening to me vent, feeding me and keeping me supplied with amusing memes.

To my husband and our families, thank you for your ongoing support — through yet another few years of study!

And to my two dogs, Sadie and Maple, my constant companions throughout — for the distractions and affection, for grounding me, and for always encouraging me to take a break from my desk.

Lastly, but certainly not least, to the core project team and all the contributors in Care-full Co-production — this thesis is for you, and would not exist without you.

Ethics statement

Multiple ethics applications were lodged and approved for different aspects of this research.

- Full ethics application #SOB22/64 approved 10/02/2023
- Low risk notification #4000026681 approved 14/09/2022
- Low risk notification #4000028204 approved 26/09/2023
- Low risk notification #4000028282 approved 19/10/2023

Copyright statement

How to read this thesis?

This thesis has been structured in a way that aims to highlight the non-linearity and complexity of the research being discussed. Instead of the traditional contents list, a map has been provided to navigate through the thesis. Hyperlinks are provided in the pdf version so the reader can move through the thesis to access different parts easily. To return to the map click on *The Ethical Octopus* header. While many of the chapters are somewhat independent, the first three set the foundational scene for the remainder of the thesis.

To reflect my personal values, and the values and principles of the research being presented, I have written in a relational tone — to continue the relationships with the people who have been part of the process, and to build a relationship with the readers. This is also reflected in some of the word choices I have made — these are explained further in the glossary.

Contents:
Map

Figures List

Glossary

Aotearoa New Zealand

Aotearoa is the Māori name for New Zealand and are often used together as a way of recognising the Indigenous people and their language. I have sometimes used Aotearoa on its own as a shorter form.

Care-Full Co-Production

is the case study of women’s health through which we explored the use of co-production. This includes the core project team and all the contributors.

co-creation

means to collaboratively create something together.

co-design

means to collaboratively design a product, service, initiative or research project with lived experience experts. It is a part of co-production, but is often used as a stand alone approach.

co-production

a way of doing research, where communities or people who are likely to be affected by the research, are included in the whole process — from deciding the research question through to sharing the results.

co-researcher

is generally used to refer to non-academics (e.g. lived experience experts) who are partners in co-design or co-production projects.

contributors / participants

contributors are the lived experience experts who are involved in the Care-full Co-production project — they chose this term instead of co-researcher as they felt ‘contributor’ aligned more with their role. They have occasionally been referred to as participants in the Aotearoa Waters chapter, when describing parts of the project that occurred chronologically before they chose the term contributor. Any other use of the word ‘participant’ refers to people who were part of other research projects (e.g projects talked about in the literature).

core project team

refers to the smaller group of people who maintained the project momentum. The team is described in more detail in the Introduction chapter.

cuppa

means a cup of any hot drink — e.g. tea, coffee, hot chocolate.

critical friends

are additional people we could discuss ideas and challenges with, who might give us a slightly different perspective by being a step removed from the project. They might be academics and/or people working in a related or complementary field.

Good Bitches Baking

the nationwide charity through which recruitment for Care-full Co-production happened.

feminist praxis

is a relational, embodied and ongoing practice that critiques and disrupts norms, processes and power structures.

hauora

the Māori word for health.

kai

the Māori word for food, meal, to eat.

kaimaanaki

means a person who supports and cares for others.
From Te Aka Māori Dictionary:

» Kai- Prefix added to verbs which express some kind of action to form nouns denoting a human agent (i.e. the person doing the action)

» Manaaki (verb) (-tia) to support, take care of, give hospitality to, protect, look out for - show respect, generosity and care for others.

kete

the Māori word for basket.

knowledges

an intentionally pluralised version of the word knowledge to draw attention to there being multiple different ways of knowing or knowledge.

koha

the Māori word for gift, or donation — especially one that is part of maintaining social relationships and has connotations of reciprocity.

kōrero

the Māori word for discussion or conversation.

manaakitanga

the Māori word for hospitality, kindness, and support — the process of showing respect, generosity and care for others.

motu

the Māori word for island, country, land or nation.

Pākehā

the Māori word for non-Māori people — generally New Zealanders of European descent.

pono

the Māori word for truth and genuineness.

power

means how much (or how little) agency people have and their ability to influence and change things in order to meet their full potential (Place, 2023).

practice-able

to incorporate relevant theory and action into practice in a way that reflexively influences a person's practice (Bailey, et al., 2022).

praxis

the process of using a theory or something that you have learned in a practical way.

rangahau

the Māori word meaning to seek, search out, pursue, research, investigate.

reflectivity

is a process of learning from observing how and why things happen, building an understanding of these experiences, and incorporating this learning into future practice.

reflexivity

is the awareness of assumptions, biases and privilege that may be held by individuals or collectively.

tapu

the Māori word for sacred which acknowledges the intrinsic value of each and every person and thing — and to behave according to this principle.

Te Pūnaha Matatini

is Aotearoa New Zealand's Centre of Research Excellence for complex systems.

tika

the Māori word for doing the right, just and fair, thing.

The Co-production Project

is the wider project exploring co-production in Aotearoa New Zealand which is led by Professor Anna Brown. Care-full Co-production and my PhD are embedded within The Co-production Project.

wahine/wāhine

the Māori words for woman/women (with a macron is plural).

whanaungatanga

the Māori word for relationship, kinship, sense of family connection — a relationship through shared experiences and working together which provides people with a sense of belonging.

woman/women

throughout this thesis I use the words ‘women’ and ‘woman’ in their most inclusive forms; transwomen are women therefore when using the words women and woman, it includes anyone who identifies as such. This also includes intersex and non-binary individuals who have experienced the health system as a female. I also acknowledge that this usage would not necessarily be the preference of all trans, intersex, or non-binary people.

Additional notes

Note on naming conventions:

When I have used or cited colleagues I have chosen to use their full honourific and name (e.g. Dr Jo Bailey) and then their first name in subsequent citations in that chapter. I have chosen this approach to align with the relational aspects of a feminist praxis.

Note on the use of ‘I’ and ‘we’:

When I say ‘I’ I literally mean I as these are examples where I made the decisions. When I use ‘we’ this indicates there was a collective process of decision making.

Introduction

Introduction

This research sets out to explore the use of co-production in an Aotearoa New Zealand context through a case study of women's health. In this introductory chapter, I start the process of building a relationship with the reader by introducing myself and highlighting my privileges, experiences and biases that underpin this thesis. I also present the background for how this PhD came about, along with an explanation of my research questions and the methodologies and methods I used to consider these questions.

Through discussing how I approached this research, I aim to untangle the complexity of investigating a research process while applying that process, clarify some of the terms used, and provide foundational information about this research to make it easier to understand the rest of this thesis. The chapter concludes with a description of a metaphor that forms the structure of this thesis.

Positionality statement

Tēnā koutou, ko Anjuli au, nō Ōkiwi au, Tēnā koutou katoa.

As will be obvious throughout this thesis, co-production relies on prioritising relationships. Good relationships benefit from a good introductory process, so let me introduce myself in more detail and share my positionality in a way that will help situate myself in relation to this project.

I grew up in the small towns of Templeton, and West Melton (just outside of Ōtautahi-Christchurch), and was not very connected to the local communities. This has resulted in me actively seeking out social connectedness as I grew up, and volunteering for local and national organisations as an adult. My parents' careers in prisons and special education led me to be curious about people's lived experiences. My mum was the first in our family to gain a tertiary education; however, my siblings and I grew up with the understanding that we would go to university. My first experience of university was not for me; instead, I left to find adventure through sailing. I spent most of my twenties sailing in different parts of the world, predominantly in the sail training/youth development space. This fed my curiosity and understanding about people, different cultures, and how we can work together, as each group on board a yacht forms its own community.

In my mid-thirties, following some personally challenging times, I decided to try university again. I completed a Bachelor of Arts, studying psychology and sociology, with a small amount of anthropology mixed in. I then went on to do an Honours degree in psychology; my research project explored people's experiences of social connectedness through volunteering (for Good Bitches Baking). This academic background gave me the foundational critical thinking needed to move from the micro to the macro levels of reflexivity that this PhD has required. I am the first person in my family to have studied at PhD level. I have no formal training in design, so joining the design faculty for this PhD, courtesy of a Te Pūnaha Matatini scholarship, has been a surprise, a steep learning curve, and an absolute joy. This gives me the opportunity to expand my critical thinking in a transdisciplinary way and corral my creative tendencies into shapes that are more useful in the design field.

From a young age, I have had a variety of experiences with health systems — standard and alternative. Hospital stays, surgeries, unexplained symptoms, overt and covert silencing and gaslighting, as well as gentle caring, genuine listening and unexpected solutions. As an adult, I have had the privilege of health insurance, health literacy, and often the flexibility needed to be able to access appointments and care. Yet I have still had the types of experiences women share via whisper networks[1]. I am also childless, not by choice, which puts me in a community that is often invisible, excluded, or not listened to.

Halfway through this PhD, I developed a post-viral syndrome following a COVID-19 infection, resulting in dynamic health challenges, with no patterns or consistency — which made it near impossible to figure out what things to do that might help me manage or improve symptoms to function and carry out this PhD. Some of these symptoms include energy limitations, exercise intolerance, fatigue, chronic daily headaches, pain in any or all body parts, sensory sensitivities, abnormally increased heart rate, temperature dysregulation and brain fog, to name a few. Throughout the three and a half years of this PhD, I have had two surgeries, more specialist and GP appointments than I can count, numerous blood tests, as well as many other investigations. I share these, in uncomfortable vulnerability, to highlight the unexpectedly embodied aspect of this PhD — I was experiencing many of the things we were talking about with the women in this project, while we were discussing them. As I learnt to create research practices that were more inclusive for the contributors, I was forced to learn how to include myself as well.

These interests and experiences are what drew me to this PhD project, which combines working with communities, developing better research methodologies and approaching both with the hope of creating positive change within women's health in Aotearoa New Zealand.

PhD background

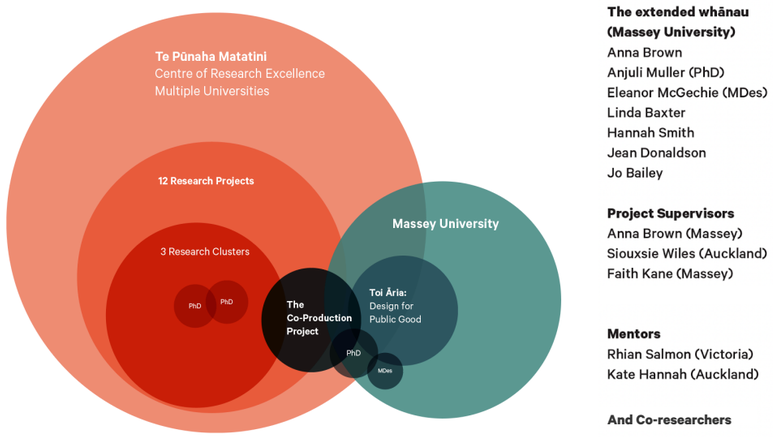
This PhD sits within a collaboration between Te Pūnaha Matatini and Toi Āria focussing on engagement and co-production. Both research groups take engagement extremely seriously.

This has been demonstrated by the high uptake of their respective research by policymakers, the establishment of long-term positive collaborations with hapū and iwi following community engagement and collaborative research projects, and funding of research into best practice in science communication and participatory design.

The Co-production Project is led by Professor Anna Brown, founder and director of Toi Āria and a principal investigator with Te Pūnaha Matatini, and one of my PhD Supervisors. Alongside The Co-production Project is another Te Pūnaha Matatini project, The Engagement Incubator. Both projects are research-grounded, and through reflecting on the design and delivery of these projects, aim to demonstrate impactful engagement in Aotearoa New Zealand. The Co-production Project explores this approach to research through a series of case studies. My PhD is embedded in this project, and through a case study of women's health, explores a specific example of this approach in an Aotearoa New Zealand context. To show the interconnectedness, these projects are visualised in Figure 1.

Te Pūnaha Matatini advertised this PhD (and the scholarship attached) in various channels — I saw it mentioned on Twitter (now known as X), proceeded to apply and am grateful I was selected. This process provided me with a research framing that was already semi-formed before I began.

Figure 01:
The project and people.



The extended whānau (Massey University)
Anna Brown
Anjuli Muller (PhD)
Eleanor McGechie (MDes)
Linda Baxter
Hannah Smith
Jean Donaldson
Jo Bailey

Project Supervisors
Anna Brown (Massey)
Siouxsie Wiles (Auckland)
Faith Kane (Massey)

Mentors
Rhian Salmon (Victoria)
Kate Hannah (Auckland)

And Co-researchers

Research questions

My PhD is process-oriented, focussing on demonstrating co-production through application, and developing knowledge of co-production in order to improve use of this approach in an Aotearoa New Zealand setting. Rather than the typical PhD project focussing on using a particular method or methodology that is best suited to answering a particular question, in this research study the question is about how we can understand and expand co-production in Aotearoa New Zealand

There is a gap in understanding around how co-production can be used within the topic of women's health in Aotearoa to i) understand what the needs actually are and ii) address these needs within the context of collaborative and relational research. The initial research questions provided to me came from the Te Pūnaha Matatini and Toi Āria collaboration outline. These were:

- How can the process and approach of co-production build a repository of relevant and robust research questions and explorations of women's health in Aotearoa?
- How can a research project make the public(s) equal partners in research and subsequent development of services and solutions for reproductive health in Aotearoa New Zealand?
- How can co-production methods be used to understand women's health needs in Aotearoa?
- How can co-production be used within collaborative / interdisciplinary / transdisciplinary research to address those needs?

Why this matters

Through my exploration of existing literature some opportunities for further research were noted, that highlight additional contributions of this thesis and areas to focus on. There are many definitions and explanations for what co-production is. Health and social care researchers, Danial Masterson and colleagues (2022) suggested that "Rather than seeking universal definitions of these terms, future applied research should focus on articulating the underlying principles and values that need to be translated and explored in practice." Focussing on principles and values of co-production is a core aspect of this thesis, and draws attention to how these can be put into practice.

Policy and systems researchers Peter Slattery, Alexander K. Saeri and Peter Bragge (2020) wrote in a rapid review[2] of co-design projects that 85% of medical research is wasted due to poor research design and lack of reporting or publications. They noted that one of the key contributing factors to this was that the questions being researched were often not a priority for clinicians or patients. Not only is this an astonishing waste of funding, but the amount of mental and emotional labour

that is also being wasted raises questions about the ethics of this research. Using a relational approach to research where those who are most likely to be impacted by the research are involved from the beginning may go some way to reducing this waste. That a key contributing factor to this wastage is down to the questions being asked suggests that collaboratively creating with women a library of research questions about health that are a priority to them will be a valuable contribution to this scholarship.

While the literature talks about the need when applying co-production for developing positive relationships, feminist scholars Pamela Ponic, Colleen Reidb and Wendy Frisby (2010) note there is a lack of commentary on 'how' to actually build these relationships between the individuals working together as well as the communities and organisations involved. It takes intentionality and deliberate action to create the relationships necessary for these projects, yet the literature assumes the researchers will automatically have the emotional intelligence and skills required to develop these relationships in a seemingly effortless way.

Science education researchers Esther Milberg Muñiz, David Ludwig, and Charbel N. El-Hani (2024) wrote that "Researchers getting stuck in that theoretical mode often fail to create better participatory practices by not focussing enough on the embodied, relational and practical aspects needed, showing that a theory-practice gap is also present in critical social sciences" (p. 18). This commentary supports the detailed, descriptive approach I have taken throughout this thesis to share practice-able ways to apply co-production.

These observations have led to a reframing of the research questions this PhD sets out to answer, resulting in the following questions:

- How can we use co-production to build a library of robust research questions about women's health that are a priority to women in Aotearoa?
- How can our understanding of co-production be developed in a practice-able way, specifically in an Aotearoa context?

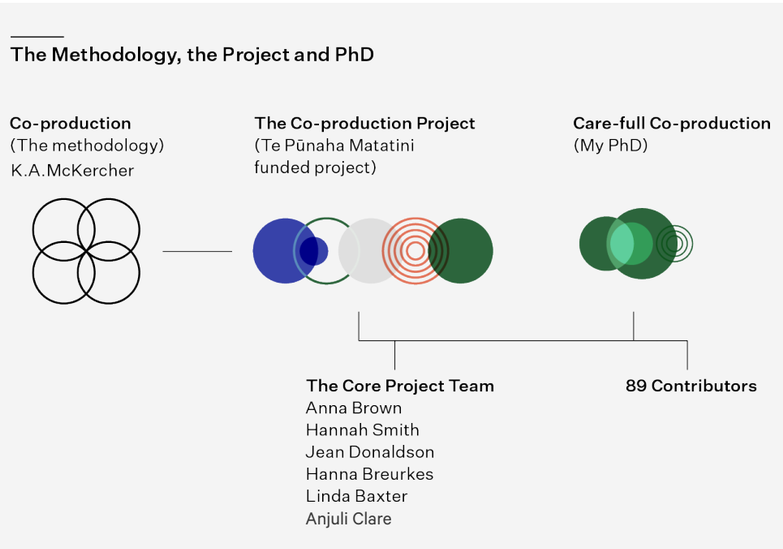
This PhD contributes to our understanding of women's health in Aotearoa, but more significantly contributes to an understanding of using co-production within research settings in Aotearoa.

Research approach

My thesis explores co-production using a participatory design ethnographic methodology involving a feminist praxis. In the below sections, I set out to explain these, and to articulate the difference between the methodologies and methods involved. Before this explanation, though, I will provide a clarification of the interconnectedness of my PhD and The Co-production Project that it is embedded in, in order to make sense of the rest of my thesis.

Me, Care-full Co-production and The Co-production Project

Figure 02:
Untangling the methodology, the Project & the PhD.



Untangling what is 'my thesis' from what is The Co-production Project has been an exercise in managing complexity on its own. Both will always overlap in some way.

The Co-production Project is the name of the wider project that my PhD is embedded in. How this name came about is discussed further in the 'Aotearoa Waters: A case study of women's health' chapter. At this point my PhD was fully entangled in The Co-production Project, and unable to be delineated. Understanding that a PhD is expected to be independent research, finding a way to describe the two separately has been a deliberate and considered process. As we progressed, the exploration of women's health took shape which formed the case study that my PhD focusses on.

This case study was a collective and collaborative practice carried out by the core project team (introduced in more detail towards the end of this chapter, p. 38). Throughout my thesis I also refer to 'the core project team' using 'we' or 'our' to indicate this collective practice. The women's health case study (which includes all the contributors) is referred to as 'the case study' or 'Care-full Co-production' to show the separation from The Co-production Project. While there was not a specific point when this separation came about, I use this labelling process from here on for clarity. My PhD, this thesis, is the discoveries that come from exploring and reflecting on this collaborative case study. The diagram in Figure 2 aims to show the separation of the case study from the project, and the separation of both from the model of co-production we started from.

Being embedded in the project itself — where I participated, collaborated, organised and reflected — gave me a multi-dimensional view of how we applied co-production. Considering this viewpoint led me to adopt a participatory ethnographic approach. I also intentionally used a critically reflexive perspective to develop an understanding of the power differentials and relational aspects of the project. This perspective can be understood as a feminist praxis, which included an ethics of care that was threaded through this research, and Care-full Co-production. The participatory ethnographic approach with a feminist praxis is unpacked in the following sections after an explanation of the transdisciplinary nature of the research.

Research methodology

Transdisciplinary research

As a complex project, where the 'sum is greater than its parts', the transdisciplinary nature of The Co-production Project, my PhD and my place within it needs to be acknowledged. As Dr Jo Bailey (2019) explains, transdisciplinary research is like making a cake. In transdisciplinary research, all the ingredients are mixed together to make something new (a cake) where the individual ingredients are no longer recognisable. Transdisciplinary projects include not only multiple academic disciplines, but also people who bring other forms of knowledge (e.g. experts of lived experience). When describing transdisciplinary research, Milberg Muñiz et al. (2024) wrote "transdisciplinary research is a messy process once you get inside of it (like a mangrove), and careless engagement creates countless risks of getting stuck or lost and therefore not living up to the emancipatory ambitions transdisciplinarity can offer" (p. 18). Paying careful attention to the different aspects of complex issues, and how one makes order out of them, can help with getting 'unstuck' or finding one's way through the mess.

Alongside this, or maybe even as an 'internal transdisciplinarity', I also had to learn about design methodologies, how they were similar or different from social sciences, and how they could work together, which was combined with my own lived experiences (of research and women's health). A lot of my knowledge in the psychology space included research that focusses on replicability and objective observations, so coming to understand the design research approach meant I had to learn about the iterative and participatory aspects. Sociology and anthropology have demonstrated models of reflexivity and unpacking power differentials, which were a good foundation for the critical reflexive approach used in my research. Both psychology and sociology perspectives aided my ability to move from the micro to the macro when viewing the process of co-production — from looking at the 'mundane' details that made up interactions, engagement sessions and relationship building, through to the bigger picture of the whole process, experience and the Care-full Co-production project.

Participatory ethnography

Ethnography, as described by science and technology studies researchers Jeanette Blomberg and Helena Karasti (2013), is a way of understanding aspects of everyday life in a deep, nuanced way which takes into account the context in which experiences are situated, as seen from the perspective of the people having these experiences. They claim that ethnography can encourage specific considerations of who should be involved in what parts of the project, rather than assuming participatory approaches will implicitly include multiple perspectives. Participatory ethnography combines aspects of participatory design, encouraging researchers to be part of the process rather than an objective outside observer — this is sometimes also called co-realisation, combining the analytical aspects of ethnography with the practical elements of participatory design (Blomberg & Karasti, 2013). Feminist design researchers Florence M. Chee, Larissa Hjorth and Hugh Davies (2022) argue that this mix of creativity and reflexive thinking helps to produce actionable knowledge that can achieve social change.

Innovation researchers and designers, Wafa Said Mosleh and Henry Larsen (2021), explain that participatory processes encourage those involved to attend to the gaps and overlaps between people, places and things, considering the interactions between them and the changes that come about from those interactions. Although design researchers Yoko Akama and Alison Prendiville (2013) discuss co-design, I think there is relevance to participatory ethnography when they say "It requires the designer to step into the 'in-between' space that is dynamic, emergent and relational. It necessitates the designer to entangle itself into this space whilst being 'crafted' by it, as well as 'crafting' it" (p. 32).

By recording and documenting the details of Care-full Co-production and my PhD in many different forms, I have allowed for a continual process of mutual and collaborative learning with and from others in the project (Blomberg & Karasti, 2013). Paying attention to the details of how, what and why we did what we did throughout the Care-full Co-production project and my PhD gives access to knowing and understanding co-production as a whole process, as well as the parts that made up our process. The ethnographic view gives us an awareness of co-production within the context of women's health in Aotearoa New Zealand and in relation to its application to co-producing knowledge, as well as what is relevant for implementing co-production in other contexts.

In participatory design and ethnographic approaches, researchers need to "be willing to engage in a continuum of 'roles' with the ability to cycle between participation" (Blomberg & Karasti, 2013, p. 91). This has been true for me throughout the project, as I took on many tasks — organising engagement sessions, e-mailing contributors, organising koha (gifts) for contributors, writing the newsletter, to name a few. The core project team worked collaboratively to engage with the contributors in the project. We collectively planned and hosted engagement sessions with contributors. Some members of the core project team facilitated the sessions, others were kaimanaaki (providing care and support), and I 'held space'[3]

as well as observing, participating, building relationships, and asking additional questions to help clarify my understanding of things, or theirs. I also read relevant content, and thought and reflected on concepts that might apply to the project, sharing them with the team or adding them to the ideas of actions we could take or methods we could employ.

Participatory ethnography embraces an iterative approach where research actions inform the methods and tools used, with the response to these then informing the research approach (Chee et al., 2022). This iterative approach also applies to processing and understanding the noticings and information collated throughout the project. Encouraging empathetic interactions between everyone who is involved in a project or process is also a focus of design ethnography, according to design researcher Dr Geke Van Dijk (2010), which is an important feature of building and prioritising relationships (a key principle of co-production). As you can see, the important aspects of carrying out participatory ethnography also overlap with the important elements of applying co-production — the ways of doing, being and understanding co-production all contribute to better participatory ethnographic explorations and vice versa.

Feminist praxis

Feminist design researcher, Sarah Homewood (2018), explains that a feminist approach involves critiquing the inequities that are embedded in systems, processes and relationships and acting on this knowledge to disrupt or challenge the inequities. For exploring power dynamics, designer and researcher Alison Place (2023) suggests considering "If patriarchy is about power over others, matriarchy is about empowerment from within" (p. 119). Taking this perspective on power can lead to new opportunities for disrupting the status quo. A feminist praxis also involves embracing emotional and embodied forms of knowledge as part of the research process — as environmental researcher Jamie Haverkamp (2021) says, it's about putting the heart as well as the mind into the research practice. Accepting the plurality of knowledge can complicate a process; however, this plurality allows for retaining complexity and avoiding over-simplification of issues.

Feminist approaches call for inclusivity, anti-racism and social justice actions, and working more slowly and differently to include more people, as discussed by geographers Alison Mountz and colleagues (2015). Focussing on the people in the project, the relationships with and between them, and how to meet their needs can be accomplished by focussing on care. While kindness had been my focus as the General Manager of Good Bitches Baking (prior to my PhD), a shift to prioritising acts of care and adopting a feminist ethics of care became a core aspect of this research. Care has a broader meaning, and wider implications — particularly within academic spaces and publishing — and tends to result in more action and practices. Care has also often been considered personal or something that is done in our 'private life', but embedding care as a practice enables researchers' authenticity (Mountz et al., 2015). As discussed in Arm 2: Care (p. 153), a feminist ethics of care is a significant aspect of Care-full Co-production and this thesis.

Including a feminist praxis requires reflexivity and an awareness of how, as a researcher, one is situated within the project. Awareness of personal privilege, along with biases and assumptions, is needed to disrupt power asymmetries and challenge paternalistic notions (Homewood, 2018). This can look like taking a matriarchal approach to research — "matriarchy is not defined by the predominance of women over men but by an entirely different conception of life based on participation, collaboration, understanding, respect, sacredness, and the cyclical and relational fabric of all life" (Place, 2023, p. 119). Challenging my own foundational understanding of how 'to do' research, a matriarchal conception allowed a gentle and compassionate way of re-learning. It also afforded space to focus on the humanness and interconnectedness of myself and of all those involved in the project.

Research methods

My research approach utilises the following methods alongside a case study on women's health, which forms the core of this PhD.

Kitchen table approach

Kitchen table conversations are a popular approach for civic engagement, especially across Australia, according to not-for-profit leaders Mary Crooks and Leah McPherson (2021). They are a way of encouraging informal conversations about complex issues, and giving a way to include people who might not usually be involved in such conversations (Crooks & McPherson, 2021). These conversations are intended to be a safe way for people to discuss different topics, value everyone's contributions, learn together and give all involved a chance to speak. While the concept originated from the idea of 'sitting round a kitchen table having a chat', as a methodology, they can happen anywhere — homes, cafes, offices, etc. These conversations can also be a way to blur the boundary between public and private spaces and topics.

Having a conversation over shared food and drinks also aligns with Indigenous methods, where a key aspect of relationship building and communication comes through the process of spending time together having a 'cuppa'. Environmental researcher, Cheri van Schravendijk-Goodman (2017), writes that having a cuppa with the people you want to connect and talk with is a reminder to slow down, listen and reflect — the embodied nature of sipping on a hot drink is a physical reminder of this. Providing food and facilitation for a conference, Te Herenga Waka, Victoria University of Wellington's The Kai-dness Crew described how sharing kai can be a tool to push boundaries while initiating connections and collaboration (Perkins et al., 2024).

The kitchen table approach also helps create an atmosphere that reduces power asymmetries and hierarchies, encouraging everyone to share their thoughts equally. Although it needs acknowledging that not everyone will have had the same previous experiences of sitting around a kitchen table, so it shouldn't be assumed

that this approach inherently responds to power asymmetries. We embraced this approach for our project team meetings as well as for engagement sessions with project contributors in the women's health case study. Not every project meeting had cake included, but many did, which also added to the kitchen table feel of these conversations (an example can be seen in Figure 3). Tea and cake has also been picked up as an approach to research (particularly in the United Kingdom) as this can help develop a relaxed, caring and friendly atmosphere (Light & Akama, 2014).

Figure 03:
A team meeting and birthday celebration — with cake!

SLIP process

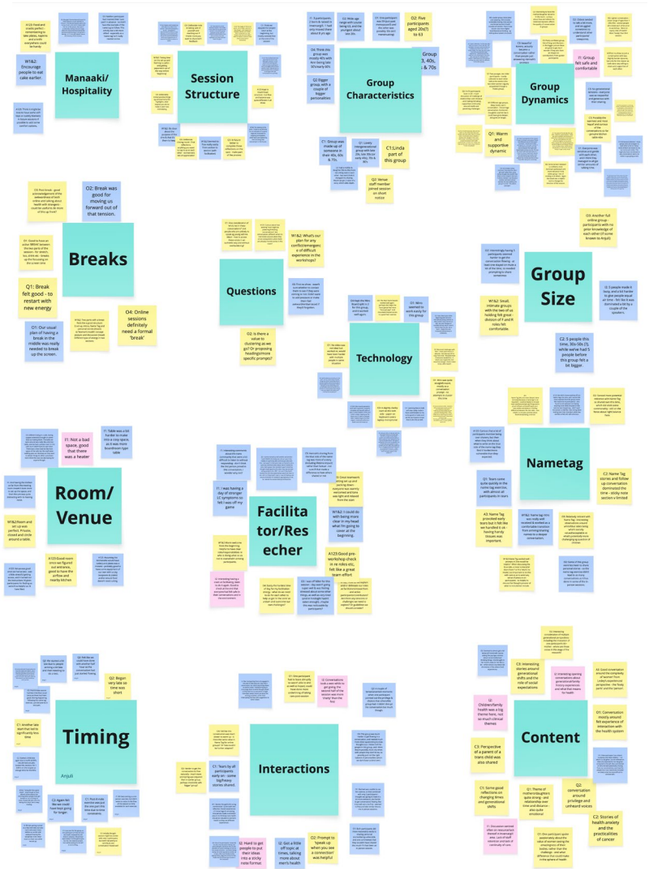
The SLIP process comes from designer John Maeda's book The Laws of Simplicity and is a process designed to bring order to complexity (2006). The process begins with the question "What goes with what?", followed by the prompts to Sort, Label, Integrate and Prioritise.

We used the SLIP process individually and as a team for synthesising the women's health content that came out of the conversations we had during the project — transcripts from the session recordings and contributors' ideas written down during the sessions. I have also used this process for organising and making sense of the various forms of 'data' that were collated throughout this project — such as feedback received and reflections — and to organise my thoughts from reading the literature. Through interacting with ideas and content this way, new knowledge was constructed and synthesised.

The analogue way to do this is to write all the ideas that are to be synthesised onto individual sticky notes. You can then move the sticky notes around while sorting

them into groups. Each group is then labelled with a relevant name or a placeholder code. The next step is to see if any of the groups are similar enough that they can be integrated — the aim is to have a small number of groups, if possible. However, as Maeda comments, this can be a tricky step, and it might result in some groups breaking into further groups instead. The final step is to prioritise the groups, with Maeda suggesting that 20% of the groups receive the most priority attention, before the rest of the groups. Using sticky notes is a great way of making the process tangible. However, as an alternative I have also carried out the process using Miro (an online whiteboard and collaborative workspace); an example is shown in Figure 4. There is no right or wrong way to use this process, and the organisation that comes out of it is not the sole option — sometimes it can feel like the sorting could continue in many different ways, but there is generally a point when the organisation 'makes sense'. When it makes sense indicates an alignment between all the ways of knowing that are being included in the project — for example, physical, emotional, intuitive and intellectual (which is discussed further in the Head chapter, p. 111).

Figure 04:
Using the SLIP process on Miro to synthesise feedback.



Warm data — documenting the processes and experiences

I am uncomfortable calling anything 'data' here — it feels reductionist, oversimplistic, and detached from the people and processes that make up this project. The term that feels closest is 'Warm Data'. Coined by filmmaker and researcher Nora Bateson (2017), warm data refers to contextualised information that focusses on the interdependent and interrelational aspects of complex systems. With a focus on relational research in my thesis, warm data more closely explains what was documented throughout my research.

There was no aim for replicable, objective gathering of information in this project; instead, we (myself and all those involved in the project) have embraced a plurality of knowledges. We have not excluded our emotions, or our embodied ways of knowing, rather these have been part of the process of constructing new knowledge, and therefore, the term data does not feel right. Though I have caught myself hesitantly using it when unable to think of a better word.

As we did not plan the project in its entirety from the beginning, I was not sure what would be the most useful 'data' to collect, so I collected a wide range of things that recorded what we did, how we did them, and what I or others thought about processes and experiences. Conversations with contributors were recorded and transcribed, and activities carried out in engagement sessions were recorded on paper and with photos, or on Miro Boards, along with survey responses and emails. I documented the processes we used, photographed moments and ways of doing things, and collated my personal reflections along with team members' reflections. Notes taken during team meetings, observations during engagement sessions, memories that arose while transcribing conversations, along with all the conversations themselves, have all played a part in developing my thoughts and understanding throughout this project.

Not documented or recorded in any way, but no doubt having an influence throughout, was what feminist researcher Elizabeth St. Pierre (2015) has called transgressive data — "dreams, sensualities, emotions, the words of other scholars, the novel just read, a neighbour's comment. These data are found in every study, though their presence and importance are seldom acknowledged" (p. 5305). This transgressive data, from everyone involved in this project, is woven through a relational research process that is entangled with the practice-based knowledge that informs this thesis.

While I have included quotes from contributors and team members throughout this thesis, removing them from their context felt like I was chopping them up, a potentially violent act of removal. I have aimed to fold them into this thesis gently, with the care and respect the people's stories deserve. In this way, the thesis is infused with the responsibility of carefully carrying these stories we were privileged to be trusted with.

What I didn't use and why

There are several popular design research approaches that a reader might expect to see used in my research. In this section, I have described these and why I haven't used them, to be explicit about what I did and didn't include.

Human-centred design

Human-centred design is popular due to its replicable processes that can be used nearly anywhere by anyone. Design researchers Yoko Akama, Penny Hagen and Desna Whaanga-Schollum (2019) write that human-centred design methods often have a 'toolkit' feel, making it easy for people who are not trained as designers to use them as well as those with specific training. Designer Cynthia Vinney (2023) writes that human-centred design focusses on centering people's psychological, emotional and behavioural needs in the design process so that the solutions developed take the whole person into consideration. Focussing on the whole person relies on empathy and empathetic conversations; however, according to Akama et al. (2019), this empathetic approach risks being tokenistic. They highlight that human-centred design comes with an industrialised, Eurocentric and colonial history, and doesn't specifically challenge power structures. Akama et al. (2019) also note that design researchers don't often share their backgrounds or positionality, resulting in reinforcing the assumption that design is neutral, objective and universal. This lack of reflexivity means there is no explicit consideration for which people and which experiences are being prioritised through human-centred design approaches. The lack of reflexivity and disruption of power asymmetries is why human-centred design is not used for my research. While people and their lived experiences are key to this thesis, I don't think human-centred design goes far enough in considering people for the aim of this PhD.

Design thinking

Education and systems researchers Rim Razzouk and Valerie Shute (2012) describe design thinking as a specific approach to problem solving that focusses on the use of design to create solutions. Design researcher Cameron Tonkinwise (2017) suggests that often the problems that design focusses on have a social aspect, requiring an understanding of people and their everyday lives. Design thinking is an iterative approach that relies on solutions being modified and refined, until a suitable or optimal solution is settled on. As part of this process, the problem is also refined and narrowed down in order to select the appropriate solution (Razzouk & Shute, 2012). Design researcher Nigel Cross (1982) wrote that compared to science based problem solving, design thinking's search for a solution is expected to happen within a specified time limit — whereas science often delays providing an answer while more research is completed. Focussing on narrowing down the problem and selecting the best solution, is part of why design thinking was not specifically used for my PhD research. Throughout the women's health case study we kept the topic broad

to develop a nuanced understanding. Also, anytime we started to narrow the topic down, we received feedback suggesting we were losing the complexity of the topic. By not using design thinking we removed the expectation to narrow down our field of enquiry.

Like human-centred design, design and art historians Arden Stern and Sami Siegelbaum (2019) observe that design thinking relies on intangible skills such as empathy and reasoning, which also aids in applying design thinking across multiple scenarios. However, despite this inclusion of empathy, traditional design approaches (including design thinking) have not paid much attention to the ethical considerations involved when designing with people (Akama et al., 2019). As ethical considerations, and specifically ethics of care, were vital to this project, choosing research approaches that forefronted ethical considerations guided our choice. Design thinking does not expressly prioritise this and so it was not an approach I specifically included.

Double diamond

The Design Council's Double Diamond is a well known and well used visualisation of the design and innovation process (Design Council, 2019). The Double Diamond is made up of four stages — discover, define, develop and deliver. It's helpful for guiding decision making about what methods to use when and as a reminder of the purpose of different parts of a design process. The process is a mostly linear one, and its simplicity makes application to many topics or problems easier. Similar to human-centred design, and design thinking, the Double Diamond has developed out of Western, neoliberal ideas (Akama et al., 2019). It does not overtly encourage practitioners to identify or challenge power structures, and therefore can inadvertently reproduce inequalities and colonial harm. For my PhD research, the Double Diamond did not map onto the model of co-production that was our starting point. Following the four stages of the Double Diamond also risked shaping the research to fit, rather than allowing the Care-full Co-production space to develop in response to the input of those involved.

People in the project

Good Bitches Baking

Good Bitches Baking is a nationwide charity, whose purpose is to spread kindness to people having a tough time. We built on my existing relationship with this charity to recruit contributors for the Care-full Co-production project. Good Bitches Baking was established in 2014, and I started volunteering for the Wellington chapter in 2016. Shortly after, I joined their National Operations Committee, running their fundraising shop. In 2019 I took over as their national manager — the only paid role the charity had at the time. By the time I left to start this PhD they had nearly 3,000

volunteers, and while I certainly did not know everyone, I knew a lot of the names of volunteers, and most of them would have known who I was from all the internal and external forms of communication. More details about the charity are shared in the Aotearoa Waters chapter, where recruitment is explained.

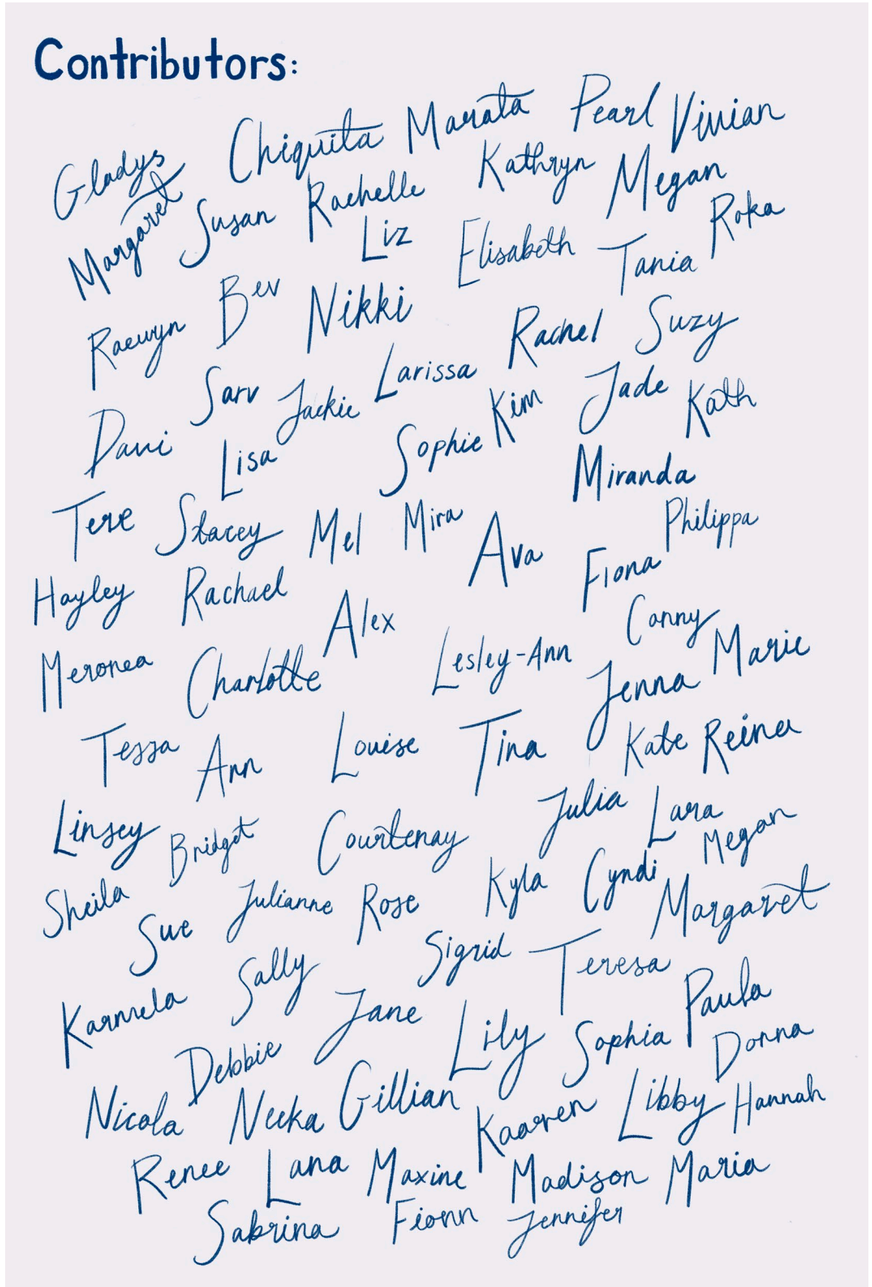
Contributors

By the end of Care-full Co-production we had 89 contributors in total from across the motu (country). We simply recruited women over the age of 16 who were interested in being part of a conversation about women's health and didn't target any particular demographics. From what the contributors shared throughout the project we had an age range from early 20's through to early 80's from a variety of backgrounds.

We intentionally didn't collect demographic data at the beginning — we were focussed on building trusting relationships and collaborative processes, and felt that the impersonal nature of form filling detracted from this. Asking for personal details that would be shared in demographic data questions can also reinforce power differentials, undermine trust (especially if someone has experienced misuse with their data in the past), and disrespect people's contributions if information collected will not be used. Throughout the research we revisited the question of whether we would collect demographic details of those involved, and each time we had no solid plan for how we would use this information to justify collecting it. In the end we recognised that the motivation to collect this data was about our understanding and expectations of 'doing research' — collecting demographic data is something 'we do' or 'should do' as part of research generally, especially in more traditional or paternalistic approaches. However, collecting data just for the sake of it, or 'because we should', would be unethical and against the values that underpin this project. We had to reflexively wrestle with this tension every time we considered asking the demographic questions — I say 'we' because there were two strands to this decision; did we need these data for the research itself (the women's health case study), and/or did I need these data for my thesis? Eventually, we identified the tension and discomfort and decided that these data was not needed for either.

When deciding who to include in the Care-full Co-production project, we intentionally choose not to start with health professionals. With the intention being to elevate lived experiences, we thought beginning with women made sense. Specifically recruiting from outside of the health system and not engaging with particular diagnoses was part of our approach to keep things broad. Most health-related research starts from within health care which assumes everyone can and wants to access care that way. However, we also recognised that people often fit in multiple categories, which, as Haverkamp (2021) wrote, disrupts the "Western notions of stakeholders fitting neatly into separate spatial and political scales" (p. 7). People's identities contain multitudes, so some of the women in the project were also working in the health space (e.g. one was a midwife and someone else worked in service design within a hospital). Welcoming women's full selves into the project was important to the authenticity of the process.

Figure 05:
Contributors to The Co-production Project.



Core project team

The core project team consisted of Anna Brown, Hannah Smith, Jean Donaldson, Hanna Breurkes, Linda Baxter and myself — a mix of Toi Āria staff, associates and students. We worked collaboratively throughout, making the most of everyone's skills and strengths but also just doing what needed to be done — we didn't have clearly defined or separated roles that we focussed specifically on. Although we didn't have specific roles, Jean and Hanna were responsible for the majority of design and illustrative aspects of the project. We met regularly and used a mix of online tools to aid our collaboration. We were curious, brave and vulnerable with each other in ways that allowed us to support each other and the Care-full Co-production case study. Through the conversations and the doing, we developed our collective understandings and ways to share our work — with contributors and others outside of the project. I think it's a sign of how collaborative Care-full Co-production was, that it has been very difficult to identify or 'own' things as an individual. While I can't truly separate or specify my role, the reflexive synthesis of theory, process and practice that makes up this thesis form my individual contribution beyond the collective work.

Core project team and contributors

Throughout this thesis I have used the terms 'core project team' and 'contributors', however I would like to acknowledge I have been uneasy doing so. Writing it this way unintentionally makes the contributors 'others'. This separation was used to clarify who was doing what throughout Care-Full Co-production but suggests the separation was more clearly defined than it was. It's uncomfortable to write in a way that separates and potentially creates a power asymmetry that we were intentionally trying to reduce or remove. Occasionally I have also written 'our contributors' — this is as a relational way to recognise connectedness and familiarity, not as a form of ownership.

Research metaphor

About a year into The Co-production Project, while sharing about each other's projects, our critical friend Dr Rachelle Martin described co-production as an approach as being like trying to 'wrestle an octopus into a string bag'. This very visceral metaphor resonated with us — it captured the feeling that co-production could be unwieldy with many arms going in different directions, and at the same time trying to contain a unique and changing shape into the processes and systems of academia (the string bag), which can feel both containing and constraining.

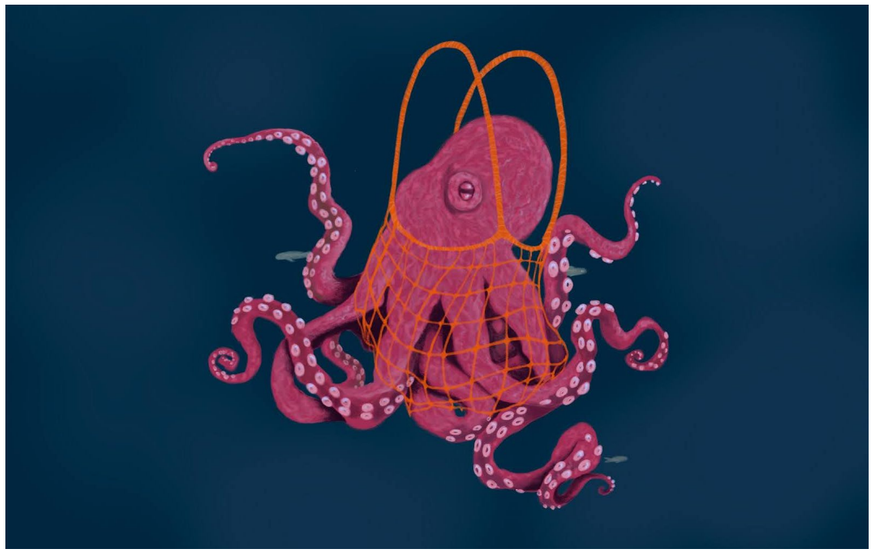


Figure 06:
The octopus in a string bag (J. Donaldson).

Once Rachelle had shared the metaphor with us, one of core project team members Jean created this amazing illustration (Figure 6) for the project. This illustration has become a core element of how we have communicated this project to those in the project as well as wider audiences. The illustration really captured the essence of the metaphor, and helped catalyse my approach to communicating this thesis.

Octopuses are known to change their colour and skin texture to suit their environment and to fit in, which reflects the need for co-production to be carried out in context-specific ways. The physical attributes of an octopus give a nod to the complexity of co-production — the eight arms are semi-independent with each one having a mini brain, as well as the central brain in the head (where all arms connect). Each arm then has multiple suckers for various tasks, which could be seen along the lines of the saying "the sum of its parts is greater than the whole". Octopuses have three hearts and the main one switches off when they swim — this means they tire easily, so they generally prefer to walk to conserve energy, with all three hearts continuing. These physical characteristics align with our experience of co-production — that going slower can be beneficial. Octopuses are known to interact with people, care a lot for their young, and while generally solitary creatures, have also been known to build cities or communities — this sounds similar to prioritising relationships, a core principle of co-production.

I have developed this metaphor further, and used it as the structure for this thesis. Partly because metaphors can make complex notions easier to comprehend, and also because using this metaphor helps demonstrate the non-linearity of co-production. To start, the 'ocean' has been presented to show the context in general for co-production or the octopus's environment. Then the thesis moves into Aotearoa

waters, the specific location this research took place in — telling the story of everything that happened in the case study where we explored women's health and created a library of research questions about women's health. The Aotearoa Waters chapter could be considered similarly to the 'results' section found in other theses. These 'environment' shifts also indicate that co-production can be moved from one location to another for each project. And, possibly, that the string bag may help carry the octopus to a new location. *The Ethical Octopus* itself is then explored, starting with the head and then moving through the arms individually (Figure 7). Following this is a discussion of what makes up the string bag and how it may help or hinder. The octopus and the string bag are similar to the discussion section found in scientific theses. To finish off the metaphor, the thesis concludes with the horizon and looking to the future.

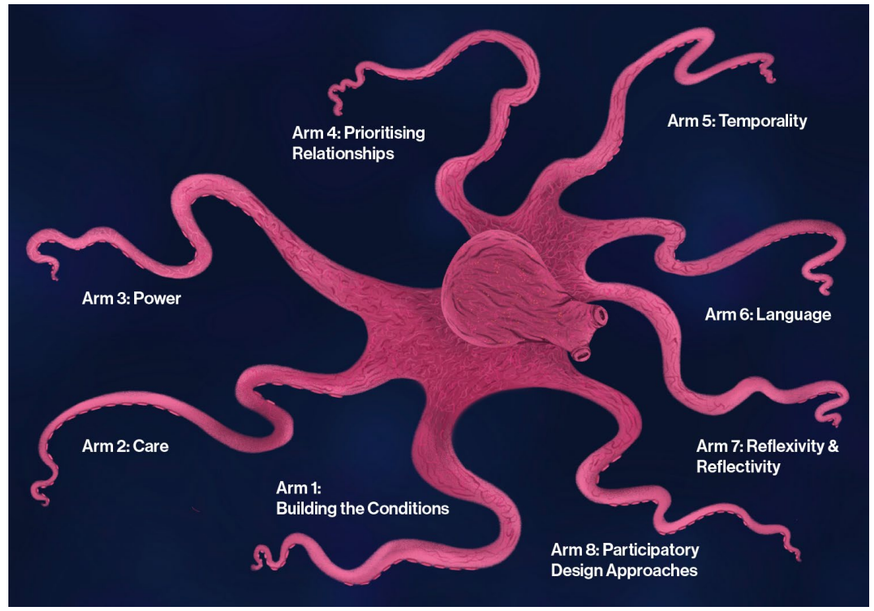


Figure 07:
The Ethical Octopus and it's 'arms' of co-production.

1 "A whisper network is an informal chain of conversations among women about men who need to be watched because of rumors, allegations or known incidents of sexual misconduct, harassment or assault. It's a way for women to protect themselves, and to do so under the radar. In one way or another, in every major industry and institution, there have been whisper networks helping women to watch out for each other." (Meza, 2017)

2 A rapid review is "an emerging approach to research synthesis that utilises systematic search and appraisal processes but, unlike systematic reviews, focuses on review-level rather than primary studies" (Slatter et al., 2020, p. 2)

3 To hold space means "to behave in a way that makes someone feel accepted, listened to, and able to share their feelings and experiences without being judged or criticized." (Cambridge Dictionary, n.d.)

Ocean:
Context Review

Ocean: Context Review

Interest in co-production has increased over the past decade, with the number of published articles increasing 25% between 2014 and 2018 alone, explain health policy researchers Floriana Fusco, Marta Marsilio and Chiara Guglielmetti (2020). However, there is a lack of consistency in defining and using it. Masterson et al. (2022) explain that some of this inconsistency comes from authors assuming the reader's understanding of the use of the term, rather than clearly defining its use in their work. The delineation between co-production, co-creation, co-design, participatory action research, and critical participatory action research, to name a few, is also fuzzy. It seems that there is no identifiable defining feature that separates these approaches from each other. There also seems to be a lack of consensus on whether these approaches are actually methods, methodologies, frameworks or theories. Co-design coach Emma Blomkamp (2022) describes co-production as a design-based practice rather than a theory or analytical tool. Health services researchers Louise Locock and Annette Boaz (2019) write that sometimes the words engagement or involvement are also used interchangeably with co-production.
Over the course of my PhD, I have tried to untangle the different definitions, where they came from, and to identify where the overlaps with other approaches, such as co-design, co-creation and action research, lie. Throughout this chapter, I aim to explain my understanding of co-production that this untangling has led to. However, I do not claim to have fully untangled all of these words. Much of the documented co-production research I have found has been carried out in the United Kingdom and other Western countries (Fusco et al., 2020). While Aotearoa New Zealand can be defined as a Western country, there is a unique context here, which is part of the reason for my exploration of co-production. I have given an overview of this context below, along with outlining the women's health context that is relevant to the case study through which we explored the use of co-production.

What is co-production?

Public policy researchers Catherine Durose, Beth Perry and Liz Richardson (2022) argue that a lack of specificity when it comes to defining co-production has led to the term having a broad use and being applied to many different purposes and often used

interchangeably with other words such as co-creation and co-design. Masterson et al. (2022) carried out a review of co-production and co-design definitions in their field and noted that of almost one thousand articles reviewed, nearly a third did not include a definition or explanation for their use of those terms. Publishing articles that lack definitions becomes a reinforcing cycle as it becomes harder to classify one's research, but it also means those who want to adopt the approach of co-production have a harder time identifying the ways projects 'are' or 'are not' co-production.
At the same time, the lack of clear definitions can aid co-production to be a more inclusive and flexible approach, but is also why it is critiqued and contested (Durose et al., 2022).

Researching in the sustainability space, Josephine Chambers and colleagues (2021) write:

> Co-production is a rapidly growing endeavour now widely applied in the fields of health, development, education, climate change, industrial production and sustainability. It broadly seeks to connect researchers with diverse societal actors to collaboratively and iteratively produce knowledge, action and societal change. (p.983)

Public health researchers, Katrina Messiha and colleagues (2023) say:

> Co-production is about engaging stakeholders in the implementation of previously set solutions to an already agreed problem, in prioritizing the optimal usage of available resources. (p. 723)

Whereas Tony Bovaird (2007), a professor of public management and policy, explains that co-production is defined as:

> the provision of services through regular, long-term relationships between professionalized service providers (in any sector) and service users or other members of the community, where all parties make substantial resource contributions. (p. 847)

These are just a few of the different definitions being used, which highlight the breadth of ideas they cover. In addition, the outputs that co-production is used for also differ — as social scientists Matthew Flinders, Matt Wood and Malaika Cunningham (2016) write, these are generally grouped into co-producing a service, policies or knowledge.

What is co-design?

Co-design is often used synonymously for co-production and is as hard to pin down. Sustainability researchers, Yokota et al. (2018) describe co-design as "a process of joint development and mutual learning with all stakeholders regarding the research

plan and protocols including research objectives, design, and methods" (p. 2). Messiha et al. (2023) give the definition as "Co-design is distinguished as the active collaboration among stakeholders relating to solution design, given a pre-determined problem" (p. 723). Whereas, specifically related to research, Slattery et al. (2020) wrote that they:

> defined 'research co-design' as the meaningful involvement of research users during the study planning phase of a research project, where 'meaningful involvement' is taken to refer to participation in an explicitly described, defined and auditable role or task necessary to the planning and/or conduct of health research. (p. 3)

Collaboration between a mix of academic and non-academic people is a consistent element of these definitions, with differing ideas on when and how that collaboration occurs.

Knowledge lineage

Sometimes it seems that co-production refers to the whole project, whereas co-design is a particular stage or something entirely separate, or vice versa. According to design researchers Luis Soares and Sarah Kettley (2024), co-production is sometimes also referred to as a separate stage that may occur before or after co-design. Knowledge mobilisation researchers Kate Beckett and colleagues (2018) also talk about research co-production being something different to co-production projects — such as co-producing aspects of health care systems. Sometimes these terms are used in a different way again, such as by environmental scholars, Meg Parsons, Karen Fisher and Johanna Nalau (2016) who write "This multi-generational approach to co-designing research and co-producing knowledge recognizes that different kinds of knowledge may be held by different people" (p. 102). Social scientists Luisa Veras de Sandes-Guimarães, Raquel Velho and Guilherme Ary Plonski (2022) highlight that knowledge co-production is often mentioned in the literature as if it is something else again, although this might be due to the different lineages involved in the development of co-production. Commenting on the recent broad use of the term 'co-production', health researchers Oli Williams and colleagues (2020) wrote that they:

> describe this phenomenon as 'cobiquity'— an apparent appetite for participatory research practice and increased emphasis on partnership working, in combination with the related emergence of a plethora of 'co' words, promoting a conflation of meanings and practices from different collaborative traditions. This phenomenon commonly leads to a misappropriation of the term 'co-production'. (p. 2)

It seems that without a clear definition of what co-production is or is not, our understanding of it gets fuzzier and fuzzier.

Masterson et al. (2022) helpfully carried out a scoping review through which they began mapping out the definitions of co-production and co-design as they are used in the health and service care sector. They commented on the interchangeable use of co-design, co-production and co-creation, and suggested that co-production might actually be an umbrella term for all the co-words. Under this umbrella term would sit other phases or activities, "such as co-commissioning, co-planning, co-prioritization, co-financing, co-design, co-managing, co-performing and co-assessing" (Masterson et al., 2022, p. 908). Beyond this, they took definitions from nearly 1000 articles and were able to sort them into the following eight clusters:

1. Definitions that form the origins of co-production
2. A clearly defined approach to health research — the six-stage process called Experience-based Co-design.
3. Definitions whose commonalities are processes that were specifically proposed by government agencies, where the outcomes or outputs were for public or private benefits.
4. Definitions with a specific delineation of roles in the use of co-production and with the differentiation between 'paid employees' (of health services providers) and the specific involvement of citizens.
5. Three related types of co-production — "consumer co-production (improving the quality and impact of public services), participative co-production (improving the planning of public services) and enhanced co-production (bringing consumer experience together with participative planning to generate new approaches to public services)" (pp. 909-910).
6. Other definitions related to the use of the term 'co-creation', where co-design or co-production were an aspect of co-creation, a specific example of co-creation, or used interchangeably with co-creation. This cluster also included the concept of co-creation being the involvement of community members in the initiation and designing of public services, whereas co-production referred to involving community members in the implementation aspect of public services.
7. Co-production as an umbrella term for co-design, co-planning, co-financing, and co-managing, among many others.
8. Definitions that recognises reciprocal relationships between all those involved in providing, delivering, using and supporting a public service, and acknowledges co-production is difficult to define.

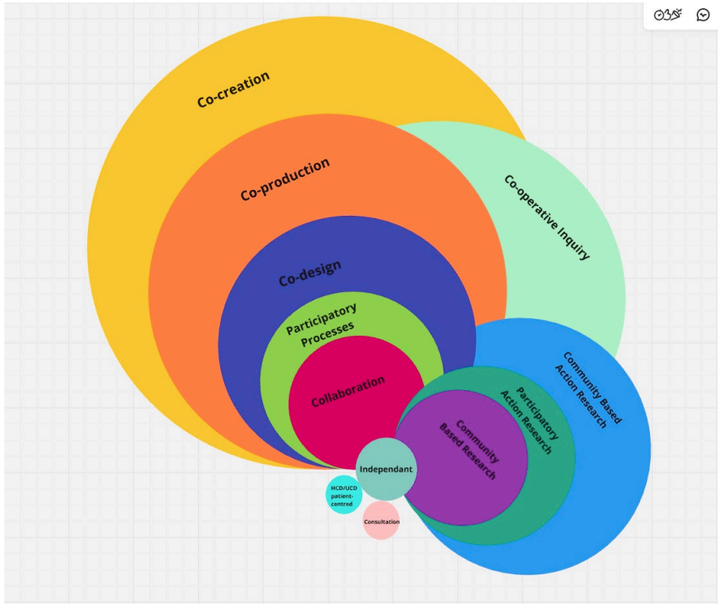


Figure 08:
A visualisation of different research approaches and how they might relate to each other. (A. Muller)

Unlike other clusters, Cluster 8 specifically highlighted the consideration of values and principles of co-production, rather than pinning down a definition — this consideration of values and principles will be explained further in the history of co-production in the next section.
As part of developing my understanding of these definitions, I attempted to visualise how these different terms, co-production, co-design, and co-creation, along with other participatory approaches, could fit together (Figure 8). While it gives a clear and simple idea of them all, I think it is too simple and categorises different 'types' of approaches as the same.

Co-production is suitable for investigating complex issues, providing a way to deal with the uncertainty of the present and the future. Durose et al. (2022) argue that this approach encourages thinking about complexity in terms of 'incompleteness' rather than 'uncertainty'. Verwoerd et al. (2022) highlight the tension between the norms of 'natural scientific' knowledge production (linear, objective, positivist) and co-production of knowledge (social constructivist, variety of stakeholders) and how often co-production is asked to 'prove' itself according to scientific norms, for example, publications as an output and impact statements. Interdisciplinary and co-production research has been touted as a way of producing relevant knowledge and social solutions. de Sandes-Guimarães et al. (2022) found that co-producing the knowledge was the key to more impactful results. As social scientist James Duggan (2021) claims, "Co-production provides a necessary space for academics and communities to challenge elitist and exclusionary knowledge production cultures"

(p. 356) — especially within the neoliberal structures of universities.
Within the variations of definitions, there is also no consensus on whether co-production is a process (Filipe et al., 2017), a practice (Blomkamp, 2022), a method (Martin et al., 2022), a framework (McGill et al., 2022), an approach (Messiha et al., 2023) or a methodology (Verwoerd et al., 2022). I thought that figuring out specific differences between co-production, co-design, co-creation, participatory action research, feminist participatory action research, community participatory action research and co-operative inquiry would help clarify the definition of co-production and 'what' it is. They all have similarly incomplete definitions that continue to evolve. Within this context review, I have aimed to give further examples that will contribute to increasing clarity.

Williams et al. (2020) suggest there does not necessarily need to be one specific definition, as co-production projects will each be different and context-specific. They also suggest a singular definition would ignore or hide the complexity of co-production — but also clarify that this lack of such a specified definition is not encouragement to label any form of collaboration as 'co-production'. According to design researchers Jotte De Koning, Marcel Crul and Renee Wever (2016), a method is the mix of tools and activities combined in order to achieve a specific goal or develop a solution. In contrast, an approach is a mindset or ways of thinking needed to implement or carry out a process.

The definition of co-production that I settled on for this thesis is:

> Co-production describes an approach to research in which communities, organisations or groups who are meant to benefit from — or who otherwise will be affected by — the research become partners in formulating, designing, carrying out, analysing, and reporting the research *(Chambers et al., 2021; Durose et al., 2022; Pain et al., 2015; Willyard et al., 2018).*

However, it has been held lightly throughout as my understanding has deepened along the way. In essence, the research is carried out equitably with the contributors — they become co-researchers in the project. Using the term 'approach' here (and throughout) is intentional, focussing on the mindsets that are useful for co-production, as it encompasses how we went about implementing 'Care-full Co-production' for my PhD. Additional reasoning for lightly settling on the term 'approach' comes from using social designer KA McKercher's diagram of co-production as the foundational starting point for The Co-production Project (discussed further in the next section). Their diagram suggests co-production consists of four parts: co-planning; co-design, co-deliver, and co-evaluation, and has four key principles: build capability, share power, prioritise relationships, and use participatory means. These key principles encourage specific mindsets when carrying out co-production rather than specified ways of doing things or particular tools to use. In alignment with Masterson et al.'s (2022) explanation of the final cluster of definitions mentioned earlier, focussing on principles underpins this project.

History and development of co-production

The documented history of co-production is predominantly Western, similar to the mostly white documented history of Design (Akama et al., 2019). However, we also need to acknowledge that academic publications and other (mostly Western) ways of documenting projects will not have been the priority for all co-production projects, which may affect the history of co-production we are able to collate. Indigenous methodologies and participatory approaches appear to overlap (M. Parsons et al., 2016; Rolleston et al., 2022) in some areas, which also needs to be considered in the history and development of co-production, even though it has not often been recognised.

Two histories of co-production

There appear to be two main lines of development that have led to co-production as used in my thesis, though that may be an oversimplification. Co-production first came about in the 1970s in response to changes in public service development and management (Bovaird, 2007). At this stage, American political economist Elinor Ostrom (1996) defined co-production as "the process through which inputs used to produce a good or service are contributed by individuals who are not 'in' the same organization" (p. 1073). She argued that "Coproduction is one way that synergy between what a government does and what citizens do can occur" (p. 1079). It had been recognised that there was a difference between the production of goods and the production of services, and co-production was one way of addressing this. Co-production focussed on using empirical data and cost-benefit analyses, and was particularly recommended for use in developing countries. This is an interesting feature, as there seems to be little acknowledgement of the power asymmetries between those making this recommendation and the developing countries themselves, nor the power asymmetries in other relationships within co-production. Some explanations suggest that just by the nature of different parties interacting (e.g. doctor and patient), they are co-producing a service or experience (Bovaird, 2007).

Co-production from service development and management seems to have been developed further within environmental, sustainability and economics spaces. Older works have less overt discussions of relationships and power; however, this may also just indicate how our use of language has developed over the decades. Recently, sustainability researchers Norström and colleagues (2020) defined 'knowledge co-production' (as mentioned earlier, this is sometimes considered different to co-production in general) as "Iterative and collaborative processes involving diverse types of expertise, knowledge and actors to produce context-specific knowledge and pathways towards a sustainable future" (p. 183). They note that being more prescriptive is difficult as projects are so context specific, and also highlight that knowledge co-production not only creates knowledge but also builds capability and relationships and encourages actions that help with sustainability. These authors suggested four key principles to aid with co-production, specifically for sustainability, but I would recommend their relevance for all co-production. The four principles are: context-based, pluralistic, goal-oriented, and interactive. Norström et al. (2020) specifically highlight the importance of discussing and addressing power asymmetries along with recognising a plurality of knowledges (including experiential knowledge). Shifting to focussing on the principles of co-production is quite recent, but something that is recommended as a way of bringing more clarity to our understanding of co-production (Masterson et al., 2022). This discussion of principles is also about the point where I think this line of development for co-production (from the public services space) combines with the second historical lineage, which I will explain next.

In parallel, design methods were evolving to specifically include participatory design approaches, with the Scandinavian participatory approaches starting in the 1980s, and incorporating the intersection of design and social sciences. According to social scientist Judith Gregory (2003), the Scandinavian approach to participatory design has three principles: a commitment to democracy; discussions of values in design and futures; and considering conflict as a design resource. These approaches also embrace change and development of all involved in projects — people, communities, organisations, technology and processes — including mutual learning and reciprocal relationships. From this perspective, participatory design openly aims to disrupt power and values relationships. As participatory approaches grew, the focus moved to user-centred design and human-centred design (Sanders, 2002). From that co-design developed — generally attributed to Elisabeth Sanders (who started out in psychology and anthropology) and Pieter Stappers (with a background in physics and engineering), they acknowledge the variety of definitions for co-design (Sanders & Stappers, 2008). For them, co-design is the process of collaborative creativity (between two or more people) between those who have trained as designers and those who have not, across the entire process of design development. They base their work on the assumption that everyone is creative and use participatory tools to encourage the creative generation of new ideas.

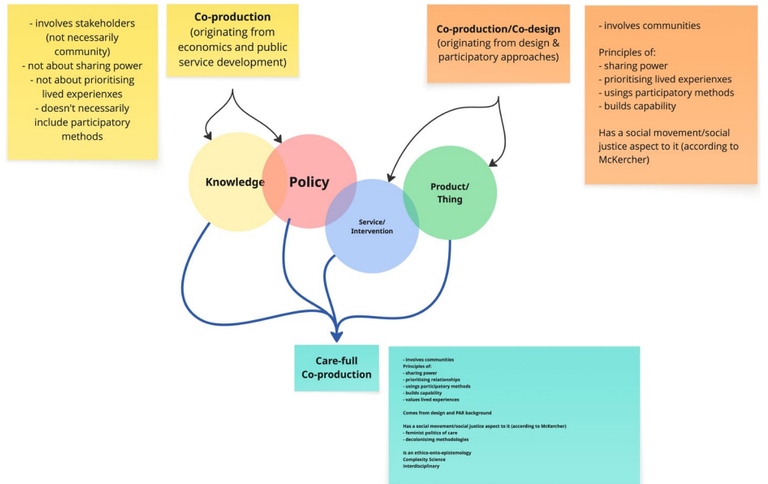


Figure 09:
A simplified mapping of co-productions history. (A. Muller)

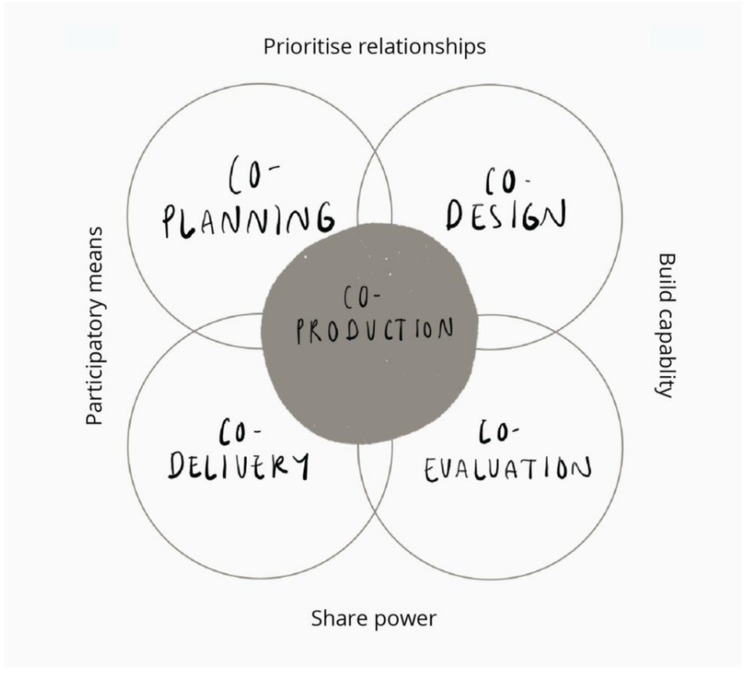


Figure 10:
Co-production, from K.A. McKercher, (2020). Copied with permission.

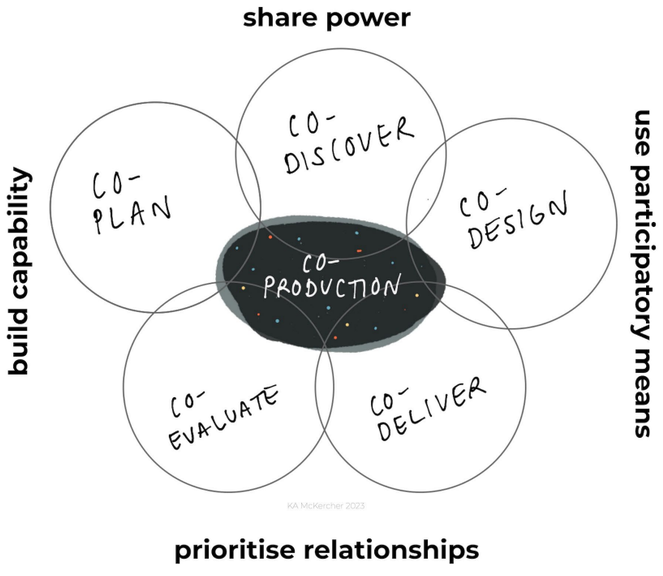


Figure 11:
Co-production, from K.A. McKercher, (2023). Copied with permission.

McKercher, who has practised in Aotearoa New Zealand and now in Australia, mostly facilitates co-design in health-related spaces and provides training for others to learn how to co-design. To my mind, their model of co-production pulls together the two lineages of co-production development (as demonstrated in Figure 9). As explained earlier, in their model of co-production (Figure 10), co-design is a specific sub-part of co-production, and co-production is grounded in four principles. In early 2023, when we first started our 'Cuppa & Cake' sessions, we termed this phase 'co-discovery' — about the same time, McKercher updated their diagram to also include a 'co-discovery' aspect (Figure 11). It was affirming to know we were on the same page as them, even though we were not working together. Due to its Australasian positioning, McKercher's model was the foundational starting point for The Co-production Project in the project outline used to gain funding. Through The Co-production Project and Care-full Co-production, we have built on and implemented this model of co-production in our own ways, which will be explored throughout the rest of this thesis.

Aims and hopes of co-production

Co-production aims to disrupt power asymmetries or to return power to those who may have had it taken from them historically (Locock & Boaz, 2019). It aims to blur the lines between researcher and participant, designer and non-designer, and challenges the way research is carried out. By including those who are likely to be affected by the research outputs from the start, co-production aims to initiate positive action and recognise that participants have something valuable to offer (Chambers et al., 2021). Public administration researchers Arwin van Buuren and colleagues (2020) suggest that design approaches in general are thought to begin with empathy rather than impartial, objective reality. Co-production also relies on empathy or compassion in order to value multiple ways of knowing. Empathy and compassion legitimise different forms of knowledge and validate people's lived experiences (Agyepong et al., 2021; Montgomery et al., 2021). Co-production offers us the hope of carrying out research in a way that nourishes and uplifts all those involved.

It is hoped that through the process of building relationships and sharing power, co-production will be a safer and more beneficial way of doing research with marginalised groups or those who have not been listened to as much. By committing to include a wide range of voices and multiple knowledges, as well as being reflexive, co-production can reduce the risk of being extractive or exploitative (M. Parsons et al., 2016) — though this requires intentionally challenging the status quo of research practice. In health research alone, it is claimed that 85% of research funding is wasted due to poor design and lack of knowledge dissemination (Peter Slattery et al., 2020). By including those who may be affected by the research outcomes from the very beginning of the research process, it is hoped that co-production can increase the relevance of research questions being asked, the appropriateness of the project

design, and the implementation of the knowledge produced.
Co-production also allows for an interdisciplinary or transdisciplinary approach across disciplines and boundaries to allow for a deeper understanding of complex topics (de Sandes-Guimarães et al., 2022). While this can lead to a deeper understanding of situations and experiences, it can also lead to more challenges (Yokota et al., 2018). Often, people are working from different base assumptions and may have different definitions for common terms, which can lead to misunderstandings (Pirinen, 2016; Salmon & Goven, 2022). While managing potential challenges along with the aims for more egalitarian and pluralist research, co-production can be seen as a complex approach to research. But this complexity is part of what increases its capacity for exploring complex problems and situations. Geographers Rachel Pain and colleagues (2015) encourage researchers to look for different forms of impact, which are generally considered from a 'donor-receiver' perspective. With co-production, looking at impact through reciprocity, relationships, and unexpected outcomes gives a more expansive idea of the impact of a project. By including community members with experiential knowledge, healthcare researchers Beatriz Vallina Acha and colleagues (2021) suggest that co-production will lead to more relevant solutions and outputs. Co-production has the potential to create numerous positive outcomes for the contexts it is applied to.

Current usage of co-production

This section provides a brief snapshot of examples where co-production has been used — primarily from the United Kingdom, where co-production appears to be most prevalent — to highlight similarities and differences with the Aotearoa New Zealand examples. While we are seeing the use of co-production across the globe in the fields of health (Masterson et al., 2022), social sciences (Enright et al., 2016), geography (Sharp et al., 2024), public policy (Bandola-Gill et al., 2023), environmental sciences (Greenaway et al., 2022), economics (Ostrom, 1996) and sustainability studies (Chambers et al., 2021), the variation of definitions and use of the term co-production can make it difficult to compare projects. Often, there is also a lack of detail about how co-production was carried out and the methods or tools used, which can add to the difficulty in identifying similarities across projects.

In Scotland, two networks focus on using and promoting co-production (and sometimes co-design). One is the Scottish Co-production Network, run by the Scottish Community Development Centre and funded by the Scottish Government. Their aim is to connect people who are using co-production, provide learning opportunities alongside spaces to share co-production projects and to have a say in local and national policies (Scottish Co-Production Network, n.d.). According to them, "Co-production is about combining everyone's strengths so that we can work together to achieve positive change" and "Co-production goes beyond participation and partnership working because it requires people to act together on an equal basis. It means we can all contribute our lived experience, skills and ideas about what works, to make our communities even better" (Scottish Co-production Network, n.d.). They also mention addressing power differentials and reshaping relationships between communities and services. The Network's website features various case studies to illustrate different stages of co-production, making it challenging to grasp co-production as a comprehensive process. One of their case studies[4] used co-production to conceptualise a new service a charity was designing to help prevent homelessness, specifically for those dealing with addiction. For this project, they had an online conversation between ten people with relevant interests or experience to consider what might be needed and how to get started. Another case study[5] discusses creating a six-week program for developing the health literacy of minority immigrants who are pregnant. An iterative process is described, using focus groups that include health professionals and ongoing feedback and support once the programme is complete. Building relationships and sharing power are specifically mentioned as part of their approach, along with the importance of inclusivity, language choice and valuing everyone's contributions. The network consists of approximately 1,700 people, so the case studies shared are not representative of all the examples of co-production as it is being used by their members.

The second network is The Binks Hub, which is based out of the University of Edinburgh. Their website (The Binks Hub, 2022) describes them as a "network of academics, researchers, community members, practitioners and policy-makers using creativity and the arts to co-create research that makes a difference to people's lives." They mostly use the term co-creation throughout their website, but also share examples of participatory approaches. One of their projects[6] is exploring how to include people living with advanced dementia in research as co-researchers. The plan is to do this through a series of workshops that include health professionals, academics, people with lived experience and carers. They also have a core project team comprising academics, a person living with dementia, and someone who works with people living with dementia (Warran et al., 2023). The work of The Binks Hub broadly covers everyday human flourishing as well as looking at social inequities and injustice (2022). Another project has PhD student Helen Berry (2023) looking into the meaning and value of co-production, which they define as "a relational and collaborative approach that is sometimes defined in reference to core principles such as fostering equal partnership, mutual benefit, and starting with and intentionally growing people's capabilities (among others)" (para 1). This definition suggests that considering co-production in relation to principles is becoming more common — maybe a new level of maturity in the co-production approach is being reached.

Aotearoa New Zealand examples

In Aotearoa New Zealand, the use of co-design appears to be more prevalent than co-production; however, this may be because of the interchangeable use of the terms (Mark & Hagen, 2020). The following examples demonstrate a range of areas in which co-production has been applied (note that this is not an exhaustive list). In the mental health space, Professor Jacquie Kidd — who has a background in nursing and

focusses on qualitative kaupapa Māori co-design research — co-led a project exploring "meeting the needs and aspirations of people using mental health housing services" (Kidd et al., 2015). The project included a team of six — made up of researchers, service users, those who had managed services, and those who worked in support roles, looking into how they could work well together as well as how supported living helps those with mental health challenges. To start with, they created an evaluation tool through facilitated hui (workshops). However, they found this was difficult for many people to use and oversimplified how experiences were captured. They changed directions after this feedback and used focus groups and interviews to develop an understanding of people's experiences, with the transcripts of these being thematically analysed. Using this qualitative approach allowed them to develop a deeper understanding that captured the nuances of people's lived experiences. In a reflective article, health researchers Jacquie Kidd and Gareth Edwards (2016) noted how difficult it had been to go slower and ensure all involved were contributing, and that through trying to disrupt power asymmetries, they ended up with no leadership or way of maintaining momentum for the project. They concluded with a recommendation that spending more time at the beginning building relationships between those involved in the project, and clarifying ways of working together, would have been useful.

Building on Kidd et al.'s (2015) work, mental health researchers Katey Thom and Dave Burnside (2018) share their early stages of using co-production for criminal justice service delivery and research. Due to a lack of details for how to apply co-production, these researchers looked to kaupapa Māori approaches for guidance because of the similarities they had noted between co-production and indigenous ways of researching (e.g disrupting power imbalances and building relationships). Thom and Burnside were working with Māori researchers and designers on digital storytelling outputs to share how cultural safety and peer support are key to the functioning of the Alcohol and Other Drug Court in Aotearoa New Zealand. They drew attention to the importance of building relationships and valuing lived experience, and highlighted their hope of developing the use of co-production further within the design and implementation of policy, service and research.

Moving into the sciences space, Ronlyn Duncan and Melissa Robson-Williams (2024) discuss evaluating a co-design process that was led by Aotearoa New Zealand's Biological Heritage National Science Challenge. They describe co-design as a precursor to co-production, using co-design to design a research programme that aims to co-produce knowledge and related outputs. In their report, co-design was described as both a philosophy and a methodology. Their co-design process involved 87 people across 34 different organisations — these people were then split into smaller groups who then engaged with a further 250 people across 130 organisations through 25 hui (workshops) (Duncan, 2020). The use of co-design in this space arose due to changes at the government level that impacted expectations and funding for potential research, which they believed a transdisciplinary and design-thinking approach would help address. Duncan and Robson-Williams used Norström et al.'s

(2020) definition of co-production (discussed earlier in this chapter), and based their evaluation of the co-design processes on the four principles that Norström suggested (context-based, pluralistic, goal-oriented and interactive). In addition to Norström et al.'s four principles, Duncan and Robson-Williams proposed a fifth principle of 'values-inspired' to be considered for co-production.

A final example of co-production being used in Aotearoa New Zealand comes from a critical friend of The Co-production Project, and my PhD, Dr Rachelle Martin (the gifter of the octopus metaphor). Rachelle led the project 'Hua Tahi: Flourishing Together', which developed methods and tools to improve the inclusion of disabled people's knowledge to co-produce health policy specifically related to housing (Martin et al., 2022). They discussed 'co-production methods' and 'co-producing knowledge', which implies 'co-production' is an action rather than other instances where co-production is described as an approach or a methodology. The Hua Tahi: Flourishing Together project also involved a core project team, along with several sub-groups made up of people with lived experiences of disabilities, and two advisory groups. Inclusivity and sharing power were important throughout this project, and people with lived experiences of disability were involved in the project from the beginning. Hua Tahi: Flourishing Together began slightly ahead of The Co-production Project, and we were fortunate to share ideas and challenges and learn from Rachelle as each of the projects progressed.

Women's health

Women's health is a broad topic, defined in many different ways. Journalist and author Maya Dusenbery's definition in their book *Doing Harm* (2018) demonstrates this broadness:

> 'Women's health' is so routinely conflated with 'reproductive health' that it's easy to forget that the latter is just an aspect of the former. Women's health is impacted by many conditions besides those that affect the uterus, ovaries and fallopian tubes. (p. 15)

Focussing solely on definitions based on body parts is not only reductionist but also exclusionary. For example, many women have a hysterectomy for various reasons, but the lack of a uterus does not make them any less of a woman. Basing definitions on body parts also feeds into the narratives coming from transphobic spaces where women are excluded and denigrated. Definitions focussing only on body parts also assume that all people are treated equally and receive the same level of care that each body part needs. This assumption ignores women's experiences of being discriminated against based on their gender (Cleghorn, 2021). The gender a person presents as impacts their interactions, care and treatment before anyone has looked at a patient's sex/reproductive organs.

Feminist researcher Elinor Cleghorn (2021) explains that throughout history, women's health issues have been hidden or silenced by a cloak of mystery or shame. Social etiquette has meant women have often not talked about symptoms with doctors or with each other. To some extent, people are more open now, making use of online forums and social media to connect with others with similar diagnoses or experiences, as social scientist Caroline Parsons notes (2019). However, there are still quite a few aspects of women's health and experiences that are stigmatised or lead to feelings of shame.

Researching women has also been limited — due to the rules that were in place regarding carrying out autopsies (improving somewhat in the 1620's), or later because researchers claimed that the menstrual cycle made it too difficult to carry out research (Dusenbery, 2018; Saini, 2017). This had led to the male body being considered the default body. Until the early 1990s women were treated as 'smaller men' with the addition of their sex organs, which were barely understood. When women presented with symptoms that could not be explained by what doctors already knew, the mysterious uterus was blamed, or it was put down to 'hysteria'.

When research does include women, participants are generally recruited based on having a specific diagnosis or through a particular hospital or medical centre. This assumes that everyone can access and wants to access mainstream or conventional healthcare. This not only ignores inequities, but also ignores other approaches to health and health care, such as Indigenous viewpoints, that are not generally accommodated in the mainstream medical system.

More recently, doctors have tended to attribute difficult symptoms to mental illnesses such as anxiety or depression, implying that it is 'all in her head' (Dusenbery, 2018). This results in it taking longer for women to get diagnoses and treatment, and those illnesses such as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia, and Long Covid, which predominantly affect women, take a long time to be recognised as a legitimate illness (Cleghorn, 2021; Dusenbery, 2018).

These difficulties barely touch the surface of different aspects impacting women's health, and as health researchers Anna Matheson, Jacquie Kidd and Heather Came (2021) note, they also combine with other inequities caused by systemic racism and socioeconomic situations. As highlighted, the topic of women's health is multifaceted and a thoughtful approach is required to untangle it further for a better understanding.

Aotearoa New Zealand context

Aotearoa New Zealand has its own unique context that this research is situated within, which will aid in understanding the rest of this thesis. Aotearoa has a bicultural foundation built on Te Tiriti o Waitangi (the Treaty of Waitangi) document, and is made up of a diverse population. In the 2023 census, Māori were recorded as 19.3% of the national population of just over five million (StatsNZ,

2025). Professor Linda Tuhiwai Smith (2021), a distinguished Māori scholar and researcher, explains that Aotearoa's history of colonisation has meant Māori have experienced discrimination, loss of language, knowledge and skills, and have been impacted by systemic racism. These impacts of colonisation are still ongoing. Māori have a shorter life expectancy than non-Māori, worse health outcomes and have been either excluded from research or harmed by research being done to them. Māori have also (rightly) raised concerns about the appropriation and control of intellectual property, including data sovereignty in research practices (M. Parsons et al., 2016). Over the past 20 years, there has been a move for research to honour Te Tiriti o Waitangi, to include culturally safe practices, and to aim for research not to be extractive (Smith, 2021). There has also been an increase in public consultation or community engagement from government departments and agencies (locally and nationally). Decolonising academia and research approaches have become important, and this has added to the motivation for using collaborative research methodologies more frequently (Akama et al., 2019). M. Parsons et al. (2016) argue for ways of doing research that embrace pluralism of knowledges and different world views, while suggesting co-design research gives space for Indigenous people to share their knowledge and worldviews in ways and forms that best suit them. These bicultural foundations of Aotearoa and its history are just a small snapshot of some considerations that influence research design and application, but are deeply important for carrying out ethical research.

Women's health research in Aotearoa has also influenced the research sector, with the 'Cartwright Inquiry' having a large impact on the development of ethical principles and expectations. The Ministry of Health requested this inquiry and confirmed that a specialist obstetrician and gynaecologist, and associate professor at the Postgraduate School of Obstetrics and Gynaecology, University of Auckland, had been studying women who had signs of cervical cancer, without informed consent or providing adequate treatment (resulting in harm) and had then falsified results for publication. Following this inquiry, there were increased requirements for ethical approval to carry out studies, and a much stronger focus on informed consent and minimising harm.

Healthcare in Aotearoa is largely publicly funded — access is mainly through a general practitioner (GP), who provides primary care or refers patients to specialists for additional care. GPs often require a co-payment, with the amount differing between medical centres and based on various factors (such as overhead costs for the centre). Access to specialist and surgical care generally does not have a co-payment but does rely on patients meeting specific criteria, and there is often a waitlist (depending on the location and health area, this can be years). Most frequently needed medications are funded when prescribed; however, they also have a small administration fee per medication. In 2023, the elected Labour Government removed all prescription fees to increase access to medications and improve health outcomes for all (New Zealand Government, 2023). Unfortunately, as of 2024, the elected Government (a National/Act/NZ First coalition) has revoked this, which, alongside

other increases to the cost of living, has made it difficult for some people to access the medications they need. This is one significant change that has happened during my PhD and during our engagement with women about women's health. The current government has made other decisions that are impacting the healthcare available in Aotearoa, and specifically impacting women's healthcare.

Some other changes of note relating to women's health — in 2020 abortions were finally decriminalised and taken out of the Crimes Act (Ministry of Health NZ, 2025), in 2021 schools started providing free period products to all who needed them, and in July 2023 the Ministry of Health released the first National Women's Health Strategy (Minister of Health, 2023). Australia has had its national women's health policy since 1989 (Gray, 1998), so this was a significant milestone for Aotearoa and came about after many years of advocacy from many people. The strategy is aspirational and promisingly states it has included lived experiences, but more time is needed to see how it will be actioned and what impact it will have.

The Care-full Co-production case study, which explores women's health using co-production, will be explained in detail in the next chapter. The background context of Aotearoa, the research space, and health situates our project within a changing political landscape with high hopes and aspirations for carrying out research differently — in a way that is affirming, innovative and embraces multiple

2 **Starting with a blank page** — Paul Stevenson from Bethany Christian Trust reflects on his experiences starting out on a new co-production project. https://www.coproductionscotland.org.uk/resources/co-pro-ideas-clinic-starting-with-a-blank-page

3 **Breaking barriers with a health literacy project** — Yesmin Begum shares her insights into the Health Literacy Project that she is involved in as a member of the Katie's Team, a women's health advocacy group in London. https://www.coproductionscotland.org.uk/resources/breaking-barriers-health-literacy

4 **INCLUDED** — Exploring ways to include people with advanced dementia as co-researchers through the arts https://binks-hub.ed.ac.uk/research/included/

Aotearoa Waters: A Case Study of Women's Health

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This case study, exploring women's health, was initiated with KA McKercher's model of co-production, which has four principles; sharing power; prioritising relationships; building capability; and using participatory methods. The nature of using co-production for research meant the project had no clear starting point, and we couldn't prescribe a specific plan for the whole project without bringing the co-researchers onboard. As the core project team we had some hunches of what things might look like, based on our own understandings and assumptions of co-production — some of these hunches are similar to what ended up happening, and some are very different. As a fully funded project, with a three year timeframe, we started with a blank slate — a daunting privilege. The following account of the women's health case study suggests a linear approach to the project, with clearly delineated stages — however the edges of each stage were fuzzy, things often overlapped, and the project moved in a more circular way between planning, community engagement and reflection.

This chapter takes a very descriptive and detailed approach to what happened throughout the case study. I have included things we considered, decisions made, and reflections to highlight the depths and nuances of the approach. Figure 12 shows the timeline or map of the project to aid with following the path we took through all these events. My explanations throughout this chapter are intentionally practical, noticing the small details that might often be overlooked but are actually important for the overall experience and process of carrying out co-production. Aotearoa Waters as the chapter title is a reference to the case study specifically being located in Aotearoa New Zealand — this chapter, combined with the Ocean: Context Review provide the foundation for the rest of the thesis where I combine theory and practice to discuss the important considerations for carrying out co-production.

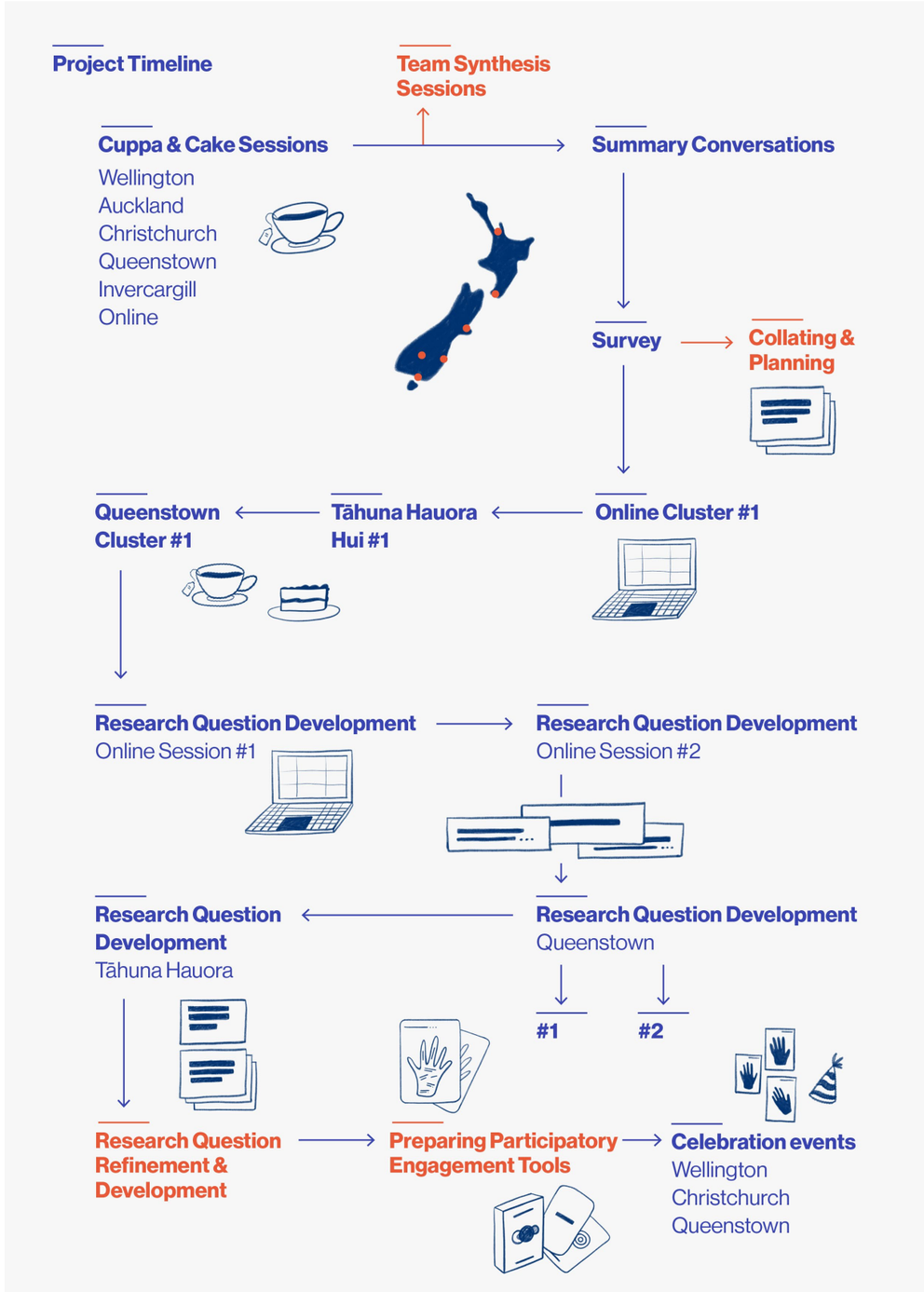


Figure 12:
A visual timeline of the project.

Building the conditions
(April 2022—March 2023)

What's in a name?

KA McKercher's model of co-production encourages taking time to 'build the conditions', in order to have a project foundation and environment to facilitate safe and meaningful involvement (McKercher, 2020). For The Co-production Project this involved spending time on whanaungatanga with the core project team, thinking about the skills we each brought to the project, and talking about our own experiences of health. As often happens with projects, we started off wanting a name for the project. Finding and confirming the 'right' name helps define and identify what is and isn't part of the project, and can create a sense of belonging for those involved in the project. This desire to have the 'right' name before being able to get started is firmly established in Western (Pākehā) projects. We started down this path, brainstorming, discussing, describing and tentatively settling on a name that had a multiplicity of meanings, was a play on words, and we could envision how we might design visual communication elements around it. We agreed upon the project name being R.A.G.E. (see Figure 13) and moved on to considering the following questions suggested by McKercher: who is involved?; who should be included?; are these people the right people?; what matters to them?; and why would the research benefit them?

Figure 13: Some of the ideas involved in the (temporary) project name R.A.G.E.

In sharing about this project with a critical friend, a senior Māori researcher, they shared that they thought the name wouldn't resonate with wāhine Māori and might also be off-putting. We were reminded that having a name to start the project was a very Pākehā approach, and that the name would come when the project was ready — which might not be till the end. Discussing Pākehā's desire to name things, Māori scholar Linda Tuhiwai Smith (2021) wrote "It is after all very arrogant of humans to assume a beginning, to name it and set its date, when we are such minor beings in the universe, really only the earth's caretakers and not its dictators" (p. 119). This feedback was also a reminder not to rush ahead into doing things just because that's how we've always done them. We continued to use the name, The Co-production Project, for the duration of the project. It has only been in the process of writing this thesis that the name Care-full Co-production has come about in order to specifically reference the women's health case study.

Experts of experience

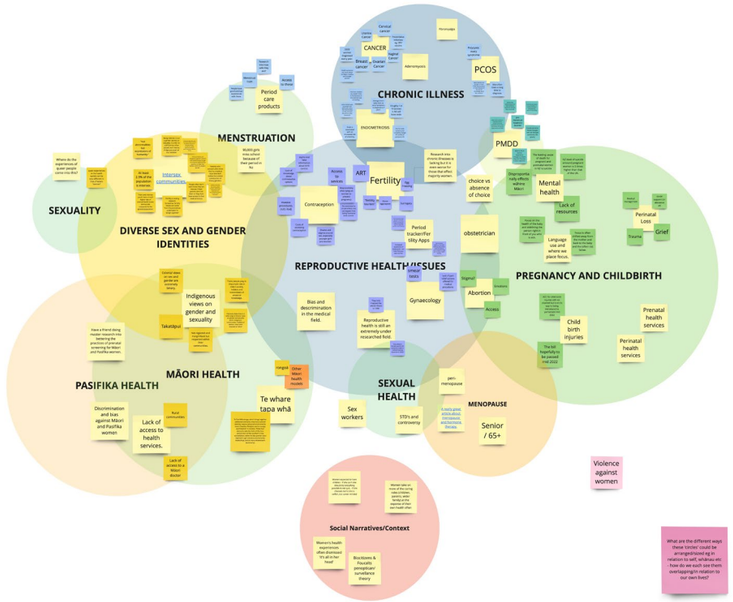
As part of this I created a list of women's health experts from across Aotearoa New Zealand. This process raised questions of who counts as an 'expert' and what 'experts' are relevant to this project. The list of possible experts was expansive, including academics as well as health professionals, and was where we thought we would begin our engagement process. On reflection though, I wondered why, if our aim is to do research differently and to include those most likely to benefit from the research, weren't we starting our engagement with women. Other co-production projects in the literature also tended to start with, or mostly include professionals in the area being researched (Fusco et al., 2020). Reflecting on who are experts and what they're experts of, led us to flip the script and focus on our co-researchers being women — after all they are experts of their lived experiences of health.

What is 'women's health'?

Further consideration of the questions that McKercher posed about who to include and why, had us exploring word choices and how words can be perceived as inclusive or exclusive. For example, saying 'a person with a uterus' may include trans or intersex people, but then excludes people who have had a hysterectomy. Using terms such as 'assigned female at birth' then excludes trans women, and may also not be language others identify with. The term 'womxn' came from feminist organisations wanting to remove the word men from women, and then progressed as an attempt to be trans and non-binary inclusive. We explored using this spelling as an inclusive approach, but sex and relationships journalist Quispe López (2021), explains that this is less inclusive of trans women than intended. In the end we settled on 'people who self-identify as women' and acknowledged that this would not suit everyone, though hopefully signified our intent of inclusivity. Discussing who to include in the project also led to considering what actually is 'women's health' — is it only gynaecological and reproductive health, i.e. that which is related to the ovaries,

uterus, vagina and fallopian tubes or is it broader? It felt reductionist to limit our language based on a small selection of body parts, even when this is the approach that is often taken in the medical field. While discussing this, we attempted to map the concept of women's health and what it might include.

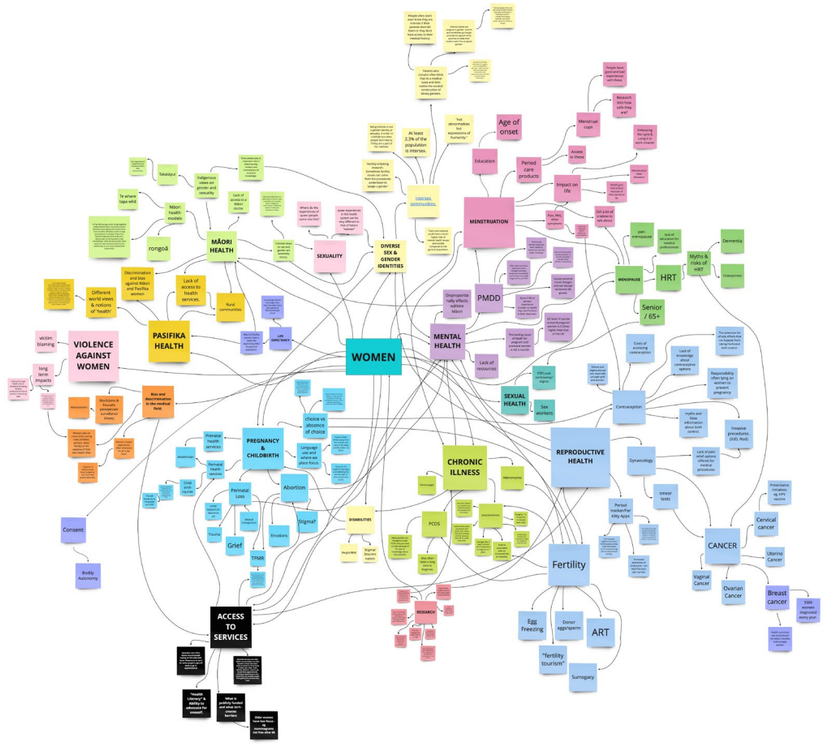
Figure 14:
Using overlapping circles to map what's included in women's health.



This first mapping attempt (Figure 14) felt constraining, and made it difficult to portray the interconnectedness of the different aspects of women's health. A second attempt (Figure 15) at concept mapping women's health resulted in a more messy, and less defined diagram. It does however draw attention to the complexity of women's health and highlights the breadth of this topic. From meandering through this web of ideas we also begin to gain an awareness of the in-betweenness and borderlines that are often not attended to in women's health. Thus using the broad concept of 'women's health' is deliberate and supported by Dusenberry's definition as quoted on p. 56.

While discussing women's health, I also explored the overlaps within the health system which led to a wider, more holistic thinking about women's health. Frequently any engagement related to health for research or service development recruits people who are already using health services. This starts with a limitation to what is being considered about women's health, as there are many reasons from access through

Figure 15:
A second attempt at mapping women's health — more like a complex and connected network.



to beliefs for why someone may not be active in the health system. The following diagram (Figure 16) is a visualisation of our discussion about the health system.

To reduce the impact of the assumptions that are made by only engaging with people already involved in the health system, we took a broad approach when considering who to include in this project and looked outside of health service settings to recruit participants.

Project values and expectations

As part of developing the core project team, we co-constructed a 'Project Values and Expectations Document' which clearly communicated how we wanted the team to function together, and the values this team and project is founded on (see Appendix 6, p. 366). These values include concepts of manaakitanga, equality, pono, tika, tapu, and include aims to do (some) good, be community centred and inclusive, to attend

Figure 16:
A visualisation of how people may or may not be active in the health system.

with an inquisitive spirit and value lived experiences. We also took time to develop our understanding of how co-production research differs from other methods, to talk through how it looked to us, and then a team member captured those thoughts in the following visualisation (Figure 17).

A reflexive practice

I also implemented a reflexive team practice for us all using the 4 L's model (Gorman & Gottesdiener, 2010). This exercise asks all team members to consider what they liked, disliked, learnt, and longed for after different sessions and events. This practice helped us to consider ways to do things differently in the future, understand each other's experiences of interactions, share learning and understanding, and appreciate the approaches that work well. Figure 18 is an example from after one of

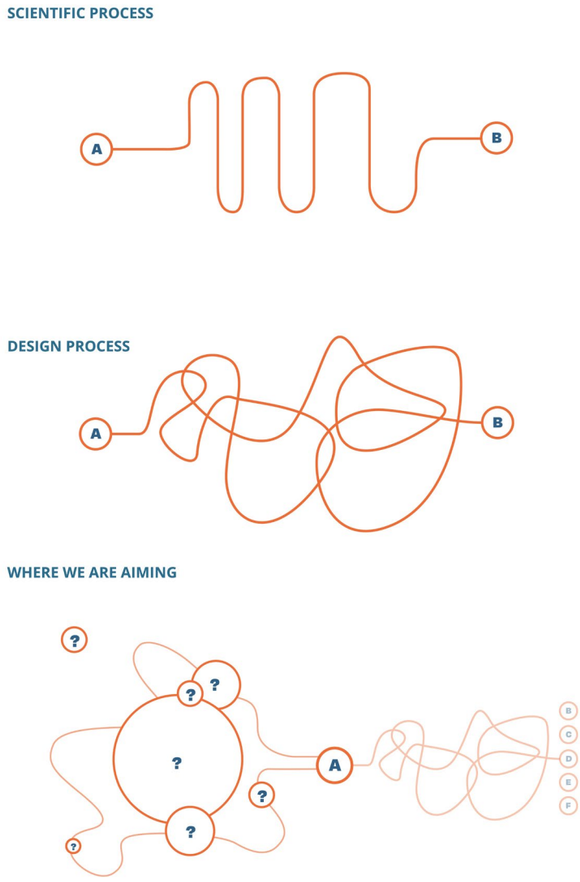


Figure 17:
Visualisation comparing different research approaches to our aim with co-production.

our first team meetings. Reflexive practice is unpacked further in Arm 7: Reflexivity & Reflectivity, p. 243.

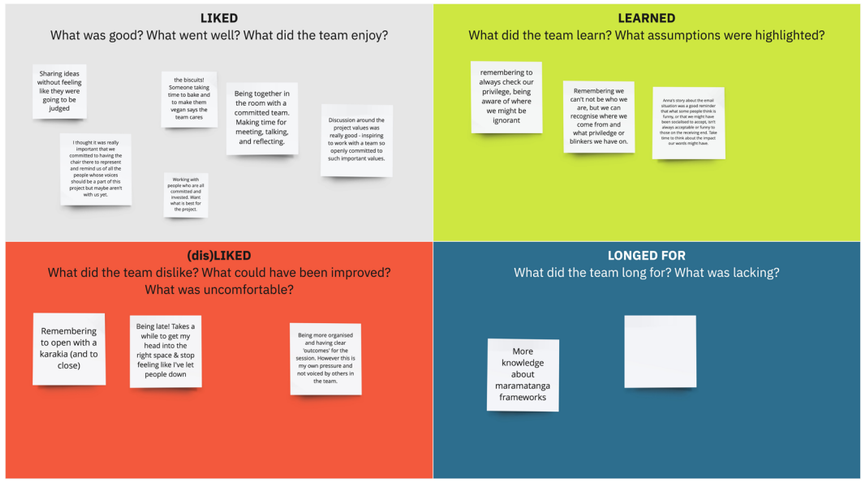


Figure 18:
An example of the 4 L's reflexive practice grid.

Building connections

We also took time to build connections with 'critical friends' — people who have some interest or expertise in the project areas, who may become involved in the project later or may be people we can discuss ideas with. With these critical friends we were deliberate in meeting over cuppas and shared kai for the sole purpose of getting to know each other and to build connections, rather than focussing on set agendas with a productivity goal. This relational approach was uncomfortable at times, as it felt in tension with the neoliberal academic environment which values productivity and a faster pace.

Our time spent 'building the conditions' was a lesson in learning to be comfortable with discomfort. It was time spent immersed in the questions, not aiming to answer them, but finding loose or 'close to' answers, until we reached a point where we had identified what a next step might look like.

This part of Care-full Co-production took around ten months, and focussed on thoughtful consideration rather than productivity — positive, reciprocal relationships take time to develop and shouldn't be rushed where possible. The value and conditions built in the early phase of the project were not fixed or definitively described and decided on. Rather the questions raised during this part of the project were frequently revisited and reflected on, and incorporated into what was happening each time.

Cuppa & Cake sessions
(March — May 2023)

Conundrum of getting started

We spent much of the previous phase wondering how we were going to get started. Working within an academic institute meant we needed ethics approval before we could start recruiting 'co-researchers'. In order to put an ethics application in we needed to have a plan for not only who to recruit, but how, why, and what the process of engagement with these people would be. However co-production requires the inclusion of co-researchers from the beginning so they can contribute to the planning and development. This conundrum was further constrained by the timing of ethics committee meetings throughout the year.

While the team had been discussing what women's health might include, we considered starting by asking women this question. This approach gave us a way to get started with recruiting participants who may become co-researchers, without needing to commit to a plan for the whole project — while also acknowledging this approach would require multiple ethics applications throughout the project.

Who to include as co-researchers?

Next came the decisions about who exactly to involve. Were we starting with an existing community or creating our own community? What opportunities or challenges came with either option? We considered other projects that we knew of, for example an abnormal uterine bleeding project, and different dynamics that might be interesting such as mother-daughter dyads. As co-production prioritises relationships, we were looking at options to build or connect with existing communities. I came to this PhD from managing the nationwide charity, Good Bitches Baking which had nearly 3,000 volunteers. While I did not know all the volunteers, my name was known across the organisation, and I had a trusted relationship with the Board of trustees and operations team.

Building on trusted connections

We decided to build on the relationship I had with Good Bitches Baking as a way of recruiting co-researchers. Good Bitches Baking is predominantly a volunteer organisation, where volunteers are connected by shared values and interests — baking, kindness and community. They spread kindness to people having a tough time through a network of volunteer bakers, and drivers in different chapters across the country from Whangarei to Invercargill. Volunteers are rostered on to provide baking to specific recipient organisations (e.g. women's refuges, hospices, food banks, cancer or other health related support groups to name a few), and can put their names on the roster as many or as few times as suits. They bake at

home with ingredients they provide, and then either deliver the baking themselves, or a volunteer driver collects it and delivers it for them. This set up means that people bake what they enjoy baking or can afford to bake. It also means that they might never meet other volunteers, or only a few, with rosters being organised via online platforms, and in most cases never meeting the people who actually eat the baking — as it's often delivered to a staff member at the recipient organisation. While volunteers might not be closely connected to each other through personal interactions, they were connected through the shared purpose of the organisation, and shared values and interests. The charity aims to be inclusive and accessible, and does not have any demographic data publicly available (they may not collect this).

Affinity recruitment

Good Bitches Baking has similar values to Care-full Co-production and we had a sense that this community might have some inherent alignment with our project. Recruiting from within this community was part of the values-led approach that we were taking — we named this 'affinity recruitment' which is a novel approach in research spaces. Recruiting through a nationwide charity also meant the group was not geographically bound and kept participation opportunities broad.

Recruiting 'co-researchers'

Having made these decisions, and developing a plan for this discovery phase we gained ethics approval (see Appendix 1, p. 327). Recruitment of co-researchers began in February 2023 using the charity's quarterly newsletter. I made an introductory video to promote the project and accompany the information and registration of interest form (Figure 19). The invitation was for any Good Bitches Baking volunteer (past or present) who self-identifies as a woman, is 16 or over and a fluent English speaker to participate. The response numbers were on the lower side for what we'd anticipated, and on reflection there are several things that may have contributed to it. The way the video was included in the newsletter required people to complete multiple steps so the process may have been off-putting or overly confusing.

Perhaps the bigger, and unexpected context was that the newsletter was sent out the day that Cyclone Gabrielle hit New Zealand. This national weather emergency could have reduced the interest or appetite for engaging.

In addition, while we provided the content for the newsletter, we had little control over how it was included (i.e. the way the video was a link rather than embedded) and I was hesitant to ask for too many changes that may have stretched Good Bitches Baking technological capacity as well as their time, knowing how stretched the operations team is. They have limits on how frequently they email their volunteers or use other forms of communication, so we were restricted in our ability to send reminders about the project signup opportunity. Through this process we had 43 people register their interest — they were located in 18 different towns or cities from Auckland to Invercargill.

Figure 19: Front slide of the recruitment video.

Planning the 'Cuppa & Cake' sessions

For this discovery phase, we decided to use the broad approach of a focus group — in that it would be small groups of people having a semi-structured conversation about women's health. In order to be as inclusive as possible, and to reduce the assumptions we were making, we didn't give any times, dates or locations for the first invitation — it was a way for people to register their interest, and tell us their preferences and accessibility needs so we could plan accordingly. I suspect not having definitive times or dates may also have contributed to the lower than anticipated registrations of interest. It also meant that once we had a plan for time and places, not everyone who had registered their interest was able to attend. We offered a variety of times on different days in order to be available for more people, but of course no option is going to suit everyone.

When organising these conversations, the aim was to create an atmosphere of 'sitting round the kitchen table having a chat'. This approach was intentionally aiming to be less 'researchy', partly as a nod to historical contexts when women might have had conversations about health, and also to reduce the power asymmetry between the core project team and the co-researchers. We specifically looked for venues that were not in a university, school, church or business/conference venues due to connotations these places might have for people, and to create spaces that were more comfortable and relaxed. To add to the 'kitchen table' atmosphere, and to show manaaki, we were very thoughtful in the refreshments we chose — not only accommodating people's dietary requirements or beverage preferences, but choosing foods that were a bit of a treat. These conversations were called 'Cuppa & Cake' sessions, and of course involved cake (some examples are shown in Figure 20). Some of these sessions were also hosted online — details of how we aimed to create a similar experience to the in person ones are covered in Arm 2: Care, p. 153.

Figure 20: Cuppa & Cake Session setups — Christchurch (left) and Queenstown (right).

A heart and head approach to gentle conversations

The conversations themselves were 90 minutes long, and structured in two parts — 'heart' and 'head' — with a short break between. They were all recorded, with permission from those involved, and then transcribed after all conversations were completed. Before attending, information sheets and consent forms (see Appendix 2, p. 333) were emailed to everyone so they could read and sign them in their own time — they were also given the option to complete this at the beginning of the session, where they could ask questions and have the information given to them verbally. A runsheet for a Cuppa & Cake session can be found in Appendix 3, p. 337.

Everyone received a 'zine' which they could take home with them — it included information about the project, places to get more support after the session if needed and room to take notes. The zine, '*More Than a Name Tag*' and other tools used throughout our engagement sessions are described in more detail in Arm 8: Participatory Design Approaches, p. 259.

The 'heart' — using More Than a Name Tag

A round of introductions was used to start things off, asking people to give an introduction by describing themselves in a way that would help anyone who was visually impaired 'see' them. While not all health is physical, this activity had people thinking about their bodies from the beginning as a first step towards talking about health. The first part of the session was framed as the 'heart' part, focussed on building whanaungatanga, developing trust and comfort, and sharing lived experiences. Using the *More Than a Name Tag* process was like a staircase that led from surface level introductions to deeper, more vulnerable sharing. The idea of this process is to explore the role of a name tag — sometimes seen as a generic sticker with your name written on it — through a process that unpacks a number of layers and concepts of connection, introduction and relationality.

The first step of this activity is thinking about things you might easily share with others on the first meeting, and then sharing what is comfortable from this with the group. The next step is to consider the things 'that make you you', which may be health related or something to do with a bodily experience. This was followed with an invitation to share things that were written on the deeper side, and (or alternatively) share how the process of thinking and writing about these parts of themselves felt. People retained autonomy of how much (if any) and what they shared, but in general most people moved quite quickly into being vulnerable with the group. Those of us from the core project team that were facilitating or holding space for the group also participated in this with the groups (examples of my name tags are shown in Figure 21). The intention behind us sharing parts of ourselves was to help reduce power asymmetries, and to develop a reciprocal process rather than us solely 'extracting' stories from the women in the group. Sometimes this part of the session could lead to lots of sharing and conversations between everyone, and the loose time schedule allowed some fluidity with the time allocated to each part of the process.

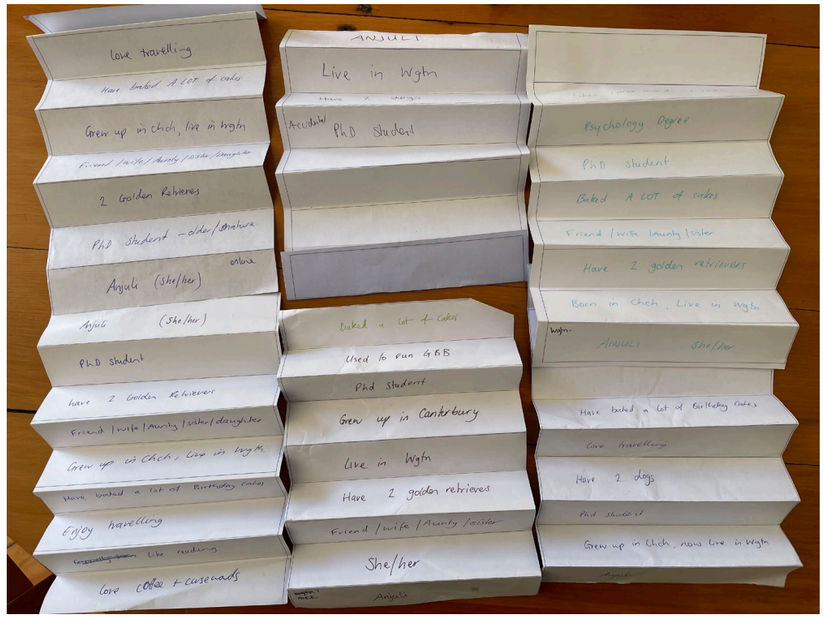


Figure 21: Some of the 'More than a Name Tag' templates I completed throughout the project.

The 'head' — using a tabletop exercise

The second part of the session came after a short break where people could refresh their minds, stretch or get another cuppa, and was considered the 'head' part of the process — encouraging a different style of thinking and sharing. This was a tabletop exercise involving writing on sticky notes what came to mind when thinking about women's health (as seen in Figure 22). Depending on the group, and if there was

time available, this exercise expanded in some sessions to include a second prompt: "In an ideal world, what would women's health look like to you?" This prompt gave space for more hopeful thinking, and also allowed an expansion of ideas as people were less constrained by the status quo. Some groups however struggled with this future focussed thinking, possibly due to having not received the care, support or information they needed when interacting with the health system. Ideation and future thinking is often a harder process than describing what the current situation is because imagining possibilities can take practice and isn't something everybody does regularly. Group dynamics and whether a person feels comfortable or not can also impact people's ability to think expansively about the future.

Figure 22:
A table top sticky note exercise, responding to the prompt "What do you think of when you think of women's health?"

An iterative approach

We took an iterative approach to these Cuppa & Cake sessions, taking onboard feedback from those involved in each one, and reflecting on the process each time. While this didn't lead to any structural changes throughout the two months we were holding the sessions, the reflective process provided space to pause and reconnect with our values and purpose.

A change we did make that has had a big impact was the size of the groups we hosted. Originally we had intended to have groups of up to ten women, plus two or three of the core project team. Our first two sessions had three, and five people respectively, and both groups indicated that they would not have been comfortable sharing with more than seven or eight maximum (including us). From there on we set the maximum per group at five co-researchers — prioritising the quality of conversations, and the comfort and safety of those involved.

Receiving an invitation

The core project team had noted that there were some groups of people who were potentially less represented in our conversations — we intentionally did not collect demographic data from those attending a session so we are unable to quantify or define any groups that were more or less represented. The women attending the conversations had also raised similar concerns, wanting to ensure that disabled people, Māori and those with less resources (to identify a few) were heard. One of the people who participated in a conversation session in Tāhuna Queenstown also noted this, and invited us back to talk with the community she is part of that is predominantly wāhine Māori. This was an ideal invitation, with someone trusted by the community opening the space for us and guiding us with ways of holding the conversations that would be comfortable for their group. The 'event' was in essence theirs, held in their space with invitations offered by them, with us there to facilitate the conversation and develop a relationship with the group. It was an honour, and a challenge, and we did not take our responsibility lightly.

A different conversation

Following their advice, we had a bigger group — 25 including us — with varying levels of connectedness amongst everyone. This time we started with shared kai (shown in Figure 23), a chance to connect, and begin to know each other in an informal way. While we started similarly with a brief introduction, and then followed with the *More Than a Name Tag* activity, this did not lead to the comfortable sharing in quite the same way. One of the women commented on how this 'name tag' process felt 'invasive', and others also found it confronting. However, I think it is possible that the process prepared people for feeling vulnerable without the risk of sharing anything at that stage, which may have helped the sharing that came later. This time instead of the sticky note activity, we spread a selection of cards across the floor, in the middle of the circle we were seated in (shown in Figure 24). These cards held words related to women's health that had come from the previous conversations we had had. The group were then invited to move around and select three or so cards that resonated, were relevant or that they were interested in. Giving the option to move around while choosing, gave them the option to manage their comfort levels with different words as they could physically distance themselves from ones that were uncomfortable or challenging. We also had blank cards available for writing down words that were wanted but hadn't been included.

Taking more time to talk

Taking the lead from the person who had invited us in, the process for this session was less time bound with no defined end time for the session. The wāhine were welcome to stay as long as they were able or comfortable, and we stayed as long as there were more conversations to be heard. This resulted in a nearly four hour

session (compared to the 90 minutes of the other Cuppa & Cake sessions), with the group as a whole (rather than just those of us facilitating) bringing it to a close as it was nearly 10pm. Although the sharing during the 'name tag' process was less open and vulnerable than we'd experienced in other conversations, once we moved on to talking about the word cards that had been chosen people really opened up. The experiences shared were complex, detailed and emotional, with the group allowing each other the space and time to share what they wanted to share, and supporting each other throughout. Not everyone in the group knew each other at the beginning of the night, but we could see the connections building throughout the session, and there was talk about reconnecting to continue conversations about hauora (separate to any involvement in this project).

The conversations throughout this co-discovery phase were all so different, but also had lots of commonalities across experiences. Rather than helping narrow down a focus or definition of 'women's health' it really reiterated the complexity of this topic.

Figure 23:
Table set up with the shared kai (food).

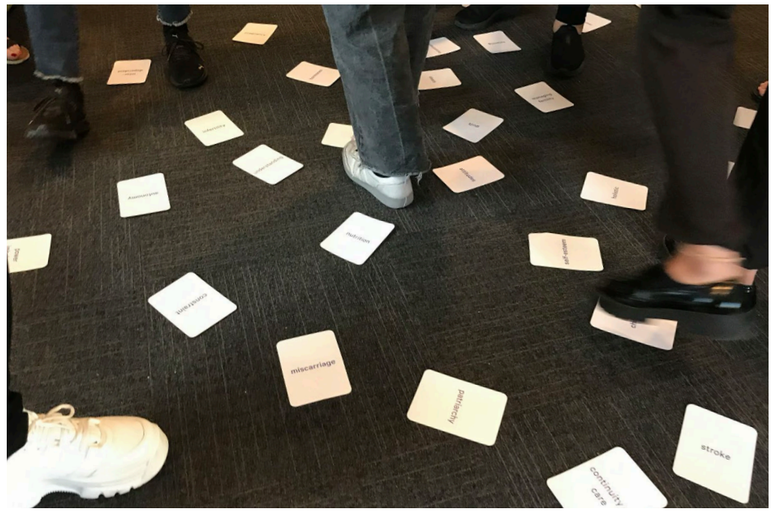


Figure 24:
Cards with words related to women's health, scattered on the floor for people to select ones that resonate.

Synthesis
(July — August 2023)

Transcribing the conversations

All of the Cuppa & Cake sessions we had were recorded, giving us 24 hours of content, that was then transcribed. Once all sessions were transcribed, they were collated along with the content from the sticky-note activities in each session. I collated a full copy of these documents ready for us to individually read and start analysing, and then gave each member of the core project team a copy. My copy is seen in Figure 25. We used John Maeda's SLIP process — Sort, Label, Identify & Prioritise (Maeda, 2006). At this stage we were focussed on the content of the conversations, however we also made note of anything that was surprising, unexpected or process-related points of interest.

Synthesising as a team

Once we'd all worked through this individually, we came together as a team to share our perspectives, and to go through the process again with our individual responses. We collected everyone's stand out points and surprises, looking at where there were overlaps, but also paying attention to the in-betweenness and the places where we differed from each other. Different metaphors for summarising and explaining the content were explored, along with different ways of visualising the content in order to communicate our synthesis, as can been seen in Figures 26 and 27.

Figure 25:
All the transcripts in a folder, with sticky notes identifying pages of interest.

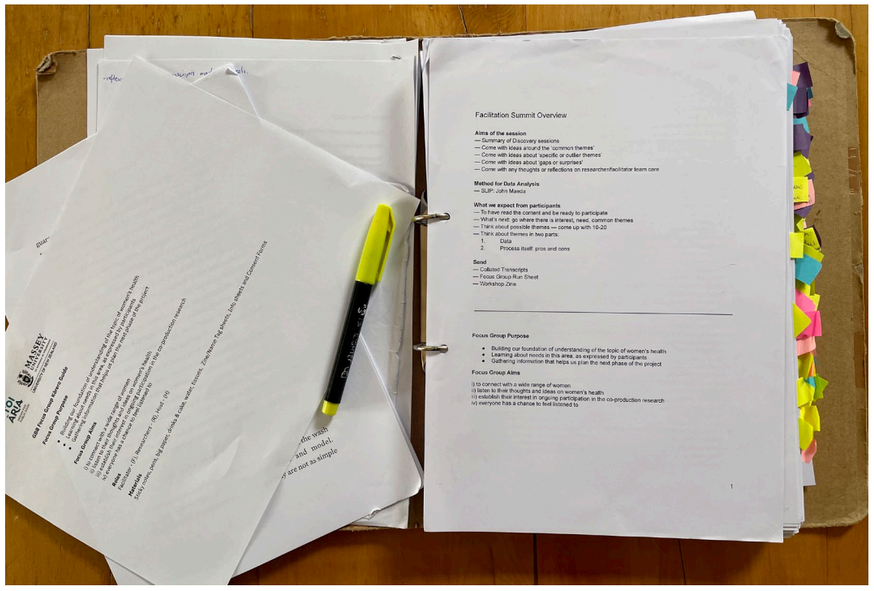


Figure 26:
Notes and visualisations from this synthesis session.

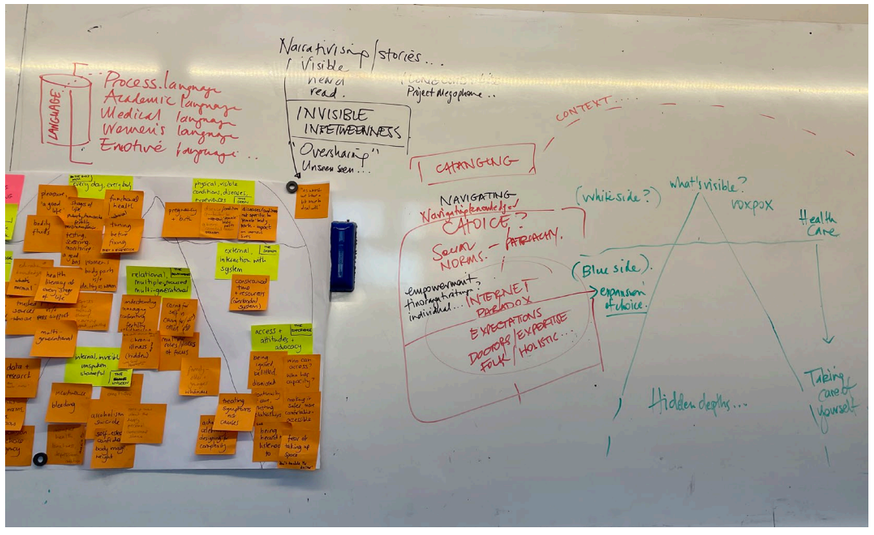
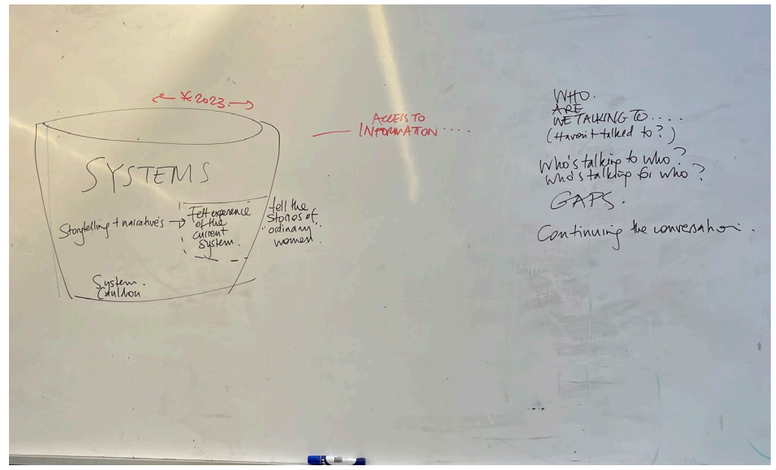


Figure 27:
Notes from this synthesis session.



Collating the sticky notes

The content from the Cuppa & Cake session's sticky note exercises were collated into a spreadsheet, and loosely sorted into similar topics to see what insights this might highlight. I transferred these to a Miro board for us to easily continue playing with the sorting of these to see what it added to our synthesis. We also explored different metaphors here as well — displaying the sticky notes in a 'slices of cake' type visualisation to see if this added to the meaning that was conveyed (as shown in Figure 28). This was further refined by team members as part of summarising and synthesising what we learnt from all the sessions.

Summarising the synthesis

The temptation with this was to order everything into a set of themes — it's how we 'know' research to be done, and how we're comfortable summarising content. While we had aimed to push beyond this in our synthesis discussion, it unintentionally came back in as we started a written summary in preparation for sharing back to our contributors. We drafted a summary that we hoped would be accessible and easy to read — we didn't want to give contributors something that would take hours to work through. The summary was intentionally kept in a draft stage so as to be ready for incorporating feedback from the women we'd spoken with, when we shared the summary with them in our next round of engagement.

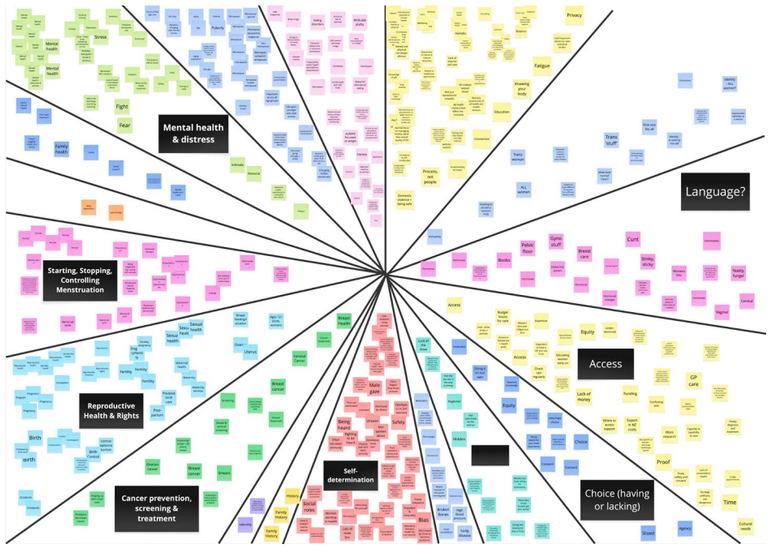


Figure 28:
Sorting the sticky notes into 'slices of cake' as we consider ways of organising them.

Summary sessions (September 2023)

The summary sessions were designed to share what we had come up with through the synthesis process with those who had been involved in the Cuppa & Cake sessions. An amendment to the ethics application was made to cover these additional sessions (see Appendix 1, p. 328). The aim of these sessions were to check if how we'd summarised the conversations landed well with those involved, and to see what might have been missed, or explained poorly. We also used this time as a way to progress the conversation about how we could continue to work together as a community throughout the project, gaining their input into processes and decisions that would keep the momentum of the project going.

Using miro as a facilitation tool

These sessions were planned as online sessions to conserve resources, and also allowed for different groups of women to interact, which broadened the conversations further. We designed a Miro Board that summarised the story so far, and then moved into the summary of the content, followed by the interactive sections for collating everyone's thoughts and feedback (as shown in Figure 29). We offered two times for these summary sessions, an evening session and a lunchtime session, along with the option to have one on one conversations for anyone uncomfortable with a group setting, or unable to make the group session times. The evening session ended

up being well subscribed with 15 people attending. This did result in feeling quite time pressured — there was a lot to talk about, even using the function of smaller breakout groups — and our aim has always been to stick to the agreed upon time allocation that people signed up for (part of valuing their time). The use of Miro is discussed further in Arm 8: Participatory Design Approaches, p. 259.

Figure 29:
The 'story' part of the Miro board we created for these summary sessions.

The importance of reconnecting

It was again clear how important it was to spend time (re)connecting and building whanaungatanga, before moving into the specific conversations of the session. With this sized group this relationship development time needed quite a large portion of the session to accommodate everyone. The lunchtime session with a smaller group better suited the time allocated, and was a smoother session without the need to split into breakout groups. We had three people take us up on the offer of one on one conversations, and these allowed for more in-depth discussions about the summary and potential ways of working. These conversations also allowed us to hear from people who may not have spoken up in a group situation, which was important to us for feedback but also for keeping our community inclusive. We also made the Miro board available in an ongoing way — this allowed people to add to the board if they had thoughts at a later stage, or if they hadn't been able to attend any sessions they could still have an input at this point in the project. Using conversations and Miro this way was an opportunity to start exploring synchronous and asynchronous engagement with the community.

Figure 30:
Word bubbles to describe the ten themes we'd used to summarise the Cuppa & Cake conversations.

Figure 31:
Longer Blurbs to describe the ten themes we'd used to summarise the Cuppa & Cake conversations.

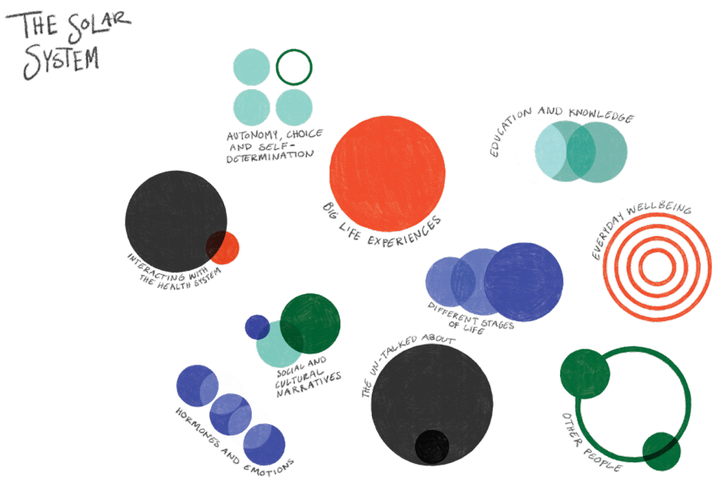
Contributors feedback on the summary

The feedback on how we'd summarised the synthesis of all the conversations was extremely valuable. We'd captured the majority of the content in 'themes' that resonated with those who attended, however there were some key points made. In the pursuit of these themes and explaining things clearly, we'd simplified everything too much and the complexity of women's health was no longer visible. Although we used circles that contained our explanations of the themes, they'd been placed in rows which automatically gave a linear and hierarchical tone to it even though we

were trying to avoid that (see Figure 30 and Appendix 4, p. 341). It also portrayed the themes as being clearly delineated and separate, where actually they are all interconnected and often overlapping (see Figure 31 and Appendix 4, p.344). Following this feedback we started talking about and visualising these themes as a solar system — all connected, orbiting each other, sometimes close together and sometimes further apart (as shown in Figure 32).

With regards to the specific content in the themes it was pointed out that abortion had not been clearly communicated. While pregnancy and infant loss had been included, the group didn't feel like this captured the different aspects of abortion and the experiences and conversations that surround it. It was also pointed out that mental health/mental distress had been included under the theme of 'Hormones & Emotions' when it would be better served by being separate. Partly because it's a big topic and influences all aspects of life, and partly because it reinforces some of the social narratives about 'women being hormonal' as the explanation for mental health challenges — these narratives are often used in a dismissive or derogatory way, which undermined our aim to value lived experiences. This placement of mental health was accidental rather than thoughtless — in writing up the different summary options it had slipped through the gaps and became a blindspot. It did demonstrate the importance of sharing back our process and work to those involved in the initial conversations — and the need to do so in a way that encourages openness and honesty.

Figure 32:
Revisualising the 'themes' as a solar system.



How could we remain connected?

During these sessions we also talked about possible ways of staying connected with the community, how they felt comfortable staying involved, and what language felt right. Based on McKercher's co-production model, we thought that moving from calling 'participants' to calling them 'co-researchers' would be welcome — we would all be researchers then, and it would be an overt sign we were sharing power. It turned out that this was not so welcome after all. Not only did women say they didn't think they were doing enough to have that role name, they also didn't want the responsibility or burden that they felt came with it. There were various alternatives suggested from 'co-conspirators' to 'research assistants', and in the end we collectively settled on 'contributors'. This was a reminder to us not to make assumptions and to remain open minded. It also highlighted that 'sharing power' is not so simple.

Through this discussion we also asked the question of what 'being valued' or having 'lived experiences be valued' would look and feel like to the contributors. For some this was being acknowledged in this thesis, for others it was just knowing that they had contributed to a project that may have positive impacts for other women and for others they wanted to be named throughout the project, rather than as a 'number' — even though research generally aims for anonymity of participants, some people don't want to be separated from the experiences they share. We also discussed what support to enable involvement was needed, what might be interesting and what was possible (Figures 33, 34, 35, 36, 37).

Figure 34:
Suggestions for how we might all work together.

Figure 33:
Conversations captured on Miro to consider ways we might all work together.

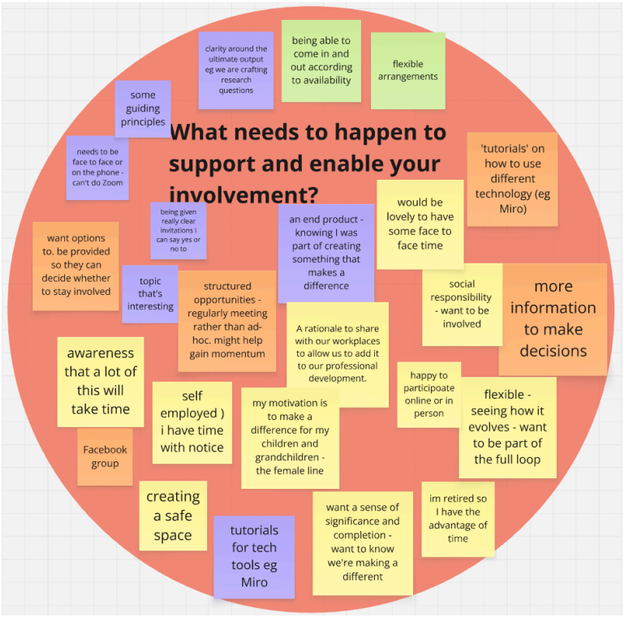


Figure 35:
Ideas for supporting and enabling involvement.

Figure 36:
Suggestions of what might be interesting or energising in the project.

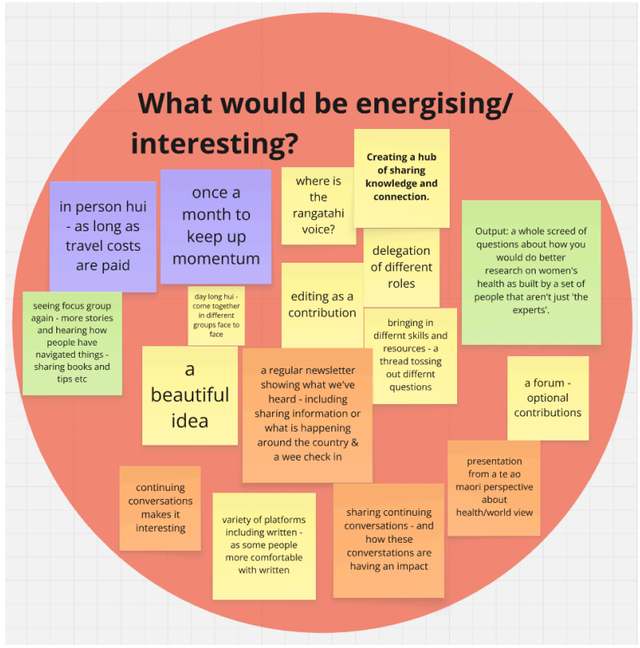
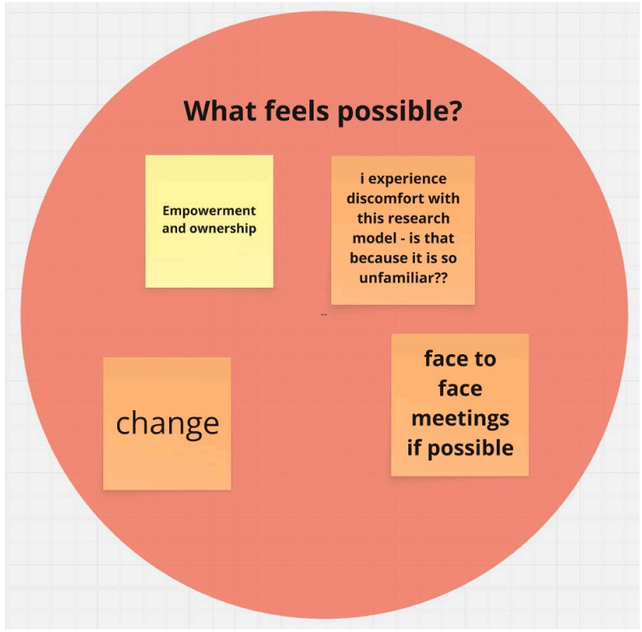


Figure 37:
Responses to the question "What feels possible?"



Sitting with the discomfort

Some of the contributors mentioned how uncomfortable they found this way of doing research, due to the lack of a long term plan of what would happen when, and what would be asked of them. By aiming to give the women as much influence in the decision making processes as possible, we generally only planned the immediate next step from the interactions we'd had so far, and then once that step was completed, we planned the next one. This stepwise approach did leave a lot of uncertainty, which the core project team was definitely feeling uncomfortable with too. It was helpful to be able to share our discomfort and uncertainty with the contributors, and to listen to their experiences of it too. Through this sharing and re-explaining of why we were taking this approach, the contributors acknowledge that along with the discomfort they also felt excited and curious — which was reinforced by them continuing to engage and show up to different ways of interacting with the project.

Survey
(September—October 2023)

Asking more questions

Informed by the discussion had in the summary sessions, we decided to carry out an online survey. We completed a low risk ethics notification for this part of the project (Appendix 1, p. 330). This survey meant we could ask more specific questions, gain input from people who prefer to respond to specific options rather than offering ideas, and also gave a chance for those who couldn't make the summary sessions to share their thoughts too. We covered options from: possible locations for in person events; preferences for times of online sessions (e.g. week day, week evening) and regularity vs occasional; different platforms for communicating (e.g. Facebook groups, WhatsApp, emails, newsletter); whether people wanted to dip in and out, or whether they wanted to make more of a commitment and join the core project team. We also asked for feedback on topics/themes they were most interested in, what motivated them to be involved in the project (example in Figure 38), how they had found the project process so far, any other changes they'd like to suggest, or whether they wanted to opt out from future input.

Collating the responses

We had a high response rate with 39 out of 61 people responding, and the answers were so valuable. It showed there is definitely an appetite for this type of research, particularly within the women's health space. Women are curious about doing research differently, and are really motivated to help make a difference for other women and future generations. They also felt welcome and safe in their engagement to date. Some of the answers around motivation and interest were:

> "First, women's health is an under-researched topic and when researched it is usually not done with women but on women so I see great value for carrying out this research and feel excited to be able to be a part of it. Second, it is interesting to me to see first hand how co-production as a research method can be carried out."

> "I am enjoying the yarns, and like watching the research methodology work. Love hearing other people's experiences in a safe and productive manner."

> "Mostly it's around it being a safe space to discuss our experiences of the health system...and the hope that the research leads to real changes in how health systems 'hear' women."

Planning a next step

Looking at the results we considered where the most momentum and energy was sitting and balanced that with possibilities, resources, and what would help us achieve the aims and outputs of this project. In amongst all the possible options we also need to make sure we were practising the principles of co-production. Decisions needed to be made about what to do next, but it felt uncomfortable to make a plan that was not going to include all the options our contributors wanted, while also knowing it was likely impossible to find a plan that would suit everyone. While we spent a lot of time considering all the input we'd received, it still felt like it was us making the decisions which had us questioning whether or not we were actually sharing power. We were also trying to keep the plan loose — so we were either only planning the next step, or planning steps that left room for changing direction if that was needed. We imagined some different ways of how the rest of the project would go, with different options that contributors could pick and mix from, or join in as and when. Imagining how the rest of the project could go was also helpful in thinking about what other ethics applications might be needed and when.

A reflection on the planning at this stage

In hindsight we probably could have planned the rest of the project out more specifically, and then gathered the community's input and made changes accordingly, but the risk was this would have made us less flexible and responsive. Too much direction and specificity also runs the risk of constraining what people think is possible, and may have meant people were less likely to share their ideas and feedback. I had noted on reflection that the moments we most felt comfortable with the process, was when we needed to pause and evaluate what we had planned or decided on, as it was likely we'd corralled the project into a more traditional research process — whereas if things were uncomfortable we were probably disrupting research norms. A couple of core project team members commented in the reflection grid that they liked having a plan — these indicate that a level of comfort was felt at the time by having decided on a course of action (Figure 39).

Figure 38:
A sample question from the survey.

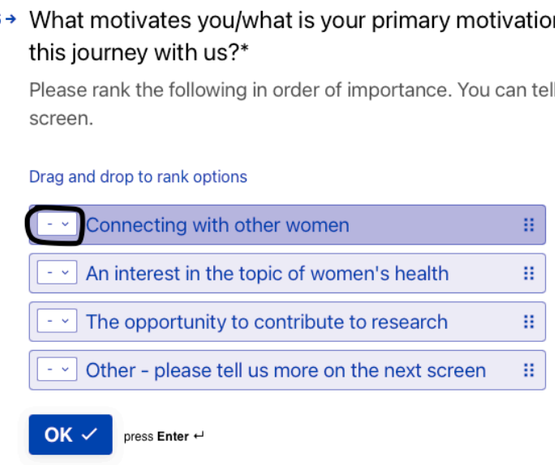
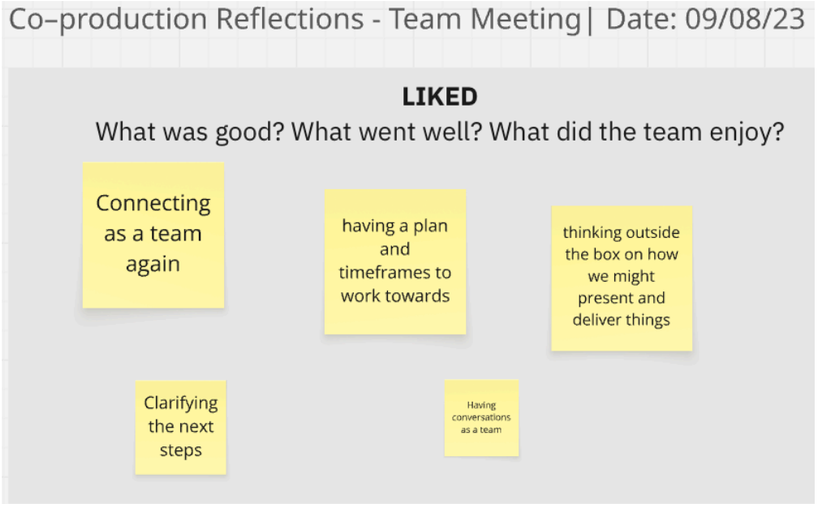


Figure 39:
From a team reflection board showing how having a plan felt comfortable.



'The Octopus' newsletter (November 2023)

The project newsletter came about as a way to build and continue connections between everyone involved in the project, and maintain momentum, in between the different engagement situations. It was sent monthly for the first year and after the end of 2024 it was reduced to an ad hoc basis since the project was finished for now. It was named *The Octopus*, after the metaphor (explained in the Introduction, p. 38), and became one element of my PhD.

This newsletter allowed us to keep the project in people's minds, so if an invitation to attend a conversation came six months later it wasn't the first time they'd heard from us in six months. We were also able to share the thinking and planning we were doing behind the scenes, along with other achievements such as sharing the project at conferences. We created the newsletter in a way that gave lots of opportunities for those involved in the project to have a say — recommending books or songs, writing a few words about their experience, for example — and included a section called 'People in the Project' so we could showcase the humans involved. It also became a way to share other research projects that were happening in the women's health space, including some recruitment calls, giving the people in our project a chance to be involved in other research projects too. An example of the newsletter can be found in Appendix 7, p. 371.

What we did find is that while it was great with sharing news and keeping people connected with the project, it was really hard to get people to take any action in response to our 'Asks and Invitations' sections. We often found we received only a small number of responses to this, and needed to follow this up with a direct, personal individual email with a clear ask. It was similar for the invitation to suggest content for the newsletter, I often had to contact individual contributors to ask for a recommendation. Once we realised this, we just adjusted our planning to involve emailing people directly as well as including the Asks and Invitations in he newsletter.

The feedback from contributors indicated it was doing as intended, it was a newsletter people liked reading all the way through — and someone said they listened to every podcast that was recommended, and loved learning about so many new things. We received this comment after our first issue:

> "You are off to a great start! It's visually appealing with the colours and imagery. It is succinct and well laid-out in bite sized chunks. The headings help direct attention to information of relevance to the reader. Lots of opportunities to engage (not just being a passive reader). Can you tell I'm a comms graduate?!"

It appeared that we had created a format that was interesting, easy to read, and not overwhelming — and that people wanted to stay connected with the project even if they couldn't attend specific engagements.

Contributor Clusters (November 2023)

The intention of Contributor Clusters

The concept of Contributor Clusters came from envisioning smaller groups of contributors that would work together over a period of time to explore and understand a topic in more detail, and then move towards creating research questions about that topic that they wanted to see prioritised. We imagined that people would choose the topic/s they were most interested in, but were aware this would also be determined by availability at the appropriate times. We decided to start with one online Contributor Cluster focused on one of the themes, the 'Untalked About', as this had had lots of interest, and the core project team were very curious about this area too. We also decided we'd have a place based Contributor Cluster in Tāhuna Queenstown, as there were quite a few enthusiastic people there who were keen to stay involved in the project, and Tāhuna Queenstown has quite a unique health care environment. We completed a low risk ethics notification that covered these conversations and the remainder of the process (see Appendix 1, p. 331).

Online Contributor Cluster

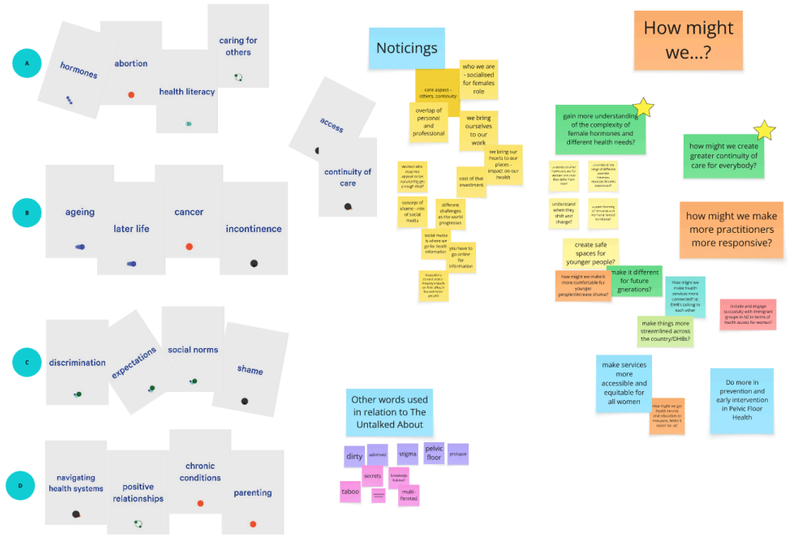
The online Contributor Cluster ended up with four people attending the first session — with everyone from a different location; Murihiku-Invercargill, Rotorua, Te Whanganui-a-Tara-Wellington and Whakatū-Nelson. Again we had a similar structure with the first half of the session focused on connecting or reconnecting and sharing from the 'heart' (personal experiences). This added layers to the conversations we'd had previously, and people shared experiences they hadn't shared before. There seemed to be an understanding of more 'traditional' research methodologies from within this group, and an interest in being part of research and academia was a motivator for why these people were involved in Care-full Co-production. This understanding and motivation possibly made it harder for the group to move to a more collaborative way of working, as they were wanting a clear research project plan with specific requests for their input.

We used Miro again as an interactive tool, however like other sessions some had technological challenges. While we always had ways to work around these (e.g. one of the core project team would scribe for the person struggling) it did disrupt the flow of the sessions a bit, and may have hindered the contributors from interacting more. The activity we set up for the second half of the session, was intended to take the conversation about 'The Untalked About' deeper. Maybe our framing was unclear, but using the 'word cards' as conversation starters resulted in the conversation going out wide again, rather than narrowing it — see word cards and notes in Figure 40. The word cards had come from the Cuppa & Cake transcripts as part of summarising them. Even when we moved on to thinking about things we'd like to change, or "how might we…." the answers still remained very broad and focussed on

'someone' rather than thinking more specifically about whether it was something we could do, or a specific expert (for example). The session concluded with contributors raising concerns that because of the lack of clear plan forward, this would be another example where topics were talked about lots but nothing ended up happening.

The specific topic we'd set out to explore more fully hadn't been discussed as deeply as we'd anticipated, though we did come out of the session with the suggestion of a future session dedicated to brainstorming research questions — a potential next step.

Figure 40:
Showing the Miro board we used for the Online Cluster, with the 'word cards' at the left.



Tāhuna Queenstown Cluster

Our Tāhuna Queenstown Cluster was quite a different experience. While not everyone who came had met before, due to being in different Cuppa & Cake sessions, they quickly built connections throughout the heart part of the session. We used the word cards as conversation starters, inviting the women to choose a few that resonated or they wanted to learn more about — the chosen ones can be seen in Figure 41. The choosing itself initiated quite a few interesting conversations, as they found it a hard task just to choose a few. Trying to group the chosen cards together and hopefully narrow down the focus of the group a bit proved difficult — which speaks to the complexity of the topic more than anything. By using a 'how might we...' prompt in response to the card choices, some loose areas of interest started to form. We also discussed what the next steps might look like, including whether there might be things they could look at doing without members of the core project team in attendance. They were apprehensive about this idea and whether as individuals they had the skills and abilities to be of value. They were also concerned they wouldn't be able to create as safe a space as we'd had to date. When talking through options of support we could give them, one of the women said she'd quite like to have a go at facilitating a conversation about health if we provided help with planning and resources. They also talked about whether they might look at organising some community education events, as something they were interested in was making more education and information about women's health available to their community.

Figure 41:
Word cards that were used as conversation starters, and thoughts on sticky notes.

Where to from the Contributor Clusters?

The Contributor Cluster sessions finished with some potential next steps, even though the sessions hadn't quite turned out how we had anticipated. On one hand this shows the importance of keeping plans loose and responsive, while on the other hand a more fixed plan may have resulted in a more directed session in order to move in the direction of the plan. Either way was potentially fine as neither stopped us from progressing towards the aims and outcomes of the project. However, having

a more fixed plan may have meant the project was driven more by how we as the core project team saw us achieving what we wanted to achieve, rather than actually co-planning with the contributors. These Contributor Cluster sessions were held in November, and by the time we came back from the summer break, the next steps we decided on didn't continue with the Contributor Cluster plan, instead moving straight to research question development. In some ways this could feel like the Contributor Clusters didn't work, but being able to change the plan in response to how ideas are received is one of the benefits of co-production.

Research question development sessions (March—May 2024)

How to move into question development?

Following the Contributor Cluster sessions, it felt like the best next step was to move into developing research questions. Before setting up sessions to do some question creating, we had several questions of our own we needed to consider. These included "what counts as a research question?" or more specifically a 'robust research question' as it's worded in the aim of the project (see Figure 42 for contributors responses), and were we wanting to focus on creating a quantity of questions or were we more interested in quality? We settled on quantity, with the big aim of creating 100 research questions which could later be refined — it was an arbitrary number really to try and encourage contributions, rather than worry about whether something was 'good enough' or not. Other considerations were around how could we encourage our contributors, who weren't necessarily experienced with research questions, to brainstorm and create them, while also not restricting them too much. We came up with a process of using 'question parts' and women's health related words (the word cards used in the Contributor Clusters), where contributors could pick the different bits they wanted and put them together to create a question — a bit similar to the fridge magnet sets for creating poetry. A detailed explanation of the research question development process is covered in Arm 8: Participatory Design Approaches, p. 259.

Online question development sessions

Our first sessions were online, again one in the evening and one at lunch time. Prior to the sessions we sent out a summary of the project so far to refresh people's memories, which included a copy of the word cards (see Appendix 4, p. 343). We also asked people to choose three to five words from the word cards that they might have questions about, or that they had strong feelings towards. For these online sessions we set up the activities to use Miro again, and offered to scribe for anyone that preferred that option. Following our previous engagement sessions we had a head and heart structure, and spent time at the beginning connecting or reconnecting with each other. The heart part of the session was talking about the words they had preselected and why, with the head part focussing on the question creation. Both sessions went well in the sense that we created a set of research questions — around 25 in each session. They both had their challenges when it came to using Miro, and the 'fridge magnet' type question building was mostly good for demonstrating and inspiring question production, rather than for actual creation of the questions.

Figure 42: Contributors 'sticky notes' to answer 'What makes a good research question?'

Queenstown question development session

Rather than building on the questions created so far, we decided to continue starting from scratch, to focus on getting a quantity of questions, and leave the building and refining for later. This also allowed each group to not be influenced by others' thinking — though there were similarities across all the groups sets of questions. For these sessions we did not restrict the number of people attending, but did want a minimum of three. As we were a couple short for one session, we suggested to the person who had signed up that they bring a friend with them. We also opened the invitation to people who we had invited to the first Cuppa & Cake sessions but who hadn't been able to attend. The additional people that we needed signed up. We were curious how the session would go with people who had not been part of the project yet — as we had one session with a mix of new or already involved people and one session with only already involved people it could be a good comparison.

Unfortunately I had forgotten to send out the summary document with the advance task of choosing a few word cards, which meant that we needed to allow time for people to do this at the start of the session. For the two new people as they were connected to people in the project they had been told a reasonable amount about the project already, and were comfortable joining in with the discussions

pretty quickly. In the online sessions we had just asked them to verbalise a response to the prompt "Something I'd like to see is…." taking into consideration the word cards they'd selected. For these in-person sessions, we asked them to draw around one of their hands and then write their words inside the hand, and an answer to the prompt alongside it. This created a record of what they were thinking so they and we didn't have to remember it for the next activity. Also hands are important when it comes to health and caring so it seemed like a nice way of bringing bodies into the process. The following Figures 43 and 44 are examples of these hand drawings.

Two of the people in the second Queenstown session had actually been at an online session as well, although this didn't seem to make a difference either way — they both created additional research questions that were different to ones they'd created in their first session. This likely demonstrates the collaborative nature of these sessions with the questions reflecting the conversations had during each session.

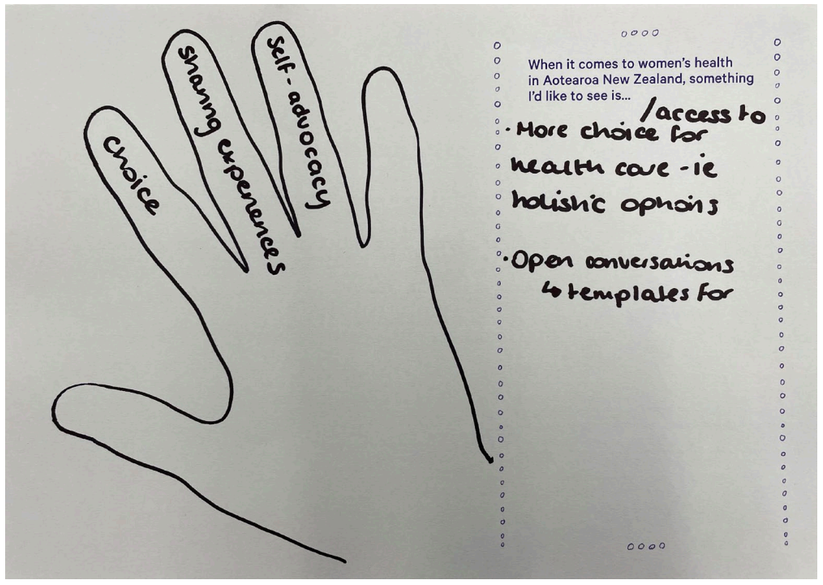


Figure 43: A contributor's hand drawn hand with their response to the prompt.

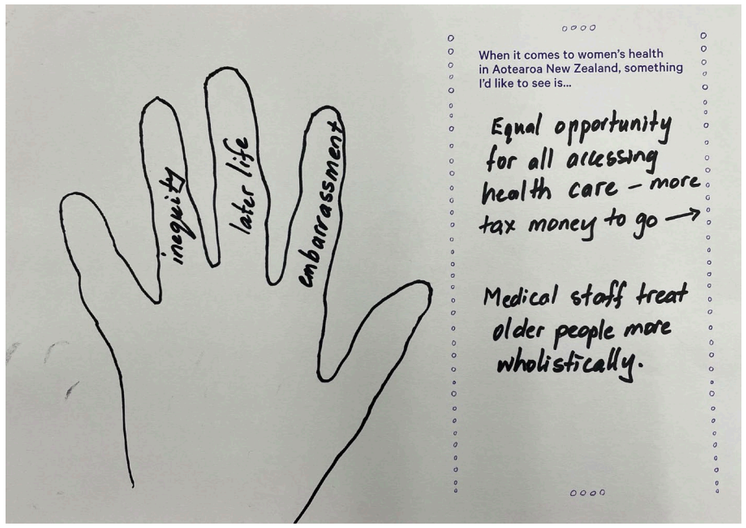


Figure 44: Another contributor's hand drawn hand with their response to the prompt.

Wāhine Māori question development session

For our second meeting with wāhine Māori in Tāhuna Queenstown our focus was on creating research questions. Based on the advice from the contributor who invited us into the community, we planned for a longer session on a Saturday, with time for reconnecting over kai on the Friday evening. Like our previous visit, we knew we wouldn't know until the day how many people would show up, and wanting to accommodate everyone's busy lives we invited people to come and stay for as short or as long as they could. This created a unique planning challenge as our other sessions have relied on everyone building a connection (or reconnecting) at the beginning of the session and then working through the process together. Not knowing how many people we were planning for or when they'd be there meant we needed a process that people could join at any stage, and that could cope with groups from just a few people through to 20+. We planned a selection of activities we could use in a flexible approach on the day. We also identified that the 'hand exercise' would give us the minimum input from contributors that was necessary. It didn't need a group of people to work best and it didn't need a lot of time, but it captured enough of a person's thoughts about women's health that we could craft them into research questions if they didn't get to be involved in the question development itself.

There was a small group on the Friday night, four people besides us and our community connector, only two of whom had come to the hauora kōrero six months before. Because of this we were able to all sit around a table together while having dinner and have casual conversations that meandered through the topics. At one point one of the women mentioned not being able to make it to the next day and asked what we'd be doing. This led to an impromptu session, condensing a couple

of the activities we had planned for the next day into one. The decision making we had already done around what was the minimum we'd like someone to do really helped at this moment, allowing us to merge the word cards and hand exercise to facilitate some conversations and capture their thinking.

For Saturday there was a small group of six, two of whom had been at the Friday night session. We used the hand exercise again, giving those who had already done it the chance to do another, expand on their previous one, or just share their previous one again. We chose not to use the 'question parts' this time, and focussed on eliciting questions they were interested in through the conversations, then scribing them and checking the right aspects had been captured. The session didn't last as long as we had prepared for as people had other commitments to get to. The time we'd allowed had been a guess at what we might need based on all the unknowns, so finishing early did not mean we had missed out on anything — it again demonstrated our reflectivity and responsiveness to the situation.

Collating and refining the research questions

Across all the sessions we did come up with a list of around 100 questions, in various states of formation — the full list of these research questions can be found in Appendix 5, p. 347. We collated them together, and then as a team we attempted to sort them. We thought sorting them into similar topics would give us a useful approach to refining the questions and looking at what to do next. We started sorting with a micro (small networks such as individuals, families, and relationships), meso (medium networks such as organizations, and communities), and macro (large systems such as national or international systems, and societal level issues) approach inspired by a description of design ethics by designer Nate Schloesser (2022). However, when we started sorting this way we realised it was not so simple — each team member made decisions differently, and also most questions fitted into more than one option (see Figure 45). This approach was creating a linear system that relied on three quite separate categories, and as we've found in the past, this tends to miss the complexity we are trying to convey. We then tried with a more circular and web-like approach which gave us more of a spectrum approach than clear categories (as shown in Figure 46). This did not result in any extra understanding, nor did it give inspiration for future next steps, and ended up being left at that.

In parallel to the team sorting process, I had loaded all the questions into an online platform, Padlet, and we sent them out to all the contributors in the May issue of The Octopus. We asked them to read through and use a variety of options to provide feedback. To get more responses this was then followed up by an individual email — this process is discussed in more detail in Arm 2: Care, p. 153 and Arm 8: Participatory Design Approaches, p. 259. As they were able to respond directly in Padlet in an anonymous way it is hard to know exactly how many interacted with the research questions.

Figure 45:
Sorting the questions according to micro, meso and macro in a linear approach.

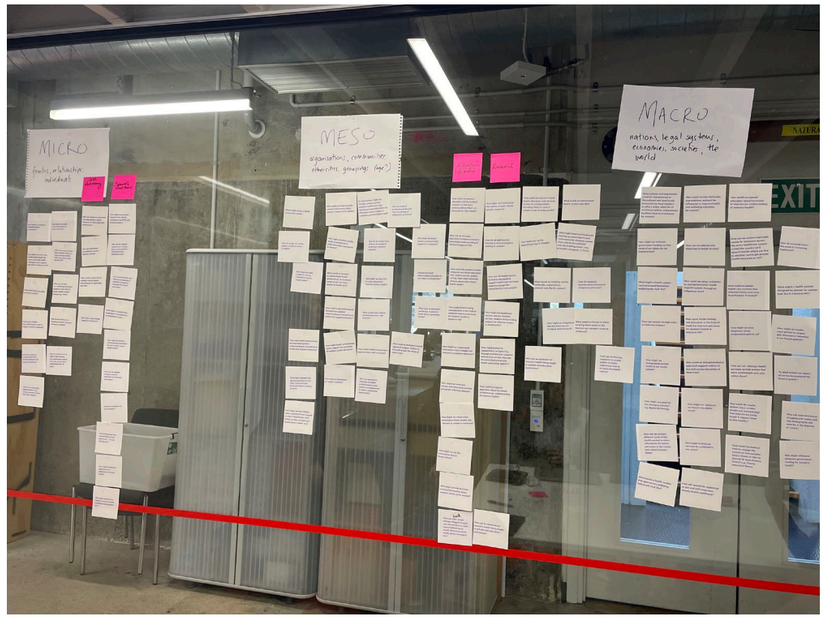
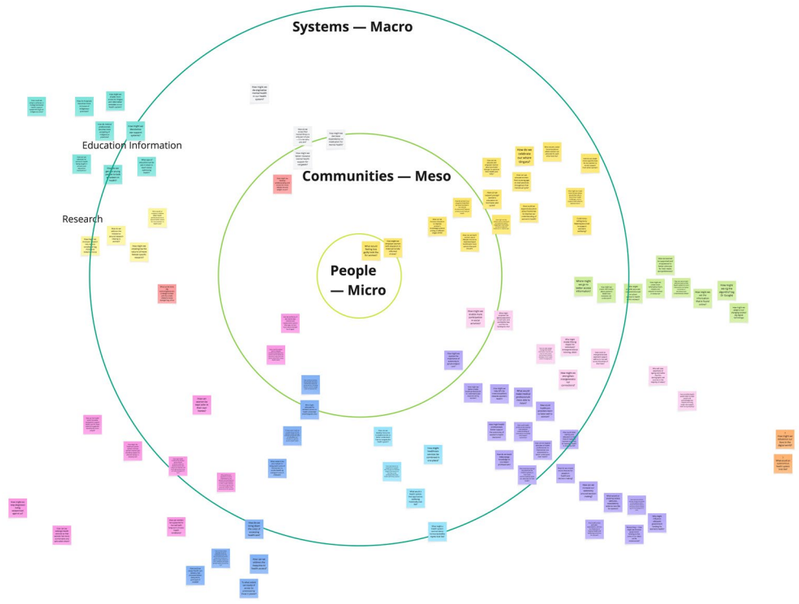


Figure 46:
A web-like approach to sorting the research questions.



Further question refinement

When preparing for the celebration events, and potential further engagement with the questions, the core project team refined them further. This was an opportunity to integrate the feedback we had received so far, and to also reduce the number of questions, so that when looking at Padlet it did not take a lot of scrolling to view all the questions. This time we removed some questions where the scope was enormous and therefore unlikely to be doable, and some that no longer made sense once removed from the context of the conversation they were created during. Where there were very similar ones, we reworded them to capture the essence of all of them. Others were related but harder to combine, so some questions became sub-questions of another less specific question. Through this process we narrowed the group of questions down to around 30, which felt more manageable for gathering people's input during an event — the refined list can be found in Appendix 5, p. 361. A few of these questions can be seen in Figure 47.

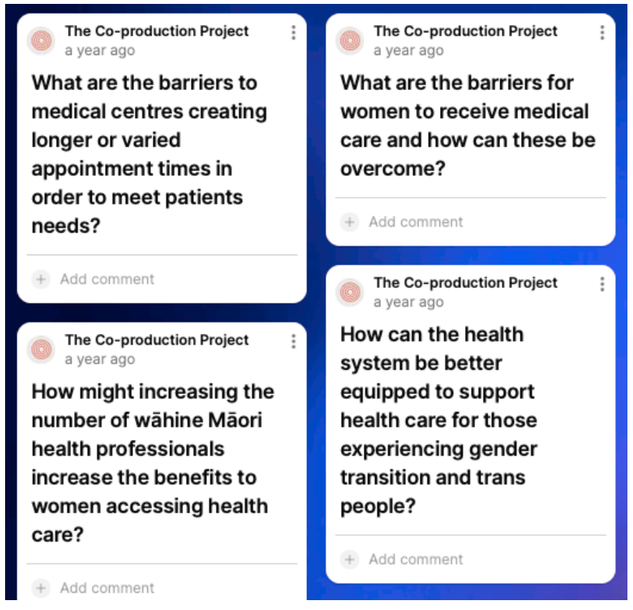


Figure 47: A screenshot of Padlet showing some of the refined question list.

Care-full Conversations card deck

An unexpected outcome of the project has been noticing how appreciated women have been to be able to talk about their health experiences with other women. Some commented that there are not really any opportunities for this, partly because time is not prioritised for them but also because it can be hard to have these conversations:

> "There were so many issues, personal and general, raised which was great. My other thought was how do we get this out there to a wider group of women."

The word cards developed out of the Contributor Cluster sessions and Research Question Development sessions. These helped us summarise and facilitate conversations. Core project team members piloted the cards within their own circles, from groups of friends to intergenerational family groups. These pilot sessions showed the potential and led us to revise the word selection and develop prompts to support hosting safe conversations — as health related chats can go quite deep and vulnerable quickly. With the assistance of one of our contributors we also added in some te reo Māori words to reflect the bicultural nature of Aotearoa New Zealand. The response to the cards has been overwhelmingly positive. We gifted them to contributors, friends of the project and other researchers at our Celebration Events to begin with (Figure 48). People told us about the people they envisioned having conversations with, how they might leave them in workplaces to organically start conversations, and other researchers shared plans to use them in their own work. While they originated from conversations with women about women's health, the suggestions for use are open to anyone. We had some people taking them home to initiate conversations with the whole family, regardless of gender. We encouraged anyone who received a pack to let us know about their experience using them — we look forward to future responses!

Another researcher shared this feedback from using the cards in their research:

> "The use of cards provided an effective means of introducing women to the study topic of navigating perimenopause in the context of a chronic condition such as rheumatoid arthritis. They served as an icebreaker, with cards such as pain, confusion, self-esteem, and embarrassment prompting initial discussion, while others, including guilt, death, and mental health, encouraged participants to reflect on and share more challenging experiences."
> (J. Miller, personal communication, 25/08/25)

Figure 48:
Care-full Conversations cards on display at the Wellington Celebration Event.

Celebration events — closing the circle

As the end of the funding and time allocated for the project was coming up, we wanted a gentle way of 'finishing' the project, in a way that would maintain the relationships we'd built and keep options open for further engagement. In our conversations with the contributors we'd lightly touched on the idea of a 'roadshow' or some form of display that would allow us to open the project up and share it more widely. Following this thinking, we settled on a series of celebration events that would allow us to loosely 'close the circle' by showcasing what had been achieved through this project back to the contributors. These events would also allow us to share with critical friends, supporters, and anyone else we or our contributors thought might be interested in learning more about the project.

Having an event in Wellington made sense as this is our base, and allowed us to prototype the event while we had access to everything we needed. An added touch of manaakitanga to this event was home baked cupcakes that were baked and decorated by core project team members — continuing our theme of Cuppa & Cakes (shown in Figure 49). Our other events in Christchurch and Queenstown did not have the home baking, but had other refreshments as part of our hospitality and care.

Figure 49:
Cupcakes for the Wellington Celebration Event that were made by core project team members.

Including interactive activities

We also wanted the event to involve participatory activities to keep it aligned with the co-production approach. We settled on two academic style posters that told the story of the wider Co-production Project and the women's health case study (Figure 50), an animation that summarised the case study (Figure 51), a display of the Care-Full Conversations cards (Figure 52), and two interactive activities. One activity was Padlet (Figure 52). This was projected onto the wall and we had it open on a tablet, so guests could add their comments and questions to the board too. The second interactive part was the hand exercise from earlier workshops, where people

drew around their hand and then responded to the prompt (Figure 53). These were accompanied by a display of hands — photos of contributors' hands, and drawn hands from previous sessions.

Figure 50:
Celebration event guests in front of two big academic posters.

Figure 51:
The animation being projected onto the wall at the Wellington Celebration event.

Figure 52:
The Care-full Conversations Cards on display and the research questions on Padlet projected onto the wall.

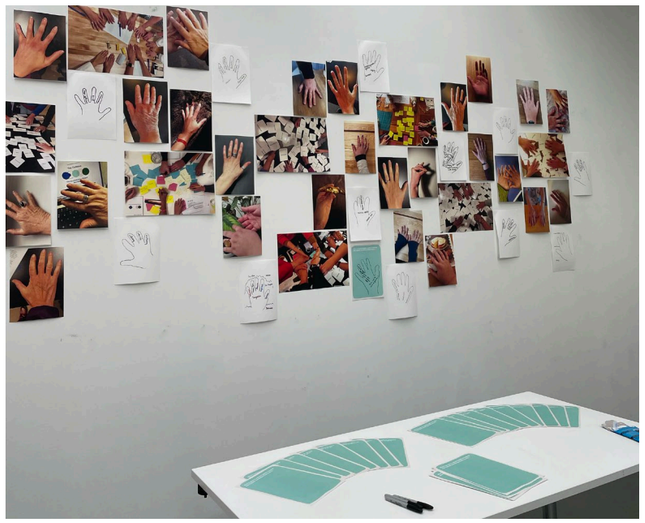


Figure 53:
A display of hand photos and hand-drawn hands with the table set up for attendees to complete their own hand.

Each event was a different mix of people, with Christchurch having a higher number of academic connections, Wellington had more friends and family of the core project team, and Queenstown had the smallest number. The number of contributors that attended the Celebration events was low. Interestingly one contributor at the Wellington event had come to the very first Cuppa & Cake session, but had not been involved in any following sessions. They were hesitant to come to the celebration event because they thought they hadn't 'done enough', but after some gentle encouragement decided to come. From a conversation I had on the evening, it transpired that they had kept up with the progress of the project via the newsletter, and had been responding to requests such as the poll for naming the card deck. We wouldn't have necessarily seen this involvement without this conversation. This reiterated the importance of these events and closing the circle with contributors, allowing the contributors to come back to the project in person in a low effort way, and for the core project team to see that the connection had continued.
We invited a contributor at each event to say a few words about their experience of the project. At the Christchurch event, the contributor spoke about their discomfort in the process, but how as they stuck with it, they started to see their input coming through, and that they could see themselves reflected back in the displays at the event. The contributor at the Queenstown event shared these words:

> "I have been treated with respect, equality (no ageism!) and kindness. Being listened to is affirming — especially for an older woman — sometimes we feel we have been 'put out to grass' despite having had rich earlier lives. It's good to have life experiences valued. Thank you for your courage in trusting us with this process — no fixed outcome, such uncertainty! Some great robust research questions have been generated for future investigation too."

Having these events that told the whole story of the project in one place also allowed us, the core project team, to see the project as a whole, and how much we'd actually achieved. For an approach that is less focussed on productivity and outputs in the same way as more traditional research, these events captured the impact of our work in tangible ways that were sometimes less noticeable during the project.

Hand Book

The hand photos and hand drawings caught the attention of our guests at the celebration events — they spent quite a lot of time reading other people's responses as well as completing their own. Collating them all into a book together has turned out to be a beautiful way of summarising the project — photographed and hand-drawn hands all telling their own stories, alongside the hopes for what women's health in Aotearoa could be. Told this way, the hopes are all so personal and emotive, very different to if they were typed up responses in a 'report'. Only a small number of these have been created at this stage, each one hand-sewn by the core project team.

Figure 53:
The Hand Book — A hand-full of hope for women's health.

Summary

A simple summary of the project through counting different aspects:

- Contributors in the project: 89
- *More Than a Name Tag*'s completed: 119
- Times I've helped facilitate *More Than a Name Tag*: 21
- Cuppa & Cake sessions:16
- Cuppa's the project is founded on: 530
- Hours of conversation with contributors: 59.5 hours
- Issues of *The Octopus* (before this thesis was submitted): 14

Head:
Co-Productioning

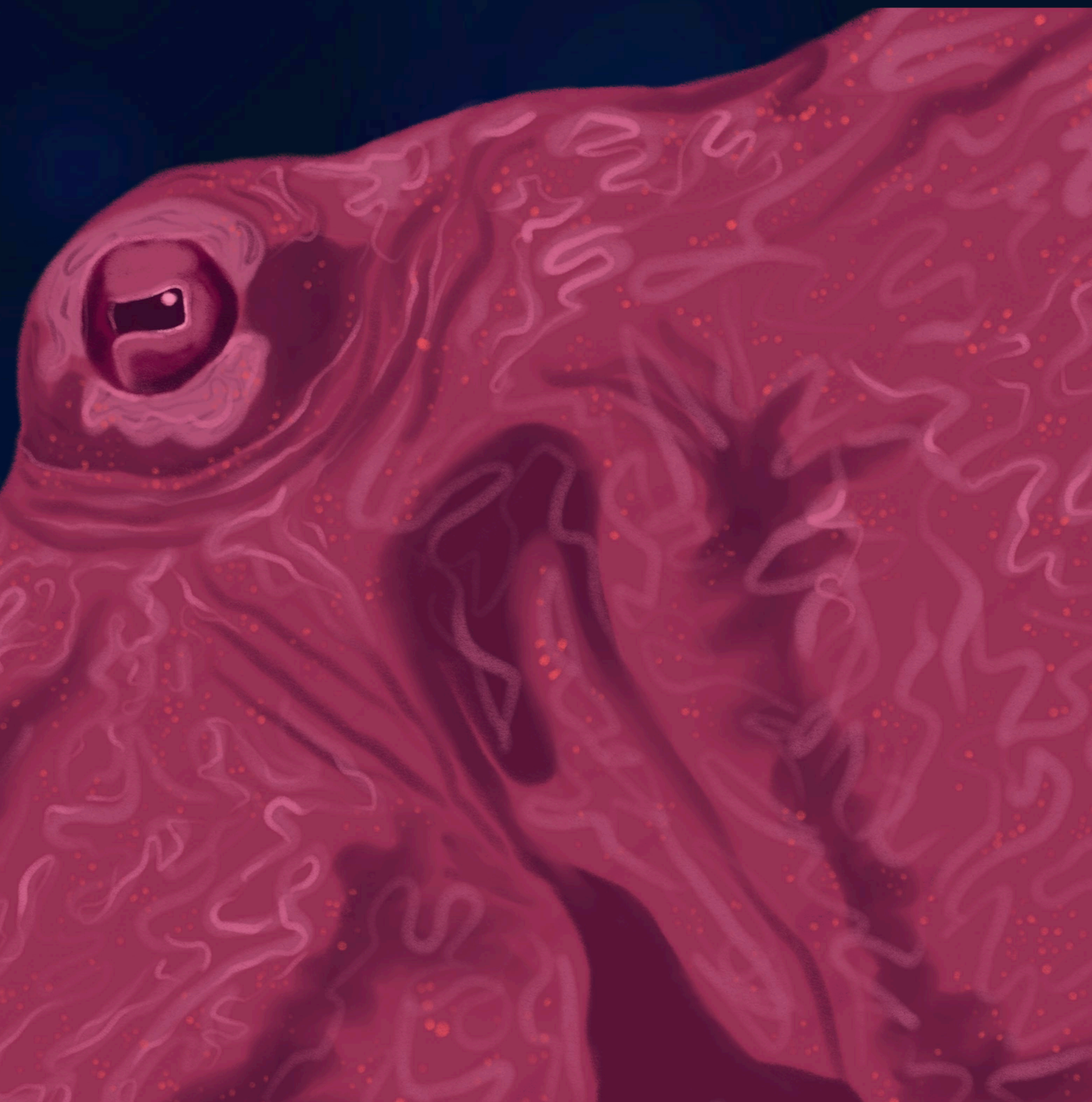
How can co-production be a robust research approach?

What knowledges can be co-produced?

What barriers or challenges are there to co-producing?

What might successful co-production look like?

Is co-production a methodology?



Head:
Co-productioning

Co-production benefits from a particular way of thinking or mindsets being implemented in alignment with its key principles. Researchers and practitioners' backgrounds will influence the areas where more change and learning is needed — if their foundational knowledge has been primarily positivist (for example the natural sciences) this may conflict with co-productions' roots in realist or constructivist mindsets (Verwoerd et al., 2022). A shift to acknowledge the legitimacy of many forms of knowledge is also needed; to share power and research with community members or experts of lived experiences, the knowledge from all needs to be valued whether it is intellectual knowledge or experiential knowledge (Milberg Muñiz et al., 2024).

A mindset that critiques power structures and acknowledges the complexity of doing research this way is also important. Through processes of critique and reflexivity, co-production can be used to disrupt the status quo, making it possible to embrace a plurality of knowledges in order to collaboratively construct, or co-produce, new knowledge (Tonkinwise, 2017). The following discussion on thinking through mess and values, potential challenges and what success could look like in co-production projects highlights some of the considerations that are valuable for applying co-production.

How can co-production be a robust research approach?

Co-production is not expected to have the same types of validity and robustness as more traditional (and especially scientific) research. But being able to explain how co-production is robust in its own way can be useful when establishing interdisciplinary and transdisciplinary research projects, and can help with building a shared understanding and language. While it might feel counterintuitive, the 'messiness' of the co-production process can actually be its strength for developing robust knowledge, especially when combined with values-led practices.

Messiness

The multiple definitions and lack of specific instructions or processes for carrying out co-production can leave those involved feeling like it is a messy, and disorganised approach to research. However, with more understanding, we can see that it is not disorganised, but a responsive and flexible approach to develop robust knowledge and solutions. Feminist geographers Emily Billo and Nancy Hiemstra (2013) encourage embracing flexibility as a 'necessary tool' for responding to the unknown, but as education researcher Alex Hotere-Barnes (2015) explains, in a way that is still critically reflexive and reflective, rather than easy going and careless.

People often like having a plan for how to get from start to finish, and to achieve all the outcomes that are proposed or expected. With co-production this is not always possible — there is the 'conundrum of getting started' where recruiting people for the project needs a project plan but without the people the plan can not be developed (discussed further in Arm:1 Building the Conditions, p. 141). Even once people have joined the project, a full plan for the rest of the project can not always be developed depending on how people are engaging with the project; within Care-full Co-production we had a large community of contributors who dipped in and out as suited them, so a step-wise approach suited our project better. Alongside this, the options for methods to use and ways of working together are as endless as the combinations of people. The step-wise approach combined with endless choices often results in creating more questions than are being answered when trying to choose what to do next in the project.

All these questions can mean the project feels chaotic and messy — from a process perspective as well as the topic being researched. Action researcher Tina Cook (2009) suggests that rather than categorising messiness as unwanted or a sign that the process is not 'good enough', actually interacting with the mess can be a way of integrating the complexity of the research and the topic being explored. They write:

> The 'messy area' can now be framed as a communicative space where participants delve into individual and collaborative understanding to disturb current knowing. It is a place where expert (practitioner) knowledge, experience, judgement, creativity and intuition are used to embrace multiple and new ways of seeing. (Cook, 2009, pp. 281-282)

Messiness does not mean negligent or irresponsible actions have led to the mess, nor will they be what gets you out of the messiness. Considered and care-full critiques and approaches will help untangle the mess and lead to new understandings and knowledge production.

Cook (2009) suggests that through spending time in the unknown, there is more space for novel ideas and thoughts to rise, and encouragement for creativity. Navigating the tensions between what is known (and how it is known) and the unknown, prompts the people involved to move their thinking between the micro to the macro, and between embodied or intellectual ways of knowing, which develops

a deeper understanding of the issue being considered (Cook, 2009). Moving between these different ways of knowing, and embracing the messiness as a necessary part of producing new knowledge can be part of the success of interdisciplinary or transdisciplinary research, especially when investigating complex problems. Cook (2009) suggests:

> When researchers and participants work together they mimic a kaleidoscopic lens to work with the myriad of ideas that occur in the mess of research. It is not easy, and participants may wish to reject it for the comfort of a single lens view. (p. 280)

Some of our contributors wanted to stick with this comfort, with one saying:

> "Well, you know from my point of view I mean it's your project you're the one that knows what you need and you know, I don't. I've got no idea really what you need and I well, yeah, I would I would just rather that you came to me and said, this is what I need and are you up for it?"

Facilitating sitting with the unknown, and processing these ideas in different ways will give us a richer and more nuanced understanding of the concept or topic being researched — because of working through the mess and uncertainty, rather than in spite of the mess.

Values-led

We all have values, personally and as researchers, but we do not always talk about them as part of our research projects (though hopefully our actions and work align even when not overtly discussed). Complex systems researcher, Philip Haynes (2018) explains "Values are beliefs and ideas that we hold in our cognitions about what is important in social and cultural life and they directly affect our behaviour and decision-making processes" (p. 984). McKercher's co-production model that was the initial framing for our project, has four key principles (build capability, share power, prioritise relationships and use participatory means) which implies inherent values, however values are not always discussed as part of the project planning (McKercher, 2020). Choosing values to hold alongside the key principles, helps to guide decision making in a project that has so many possibilities for how to get things done, and helps build the project environment that gives contributors the type of experience we hope they will have. As part of the 'building the conditions' phase (shared earlier in Aotearoa Waters: Women's Health, p. 69) of Care-full Co-production we co-produced a set of values for the project along with expectations for how these would be enacted. These values are: manaakitanga; equality; attend with an inquisitive spirit; community centred; inclusivity; and prioritise lived experiences (Figure 55). A full explanation of these values is included in appendix 6, p. 366.

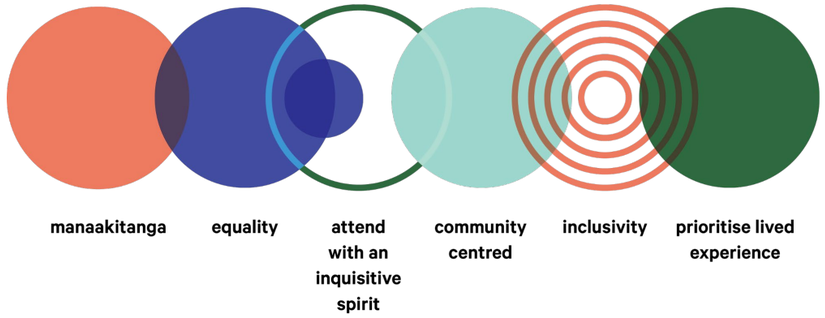


Figure 55: Visualisation of our shared values.

From Te Aka Māori Dictionary (n.d.) the definition of manaakitanga is: hospitality, kindness, generosity, support — the process of showing respect, generosity and care for others. It must be acknowledged that the use and discussion of this term is done so from my Pākehā understanding of Māori concepts. The word manaakitanga is reasonably well known and is commonly used in New Zealand English. These values can be seen woven through the rest of *The Ethical Octopus* (that makes up this thesis), though they are not always mentioned in the exact phrasing used here.

While manaakitanga, equality and inclusivity can help us to support all those involved in a project to carry any challenge and discomfort, encouraging everyone to 'attend with an inquisitive spirit' can help with processing and learning from the unknown. We described attending with an inquisitive spirit as considering the following prompts:

This project is new in so many different ways, so some things will work and some things won't:

- *Be supportive of trying new things — failures are learning opportunities;*
- *Be willing to try new things and be open to new ideas;*
- *A lot of this project is being determined as we go along, so be flexible to changing plans and directions if the current information indicates it is needed; and*
- *Be curious.*

Design researchers Anne-Lene Sand, Mikkel Vinding, Marie Kremer and Lene Tanggaard (2024), write about a sensory approach to ethics in design research, and how this sensory approach can help us deal with doubt — where doubt is the feeling of not knowing, or could also be called uncertainty. They say:

> Doubt is often something we want to avoid because it is not culturally valued in the same way as certain knowledge and fixed answers. Hence, we tend to lack an 'integrated or habitual preparedness' to help us deal with doubt in constructive ways. Because society views doubt negatively, we may avoid disturbing experiences that could guide us as design researchers. (Sand et al., 2024, p. 15)

Embracing an inquisitive spirit is a way that practitioners and researchers carrying out co-production can explore doubt and uncertainty in order to generate new conversations and ways of understanding.

Values can often be felt intuitively too, so paying attention to sensory information, such as physical sensations, can help identify discomfort or uncertainty (Sand et al., 2024). People experience sensory information or intuitive thinking in different ways, and this may not be a form of knowing or information that everyone can access (e.g. those with low interoception and/or neurodivergence), so encouraging open conversations about feelings of doubt, uncertainty and values-in-action can help guide everyone through these experiences. I personally find it very uncomfortable to work without a clear plan or idea of what a project goal looks like — with the fear of not doing things 'right' or 'good enough'. This whole project has been a lesson in learning to be (somewhat) comfortable with discomfort and uncertainty, but as the Care-full Co-production project progressed it did get easier. What helped was having a team that shared this discomfort and talked about it directly, or shared via our reflective process. Sharing our feelings about the project in these ways allowed us to support each other and acknowledge our experiences. In Figure 56 core project team members give some examples of sharing through our reflective practice:

> "the gentle pace of discovery continues to be both wonderful and uncomfortable"

and learning:

> "how uncomfortable Anjuli feels at sharing her work-in-progress."

Other moments of discomfort for myself included recognising my energy and health limits and needing to ask for and accept help from the rest of the team in order for events to go ahead as planned (this is discussed more in Arm 2: Care).

Societal norms of individual productivity rather than collective productivity, play into this but as co-production is about collective collaboration we need to allow for this and to embrace being part of a project team. Similarly the Care-full Co-production project's value of inclusivity also needs to apply to the project team and finding ways of working that meet each other's needs is important. Exploring these feelings and experiences were part of the project's investigation, and keeping our decisions and actions grounded in the values and principles assisted us to achieve what we did.

Figure 56:
The core project team's reflective practice.

What knowledges can be co-produced?

There are many different ways of knowing and understanding things, but not all ways have always been accepted — especially when it comes to being suitable knowledge for research purposes. Beckett et al. (2018) suggest a 'paradigmatic' shift is needed to reframe what knowledge we legitimise and our relationship to different forms of knowledge. According to Jo Rycroft-Malone and colleagues (2016), co-production is entangled in acknowledging a plurality of knowledges and using them to construct new knowledge for specific contexts.

Plurality of knowledge

In order to co-produce new knowledge we need to recognise and value a plurality of knowledges. Similar to how co-production aims to be less hierarchical in its relationships, it also tries to value multiple ways of knowing without prioritising one form of knowledge over others. However, social theorist Katharina Block (2024) critiques co-production, arguing that it often reproduces the dominance of Western knowledge and ways of knowing, and therefore requires intentional choices and actions to reduce this risk. Design has a history of considering the 'single story' about people and experiences, and over simplifying problems and solutions (Place, 2023). In doing so, our understanding of the world has often been viewed through a search for unity and universality, which leaves anything that is dissimilar excluded (Place, 2023). Considering knowledge from this universal perception can often end up creating or reinforcing binaries — such as academic knowledge versus lay-people's knowledge. Indigenous scholar, Tyson Yunkaporta (2023), talks about the two worlds of academia and lived experiences, writing "A key idea here is that dominant and subaltern worlds can be partially connected, even coproduce each other, while

remaining distinct; said otherwise, worlds can be part of each other and radically different at the same time" (p. 29). While Yunkaporta's idea still suggests a binary, it also implies they are intertwined and non-hierarchical.

Valuing lived experiences involves embracing emotional and embodied ways of knowing along with intuitive and intellectual knowledges. Giving lived experiences legitimacy and valuing this form of knowledge comes about through processes and acts of sharing power and prioritising relationships (Williams et al., 2020) which are key to co-production. Discussing openly the ways that power is shared and the acts that build and prioritise relationships is important, rather than just assuming they will happen automatically through using co-production (these are discussed further in Arm 3: Power, p. 173 and Arm 4: Prioritising Relationships, p. 189). Intentionally and overtly legitimising different forms of knowing help different knowledges to co-exist in ways they might not have before. As public health researchers Kath Maguire and Nicky Britten (2018) argue, lived experience experts "Bring the language, values and attitudes of their lifeworld into contact with the alien world of health research" (p. 464) — the same can be said for other areas of research too. In Care-full Co-production, being design researchers rather than medical researchers helped to elevate lived experiences alongside other knowledges as we were not trying to prioritise or listen from a medical perspective.

Acknowledging that there will be different people who hold different knowledges — through different experiences and different life stages, as well as through different societal or cultural positions they hold — is also important. For example, Māori have different knowledges from their positions within their whanau (extended family), hapū (subtribe) and iwi (tribe) (M. Parsons et al., 2016). Multi-generational and intergenerational relationships and conversations will also make different knowledges available. Some of our Cuppa & Cake sessions included Mother-Daughter dyads, which introduced different understandings of lived experiences into the conversations. Also having women from early 20s through to early 80s in the project added different generational perspectives to our conversations and understandings.

Embracing the idea of having a plurality of knowledges, and valuing them all, gives us multiple ways to consider complex issues. These multiple perspectives encourage interdisciplinary and transdisciplinary ways of working, and set projects up well for co-producing new knowledge to understand these complex issues and create potential solutions.

Co-producing knowledges

While co-production relies on acknowledging and valuing a plurality of knowledges, the resulting knowledge from co-production projects is different again. These projects collaboratively produce new knowledge — it is not simply one person learning about another person's experience and vice versa, but by jointly discussing, sharing and questioning a new understanding is built, that is 'greater than the sum of its parts'. We need to remember that knowledge production is not neutral or objective — as we create new knowledge we need to consider what it is and who it

is for. As geographer Kelly Dombroski, and placemakers Rachael Shiels and Hannah Watkinson, (2025) write:

> We are not fully separate or even cognisant of the thinking infrastructures we are part of, but when we work with others we can sometimes glimpse the edges as we communicate across difference and lean into moments of awkward engagement. (p. 14)

The literature distinguishes knowledge co-production (or co-produced research) from co-producing a product or service, though there are many overlaps and similarities. Filipe et al. (2017) demonstrated the intertwined nature of the different forms of co-producing, sharing that "the notion of co-production of value and services in health care cannot be dissociated from the values and implications of co-producing knowledge or the meanings of participation as a social and political process" (p.2). Care-full Co-production, with its aim to build a library of research questions, could be considered to be co-producing knowledge, however because of the way we went about it we could also say we co-produced an experience (people's experience of being in the project). With the approach of valuing different forms of knowledge, this co-produced experience can also count as new knowledge — which is a good example of how co-production becomes complex! This section explores the different aspects of co-producing knowledge, and how that is different from the plurality of knowledge discussed in the previous section.

Complexity of knowledge

Co-producing knowledge is a useful approach for building an understanding of complex problems, and at the same time complexity concepts can be useful for understanding how knowledge is co-produced. Instead of trying to wrangle the complexity of problems into a manageable shape, embracing this complexity and building an environment where all aspects of the complex issue can be investigated and explored will lead to better understandings (Beckett et al., 2018). Using a complexity approach can help to identify all the different influences on knowledge production and dissemination, and can highlight the relationships between the different aspects so we know what we need to be tending to. While Beckett et al. (2018) mention specifically that "Research implementation can be understood as a series of feedback loops, rather than as a linear process" (p. 7), this also applies to understanding the co-production of knowledge, because co-production is prioritising the experiences of people or communities who will be affected by the research. The iterative approach used in Care-full Co-production can be seen as this series of feedback loops, with the contributors giving us feedback every step of the way that was then incorporated into the project. We also saw the feedback loops in effect during the synthesising of the Cuppa & Cake session conversations. By looking at different ways of organising the ideas from the sticky note exercises, with different sorting techniques (as shown in Figure 57 and 58), we then combined that with the

Figure 57:
An overview of the different approaches to sorting the sticky notes from Cuppa & Cake sessions.

Figure 58:
One of the ways we used to organise the sticky notes from Cuppa & Cake sessions.

team members sorting of the transcripts. While we settled on one way of presenting this, there were many other ways of organising the content that we could have kept on going indefinitely.

In-between knowledges

Because co-production is good for complex issues, it is also a great approach for the intersections between disciplines, the in-between gaps between disciplines, or as some describe it, good for 'boundary crossing' (Pirinen, 2016). The flexible, iterative and reflexive approach to co-production helps to bring together the different knowledges that each person in a project brings with them, and blend them together into a new co-produced knowledge (Beckett et al., 2018). To aid with boundary crossing, it's wise to use methods that suit multiple contexts, are commonly understood, and are responsive to the situation they're used in. The participatory approaches used in co-production projects can often be boundary objects (these approaches are discussed further in Arm 8: Participatory Design Approaches, p. 259).

The boundary crossing also incorporates the gaps between different types and sources of knowledge which can be fuzzy rather than clearly defined. Public policy researchers Catherine Durose and colleagues (2012) suggest that to link up different types and sources of knowledge, aspects of co-production such as the prioritising of relationships, sharing power and building peoples capabilities act as the boundary space, where academia and communities come together. In my PhD case study, an example are the different venues where our Cuppa & Cake sessions were held. As Pirinen (2016) wrote:

> collaboration is a transformative capability that necessitates the crossing of the structural, cultural and other boundaries of individuals, organisations and networks and can be supported by strategic, operational and cultural integration, by the creation of trust and through the recognition of mutual value among the actors. (p. 28)

Through building relationships, and embedding an ethics of care, people involved in a co-production project are supported to develop new knowledges through their interactions and shared experiences.

Constructing knowledges

One of the main forms of knowledge that is co-produced is 'actionable knowledge' because it is generally context specific, and aimed to be of benefit to those who it may affect (Beckett et al., 2018). This will not always look like big changes, or solutions to an entire complex situation. Instead it may be seen, for example through capability building of contributors and unexpected outcomes that sit alongside other knowledge that is being co-produced. Human-computer interaction researchers Austin Toombs and colleagues (2017), suggest projects aligned with feminist theory are also often

juggling the tensions between combining new knowledge with ethical action, as this gives more value to the knowledge that has been constructed. The process of co-constructing 'actionable knowledge' is also a way of making sure it is useful for all the people in the project, whether they are researchers, practitioners, experts of lived experience or other experts, according to implementation scientist Sarah Knowles and colleagues (2021). By involving multiple knowledges from different sources, the newly formed knowledge also integrates needs and priorities of multiple sources.

Participatory design approaches allow for the immediate production of new knowledge, through the interactions, experiences, and any outputs of the methods used in an engagement session (Knowles et al., 2021), that is not reliant on waiting for typical research processes such as analysis, or reports (which may come at a later stage). Alongside this knowledge production, health researchers Jenelle Clarke, Justin Waring and Stephen Timmons (2019) explain there is also the experience of being in a project as a whole, which develops across the timeline of the project. Some groups more than others, such as women or marginalised groups, have a history of being exploited through research or experiencing research as extractive or unhelpful (Cleghorn, 2021). By engaging in the process of co-production they (ideally) will have a new experience of research as a care-full, thought provoking and valuable experience — they learn the new knowledge of research being done differently.

Some of the knowledge being co-produced will be quite specific to the context it is created in, particularly for place-based projects and projects that include the more-than-human. Mixing inter-relational knowledge with other people and places, to embodied knowledge of places and spaces, and intuitive, emotional and intellectual knowledge gives a deep and nuanced understanding of a phenomena (Greenaway et al., 2022). Through this combination, new ways of seeing, doing and understanding are uncovered. In Care-full Co-production, some of the project was place based as there was a unique enthusiasm and energy within the contributors in Tāhuna Queenstown. Whether it was the community focussed nature of the place itself, or the health care challenges specific to the region, or a combination of both, it is not clear, but a significant part of the project took place with the contributors in Tāhuna Queenstown in person and online. The group had a broad age range, and a lot of the contributors had moved there from somewhere else, so their experiences often included comparisons to other places. The core project team all had different connections to the place too, as well as then developing relationships with those people who became contributors. These overlapping relationships between the core project team, the contributors and the location all contributed to knowledge built during the project.

By having our engagement sessions in places around the country or online we tangibly demonstrated research happening outside of the university. While the core research team was obviously still associated with the university, the physical separation combined with venue choice and other elements of care and hospitality (discussed in detail in Arm 2: Care, p. 153) helped distance us from contributors' perceptions of university and university research. Although these engagement

sessions did not necessarily happen in locations that were of specific meaning to the contributors, the careful venue and location choices aimed to keep contributors located in their contexts and environments, rather than disrupting their relationships with places and connections. For some of our online sessions core project team members were in their own homes, which also helps blur the boundaries between the university and the public, or the community. These ways of locating the research outside of the physical university, help reduce the power differentials that come with university-led research, and maintains the complexity of interconnected knowledges rather than separating them into pieces of independent knowledge (Greenaway et al., 2022).

Social designer and researcher, Janka Csernák, (2024) suggests that by sharing lived experiences with each other, people can develop new understandings which may then give another way for making sense of these experiences. This might be a sense of solidarity, feelings of validation, new ways for handling situations or a different understanding of what is 'normal' or not. Action researchers John Heron and Peter Reason (2008) explain that combining this with 'propositional knowing' or the intellectual understanding of ideas and theories constructs a deeper understanding of the topic or issue being explored. As Haverkamp (2021) explains, relational research "means bringing the heart, feelings and senses back into the research praxis, not separate from reason but with mind/reason" (p. 5). Our Cuppa & Cake sessions were structured around 'heart' and 'head' stages which also demonstrates both emotional and intellectual knowing. In Care-full Co-production this can be seen in the creation of research questions about women's health. Some examples of these questions can be seen in Figure 59. While it would be possible to go straight to brainstorming research questions without all the conversations that were had beforehand, the shared understanding of women's health that had been developed through these conversations gave additional depth to the questions. Rather than a series of individual questions addressing individual people's personal concerns or interests, the conversations had given contributors a broader understanding of women's health experiences and where their queries fitted into this collective understanding. I think this is partly what led to so many of the research questions we developed being high level or systemic focussed, rather than specifically focussed on diagnosis or body parts.

In the process of refining the research questions, the core research team tried sorting the questions in different ways — such as micro/meso/macro — which brought up another layer of complexity, as any attempt to sort the questions was not a simple task. One example of this sorting process is seen in Figure 60. It highlighted that some questions could not stand alone without the conversation they had come out of, and showed other questions were all interconnected at individual, community, and societal levels.

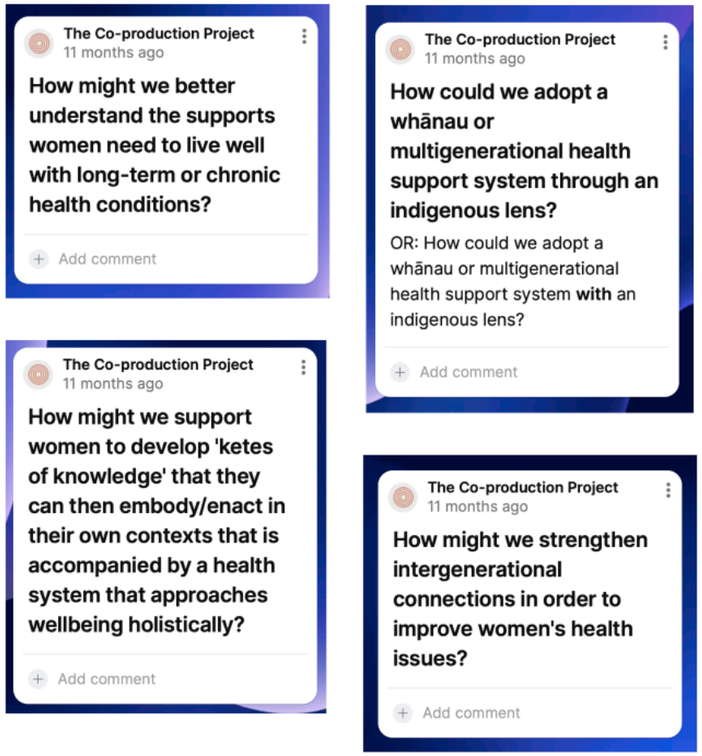


Figure 59:
A few of the co-produced research questions.

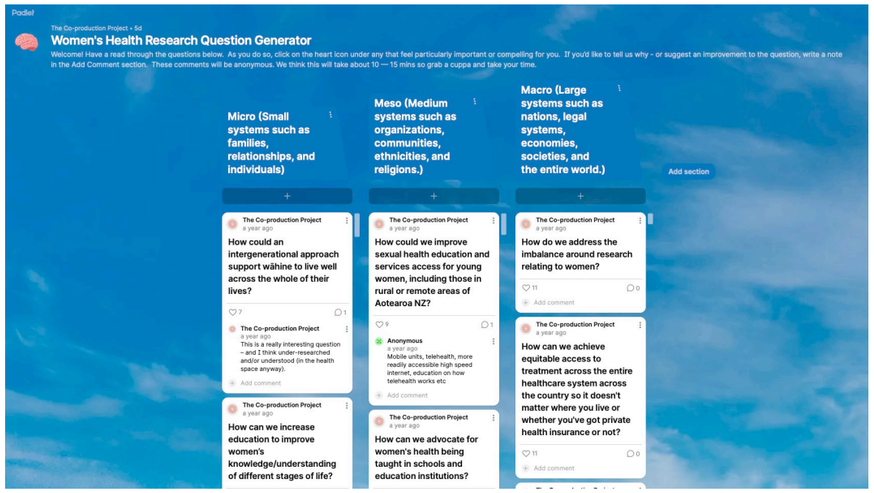


Figure 60:
Trialling sorting the research questions using Micro/Meso/Macro.

Co-production might not be the best approach for all research, but it is likely a good approach for more projects than one thinks of automatically. There are lots of examples showing its applicability for health related research (McGill et al., 2022; Rycroft-Malone et al., 2016), and its suitability for other areas can be seen by the expanding use across different disciplines, such as sustainability science (Norström et al., 2020), futures design (Durose et al., 2022), psychology and mental health (Kidd et al., 2015; Roper et al., 2018), and public policy making (Bovaird, 2007) to name a few. Even projects that look to be more traditional science (and less boundary crossing) could likely benefit from using co-production. As discussed throughout this chapter, co-production can improve research questions, expand impact, and provide relevant and robust insights (Locock & Boaz, 2019).

What barriers or challenges are there to co-production?

Unsurprisingly there are several barriers and challenges to carrying out successful co-production projects. Some of these include academic systems and processes (which are discussed in the String Bag chapter, p. 283). Other challenges are mismatches of values and priorities between the different organisations and communities involved, lack of understanding (and championing) of the co-production approach (Beckett et al., 2018), and the constraints of hierarchical structures (Pirinen, 2016) and power asymmetries (discussed further in Arm 3: Power, p. 173). Another significant challenge is resource allocation as co-production needs generous time, funding and people with motivation, energy and capacity (Pirinen, 2016). It is also often difficult to get funding, as funding applications generally require a plan for the whole project, but without the contributors onboard a full plan cannot be generated. If contributors are involved in funding applications, as they should be, it often requires them to do so without any financial support (e.g. transport or childcare costs) or remuneration of any sort. This is not necessarily an issue, especially if funding is gained so the project can continue, but it is a big ask to have people contribute to funding applications with no certainty that the project will go ahead, meaning they may not receive any benefits from being involved in the process. It also means that those who are able to contribute to the funding application process will be those who have the privilege of available time, or personal resources to access involvement, which may end up excluding the very people who would most benefit from the final project.

Additionally, there are three challenges that are of a more theoretical or mindset nature, that if not addressed throughout a project could really impact its success. In an Aotearoa context there is ‘Pākehā Paralysis’ (coming from what’s termed ‘white fragility’), along with ‘Perfectionism Paralysis’, and ‘Tokenism’. These challenges require intentionality, reflexivity and reflectivity (which is discussed further in Arm 7: Reflexivity and Reflectivity, p. 243) to overcome them throughout the duration of the project.

Pākehā Paralysis

Aotearoa New Zealand is a bicultural country at a constitutional level with Te Tiriti o Waitangi the founding agreement between Māori and non-Māori settlers. The history of colonisation, and the harm this has done to Māori has impacted all aspects of life, including research carried out in Aotearoa New Zealand and healthcare, with systemic racism built into the academic and health systems (Smith, 2021). While there are many efforts to decolonise research, this is an ongoing process.
As part of preventing more harm from research, it is widely understood that research about Māori people or phenomena should be done 'by Māori, for Māori' rather than by non-Māori or Pākehā (Smith, 2021). Unfortunately, as sociologist and ethicist Martin Tolich (2002) explains, this has often unintentionally resulted in more harm, with Māori being excluded from research in Aotearoa New Zealand, partly through academic staff misunderstandings, and from university ethics committees failing to ask questions that would catch these well intentioned decisions. Failure to include Māori in Pākehā research can happen due to what has become known as Pākehā Paralysis. A Pākehā education researcher, Alex Hotere-Barnes (2015), describes Pākehā Paralysis as:

> Emotional and intellectual difficulties that Pākehā can experience when engaging in social, cultural, economic and political relations with Māori because of: a fear of getting it wrong; concern about perpetuating Māori cultural tokenism; negative previous experiences with Māori; and confusion about what the 'right' course of action may be. (p. 41)

The fear of getting things wrong can hinder the development of relationships with Māori, can directly or indirectly exclude them from recruitment for research or even reinforce existing power asymmetries (Hotere-Barnes, 2015). What is often forgotten is that a lack of action or decision making is actually an action on its own, and rather than accidentally allowing that to happen, we need to intentionally take action.

Lack of action can also come about not only through lack of knowledge, but also from having got it wrong previously. Health practitioners and researchers Andi Crawford and Fiona Langridge (2022) explain that non-Māori often have the privilege of being able to move away from uncomfortable situations, to avoid even engaging in conversations about racism, and to operate without having their ways of being or expertise challenged (Hotere-Barnes, 2015). This privilege is a demonstration of power asymmetries in action. Because of this ability to avoid difficult situations, being in interactions or spaces where one gets something wrong, or has their research and research methods challenged by Māori, can be very uncomfortable and disconcerting. Pākehā often end up responding defensively, experience feelings of embarrassment or shame, or they can have a freeze response and feel paralysed (Hotere-Barnes, 2015). To overcome this paralysis, we need to learn ways to process the emotions, be humble in the face of criticism or feedback,

and be open to learning new ways of doing and being. Rather than trying to leave emotions out of the project, we need to accept emotions as another form of knowledge that adds to our understanding — of our experiences, and of others. Crawford and Langridge (2022) write "What is the tangata Tiriti role when it comes to paralysis? For us it is being comfortable with being uncomfortable" (p. 104). Becoming comfortable with discomfort is a frequent suggestion for co-production at large, but is obviously involved with overcoming Pākehā Paralysis.

Paying attention to our own positionality as researchers or practitioners is important for understanding the biases and assumptions we might have about the world, and any 'taken for granted' privileges and power and how they're influencing our interactions and research (Crawford & Langridge, 2022). How our positionality impacts our power and privilege is context specific, does not remain static and in most spaces is maintained and reinforced by colonial history and policies, and how resources such as research funding are allocated (Crawford & Langridge, 2022). Pākehā Paralysis can keep us stuck, frozen in inaction. Non-Māori need to do their own learning about how Te Tiriti has not been honoured, broadly within Aotearoa New Zealand, and specifically within our research areas (Crawford & Langridge, 2022). Learning to pause rather than becoming defensive, and taking time to be reflexive, independently and collectively is also needed — discussed further in Arm 7: Reflexivity & Reflectivity, p. 243. It also requires reflecting on who the right people for the project are, how to build and support the relevant relationships, and if the project is going to deliver the outcomes that are being promised (Hotere-Barnes, 2015). Sometimes the ethical approach is to not do the research if it can't be done with the right people involved. However, failing to do what you have said you are going to do, or ending a project early, can also be harmful so staying accountable to the people and communities that are involved in the project is important (Crawford & Langridge, 2022).

Hotere-Barnes (2015) writes:

> In summary, working the spaces in-between Māori and Pākehā educational research entails the creation of conditions where disagreements, emotional flux, and living with doubt are recognised as normal. Impermanence and complexity are inevitable. Arriving at this recognition takes intellectual and emotional work over time, which is challenging. (p. 47)

Australian digital storytelling researcher Son Vivienne (2023) argues that creating space for this challenging work calls for 'brave spaces' rather than safe spaces — a space where it is safer to make mistakes, and where conversations to repair and heal are encouraged and supported. The acceptance of complexity, doubt and discomfort shows support for how co-production can be an appropriate approach for carrying out research that is culturally safe within Aotearoa New Zealand. Rolleston et al. (2022) explains:

> co-design is a Western methodology and despite its obvious benefit in general for communities, for Māori and other Indigenous people, a more culturally aligned approach is required. Mahitahi is a Māori, culturally responsive co-design approach that builds knowledge from within the worldview of the people that the health system most needs to respond to. Co-design and mahitahi have synergies, and working at the interface between Western and mātauranga (knowledge) Māori systems can provide innovative solutions that draw on the strengths of both worldviews. (p. 2)

Co-production generally involves co-design, so Rolleston et al.'s explanation is also relevant to co-production — it too exists within a Western worldview, and is contained and constrained by Western academic systems and processes. However, a care-filled approach to co-production that is critical and reflexive, can be a step in the right direction for safer and more inclusive practice. It does not replace or supersede kaupapa Māori research, or research that is by Māori, for Māori. Aligning participatory design approaches with feminist and indigenous ethics of care can also lead to culturally appropriate changes to research practices (Haverkamp, 2021).

Overcoming Pākehā Paralysis is not about appropriating Māori research methods, instead as textile designer Julia Hope (2024) wrote, "Pākehā need to realise and embody new, *non-colonial* cultural habits and ways of being that transform Pākehā culture" (Take responsibility section). Developing new ways of researching that is values-led, embraces complexity and embeds an ethics of care, like co-production as described in this thesis, is a way that we go about building non-colonial Pākehā ways of being and doing. Creating an introductory practice focussed on relationality and connectedness, such as the *More Than A Name Tag* activity used in this project is an example of this. This activity is explained fully in Arm 8: Participatory Design Approaches, p. 259. Embedding our own ways of showing kindness, hospitality and care practices throughout co-production is another part of developing non-colonial approaches — these may not look that different on the surface, but the intentional decision making behind these choices that takes into consideration the people and power asymmetries involved, moves these towards being non-colonial actions. Developing the way we carry out co-production in an Aotearoa New Zealand context to embody new Pākehā cultural approaches, can feel overwhelming — and may be challenged by Perfectionism Paralysis which is unpacked in the next section.

Perfectionism Paralysis

Co-production has big ideals for creating impacts that are more emancipatory and egalitarian (Williams et al., 2020). The potential and promises of this way of doing research are inspiring, hopeful and limitless (Beckett et al., 2018). However with this comes high expectations and responsibility. The desire to 'do co-production properly' is immense, but the instructions for how to do co-production are vague, lacking or hard to translate from one context to another (Thom & Burnside, 2018). The lack

of prescribed ways to do things, and the flexibility that comes with it is one of the strengths of co-production, but this freedom can also make it hard to know where to start or how to continue. This conundrum of being stuck trying to decide what to do and how to do it, is what I've called Perfectionism Paralysis — being paralysed by the fear of not getting it right or not meeting the ideal of co-production. But without trying out new ways of doing things, we will never figure out what 'proper' co-production looks like anyway. In the examples of co-production that Verwoerd et al. (2022) discuss, they noticed that projects often modified the way they did things to get the project started. While this modified approach may not have strictly fitted the ideal of co-production, once the project was underway it was able to change its approach to be in alignment with co-production. Giving projects the grace to get started however they can, may just be the freedom that is needed to overcome the paralysis and move into a more ideal co-production space.

As discussed further in Arm 3: Power (p. 173), one of my assumptions early on in the project was that the principle of 'share power' meant everyone in the project had to have equal power. This was definitely a paralysing thought — what would that even look like or mean in practice, and if we did not achieve that would that mean this whole exploration of co-production would be invalid? Sharing power in a perfectly equal way is also unlikely for a project that has been initiated from within a university, as academic institutions inherently have a power imbalance with communities. Embracing thinking about power as dynamic rather than fixed helped overcome this example of Perfectionism Paralysis, as we could approach power as something fluid that moved between people and contexts. As long as we paid attention, considered things reflexively and made decisions intentionally to challenge power asymmetries, we could visualise how power was being shared throughout the project.

Disability performers, artists and scholars, Kelsie Acton and colleagues, shared about their experience at a performance and politics conference where they were focussed on making sessions accessible and inclusive (Acton et al., 2019). Jessica Watkin wrote:

> Bringing attention to the work we do, or the work that we try to do, is a way for me to combat what Ash refers to as 'turbo-capitalism'. Admitting when things are not perfect — because when are they ever perfect — is a part of this work. I'm referring here to the work of welcoming, to bringing in, to bolstering energy, to reaching and holding each other up and together, and collaborating in ways that feel comfortable (or as comfortable as possible) to everyone involved. (p. 52)

Like Watkin's mention of sharing when things aren't perfect, communicating our intentions, and actions, openly also helped with overcoming perfectionism — it allowed contributors to know what we were thinking as well as see our actions, and they could then share their thoughts and feedback in more detail and at times

when it was easier to incorporate. This timely sharing was more useful than just providing feedback at the end of the project when it was too late to make the changes. Again, learning to sit with the doubt, and be (somewhat) comfortable with discomfort was a mindset that helped push through any Perfectionism Paralysis. We realised part way into the project that often when we felt comfortable it was a sign to pause and reflect as there was something to be learnt in that moment. Science communicator Maja Horst (2013) commented that in their science communication initiative, discomfort was their sign to pause as there was learning for them to do, and that is often the way. However, because we were exploring doing things differently, comfort often meant we were approaching the project in ways that were familiar and expected, rather than new and different. Having a generous timeframe for the project also helped in these situations, as we were able to slow our processes down and take more time for reflection and discussion in a responsive way, rather than being reactionary all the time.

Despite the fear of getting things wrong, or not doing co-production well enough, this is not an excuse to not try at all. For example, aiming to be inclusive and culturally safe is hard, it requires lots of thinking and resources, and because there are so many ways of being safe and inclusive it is difficult to get it right for everyone. However we need to try, and we need to continue learning, so that once we know better we can improve how we do things. This also becomes part of the capability building that is a principle of co-production — if core project team members are learning more about how to be inclusive, they can share this with other team members and contributors, so everyone develops their understanding and practices.

Tokenism

A challenge that is almost the opposite of Perfectionism Paralysis is tokenism. It is easy to use words that are positive and catchy but without necessarily having the actions and impacts to back them up. Decolonial researcher and designer sahibzada mayed (2024) argues that all the 'co-' words such as co-design, co-production and co-creation risk being used as buzzwords with the assumption that they inherently convey equity, inclusion and benefit to those involved. Inconsistent or vague definitions for these co- words also add to the risk of tokenism, as people use these words interchangeably and often do not clearly define them for their particular use. Health researchers Sandra Moll and colleagues (2020) explain that using the terms interchangeably makes it difficult to notice when words are being used genuinely or if they have been co-opted and used for approaches that miss the key elements such as sharing power and prioritising relationships. Sometimes because of the popularity of an approach, such as co-design or co-production, organisations or researchers use these terms even though what they are doing is actually more like consultation — they have already decided in advance what they are going to do and how to do it, with little room, if any, for including people with lived experience and their thoughts (Rolleston et al., 2022). Indigenous researchers Elizabeth Sumida Huaman and Peter Mataira (2019) write that co-opting of terms can also be driven by research funding

opportunities and universities, where using popular terms increases the chance of getting funding and approval, but decision makers do not know enough about these terms to identify tokenistic use of them. While universities often say they value community-engaged research, this may not stretch to embracing community-led research, often unintentionally through processes and systems, so managing the tension between these research approaches can lead to tokenistic framing. In design spaces this can also look like describing projects as 'community-centered' and using 'community' instead of 'users' when all that has changed is the words, without actions or thought processes changing too (Place, 2023).

This discussion of tokenism is not to invalidate the challenge of overcoming Perfectionism Paralysis, rather it is to help recognise the difference between tokenistic approaches and good faith attempts at co-production, even if they fall short of doing co-production 'properly'. Paying attention to the small details, making intentional decisions and actions that align with the key principles of co-production will help to avoid tokenistic approaches (all of which are discussed in more detail throughout the rest of *The Ethical Octopus* part of this thesis). Establishing reflexive and reflective practices throughout a co-production project is also a key element to ensuring authentic engagement (Cook, 2009) in the planning, designing, delivering and evaluating of a co-production project.

What might successful co-production look like?

The ways of measuring success for co-production projects need to be different than for more traditional ways of doing research to take into account the different priorities, principles and methods. With more people involved, and not all from academia, there are multiple expectations and ideas of success, as well as a variety of different outputs needed which all contribute to different forms of impact and value. Including contributors' ideas of success and impact as well as including them in evaluation processes is also an important aspect of co-production (Filipe et al., 2017). What success looks like will be specific to each project and the context of that project, but it is a good question to consider throughout the project. The following sections on impact, community building and value, all provide context and examples for considering what success can look like.

Impact

Pain et al. (2015) define impact as "the social, economic or environmental changes that result from a particular intervention (in this case, changes that are created or influenced by research)" (p. 4). Measuring impact has become increasingly important for research projects as these measures are used for funding decisions, and impact measures are also often used for staff promotion decisions. Outputs, such as publications, are often used as a proxy for impact measures, as it can be

difficult to measure impact (Enright et al., 2016). These impact measurements can be in tension with the aims of co-production projects. For example, academic publications which are frequently a part of impact measures, are often not a priority for the communities and contributors involved. Pain et al. (2015) summarised this problem as:

> the attempt to measure 'impact' as a concrete, visible phenomenon that is fixed in time and space, that one party does to another party... whereas deep co-production is a process often involving a gradual, porous and diffuse series of changes undertaken collaboratively. (p. 4)

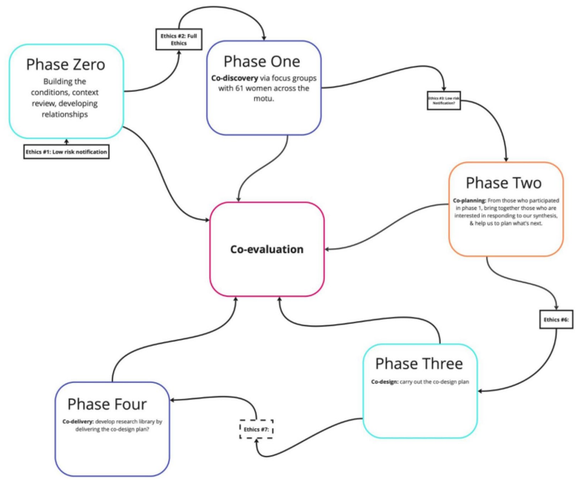
They suggest instead to consider thinking about and implementing impact as a practice — interwoven throughout the project as a form of collective reflexivity and reflection. Approaching impact this way aligns well with the iterative, participatory approaches that are important to co-production projects. Thinking of impact as a practice also encourages an expansive perspective on outputs and outcomes that includes noticing synergies and unexpected outcomes.

Because co-production is often constructing actionable and interdisciplinary or transdisciplinary knowledge, changing the way we think of and measure impact is important for recognising a plurality of knowledges. Beckett et al. (2018) recommend expanding on traditional impact measures to include recognition of capacity building and relationship building (both of which are key principles of co-production). They also iterate what others have said about embracing the complexity and messiness of co-production, and considering the non-linearity and unpredictability when looking at impact. Another element relevant to considering impact is highlighted by public policy analyst Sherry Arnstein (2019) who writes "There is a critical difference between going through the empty ritual of participation and having the real power needed to affect the outcome of the process" (p. 24). In order to do this, attention needs to be paid to the processes involved in co-production, as well as the content of the research project (Beckett et al., 2018). While measuring relationships in a useful way is difficult, there are ways we can quantify them as a way to visualise and highlight the importance but also the resource-heavy nature of them. In The Co-production Project, following the Cuppa & Cake theme, we started counting the number of cuppas the project was founded on. The counting was quite simplistic, not literally the number of drinks consumed, and more realistically indicated the number of organised interactions that were had. An updated total was provided each month in the project newsletter, and by the end of the project the number was 530 (as seen in Figure 61). A slightly playful measurement, but it does give a feeling for the level of engagement involved in the project.

Figure 61:
The 'Cuppa Count' displayed at the end of the newsletter.

Collating reflections-in-action and reflections-on-action continuously throughout the project forms a process of co-evaluation (Knowles et al., 2021). The co-evaluation process is also a way of noticing the non-linearity of co-production, as this reflective process can be cyclical or a spiral, or even more messy than that as different people give input at different moments. Unlike co-design which is often a specific stage of a project, co-production is a continual process of applying key principles and values throughout a project (Knowles et al., 2021). When first looking at McKercher's model of co-production, I saw four distinct stages that might overlap at times, with one of those stages being co-evaluation. Having distinct stages had suggested to me that the co-evaluation would happen separately or mostly in the last part of the project, and would be a very specific process — a visualisation trial of this can be seen in Figure 62.

Figure 62:
Trialling a visualisation of the potential project phases to understand where co-evaluation might take place.



However, once we started engaging with contributors, I could see how co-production was not that simple or clearly defined in stages, and appreciated how co-evaluation was actually a constantly negotiated interaction throughout the whole project. Care-full Co-production had many layers of evaluation that incorporated reflexivity and reflection as individuals, within the core project team and with the contributors. The practices we incorporated are discussed further in Arm 7: Reflexivity & Reflectivity, p. 243 and Arm 8: Participatory Design Approaches, p. 259.

Considering impact from a micro, meso and macro level opens up new ways of noticing impacts (Beckett et al., 2018). However, it is not always possible for us to know the size of impact an action has — what feels small to one person may be very significant to someone else. When you throw a pebble into a lake, you cannot always see where the ripple from that impact finishes up. It is particularly difficult to know the impacts when it comes to relational research — where interactions with other people can change things immeasurably. The experience of being in a group and having personal health experiences heard and validated, can be healing, empowering and uplifting, but those impacts may come after and outside of the conversation when we are not able to notice them. Unexpected outcomes from projects can also have unexpected or unseen impacts. We had three (that we know of) unexpected outputs from Care-full Co-production; the Care-full Conversation cards; the Handbook; and the project newsletter The Octopus. The conversation cards are a way to generate conversations about women's health without needing someone from the core project team, or a trained facilitator, to lead the conversation. We've heard they will be used to initiate conversations with granddaughters, for fathers to have conversations with their daughters, and other researchers have plans to use them in their inquiries. Some early feedback we have received said:

> "I just received my deck of cards today — thank you so much. They are fantastic, and are so well designed and produced. I went on a little girls' day out on Waiheke with some friends at the weekend, and we ended up talking about a few things on these cards already! Looking forward to having some more chats with my friends using the cards as prompts."

Now that these conversation cards are out in the wild, there is no end to the impact they may have. The handmade *Hand Book: A hand-full of hope for women's health* is literally filled with photos or hand drawn images of the hands of people in the project (more about these two types of hands can be found in Arm 8: Participatory Design Approaches, p. 259). With only a small number of these books made physically, they have not been shared as widely — although the book has been presented as part of a bigger project on Emergent Engagement in Scotland at the Public Communication of Science and Technology conference 2025. I have shown my copy to a contributor and to a health professional who supports the project — both commented how amazing it is, and what a beautiful story it tells. The project newsletter came about

following a suggestion from some contributors, with the purpose of it being to maintain connection to the project in between engagement sessions. We can track metrics such as open rates and clicks in the platform we used for the newsletter which demonstrates the newsletter was being read. However feedback from contributors showed the impact of the newsletter with more depth. One contributor told us:

> "I honestly enjoyed reading this and the further we get into the co-production project the more excited I am to be part of it."

And another shared:

> "I've enjoyed being part of women's health, by listening and learning, and I enjoy The Octopus magazine, reading and looking at podcasts, which I don't normally find, but I enjoy that."

Maintaining connections

Prioritising relationships is a key principle of co-production, and being community-centred is one of the specific values of Care-full Co-production, so exploring the community that makes up the project can be an indicator of the success of the project. How a co-production project's community is built and maintained will depend somewhat on the community and its structure that exists prior to the beginning of the project. For Care-full Co-production we recruited contributors through the charity Good Bitches Baking, which is in some ways an existing community, and we were building on my existing trusted relationship with that organisation and community. The nature of their set up though means that the charity's volunteers do not always know other volunteers, and they feel varying levels of connection to the organisation as a whole. Because of the variability of connections between the people we recruited for the project, it meant we were also developing a community specific to the project. The process of co-production itself pulled everyone together into this new community specifically for Care-full Co-production, and also included people who were supporters of the project. The project newsletter was mentioned in the previous section, which was part of maintaining the project community, and the relationships in the project are unpacked in more detail in Arm 4: Prioritising Relationships, p. 189. Relationships, empathy and care are important aspects of co-production (Haverkamp, 2021), for building the project community and for encouraging the continued involvement of contributors. Care-full Co-production operated in a way that encouraged contributors to give as much or as little time and energy to the project as worked for them. In some ways it could be expected that people would consistently stop being involved in the project until we were left with just a small group of contributors. Instead what we saw was people dipping in and out as suited them, some came to a Cuppa & Cake session and then we did not see them again until a celebration event at the end of our project.

This was likely because as design researchers Geert Brinkman and colleagues (2023) recommend, a shared identity and a sense of belonging had been created. Contributors were not just included in the project, they felt like they belonged and shared the ownership of the project — as shown in the following excerpt a contributor shared at a celebration event:

> "It has been a real honor to be both a participant and research assistant in this incredible research project centered around women's health. One of the things I've especially liked is the collaborative nature of this work. This project wasn't just about gathering information; it was about fostering a community where every voice mattered, and that's something truly special—it's been about connecting with each other, sharing stories, and working together to make a real impact in the field of both research design and women's health."

Value

Similarly to impact, it can be hard to measure the 'value' of co-produced research so we need to expand our ideas of what research value is. We can look at the ways the people feel valued for their contribution to the project. When they feel like their contributions are included and important this can be a sign of the value of the research. Knowing that research into something that is important to them is being carried out can also be of immediate benefit to contributors well before any of the aimed for outcomes are achieved. A contributor shared with us:

> "I enjoyed the group very much! It was heartening speaking with women from different generations and seeing how much we have in common."

Heron and Reason (2008) explained that collaborative experiences can "validate an inquiry in quite basic and long-lasting ways, through living repercussions and ripples, even if there are no written or presentational outcomes of any kind" (p. 370). As part of increasing the value of the project to the contributors, we decentered academic outputs and individual ownership, and instead we focussed on collective ownership and unexpected or alternative outputs. This has meant that academic publications have been left to a later stage (although there have been a couple of conference proceedings) and instead we have prioritised outputs such as the newsletter, the Care-full Conversation cards, and creating an online presence for The Co-production Project and my PhD outputs. The value is also seen in achieving the anticipated aims and outputs — for Care-full Co-production this was the library of research questions, and through the development of new knowledges throughout the project.

Is co-production a methodology?

Across the literature co-production is referred to as a method (Bell & Pahl, 2018), a framework (McGill et al., 2022), a concept (Durose et al., 2022), an approach (Yokota et al., 2018) and a methodology (Verwoerd et al., 2022). As discussed in the Ocean: Context Review (p. 41) this combines with the variety of definitions and creates uncertainty about what is or isn't co-production. My attempts to map co-production against the various ways it has been or could be classified (as seen in Figure 63 and 64), has not made it any clearer. Design researcher Gjoko Muratovski (2022) describes methods as the tools (such as interviews, observations, user testing) and a methodology as the toolkit, or the explanation for choosing the specific tools. A methodology is the guiding principles for making decisions on which methods will best answer the research question.

Co-design, which is often considered a part of co-production, gets described as both a method and a philosophy by Moll et al. (2020). In this use, I would argue that co-production is the methodology. However, co-design also seems more like a methodology to me, as it can use different methods or tools such as workshops, interviews and other participatory activities. Soares and Kettley (2024) discuss giving co-production a foundation in a "relational ontology, moving away from methodological individualism to focus on the emergent relationships between roles and individuals, and the interactions between people and their environments" (pp. 10-11). Focussing on the relational not only fits with the key principle of co-production— to prioritise relationships — but also highlights an aspect of how new knowledge is constructed when applying co-production. Akama et al. (2019) claim that "co-designing is ontological and phenomenological" (p. 67) because of the way it explores social interactions and embodied experiences, and how people are together or apart. Co-production could be considered in a similar way, which also suggests co-production is more than a methodology.

Haverkamp (2021) argues that participatory methodologies generally run the risk of reinforcing positivist notions, where the knowledge generated is separate from its context, extractive, and aims to be objective and rational. To counter its colonial past, a critical approach to participatory methodologies is needed — where challenging power differentials and being reflexive are considered part of the methodology. Co-production makes its critical approach clear within the key principles, though intentional practice is still needed to ensure sharing power is considered rather than assumed to be inherent.

Cooperative inquiry, a participatory approach from the social sciences field, is described as having an extended epistemology. Heron and Reason (2008) explain this extended epistemology includes four different ways of knowing — "experiential, presentational, propositional and practical ways of knowing" (p. 366) — and it is through the alignment and combination of these that new knowledge is formed. They also state that this extended epistemology is not limited to cooperative inquiry. As highlighted in the discussion earlier this chapter, on the plurality of knowledges

Figure 63:
An attempt to untangle what co-production is.

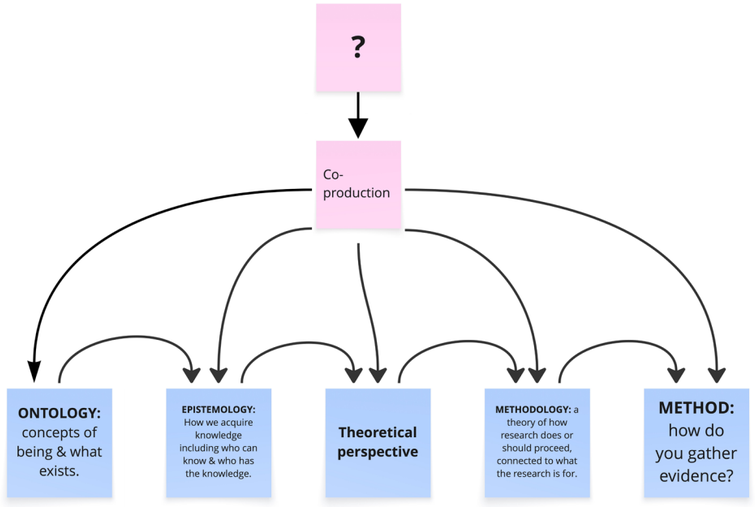


Figure 64:
A zoomed in view of attempting to untangle what co-production is.

which are involved in co-production and created with co-production, an affinity between this extended epistemology and co-production can be seen. Perhaps then, co-production is more easily classified as an epistemology rather than a methodology?

Summary and provocations

Co-productioning covers the ways of thinking about processes from a co-production perspective. Through embracing the 'messiness' of co-production, and focussing on principles and values-led practice, co-production is a robust approach to research. This approach requires valuing a plurality of knowledges and aims to avoid valuing some forms of knowledge more than others. Some different forms of knowledge include intellectual, embodied, experiential and cultural ways of knowing. Through the relational approaches of co-production, new knowledge is created, some specific to the topic being explored and some specific to the experience of being involved in a co-production project. Identifying the complexity of this knowledge, and recognising it can be found in the in-between spaces where interactions happen leads to noticing the co-produced knowledges.

Taking time to consider the potential barriers or challenges that may be faced when carrying out co-production, can help with identifying ways to minimise or overcome these. The barriers and challenges mentioned in this chapter — Pākehā Paralysis, Perfectionism Paralysis and Tokenism — call for researcher reflexivity, humility and mutual learning. Thinking about what success might look like — the impact of the research, the value, and how to maintain relationships during and beyond a project — is also helpful as part of planning and evaluating the process and outcomes.

The provocations that make up the Head are:

- How can co-production be a robust research approach?
- What knowledges can be co-produced?
- What barriers or challenges are there to co-producing?
- What might successful co-production look like?
- Is co-production a methodology?

Arm 1:
Building the Conditions

Who is initiating the project?

Who could and should be involved as co-reserchers?

What does involvement look like?

Who else is working in this space that you could connect with?

What constraints or restrictions does the project (or those involved) have?

What is the scope of the research context?

How to sit with all the questions?

Arm 1:
Building the Conditions

Spending time preparing for a project is always time well spent. When it comes to co-production, McKercher (2020) talks about having a period of time to 'build the conditions' for a project — a dedicated time for thinking about key questions that are helpful to start and continue the project well. This is also a good time for developing a strong foundation for the project team and project to build on. There are so many variables for each project and different elements to be considered in this stage that a detailed process to follow is not possible (Blomkamp, 2022), nor would it be desirable.

Building these conditions focusses on creating an environment that is safe for lived experience experts to contribute in a meaningful and open way (McKercher, 2020). This environment also needs to encourage those involved to be curious and open to mutual learning between all those involved (Gregory, 2003). Making knowledges available in different formats can help all involved to access knowledge, and develop a shared understanding within the group.

Spending time 'in the question marks' is necessary for figuring out how and when to get started. Depending on the nature of the project, this may take more or less time or be more or less complex to figure out. For Care-full Co-production, getting started was a conundrum, as to begin, we needed answers to these questions, but to answer these questions, we needed a community to engage with. In situations like this, the building the conditions phase may not be a distinct phase carried out prior to the beginning of the project; rather it may overlap with early parts of the project, and in some cases may even need revisiting throughout.

Some of the questions that need considering to build the conditions include: thinking about who is initiating the project; who and how people will be included in the project; who else is working in this field; what constraints there might be; and what the research context is. More detailed thoughts about why these questions are important and what considerations to include will be unpacked in the following sections. It's important to note that these questions are not hierarchical, and the order they are offered in is not intended to give preference to the earlier ones.

Who is initiating the project?

Considering who is initiating the project is a key part of developing the project structure. Identifying whether the project is being initiated by a community (with all the variations that the term community offers), a specific organisation, or an individual will help narrow this down. Who is initiating the project will also be impacted by how a project is being funded, as this generally comes with attached responsibility and power. Whether it is an individual, organisation or community initiating the project will likely influence the structure of the project team and who is involved in the project more broadly. It might be that there is a 'core project team', initially at least, who spend the time building the conditions and getting the project underway (McKercher, 2020). This core team may change during the project, developing or reshaping in response to future aspects of the project and input from 'co-researchers' as they come on board.

Prioritising relationships comes into all parts of co-production projects, so whatever the initiation of a project looks like, developing and building relationships will be part of it. If there is a core team, then spending time to get to know each other — including skills, expertise and work style preferences — is vital. Getting to know each other on a more personal level also helps build trust and shared values. Kidd and Edwards (2016) mentioned that their co-design project lacked spending time to get to know each other, and because of this, they missed out on identifying experience and expertise that team members had that could have been useful for the project. In Care-full Co-production, the initial core project team took time to complete the *'One Face, Many Facets'* exercise (explained in detail in Arm:8 Participatory Design Approaches p. 259). This tool is a structured way of getting to know each other, build whanaungatanga, and gently explore having health conversations with others. Not only did this process help develop relationships within the core project team, it also allowed us as a team to have vulnerable conversations, an experience that was useful when planning future engagements.

Part of developing those initial relationships within the core team may include considering the values that will underpin the project. While McKercher's (2023) co-production approach has four principles, there is room to have project-specific values as well. Clearly identifying these values can also help set expectations for ways of working together as well as give options for reducing tension or conflict. Depending on the structure of the project and how the project team is formed, it might be more appropriate to co-develop these values at a later stage when key people are involved. Identifying these values can help with answering the questions to be considered while building the conditions.

Who could and should be involved as ‘co-researchers’?

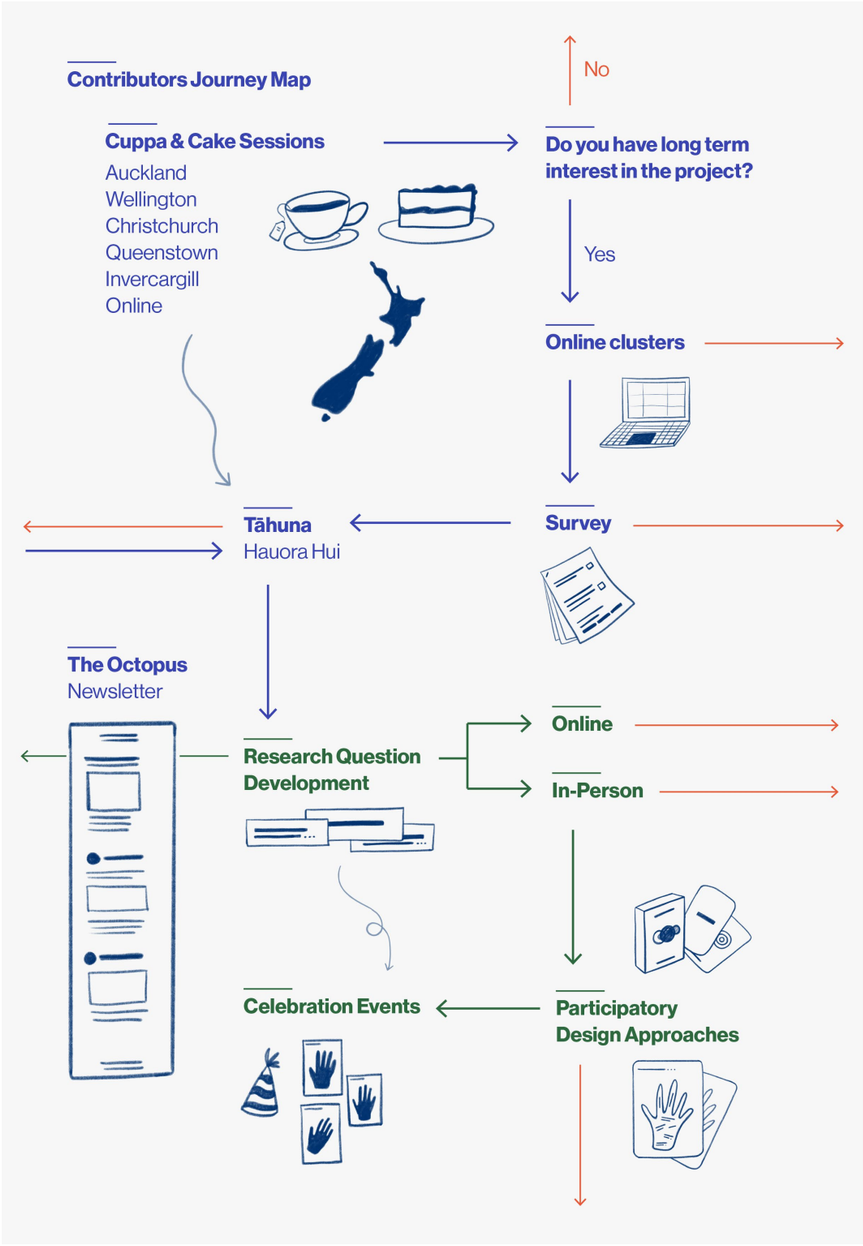
There can be a lot of possibilities when it comes to who could or should be involved in a co-production project, so it is worth spending time thinking about these possibilities. A good starting point is considering if the project is with an existing community, or if approaching an existing community is appropriate, or if you will be creating a community specific to this project. For Care-full Co-production, we utilised an existing community through Good Bitches Baking. However, the way their organisation works means that it’s common that volunteers don’t actually know each other, so we were almost developing a new community for the project as well. We also weren’t working with the leadership of Good Bitches Baking, so while they approved our recruitment callout, they didn’t remain involved in the project, nor did we use their communication channels or means of connection beyond recruitment, which added to the perception of developing a new community.

Within health research, many projects are focussed on specific conditions, so the people who could be included are those who have that particular diagnosis, but it may also include medical professionals in this area, and others who care for or support people with this diagnosis (Filipe et al., 2017). This approach is limited in the sense that access to a diagnosis is not equitable, so some people may be left out. McKercher (2020) recommends including a mix of people with lived experience expertise, professionals from the space and what they term ‘provocateurs’ (people without specific lived or professional expertise related to the project, who attend with curiosity). Care-full Co-production intentionally focussed on lived experience experts because of a long history of women not being listened to. Not including health professionals specifically helped create a space where women were more comfortable sharing their experiences with us. Women’s health is such an expansive topic that it would be hard to include all the relevant professionals. We revisited the question of when to bring health professionals into the project on multiple occasions throughout the project, each time deciding it wasn’t the right moment.

While considering who to include, it is also worth thinking about the reverse — who will be excluded by the choices made and language used? For example, when using the phrase ‘women’s health’, is this including or excluding trans and non-binary people? Consider whether this inclusion or exclusion is intentional and an acceptable option for the project. Language considerations will be discussed in more detail in Arm 6: Language, p. 229. This leads to further questions relevant to recruiting people for the project — are there specific demographic groups that may be intentionally invited (e.g. Māori, disabled, LGBTQIA+)? If so, do the initiators of the project have existing relationships to facilitate this? As co-production prioritises relationships, targeted recruitment needs careful consideration in order to offer genuine and respectful engagement in the project that avoids tokenism (McKercher, 2023).

Having an idea of who could be involved in the project as a ‘co-researcher’ will influence what involvement might look like, and at the same time, envisioning what involvement might look like (and any restrictions there are to that) can influence who might be invited to be involved.

Figure 65:
Contributors journey map.



What does involvement look like?

There are many different ways of being involved in a co-production project, and involvement may not even be the same for everyone in the same project (Figure 65). When thinking about how co-researchers might be involved in the project, my default position was to assume that co-researchers would join the initial project team, making a team of 10–15 people who would work together and be involved in all aspects for the duration of the project. This assumed that co-researchers' involvement needed to 'look' like traditional research and research teams. For Care-full Co-production, the reality was that our contributors dipped in and out of the project as they were available or interested. Allowing the contributors to shape what their involvement looked like gave them autonomy and created a more inclusive environment. Contributors in Care-full Co-production commented:

> "I work 4 days a week. I like the idea of a hui to really have time to talk, think and listen. I do not want any of these things, however, to be too regular."

> "I am genuinely interested in participating in whatever medium is available to me to support and offer whatever knowledge/ understanding I have. I work full time as a Guidance Counsellor so daytimes, whilst not impossible, may be slightly more difficult to negotiate."

A contributor's involvement in a project like this will not always be their main priority, especially if it's not part of their paid work. Differing priorities mean their involvement is likely to need to fit in around other commitments, so having multiple options for participating in the project makes it easier for people to contribute in a way that suits them:

> "The main barrier for me is simply time. Juggling parenting and work can keep me pretty solidly booked but I loved being part of the initial conversation and really believe in the design of the process so keen to participate when I can make dates work."

Having multiple options for involvement also challenges the way we value people's contributions. With a paid position, the value or remuneration is often tied not only to the tasks or expertise contributed but also to the time contributed. This focusses on measurable contributions and assumes everyone has the same time to offer. By encouraging people to be involved in ways that work for their individual circumstances, we move the focus to valuing their expertise with a more equitable approach. This allows for dynamic contributions throughout a project. As Csernák (2024) says "In cases where stakeholders can't engage fully, creating conditions for

partial involvement is valuable" (p. 15). Considering what 'good enough' involvement may look like, or what the 'minimum' needed from a co-researcher is, can help clarify what involvement may look like.

Who else is working in this space that you could connect with?

Co-production relies on prioritising relationships. However, we must be careful to avoid extractive relationships. When there are certain outcomes the project is aiming for, it can be tempting to only build the relationships needed to achieve these aims, which can result in one-sided relationships that are inauthentic. Approaching relationships with a long-term point of view rather than just the duration of the project can help, along with an attitude of reciprocity. Taking time to meet with others working in the same field, in an agenda-less way that focusses on getting to know one another rather than productivity, is valuable. This means there are no promises or commitments for any party, rather genuine connection building — preferably through shared kai (food) and cuppas.

Connecting with people in this way may or may not lead to involvement in the project; it may lead to other introductions and connections, or maybe nothing at all. These connections may, in time, lead to the role of 'critical friends' — people who have relevant knowledge and experience who are able to offer critique on proposed project steps and offer alternative viewpoints or considerations, or help talk through conundrums. The conversations and relationships can often be useful for helping identify blind spots or unconsidered aspects, due to their external but adjacent position. One critical friend commented:

> "It was so lovely to come together in the way we did and we appreciated your careful thought around it. This was the first time our team had come together to share with others what our kaupapa is about. It was great for us to begin this and build comfort in telling our story and sharing who we are." (S. Knox, project communication, 19/06/22)

The impact of taking time to have a coffee with someone is often not measured in Western research approaches but is more common in indigenous methodologies (Haines, 2022; van Schravendijk-Goodman, 2017). The conversations and connections these lead to can become vital to the progress of a project — often when you least expect it.

What constraints or restrictions does the project (or those involved) have?

Identifying any constraints or restrictions that the project and those involved face is useful for building the conditions to ensure these are factored into decision-making. Some of these could be conditions attached to the project funding — though funding isn't always granted prior to the initiation of the project. Ideally, co-researchers will be involved from the beginning, including the co-production of research questions and proposals; however, it can be difficult to get funding for this part of the process (Bell & Pahl, 2018). It can also take multiple applications before funding is granted, so asking communities and co-researchers to contribute time, energy and expertise without providing resources and support may be too much to expect (this will differ depending on how the project is being initiated).

Co-production can require more resources than other approaches to research, as health researchers Albine Moser and Irene Korstjens (2022) explain, so having the budget necessary to carry out co-production well and provide support for co-researchers to be able to participate when it's not their job (e.g. transport options as well as remuneration) can be a challenge. With this can come timeline constraints, as funding cycles and expectations can often be shorter than what is ideal for co-production projects, which often need more time and to go at a slower pace to build the conditions for good research and to prioritise relationships. There may also be restrictions on how funding is used, such as what koha or remuneration can be given to co-researchers to value their contributions (this is discussed further in the String Bag section, p. 283).

Other constraints may relate to the people in the project and any capacity challenges they may have. These could include disabilities, neurodivergence, chronic health conditions or employment restrictions. Some of these may be predictable, or at specified times — such as the due dates of different milestones throughout my PhD — while others may be dynamic and therefore different at any given time. There are also the unknown constraints, such as team members getting sick or changing employment. While it can be hard to plan for these, thinking about how the project might handle different challenges can help prepare for them, and practices such as good record keeping or 'continuous handovers' can minimise any disruptions. Organisational design consultant Emily Bazalgette (2023) describes continuous handovers as a practice where all team members have an overview of where the project is at and what tasks need doing, so anyone can step in for someone else if a team member becomes unexpectedly unavailable, and focusses on balancing the team's capacity as a whole rather than individuals becoming overloaded to cover for others.

While these constraints add another layer of detail management to the project, they can also provide a frame for containing the project so it doesn't become

unmanageable. Consideration for these during the building the conditions phase helps ensure the project is set up for success, and while all eventualities can not be planned for, the mitigations already thought about can be adjusted and altered to fit any new constraints that arise during the project.

What is the scope of the research context?

Specifying the context that the co-production project is taking place within is an important part of defining the question the project is exploring. Locating the project in its topic field as well as geographical location can help with creating a project that is achievable and manageable. While the geographical location may be place-based, it may also be at a national or global level, or alternatively it might be organisation or industry-specific instead (Norström et al., 2020). For example, health research is often located within the health care system itself, with participants recruited from hospitals and medical centres. We intentionally located Care-full Co-production outside of the health system. We did this because we understood that this would welcome a broader group of people into the project. People who may not currently engage with the health care system have valuable lived experiences that may differ from those within the health care system. By locating the project outside of this system, we aimed to make the project more inclusive. As the core project team are also not health professionals, we avoided reinforcing or recreating the power asymmetries that social scientists Felicity Goodyear-Smith and Stephen Buetow (2001) write are often seen between health professionals and patients. Clarifying the context can highlight the need for constraining the size of the project scope, and can go some way towards answering the questions that lead to deciding how to get started.

How to sit with all the questions?

Co-production in general, but especially while building the conditions for a co-production project, requires sitting with a lot of unanswered questions. For me, as someone who prefers having a plan to follow and clear signs that I'm 'doing things right', the concept of holding ideas and plans for the project lightly was something that required practice throughout the project. It can be easy to become overwhelmed by all the questions and unknowns in such a project, especially when implementing the principles of co-production and ensuring we're sharing power with the contributors. What involvement looks like in a project will influence how much of the project can be planned in advance. Because contributors could dip in and out of Care-full Co-production, we were not able to have a plan for the whole project to start with. Instead, we settled on a step-wise approach, making enough decisions to keep the momentum going, but not having things set in stone so we could alter the plan in response to contributors' input.

Co-production also requires finding ways to be comfortable with discomfort — or at least less uncomfortable with discomfort. Horst (2013) set out to use creative installations to encourage dialogue with the community about research by facilitating people to interact with the installations. They shared their realisation that feelings of discomfort were a signal that there was something for them to learn about their practice at that moment. We found for Care-full Co-production the opposite was true — when things felt comfortable, we often needed to pause and reflect on the decisions or plans being made. Frequently, this feeling of comfort was because we had corralled the project into a familiar shape (something similar to more traditional research projects), which wasn't always the right approach for this project. Another distinct experience of discomfort was the meetings we had that were not focussed on productivity or achieving specific outcomes — e.g. meetings focussed on whanaungatanga and developing relationships. As feminist researchers Kye Askins and Matej Blazek (2016) write, this discomfort can come from the contrast with our neoliberal world, which values productivity. As one of the core project team has stated:

> "It's interesting to watch how easy it is for a group to want to have a conclusion and/or a clear next step to conclude a meeting on — even though the purpose of the gathering was connection not necessarily progress or productivity."

Considering these questions leads to more questions rather than answers, and it can be a good idea to collate all the questions together — a 'kete of questions' as it were — to come back to as other decisions are made.

Summary and provocations

Co-production is innately variable, and every project will be different. Because of this, the questions provided here are not an exhaustive list of considerations to build the conditions for a project, but rather a set of explorative and provoking questions. It should be reiterated that these questions may not necessarily have answers, and delaying the beginning of a project in order to answer these questions is not required. Sometimes these questions will need repeated consideration throughout the project, and this phase of 'building the conditions' may overlap in an undefined way with the beginning of the project.

While it has been argued that the flexibility of co-production may reduce its robustness and quality, it is often this adaptability that allows for building the conditions needed for quality co-production to be carried out (Verwoerd et al., 2022), particularly when reflexive and iterative approaches are incorporated. Dedicating time to think about the people who will be in the project, their possible needs and how and where they will be involved, really sets the foundation for a successful

project. This phase often takes more time than expected, and the slowness can feel uncomfortable in contrast to how we may generally operate, but the benefits of this phase will ripple through the rest of the project.

The provocations that make up this arm are:

- Who is initiating the project?
- Who could and should be involved as co-researchers?
- What does involvement look like?
- Who else is working in this space that you could connect with?
- What constraints or restrictions does the project (or those involved) have?
- What is the scope of the research context?
- How to sit with all the questions?

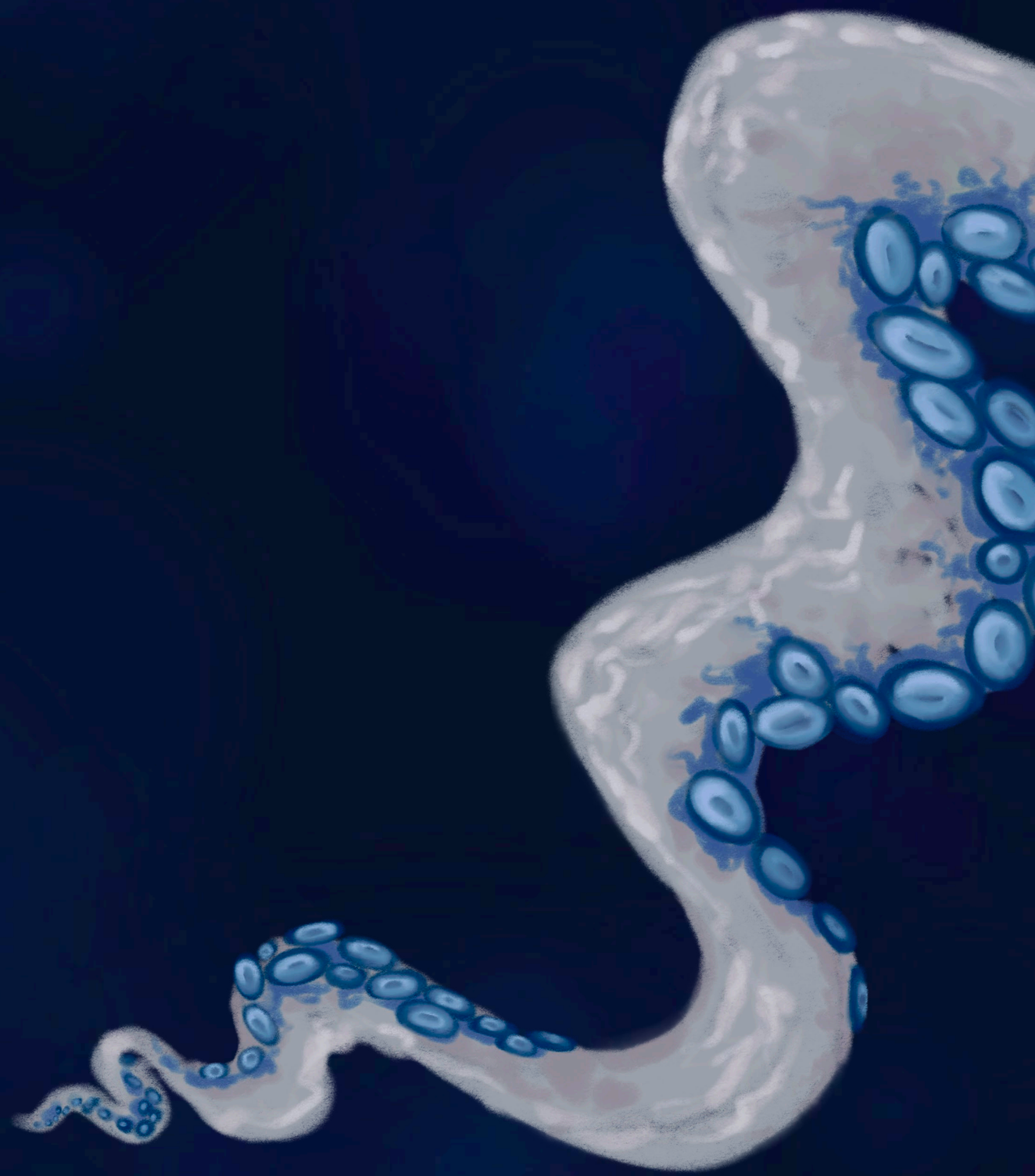
Arm 2:
Care

How might we embed an ethics of care in co-production projects?

What might a practice of care look like?

How and why is safety an important aspect of care?

What might researcher care look like and why is it needed?



Arm 2: Care

Care is multifaceted and includes overt physical acts, emotional responses and foundational principles (MAIA, 2024). Safer and brave space designer, Lana Jelenjev (MAIA, 2024) defines care as "a deep concern and tending of the self, us, the others and the bigger field. It can strengthen relationships, promote systemic sustainability, and lobby for just practices and policies." Care, therefore, can be interwoven through all aspects of a project. Throughout my PhD, care has been a key consideration, guiding decisions and the actions taken.

Political scientist Joan Tronto (1998) was one of the first to openly discuss care and developed the concept of an 'ethics of care'. She states care is frequently considered a personal matter, something that is kept in our private worlds rather than openly acknowledged in our public spaces, including employment places and research practices. This separation between public and private aspects of our lives is partly why acts of care can be invisible or less discussed. Care has also been historically considered women's work, and as a result, it has often been viewed as menial and undervalued by society (Tronto, 1998).

Berenice Fisher and Joan Tronto (1990) define care as:

> a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web. (p. 40)

Care is also considered to be made up of two parts: a thoughtful concern as well as the actions taken in response to these cognitions. Tronto (1998) suggests there are four phases of caring that form a reflective cycle of 'good care' — these are: (1) caring about, (2) caring for, (3) caregiving, and (4) care receiving. It is unlikely that this cycle will happen perfectly in this order, which suggests we may instead need to consider what 'good enough' care might be. Askins and Blazek (2016) also suggest different types of care, with 'caring about' being more about our thoughts, and 'caring for' covering our actions. They also argue these are individually focussed so suggest a more communal and interdependent approach of 'caring with'. Toombs

et al. (2017) argue that empathetic relationships between those involved in research can't be achieved without interdependence, and that exploring care in practice helps make these relationship aspects more visible. A critique of care as a concept is that it is often limited by only focussing on the binary of carer and cared-for; instead, critical ethnographer Barbara Korth (2003) suggests we would benefit from broadening our exploration of care. Social scientist Katharina Block (2024) describes participatory research as a "situated process of caring-with" (p. 14) where knowledge is produced *with* others in order to make sense of others. They say "The point is not to wave the banner of this caring-with as an ideal, but to implement it in practice" (p. 14). Regarding care as an action as well as a thought process is key to adopting a care praxis.

While care is a positive element in projects, we need to be mindful that it is not creating or reinforcing power asymmetries between the 'carer' and the 'cared' (Askins & Blazek, 2016). Often, the people doing the caring have something — such as knowledge or resources — that those receiving care lack or have less of, which can contribute to these power differentials (Tronto, 1998) and create tension within projects and relationships.

Rather than judging care as 'women's work' or feminine, feminist researcher Carol Gilligan (2014) states we could instead embrace a feminist 'ethics of care', an approach that aims to make equitable decisions about acts of care that enable better research projects. Considering how care is made up of thoughts and actions, we can think of it as 'care as praxis' (Askins & Blazek, 2016; Tronto, 1998). It is this care as praxis that is important to co-production, a thread that weaves quietly and gently throughout the project, a part of how the four principles are enacted. By making some of these acts of care visible, I highlight how essential care is for carrying out co-production projects for all involved.

How might we embed an ethics of care in co-production projects?

For co-production projects, embedding an ethics of care is necessary for creating a project where people are safe, valued and heard. An ethics of care is what guides our decisions about who receives care and what acts of care are facilitated, while also considering the impacts of a lack of care (Gilligan, 2014). This ethics of care highlights how valuable care is, while also recognising that the practice of care is complex (Tronto, 1998). Embedding an ethics of care into a project such as co-produced research is an iterative process requiring reflective thinking, considered resource allocation and embracing multiple forms of measuring value and impact.

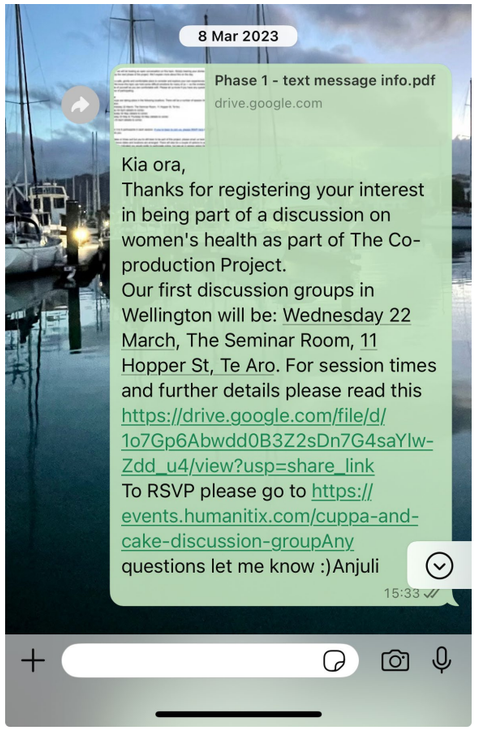
One of the core principles of co-production is valuing lived experience expertise and legitimising it as a valid form of knowledge. Providing support for experts of lived experience to be included in the project, such as helping with transportation or child care logistics and expenses, or ensuring accessibility needs are covered, and removing any burdens participating might add, are ways of demonstrating that lived experiences are valued. It also requires moving away from more traditional methods of valuing contributions, such as quantifying contributions based on hours spent participating, to include people's embodied knowledge and labour (Bell & Pahl, 2018). If we only value people's contributions based on the time involved, we privilege

people who have more capacity and fewer constraints or challenges, which could result in missing out on learning from others with different lived experiences. For example, someone dealing with an energy-limiting health condition may only be able to contribute five minutes, and then only in certain circumstances, but the knowledge they have to offer in those five minutes is no less valuable than that of someone who can contribute five hours to the project. Accepting people's contributions as valuable, whatever they look like, without requiring everyone to contribute equally, or to give a 'specific number of contributions', is an act of care. Care is a way of demonstrating that people's contributions are valued (Askins & Blazek, 2016; Puāwai Collective, 2019).

In the Care-Full Co-production, contributors were given a koha to recognise and value their contributions to the project. We decided on the amount of $100 per session, as this felt significant enough to demonstrate the value of contributions and be a meaningful amount for the contributors.

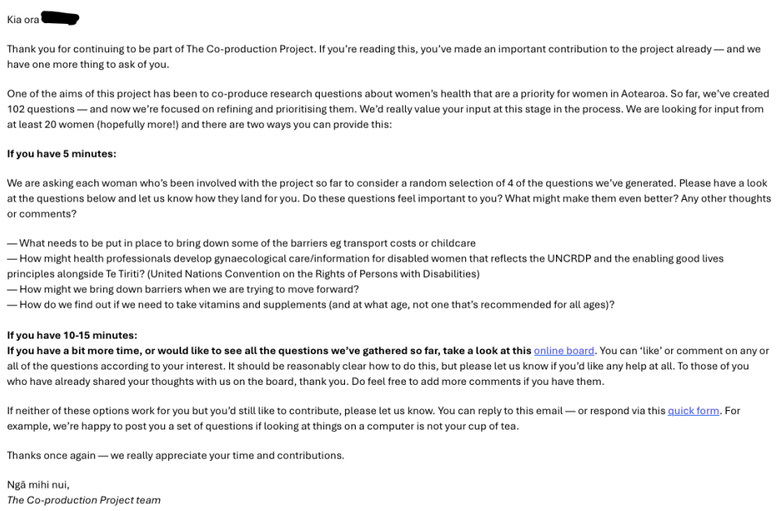
Embedding an ethics of care into a project is often time-consuming, as well as energy and resource intense. It can require more communication as well as different communication options to make it easier for people to participate. For example, during recruitment, we offered options of email, WhatsApp or text messaging, which required slightly different processes for providing all the information that we needed to share (See Figure 66).

Figure 66:
A screenshot of the WhatsApp message that was sent during recruitment.



Later on in the project, we realised that to get responses from more contributors, we needed to send out individual emails with specific tasks, rather than using the project newsletter to gather interactions. It often also required sending emails multiple times to account for how easy it is to miss emails in full and busy inboxes. Another example of offering communication and input options was gathering responses to the research questions that had been developed across a few sessions (Figure 67). A combination of emails and a Padlet board (full details in Arm 8: Participatory Design Approaches, p. 259) was used to give contributors options for providing feedback on the questions.

Figure 67:
The email we sent giving different options of interacting with the co-produced research questions. Full size version is in Appendix 8, p. 373.



Kia ora [redacted]

Thank you for continuing to be part of The Co-production Project. If you're reading this, you've made an important contribution to the project already — and we have one more thing to ask of you.

One of the aims of this project has been to co-produce research questions about women's health that are a priority for women in Aotearoa. So far, we've created 102 questions — and now we're focused on refining and prioritising them. We'd really value your input at this stage in the process. We are looking for input from at least 20 women (hopefully more!) and there are two ways you can provide this:

If you have 5 minutes:

We are asking each woman who's been involved with the project so far to consider a random selection of 4 of the questions we've generated. Please have a look at the questions below and let us know how they land for you. Do these questions feel important to you? What might make them even better? Any other thoughts or comments?

— What needs to be put in place to bring down some of the barriers eg transport costs or childcare
— How might health professionals develop gynaecological care/information for disabled women that reflects the UNCRDP and the enabling good lives principles alongside Te Tiriti? (United Nations Convention on the Rights of Persons with Disabilities)
— How might we bring down barriers when we are trying to move forward?
— How do we find out if we need to take vitamins and supplements (and at what age, not one that's recommended for all ages)?

If you have 10-15 minutes:

If you have a bit more time, or would like to see all the questions we've gathered so far, take a look at this online board. You can 'like' or comment on any or all of the questions according to your interest. It should be reasonably clear how to do this, but please let us know if you'd like any help at all. To those of you who have already shared your thoughts with us on the board, thank you. Do feel free to add more comments if you have them.

If neither of these options work for you but you'd still like to contribute, please let us know. You can reply to this email — or respond via this quick form. For example, we're happy to post you a set of questions if looking at things on a computer is not your cup of tea.

Thanks once again — we really appreciate your time and contributions.

Ngā mihi nui,
The Co-production Project team

This got a much better response, demonstrating the need and value of simpler options and clearer requests. Because these processes require more energy and mental labour, considering who takes these tasks on is vital — this is something that could be considered during the 'building the conditions' phase when considering the capacity of the project team.

Decision-making throughout a project is also underpinned by the ethics of care. Choosing courses of action that demonstrate contributors have been listened to and their ideas included demonstrates this. Reducing burdens and responsibility for those who have (potentially) less power and resources in a project is also important. As the core project team, we had a responsibility to keep the momentum of the project going — this was not the contributor's responsibility. Which is not to say contributors had no responsibilities, rather theirs were different and included attending conversations and sharing their thoughts with us.

An ethics of care is also embedded in a project through the acts of care included, which form a care praxis. Examples of these and other aspects of care are unpacked more throughout the rest of this chapter.

What might a practice of care look like?

Care is often talked about as a personal attribute, leading to the assumption that some people are naturally better at it than others (e.g. women) and therefore it comes easily to them (Place, 2023). Instead, care is actually a learned skill that can be developed through practice, and by being overt with care acts, and talking about how to embed care in projects, we can undo or minimise the default expectations about who will carry out these acts of care. Throughout Care-full Co-production, our team has spent many hours considering acts of care we could include through being inclusive, paying attention to hospitality details, as well as considering how these transfer to online spaces and interactions. The following subsections describe some of the ways we practised care throughout.

Inclusivity

Creating a project environment that is inclusive is often expected and aimed for. However, inclusivity is complex, multi-layered and not always easy to achieve. Inclusivity can mean anything from bringing together relevant people or organisations (Clarke et al., 2019) to making access and resources available to marginalised or vulnerable people (Place, 2023). Inclusivity is often simplified to focussing on meeting people's accessibility needs; however, accessibility does not necessarily equal inclusion (Acton et al., 2019; Clarke et al., 2019). Including people in a project is more than just making sure a person or group has been invited, but is also about making sure their needs are met throughout the project in a way that allows them to participate fully. It is easy to assume that if a space or project is inclusive, then that will be a comfortable experience for those involved. However, as arts-based health researchers Louise Phillips, Lisbeth Frølunde and Maria Bee Strynø-Christensen (2021) suggest, inclusion is not inherently warm, welcoming or even necessarily caring — instead, aiming to create a sense of belonging for all those involved is ideal. Creating a sense of belonging would mean people not only access and be included in an experience, space or project, but can also feel like they belong in the group involved (Brinkman et al., 2023).

Care through inclusion

Ways of being inclusive can include: meeting people's physical requirements (e.g. mobility needs and seating options); caring for their sensory needs (e.g. reduced sounds and volume, lighting changes, removing scents, or providing fidget toys); offering to use a person's preferred communication methods; reducing risk of infectious disease spread; catering for dietary requirements and other options that help people to fully participate (not just attend) in the activities that make up a project. Accommodating people's needs requires attention to detail and spending extra time considering what and how to provide these. But the payoff for this, designers Ellen Lupton and colleagues (2021) explain, is that not only are we able to have more diversity of people involved in a project, but often these accommodations make it easier for everyone to participate and contribute fully.

A challenge when aiming to create an inclusive environment is finding out what individuals' needs are. Asking people what they need (e.g. in an invitation), even if including suggestions, might not always be enough for someone to be comfortable sharing their needs. In requesting different options, people may feel required to share more about themselves than they are ready to share (yet, or at all), so they may end up avoiding being involved rather than asking for what they need. Or they may engage, but without the additional support they need, resulting in a harder time or less positive experience. Unfortunately, this is an area where it is hard to know what has helped or not, as those whose needs have not been met and are not comfortable asking for what they need are less likely to share that this has happened. People's ability to receive care and kindness from others will impact how or if they access what they need to be supported in the project (Tronto, 1998).

Care through accessibility

Including offers and questions about accessibility needs in all planning communications (e.g., RSVP forms, invitations, reminder emails) can help demonstrate that inclusivity is a genuine aim rather than a tokenistic offer. Having different options available during project engagement, even if someone has not specifically requested them, can also show that inclusivity is an act of care embedded in the project. Examples we used in Care-full Co-production include the RSVP form we used for Cuppa & Cake sessions, where we asked not only for dietary requirements but also for their preferred beverages, along with asking what they needed to fully participate. We worded it in a way that suggested everyone would have specific needs, rather than suggesting it was unusual to ask for anything extra. During conversations, we also included options for people to doodle or take notes, including pictures to colour in in the zine we provided them, as a way to acknowledge that people concentrate and process in different ways.

Meeting people's needs often requires prioritising, depending on what resources are available, which may result in some needs not being accommodated. It often requires balancing the needs of the core project team members with the needs of contributors — both are valid, but they may contradict, which can be a dilemma. Often, in order to facilitate best or 'good enough' participation, contributors' needs will require prioritising — these may not be the easiest to fulfil, and may require compromising. An example of this is holding conversation sessions in the evening when more people are available, even though this time is not the facilitator's most energetic time.

The ways in which we can be inclusive are infinite, and it is unlikely we are going to always provide everything that is needed. However, if we think of inclusivity as a practice, and keep practising through acts of care, we will demonstrate an attitude and atmosphere of inclusivity even when we don't get it perfect.

Hospitality

Hospitality is often made up of small acts of care and can be vital for getting people's full participation (McKercher, 2020). Care acts are often taken for granted or overlooked, and this lack of attention can lead to undervaluing care (Place, 2023). Instead, there is lots to be learnt by highlighting the different acts of care included in hospitality, whether it's the choice of cake provided or where an event or conversation is held. Tongan social work educator Tracie Mafile'o (2019) suggests that through looking at these different forms of care, we can recognise the sensory and emotional layers of knowledge sharing and creation which are involved in co-production.

Care in hosting

By paying attention to the details, we can see the acts of care that are involved in hosting and facilitating interactions, whether these are project planning meetings or research engagement sessions. Disability and theatre researcher, Ash McAskill described their experience of hosting at a conference they were involved in:

> What emerged in my feeling of failure was the ways my colleagues began to share my hosting duties. Hosts became guests, and guests became hosts. There was a fluidity of trying to ensure that our meeting was hospitable for all of us. We were generous with each other. Small actions such as gentle check-ins were a regular thing with each other. There was conscious attention paid to sharing labours. Ultimately, the working group became a site of collectively hosting — something which some of us later called 'careformances.' (Acton et al., 2019, p. 52)

They describe careformances as the actions that make up a practice of care, keeping in mind the interactive and collaborative nature of care (Acton et al., 2019). These acts can look like the small ways of welcoming people into a space — the kind words, helping them find things such as toilets and where to sit, and making sure they have refreshments.

Showing care through food and drinks changes the dynamics of a meeting, and therefore also influences the relationships being developed and maintained through that interaction (Light & Akama, 2014; Perkins et al., 2024). Socio-cultural anthropologist Harry West (2021), explains food can be comfort (unsurprising, culturally relevant, easily consumed), it can also be a celebration or create a feeling of specialness (e.g. treats people don't normally consume because of cost, or only had at special occasions) — but careless choices can have people feeling excluded or uncomfortable (e.g. no vegetarian food, or different food to what someone is used to).

The times when food is provided influence people's experiences — is food provided at all gatherings, or only certain ones? Is it generous or tokenistic? Food choices may seem such a small part of a project, often made quickly in passing, but a bit of extra time and thought can make a big impact. For our engagement sessions, we wanted our contributors to feel special and cared for — most of them bake for others as a way of spreading kindness, so this was an opportunity for us to give them that experience. We chose cakes (see Figure 68) and other snacks that had an element of decadence (though not so decadent they'd be off-putting or difficult to eat) rather than standard catering options that have a very same-same feel about them.

Figure 68: A decadent cake platter for one of our Cuppa & Cake sessions.

Providing for different dietary requirements, especially ones more likely to be requested (even if we hadn't collected people's preferences), often resulted in more people being catered for. For example, ensuring there was vegetarian food at a dinner we provided in Tāhuna Queenstown resulted in a contributor having a nice meal when they were expecting to not have anything suitable. Sometimes, though, in spite of good intentions, the food that turns up is not quite what was envisioned when we ordered it — the reflections from core project team members, in Figure 69, show we weren't happy with the food for our Christchurch Celebration Event.

Figure 69: Team reflections on the Christchurch Celebration Event (November 2024).

Care in venues

Selecting venues for hosting conversations or engagement sessions is another process that benefits from careful consideration. There are multiple aspects of venues that influence the atmosphere they create or not — it pays to have a clear idea of what is being aimed for before deciding on a venue. Bell and Pahl (2018) write:

> Accessible and comfortable space is clearly key, and we encourage reflection on the politics of location: university spaces may be intimidating or unwelcoming for some co-producers; public spaces will be inappropriate if sensitive information is to be discussed; and many communities are seeing communal spaces closed down or sold off as part of neoliberalism's assault on public services. (p. 111)

Schools, universities and churches can reinforce power asymmetries, but may also be attached to negative memories, potentially leading to people not agreeing to participate. They may also give the impression of expectations regarding who is wanted in the project. One of our contributors said *"I have had no education beyond high school and no experience of research methods.....I would be happy to be involved in the ongoing project if you think I have anything to offer"*. If we'd hosted our sessions in a school or university, they may not have turned up on the day. Other bookable meeting spaces are often part of hotels or conference centres; these can be intimidating and often lack warmth and intimacy, generally having a very 'businessy' feel to them — appropriate in some situations, but not the right atmosphere for our project. Venues such as cafes or community centres, sometimes referred to as 'third places', can often be supportive for initiating informal conversations (Light & Akama, 2014). A private room in a cafe that was located in an old house was one of the favourite venues for a Cuppa & Cake session as it had a comfortable atmosphere.

Along with other considerations like easy access (parking facilities, public transport availability, mobility options, etc), the time and day being considered, budgetary constraints and kitchen facilities, it can be hard to find suitable options, and sometimes compromises are needed.

Care as small details

These examples are just a few, but they demonstrate that acts of care are often small and easily overlooked or taken for granted. Often these acts are more noticed by their absence, as the contrast between what has and hasn't been included is easier to see. In one of our first Cuppa & Cake sessions, we had someone join us at the last minute. Because of this, they had not been through our RSVP process, which collected dietary requirements, and while we had tried to cover most options, their food option was the one we had not catered for. As they were the only person in a room of nine not able to eat anything, I felt it was more obvious we'd not met their needs. This led to a moment of discomfort for me since we were aiming to create a welcoming and inclusive space. However, it also demonstrated that care is not without conflict, as we are continuously having to make decisions and prioritise care acts (Tronto, 1998).

Online spaces

Online spaces for meetings and events have been around for a long time now, though their popularity has increased since the beginning of the pandemic, and people have been creative with different ways of creating online spaces for different purposes. Online options give us flexibility for bringing people together from different locations and time zones, while removing the burden of travel time and energy, and allowing for different individual needs that offline engagements may not. They can also be a great way to minimise health risks when this is a concern. However, while they are often convenient, they also pose many challenges, which can require different approaches than those in offline situations.

Care through atmosphere

It's harder to create a welcoming, supportive environment online where people feel connected to each other when everyone is physically in their own space. Our aim for our Cuppa & Cake sessions was to create a space for a gentle, informal conversation. As mentioned in the previous section, care through hospitality was an important aspect of creating a suitable environment for this. So to try and provide a similar feeling of care, people participating in online conversations were sent care packages in advance (though a few people had not received theirs in time). These packages included tea, coffee and hot chocolate sachets (to give options for individual preferences), chocolate, small pieces of cake, sticky notes, a couple of coloured pens (for writing and colouring in) and the project zine (Figure 70).

Figure 70:
Preparing the 'care packs' to be sent out for online Cuppa & Cake sessions.

While it might not have been the same feeling of care that was felt by people in our in-person sessions, the joy at receiving an unexpected package of sweet things was a feeling of care our online contributors experienced. A contributor said:

> "The correspondence leading up to it was great, and the little treat package was a really nice touch, thank you."

It was also more difficult to provide what felt like an appropriate level of support for people who may have become upset during difficult conversations — passing someone the tissues when in person can be a suitable sign of care without any words, however online this is not an option and words or facial expressions don't always have enough feedback to know if they were received the way they were intended.

Care with technical skills

Online events also require a certain level of technological comfort and skills, along with the basics of having a suitable internet connection and the required technology. It's easy to assume that in 2025 everyone has these resources, but this is not always the case. In the 2025 digital report, 96% of people in New Zealand had internet access (Kemp, 2025), although this doesn't consider whether they have the right technology or enough data access. We included options in our planning for supporting people with different skill levels — from teaching them how to turn off 'self-view' in Zoom (as an option for managing comfort and energy), having practice exercises to learn how to use Miro (an example is shown in Figure 71), and offering to scribe for them during different activities. We also created activities with different skill levels in mind, so contributors could choose the option they felt comfortable with (see Arm 8: Participatory Design Approaches, p. 259 for more details on these).

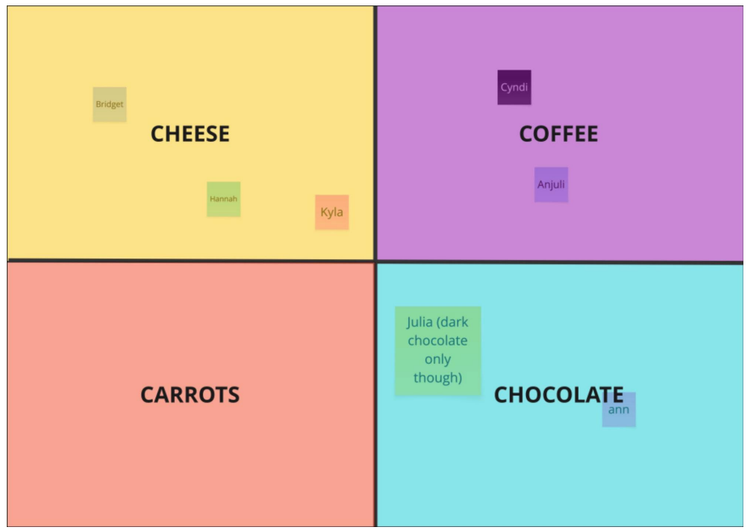


Figure 71:
Practice activity on Miro.

Care through online inclusivity

Because online options are a convenient way of including people who may have accessibility constraints, it can be easy to decide that by offering an online option, the project is inclusive. However, if the main experience or involvement you want people to have is the connectedness and collegiality often experienced through in-person events, then to actually be inclusive and accessible (and build a sense of belonging) will require more thought for how to achieve that. Having an in-person event and then just providing a Zoom link so those who are unable to attend can join from home is a bare minimum approach to inclusivity. As mentioned earlier, this option wouldn't necessarily feel like a great experience just because someone could now 'attend'. This isn't to say don't offer the online option, rather a prompt to consider if that's the best way to include a diversity of people.

Care through online accessibility

There are also many reasons why an online option is not more accessible for some — online options can use more energy for some people, particularly those with sensory needs. And interacting with others online can be uncomfortable and difficult, regardless of the size of the group, with social cues and conversation turn-taking harder to navigate. This can be particularly true for people with neurodivergence. As journalist Jenara Nerenberg (2021) writes, there has been an increase in women receiving adult diagnoses, so this was something we needed to consider in Care-full Co-production. It is harder to accommodate these needs in online spaces, but some options include encouraging people to turn off cameras when they need a break, scheduling regular breaks during a session and providing more details in advance

about what the online session will involve so they can be mentally prepared. As someone who finds online interactions difficult, considering ways to make them easier was something I thought carefully about while planning our online sessions, but for facilitators who find online spaces easy to operate in, it could be easy to skip over these accommodations.

How and why is safety an important aspect of care?

Research projects generally need some form of ethical approval, which includes looking at ways to minimise harm to anyone involved in the project. Additionally, projects (whether or not they are research projects) need to keep in mind how to create a sense of safety, especially when the project involves vulnerable conversations. Creating safe spaces is often talked about, but what does a safe space look like? Vivienne (2023) explains that defining or even describing a safe space is very difficult, as it varies widely across different contexts. When thinking about safe spaces, it covers physical, psychological, emotional and cultural safety.

Care in spaces

People deserve to feel safe, but what gives them that feeling is going to be different for everyone — and what makes someone feel unsafe is not always predictable. There is also a risk that, through expressing the 'right to feel safe', it will reinforce the status quo where those with more power and privilege (Vivienne, 2023) and who already feel the safest, continue to feel safe, rather than expanding the safety to include those who need it the most. Because safety is different for everyone, it actually isn't possible to guarantee a safe space. Vivienne (2023) recommends considering 'safe enough' spaces, or reframing it to consider creating 'brave spaces' — where people feel safe enough to be brave. They suggest that through opportunities to be brave, we can find ways to talk about difficult things, especially things people in a group might disagree on, in a way that we can learn and expand our understanding of others. While the aim is not to do harm, this approach recognises that sometimes, despite our best intentions, harm may occur and offers space to repair and reconnect. This is not an attempt to remove responsibility from facilitators or participants, but rather a way to respect individuals' autonomy and self-determination.

Care for each other

In group conversations, like our Cuppa & Cake sessions, it is harder than one-on-one conversations to create this safe enough space. We can protect the space in some ways by having content or trigger warnings but it is unlikely these will cover all possibilities, and it could result in people opting out of participating completely. Rather than a specific content warning, we used a more general framing for the Cuppa & Cake sessions, as shown in Figure 72.

We also asked everyone at the beginning of sessions to think about each other's safety, and how everyone could support each other:

> "I suppose the main thing is just to underline, it's possibly common sense but I'll say it anyway, is just to take care of each other's stories and things."

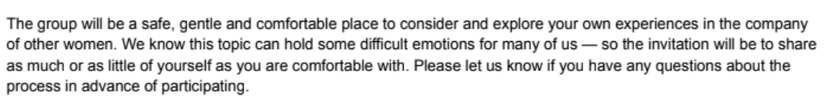

The group will be a safe, gentle and comfortable place to consider and explore your own experiences in the company of other women. We know this topic can hold some difficult emotions for many of us — so the invitation will be to share as much or as little of yourself as you are comfortable with. Please let us know if you have any questions about the process in advance of participating.

Figure 72: A paragraph from the invitation email describing the conversations that might be had.

This is an example of the different layers of care involved, from caring for and about each other to caring with each other (Askins & Blazek, 2016).

Care in conversations

Creating a safe enough space is important not only so people will attend but also so they will contribute and interact. This is quite necessary when hosting conversations about people's health experiences, which can be very personal and vulnerable. All our other acts of care (described earlier) contribute to a sense of safety, along with listening well and responding to people's requests. As mentioned previously, in response to contributor feedback, we reduced the number of people recruited for each session, as smaller groups felt safer and comfortable. Another action that contributed to a sense of safety was reciprocity in sharing — we not only listened to our contributors' experiences, but also shared our own. We also recognised people may need more support than we could offer if the conversations raised uncomfortable emotions, and provided contact details for other support options (in the zine everyone received, as well as in follow-up emails). Figure 73 shows checking in with contributors a few days after our conversations, to gain feedback on ways we could change things to increase safety, and so if anyone had had an unsafe or uncomfortable experience, we could respond and repair that connection.

This is important when considering relationships with a long-term focus, rather than just developing them to 'get what you need' for a project. Creating safe enough or brave spaces is an important element of embedding an ethic of care into a project, with all acts of care contributing to people's experience of safety.

Figure 73:
An example of a session follow up and check in.

Anjuli Muller
To: [redacted]
Thu 4/6/2023 3:49 PM

Kia ora [redacted]

It was so lovely to meet you at our discussion group this week. I just wanted to check in on how you're doing, if you have any other thoughts you want to share etc

I realise these conversations can sometimes raise tricky memories or feelings. If you need more support, you can always call Lifeline (0800 543 354) or text 1737.

We'd love any feedback you have on the focus group itself, and also the recruitment and lead up to the session (eginteractions and information provided).

I'm also keen to know whether you think might be interested in being involved in the ongoing project - not asking for any commitment, as I mentioned at the end of the focus group, we'll go through the recruitment process properly at a later date, but just looking for an indication of whether people are interested in this being part of this kind of research.

And again, massive thanks for your sharing, participation and time.
Ngā mihi
Anjuli

[redacted]
To: Anjuli Muller
Wed 4/12/2023 7:26 AM

You replied on Wed 4/12/2023 2:22 PM

Incredible work Anjuli - this is the first focus group I have been a part of and I was in awe of your attention to detail, compassion and vision. I'd love to be involved in whatever capacity you decide moving forward.

Ngā mihi,

What might researcher care look like and why is it needed?

Commonly, when considering researcher care, we are only looking at how we can take care of ourselves within the research experience. These considerations might include aspects of physical safety when meeting participants, so always meeting in public spaces and/or ensuring a colleague knows where you are and when you arrive or leave. It has slowly expanded to include considering emotional and psychological well-being from listening to the experiences participants share. McKercher (2020) comments that in the design field, this has not been addressed enough, and that more and more often design research projects expose designers to potentially traumatic stories, and we therefore need to consider how to handle this. In McKercher's *Modes of Care* card deck, social worker and designer Rachael Dietkus offers the prompt "how can we hold with care and not absorb or minimise others' pain?". This will be different in different contexts, so it is worth exploring possible answers during each project to develop what suits the people involved.

Care for self

Researcher care is a consideration required within ethics applications, and the approach we submitted can be seen in Figure 74.

Figure 74:
Our approach to researcher care laid out in an ethics application.

G 3.a Describe the strategies you will use to deal with the risk of harm to the researcher.*

As part of this project people may share stories of different health related experiences. Some of these may be distressing, especially in an accumulated way.

While the research team is experienced in research involving sensitive topics, we must continue to be mindful of the impacts this research can have. Researchers, working in twos will lead the focus groups and will debrief any issues arriving after each engagement. An additional member of the team — not directly involved in the engagements — will be available to support with debrief conversations if required. If further support is required, researchers will be assisted to access professional counselling.

The Toi Āria research team, who will assist in the project, are experienced in research involving topics which are highly sensitive to participants and conduct themselves professionally with high interpersonal empathy. In any event of feeling threat of harm (whether physical or psychological) in any research situation, Toi Āria researchers are aware that they may take reasonable and sensible steps to avoid harm, including withdrawing from research.

From the original conversations, to transcribing recordings, to analysing transcripts, there are lots of exposure opportunities to potentially emotional and heavy experiences, and it can be easy to underestimate the cumulative effect of processing these stories. While the available support we outlined in our ethics application was suitable, it relied on members of the team asking for it. It's not always easy to ask for care or support; even in a really supportive team, it can feel risky to bring our full emotions into a workplace or academia (Askins & Blazek, 2016). So it might be better to have processes that are more specifically about processing the emotional load of a project, but that also require opting out of (rather than in to) — so it becomes a practice, and so individuals don't need to request it themselves.

Care for other researchers

If a project is structured like Care-full Co-production was with a core project team, then caring for each other also needs consideration. Having a team that cares for each other well helps with the discomfort of the unknown that comes with projects like this, and does make it easier to access support as needed. Care was similarly shown through sharing baking at our team meetings. A core project team member reflecting on what they'd liked in a meeting said:

> "the biscuits! Someone taking time to bake and to make them vegan says the team cares."

We also realised after our first couple of Cuppa & Cake sessions some elements of care that were needed. It's easy to aim for efficiency, especially when travelling to events, and try to fit as much into the time available as possible. But this often leaves little room for rejuvenation, debriefing and meeting our individual needs, and it also increases the risk of stressful, unplanned events. We took to making sure there was lots of space around our engagement sessions, so that preparation was not rushed, we could reconnect and collect ourselves before the next session and be responsive with any changes that were needed. This also included our travel arrangements, often arriving the evening before, so we had plenty of time to prepare ourselves and the venue — particularly as we always needed to locate our cake supplier!

Slowing things down and having extra time, was especially important because of the energy limiting health condition I started dealing with just before we commenced our Cuppa & Cake sessions — this allowed my need for rest to be met, as well as allowing others in the core project team time for themselves, even if they ended up with more tasks because of my capacity limits. As mentioned we didn't expect our contributors to all be involved in the same way, or the same amount of time, and this also extended to our core project team — however it was easy to get caught up with standard measures of productivity and 'doing enough', that I frequently found it hard to accept my limitations, and to accept the team's help (as much as it was appreciated). Caring for the project and everyone else involved is much easier than caring for oneself, but if these considerations have been thought about while 'building the conditions', it makes it easier for everyone to manage the ebbs and flows of each other's capacity.

Receiving care

In participatory approaches, like co-production, there is also the care between the researchers (or core project team) and the contributors (participants or co-researchers), which, in the process of building relationships and sharing power, ideally becomes more reciprocal and less paternalistic (Toombs et al., 2017). Receiving care from contributors can be a vulnerable feeling, as Toombs et al. (2017) write, "it reframes the role of the participant from that of performing a service for the research project to engaging in a reciprocal relationship with the researcher as a fellow, interdependent being" (p. 47). However, in co-production we are aiming to work together, rather than bracketing off and keeping separate the 'researchers' knowledge and influence (Place, 2023). Receiving care from contributors can also increase how valued they feel, and reiterate that their involvement is a benefit to the project. Examples of contributors showing care to core project team members include:

> "I think anxiety concerns, mood, worries, the things that are there and they aren't seen, health things that have to manage every day, the long covid those that's actually really hard" (acknowledging my experience of long covid, which I had shared).

It does require thoughtful reflection-in-action, to ensure receiving care from the contributors does not unbalance the reciprocity — not only to ensure that the contributors aren't burdened with being expected to care for the researchers, but as healthcare researcher Paul Batalden (2018) notes, so it doesn't also constrain the conversations or potential in the project. In the process of sharing women's health experiences, I could have shared more about my feelings on motherhood and experiences of pregnancy loss; however, this could have risked other women feeling less comfortable sharing their thoughts out of fear of hurting me. These situations prioritised care for the project as a whole, rather than care for myself as an individual. If we're 'holding space' for conversations as the core project team we will intentionally be paying attention to the rest of the groups feelings and how to support them, but it's also likely that the contributors are doing this too, including noticing the core project team's emotions (Toombs et al., 2017) — particularly when we have asked everyone to care for each other in the session.

Summary and provocations

By making acts of care explicit and valuing care more openly, we make it easier for an ethics of care to be embedded in research. An ethics of care doesn't prescribe the ways care must be shown. Instead, care ethics influence decision making and considerations, resulting in more acts of care taking place throughout. An ethics of care also helps prioritise what gets care and at what expense, when it isn't possible to care for everything all the time — rather than aiming for perfection, we need to approach care as a practice that can be improved, and through that achieve 'good enough' care (Tronto, 1998).

It could be easy for care to become part of a transactional interaction, but by paying attention, care acts can remain reciprocal and equitable (MAIA, 2024). By highlighting and valuing care as essential to relationships (and therefore co-production projects), we can encourage care giving and care receiving to ebb and flow in response to individual and collective needs (Askins & Blazek, 2016). Embedding an ethics of care involves recognising all the time and places care shows up in projects — such as in safety, hospitality online and offline, and caring for each other — as well as recognising how contributors care in return.

Making care visible gives everyone the opportunity to carry out acts of care, rather than just assuming care comes naturally to some and the responsibility defaulting to them. Taking time to value these contributions, and to make them more visible and talked about, rather than letting them go unnoticed and taken for granted, is an act of care itself (Puāwai Collective, 2019).

The provocations that make up this arm are:

- How might we embed an ethics of care in co-production projects?
- What might a practice of care look like?
- How and why is safety an important aspect of care?
- What might researcher care look like and why is it needed?

Arm 3: Power

What power asymmetries exist in the different relationships in the project?

Who has what decision-making power?

Who is responsible for the project momentum?

How do power and responsibility interact?

What could sharing power look like in a specific project?

Arm 3: Power

Power is a dynamic concept that changes with the context and relationships that are involved. Design researcher Jessica Meharry (2024) explains that power can be seen from an individual perspective, through a person's agency, or as a structural aspect, where it is embedded in systems. Design has often been considered a neutral process without power differentials, based on an assumption that design approaches either remove the different dimensions that influence power asymmetries or inherently lack them (Mosleh & Larsen, 2021). Deliberate and overt consideration of ethics, biases and systemic issues is often missed, or even hidden, through this assumption of neutrality (Meharry, 2024). Researchers and practitioners are encouraged to embrace a reflexive approach (discussed further in Arm 7: Reflexivity & Reflectivity p. 243) to identify the power and privilege they have, or have not got, as well as considering what other people in the project may have. Taking a pluralistic view of how power is operating in a project helps identify potential changes that can be made (Meharry, 2024).

For community-engaged research, the partnership between universities and communities is often seen as a reciprocal transaction that assumes equality; however, this overlooks the importance of considering power differentials (Huaman & Mataira, 2019). Transdisciplinary researchers Turnhout and colleagues (2020) argue that participatory design is often assumed to offer an egalitarian approach; however, without intentionally addressing power differentials, these approaches can end up reinforcing the status quo. Information technology researcher Eevi Beck (2002) suggests that participatory design should focus on power as much as on participation. Not all forms of co-production have focussed on sharing power or disrupting power asymmetries. Co-production within the science and environmental sustainability fields tends to be implemented within the scientific positivist epistemology — which increases the risk of power imbalances being reinforced and political considerations being missed (Turnhout et al., 2020)

Social change designer George Aye introduced me to the term 'power asymmetries' as an alternative to 'power differentials', describing the asymmetry like a wedge where the people or community at the pointy end have less power than those at the wide end, and that the people in the middle have less than some and more than others (personal communication, 7/9/23). Using this term highlights

paying attention to who has more or less power in relation to others, and how that will differ depending where on the wedge you are. Power asymmetries often result in harm for those who have less power. Rarely is it intentional; however, lack of awareness and knowledge can mean people are complicit in systems of oppression (Vivienne, 2023). The following sections discuss how power and power asymmetries show up in co-production projects to build awareness and suggest opportunities for considering different ways of carrying out the project.

What power asymmetries exist in the different relationships in the project?

In co-production, where the key principles include sharing power and prioritising relationships, considering what relationships exist and what power differences might be in those relationships is essential. There will likely be numerous relationships, as well as changing relationships and power dynamics throughout the project, so this is something that needs to be an ongoing consideration (Milberg Muñiz et al., 2024). In research projects, there is an inherent power asymmetry between researchers and participants, which is also amplified by the power that academic institutes hold (Turnhout et al., 2020). Power asymmetries are entwined with the political, so when carrying out research with people and communities outside of academia, this can require gently navigating the power imbalances to disrupt rather than reinforce or replicate historical asymmetries (Haverkamp, 2021).

From the beginning of projects or relationship building, researchers need to consider ways that they can share power in order to reduce this imbalance. Some of the ways we worked to reduce the power asymmetry between the core project team and the rest of the people in the project were: taking the research into the community (e.g. venue choices); promoting the use of everyday language (see Arm 6: Language, p. 229, for further details); reciprocating with being vulnerable (see Arm 4: Prioritising Relationships, p. 189, for discussion of this); avoiding being extractive; and integrating participants feedback into the project's next steps. If co-production projects neglect to address power asymmetries, especially those that exist at the start, then there is the risk that those with less power will be silenced (Williams et al., 2020) — this is a form of harm, and contradicts co-production principles.

Power as a researcher

Along with power that comes with being a researcher, there is also power involved in the societal expectation to be 'professional'. Thinker-organiser Aysa Gray (2019) argues that the behaviours that make up professionalism are founded on white, privileged people's expectations and cultures. This can encompass aspects such as the clothing you wear, the way you speak, whether you eat with the other people in the project (e.g. contributors or participants), and how much personal information you share. Being 'professional' can result in being more distant from others, which

can be experienced by others as a bigger power differential. It can be tricky to find the balance to reduce the power asymmetry, while still maintaining reputations and not burdening contributors.

Power in the health system

For projects working in the health space, the relationships between health professionals and patients need to be considered, and how that may or may not fit within the project. Goodyear-Smith and Buetow (2001) share that, similar to researchers, health professionals' default position is having more power than the patient. Additionally, there is also the patient's past experience to consider. Women have frequently been unheard and dismissed by medical professionals (Cleghorn, 2021), leaving them feeling that they can not trust the health professionals or the health system, and maybe feeling unsafe. One of our contributors shared

> "I have felt not heard or ignored or like I don't know what I'm talking about or I'm stupid or something and that has been difficult because I don't think I'm particularly stupid."

For Care-full Co-production, we intentionally stayed outside of the health system to reduce this power asymmetry. As the priority was the lived experiences of women, it made sense to focus on listening to women rather than engaging specifically with health professionals. Health research frequently recruits from within the health system, or based on a specific diagnosis, which potentially ignores the power of the health system (and why some people may not engage with it) and also excludes people who haven't accessed a diagnosis, which risks reinforcing the inequities in the health system. Having the core project team of Care-full Co-production made up of design researchers, rather than health researchers or health professionals, helped us to reduce the power asymmetries from the beginning, and gave us a better foundation for building trust. During a Cuppa & Cake session, a contributor commented about sharing with the group:

> "I think the fact that we're all women, I guess, makes me feel a little more comfortable. And the fact that we're not in the medical profession."

Power between contributors

Other relationships that also exist within a co-production project are those between contributors themselves. In these relationships, it may be harder to identify any power asymmetries in advance, and these may change throughout the project. For Care-full Co-production, this was potentially different each time we had a conversation with a group of contributors, as we never had the exact same combination of people twice. While navigating how to share our power with

contributors, we also needed to facilitate interactions in a way that did not reinforce existing asymmetries or create any. Creating a safe or brave space (as discussed in Arm 2: Care, p. 167), spending time on introductions and whanaungatanga, and facilitating conversations in ways that encouraged equal opportunities to be heard, helped navigate the power asymmetries that existed between people in each group session. Sociologist Norbert Elias described power in these situations as a form of interdependency that is constantly being negotiated throughout people's interactions (Mosleh & Larsen, 2021). The following quote from one of the contributors shows this negotiation, as they point out the privilege that the women in the room hold, which others don't have:

> "So you know, we're all white women sitting here who have, you know, access to good health, money to do what we need to do. We don't have to think too hard. We're able to have choices — I tell you that's not a lot of people's reality. Yeah. And access and equality are not most people's privileges, so that's the reality too."

Power in academic spaces

Academic environments also have inherent power asymmetries, such as those found in the relationships between supervisors and students. Supervisors are in a position where they can help or hinder a student's progress — for example, through the processes that approve enrollment, sign off on ethics applications, or access resources. University processes made the split between staff/supervisor and students quite clear to start with, as my desk allocation was in a different building to the rest of the core project team. This differential was reduced partway into the project when reallocation of spaces occurred, and I had access to a desk with the team. The power dynamics in this relationship between supervisor and student can be influential at all stages of the PhD (Billo & Hiemstra, 2013). The pressure that comes from academic timelines and deadlines can be an additional layer of complexity to these power differentials.

When a PhD sits within a wider project (like mine), there are impacts of power to consider. Additional requirements and deadlines of the wider project (e.g., funding and reporting) are added to the mix of expectations that need to be met and managed. Balancing the requirements to produce a thesis with the requirements and values of the project (such as collaborative ownership and authorship) can require careful attention. Having the aim to share power and have a less hierarchical approach within the core project team led to collegial relationships and friendships, while also being supervisor and student. These nested relationships can (as discussed further in the next section) result in less clarity around who is responsible for decision-making, and in which circumstances.

Power in care

Embedding co-production with care practices also creates situations where some people are care-givers (they possess knowledge, resources, or abilities to share) and others are care-receivers, which can manifest as a power imbalance (Tronto, 1998). While care givers generally have something to share with care receivers, if it is always the same people or person giving care, it can become burdensome. Encouraging everyone to practice acts of care (within their capabilities) can encourage the dynamic nature of power, so the imbalance does not fall on the same people all the time. Observing how care is transitioning through the project could be a way to notice how power is balanced and shared within the project.

Who has what decision-making power?

To consider power and power imbalances in a project, querying who benefits from the project is important — rather than just assuming that participatory approaches such as co-design and co-production do actually share power (Vivienne, 2023). An element of this is identifying who has decision-making authority, and for what decisions, as well as who benefits from those decisions. Often, the decision-making authority goes hand in hand with financial control for a project — and if the project originates from within a university or similar institute, then this may be constrained by the university's systems and processes (see String Bag chapter, p. 283, for further discussion of this). To open up ways to reduce the power imbalances imposed by financial decision-making, researchers could consider whether it is possible within these systems to share financial reporting and any financial decisions with those involved in the project. If the systems prevent this from happening, then sharing those constraints with the people in the project can help minimise the impact of this imbalance.

Project team decision-making

Aiming to build a project team with a less hierarchical structure is a demonstration of the 'sharing power' principle of co-production. In our core project team, the less hierarchical nature was commented on, one member saying they liked:

> "The vibe in the team, the lack of competition and the focus and energy in the room" and another saying "I really felt comfortable in that meeting, even though I was mostly just listening and learning and didn't really have much input, I felt that it truly is a non hierarchical structure. Everyone is important."

However, a less hierarchical structure can also result in a lack of clarity about who is able to make decisions and when. In the project team's reflection process, there was the following comment:

> "Sometimes felt unclear as to who could/should be making decisions".

Kidd and Edwards (2016) reflected on their project exploring supported housing experiences and commented that a lack of clear leadership (partially because of distributed financial responsibilities across multiple people) hindered the project and nearly stalled it. Who can make decisions and when is likely to be something that will change throughout the project, and potentially more so when there is less clarity. It would be useful for the project team to have discussions about decision-making processes during the building the conditions phase. Communicating expectations about who will or can make decisions is important for maintaining the momentum of the project (discussed further in the next section), as waiting for decisions to be made can slow the project down unintentionally.

Sharing decision-making power

We often talk about 'empowering' people and communities, which can be seen as an admirable aim; however, the ability to empower is based on the existence of an inherent power asymmetry to begin with. Gender studies scholar Naila Kabeer (1999) writes "the notion of empowerment is that it is inescapably bound up with the condition of disempowerment and refers to the processes by which those who have been denied the ability to make choices acquire such an ability." (p. 437). Considering empowerment needs to include highlighting how people or communities have been denied choices or had options removed by the groups with more power. Identifying ways that everyone can make decisions throughout the design process can go some way to empowering, or returning choices to, all of those involved. We observed during Care-full Co-production that not everyone wants to have decision-making abilities within a project, because making decisions can feel like too much responsibility. Not taking on this responsibility could be seen as a choice, though, so accepting contributors opting out of making decisions can also be seen as empowering. This was seen in the conversation we had with contributors about how they wanted to be involved in the project, when one of the contributors said:

> "being given really clear invitations I can say yes or no to".

At the beginning, I envisioned that sharing the power to make decisions would look like more overt decision-making than agency to participate or not, but as the project progressed, these choices about how to participate were actually key decisions for contributors. It allowed them to increase or decrease their level of participation and contribution based on their interest and their availability — as the available options were based on contributors' thoughts and ideas, their participation was feedback on the decisions the core project team had made using their input.

Who is responsible for the project momentum?

The conundrum of getting started has been discussed elsewhere (see Arm 1: Building the Conditions, p. 141), and while we found a place to start, it felt like this conundrum also existed in building project momentum. The core project team had made the decisions required to get started, but then we needed to figure out the next step with the contributors, and so on. Only planning the next step at a time gave us the flexibility to change as needed, and made it easier for contributors to dip in and out, rather than having to commit to everything upfront and as yet unspecified. Because there were too many options for what the next step could be each time, there was always this additional confusion and uncertainty, which left everyone, us and the contributors, feeling more uncomfortable. This uncertainty was apparent in how the Contributor Clusters played out — while they were interesting, in some ways, they slowed the momentum of the project down and didn't as clearly move us closer towards the planned output (the library of research questions). As one contributor commented:

> "I think for me this research model it's gone too far the other way and there's such a lack of direction that it's really hard to get us started about something."

Through reflections and conversations with contributors and critical friends, we realised that in order not to burden the contributors, and because we had more time to dedicate to the project, the responsibility for the project momentum lay with us.

As Meharry (2024) says "Designers are architects of choice; they shape the possibility of choice available to others" (p. 11). Giving people more choice often equates to more agency. We shaped the choices available for each next step, based on what our contributors had told us either in the previous step or via requested feedback. There was always the proviso that if the choices available did not feel in alignment with the contributors, we could change them. When discussing ways of working together, a contributor shared this thinking:

> "So if it's going to be in that end of the spectrum, you need to meet more regularly so that you can get momentum going with people or you need to allow yourself the ability to put a few guiding principles out there to help people get into the swing of things because that's what we're used to and I totally get what you're trying to do and it's really cool but it's like bridging the gap, a little bit, to help people feel more comfortable and safe in the space to contribute, that's my thought."

'End of the spectrum' referred to this research being highly flexible and having less specified direction provided by the core project team. We were often shaping these choices as part of our engagement sessions with contributors — an example of reflection-in-action (Schön, 1983). This reiterated that the core project team needed to look after the project's momentum more. Sand et al. (2024) discussed the entanglement of power and embodied ethics, where ethical issues and our responses to them (that shape choices) can be experienced through our bodies and senses — for some this might be understood as following one's intuition or 'gut feeling'. Through shaping these choices, we shape the momentum of the project. However, who is responsible for maintaining project momentum may change with a different project structure.

What could sharing power look like in a specific project?

It can be easy to assume that 'sharing power' means an equal 50/50 split of power, and then, if this is not achieved, to assume the project has failed at being a co-production project. Alternatively, being unable to achieve this equal power can lead a project to be paralysed by perfectionism. While an equal split of power might be ideal, it also assumes that power balances are static. Instead, recognising that power is dynamic and that different people will experience power differently will allow for flexibility and fluidity throughout the project (Vivienne, 2023). The iterative approaches used in design methods can also enable power sharing as a dynamic process rather than a static one. Mosleh and Larsen (2021) explain that "Complex responsive processes of relating challenges the assumption that participation in a design or development process equalises power relations or enables consensus" (p. 466). They state that while we may have intentions for contributors to participate in a specific way, we cannot predict how individual contributions and social interactions will unfold or how they will impact power balances or imbalances.

In order to action these intentions, we might put policies or documented practices in place, but we need to be mindful that this does not always create change on its own. Author and feminist scholar Sara Ahmed (2024) notes that, in fact, sometimes the existence of these policies might actually result in maintaining or reinforcing the status quo. This reinforcement is more likely to happen if it is treated as something that is completed once, rather than being a practice that is embedded throughout the project.

Sharing power without burden

When we discussed wanting to share power with the contributors to the project, we realised that for some this felt burdensome — particularly when talking about what 'label' to use for their role (discussed further in Arm 6: Language, p. 229). We had expected them to like being called co-researchers. However, they felt that

this title and role held too much responsibility. This was one of those moments we knew we had to pause and reflect. By trying to share power with contributors in the same way as the core project team, we were stuck envisioning power sharing from a traditional research perspective. Instead, we needed to find a way to share power differently. Some of this can be seen with the core project team taking on the responsibility of the project's momentum. It was also demonstrated in the creation of more choices for contributors to be involved in the construction of the monthly newsletters — from recommending something to read or listen to, or sharing in their own words their experience of being in the project. While there was not a big uptake of this contribution option, having these choices easily available was an example of increased autonomy.

Sharing power through invitation

A clear example of sharing power during our Care-full Co-production project was receiving an invitation from a contributor to return and have a conversation with their community of wāhine Māori. This contributor is non-Māori themselves, but an important member of their local Māori community, convening events and building connections, as well as running a health and safety service. Responding to this invitation allowed us to continue building a relationship with this contributor while starting a kōrero with their wider community. Historically, research has often been done 'on' Māori communities, in an extractive way that reinforced discrimination and deficit narratives (Smith, 2021). Understandably, this has resulted in many Māori distrusting research, researchers and universities, and wary of the harm that can come from being researched. There have been changes to carrying out research so that it is now done 'with' Māori. Unfortunately, this sometimes ends up being tokenistic (regardless of how well-intentioned people are), especially when research is being initiated by non-Māori researchers. This can also be unintentionally enabled by the processes that approve research funding, as explained by Tara McAllister and colleagues (2025).

The New Zealand government introduced their Vision Mātauranga policy to increase Māori research and innovation by requiring funding applications to include details of relevance to Māori and demonstrate how Māori are involved in the research (Ministry of Business, Innovation & Employment, 2024). An evaluation of one of the biggest funds highlighted that this policy had little impact on the funding decisions (McAllister & Riva, 2023). Understanding this history, we were mindful when accepting the invitation that we wanted to create a positive experience that benefited those who contributed, and that the values and principles of co-production were upheld. We also did not want to let anyone down or promise things we could not deliver.

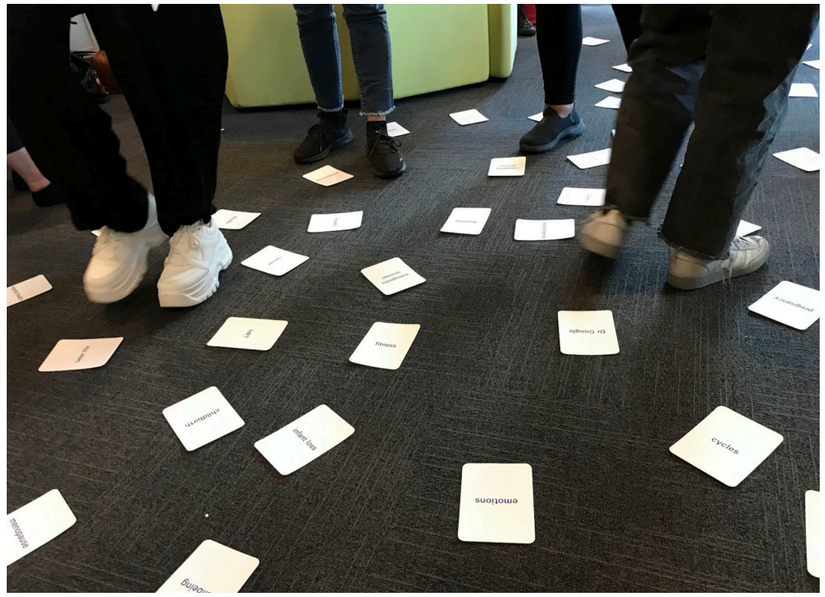
Throughout the planning and facilitating of the conversations we had with this group, we took our lead from the contributor who had invited us in. From how long the sessions should be through to what food and drinks should be provided, and how we might encourage conversations and sharing, we followed their advice. Similarly,

we did our best to ensure this was not burdensome, including remunerating her and her team for their time. Sometimes this looked like us doing the preparation work that provided her with choices, and other times it meant leaving aspects (e.g. invitations and recruitment) to her. It also required going in prepared to learn and adapt as we went, and our approach to holding space for conversations was very flexible from the start. One of the core project team reflected after the session:

> "Good preparation both within our team and with [contributor] — and willingness to roll with whatever emerged, however big the group, however long the session."

Showing a willingness and preparedness to adapt can be seen through how we used word cards as conversation prompts. Responding this way may seem inconsequential, but when someone asks for something that does not already exist, being met with an instant solution is powerful. In the Care-Full Co-production project in Tāhuna, as we laid the cards out on the floor before using them (Figure 75), one person asked if we had a particular word that she wanted. These words had been generated from previous conversations with other women. We had anticipated there would be words that were not included that might be wanted, and so we had blank cards and pens available. We didn't have that word, but we were able to immediately offer her a blank card and pen to create what she needed. This showed: that the person was not a problem for wanting something different; their lived experience was important even though it was not yet reflected in the existing words; and allowed the group to know that we were genuinely there to hear them and learn from them.

Figure 75:
Word cards being used as conversation prompts.



The ability for individuals to choose what their interactions looked like was important for this group as well — coming to sessions for as long or as short as they were able to, and coming to multiple sessions or just one. At one of the follow-up sessions, where we were focussed on creating research questions with them, contributors made comments that highlighted the importance of how we had approached things. Some expressed gratitude for us returning to talk with them again. Another made a comment regarding creating research questions, suggesting we were using a 'rangahau' approach. The contributor said:

> "The first [word] I picked was research but along with that is rangahau because there's a difference between, because you know, in the academic world, research is about extraction, where as rangahau, which is where it's lovely that you three wahine are here, because it's actually putting yourself into the research itself, and that's what rangahau is about."

This comment was very affirming — showing that we had managed to demonstrate that relationships were a priority, along with sharing power.

During our celebration events (at the end of this part of the project) some of our contributors shared about their experiences of being involved in the project. One said:

> "The usual power dynamics have been non-existent — thanks to the personal qualities of Anjuli and Hannah — such a great demonstration of female co-operation. You have created a safe place for personal sharing."

How do power and responsibility interact?

Having power often comes with having more responsibility, but they can be separate and therefore interact together in ways we might not necessarily notice. Two particular examples came up during Care-full Co-production, and as they are both very different, they provoke different considerations. As mentioned earlier, the contributors for this project did not want the responsibility they thought came with the role 'co-researcher', whereas we had thought this was a way to share power with them. Realising their perception was different to ours led us to look for ways that power (and therefore choices and decision-making) could be shared without it being a burden to them. Contributors' responsibilities were simply to turn up and engage in sessions, and to care for each other during conversations (especially the vulnerable conversations). Frequently, though, contributors did not see this as being enough, so we had to reassure them of the value of their input — regardless of the 'quantity' of their contribution. In response to being invited to a celebration event, a contributor said:

> "Hadn't originally planned to come as don't feel I've contributed much to the project this year."

In hindsight, communicating these responsibilities overtly during conversations about how we could all work together would have been beneficial — not to convince them to take on a label they did not want, but to make it visible how responsibility did not necessarily need to be a burden.

Navigating disinformation

The second example of power and responsibility interacting is through the intention to 'do no harm'. During facilitated conversations with contributors, there was a risk of contentious topics being raised, and misinformation or disinformation being shared. These topics of conversation might unknowingly harm people in the room or may reinforce or encourage a social narrative that could be harmful to the wider community. There is a tension here between whether or not we should intervene, by either changing the topic of conversation or by making our views (individually and as part of the project) known.

Traditionally, in Western research frameworks, there is an expectation to be impartial or objective and therefore minimise the researcher's influence on the conversations. However, this conflicts with caring for our contributors and the world we are contributing to (Toombs et al., 2017). The misinformation that was brought into a Cuppa & Cake session didn't stray into openly hateful commentary, but it could still have made people in the room feel unwelcome or unsafe, which we (the facilitator and I) would not have known. If they had felt that way, it was quite unlikely that they would have shared this with us after such an experience. Because people had felt safe enough to discuss their uncertainties around the topic, it could have been an opportunity for a brave space (Vivienne, 2023) and a discussion that could have led to greater understanding and a slight positive shift in social narratives. In this case, it is hard to say where our responsibilities lie. While we had the power to make things different, we were also trying to reduce the power differences rather than reinforce or draw attention to them. Changing the conversation may have counteracted the other things we had done to reduce power asymmetries, so whatever action we took may have resulted in an outcome that was in conflict with our aims.

Summary and provocations

With a key principle of co-production being to share power, open and honest considerations and conversations about power are vital for building co-production projects that disrupt power imbalances. Power is dynamic and changes according to the context, and can also be considered from a systemic perspective as well as for specific relationships. Using the term 'power asymmetries' helps draw our attention to who has more or less power in a situation. Taking time to identify

who has decision-making rights can help researchers notice where power is sitting and who has more or less. Understanding who can make what decisions when can lead to opportunities to make changes that will help share power.

It can be easy to talk about sharing power within a project, but to actually do so requires intentional action and considering what success would look like. Open conversations about power with all who are involved in the project can uncover assumptions that may be being made or highlight how attempts to share power may feel burdensome. Sometimes, there can be conflicting priorities between sharing power with lived experience experts and maintaining the project momentum. In order not to add to their burdens, researchers need to take responsibility for the project's momentum and give space for incorporating contributors' feedback, as a way of managing both priorities. Researchers may also have the additional responsibility of navigating contentious topics and disinformation in a way that balances prioritising sharing power with contributors and doesn't cause possible harm to the wider community.

The provocations that make up this arm are:

» What power asymmetries exist in the different relationships in the project?

» Who has what decision-making power?

» Who is responsible for the project momentum?

» What could sharing power look like in a specific project?

» How do power and responsibility interact?

Arm 4:
Prioritising Relationships

Why is it important to prioritise relationships?

What will a ‘good’ relationship look like?

What are key elements for building these relationships?

How do we build & maintain good relationships?

Who are the relationships with/between?

Arm 4:
Prioritising Relationships

We started this project with the theoretical model of co-production that stems from McKercher's (2023) work in systems design and specifically co-design, where one of the core principles is prioritising relationships. The importance of relationships and relational practice is a common theme throughout the literature on co-production and participatory design approaches (Knowles et al., 2021). However, relationships are often not discussed in great detail. Initially, I thought assumptions were being made about everyone knowing what 'good' relationships would look like, and that we would inherently know how to build these relationships. Reflecting on the relationships in Care-full Co-production, I wonder if the lack of discussion is partly due to these assumptions, and also a response to the complexity of relationships themselves and the complexity of relationships in the context of participatory design. While there appears to be an assumption that everyone knows how to build and identify good relationships, health policy researchers Kathryn Oliver, Anita Kothari, and Nicholas Mays (2019) argue that academics are not overtly trained in interpersonal skills — and that this can be a reason that co-production projects are not always successful. These interpersonal skills, like acts of care, are often taken for granted (Williams et al., 2020) and end up being invisible.

The details of relationship complexity are hard to describe in a way that is useful and understandable to those who are not directly involved. This difficulty likely contributes to the lack of discussion in the wider literature, along with a hesitancy to turn relationship building into a prescriptive and methodical task. However, by showing examples of the small actions and considerations that contribute to building relationships that make up a co-production project, attention can be directed to creating an environment or conditions where these relationships are likely to blossom. Relationships do not fit prescriptive processes, but we can develop intentional practices that encourage connections and allow us to notice serendipitous opportunities we can follow through on. Considering relationships from an interdependent perspective of interactions, keeps in mind the multiple people involved. Organisation management scholar Ann Cunliffe (2016) draws attention to the complexity and interconnectedness of relationships, writing:

> recognizing that we are always in relation with others—we influence each other in responsive and often tacit ways. I use "with" deliberately: relationship "to" implies a connection between separate entities or individuals, whereas "with" implies a more deeply embedded, embodied, and mutual relationship. (p. 743)

For my PhD, there were several unexpected meetings and connections that we built relationships through that ended up being vital to the project, in ways we could not have envisioned beforehand. Starting from a position that values and prioritises relationships, while being mindful of power asymmetries, gives a foundation for developing the relationships co-production relies on.

Why is it important to prioritise relationships?

For co-production to have the positive outcomes and impact that it claims to be able to achieve, relationships are key to making this happen. What is created through co-production projects is richer and more nuanced because of the depth of sharing and the variety of knowledge and experiences that come from different people, and therefore more likely to be of benefit to the people the project is designed for. Building relationships intentionally — and with care — creates conditions that encourage generosity of sharing and vulnerability in sharing these experiences. More traditional types of research interactions are often perceived to be extractive and are less likely to design spaces for generous sharing and vulnerability. In work looking at environmental change with indigenous peoples, M. Parsons et al. (2016) commented that for co-design and co-production, committing time specifically to building relationships and trust with contributors is vital.

The ethics of care, or politics of care as it's sometimes called, is tightly entwined in the principle of prioritising relationships. Embracing and embedding care in a project, and highlighting its role in relationships that are reciprocal, may help us find ways to hold human vulnerability (Tronto, 1998), which is especially important when exploring topics like women's health. Considering how to be inclusive and accessible is part of an ethics of care and important for including a diversity of voices. Performing arts researcher Kelsie Acton wrote:

> For me, there is emotional value attached to having access practices in place and discussed. If access is not addressed (as it often is not), I read it as a refusal to be in relationship. The absence says: You, and the people you love, are not welcome here; you are not worth hospitality. I want to acknowledge that access takes labour and often capital. But all hospitality, all relationships, involve labour and cost. (Acton et al., 2019, p. 52)

Inclusivity and accessibility practices are more than just whether someone can attend, but as mentioned in Arm 2: Care p. 159, are also about having a sense of belonging in the space or event they've been invited to.How reciprocity is shown in the relationships involved in co-production is unpacked in a section below. Building relationships that are founded on care also means that flexible participatory design approaches, like co-production, have the stability to progress towards outcomes that come about from collaboration rather than being directed solely by designers and researchers (Light & Akama, 2014). Exploring knowledge mobilisation in health care settings, Knowles et al. (2021) highlighted that the success of a co-production project was not determined by the methods used but by the relationships between researchers and contributors — regardless of the method, contributors could be included inauthentically, which would undermine the relationships and success of a project.

What could a 'good' relationship look like?

The literature about participatory design approaches frequently mentions the importance of relationships (Knowles et al., 2021; Turnhout et al., 2020; Verwoerd et al., 2022), without describing the relationships or how to know if they are 'good' or 'the right' ones. Describing relationships as good, positive, robust, and constructive will always come with views that are subjective and context-specific. These ways of describing relationships feel uncomfortable or overly simplistic. While I use the phrase 'good relationships' in this Arm for the sake of clarity, I aim to focus on the elements of relationships that make them important to co-production, without losing the complexity of relationships.

Huaman and Mataira (2019) share, in reference to working with Indigenous communities, that relationships need to be developed to be ongoing and founded on reciprocity and mutual respect. This indicates the need for building relationships that will last beyond the end of the current project or a particular aspect of a project, which generally requires agenda-free relationship building. Light and Akama (2014) support this, writing "Inspiring the design of relations is intangible and we see it as on-going and never completed, spreading through encounter and exchange" (p. 158). This ongoing view of relationships will ideally lead to less extractive relationships and avoid burdening those with less power or resources.

Some examples of what might indicate a good relationship, or the beginnings of one, include noticing signs of trust, reciprocity and vulnerability. The depth and intimate nature of sharing that contributors displayed in our Cuppa & Cake sessions show they trusted us, and each other, enough to be vulnerable. One woman reflected during a session that:

> "It's also quite surprising to see how quickly with a group of strangers, you have that level of trust to, just go ahead and do it, but maybe it's what you said, that the more you share or the more you show that you're vulnerable and honest then that comes back so everyone just feels comfortable."

Continued engagement and involvement in a project is also a sign of a good relationship. For Care-full Co-production, contributors dipped in and out as suited them but remained involved til the end, and included responding to requests such as being the 'person in the project' in our monthly newsletter.

At in-person engagement sessions, core project team members offered to get contributors' drinks or suggested they eat the treats provided, and they were also encouraged to help themselves throughout the session. Not only did contributors feel comfortable enough to get themselves a cuppa, but they also offered to get core project team members one while they were up, and would pass food to everyone around the table. Reciprocity like this can indicate comfort and belonging, as well as a blurring of the host-guest differentiation — as Acton et al. (2019) describe, the host becomes a guest and the guest becomes a host, or in other words, people feel at home and like equals.

Being comfortable in the space and with each other can also be seen in how contributors would linger after the 'official ending' of a session to keep chatting, especially the ones in Tāhuna Queenstown who met multiple times. Another indication of a relationship going well is people giving feedback or suggesting changes to the process. Providing feedback can be in response to direct requests or initiated by people themselves. We had a process to ask people after most sessions for feedback via email, which gave us really valuable suggestions. For example, some contributors raised concerns about whether they were the best person to be involved in the project because of their privilege and positionality — this allowed us to reassure them that their contributions were valuable and discuss ways other voices might be included in the project.

These examples of signs of a good relationship are context-specific and not prescriptive. However, considering the question of 'what relational elements are important in this context?', could be valuable in the building the conditions phase and when thinking about how to work as a group throughout the project. Content covered in other chapters, such as Arm 2: Care, p. 153 and Arm 3: Power, p. 173 will also help with imagining how relationships in a co-production project might look. An ethics of care helps build interdependent relationships, where looking after one another is valued (Haverkamp, 2021). Considering relationship building specifically within research projects, Toombs et al. (2017) mention how care permeates through the building of trust as well as the development of relationships which are deep enough for reciprocal vulnerability.

What are key elements for building these relationships?

There are many important aspects that are helpful for building relationships that are desirable for the context. Because co-production aims to include and elevate lived experience, building relationships in which people are comfortable sharing their experiences is important. These relationships are likely to be built on aspects such as time, empathy, vulnerability, reciprocity, and trust (which will be unpacked further in this section). Describing the building of relationships suggests that there is a particular endpoint when the building phase is complete, whereas in reality, it is an ongoing process — or both building and maintaining phases. An ethics of care and an awareness of power dynamics are also important in relationships — as these have been discussed fully in their own chapters, they will only be touched on here.

Time

Maintaining authenticity and strong connections and relationships can be a time-heavy and resource-heavy process (Csernák, 2024). In reference to Feminist Participatory Action Research, Ponic et al. (2010) write — and I believe their discussion is relevant to co-production projects — the main practical element for developing relationships is to allocate resources for relationship building into the project planning from the beginning. Healthcare researchers Tina Janamian, Claire Jackson, and James Dunbar (2014) discuss the importance of time and how it takes time to build relationships to a depth of trust and understanding in order to have the most benefit. Often, timelines and time expectations for policy and research don't match those of co-produced research, as it needs more time. In a report exploring reflections on decolonising research, Carmen Timu-Parata, Susan Knox, Eva Neely, and Anna Brown (2025) discuss the impacts of a timeline that's too short for the project's aims. Anna writes "I'm interested in practicing shifting from timelines to trustlines. A practice of giving to not taking from" (p. 44) — where trustlines indicate "working at the speed of trust" (p. 41). Having trust guide the pace of working would be a responsive approach to time, that is specifically suited to the people building relationships together.

Throughout Care-full Co-production, we knew that some parts of the project would need more time and the ability to go slower. This was practised at the beginning of the project, in particular, when we took what felt like a long time to get started, but also in each engagement session, where we took time for introductions and building connections. Time is important for other aspects of the project as well as relationships. Its wider importance throughout the whole project is discussed more fully in Arm 5: Temporality, p. 211.

Empathy

Empathy is often described as 'to put oneself in another's shoes' or to imagine being in another person's situation and feeling what they would feel, writes human-computer interaction researchers Cynthia Bennett and Daniela Rosner (2019). Human-centred design claims to be grounded in empathy, and designers use practices such as simulations and user personas to develop empathetic understandings of others. There is a risk with these practices as they can result in designers foregrounding their own feelings or experiences within the empathy they develop, rather than those of the people they're aiming to understand (Bennett & Rosner, 2019). This approach to empathy can also end up reinforcing insider/outsider positions and the power differentials that may come with that.

Cognitive psychologist Paul Bloom (2017) agrees that empathy from the perspective of putting oneself in another's shoes is flawed and biased. People are more likely to be more empathetic towards people who are similar — making it harder for minority groups to be considered — and generally display empathy towards individuals rather than groups of people. Additionally, this form of empathy rarely leads to action. Bloom suggests that compassion, or compassion and kindness, could be more useful, as compassion relies less on feeling what another is feeling and focusses more on what might make things better for the other person.

While not exactly the same, compassion is an act that sometimes overlaps with empathy. Goodyear-Smith and Buetow (2001) commented "True compassion can be seen as power with another, not power over or power under" (p. 457), which also highlights the need to pay attention to power differentials. Being empathetic can be in contrast with the rational and objective approach that positivist-based research aims for (Toombs et al., 2017). However, in participatory design approaches that aim to share power, empathy or compassion is essential to the relationships being developed. In the Care-full Co-production project, we aimed for an empathetic and compassionate environment so contributors would feel comfortable enough to share their health experiences. Modelling empathy also acts as encouragement for the rest of the group to be empathetic towards each other as well, so the core project team aspired to set this example.

Bennett and Rosner (2019) suggest we "reimagine empathy as the work of attuning – noticing and realigning different bodies and relationships to one another toward respectful connections" (p. 2). Thinking of empathy this way, then, Liz Bondi (2003) suggests that being able to empathise with people allows us to understand them on a mental and emotional level, and to validate or recognise their experiences. It is often assumed that empathy is something inherent, but it is a skill that can be learnt and honed. Danish schools include teaching empathy as part of their curriculum, journalist Jessica Alexander (2016) writes. Classes share cake together and discuss experiences or issues to build connections and develop an understanding of how their classmates experience the world. Additionally, Mafile'o (2019) describes how she shares cakes with others to build connections and 'ofa' (Tongan for compassion/love), and that it can be part of a decolonising approach. Cake can be so meaningful, and was an important part of the relationships process within our Care-full Co-production project.

Vulnerability

Sharing vulnerability is important for developing trust and respect between people (Batalden, 2018), but sometimes can be seen to be in opposition to being professional (Vivienne, 2023). Batalden (2018) writes that "A willingness to be vulnerable arises from being fully present and able to fully engage with another person" (p. 2). They suggest this is an ideal that is not always possible, especially in health spaces where the relationship is between a patient and a health professional. Batalden explains that by identifying and discussing the importance of vulnerability in relationship building, permission to be vulnerable is given, and this enables people to genuinely value the knowledge that comes from lived experience. As part of getting to know each other, the core project team used a tool called 'One Face, Many Facets', which is a process to consider connections with people and communities. This tool is explained in more detail in Arm 8: Participatory Design Approaches, p. 259. Our use of it was framed around health, and also led to vulnerability and building connections within the team.

In our Cuppa & Cake sessions, as well as encouraging our contributors to share their thoughts and experiences of women's health, these were also the early stages of developing our relationship with the contributors. Being vulnerable was a way that we (the core project team) could reduce the power asymmetries and make it less 'us and them'. Vulnerability was also a way to demonstrate we trusted and respected them, along with indicating that we didn't want the relationships to be extractive. Deciding how much, or which, of our own experiences to share felt like a fine balance — we did not want to dominate the conversations with our experiences, influence the experiences that contributors would share, nor put them in a position where they felt they had to support us. Some of this we managed through the timing of when we shared — we wouldn't all share before or after the contributors, but would space our sharing throughout the conversations. There were also moments of tension (for me at least) between perceived expectations of being professional and being vulnerable and expressing emotions (Vivienne, 2023). I feel emotions strongly and easily become teary out of compassion for others, especially when contributors cried in sessions, or from sharing my own experiences. Repressing this part of me would have been inauthentic, and may have made contributors feel less comfortable being vulnerable themselves, and at the same time, contributors may also be uncomfortable with too much emotion, especially if they were expecting us to be professional. In general, I think we got the sharing and supporting balance right, with one contributor saying in their feedback:

> "I think it was facilitated really well. I enjoyed that you participated as well — it was a safe and inclusive place."

Another way in which we, as researchers, were vulnerable with contributors was through sharing our uncertainty and discomfort about the unknown and the lack

of a plan for the project. Being open about this and demonstrating that we were working on being comfortable with discomfort allowed them to also sit with this discomfort. As a contributor shared:

> "I experience discomfort with this research model — is that because it is so unfamiliar??".

On reflection, we could have been clearer and shown more certainty by explaining earlier that the aim of the project was to create a library of research questions, which may have aided contributors to feel more comfortable with the unknowns of the project. We had mentioned this aim from the beginning, but in a low-key way to avoid forcing or prescribing a view of this too early in the process. However, it was over a series of conversations that we realised that contributors had not fully understood that this was the aim, which may have been a response to lots of information at the beginning, as much as it was about our clarity or certainty.

Toombs et al. (2017) wrote "Despite how impactful these researcher vulnerabilities are to the research process, they are rarely able to be discussed when reporting research, and they often are not critically thought through during the research design process" (p. 54). Researchers, especially in the social sciences and creative arts spaces, are getting better at acknowledging vulnerability and emotions, but it does require this being intentionally part of the process, rather than trying to remain separate or objective (Askins & Blazek, 2016; Toombs et al., 2017). To include emotions and vulnerability in the process and in research reporting requires another type of vulnerability within the research system, inside academia and with colleagues. Sharing so much of oneself has not always been considered positive for employment situations (Askins & Blazek, 2016)— and particularly those in precarious positions — so a person's privilege and power often influences these choices. Developing processes and time for discussions about engaging and acknowledging vulnerability within research and academia will make it easier to openly consider this aspect of relationship building, particularly for participatory approaches such as co-production.

Reciprocity

Reciprocity is imperative to disturbing power asymmetries, especially with communities who have experienced oppression, exploitation and lack of resources (Akama et al., 2019). This also calls for relationship building to be carried out in a way that does not further disadvantage the communities involved. Those with more resources and power need to prioritise the relationships and do their own work to understand the people they are working with rather than relying on communities to do the teaching (Greenaway et al., 2022). As part of making sure the relationships being developed are not extractive or transactional, reciprocity needs to be considered.

Reciprocity doesn't require each person involved to give exactly the same thing to the other people and vice versa, but it does mean thinking about how giving and receiving can both be positive or beneficial. In her book *Decolonising Methodologies*, Linda Tuhiwai Smith (2021) writes:

> Sharing is a good thing to do, it is a very human quality. To be able to share, to have something worth sharing, gives dignity to the giver. To accept a gift and to reciprocate gives dignity to the receiver. To create something new through that process of sharing is to recreate the old, to reconnect relationships and to recreate our humanness. (p. 121)

Sharing this way was touched on previously when writing about vulnerability, with the core research team being vulnerable as well as the contributors. Sharing experiences both ways not only builds connections and trust but is also a form of reciprocity. In thinking about the ethics of care underpinning Care-full Co-production, having opportunities for people to both receive and give care is an example of reciprocity. This response from a contributor, while possibly a simple social nicety, could also be an example of them showing care to me:

> "Best wishes for the upcoming festive season and summer — hope you get a chance to rest and recharge."

Valuing people's contributions to the project in ways that are meaningful to them helps create an environment of reciprocity — the project benefits from contributions such as time and knowledge, and the contributors benefit from receiving a koha, being recognised in project outputs, and seeing their contributions reflected in the project.

Another less obvious way of demonstrating reciprocity in Care-full Co-production was through the Cuppa & Cake sessions. While there were many reasons for having cake as part of those sessions, and specific choices around which cake to share, a key reason was that we had recruited the contributors through Good Bitches Baking. These contributors volunteer their time and resources to show kindness to others through baked goods — so we showed kindness and caring by giving these bakers cakes they had not had to bake themselves. This was a small recognition of what they contribute to their communities, and also a way to build a connection through something familiar and a shared interest. Reciprocity is not always obvious and does not always happen in close time frames, but having reciprocity embedded in relationships helps to show the relationships are intended to have longevity, not necessarily just for the duration of the project.

Trust

Trust is often more of an embodied experience or 'gut' response we feel when we think someone is trustworthy or whether we trust them. This is often perceived as

a sense, more than something we're able to describe. Sometimes it is easier to notice when trust has been broken, and how it was broken, more than how it was built. Often relationships develop because there is trust there, but trust can also come as a relationship builds — adding to the complexity of prioritising relationships! Verwoerd et al. (2022) identified one of the first priorities in a policymaking project was to build trust between those involved in the project, and did so "mainly on a personal level by investing in interpersonal relations" (p. 8). Throughout Care-full Co-production, we started all facilitated conversations with explicit time set aside to get to know each other. While each session differed in depth and vulnerability depending on what conversation we were beginning, they all focussed on sharing a few details about ourselves that were more holistic than just where we worked and what our job is. Listening is also a part of building trust, in particular listening to hear what a person is sharing, not listening for what you expect them to say (Gilligan, 2014). Treating the speaker and their experiences with respect and gentleness also adds to the trust that is built through listening.

To build trusting relationships in a co-production project, starting with existing connections can help. For Care-full Co-production, we built on my connection with the Good Bitches Baking charity I'd worked for previously. Having our call for expressions of interest in the charity's quarterly newsletter also added to that trust and connection, because to do so, we needed permission from the leadership team at the time. Using existing connections also made it possible for our conversations with wāhine Māori to happen. While the contributor who invited us into that community never said so specifically, I do not think she would have given the invitation without trusting us.

One of the ways that trust can be broken quickly is by not meeting people's and communities' expectations. This could look like promising something that cannot be delivered. We were very conscious of this responsibility, and sometimes this meant we did not give definitive answers even though more certainty would have been appreciated by the contributors. During our first session with our wāhine Māori contributors, we said we wanted an ongoing conversation and relationship, not just that one session — so we made sure to return. When we explained to the contributors what we hoped would happen with the library of research questions at the end of the funding timeframe, we made sure to explain that our hopes and aspirations were not certain and that it depended on other factors, such as getting new funding. Not breaking people's trust is as important as gaining and maintaining their trust.

How do we build and maintain good relationships?

This section connects closely with the previous section, and is linked with Arm 2: Care (p. 153) and Arm 3: Power (p. 173), as all are important for building and

maintaining relationships that co-production projects rely on. While the examples of actions that helped with developing relationships often link closely to the methods we used (which are discussed in Arm 8: Participatory Design Approaches p. 259), it's not necessarily those specific methods that are needed for building relationships. As Knowles et al. (2021) wrote "Even formal academic meetings can achieve partnership, if relational elements are attended to" (p. 11), while noting that partnerships are not always the same as the relationships desired for co-production projects. It must also be acknowledged that relationships are dynamic, responsive to actions by all involved and impacted or generated by the environments and choices we design (Light & Akama, 2014). In this section, I have split the discussion into 'beyond the room' and 'in the room' considerations — inspired by Knowles et al.'s (2021) discussion of relationship-building factors. They wrote:

> While the researcher's original conception of the evaluation focussed on activities 'in the room' referring to interactions within the workshops, it became clear that contributors evaluated the process as a whole, including 'beyond the room' factors such as how practical issues of reimbursement were organised. (p. 8)

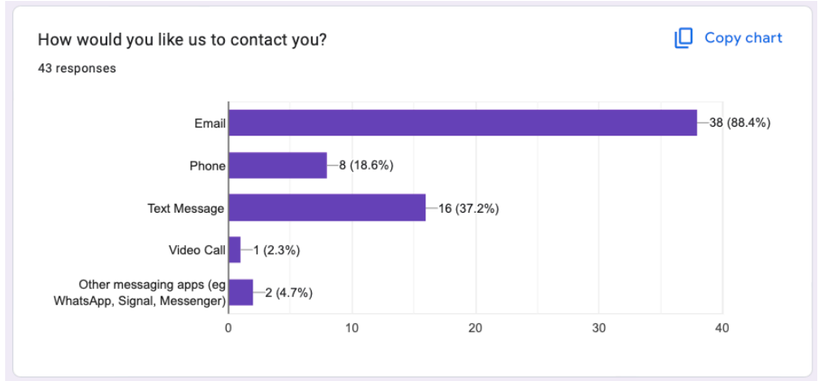


Figure 76: Communication preferences as indicated when people completed the expression of interest form.

Beyond the room

Knowles et al. (2021) talked about 'beyond the room' factors mainly in relation to elements such as getting reimbursements organised. I've expanded this to include any form of interaction that happens outside of the face-to-face (in-person or online) interactions, or what might also be called asynchronous engagement. Organising people coming together for a group conversation requires lots of communication — each moment of communication is a moment of relationship building. In our very first request for expressions of interest (through the Good Bitches Baking newsletter), we asked people to indicate their preferred way of communicating (e.g. email, text message, WhatsApp, phone call — responses shown in Figure 76) and then did our best to accommodate their preferences

As the project progressed, we moved to communicating mostly via email. However, we always offered other options in case someone found email difficult. A contributor mentioned an example of this in the feedback they sent us:

> "I was happy with being asked though I had problems with the technology — however you solved that by giving a contact number."

We aimed for a warm, friendly tone in our communication with easy-to-understand language. Before in-person sessions, we made sure we had provided information about how to find the venue, accessibility details and what to expect. After all sessions, we also followed up to get feedback and to provide information about getting further support if they needed it. We made it a habit to ask before sessions if there were any accessibility needs they had, and (when relevant) any refreshment or dietary preferences. Making it a practice to ask these things helps to demonstrate that providing them is not a hassle — and helps build trust.

In a conversation where we discussed options about how we could work together in future sessions, some of the contributors mentioned a newsletter might be helpful for maintaining connection and momentum within the project. As our synchronous engagement sessions were often months apart, having a regular moment of connection in between them was a good idea. We took this on board and created a monthly newsletter, *The Octopus*, where we shared updates, introduced people in the project in a lighthearted way, and offered resources such as book recommendations and podcast suggestions (Figure 77). There were opportunities for contributors to recommend content or even write parts of the newsletter, and although not many people took those up, the feedback we received and the readership data from the newsletter platform showed how valuable the newsletter was. This was somewhat surprising considering how many newsletters people receive these days, and often do not read. Mailchimp shows that, in general, newsletters have an average open rate of 36% (Mailchimp, 2023), while our open rates were between 63% and 81%.

Another moment that was important to our relationship building was when we were invited to a community event in Tāhuna Queenstown the evening before we were due there. The event was not directly related to Care-full Co-production. However, the people organising and attending the event were going to be part of the conversations for the project. By accepting this invitation, we demonstrated reciprocity, trust and vulnerability as well as using time and resources for something relating to their community and not just our research agenda. It was also an opportunity to get to know some of the people we would be talking with further.

Paying attention to the details involved in all processes, such as recruitment, organising engagement sessions, and communication, provides important insights for developing 'power-with' approaches to research (Ponic et al., 2010). These beyond the room considerations are important aspects of connecting in the room events together and creating the overall experience of being part of a co-production project.

Figure 77:
Header image from the newsletter 'The Octopus'.

View this email in your browser

The Octopus

The Co-production Project Newsletter

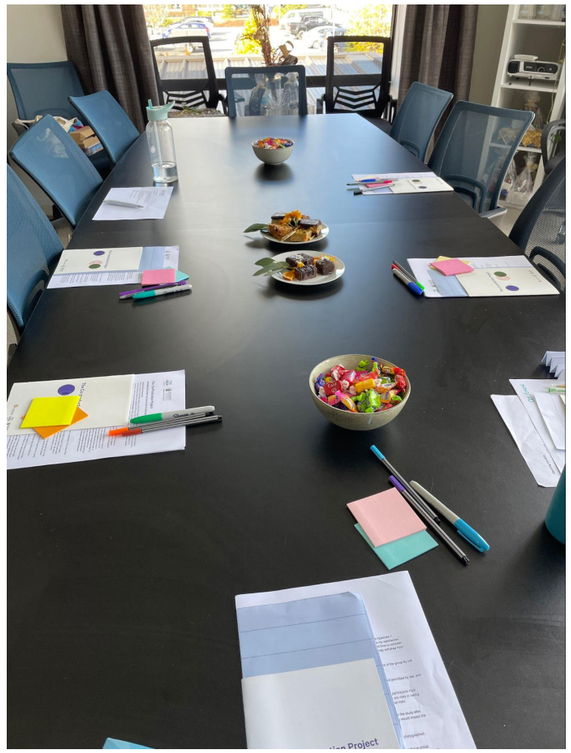
Issue #9 — 23 August 2024

In the room

The 'in the room' space includes our online conversations (using a platform such as Zoom) or could also be thought of as 'synchronous engagement'. Face-to-face interactions are, for many people, the preferred way of developing relationships, especially when working together on a project (Knowles et al., 2021). While the relationships start before these engagements (with 'beyond the room' elements), the first impressions for people arriving at our Cuppa & Cake engagement sessions set the foundation for developing the relationships further. For us, this included how we had set up the space and the tables and how welcoming we managed to make the room (see Figures 78 & 79), within the limitations we had, as these spaces were often hired.

Figure 78:
The table set up for our first Cuppa & Cake session in Wellington 2023.

Figure 79:
The table set up for our Cuppa & Cake session in Queenstown 2023.



A warm welcome on arrival included offering people a drink and explaining where they could sit, when we would begin, and where important amenities like the bathroom were located. When we travelled for sessions, we ensured we had an extra person (from the core project team) with us. Along with a facilitator and a researcher (me), we also had someone in a kaimanaaki role. A kaimanaaki is someone who provides support and care for the people and space they're in. This role has specific tasks, such as to focus on this welcoming process, and to be available to provide support if someone needed to leave a session partway through (e.g. if they had got upset and needed a break), and to help with the smooth running of sessions. In a reflection after a session, one of the team shared:

> "Was good to have three of us witness the stories/process and be part of the connecting/welcoming process."

This was an important role for also ensuring that the facilitator and I had what we needed to lead the session, including acts of care such as ensuring we had also eaten.

We allocated a generous amount of time at the beginning of all engagement sessions for introductions and getting to know each other. We purposely chose

opening tools that felt more genuine, rather than icebreaker activities, which can feel tokenistic. We designed these processes with specific groups in mind, taking into account whether the sessions were in-person or online. For our Cuppa & Cake sessions, which were the initial conversations about women's health that included sharing of personal experiences, we used a body and health focus to gently lead into the conversation. We also developed a layered approach to the introductions, with an initial light introduction to get people's names and voices in the room, followed by the *More Than a Name Tag* exercise (described in detail in Arm 8: Participatory Design Approaches, p. 259), which led people to more sharing and what we called the 'heart' part of the conversation. For one online contributor, this process did not feel as important as the sticky note exercises, which asked questions such as "What does women's health mean to you?" and "In an ideal world what would women's health look like?". In feedback after the session, they said:

> "My only feedback would be that I think the introduction activities could have been cut shorter, to leave more time for discussion among the focus group about the questions."

Whereas a contributor from a different online session said:

> "I think Zoom is fine normally but can be hard when you haven't met any of the people in-person previously, especially for a co-production project where building relationships is so important. In saying that I still liked the structure of the session (getting to know each other, then doing those whiteboard tasks on women's health). Maybe having some more silly/fun discussion topics at the beginning might make the conversations less stilted throughout."

Getting the balance for everyone's preferences is tricky and is unlikely to be just right for everyone every time. From a facilitation perspective, I do not believe we would have had such open and vulnerable sharing of experiences without this focus on getting to know one another. Even though other engagement sessions in the project did not specifically facilitate as much personal sharing, these introductory activities continued to feel important for encouraging the deep and thoughtful conversations we had.

That last comment from a contributor also highlights the challenges of creating an environment and opportunities for relationship building on online platforms — especially among contributors themselves. We had helped the relationships between us and contributors by sending out care packs that had cake, drink sachets and stationery with the aim to give a similar experience to those who came to in-person sessions. While being able to hold conversations online gives options for more people to participate without the need to travel, other accessibility needs and reduced risk of catching an infectious illness, the reality is it is much harder to attend to relational aspects in online settings — particularly when the relationships are new.

An 'in the room' aspect that is frequently talked about is creating a safe space. This is important when it comes to specific topics, particularly women's health, but it is also important for having a variety of people involved. As talked about in Arm 2: Care (p. 153), what is considered a safe space will be different for specific contexts and people, and we need to be mindful when making decisions about safe spaces that we don't reinforce power imbalances. As Vivienne (2023) suggests, thinking about creating brave spaces may be a better approach to keeping people as safe as possible and creating inclusive spaces for all, while also fostering an environment and attitude where people can repair and rebuild if conflict, tension or upset happens. This also includes making it clear how people can share if they're not feeling safe or heard, or how they can leave if they choose to.

In the Care-Full Co-production project, we started conversations with gentle requests to treat people and their experiences kindly and respectfully, while also acknowledging that people were free to leave or not participate at any stage — recognising these requests came from our position of privilege and our experiences of facilitating group discussions. We also asked everyone to be mindful that some people are more comfortable speaking than others, and to try to allow time and space for those who are less comfortable. This is hard to balance, whatever your role in a conversation might be. One contributor mentioned in their feedback:

> "I did find that the conversation was somewhat dominated and led by one person in our group. I know that it was stated that we should recognise this individually and monitor ourselves but for some people this is hard to do, as there is an inability to even notice that they are speaking a bit much. For the more reticent (i.e. me) I am inclined to switch off when this happens and perhaps more guidelines at the start about managing this would have been useful and would have given me more tools to state how I was feeling? It is tricky though as there is a need to also be polite."

This highlights the importance of giving everyone in the group the tools and capabilities to help navigate these situations bravely. This is aligned with Knowles et al.'s (2021) evaluation of a co-design project, where they found that having 'space to talk' was as important as having 'space to change'. Space to talk refers to ongoing conversations between all involved in the project (including agreeing and disagreeing), while space to change means room for individuals to change their views or come to compromises, as well as project-level changes to how things are done. They wrote "It is necessary to consider how such encounters can be supported, to enable both contributors and researchers to engage openly with what can be difficult processes" (2021, p. 10).

Who are the relationships with or between?

Different projects will have different relationships, depending on such things as who initiates the project (as discussed in Arm 1: Building the Conditions, p. 141); whether the community being engaged with is a clearly defined existing community; and the topic of the project. Taking time early on, and throughout the project, to consider what relationships exist, what ones need nurturing, and if there are any missing, is beneficial. Toombs et al. (2017) argue that a difficult question that "should be discussed when designing a research project — and throughout the duration of the project — is: how can we be intentional about, or at least more aware of, what kinds of relationships we are designing for?" (p. 55). Making visible the relationships in a project not only aids in identifying what elements relationships need to thrive, but also helps to demonstrate the complexity of a project and the different parts that need attending to throughout the project. Filipe et al. (2017) point out that while co-production may look different in different contexts, what they all have in common are "the new forms of knowledge, values, and social relations that emerge out of co-productive processes" (p. 2).

It is also worth considering relationships more expansively, and as Place (2023) says "Plural understandings of people and problems also call for seeing relationships — between the parts of systems, between people and systems, and between designers and people." In considering Care-full Co-production, we could take this approach to reflect on whether the relationships were solely between the people involved, or if (for some at least) the relationship was with the project as a whole. For example, did it matter which person from the core project team was sending the emails to contributors, and if that changed, did it make a difference, or was the important part that the person was from the Care-full Co-production core project team? While I met all the contributors, and most of the emails came directly from and to me, there were times when another team member (who had met some of the contributors, too) took on some of the communication to help share the workload. We saw no obvious difference in who or how many came to the engagement sessions organised that way, but we were not intentionally making those changes to see what the impact was. As the core project team are all part of a university, it means that the contributors also had a relationship with the institution. However, by carrying out the research outside of the university, the relationship becomes more ambiguous and dynamic (Maguire & Britten, 2018).

What follows is a description of all the relationships within Care-full Co-production, and points of interest that may provide suggestions for what to attend to in other co-production projects. The initial layer of relationships began between the members of the core project team and myself. We dedicated time at the beginning for whanaungatanga and getting to know each other. We also spent time co-creating a set of values and expectations for working as a team, informed by Ponic et al. (2010), who writes that "Co-creating values statements, vision documents, and group agreements for how team members will work together can provide heightened clarity amongst team members" (p. 331). While we did not openly discuss people's individual roles or who had what decision-making authority, within the project, some of these came about by the nature of their position within the research c luster of Toi Āria at the University. However, as discussed in Arm 3: Power (p. 179), having more clarity about who can make what decisions is useful for maintaining project momentum.

Relationships with and between contributors are another layer within this project, many of which were initiated via a relationship with Good Bitches Baking. The relationships between contributors were all very different. When asked about building ongoing connections, some contributors wanted to continue to work with the same contributors in order to build relationships with each other. In contrast, others were not interested in that, just wanting a connection with the project:

> "I am not very interested in building relationships as such but I am keen to hear other women's opinions."

> "I really enjoyed meeting the women in my original group so would love to contact them again. But also I would love to meet other women in my age group."

Partly because of these differences, we did not focus specifically on keeping the same people connected; instead, we left that down to who turned up to what sessions. Since we had created an environment where people could dip in and out depending on capacity and availability, we tended to have a different combination of people at each session. This was different in Tāhuna Queenstown, where we had a place-based element show up with contributors here having lots of energy and enthusiasm for being involved. In both our initial Tāhuna Queenstown groups and our wāhine Māori group, there were conversations about taking the connections made in the sessions outside of the project — and we heard about how some of these had happened when we visited again. A contributor commented:

> "I didn't meet you at the last one, but I'm going to come and see you on Sunday because I have two children. And I live by Henlys Farm so I'll be there."

It was not clear why Tāhuna Queenstown was different to other places we had met people in person, but they have some unique health care challenges that are different to other parts of the country, so they may have played a part.

We also maintained connections with people who had the potential to be contributors, and who had, for example, been invited to one of the first sessions and not attended for various reasons. Some of them were added to the distribution list for the newsletter, allowing them to stay informed and respond to other invitations for involvement. A couple of them we invited directly to a Research

Question Development Session, which they attended. It was an interesting moment introducing new people to the project and each other; however, they were either linked to someone in the core project team or a contributor, and this helped connections develop quickly. This is a point to consider, though, whether existing relationships help or hinder. Several of the contributors were friends with people in the core project team, and we thought this would help with trust and comfort, especially for conversations about something so personal as health. However, a contributor with no direct connection to the core project team mentioned in their feedback:

> "I wondered if the connections participants had to you might inhibit them from speaking openly. It seems like a risk to this type of research to recruit participants through [shared connections]. As a total outsider with no connection it felt safe to me to speak freely."

Contributors knew before coming to a session that they might know others in the group; most often, they were likely to know me, so were making their choice to be involved with that knowledge in mind. Toombs et al. (2017) also discussed this, suggesting these shared connections:

> had clear impacts on the trust that participants demonstrated toward researchers. This often resulted in an increased level of privilege that the researchers enjoyed, both explicitly and implicitly, which problematized their relationships from a care ethics standpoint in that it made the participants more vulnerable to the researchers in several ways. (p. 50)

I think because we had cultivated an environment where contributors could come in and out of the project as suited them, and also had a broad topic that benefited from any level of contributor input, the potential downsides to these existing relationships were minimised, and our ethics of care helped minimise them.

Other relationships that are often paid less attention to are those with people who are not always directly involved in the same way as contributors are. Some of these unattended to relationships were the serendipitous meetings, also called affinity connections. As sociologist Jennifer Mason (2018) describes:

> Affinities are those connections that feel 'kindred' in some way, or make things kindred, whether or not they involve a family or kinship link as conventionally defined, and indeed we shall see that affinities can take shape between elements other than people too. Crucially, affinities are personal connections that have potency." (p. 1)

These connections often started from having a shared interest in women's health and/or participatory approaches to research, and some became what we termed 'critical

friends'. These critical friends were people who we could discuss ideas and challenges with, who might give us a slightly different perspective by being a step removed from the project. There is also the potential that some critical friends may end up helping progress the work, beyond the end of this project. Taking time to talk with colleagues and critical friends about different elements of our life and work is also an act of care (Mountz et al., 2015) — caring for ourselves as well as our relationships.

Our relationship with Te Pūnaha Matatini (the project funders) was often *more* than just a source of funding. As a Centre of Research Excellence and community of researchers, they also hosted (in some way) members of the core project team. They have been a champion and also an audience for whom we have shared knowledge gathered from Care-Full Co-production. Sharing the project with people in Te Pūnaha Matatini has helped us consider various ways of communicating different forms of knowledge and ways of untangling the complexity of this project, so those who are not directly involved can understand.

Likely, there are other relationships within this project, specifically, and within projects in general. However, the ones discussed demonstrate a variety of different relationships and the considerations that come with them. Although the ethics of care is discussed in its own chapter, care underpins the relationships shared here and gives a helpful lens for reflecting on the relationships in a project (Toombs et al., 2017).

Summary and provocations

Throughout this Arm, I have discussed how prioritising relationships in co-production projects is important for developing deep and nuanced knowledge, for supporting each other through the uncertainty of these projects and for the success of the projects. Developing trusting relationships where people feel safe and supported to be vulnerable and share their lived experiences requires time, empathy and reciprocity. While it is hard to be definitive about how to develop these relationships and what 'good' ones look like, I have shared examples that can be considered and transferred to other contexts. Paying attention to the details and processes that happen in the room with contributors and beyond the room is part o f building the whole experience of being involved in a co-production project. These details may appear small at times, but they can be very influential. Considering who the relationships are with and between in a project means we can develop processes with intentionality and care.

The provocations that make up this arm are:

- Why is it important to prioritise relationships?
- What will a 'good' relationship look like?
- What are the key things needed to build these relationships?
- Who are the relationships with/between?
- How do we build & maintain good relationships?

Arm 5:
Temporality

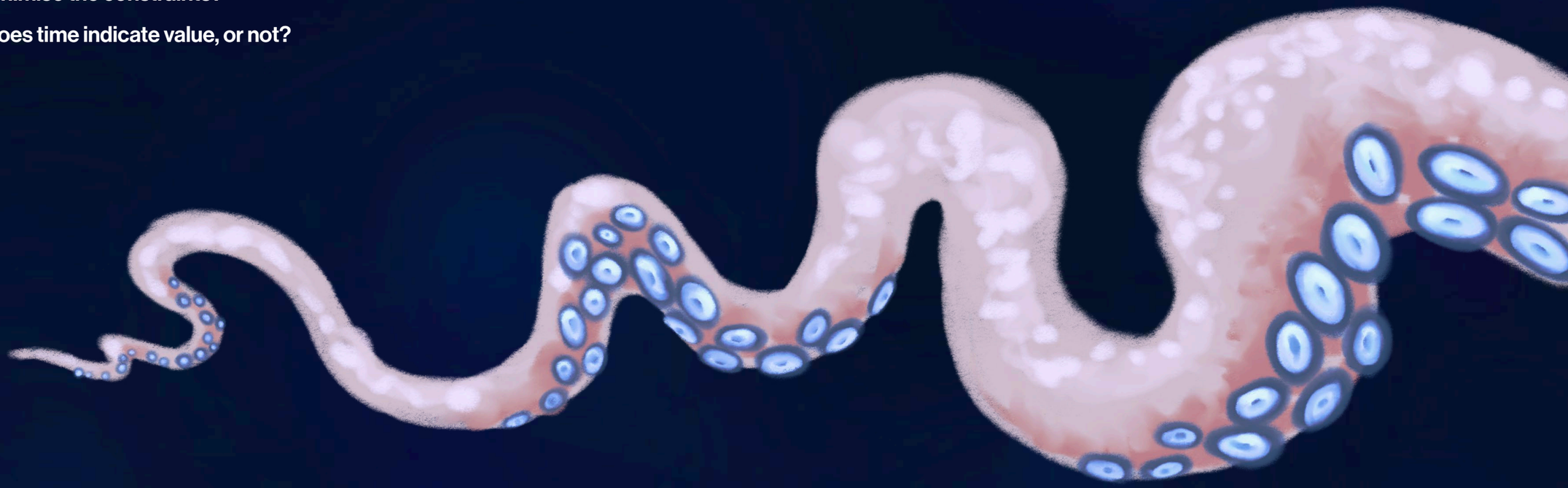
How might different concepts of time shape a project?

What are the constraints of time you're working within?

What are the flexible aspects of time you're working with?

What processes or ways of working can you put in place for this project to maximise the flexibility of time and minimise the constraints?

How does time indicate value, or not?



Arm 5: Temporality

Time is a concept we often think of as stable, precise and experienced the same — we all have 24 hours in a day after all — however, as interaction designer Larissa Pschetz and critical time scholar Michelle Bastian (2018) explain, there are many different ways of thinking about time, and how it influences projects. Design researchers Catherine Wieczorek and Laura Forlano (2024) write that time also tends to be thought of in binary ways (fast/slow or work/leisure) and from a linear perspective, which fits with the Western scientific approach. Because co-production focusses on prioritising relationships, it is recommended to allow time for this, as it is not always a quick process (Janamian et al., 2014). We started Care-full Co-production with the aim of going slower to build relationships and ensure people with lived experiences had the time to contribute meaningfully to the project. Aware of project constraints, such as funding timelines and my PhD deadline, we had the approach that time would ebb and flow — we would go slow when we needed to, and then faster when we could to 'make up' time. This is the linear approach to time. But there are many other ways of exploring time that are worth considering in co-production projects — slow scholarship (Mountz et al., 2015), feminist time (Felski, 2002), Indigenous time (Yunkaporta, 2023) and crip time (Evans et al., 2024). As designers and researchers, we can't separate ourselves from our own values and lived experiences to be 'objective' parts of the research process (Toombs et al., 2017). We're also not static beings and therefore change throughout the project, and so too can our approach to time and temporality. Sometimes this change is intentional, and encouraged by reflexive and reflective practices (see Arm 7: Reflexivity & Reflectivity, p. 243), and other times it is the result of working collaboratively. Changing our approach to time can also be forced on us, such as in my case, where acquiring an energy-limiting chronic illness resulted in managing time differently (with impacts on Care-full Co-production and this PhD).

When discussing slow scholarship, Mountz et al. (2015) write that slowing down also aligns with an ethics of care, encouraging a resistance to productivity for productivity's sake and instead aiming to carry out research with care, and while caring for each other. Alongside this, they suggest that slowing down allows for considering inclusive practices and power asymmetries, which link closely with other co-production principles. In a paper about inclusive practices, Ash McAskill writes:

> Slowness is a concept I pedagogically value and embrace, particularly in the way it invites cognitive multiplicity and diverse rhythms to simultaneously move together. Yet, in the end, slowness was something very difficult to practice in my role as host. Time moved quickly. (Acton et al., 2019, p. 51)

This observation about slowness is a reminder that slowness doesn't mean simple, and in fact, it could be the very act of slowing down that allows the layers and complexity to be visible.

Feminist theory also provides an intersectional lens for lived experiences and temporality (Wieczorek & Forlano, 2024), giving a useful approach for understanding elements of co-production projects. Human geographer Bethan Evans and colleagues (2024) explain that 'crip time' comes from disability justice studies and the movement to reclaim the word crippled, and state that crip time is also interlinked with slow scholarship, feminist theory and ethics of care. Feminist and disability scholar Alison Kafer (2013) coined the term 'crip time' as a way to describe how disabled, neurodivergent and mentally ill people experience time in ways that are different and unpredictable to the linear, normative approach to time. She says "Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds" (p. 27). Expanding approaches to inclusivity through these different perspectives of time ensures that people with chronic health conditions, neurodiversity and other disabilities can participate even when their experiences and management of time might be different. Making a practice of discussing time and sharing strategies for slowing down can make the ways time influences projects more visible (Mountz et al., 2015), which can help with making changes — especially as it is mostly an unseen element of projects. This chapter aims to do just that, explaining the ways different concepts of time can influence a project, ways in which time can be flexible or constraining, and suggestions for working with these aspects.

How might different concepts of time shape a project?

Time is often thought of in terms of efficiency and productivity, especially in research projects carried out in more traditional research approaches and neoliberal academic environments. Mountz et al. (2015) suggest that taking time for care-full (and slow) scholarship can allow for engaging with more people in different ways and increasing the impact and dissemination of knowledge rather than rushing on to produce the next thing that fits within academic measurements. However, Wieczorek and Forlano (2024) note that slow scholarship and common design methods reinforce dualistic or binary ideas of time, for example, slow and fast, rather than other approaches, which are more cyclical or messy and more equitable. Pschetz and Bastian (2018) encourage designers to broaden their perspectives of time beyond binaries or linear

past/present/future viewpoints. Design researchers Aaron Davis, Niki Wallace, Joe Langley, and Ian Gwilt explain "The principles of co-motion create an acceptance of more inclusive aims — to move 'a whole' group forwards without leaving anyone behind" (p. 126), encouraging a collective approach to time to support collaboration. Some other perspectives could be relational time that draws attention to how interactions between people and their different contexts create an individual's experience, and encourages using design practices, such as systems mapping and causal diagrams, to support understanding of interconnectedness and relationships (Wieczorek & Forlano, 2024). Pluriversal time is similar, and as Wieczorek and Forlano (2024) write, it "supports multiple accounts of time and experiences in order to better allow for use/not use of outputs. Here, time is something to reconsider, situating what is happening now into broader political temporalities" (p. 13).

Pluriversal time maintains the complexity of contexts and experiences that coexist. Pschetz and Bastian (2018) argue that pluralistic approaches to time help untangle complex problems and encourage more inclusive understandings of time. Relational and pluriversal time ideas align well with Indigenous views of time, where cyclical connections between past-present-future are openly maintained. This is illustrated in the common Māori phrase "ka mua ka muri" (walking backwards into the future), which highlights that ancestry and actions maintain connections between the past, present, and future.

Cyclical time

Wieczorek and Forlano (2024) suggest that, rather than specific isolated moments in time, cyclical time encourages taking a more holistic view of experiences. They argue that having a cyclical perspective of time interrupts our tendencies to move quickly to solution-building and instead encourages sitting in the discomfort of situations that need deeper understanding, such as experiences of trauma. This is relevant to co-production projects where the plan for progressing forward is not always clear, and to figure out this plan with contributors, time needs to be spent in this uncertainty while listening to people's lived experiences and having conversations to develop the plan. For Care-full Co-production, we described our process as a cyclical one — where we would have a period of engagement with our contributors, then a period to synthesise and think as the core project team, before returning to share with the contributors our thoughts, ideas, and planning the next steps, and so on. Taking this cyclical perspective made it (somewhat) easier to sit with the discomfort of uncertainty, and kept our approach for considering the next step broad rather than only looking for actions that would promote 'forward' movement. Wieczorek and Forlano (2024) encourage designers to think about historical and cultural contexts, create experiences that have space for uncertainty and open-mindedness, and include interactive processes, which can help with taking a cyclical view of temporality.

Feminist time

Feminist theory gives multiple ways of understanding time. For example, Mountz et al. (2015) take a feminist approach to slow scholarship, while Wieczorek and Forlano (2024) write "feminist theory offers a nuanced and intersectional understanding of how lived experiences and temporality intersect" (p. 7). Looking to earlier work from feminist scholar academic, Rita Felski, (2002), she suggests the use of four R's for understanding feminist time; Redemption (looking to the future, advocating for change); Regression (respecting the past to critique the present); Repetition (women operate on cyclical time); Rupture (breaks from the past and emergence of new ideas or states). She argues this approach is more expansive than normative or clock time, and that "repetition is linked to the everyday, and the everyday to woman" (Felski, 2002, p. 25).

Everyday activities are often overlooked because of their repetitive nature, and because of this, they can be undervalued. Paying attention to these everyday activities, such as providing hospitality and considering the small details in communication, has been a large part of my reflexive and reflective practices throughout this PhD. While they can at times seem 'mundane' or insignificant, they can be key to co-production principles of prioritising relationships and sharing power — and form the basis of the ethics of care woven throughout the project. Mountz et al. (2015) suggest that encouraging slower approaches helps make more room for care practices. Talking about the ways we work, and how to go slower, helps make time visible — generally, we can't see all the effort and ways people use to manage their time, but understanding it more can provide ways to support each other. For example, we might just see emails arriving late at night and assume they're working really long hours. This might lead to others feeling pressured to work more, and/or worry about people working too much. Whereas a conversation about ways of working might uncover that that person works best in the evening, so takes leisure time during the day and works later. Developing this shared understanding of flexible time and everyday activities can support team dynamics and care practices.

Repetition is also linked to women by including biological cycles and their embodied experience of time. Felski (2002) suggests that any general discomfort people experience with cyclical time is because of these links to the 'feminine', and suggests that it would be more beneficial to see cyclical and linear times as intertwined rather than opposites. Considering time, and therefore individuals' energy levels, as cyclical can be useful for developing and demonstrating empathy towards each other within a team. Using the four R's — redemption, regression, repetition, rupture — to explain time also links to how we experience emotions. Examples of this are sharing the discomfort of a new approach to research or acknowledging that change can induce feelings of loss and grief, particularly in an ever-changing world (Felski, 2002). Acknowledging and discussing the emotions that are experienced throughout research, and especially co-produced research, is an essential part of relational work, adding depth and nuance to conversations and understandings of contributors' lived experiences.

Crip time

The word ‘crip’ comes from the disabled community reclaiming the ableist slur ‘cripple’ (Evans et al., 2024). Crip time contrasts with normative perceptions of time that include ableist approaches to scheduling and productivity (Wieczorek & Forlano, 2024). This is not solely about accepting that things might take disabled people longer than others or that things might need to go slower, but also about being more flexible and adjusting expectations (Evans et al., 2024). Feminist and disability studies scholars Erika Katzman, Elizabeth Kinsella, and Jessica Polzer (2020) write “In contrast to clock time, crip time is fundamentally grounded in human needs. It is a temporal orientation in which bodyminds, rather than clocks, determine the pace of everyday life” (p. 533). It is an invitation for designers and researchers to go beyond the more frequently considered approaches to inclusivity and accessibility, which enable people to be part of normalised, and generally ableist spaces, and instead create an environment and mindset that incorporates different experiences of time. An environment founded on crip time ideas values rest and reset, incorporating processes that care for one another and are sustainable (Wieczorek & Forlano, 2024). Some key considerations that disability and gender studies researcher Ellen Samuels (2017) suggests include: allowing for dynamic energy limits; widening what is considered productive or valuable; prioritising interdependence (and therefore relationships); and allowing for people to do things at their own pace and to engage using different methods. These considerations encourage designers and researchers to challenge linear approaches to time and how we make sense of experiences, and create room for complexity and messiness (Wieczorek & Forlano, 2024).

One of the considerations that led to the hand-drawn hands exercise (described in detail in Arm 8: Participatory Design Approaches, p. 259) was wondering to myself how we could include people who only had five minutes to contribute — for example, if they had an energy-limiting condition, and that was the most they could do (Müller, 2024). Figure 80 shows an excerpt from the newsletter where I put this thought to the project community. While we made accommodations for people who needed to have their camera off during online sessions, needed extra breaks during engagement sessions, or had to leave sessions early for any reason, the expectation generally was that people would join for the whole 90 minutes or two hours (depending on the session), which didn’t overtly show we were open to other ways of including people.

Trauma-informed approaches fit well within the ‘crip time’ perspective as the expansion of inclusivity, accessibility, and flexibility is likely to make it a safer, more welcoming and more comfortable space for those who have experienced trauma to be involved (Wieczorek & Forlano, 2024). While health experiences are not always traumatic, many are, and sharing health experiences requires a similar vulnerability to living with (and potentially sharing experiences of) trauma. Embedding flexibility into perceptions of time allows for ebbs and flows to occur as if they are a continuous process rather than individual events (Wieczorek & Forlano, 2024). Having multiple layers to the introductory processes we used in our Cuppa & Cake sessions allowed

Figure 80:
Excerpt from the newsletter The Octopus sharing my thinking about including people with energy-limiting conditions. The interesting article is “Why the feminist practice of embodied knowledge is vital for people living with chronic illness” by Madelleine Müller.

Finally…

Anjuli shared this interesting article with the team recently, on the knowledge of lived experience, which links to a lot of things we’ve covered in our conversations. Because of the energy-limiting nature of the author's chronic illness, they’re often only able to do something like write or play music for 5 mins at a time — possibly only once in a week. Anjuli’s been pondering since how we could include people with these limitations into a project like ours, when those 5 mins appear so unpredictably — if you have any thoughts or ideas, please share them with us!

Noho ora mai,
The Co-production Core Team

for these variations in time. It encouraged people to speak at whatever point they felt more comfortable to, and offered them opportunities to add to what they had already shared — rather than expecting everyone to speak for the same amount of time at the same part of the session.

Pschetz and Bastian (2018) discuss how standard time management systems, such as scheduling approaches, are based on Western approaches to time, pace and productivity. As mentioned before, these are generally ableist, which can result in those who are disabled, or with less capacity or power, having to compromise more in order to participate. This is an additional ‘cost’ that is not always factored into project planning or even acknowledged within project reporting or dissemination. From this point of view, our attitude of going slower and only planning one next step at a time potentially helped provide flexible opportunities for contributors to be involved. Our engagement sessions ended up quite spread out, so the demands on contributors’ times weren’t all close together. As part of the process for sharing the summary of the Cuppa & Cake sessions back to contributors, we offered a variety of options. Instead of only group sessions, we also offered people to have a conversation with us individually, which three people chose for multiple reasons, including making it easier to concentrate as they didn’t have to interact in a group setting (which would require extra energy). Pschetz and Bastian (2018) suggest that time would be better understood as a process of coordination and social negotiation. Understanding the power dynamics involved in a project and how they show up in approaches to time within co-production projects is important, and understanding the elements of crip time that support the complex nature of these projects can help navigate these aspects.

What are the constraints of time you're working within?

Projects often have time constraints that are not flexible, so it is worthwhile highlighting these and ensuring the whole project team is aware of them. Having the whole team aware can help minimise tensions and encourage the team to embrace different paces of working as needed. Project funding generally comes with a specified time limit, for example, The Co-production Project, and therefore Care-full Co-production had a three-year limit. There is a balance to be found between having a well-funded project and the issues arising from neoliberal universities' expectations of productivity (Mountz et al., 2015). These expectations can conflict with the fluid and flexible time approaches that a co-production project favours. The amount of funding will also impact the time available, as relational and participatory research often requires more resources. Having discussions about what is possible and what constraints there are on resources is something that needs considering as part of the funding application process. It is also worth revisiting this early on during the building the conditions period to ensure these plans are still achievable, and to make sure everyone in the project has the same information.

Time constraints of academic processes

Specific academic processes can also impact timeframes and experiences of time of a project. Gaining ethics approval generally requires fitting in with the meeting schedule of a university's ethics committee, and then there may be additional time required if changes to the application are requested. This can result in slowing a project down, especially because recruitment of contributors cannot begin until the application has been approved. Due to the 'conundrum of getting started' and the difficulty of planning a whole co-production project from the beginning, it is likely that multiple ethics applications are needed. This can result in a mismatch between the stages of relationships — if someone (or a community) is trusting and open to being involved in the project, but the ethics process slows that down while approval is gained.

Another academic process that can feel constraining is university payment processes. In Care-full Co-production, we did not experience this for our contributors, as we were able to purchase the vouchers we gave as koha in advance. However, for those in the core project team who travelled as part of the project, there is an expectation that they will pay for expenses up front and get reimbursed afterwards. This process can be slow and time-consuming (Bell & Pahl, 2018), and it assumes that team members have the financial capacity to pay for things they might not normally spend money on (e.g. meals and taxis), and then have to wait a month or more to be reimbursed. I was only in a position where I was able to cover expenses and wait to be reimbursed because my financial privilege meant I was not trying to live solely off my PhD stipend. To try to use a different process in the reimbursement

system requires an individual to expend more mental labour to request an alternative, and not everyone has the confidence or power to make these requests.

Capacity limits of team members

Another constraint that can impact projects is the capacity limits of team members. This may be due to other commitments, or other human experiences such as neurodivergence, chronic illness and disability. Within Care-full Co-production, most of the core project team were also working on other projects throughout the three-year time frame, which relies on managing priorities. The contributors also had other commitments, as the project was not necessarily their paid employment or study focus, so they were juggling multiple requests for their time. For me, it was the main focus. PhDs come with their own timeframes and deadlines, though, and these need to be woven into the timeline of a project that has a PhD embedded in it. As Billo and Hiemstra (2013) wrote:

> We emphasize that these constraints may be more daunting to PhD students, who are only just beginning a project. Time is of the essence, and the feeling that it is rapidly slipping away can add to a mounting feeling of panic. Moreover, we found that the power dynamics linked to graduate school relationships follow the PhD student into the field, and present a constant challenge to prove oneself. (p. 317)

Acquiring an energy-limiting condition as well as other health challenges throughout the time period meant that taking on a flexible crip time approach was somewhat forced upon the project. For example, there were occasions where I needed to spend a week resting and not working at all, to recover from a series of engagement sessions, which fortunately, our flexible approach to time and productivity was able to accommodate. It is noteworthy that our accommodating attitude to time and pace from the beginning of the project made it possible to work with these unexpected capacity constraints, supporting and caring for each other as a team and still complete the project within the allocated time frame.

What are the flexible aspects of time you're working with?

Looking at where time might be flexible for a project can make it easier to sit with the discomfort of uncertainty. It is not always possible to plan a co-production project from start to finish, but having an idea of when there is flexibility to change the pace of a project and to embrace the complexity and disarray can help minimise this uncertainty (Wieczorek & Forlano, 2024). Billo and Hiemstra (2013) encourage embracing flexibility as a specific tool and using it to the advantage of the research project. While discussing a project in primary health care, their example of using

flexibility to transfer the research proposal into the 'field' aligns with design's iterative approach taking place "within a culture of revision, evolution, and feedback" (p. 317).

The three-year project funding was generous and gave us freedom and flexibility to go at the pace that best suited the project team and contributors. Building relationships for longevity, not just for the sake of the project, also allowed for slow starts and soft endings, rather than a hard, definitive finish. Haverkamp (2021) shared that her colleague's "'goodbye' was not an end to the project, but a vision of a cyclical, continued relational research commitment, reminding me that this research is in its infancy, and that this is just the beginning of our relational research engagement" (p. 12). This reflects our approach within Care-full Co-production, and while we've had the celebration events to gently finish the project so far, and my PhD (once) completed, we continue to think of the project in a way that allows continuation. Embracing complexity and fluidity can support flexibility within a project and enable human-centred and sustainable environments that support people in the projects to thrive (Mountz et al., 2015).

What processes or ways of working can you put in place for this project to maximise the flexibility of time & minimise the constraints?

A 'continuous handover' practice

Taking inspiration from feminist and crip time approaches can lead to ways of working that are more inclusive in general, and allow for a flexibility that normative time might not. Bazalgette (2023) suggests embedding a practice of 'continuous handover', where team members maintain up-to-date record keeping and handover notes, so if an individual were unexpectedly unavailable, the rest of the team could pick up where they had left off. While this is an extra task and heavily reliant on written communication, when done 'continuously' and by all team members, it often becomes easier and requires less labour. For Care-full Co-production, this showed up in different ways, such as using Slack (an online team communication platform) for project communication, keeping documents like run sheets and session organisation plans saved in online folders that the whole team could access, and having multiple team members who could facilitate engagement sessions as needed. The situation where a form of continuous handover was not in place was our communication with contributors. Most direct communication, particularly when organising an engagement session, came from my university email address, which no one else had access to — fortunately, I was always able to check this, so it did not become a difficulty. For our first round of engagement, the Cuppa & Cake sessions, we had used an online ticketing platform, which meant more than one person had access

to this information. However, there were often individual changes made via email, so I had to ensure that information was shared. We did try to move the direct communication into Mailchimp, as we were using this for the newsletter, so all contact details were saved there. This would have allowed anyone in the team to look after direct communication. Unfortunately, we found that these emails got missed more than direct emails from a person's email address, so it was not very effective for getting people's involvement. A specific project email address could have been a solution for this.

Synchronous and asynchronous modes of interaction

Time is often about building and maintaining momentum, but this can be difficult when there are large gaps between engagement sessions. To help with this, and to give contributors flexibility, we looked to have a mix of synchronous and asynchronous modes of interactions — these were also discussed in Arm 4: Prioritising Relationships, p. 189. Davis et al. (2021) state that "the way in which co-design can engage with people across longer time periods and build evidence through asynchronous participation is not often recognised as being of significance in projects, despite the use of methods that may allow this" (p. 127). For Care-full Co-production, we certainly acknowledge that asynchronous modes of interaction were beneficial to our process.

An asynchronous tool we used was a Miro board (like an online whiteboard, seen in Figure 81) for the project that collated contributors' input through conversations — it was also available all the time, so contributors could go back and add more at any time, or anyone who was unable to attend a session could also add their thoughts. As part of the research question development phase, we also used asynchronous methods — direct individual emails, and the platform Padlet (seen in Figure 82) — which allowed individuals to respond at a time and location convenient to them, and also let them take as much time as suited.

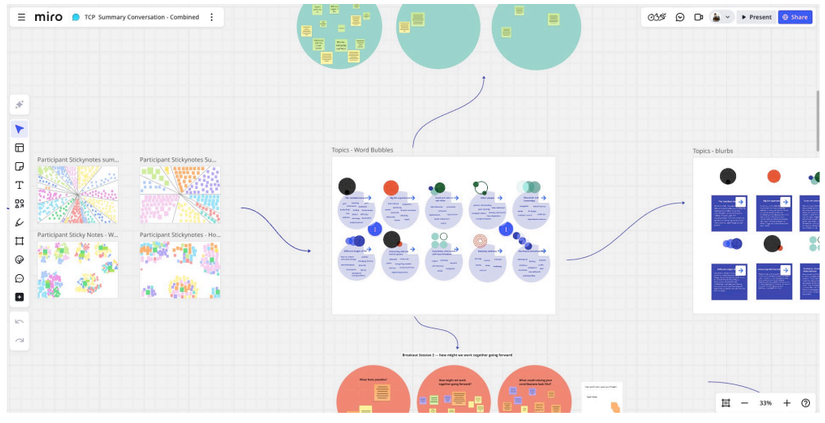


Figure 81:
A Screenshot of part of the project Miro board.

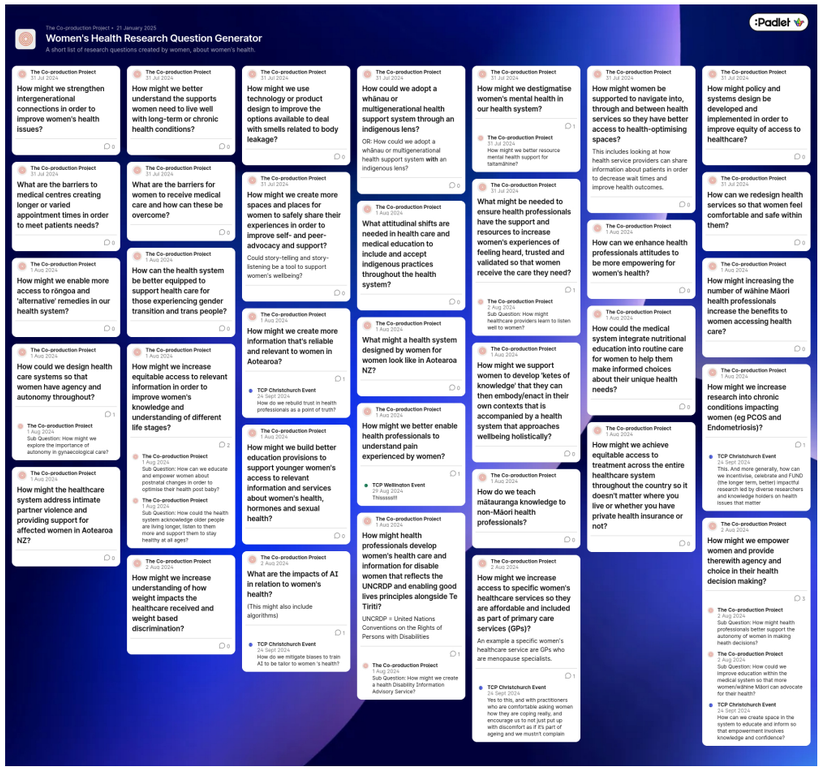


Figure 82:
A screenshot of Padlet showing the list of research questions we developed.

We held both online and in-person sessions to develop research questions, providing opportunities for contributors to participate in various ways, depending on their preferences. Our other asynchronous method was a monthly newsletter (discussed previously in Arm 4: Prioritising Relationships, p. 201), which kept people connected to the project in between our other forms of engagement. One contributor highlighted this connection when they commented:

> "Sorry that I have been unable to attend other co-production events and catch ups, the times all seem to clash with my kids' activities. I do read the emails that come through and follow the progress the project is making."

The mix of synchronous and asynchronous methods, as well as not requiring contributors to commit to a specific amount of time, created an environment where they could dip in and out of the project as suited them. This gave individuals the flexibility to be involved based on their needs and preferences, and gave the core project team flexibility in organising opportunities for input — we did not need to coordinate sessions that had everyone attend every time. Kidd and Edward (2016) noted that life changes, variable motivation and interest, and project changes took their toll on their project, and who remained involved. They commented that "the number of researchers on the team is less important than their desire to be included" (p. 284). This aligns with my experience of Care-full Co-production, where having no fixed or specified way of being involved meant that interest and enthusiasm for the project were prioritised, and allowed more people to be part of the process.

Mountz et al. (2015) suggested as part of their slow scholarship approach to "Count what others don't" (p. 1250) as a way to push back on academia's normative approach to productivity, which mostly counts outputs. As part of Care-full Co-production, we counted how many 'cuppas' the project was built over, throughout the duration of the project (Figure 83). It was not a precise measure necessarily, but it was a way to visualise the importance of relationships and interactions in the project. Cuppas were counted based on having a cuppa with someone, not just having one as an individual. In a conversation about building trust between Māori and Pākehā that Te Huia Bill Hamilton (Ngāti Kahungungu, Ngā Rauru, Ngāti Raukawa), a Te Tiriti o Waitangi and human rights specialist, facilitated, one of his participants commented that 100 cups of tea were required to build trust (Hamilton, 2023) — this speaks to the collective aspect of having a cuppa together, and the length of time it can take to build trust.

Figure 83:
Cuppa counts from Nov 2023, July 2024, & Sept 2024.

Counting cuppas draws attention to the work that happens within a project, not just what comes out of a project. Drawing attention to the interactions that grew the project, and how these can be 'seen' also demonstrates Pschetz and Bastion's (2018) point of moving "from time as flow to time as social coordination" (p. 172). Managing the time of a co-production project is not just about managing the pace of work or scheduling engagement sessions, but is also about coordinating the relationships and social interactions, which can benefit from a flexible and non-linear perspective of time.

How does time indicate value, or not?

Time is often reduced to a monetary value, based on Western notions of efficiency and productivity (Pschetz & Bastian, 2018), but there are also other ways time is used

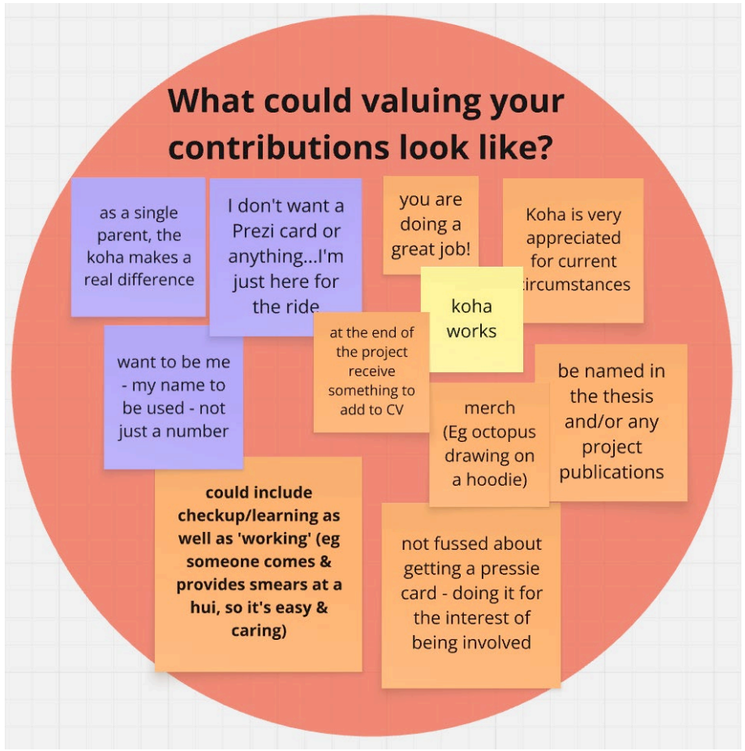
to indicate value. People often talk about being ‘on time’ as a form of respect, and about sticking to schedules as a way of valuing people’s time (by not taking advantage of it), but these may be constraining projects and perspectives of value. In Care-full Co-production, one of the ways we valued contributors' time was by making sure we stuck to the agreed schedule and always finished on time. However, this did remove some of our flexibility and meant we were not in a position to adapt as we went if the conversation appeared as if it would benefit from more time. Some of the contributors said in their feedback that they would have liked more time:

> “I left the session feeling “oh, it went so quickly”, “I hope the next session is a bit longer” and warm and fuzzy.”
>
> “I felt like we were just starting to get into the conversation when we ran out of time.”
>
> “I would have been happy to spend longer discussing the post-it note thoughts.”

In hindsight, we might have benefited from negotiating some flexibility in the session finishing time beforehand, so that we could be more responsive to how the session happened. Interestingly, we often took a flexible approach to sessions that only involved the core project team. While contributors needed the ability to plan in advance, if we had had a more flexible approach to our conversations with them, I wonder if that would have been experienced by the contributors as being more equal. In contrast, when we were invited to meet with the group of wāhine Māori, we were advised to have a more fluid schedule and to allow sessions to go for as long as people wanted to talk. This fits in with Indigenous perspectives of time and moves the focus away from efficiency, although it can make it harder to plan sessions and give people an experience they appreciate.

Giving contributors a koha or monetary compensation is part of valuing their contribution. In the United Kingdom, co-researchers are often paid an hourly rate (National Institute for Health and Care Research, 2024) in a way that focusses on contribution as time. Bell and Pahl (2018) argue that if academics are being acknowledged for the cumulative knowledge and experience they bring, then co-researchers or contributors need to be recognised for their cumulative lived experience and emotional labour they share with the project. Giving them an hourly rate similar to what an academic might be, could be one way of demonstrating their ‘lived experience expertise’ is valued alongside their time. Academics often receive rewards or recognition from the research they’re involved in, such as publications and employment opportunities. Considering ways that contributors might gain other rewards or recognition through their involvement, besides a monetary koha, could help move beyond time being the focus of what is valued. Thinking about how time and experience are valued can hide or highlight power dynamics, and different perspectives of time can help unpack this. We asked the contributors in Care-full Co-production for suggestions of how they would like to be valued (seen in Figure 84) — this is what led to their first names being included in the introduction of this thesis. Taking a holistic view of contributors’ experiences within the project, rather than just considering specific tasks they are part of (Wieczorek & Forlano, 2024), can help to look more broadly at how time is valued, and at whether time indicates value.

Figure 84: Contributors ideas of how their contributions could be valued.



Summary and provocations

This Arm discussed how taking different perspectives on time might influence a project, specifically looking at the concepts of cyclical time, feminist time and crip time. These three concepts of time give an alternative or additional view to the normative, linear time, i.e. ‘clock time’ and align with the complex and messy processes of co-production. Feminist time and crip time perspectives also encourage expansive thinking about how to include people with care. While crip time comes specifically from considering disabled, neurodiverse or chronically ill people, acts of care that will aid their inclusion are likely to be of benefit to many others too.

Considering the aspects of temporality that might constrain research can be useful for planning and decision-making. These potential constraints may come from academic processes and expectations as well as the capacity limits of team members (such as their own health or disability needs). Identifying the flexible elements can help counterbalance the constraints or give space for thinking of new ways of working. Adopting asynchronous and synchronous methods of working can provide different options for working flexibly with people while maintaining project momentum, and a continuous handover approach can build sustainable practices into a project. Time is often equated to money and value, but reflecting on whether that encapsulates contributors' input to a project is an important part of the process to elevate lived experiences. Exploring our perspectives and approaches to time can bring new insights to the principles of co-production.

The provocations that make up this arm are:

» How might different concepts of time shape a project?

» What are the constraints of time you're working within?

» What are the flexible aspects of time you're working with?

» What processes or ways of working can you put in place for this project to maximise the flexibility of time & minimise the constraints?

» How does time indicate value, or not?

Arm 6:
Language

What are the words specific to the research context or question?

Is the language being used the most inclusive option?

How can everyday language aid with communicating within and about the project?

What can language ‘do’?

Arm 6: Language

Throughout this project, considerable time has been spent considering the importance of language and the meanings and uses of words. Social work researcher Nigel Parton (2003) states that from a constructionist point of view, language not only describes and explains aspects of our experiences and the world we live in, but also creates aspects of our experiences — especially within relationships. Language is how we make sense of the world and our experiences, and is how we build connections with others. As Mountz et al. (2015) explain "writing is both personal and collective; what we say and how we say it matters" (p. 1252). For relational research, where time and resources are put into building and maintaining positive relationships, finding (or developing) a collective language is necessary for building shared knowledge and solutions (Sanders & Stappers, 2012; Verwoerd et al., 2022). Health researchers Shemana Cassim and colleagues (2021) explain that words can have inherent power, which may reinforce existing power asymmetries or help to disrupt power differentials. Words can also include or exclude people and experiences, so being intentional about the words and terms used is important. Organisation studies scholars Janet Sayers and Deborah Jones (2015) suggest positivist research relies on empirical data and assumes language use is objective, whereas relational research, such as co-production, values personal experiences and subjective language. Language has multiple meanings, and it can be easy for communication to be misunderstood or interpreted differently than intended. While it is important to begin with the best possible word choices, it is important that all people in co-production projects feel able to ask for clarification, and that iterative approaches then incorporate this feedback. A reflexive and reflective practice (discussed further in Arm 7: Reflexivity & Reflectivity, p. 243) is an important aspect of using language intentionally

What are the words specific to the research context or question?

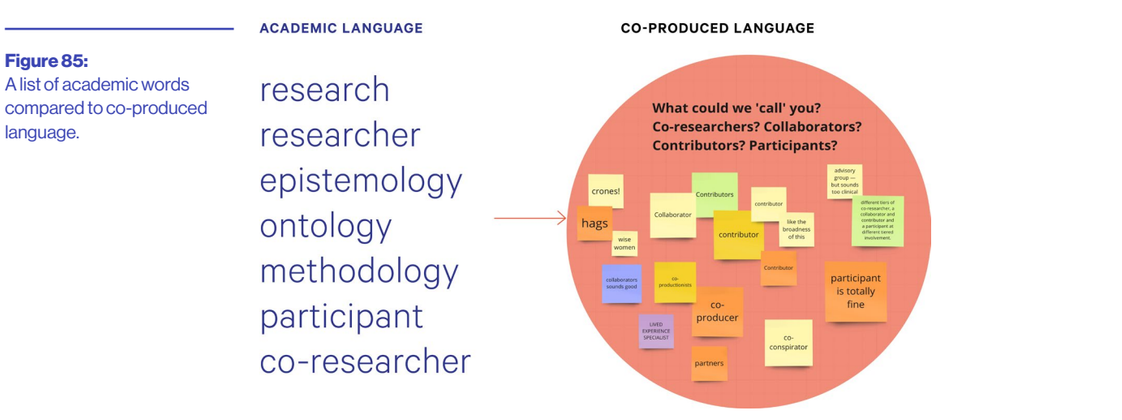
It is easy when working with people in the same field to assume that everyone understands the words being used, but often the words have different meanings in different disciplines, and can have different everyday uses. Taking time to reflect on what words might be discipline or research context specific can help identify

words that may need explaining or changing. This section has been split into a discussion about words related to research more broadly, and a discussion about the words beginning with 'co-', and how consideration of their meanings and uses might influence a project.

Research words

There are lots of words that are frequently used within research spaces — researcher, participant, data, analysis, method, methodology, epistemology, expert, to name a few (Figure 85) — and they can come with impressions, feelings or preconceived ideas based on past experience. For people who have been 'researched' or participants before, these may not be positive experiences. Because of these associations, by telling people we are 'researching women's health' (or whatever topic it is), we can end up constraining our ability to carry out research differently. Even though our aim has been to share power and use terms that describe the role (e.g. contributor), we still end up with labels for the different people involved — particularly in written outputs — that can reinforce the power asymmetries we are trying to reduce. Changing the terms we used from researchers and participants to core project team and contributors — or co-researcher for projects that use that (Phillips et al., 2021) — still creates separation and difference.

Figure 85:
A list of academic words compared to co-produced language.



The term 'research question' has similar associations attached, which may have influenced why people interacted or didn't interact with the Padlet board of questions at the project celebration events. As one core project team member reflected after our Wellington event, something they longed for was:

> "That more people had interacted with the research questions — but maybe 'research question' is off-putting?"

In our sessions with contributors, we had more time to discuss what a research question is and ensure everyone felt able to contribute useful ideas and questions. We also had a participatory method (see Arm 8: Participatory Design Approaches, p.259, for a fuller description) that provided prompts and support for creating research questions. The extra time and hand-holding through the process, along with the existing relationships we had with people in these sessions, may have helped our contributors move past any negative preconceived ideas or uncertainties about developing research questions. These processes were also collaborative, whereas the way of interacting with the questions at the celebration events was more individualistic — which demonstrates one of the benefits of the co-production approach itself.

Even though the research questions were created by our contributors, the language used wasn't entirely comfortable for all of them. In response to our request for feedback on these research questions, a contributor told us:

> "I've just had a quick look at the online board. For me some of those questions are a bit hard for a lay person to understand. For an academic I can imagine they make perfect sense – but for a lot of women I think they would look at some of those questions and be like "What" 😊 For me – simple is best."

The work of Care-full Co-production and its women's health case study easily fits within a feminist research approach, and my PhD has taken that approach here. However, we have never described this work elsewhere as being feminist research, predominantly because there are varying understandings of how feminism and feminist research are enacted. People have also had different experiences with these words and processes, which we did not want to influence their experience of this project. Askins and Blazek (2016) share how, in a participatory action research proposal, using the word 'feminism' was cause for concern for the community members they were working with. Their collaborators had different emotional responses to the word and understood it in ways that were different to Askins and Blazek's academic knowledge of the concept. This example suggests we were wise not to describe the project as feminist research, although we have no specific reactions from contributors to base this on. Avoiding using the word did not change how we carried out the project, but likely helped keep it broad and inclusive.

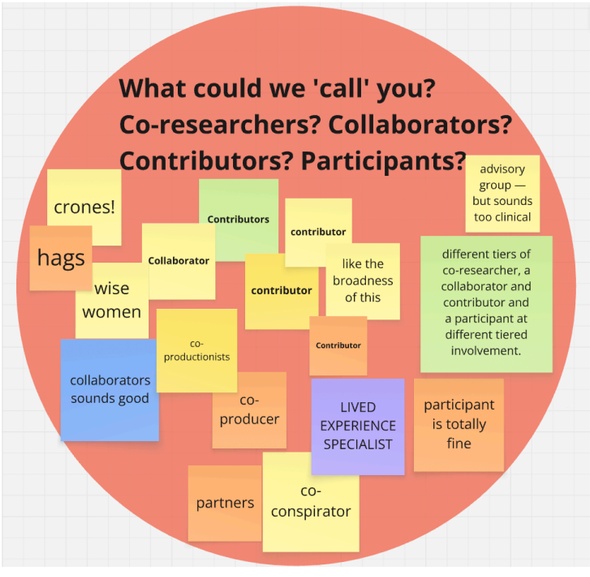
All the 'co-'s'

There are many different 'co-' words in the field of participatory design, including the more commonly used terms of: co-production; co-design; co-creation; co-delivery; co-evaluation; co-researchers; and co-governance. As discussed in the Ocean: Context Review, p. 41, the meanings of some of these words often overlap, and they are used interchangeably at times. Design researchers Euan Winton and Paul Rodgers (2024) claim that because design has come to mean a broad range

of things, and is not limited to specific education or work spaces, definitions and understandings are often fuzzy — which adds to the lack of clarity of the term co-design, and also co-production. These fuzzy and contested definitions of co- words, along with terms such as public involvement, engagement and participatory action research, can make it difficult to comparatively evaluate different projects, which, as Locock and Boaz (2019) argue, can lead to dismissing some work as being less 'co' than other projects. They also mention that the boundaries between definitions or approaches may actually be less about a difference in application and more to do with the differing origins of words — more 'language work' could help clarify each project's contributions and avoid territorial protectiveness.

'Co-researcher' is another term that needs consideration — on the surface, it appears as a simple way of sharing power with the people who in other projects would be called participants, and a nice way to elevate the value of people who are experts of lived experience. However, what we discovered in Care-full Co-production is that this word felt like it carried a responsibility and burden that our contributors did not want. This partly reflected that the project was not part of their paid work and/or full-time commitments, and was also because they did not feel they were doing enough to warrant the term. The people in our project discussed the terms they might choose instead and chose the term 'contributor' based on what they felt comfortable with (Figure 86). Knowles et al. (2021) also note "Public contributors refers to members of the public with lived experience as patients, service users or carers who are actively involved in research as collaborators rather than as participants" (p. 3). Perhaps the term 'contributor' will become normalised for collaborative, relational research projects, but for now, even this word needs clarifying when sharing work.

Figure 86:
Responses to the questions What could we 'call' you? Co-researchers? Collaborators? Contributors? Participants?



Is the language being used the most inclusive option?

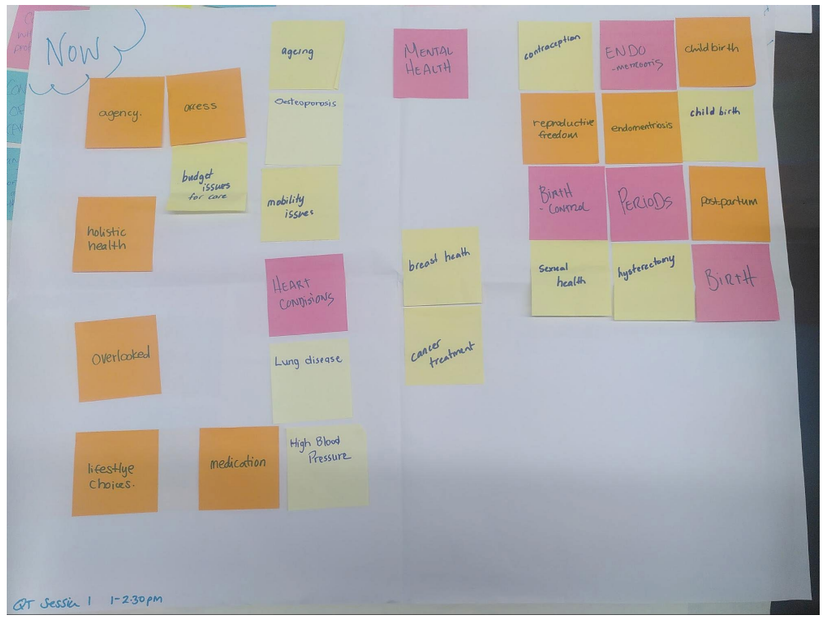
Language can intentionally or unintentionally include or exclude people. As Vivienne (2023) writes “Language itself can be alienating, impenetrable or incomprehensible, or with multiple simultaneous meanings” (p. 86). For Care-full Co-production, we spent a lot of time considering the terms ‘reproductive health’, ‘gynaecological health’ and ‘women’s health’. Reproductive and gynaecological health focus on body parts or functions, and may not always include trans women, non-binary or gender diverse people. We also considered the phrase ‘people with a uterus’, however, this excludes trans women, people who have had a hysterectomy and others — and we felt it was not how many women refer to themselves. In our recruitment information, we used the phrase ‘self-identify as women’ — hoping this indicated an attitude of inclusivity — while also acknowledging this was likely to exclude some people (e.g. non-binary and gender diverse). We would have liked to be more inclusive, but at this stage, did not think we had the right people in the core project team to hold this space. In this situation, we chose words that allowed us to best align with the project's principles and values, while acknowledging that we were unable to include everyone we would have ideally included. As part of our getting started phase, we thought asking women what women’s health meant to them would be useful, rather than our core project team defining it. We used a sticky note exercise to capture thoughts (seen in Figure 87 and 88) alongside conversations. One response said:

> “I think for me it is literally everything, so physical health, mental health, everything that effects us, just as sometimes it does men. And then you have, of course, those things that you know, [are] particular to women.”

As the initiators of projects and the people generally with more power in a project, the designers or researchers tend to be the ones choosing the words and language that get used. While normally well-intentioned, we can often talk about empowering people who might have less power, less agency, less resources, etc, or we describe ‘making space for’ or ‘giving voice to’ communities that are less heard, or have been categorised as vulnerable. Social work researchers Christa Fouché and Laura Chubb (2017) argue that categorising communities with the word vulnerable creates a power imbalance and assumes that the people/person doing the categorising has more power (and therefore is not vulnerable). To say one is going to ‘make space for’ someone else suggests an ownership or privileged access to that space, and suggests others need permission to be there. This is often the case for marginalised groups, such as Māori. In situations like these, a more suitable phrase could be ‘returning space’ — which acknowledges the impacts of colonisation in Aotearoa New Zealand. As design researcher Eleanor McGechie (2024) wrote in their interrogation of language and power, we so often use words such as ‘empowering’ to do things to other people, which inadvertently reinforces the status quo (no matter the good intentions). M. Parsons et al. (2016) also discussed the impacts of words:

Figure 87:
Contributors responding to the prompt “So what are the words and phrases that come to mind when you think about women’s health? Or how do you define women’s health?”

Figure 88:
Responses, during a Cuppa & Cake session, to the prompt “So what are the words and phrases that come to mind when you think about women’s health? Or how do you define women’s health?”



> For example, several indigenous workshop participants noted that the concept of 'transformation', which was a major theme in the workshops, had negative connotations because of colonization and the forced transformations indigenous communities have had to endure. This stimulated a rich discussion on the roots of concepts in use. (p. 102)

Like most things, though, individuals will experience words differently and have different preferences for word use (Montgomery et al., 2021), and it can be difficult to use words that suit everybody. It can be important to have conversations with those involved and then make conscious decisions about what words to use, while maintaining awareness of their impacts. Sometimes this may result in using one set of words when communicating with individuals and others for group-level communication. It can also mean we need to use more words and take a bit more time to explain concepts. Like with spaces, sometimes we need to aim for 'safe enough' (Vivienne, 2023), rather than trying to guarantee our words are safe and inclusive to all (and then not meeting these expectations).

How can everyday language aid with communicating within and about the project?

Communications scholar Roslyn Petelin (2010) explains that 'plain English' came about as a response to power asymmetries between government departments and legal institutions, and the 'general public', with the aim that more people would understand laws and government policies. In general, plain English refers to using everyday language that is not specific to a discipline, field or particular job, does not rely on jargon or acronyms, and is clear and easily understood. To move away from the colonial connotations of specifically focussing on the English language, I use the term 'everyday language' instead of 'plain English', as this allows recognition of Māori words that have become part of Aotearoa New Zealand's everyday use.

When we work or study in a particular field for a while, we often lose awareness of how different our field-specific language is from everyday language, and no longer notice the jargon or acronyms. Taking time to intentionally consider the words we use can help with identifying words or phrases that may need to change. I always found it difficult to explain what Care-full Co-production was about, and co-production itself, without using lots of academic words or jargon. It was a relief to receive this feedback from one of the contributors, partway through the project:

> "I'm a high school dropout and I think you guys…do a really good job of using everyday language, the majority of the time and it makes it very accessible for someone like me. I appreciate it."

The 'someone like me' part of this quote also highlights the privilege (and therefore power) that can come with further education — so everyday language can be important for disrupting power asymmetries.

Participatory approaches can make it easier to use everyday language, particularly because these methods often make other options besides the written word available. This can also help with developing a shared language for a project. As Sanders and Stappers (2012) write:

> A participatory mindset can break down the disciplinary and/or cultural boundaries. Add to that the tools that can put everyone on the same playing field and support a shared language, and you have a design space that supports the exploration of new ideas, even in wicked problem situations. (p. 23)

Their thoughts on breaking down boundaries are particularly relevant to co-production projects where there is likely to be an interdisciplinary or transdisciplinary team and people have a wide range of lived experiences.

Development of a shared language, or shared understandings, can open up new ways of explaining and sharing experiences — this is an example of capability building, which is a key principle of co-production (Sanders & Stappers, 2012)— that can encourage contributors to take these new capabilities outside of the project. At the end of one of our Cuppa & Cake sessions, a contributor commented:

> "I love being able to just share narrative and talk openly. I think there's power in that. Yeah, and I think we've probably lost our power a lot in society, because as women we don't have the space. But this, you know, this kind of stuff invigorates me to go back out and say, actually, I do have my period this week, you know, and that's okay. So you know, I think beyond what you're doing for the research, which sounds amazing. It also has given me, yeah, more oomph to promote this more and to yeah like question researchers, get the advocate part of me to go forward."

This is an example of an impact from the project that is immeasurable and has the potential to ripple outward without our ability to see any further impacts.

Everyday language is also more inclusive and accessible — as jargon and acronyms exclude those who do not understand them. Accessible language is important in co-production projects to ensure that those who will be affected or benefit from the research can understand and access the knowledge produced. This can contrast with academic expectations of how and where knowledge is disseminated. Enright et al. (2016) state:

> increasingly challenging in a context where there are counter-claims for jargon-free, accessible publications that speak to a wider audience, and sometimes even calls for collaborative writing as well as co-produced research design. (p. 47)

Co-production practitioners often need to move between the types of languages used to match the needs and expectations of the audience. Everyday language is likely to be easier for everyone to understand; however, as sociologist Damien White (2015) writes, with some audiences, a more academic or 'science' based language may have more legitimacy. Sometimes we may need to intentionally push against these concepts of legitimacy to broaden accessibility.

What can language do?

Considering what language can 'do' is not an argument for objective language, as other forms of empirical research might make. Rather, it is a call for intentionality and awareness — and an expansion of the ethics of care. Words create things and influence processes in ways that can often go unnoticed. For example, the way we give instructions for participatory methods can influence the results of these methods. They're not experiments, so we don't aim for having exactly the same words every time, but from a reflective iterative perspective, observing differences can be valuable. As one of the introductory activities in the Cuppa & Cake sessions, we often asked people to introduce themselves as if doing so for visually impaired people. This led to delightful descriptions and sharing of the stories behind jewellery or items of clothing. It also sometimes resulted in potentially unhelpful focusses — if the first person made a comment about their weight or body shape, others frequently did too. However, if that first person focussed on other things, such as the colour of clothes, then generally weight was not mentioned by anyone.
An example:

> **Prompt: Introduce yourself to everyone in the room in a way that might make sense to people who are visually impaired and tell us about something that you love doing.**
>
> **Person 1:** I'm quite tall and I have kind of chin length, brownish going slightly gray hair and **sort of angular**. I really love trees and sometimes I hug them because they make me so happy.
>
> **Person 2:** I have shoulder length hair. And I'm probably **rounder than** Person 1. Talking about myself, nah haha.

> **Person 3:** Kia ora I'm (name) and I'm probably shorter than most people in this room. I have shorter length curly frizzy hair starting to go grey and I'm really stoked about it, **I'm not that shapely**, I was when I was on the pill.

Discussing weight or body shape is not necessarily an issue — in fact, we wanted everyone to be comfortable sharing any experiences. However, many women have been dismissed by healthcare professionals, simply being advised to lose weight rather than receiving the appropriate medical care (Dusenbery, 2018). Unintentionally setting contributors up to focus on weight or body shape as part of their introduction may have influenced how comfortable and safe contributors felt in the rest of the sessions. I must also acknowledge my personal discomfort with weight-focussed comments, and how this added to the complexity of navigating being vulnerable with the groups at the same time as not burdening them with concerns about my feelings. As Vivienne (2023) mentions "With an awareness of our own body, facilitators can model the curiosity they wish to elicit in their participants. Unconsciously, we mirror what we see and can be coaxed into a mutually receptive state for learning" (p. 191). The observation about the impact of words in the introductory exercise was not made until the synthesis of transcripts. If the observation had been made earlier, we could have intentionally changed our process, as part of setting up an inclusive environment. This also aligns with the discussion in Arm 3: Power p. 173, about our responsibility to the world we are contributing to, and whether we try to change social narratives (for example, fatphobic narratives about weight and body shape/size).

Ahmed (2016) discusses how the existence of policies sometimes provides a way for people and institutions to not do things — because the words exist, people think they are being done, so no one checks for actions or accountability. For example, she writes "Indeed, intersectionality can be said in order not to be done, as if saying it is doing it, almost as if the word takes the place of something" (Ahmed, 2016, p. 4). In Care-full Co-production, we had the Project Values and Expectations document, setting out the way we aim to work as a team and within the project. This always seemed like a good thing — we could show the project was values-based — but did we actually have the actions that go with it? Individuals were asked to read the document when we first co-created it, but I am unsure if any of us ever revisited it or specifically followed it. There were not really any disagreements or conflicts in t he project, but I am unsure if this was because we actually dealt with things well or because people did not feel comfortable voicing them. Words in all forms, written or spoken, are important and have consequences — we need to pay attention so that more of these consequences are intentional.

Summary and provocations

Language is powerful and can have unintended consequences. Consciously thinking about what the impacts of words could be, and whether those impacts are desirable or not, can help with the success of a project. The context of a project, such as women's health or even research in general, can influence the words likely to be used as well as jargon or acronyms that might be common. Defining and explaining words or acronyms is helpful for ensuring everyone understands and is included, but going further to have a shared language with those who are involved is beneficial for collective understanding and identity. A shared language may not result in everyone feeling safe (enough) or included, as it is difficult to get consensus on the words' impacts. However, having the conversations to share how words impact different people involved in the project, and considering alternatives, may help people feel more comfortable with word use, even when those words are not their preference.

The provocations that make up this arm are:

» What are the words specific to the research context or question?

» Is the language being used the most inclusive option?

» How can everyday language aid with communicating within and about the project?

» What can language 'do'?

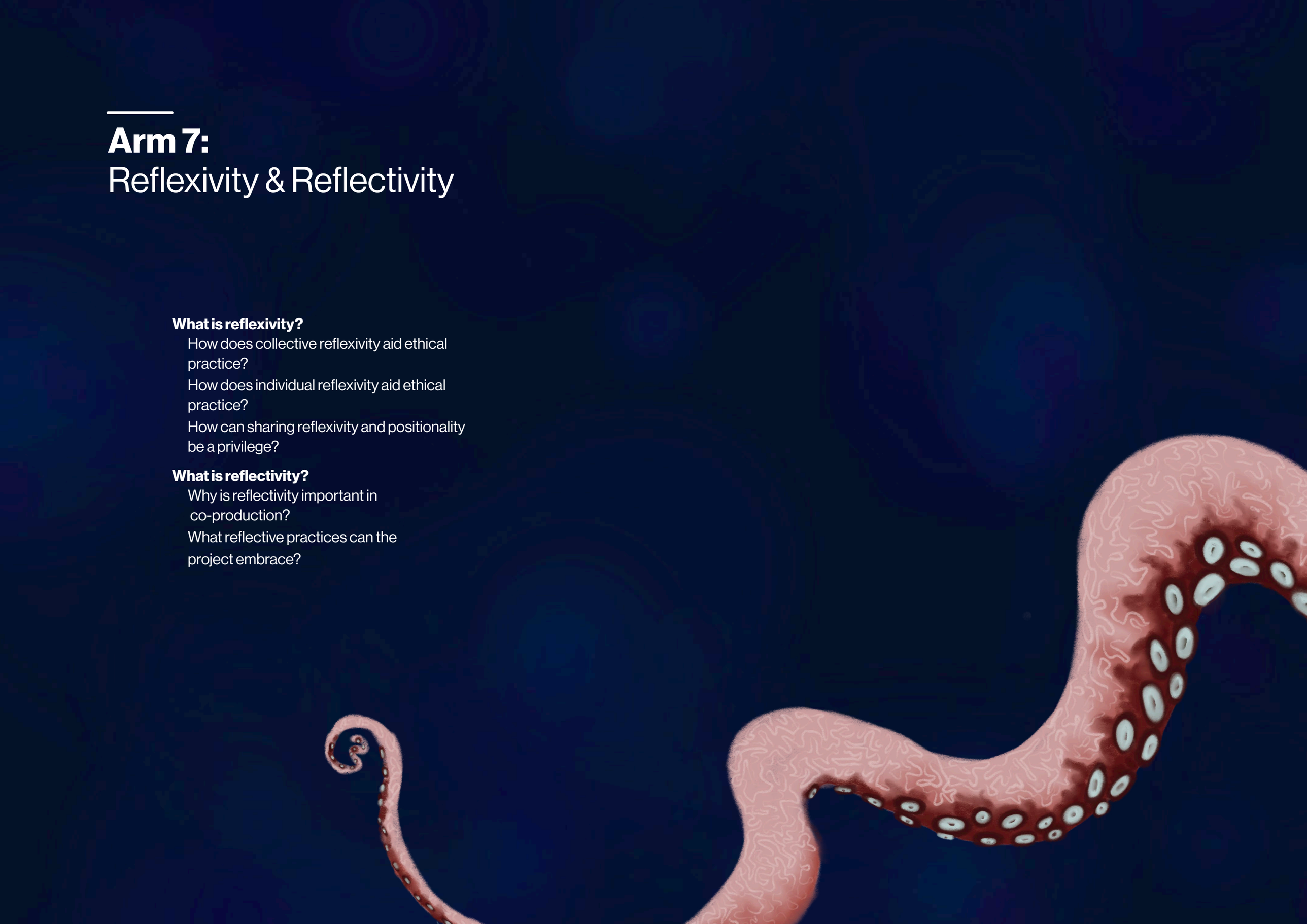
Arm 7:
Reflexivity & Reflectivity

What is reflexivity?

- How does collective reflexivity aid ethical practice?
- How does individual reflexivity aid ethical practice?
- How can sharing reflexivity and positionality be a privilege?

What is reflectivity?

- Why is reflectivity important in co-production?
- What reflective practices can the project embrace?



Arm 7:
Reflexivity & Reflectivity

Reflexivity and reflectivity are meaningful aspects of relational approaches to research, and useful for approaches such as co-production. Both reflexivity and reflectivity can help us build our awareness of other people and their experiences, and through that, we can develop and increase empathy and compassion. Participatory public engagement scholar John Forester (1999) reminds us "We learn not just with our ears but with our eyes, not just with our heads but with our hearts" (p. 129). Reflexivity is an awareness of assumptions, biases and privilege that may be held as individuals or collectively (Ponic et al., 2010). Whereas, as health psychologist Rachel Shaw (2010) explains, reflectivity comes from observing how and why things happen, and building an understanding of these experiences.

Disrupting power asymmetries, considering the impact of language and embracing an ethics of care all rely on individual and collective reflexivity, and also involve being aware of our needs and emotions, as researchers, practitioners and humans (Billo & Hiemstra, 2013). Reflexivity is, as suggested by Ponic et al. (2010), a useful way of handling the relational intricacies of research. Moll et al. (2020) use co-design within the healthcare space and they suggest beginning with "critical and embodied reflexivity that attends to (1) ourselves—the subjective self or 'I'; (2) our relationship with others—the intersubjective 'we'; and (3) the systems in which we and others are embedded—the objective 'it'" (p. 2).

Meanwhile, reflectivity involves — as Donald Schön (1983) puts it — reflecting-in-action and also reflecting-on-action. These are thought processes that occur throughout project work (such as engagement sessions) as well as after. Reflectivity allows for an interactive design approach that is responsive to the contexts and experiences as they are happening, as well as incorporating feedback for different stages.

A reflexive approach helps develop ethical practices and is discussed in more detail below, looking at collective reflexivity and individual reflexivity, and how sharing reflexivity is a privilege not everyone has. This is followed by further discussions of reflectivity and what reflective practices could be used.

What is reflexivity?

Sociologist Michael Lynch (2000) explains that reflexivity originates from within the social sciences and was a way for social scientists to fit their qualitative work into the objective, empirical ways of researching by acknowledging the influence of the researchers' assumptions and biases. Once acknowledged, researchers would attempt to 'bracket' these assumptions and biases to try to separate them from the research (Lynch, 2000). It has since been recognised that aiming for objectivity is not the only way of doing research, with reflexivity adding depth and nuance to research as well as increasing awareness of ethical considerations (Shaw, 2010). A reflexive approach suggests there are unreflexive approaches; however, Lynch (2000) argues it is not a binary — instead, there are different ways of being reflexive that come with differing levels of awareness and intentionality. Reflexivity is not a specific procedure as such, but as Cunliffe (2016) says "being reflexive is about having "a heart," it is not a technique but a way of being in relation with others that brings with it moral and ethical considerations" (p. 745). Cunliffe's explanation suggests reflexivity is key to relational research approaches, such as co-production.

The words and phrases used in co-production, such as sharing power and participation, can suggest that co-production achieves these promises of partnership and equality, regardless of whether or not the project team is intentionally acting to change power differentials (Phillips et al., 2021). A critical reflexive approach can help to identify and address power asymmetries, but it does require actions to follow the considerations to have an impact. As scientists Rhian Salmon, Rebecca Priestley and Joanna Goven (2017) state "Reflexive thinking makes possible ways of acting that would not otherwise be possible" (p. 6). While empathy can be developed through reflexivity, empathy and care can also enhance reflexivity (Toombs et al., 2017) — they can be a reinforcing cycle or feedback loop. This cyclical process fits well with the iterative process of co-production and helps ground co-production in a values-led, ethical practice.

How does collective reflexivity aid ethical practice?

Collective reflexivity is about thinking reflexively as a group (for example, a project team) and also thinking about systems and institutions with a critical reflexive approach (Cunliffe, 2016). While collective reflexivity is important for how research is carried out, Ponic et al. (2010) point out that this is often what gets left out when funding and resources are limited. Reflexivity is not only helpful for data collection or analysis, it is particularly helpful in all aspects of participatory research approaches. A lack of reflexivity runs the risk of not identifying ethical challenges or can result in creating ethical issues that have not been considered during planning or carrying out research (Shaw, 2010). Alongside this, most literature about reflexivity considers the relationship between researchers and participants, but misses the broader relationships when building partnerships with communities and other organisations (Ponic et al., 2010). For co-production projects, where relationships are prioritised,

all the existing and potential relationships need identifying and then considering with reflexivity. Cunliffe (2016) touches on this relational aspect of reflexivity when she describes being reflexive as:

> a way of thinking about who we are in the world that is based on the belief that we are not separate individuals (entities) but we are always in relation with others—with particular persons, communities, history, culture, language, and so on. (p. 742)

In this description, Cunliffe (2016) also draws attention to the importance of the context surrounding these relationships, as this is also important for reflexive considerations.

Reflexivity also requires considering the system/s the project is taking place within. Moll et al. (2020) point out "There may be a clash of values since many organisations operate within a sociopolitical environment that privileges individualism over collectivism, self-sufficiency over collaboration, and scientific expertise over other ways of knowing based on lived experiences" (p. 2). Being aware of these differences in values can help projects be prepared for them, and gives an opportunity to take action in advance with the aim of mitigating them. Taking time when building relationships and building the conditions for a project, can allow for openness about differences and for developing a joint approach for working together.

Feminist geographers Eden Kinkaid, Aparna Parikh and A. Marie Ranjbar (2021) point out that a reflexive approach to research and practice that takes into consideration the impact of power and privilege is not limited to those using feminist approaches. Reflexivity is also important for research that has a social justice element to it, aiming to reduce discrimination and improve equity (Phillips et al., 2021). Writing in the organisation and management studies field, Cunliffe (2016) said:

> Embracing intersubjectivity, relationality, and reflexivity brings a moral responsibility to:
> - Think about "we" not "I" in our relationships and responsibility for the world around us
> - Recognize the uniqueness of others
> - Treat others with solicitude and respect
> - Treat people as irreplaceable, not as a means to an end as we so often do in organizations. (p. 743)

This encourages us to think expansively when planning projects, and particularly in aspects such as writing ethics applications. It can also be actioned by weaving an ethics of care throughout.

One of the ways the core project team practised collective reflexivity was by having an empty chair at the table when having project meetings — this chair can be seen in Figure 89. This chair indicated the people or communities that were not

involved in the project but potentially should be. It was a reminder that we did not represent all the different experiences that might be relevant to the project, and to remain open to opportunities to include others as the project progressed. It can be easy to talk about being mindful that there are voices we are not hearing from, but the visual reminder of the empty chair was more impactful. Sand et al. (2024) argue the importance of developing an "awareness of the bodily aspects of ethics to connect our sensory experiences with moral discourses. A way to disrupt order is to promote ethical curiosity and reflexivity" (p. 14). Because we are always aware of the physical presence of others in a room, the empty chair gave us a tangible bodily experience of there being people who had not been included (yet). In the team reflective practice, a member commented:

> "I thought it was really important that we committed to having the chair there to represent and remind us of all the people whose voices should be a part of this project but maybe aren't with us yet."

Figure 89:
A photo of the core project team and critical friends, including the empty chair.

Through thinking reflexively as a team about all aspects of the project at all stages, along with critically reflexively considering the context that a project exists in, we can increase the ethical considerations and practices that underpin our projects.

How does individual reflexivity aid ethical practice?

Being reflexive about ourselves and our practices is important for ethical research, especially in relational and collaborative approaches. Considering our own assumptions, biases, beliefs, and values can help us to understand the relationships we have as part of a research project (Cunliffe, 2016), and to alter our actions to

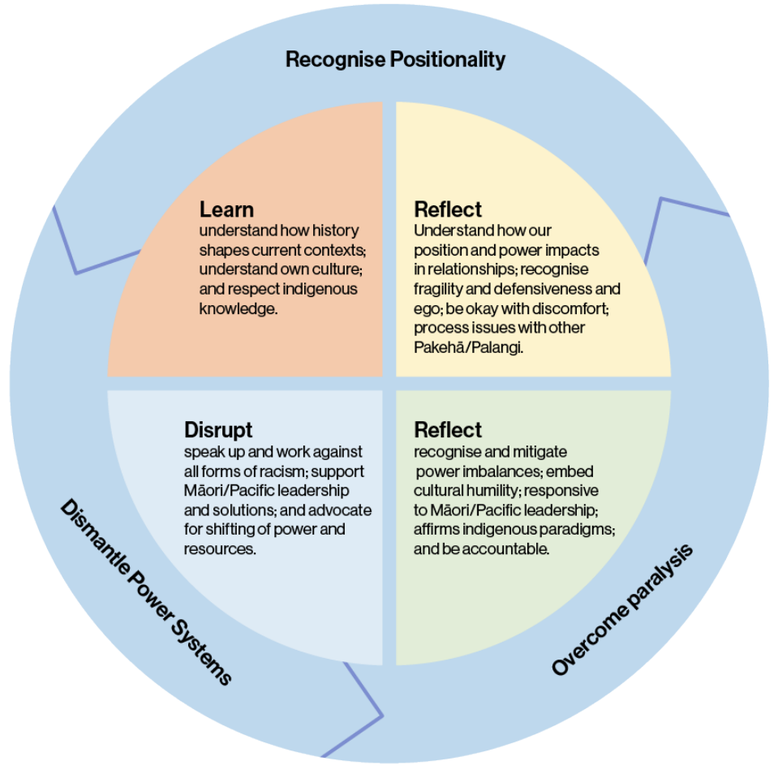
intentionally align with our values or minimise the impacts of biases. Understanding ourselves in this way can also highlight how interactions with others help or hinder the development of relationships (Cunliffe, 2016). When planning the Cuppa & Cake session, I made a note to myself that balancing what might work best for the contributors with what worked best for the core project team was a tricky tension with the potential to unintentionally recreate power asymmetries. This reflexive moment didn't necessarily lead to direct changes in our processes; however, it highlights that attention was being paid to our possible biases, so when we found ways to change, we could do so then.

Our positionality is how we enact our reflexivity — our awareness of assumptions and values. Positionality is how, as individuals, we experience and reproduce our identities, but also how our identities are seen and interpreted within the discipline we're operating in (Kinkaid et al., 2021). This can include our politics, our worldviews, how we express our gender and sexuality and how we experience class and race. Positionality is not static, though, so what we experience (for example, throughout the research project) can influence our positionality (Billo & Hiemstra, 2013), which is why reflexivity needs to be a practice rather than a one-off activity.

Reflexive practices are useful for disrupting power asymmetries and for overcoming Pākehā Paralysis and Perfectionism Paralysis (as discussed in Head: Co-productioning, p. 111). Crawford and Langridge (2022) argue there are four processes that need to be practised as part of recognising our positionality in order to overcome paralysis and disrupt power structures (Figure 90). They specifically refer to Pākehā Paralysis, but I suggest these processes are also useful for Perfectionism Paralysis and in order to share power. These processes are: learn; reflect; serve/act; and disrupt. Learning requires developing an understanding of your personal culture, the historical context and how that influences the present, and about those who have less power than yourself (for example, Indigenous knowledge). Reflecting includes considering how power and privilege influence your relationships, becoming more comfortable with discomfort, recognising defensiveness and processing these experiences and emotions. Serve/act means to be accountable and committed, encourage cultural humility, recognise and reduce power asymmetries and prioritise Indigenous knowledge. Disrupt calls for anti-racism actions and to take actions to share power.

Thinking reflexively and understanding our positionality can help us see how our own lived experiences become part of our research. My experiences of the health care system, as a woman, obviously underpin my listening and understanding of the stories we heard throughout this project. However, having a reflexive awareness means I know my experiences are not the same as everyone's, and that I have a lot of privilege helping me access the care I've received. At the same time, having heard all the stories from the women in the project gives me a different approach in my own health care experiences — appreciating what I have, but also giving me a little bit more confidence to ask for what I need, in the hope that that can improve things for other women.

Figure 90:
Crawford and Langridge's mode of actions needed to overcome paralysis, recognise positionality and dismantle power systems (Crawford & Langridge, 2022). Reproduced with permission from authors and NZMJ.



Reflexivity helps highlight who has power in what situations and the privilege that goes with it, which aids in creating inclusive spaces and practices within a project. As M. Parsons et al. (2016) states "A commitment to inclusivity (who engages in research co-design) and reflexivity (how the research is performed) protects against research becoming extractive or exploitative." (p. 102). The co-production principles of prioritising relationships and sharing power align with doing research in ways that are not extractive, and reflexivity is embedded in these principles. It can be tricky to know whether a research project is extractive or exploitative, as contributors may be unlikely to openly share that's how they're feeling about the project. Noticing moments of reciprocity in relationships (as discussed in Arm 4: Prioritising Relationships, p. 189), contributors' continued involvement and their openness to share feedback were subtle signs within Care-full Co-production that we interpreted to mean we were not being extractive.

Having conversations with the core project team (or other researchers) about inclusive practices and planning events with inclusivity in mind can help us identify assumptions or biases that we might have. In the core project teams 'Reflexive & Reflective' practice, one of the prompts is about what the team learned — "What did the team learn? What assumptions were highlighted?". After planning one of the celebratory events, one member wrote in response to this prompt:

> "Seats are needed for whomever might need them — not just old people."

This is an example of being reflexive and acknowledging an assumption they weren't necessarily aware they had made, and changing practice accordingly. Sharing our moments of learning from individual reflexivity also gives other team members opportunities to be reflexive themselves, and also change behaviours. Openly sharing reflexively, and talking about our positionality involves being vulnerable — and also encourages vulnerability — which becomes part of the trust and relationship process that co-production projects value.

How can sharing reflexivity and positionality be a privilege?

As well as taking vulnerability, sharing our reflexivity and positionality also requires privilege that not everyone has, or may only be available in certain circumstances. Sharing these parts of ourselves, whether personally or professionally, can leave us open to judgement and commentary from others, which may have associated risks (Bailey et al., 2022). Feminist sociologist Bev Skeggs (2014) argues that people who have less power, for example, through precarious employment or people from marginalised groups, have potential to lose by sharing — from not getting promotions to experiencing microaggressions. In some spaces, it may not be safe to share political positions, gender, sexual identities or health conditions as these details can inadvertently result in discrimination. PhD candidates are also in a precarious position that requires navigating how much to share and when — especially when it comes to health or neurodiversity information. Their safety for sharing can depend on their relationship with supervisors and other staff members, and how accommodating and inclusive their university is. Because of this, before engaging in any reflexive activities that expect sharing, it is worth considering if there is anyone in the group who might not have the same safety and privilege as others.

Early on in Care-full Co-production, as the core project team were getting to know each other, we used an activity '*One Face, Many Facets*' (explained in more detail in Arm 8: Participatory Design Approaches, p. 259) to encourage thinking and sharing about our individual positionality. While we all would have had different levels of comfort and privilege when it came to sharing, we were all there with agency and

an inquisitive mind. We were all women interested in women's health and understood we all had similar intentions and shared values. I think we were all surprised by how quickly we shared some deep and personal experiences. This would not have happened in any group of people, but it set the tone for how the project unfolded, and really encouraged trusting and supportive connections within the group. Milberg Muñiz et al. (2024) commented on how vital self-reflexivity is, but that is often avoided, particularly in project teams.

When considering inclusivity for a project, the project team needs to be considered as well as the contributors, and an environment created where everyone has the privilege to share or at least the autonomy to choose what to share with what audiences. Place (2023) discusses plurality of knowledge and experiences, and writes: "Embracing plurality may imply a capacity to hold space for others, but it might also require holding more space for ourselves" (p. 120). This is relevant to individual reflexivity too, ensuring that a supportive space is created for researchers to share with each other and with other project contributors. Sometimes sharing our experiences can unintentionally create or reinforce insider/outsider dynamics, so we may need to be selective about what we choose to share to avoid this, even if sharing seems safe to us.

This ability to navigate what to share with whom is also an aspect of individual reflexivity (Maguire & Britten, 2018) and can aid ethical practice by avoiding burdening contributors. Being aware of how sharing may impact those on the receiving end is also a vital part of building relationships with communities, especially those who have been marginalised or have fewer resources. We don't want our desire for reflexivity and open sharing to harm them or result in them needing to teach us about how they've been marginalised (Greenaway et al., 2022). Projects or processes are often talked about from a sustainability perspective, but this often focusses on resources rather than people. If we expand sustainability to considering people, we can look at more ways to care for each other and minimise (or remove) any harm that may come from research projects (Place, 2023). A critical reflexive approach will help us identify the actions and practices that can be implemented to achieve sustainability for the project.

What is reflectivity?

Reflectivity is a process of learning through experience, and incorporating that learning into future practice (Schön, 1983). A reflective practice has become a key element of design's iterative approaches, encouraging responsive changes throughout a project. Health researcher Elizabeth Anne Kinsella (Kinsella, 2007) writes that reflectivity incorporates cognitive and embodied feedback, resulting in learning that can feel more intuitive than purposeful. Through Schön's (1983) concepts of reflection-on-action and reflection-in-action, we can take a micro and macro view of experimenting with tools to create experiences and processes that align with the project's aims. The following sections discuss why reflectivity is important in co-production projects and share some reflective practices we used throughout Care-full Co-production.

Why is reflectivity important in co-production?

Co-production benefits from a flexible, learning-through-experience attitude as it allows for creativity and curiosity (Verwoerd et al., 2022). Reflectivity gives space for responsiveness in a way that contributors' input can be included and acted upon as and when it suits, rather than having defined periods for input. Some scholars argue that reflectivity is what gives design research approaches their validity, while others have critiqued this and suggested instead that reflectivity can become an easy way of monitoring and regulating oneself and one's practice (Tonkinwise, 2017). Instead, what is needed is a reflection-in-action and reflection-on-action process that moves regularly between considering the details of the project and looking at the context of the project (Schön, 1983). Then, through this process, recognising how the choices made at one level impact the other and vice versa — these choices then set people up for the next set of decisions, forming a cascade of choices and actions. This process of moving between the micro and macro views is how we navigated our way through Care-full Co-production, as the nature of our community and project set-up didn't encourage planning all the details of the project from the beginning. By reflecting on subjective and objective observations as the project progressed, we were able to suggest next steps to contributors and gather and include their thoughts and ideas.

Embedding an ethics of care into a project also requires a reflection-on-action and reflection-in-action approach, as each moment of care can change the way people engage with the process and encourages reciprocity, which then needs responding to (Tronto, 1998). Care becomes a cycle of action, reflection, and decision-making. Reflective processes also include caring for our emotions and feelings as well as our contributors (Askins & Blazek, 2016). Paying attention to our emotions can give us insights into how parts of the project are going (e.g. specific activities with contributors), how our relationships with each other are, and can also help us notice when emotions that are not specifically project-related are impacting the way we are experiencing the project. When unrelated feelings impact our experiences of parts of the projects, what we learn through reflectivity may be different. Sometimes, a part of the project may feel like it didn't go well simply because we are tired or stressed about something at home, rather than there being anything about the process that needs to change. Group reflective practices can help with identifying whether our emotions are project-related or not — this is partly why it can be useful to embed reflective practices throughout the project for those involved.

Some reflective comments from the core project team about their feelings:

> "I was off kilter for this session — day wasn't going super well & was feeling stressed about some other things, as well as very tired (and in hindsight hadn't eaten enough)...maybe this was noticeable by participants?"

> "Easily the hardest time of day for my facilitation energy — what do we need to do for each other to help us get 'in the zone' as a team and overcome our own challenges?"

On the other hand, emotions can also help us better understand the project and what is needed next. As mentioned earlier, Horst (2013) commented that moments of discomfort were an opportunity to pause and reflect on their project, whereas for us, we found that moments of comfort were our signal. If we were feeling comfortable, it often meant we had started planning ahead too far, so felt an increased sense of control, or we had shaped the project into something closer to more traditional projects that had a feeling of familiarity. Reflecting on these feelings was a chance to recheck and make changes if needed. Figure 91 below shows one of my attempts to visualise what the final 15 months of the project might look like — having a plan to follow was comfortable and comforting. The comfort was recognised, and we did not end up following this plan.

Reflectivity aligns with a non-linear approach to time (discussed in Arm 5: Temporality, p. 211) that allows more awareness of the complexity and messiness of the co-production process. The flexibility gained through reflectivity and an iterative approach, entwined with being critically reflexive, gives co-production projects the ability to enact the key principles and align with core values.

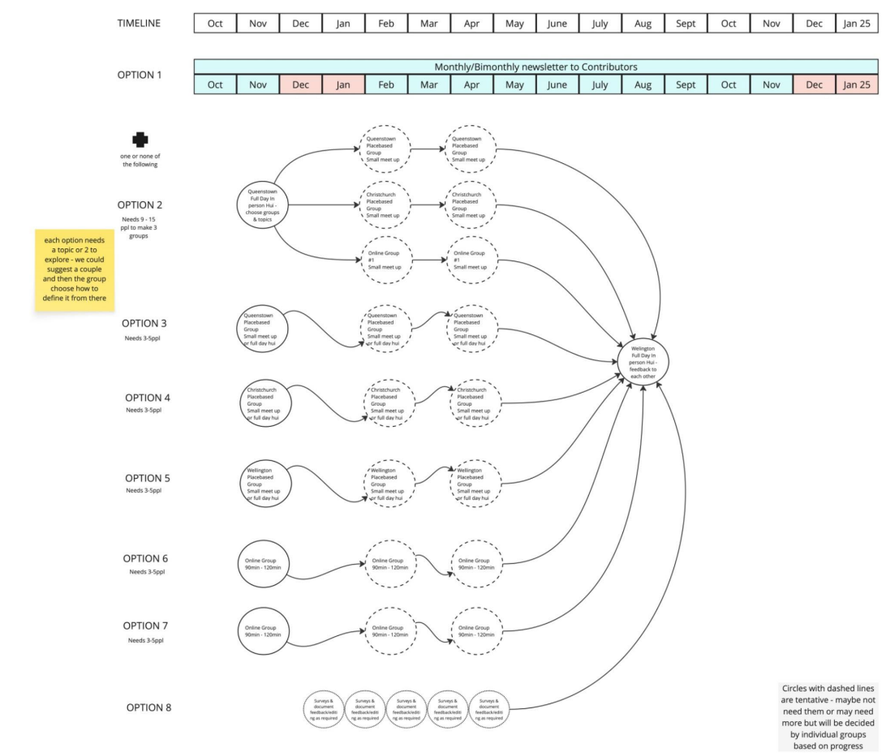


Figure 91: A visualisation of a possible plan for the remaining 15 months of the project.

What reflective practices can the project embrace?

There are numerous ideas for reflective practices; this section shares a few methods for being intentionally reflective that were used throughout our project. Often, the reflection-in-action happens ad hoc throughout engagement sessions and activities. In our Cuppa & Cake sessions, this sometimes meant allowing more time than originally planned for the 'heart' stage — the sharing of personal experiences — and reducing the time spent on the sticky note exercises, the 'head' stage. In our research question development sessions, a reflection-in-action moment occurred when we realised that scribing for the contributors, rather than having them move text boxes around, meant they could get their thoughts onto the Miroboard more easily, so we encouraged that option more. These methods are discussed further in Arm 8: Participatory Design Approaches, p. 259.

A moment of reflection that happened at the end of an engagement session can be seen in the following exchange between one of the core project team members and myself:

> **Hannah:** *I think I really like having those two boards, I'm speaking iteration like we did iteration…and yeah, I like that kind of, you know, closing out properly as well. It feels really good to let everyone just have a bit of a chance to say thanks to each other and things. Yeah keeps a little bit sort of sacred or something but yeah. And I also [would] be interested if you noticed or any thoughts you have about doing that name tag, with a, what would you like to add? You know, because they all gave quite rich introductions at the beginning in this group. So I just did that framing as like once you've done the name tag, what else would you like to add to your introduction and if nothing tell us how [that felt]?*
>
> **Anjuli:** *Yeah, it worked…I think it helps get them to kind of contribute [more] as well because it's something to sort of follow on from rather than [just] deciding whether they would or wouldn't share something.*
>
> **Hannah:** *Exactly. Like I've just been sort of, playing with like, what's the best, segue, I suppose, but that, that I felt quite pleased with.*

This example highlights reflection-in-action that happened during that session, where the person facilitating altered the plans on the go and used two 'boards' for the sticky note activity, as well as changing the prompt following the name tag introductory exercise. As a whole, this exchange is also an example of reflection-on-action, as we shared what we thought about those changes.

The 4L's: A retrospective technique

When it comes to reflection-on-action, it can be useful to choose specific reflective practices to add to the project. This is particularly important for making sure the reflection-on-action takes place close to the action, when people are likely to remember the details of what happened — if this is left too long after the event, people will often have forgotten anything that was not recorded. The main method for our project's reflective practice was a process inspired by agile product coaches Mary Gorman and Ellen Gottesdiener (2010) — The 4L's: A Retrospective Technique, where the L's stand for Liked, Learned, (dis)Liked and Longed for. The authors developed it from their own experience of something similar at an Agile event, to use as a reflective process for Agile Teams. Agile is a type of project management methodology (Agrawal, 2025). We adopted this process, and I set up labelled grids on a Miro Board to make it easy for us to record these reflections. Each L came with some additional prompts to demonstrate the sorts of things team members might want to reflect on. The core project team completed 16 of these across the three-year project, sometimes after specific meetings, and other times after a specific phase (e.g. the planning of a particular series of engagement). This particular way of facilitating reflectivity worked well. It was simple enough that the process wasn't overwhelming and didn't require too much cognitive labour, so people were willing to complete it. The prompts themselves were specific enough to elicit useful information, and allowed people to reflect on our processes for meetings and guiding the project, as well as reflecting on the content of what we discussed in meetings. The 4L's technique encourages collective reflexivity as well as team reflections. Figure 92 shows a completed reflection grid, and other examples from these reflection grids have been shared throughout this thesis to demonstrate how they helped our learning and understanding.

Session debriefs

Another means of reflective practice was less structured, but happened more frequently. After each engagement session with the contributors, the core project team members who had been involved in the specific session would complete a written debrief (an example can be found in Appendix 3, p. 339). I describe this practice as less structured, as we didn't have prompts. Each team member simply wrote down things they thought were important to remember, which could be about the content of the conversations, interactions between people, details about the venue or hospitality aspects and what things went well or any suggested changes.

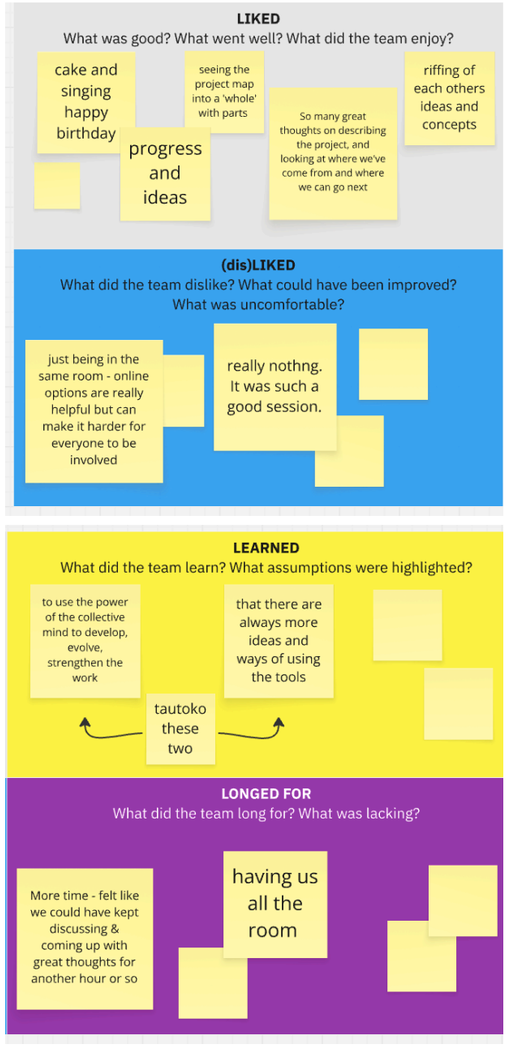


Figure 92:
An example of one of the completed core project team reflection templates.

These reflections were useful for making changes from one session to the next (especially if they happened close together). It also meant that when we received feedback from our contributors, we could use our written reflections to remind us what had happened and match our experiences with the contributors' experiences, giving another layer of nuance to our reflective understanding of the project and its processes.

Throughout the project, and indeed while writing this thesis, it has been challenging to untangle what records, documentation, and thinking were required for Care-full Co-production itself (and the focus on women's health research questions) and what was needed for my PhD research exploring the use of co-production.

Looking back, I think that the entanglement actually led to better reflective practices for the project as a whole. This is not to say all co-production projects should have a PhD embedded, rather an observation that reflecting and learning about the research approach and processes, as well as the research aims and content, can be beneficial for all projects. Milberg Muñiz et al. (2024) acknowledge that reflectivity within transdisciplinary projects can often be at the theoretical level, and this is difficult to transform into practical actions. They suggest this difficulty comes from needing different skills for theoretical reflectivity to what is needed to put these reflections into action. Taking a micro and macro approach to reflection throughout a project can help with transitioning between theory and practice, and with more experience of reflecting this way, it will become more comfortable.

Summary and provocations

Reflexivity and reflectivity are important for ethical research and rely on intentional practices and related actions. Practising reflexivity is a way of identifying our assumptions, biases and privileges in the world — and needs continual consideration as we change and grow, or for different contexts. Some people have more privilege when it comes to being able to share their positionality, such as those who have secure employment and are members of the dominant social groups. Keeping in mind that people have different abilities to share positionality is important for creating safe-r spaces.

Collective and individual reflexivity can both offer valuable insights for relational research. Reflexive practices, such as considering Crawford and Langridge's (2022) model and sharing considerations with team members, can increase each member's understanding of the assumptions and biases that are held.

Reflection-in-action and reflection-on-action are important parts of design research validity, supporting feedback loops for iterative approaches. These feedback loops allow for responding to input and feedback throughout the process, rather than waiting until the end of a process or just specific moments throughout. Practices seen in Care-full Co-production, such as The 4L's and written debriefs, can be useful ways of embedding reflexivity and reflectivity into co-production projects.

The provocations that make up this arm are:

» **What is reflexivity?**
How does collective reflexivity aid ethical practice?
How does individual reflexivity aid ethical practice?
How can sharing reflexivity and positionality be a privilege?

» **What is reflectivity?**
Why is reflectivity important in co-production?
What reflective practices can the project embrace?

Arm 8:
Participatory Design Approaches

Why are iterative approaches important?

Why are ‘spaces’ important for participatory design approaches?

How might we encourage building connections?

What are some asynchronous tools?

What are some embodied methods?

How can research questions be developed collaboratively?

How might we generate more conversations?

Arm 8: Participatory Design Approaches

Participatory design approaches developed as part of the ethical and emancipatory move towards doing research with and for people (Light & Akama, 2012; Mosleh & Larsen, 2021). Sanders and Stappers (2012) highlight the assumption that underpins their work about participatory approaches — the idea that all people are creative (not just those with talent or specific education). They suggest participatory methods and tools are a way to tap into people's creativity. Health researchers Edel Tierney and colleagues (2016) suggested more details of participatory methods used and what participation looked like in different projects would be useful for the design field, in order for practitioners to have more options to draw on. They did highlight that as part of this more evaluation from those participating, not just those facilitating, would be ideal.

Participatory methods are a way of valuing different forms of knowledge, particularly experiential and embodied forms of knowledge (Knowles et al., 2021), and can encourage expression of these in different ways. These methods are also ways to facilitate and promote conversations, and through these interactions the development of new knowledge and understandings. The collaborative and participatory nature means the outcomes and impacts are not a given nor are they predictable (Mosleh & Larsen, 2021). Valuing different forms of knowledge also encompasses including Indigenous knowledges. As discussed in the Head: Co-productioning chapter (p. 111), adopting non-colonial Pākehā practices can allow for an alignment of values between Indigenous and non-indigenous methods (Hope, 2024). For example, recognising the importance and cultural relevance of participatory approaches that encourage whanaungatanga (relationship and connection building), saw Care-full Co-production dedicating time in each engagement session for getting to know one another more holistically than a cursory introduction. These sorts of activities can be seen, as Clarke et al. (2019) describe them, as 'interaction rituals' and are part of continued processes to develop inclusion and belonging.

Participatory approaches are also a way for those involved in the project to build capabilities (Forester, 1999) — which is a core principle of co-production, along with 'using participatory means'. Participating in these methods is an opportunity to learn new skills, learn about oneself and others, and expand understanding of the world

and others' experiences. Building capability in this way is not limited to the project, and can be beneficial in other aspects of people's lives.

However, it is not the methods on their own that achieve the benefits of participatory approaches (which include relationship building, power sharing and capacity building), it is also the facilitation of these methods, the environment they take place in and the overall context (Knowles et al., 2021). Regardless of the outcomes of these methods, the process of interacting and collaborating throughout them is just as important, if not more (Davis et al., 2021). A contributor in Care-full Co-production commented:

> "I wonder if this approach does depend somewhat on the personality of the researcher? You have made us so 'safe, valued and heard' and demonstrated the ethics of care."

In a discussion about participatory design, Mosleh and Larsen (2021) describe the concept of infrastructuring, stating it "addresses some of the challenges related to an increasingly connected world and focusses on the politics in processes of collaboration." This aligns with the emancipatory aspect of participatory approaches, and also draws attention again to the processes used, not just the methods. In a co-production context, infrastructuring includes the actions that happen in between methods — for example, how multiple methods can be used in one engagement session — the actions and processes that link them together — and also the temporal aspect that connects all engagement sessions to each other throughout the duration of a project. All the methods chosen for a project are interconnected, making up the complete experience of being involved rather than the methods standing alone. From the infrastructuring perspective, we can see that the threads of care, power, language and time weave together around and through the participatory approaches to create the outcomes and aims of a project.

Why are iterative approaches important?

In more traditional science research, a consistent and unchanging method is important as scientists generally desire replicability in their results (Cross, 1993). Whereas in design research, and especially participatory design research, the aim is not to replicate results but to learn throughout the process to produce a solution or new knowledge and understanding. Embracing flexibility as an essential tool for participatory methods allows researchers to be intentionally responsive to feedback and reflections (Billo & Hiemstra, 2013), and can help minimise the discomfort that may come with not having a definitive plan for the whole project. These iterative approaches that are responsive to reflection-in-action noticings, and the feedback received from those participating and interacting, create a somewhat messy and complex process that maintains the depth and nuances in what is created out of this process.

Mosleh and Larsen (2021) argue "our freedom lies in our ability to notice the moment-to-moment of an emergent situation and contribute to its next iteration" (p. 465) and that "participation involves moment-to-moment negotiations that emerge as a result of the unpredictability of a response to one's own action. This differs from a grand ethics where one decides on ethical and unethical action upfront" (p. 465). This aligns with the reflection-in-action discussed earlier in Arm 7: Reflexivity & Reflectivity (p. 243), and as social justice researcher Sarah Banks and colleagues (2013) suggest, encourages an 'everyday ethics' of regular decision making as opposed to the procedural ethical decisions made during an ethics application process. From this, we can see how iterative approaches and reflective practices are part of carrying out ethical research. While the following participatory design methods are discussed as standalone methods, they were all linked together in different ways to create the entire experience of Care-full Co-production — but they were also not so entwined that contributors had to be part of all methods to enjoy the experience.

Why are 'spaces' important for participatory design approaches?

Part of building an environment that connects methods together when creating an engagement session is 'holding space' for these methods to occur in. Holding space refers to the intangible nature of creating safety and comfort for sharing experiences and conversations (Vivienne, 2023). The people involved in hosting an engagement session — for example, the core project team in Care-full Co-production — play an important role in holding space, and the key elements of relationship building such as trust, empathy, vulnerability, and reciprocity are part of this process. One of our contributors shared:

> "I felt very safe at the discussion.The activities were not intimidating and they were very carefully planned."

This feedback highlights the feeling of safety for the conversations, plus the consideration of the methods too.

Health care spaces have often been unsafe for patients (Vivienne, 2023), and research has also been unsafe for some groups, such as Māori (Smith, 2021), which is in contrast to what we were aiming to achieve. Vivienne (2023) points out that a "distinction between aspirational intentions and rock-solid guarantees of safety is a useful acknowledgement that shapes the experience of participation" (p. 101). Creating and holding a space where people feel safe enough to provide feedback on the tools and environment, and especially to share moments they felt less safe, is particularly important for the iterative approaches of participatory design research. Spaces are discussed further in Arm 2: Care, p. 153 and Arm 4: Prioritising Relationships, p. 189, but it is also important to keep in mind safe-r and brave spaces while considering participatory approaches.

How might we encourage building connections?

More Than a Name Tag

More Than a Name Tag is an introductory activity designed to build relationships and connectedness (Toi Āria: Design for Public Good, n.d.). This activity offers an alternative way to develop rapport in a group setting by bringing more of our personality and lived experiences into a process of getting to know one another. It is inspired by the Māori pepeha, which linguist and teacher Keri Opai (2022) explains is a way of introducing oneself with the purpose of building connections through places and other relationships (e.g. familial ties). Pepeha is part of the Māori process of whanaungatanga, which is the development of "a relationship through shared experiences and working together which provides people with a sense of belonging" (Te Aka Māori Dictionary, n.d.). With Care-full Co-production focussing on prioritising relationships, we wanted an introductory activity that promoted relationship building and care, and was not a typical 'ice breaker' activity that might feel tokenistic or off-putting.

One Face, Many Facets — The foundational tool

The history of *More Than a Name Tag* is also a great example of an iterative process, which has helped open up new ways of practice for this activity. The starting point was the activity *One Face, Many Facets* — a tool originating from Anna Brown of Toi Āria — used to unpack relationships and commitments with other people or communities, encouraging inclusive and human-centred thinking (Toi Āria: Design for Public Good, n.d.). The tool (Figure 93) starts with a square, where you centre the person or topic being considered at 'face value'. The exploration is then widened by considering the square one side of a cube and all the other sides (or connections) are completed, and then finally the same is done as if the shape were an icosahedron flattened out to expand the connections even further. This was the activity that the core project team used as part of their relationships building process, which we loosely framed around health (as another connection to the project). It was amazing how the team opened quickly to sharing deeply and vulnerably. Some of this openness will be down to the individual personalities of each team member, along with being interested in this project and way of working. However, dedicating time to getting to know each other personally, and having an activity to facilitate that process helped ground the team in deeper connections and understanding of each other.

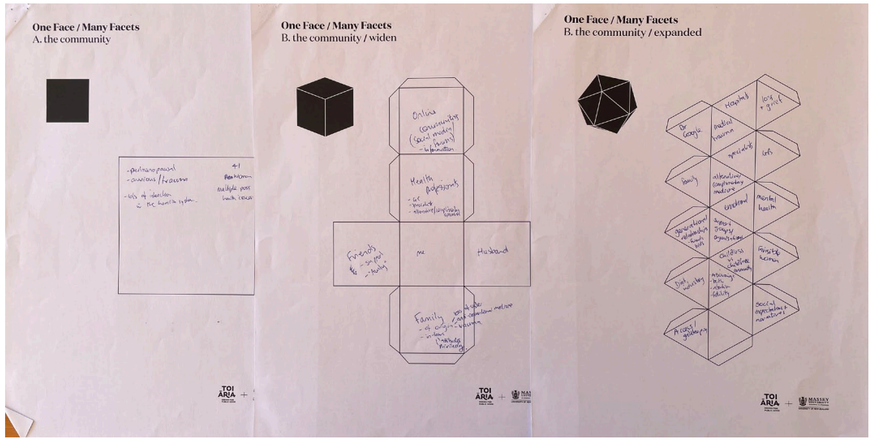


Figure 93:
A completed example of One Face Many Facets.

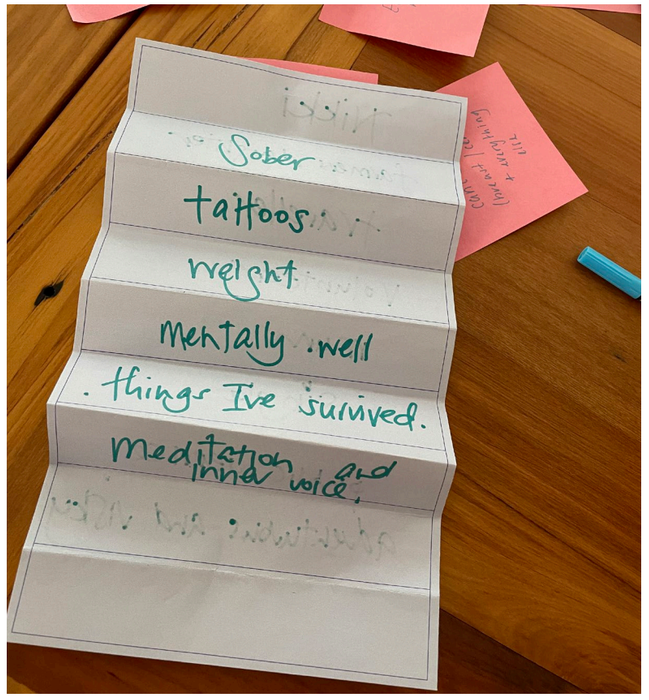
Development of 'More Than a Name Tag'

We had considered using *One Face, Many Facets* as a way of beginning the Cuppa & Cake sessions to build connections and facilitate the sharing of lived experiences. However, by the time we were creating the plan for these sessions, we had experienced designer and science communication researcher Dr Jo Bailey's (2024) next iteration, "name tag" (p. 269), as part of the Engagement Incubator we attended as a team. This version involves a simple paper template that gets folded in a zig-zag or fan shape. On one side, the person completing it fills each box or step of the 'staircase' with a fact about themselves, working their way up to the top box where they place their name — with it folded like a staircase, it is as if the facts are what are behind the name. Turning over, the other side is then completed with 'hidden depths' — more facts about oneself, but this time thinking about things that aren't so readily shared (often things related to one's positionality, such as politics, privilege, sexuality). Participants then take turns to share some of the facts about themselves, from either side, depending on how comfortable they feel to share. Jo's version was created with the intention to develop a reflexive mindset and understanding of oneself, also through an introduction and connection process. This set the tone and embedded reflexivity into the Engagement Incubator — a residential retreat for researchers to consider engagement in a specific project they were working on. Jo's version amplified the 'tagging' element, where if you connected to something the person prior to you shared, then you could choose to go next using that connection as a starting point (for example, if the person prior shared they had a dog, and you also had a dog, this could be a connection that you tagged on to). By using this tagging aspect, an invisible web that connected all the people in the room was created — these could become conversation starters later on, and it was also a change from other introductory activities that often involve going around the circle of people in the room.

The 'Heart' of our conversations

Using this name tag activity for the beginning of our Cuppa & Cake sessions was decided on because it is simpler to complete than the *One Face, Many Facets* task, and felt easier to frame in a way that was connected to health conversations. We anticipated this would be a short portion of the 90 minutes we allowed for the Cuppa & Cake sessions, focussed solely on introducing oneself to the group. It turned out to be much more integral to the whole session, and because of the conversations and sharing it sparked, it often ended up taking up nearly half of the session. We took to calling this part of the session the 'heart', as people were speaking and sharing from the heart, whereas the second half of the session we termed the 'head' part, as the sticky note activities suggested more 'head' thinking. Inspired by Jo, we included instructions for the name tag in the zine we provided contributors (giving written as well as verbal instructions is helpful for many neurotypes), and a name tag template. We described the process slightly differently — inspired by reimagining the name tag sticker you might pop your name on at a meeting, and asking contributors to write things they share easily on the top side. For the 'hidden depths' side, we asked people to think of the 'things that make you, you' and encouraged them to include thinking about experiences they had had that might be specific to their body or their health, as well as the other prompts, such as politics and privilege. Figure 94 shows a name tag template that was completed by a contributor.

Figure 94:
A completed name tag template from Care-full Co-production.



Stepping into vulnerability

For the Cuppa & Cake sessions this name tag exercise became what I described as a staircase to walk us down to vulnerability. Our template had a white side and a blue side, with the white side generally being the same as Jo's 'top' side. Sometimes we would break the activity up by giving people a chance to share what was on their white side before asking them to fill in the blue side, and then following that with an opportunity to share. We also encouraged the contributors to reflect on how they had found the experience of filling in both sides — and the answers to this often gave us added depth and nuance to what they had actually shared from either side.
A contributor told us they:

> "Loved the name-tag task – great way to facilitate 'deeper' talk sooner."

When going through the session transcripts later, I noticed from a process perspective that people would share differently based on how the request was phrased. Asking people to fill in the blue side (hidden depths) and saying:

> "We are not going to ask you to share them"

would get fewer people sharing specific things from their blue side than if the request was:

> "We're not going to ask you to share them here, unless you want to".

While some of the difference would have been down to individuals and group dynamics, the slight change to the phrase set a different expectation for whether people would share anything or not — this example also links to the discussion in Arm 6: Language, p. 229 about what language can 'do'.

Discomfort in sharing

However, the lack of sharing specifically from the name tag did not necessarily mean a lack of sharing lived experiences in general. Some people would reflect on the activity being uncomfortable:

> "Just the thought of having to, like, share that stuff made me really uncomfortable. Which is weird because I don't like small talk, so the fact that it was really hard for me to write the probably more meaningful things in my life made me feel uncomfortable."

One person even shared:

> "I thought it was invasive"

and did not share any personal details from their name tag. Later on, though, when the conversation was flowing more, and other contributors had shared more of their experiences, the people who had not shared from their name tag often ended up sharing then. My explanation for this (which has not been validated by any contributor) was that feeling the feelings of being vulnerable during the name tag process, without sharing any actual details, helped them to move through that discomfort, and then as the session progressed, they became more comfortable and so opened up more. This explanation adds to the idea of walking down the staircase of the name tag to vulnerable sharing.

Translating to other contexts

We also tested out this activity in other settings. To understand if the activity would be useful outside of an Aotearoa New Zealand context, Anna and I offered this as a workshop at the Art and Design Research Conference *Limit/No Limit* in Paris in January 2024. We named the workshop *More Than a Name Tag,* and it has since come to be used as the name of this participatory method. In what felt serendipitously aligned with the rest of the project, we had six people attend this workshop — a similar number as when we used it in the Cuppa & Cake sessions — and it was another warm and heartening conversation. Some of the people in the group reflected that it would have been great to have the workshop earlier in the programme (it was held in the afternoon of the last day), so the connections made through the workshop could have been built upon throughout the conference. We also offered this workshop at the DRS2024 Boston conference, and as Anna was unable to attend, I facilitated the workshop on my own. The sign-ups for the workshop suggested that there would be 20 people attending, so I had prepared ways to work with a larger group. In the end, it was not needed as again there were six attendees. The workshop led to some thought-provoking conversations about where and when attendees might use such a method, as well as any concerns or considerations they had. I received the following feedback later that day:

> "Hi Anjuli, I'm not quite sure if it was you who led the 'more than a name tag' workshop. But I really enjoyed it (I think it was the most well thought [out] thing I went [to] today). Hope we can exchange more!" (personal communication, 26/06/24)

Expansions of use

We have also used *More Than a Name Tag* with larger groups — as an introduction, connection-building activity and as a workshop to share the tool. Larger groups require a lot more time when it comes to sharing what has been written, and can work well if the intention is similar to Jo's — to encourage reflexivity. If the aim of the activity and the group is to encourage vulnerable and open sharing, then we found it worked better to split into smaller groups, or to first share in groups of two or three,

and then progress to sharing with the rest of the group, as this helped people to feel safer and more comfortable being open with the group. *More Than a Name Tag* has enough flexibility in the activity that it can be adapted for many different groups, and can be framed to suit any topic (like we did with women's health) if that is useful for the situation. And while the template is useful for the tangible and visible name tag, if necessary, it could be done just with a blank piece of paper, making it easier for anyone to facilitate.

What are some asynchronous tools?

Zine

To support our inclusivity and accessibility approaches, we created a zine for everyone who attended a Cuppa & Cake session to have. The term zine comes from 'magazine' and is a lo-fi booklet for a specific purpose or interest, and is generally self-published in small runs (Bailey, 2024). Acknowledging that everyone has different ways that help them concentrate and engage with information and conversations, we set out to include some different options (Figure 95). Inspired by some of the things that can help people with neurodivergence, the zine had information about the project, the co-production approach, ways to care for each other and instructions for the *More Than a Name Tag* activity. There were also a couple of hand-drawn illustrations by Jean Donaldson (an illustrator and designer in the core project team) for colouring in, and pages to take notes or doodle on.

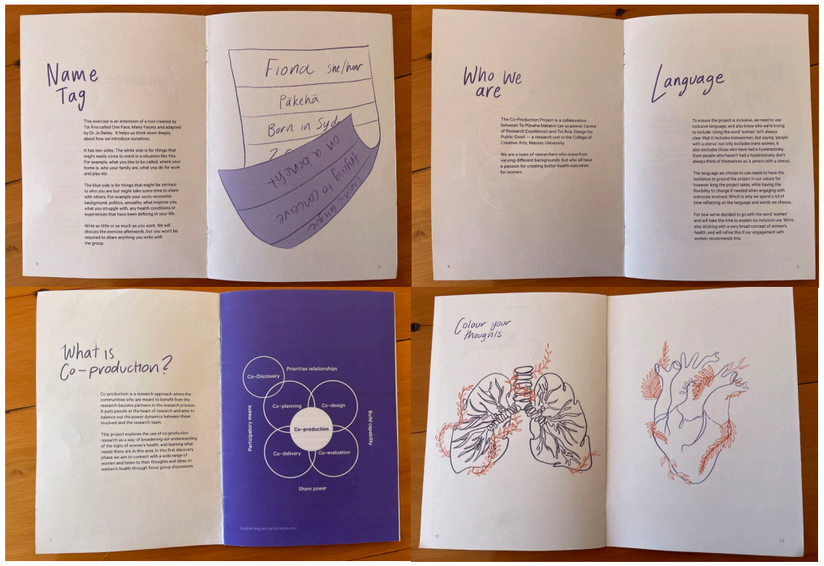


Figure 95:
A collage of the zine opened to different pages.

Colouring in and doodling have been shown to help people concentrate and learn more easily, so providing these in the zine was another way of being inclusive and supporting people's needs (Chi-yu Chang, 2024; Dresler & Perera, 2019). As well as providing support during the session, the zine also meant contributors could take information about the project home to read in their own time. As one of the contributors told us:

> "It was also very helpful having info about the project to take away and digest later."

Miro boards

Miro is described as a "collaborative online platform designed to support teams in innovation, planning, and execution across different locations and time zones. It is used for a variety of purposes, including brainstorming, agile planning, customer journey mapping, product design, and remote workshops" (Wikipedia contributors, 2025). The ways Miro can be used are endless, and the site itself is reasonably easy to navigate and learn how to operate. I really enjoyed the ease with which I could create visual maps and representations of ideas, and ended up using Miro for many PhD and thesis purposes as well as for the project.

Core project team uses

For the core project team, we used a Miro board for recording our reflective practice (as seen throughout this thesis). It was an easy place for everyone in the team to add their thoughts, and gave it a visual aspect that we would have been less likely to have in a word document. Having it set up so it was like using sticky notes was a way to encourage the team to be open with their sharing, as the sticky notes take the focus away from 'getting it right' towards more 'top of mind' thinking.

We also had a team board for recording things that might be useful for the project, such as meeting notes, design concepts and resources, as can be seen in Figure 96.

Engagement session usage

To engage with project contributors, we used Miro boards in various ways. They were useful as a collaborative space for our online sessions, but also as a way to encourage asynchronous interactions (as discussed in Arm 5: Temporality, p. 211). For our online Cuppa & Cake sessions, the Miro board was used for the sticky note exercise, where contributors were asked to write down words or thoughts in response to the prompts 'What came to mind when thinking about women's health?' (a present-day focus, shown in Figure 97) and 'In an ideal world, what would women's health look like to you?' (future-focussed).

Figure 96:
A Miro board for project resources, design concepts and notes.

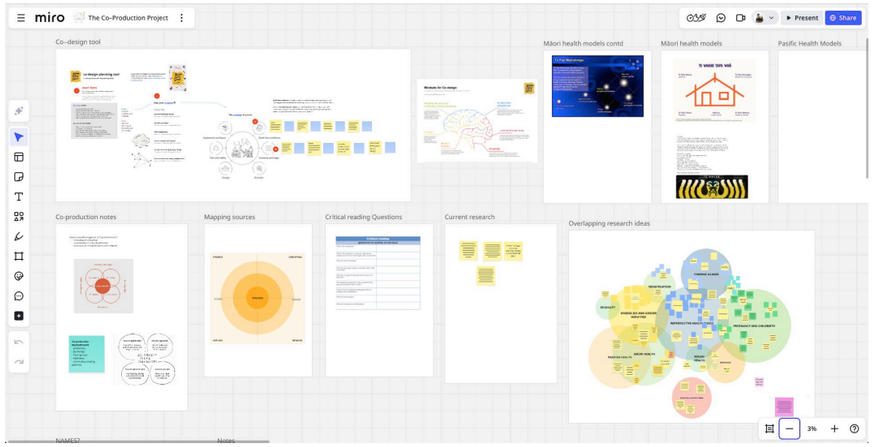
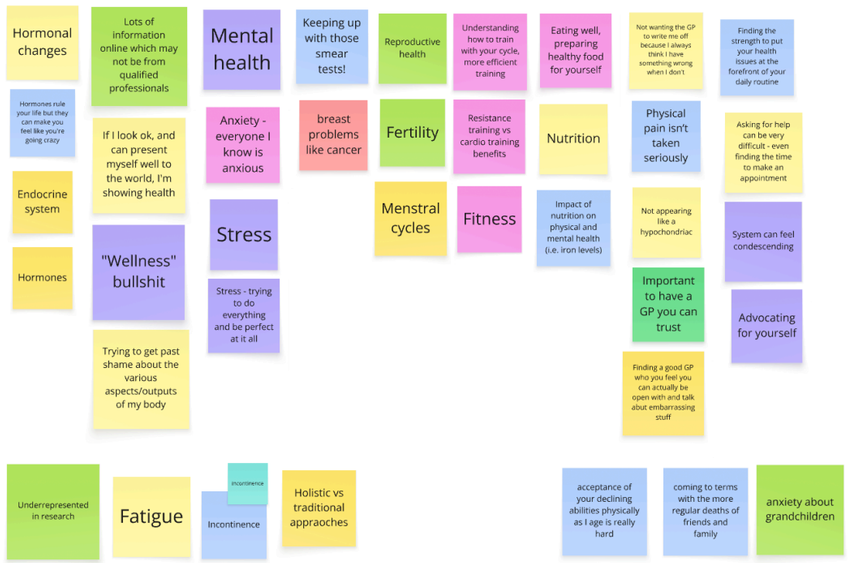


Figure 97:
Sticky note responses on Miro to the prompt 'what came to mind when thinking about women's health?'.



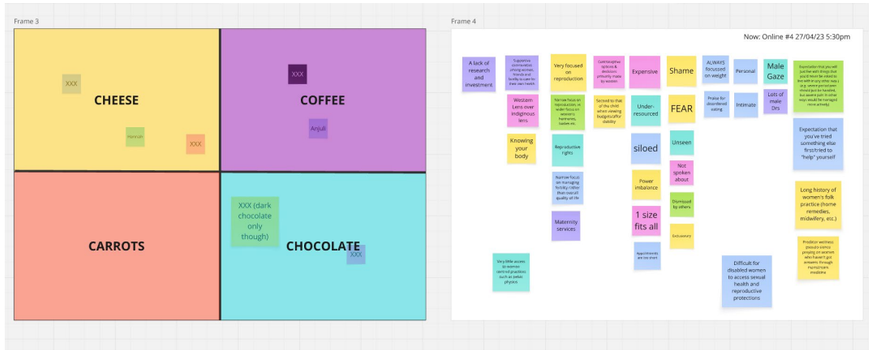
We used a Miro board for our summary conversations, where the first part of the board told the story of the project so far, and was set up so we could use it as a presentation (screenshots of this were shared in the Aotearoa Waters chapter, p. 61). The board then had the way we had summarised the conversations, with a long and short form of the ten themes. There were also areas set up to record contributors' responses to these themes, and thoughts about how we could work together, what they would like to be called and ways we could show their contributions were valued. We had two group summary conversations and a few individual ones, so we had separate boards for each conversation, so the contributors in each group were starting with their own ideas, rather than being influenced by other groups. After all these conversations were held, I collated all of the responses into one summary board, so we had all the information in one place. This board was then shared with our contributors, allowing those who had not been able to attend a conversation to see the ideas and add their own thoughts to it. Contributors were encouraged to come back to this board at any time to re-read the shared thoughts or add more of their own to it. Like the zine, having this board summarise the project (and be kept up to date) allowed contributors to process the information in ways that best suited them.

For developing the research questions, we also had a version of the process that used Miro — this is discussed in more detail in the Research Question Development section later in this chapter.

Getting comfortable with Miro

When we used Miro, we often had a small activity first to help contributors get used to using Miro. An example of this was having a frame set up as a quadrant, with each quarter a different colour and labelled either Coffee, Cheese, Carrot or Chocolate (this can be seen in Figure 98). Contributors were then asked to put their name on a sticky-note and move the sticky-note to the quadrant that was their favourite out of those four options.

Figure 98:
A screenshot of using Miro for an online engagement session showing a getting comfortable activity on the left and a sticky note exercise.



This was a playful way to connect with each other and to figure out the basic skills they needed to be able to put their thoughts on a sticky note and add it to the 'board'. We knew some contributors were apprehensive about using new technology, so right from the beginning we always offered the option of having one of the core project team scribe for them. We didn't want anyone to struggle, be stressed out by the process, or to find it hard to ask us for help, so by offering solutions in advance we aimed to reduce any barriers.

Challenges with using Miro

Some of the challenges we encountered with Miro were related to contributors' individual setups. It's hard to be using Zoom for an online conversation and then also use Miro if you're on a laptop or tablet and needing to switch between browser windows. It was even harder for those who were using their phone for Zoom, and while we could scribe for them, the person using their phone generally couldn't see the Miro board, so wasn't able to see the prompts or other people's contributions.

We had aimed to send the link to the Miro board out in advance of the sessions, so contributors could have looked and read the content before the actual online session, but we did not always manage to have the board finished until just before the sessions. Some of the contributors also just found Miro really hard to learn how to use. On reflection, it might have been worthwhile to have had a session specifically for learning how to use Miro for those who wanted it — this would have meant they were not trying to learn Miro at the same time as engaging in the conversations we were having. Unintentionally, learning how to use Miro ended up being a way that we built capability with the contributors throughout the project.

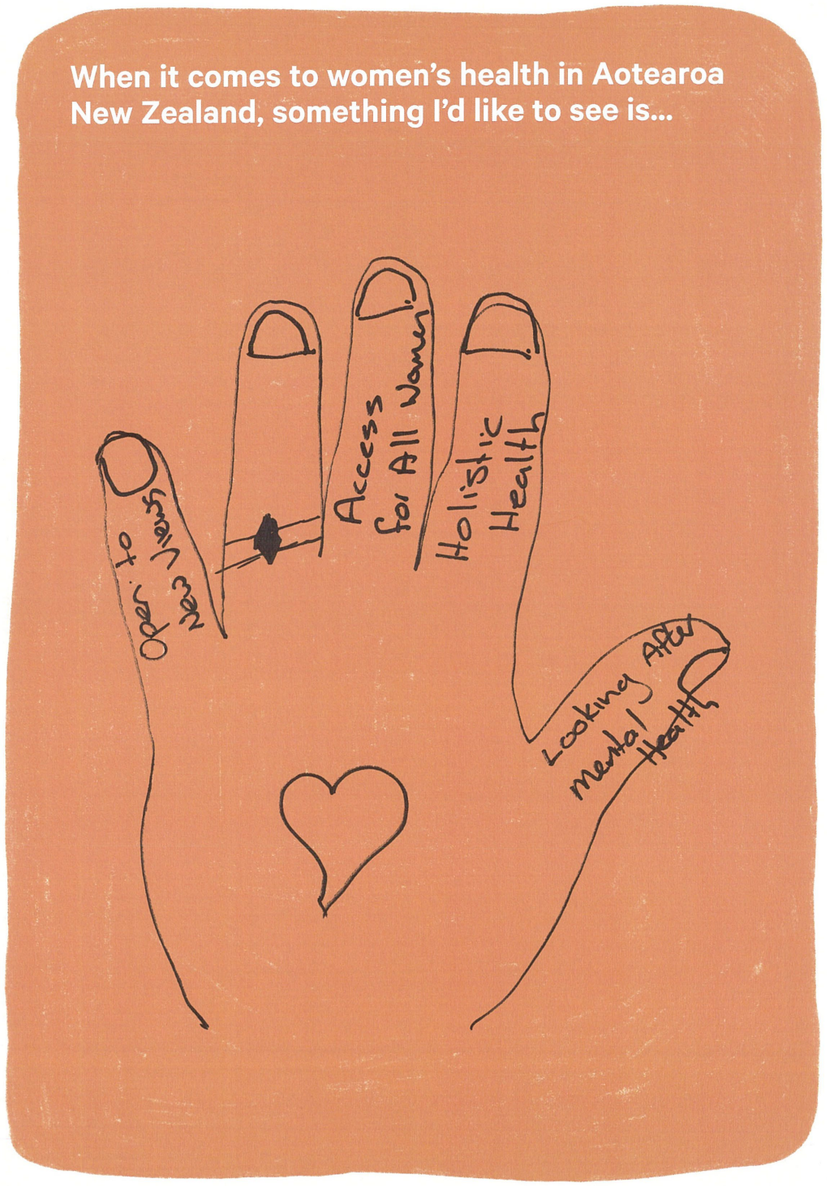
What are some embodied methods?

Hand + prompt

To show that people were embedded in the research process, and to add another embodied element, we asked contributors to draw around their hands. Inside the drawings of their hands, each person responded to the prompt: "When it comes to women's health in Aotearoa New Zealand, something I'd like to see is..." (Figure 99). This was a simple, playful activity that gave a starting point for creating research questions. Writing directly into their own drawn hands created a visual and physical reminder that people are at the core of these research questions. Drawing around one's own hand and responding to the prompt required a small commitment of time and energy, allowing for people who were limited in either to share their thoughts in a way that could be incorporated into the rest of the development process.

People were really creative with how they drew their hand, and how they then responded to the prompt — using words, sentences and other images to share their ideas. We included this activity in the Celebration Events and encouraged everyone who attended to draw and respond. It was such an inviting and satisfying activity, and nearly everyone participated in it. The hands were then added to a wall display of all the other hands completed previously (Figure 100) — event guests spent lots of time reading other people's contributions and talking with each other about what the hands were sharing.

Figure 99:
A hand drawn hand and the response to the prompt *'When it comes to women's health in Aotearoa New Zealand, something I'd like to see is...'.*



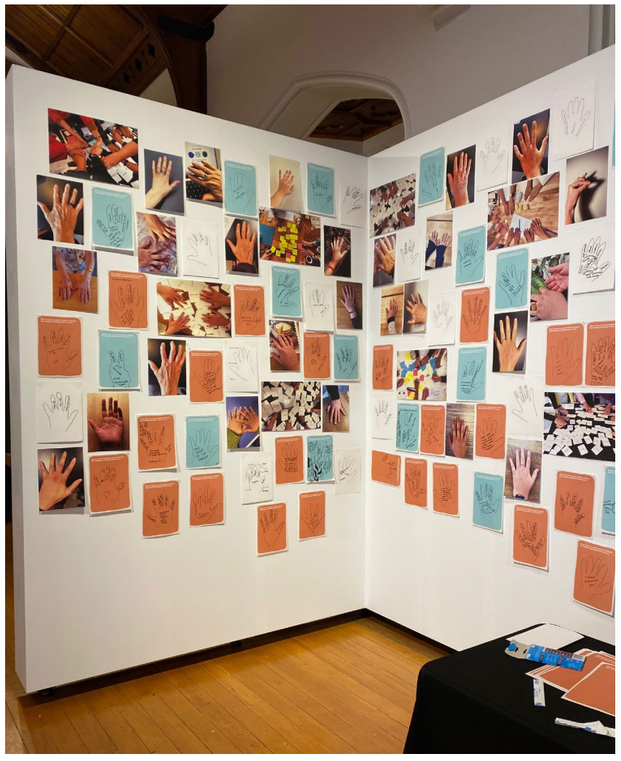


Figure 100:
The hands displayed at the Christchurch Celebration Event.

Hand photos

People are at the heart of co-production research, but it can be hard to find ways to really visualise and demonstrate this. The contributors in the project told us they wanted to be 'more than just a number', but for ethical reasons we couldn't take photos of people's bodies and faces. Instead, we collected photos of contributors' hands to show the number and diversity of the people in the project, while still giving contributors' a level of confidentiality. These hands became a substitute for the faces and personalities that make up the research. Seeing the hand sizes and skin types; any jewellery; the spots and scars and wrinkles; the long, short or decorated nails, hands can also give us insights into a person and their identity. Our hands, and their abilities and capacities change (through ageing, illness or injury) and influence how we experience the world and our place within it. By photographing the hands of those involved in the project, we can share so much more about the people who are in the project. Having these hand photos be part of the ways we share this project more widely, also gives a way for the contributors to actually see themselves in the project, as most people are able to recognise their own hands. A couple of the photos are shown in Figure 101, and the rest are collated in the *Hand Book: A handful of hope for women's health*.

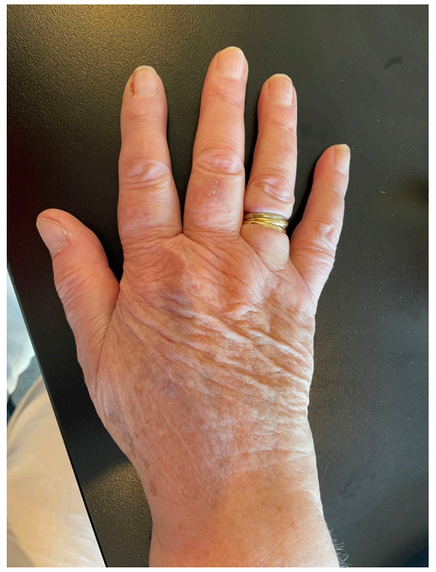


Figure 101:
Some of the hand photos from Care-full Co-production.

How can research questions be developed collaboratively?

Research question development

We wanted a hands-on approach to building research questions that would support anyone to create questions, no matter their comfort level or experience with research. We needed the activity to be affirming, capability-building and slightly fun without constraining or limiting people's creativity and ideas. In the end, we took inspiration from the fridge magnet sets for writing poetry on fridges, aiming to create a set of question parts and topic words that could be mixed together to create endless questions. While we knew we could never cover all options with the question parts and topic words, we had blank cards for writing other ideas on. The core project team came up with a prototype for testing and refining with each other to start with, and then as we used them with contributors' we tweaked them in response to feedback and observations. We also created an online and an offline version of them. When we used them offline, at in-person sessions, we discovered that to use them well, a lot more space was needed than we'd anticipated (Figure 102). This meant it was actually difficult to move the different pieces around and create a complete question with the cards, so most contributors ended up just writing the whole question straight onto a sticky note (though they used the wording from the question parts along with topic words).

Figure 102:
Using questions parts and topic words to create research questions.

For the online version (Figures 103 and 104), which was facilitated on a Miro board, space was less of a concern (Miro boards are endless). However, the challenge with this method is that the contributors found it difficult to move the parts into the right places, and adding new words that they needed was fiddly. Often, we found that once we had demonstrated the process and had a practice, it was then easier for us to scribe whole questions for the contributors, or for them to type out their question on an electronic sticky note. While the idea was better conceptually than in practice, using this method to demonstrate how to build a research question was definitely helpful for contributors who needed a bit more support or a confidence boost. The process was also simple enough that we were easily able to adapt in response to how we observed the contributors working. The core project team had joked that it would have been fun to have an actual fridge with magnets for this activity — and maybe if we had, the process would have been easier to use.

Figure 103:
A Miro board set up with question parts and question examples ready for creating questions.

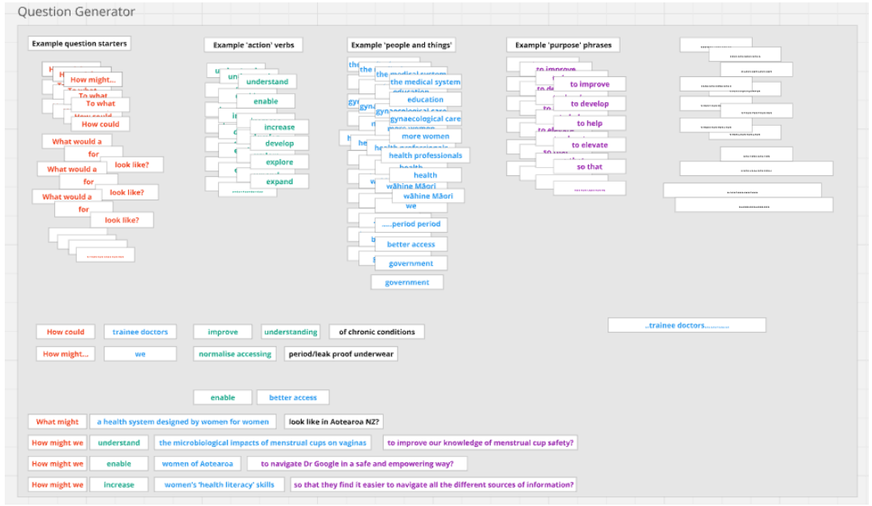
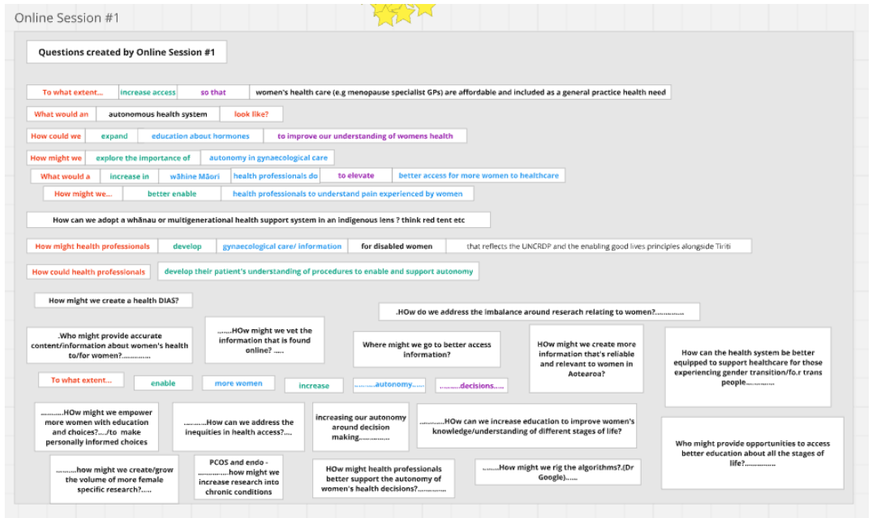


Figure 104:
A Miro board showing examples of questions created using the question parts or writing the whole question out.



Padlet

Once we had created over 100 research questions, we needed a way to get feedback from all the contributors on these questions, and to come up with a way to sort or refine them all. We considered the Delphi approach, which involves using a series of surveys to individually ask experts their views to build a consensus on priorities (McIntyre et al., 2010). The Delphi approach encourages a different way of consensus building that has a more formal feel than the collaborative style we had created with Care-full Co-production. Also the online ways of running a Delphi approach to build consensus required a platform that was costly, and required more technical skill to

use, which made it less accessible for us to use. Padlet was suggested as it is simple, often used in school settings, and gave us a way for all 89 contributors to interact without each of them needing an account — and it also gave us an easy platform for sharing with people outside the project. Similar to Miro, "Padlets are visual collaboration tools for creative work and education" (Wilds, 2025), where people can upload, organise, and share content online. The way I loaded all the questions onto Padlet meant each question was displayed as an individual 'card' on the 'wall', and underneath each question was the ability to respond using an emoji or rating system, or to add comments attached to individual questions (see Figure 105). We chose to use an emoji response, similar to 'liking' or 'hearting' posts on social media, as it was simple, and we thought a rating system might become difficult to interpret. For the full list of 100 research questions, see Appendix 5, p. 345.

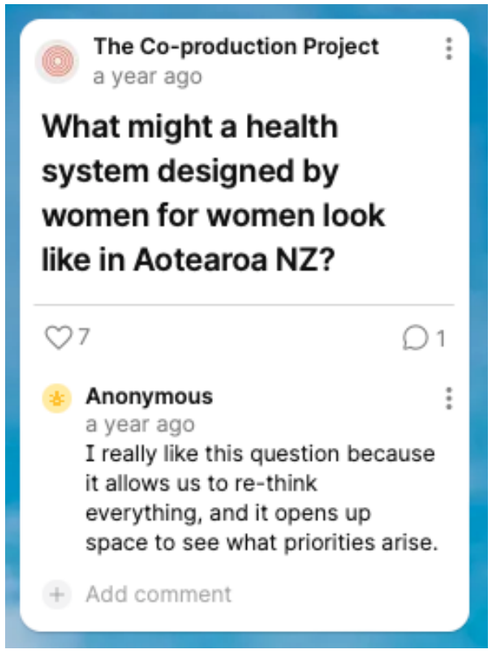


Figure 105:
A screenshot of a question on Padlet that has had 'heart' responses and a comment.

Padlet gives different options for sorting and displaying the question cards, so as part of the development process, we tried out different approaches. We settled on having the questions display randomly, and for that randomness to change each time someone looked at the board. This might have been slightly annoying for anyone who split their viewing of the questions into multiple sessions, but it ensured that people were not favouring the same few questions that were displayed first. Contributors were emailed the link, along with instructions, and were encouraged to add new

questions, 'like' questions or comment on existing questions. There wasn't a big response, so I then emailed all the contributors three questions (each set of three was different) and asked everyone to either respond to those questions by replying to the email or go to the Padlet board and respond there. This got a better response, and any response that came via email, I added to Padlet. The core research team then sorted through all the questions and feedback, and refined them to 34 questions (see Appendix 5, p. 359). The list of 34 research questions was shared at our three celebration events — we projected them onto a wall to make it easier for people to view them, and then had a laptop and tablet available for people to add new questions or interact with the questions already there. Having the library of questions on an online platform makes it easy for us to share them in the future, although we may also want to look at other ways of storing and sharing the questions so that we can progress some of them.

How might we generate more conversations?

Care-full Conversations card deck

During the Cuppa & Cake sessions, some of the contributors told us that women did not often have opportunities to chat about health, and that talking with other women about experiences was empowering. These conversation card decks are a way to help facilitate conversations without the need for a trained or experienced facilitator:

> "I enjoyed the group very much! It was heartening speaking with women from different generations and seeing how much we have in common."

> "Really nice talking to you, it was really, really interesting to listen to other people's views on the topic and yeah, just gained more insight and to what may be possible or, you know, could happen in the future, what we could have potentially for those."

The words on the cards originally came from summarising the Cuppa & Cake session conversations, and then were used as part of the research question development process. We then reworked the words specifically with the focus of generating conversations. The core project team piloted using the card decks in different ways with different groups of people. This gave us valuable information about the word selection, and also about the suggestions for how to use the decks. Each card deck comes with ideas of how to host conversations, from light-hearted to deep and meaningful, with some suggestions for keeping each other safe during conversations,

which Hannah Smith developed. Jean Donaldson illustrated the cards, and along with the Toi Āria team designed the card deck, instructions and boxes. I was also involved in this process, giving feedback at all stages, as well as piloting the cards.

To name the card decks, we asked contributors to vote on a few ideas or suggest alternatives — 'Care-full Conversations' was the most popular name (Figure 106), and writing 'Care-full' in this way highlights the idea that conversations will be full of care.

Figure 106: The potential names for the card decks we asked Contributors to vote on.

Contributors in the project received a set of these cards, and we've also given them to other researchers, health professionals and other interested people. The cards were also displayed at the celebration events (Figure 107). Some feedback from a contributor said:

> "Wanting to say a huge thanks for the cards. What a beautiful thing to use to prompt conversations with women and more importantly with myself. Well done again on such a wonderful project."

Figure 107: Different displays of the conversation cards at our Celebration Events.

Summary and provocations

Participatory design approaches encourage creativity, conversations and connectedness. The overall experience of collaborating through processes and methods is as important as the methods and tools themselves. However, considering the benefits and challenges of different methods helps with choosing the ones that best mix together to align with the principles of co-production. Making these choices in a way that allows an iterative approach gives room for flexibility and responsiveness in order to incorporate feedback from those involved. It is also important to consider ways of creating and holding space for safety and vulnerability.

The detailed description in this chapter of the development and use of different participatory approaches demonstrates the considerations involved in planning engagement sessions and projects. Looking specifically at methods that can encourage the inclusion of embodied knowledge and/or align with Indigenous knowledges can support valuing a plurality of knowledges, which aids the production of new knowledge. Asynchronous tools provide additional ways for people to be involved in the project in ways that suit them, and combine well with synchronous methods for developing research questions and future conversations. While the examples shared here are a small sample of options available, they demonstrate the many possibilities for participatory design approaches.

The provocations for this chapter are:

- Why are iterative approaches important?
- Why are 'spaces' important for participatory design approaches?
- How might we encourage building connections?
- What are some asynchronous tools?
- What are some embodied methods?
- How can research questions be developed collaboratively?
- How might we generate more conversations?

String bag

How is academia containing and constraining?

How does funding impact co-production?

What ways do procedural ethics contain and constrain projects?

How can university systems be challenging?

String bag

In the metaphor of the ‘octopus in a string bag’, the string bag represents all the structures, systems and processes that make up academia and therefore shape the environment that research is carried out in (Figure 108). The string bag draws your imagination to a sense of containment as the octopus is held by the string bag, indicating potential tensions between a co-production project and the university. It also suggests imagery of the octopus escaping (even if it's just an arm or two) from the string bag — similar to the potential of the project to get away from you, or for certain inquiries to lead you far away from the start of the project, or deep into the community and away from the research institute. But it also draws attention to how the constraints of a string bag can not only be a hindrance but can also help to contain a project — providing boundaries (albeit flexible ones) to something that could otherwise become unwieldy and unmanageable.

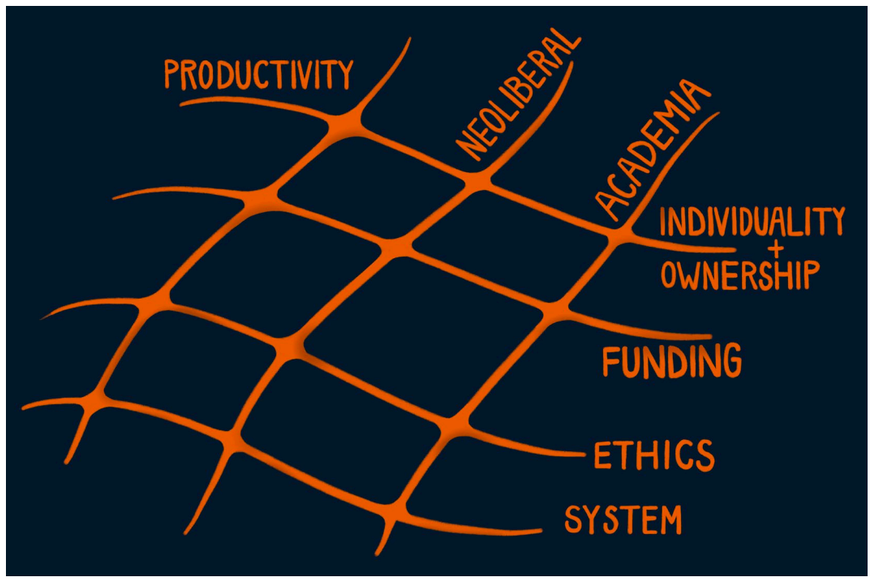


Figure 108:
The String Bag part of the metaphor, with the threads labeled to show what makes up the bag.

A co-production approach aims, and hopes, to be of benefit to those who will be affected by the research through valuing both the expertise of academic researchers as well as that of people’s lived experiences. Social scientists Julia Zielke, Matthew Thompson, and Paul Hepburn (2023) remind us that we need to be mindful that while we can have the best of intentions, the research environment (e.g. academia and the university) will have an impact on the process and results of a research project, which may constrain or undermine these aims. Ideally, we would be able to make long-lasting changes to university systems and processes that would benefit future research projects. However, these changes can be very slow to happen, which meant that for my PhD, we sometimes needed to rely on short-term workarounds to make progress. The following section discusses the impacts of academia on Care-full Co-production, including aspects such as research ethics, funding and procedural challenges, and considers the way these may have helped or hindered this project.

How is academia containing and constraining?

Community engagement, consultation, or similar terms are frequently used by universities as part of their marketing strategy (Place, 2023). However, they can often be empty phrases that lack genuine and relational grounding — or lack the systemic changes needed to back up the intentions. As Ostrom (1996) wrote “Designing institutional arrangements that help induce successful coproductive strategies is far more daunting than demonstrating their theoretical existence” (p. 1080). Academia is often missing the systems that encourage and allow for carrying out research which prioritises relationships (Haverkamp, 2021), making it more difficult to do research that challenges some of the priorities of academia. This gap in the systems, or mismatch of priorities, was highlighted in the complexity of getting my PhD accepted by the university; it was difficult to explain where there would be individual research (required for a PhD) in a collaborative, co-produced project in advance of doing the project. Other tensions between academia and co-production can be seen in the conflict between co-production priorities and academic values of productivity, individualism, and neoliberalism.

Productivity

As discussed by social scientists Sara Goodkind and colleagues (2023), academic institutes expect their people to deliver a high level of productivity, promoted by capitalism’s value of quantity and forward progress. The rise of measurement systems such as impact factors and publication rankings creates reinforcing feedback loops and leads to productivity cultures referred to with phrases such as ‘publish or perish’. These expectations become so internalised that it can be difficult to work at a slower pace, focussing on quality and other ways of assessing impact besides publications and impact factors. With co-production research, the focus of outputs

is on what is needed by the people who will benefit from the research, predominantly those with lived experience who may not be involved in academia. This can mean that academic publications are a lower priority for a project, resulting in fewer of them or the academic publications happening at a later stage. Delaying academic publications until later has the risk of impacting funding for future projects and can have implications for researchers' employment. Oftentimes, the outputs may not look like regular academic outputs, for example, the Care-full Conversation cards. Williams et al., (2020) question why "is publishing in high impact journals valued more highly than working directly with fellow citizens to improve society?" (p. 5), which highlights a tension that is at the core of co-producing research.

One of the prompts for our core project team reflection practice is "What did the team dislike? What could have been improved? What was uncomfortable?" The following response to this demonstrates the ingrained drive for productivity:

> "Being more organised and having clear 'outcomes' for the session. However this is my own pressure and not voiced by others in the team."

A contributor also alluded to productivity and outputs of the project, commenting:

> "The looseness is exciting, but actually, how might we get something? You know, what is the purpose of all of this? And I feel over the years, we've talked so much around the many, many issues. But yeah, and I'm mindful, and certainly in the current climate, without getting into politics, but it's going to be a time of change. And that's the thing, you know, how you actually can get some traction for improvement in some discrete way."

Individuality

Although universities talk about community engagement and working with stakeholders, collaboration is not fully encouraged (Place, 2023). Expectations and responsibilities tend to be placed onto an individual rather than focussing on systemic or collective approaches to managing these responsibilities and expectations (Haverkamp, 2021). Regardless of whether collaboration of any sort is involved, academia relies on individual ownership and authorship, for example, publication ratings and rankings or funding processes. Like one of the string bag threads pulling uncomfortably tight, this focus on individuality creates tensions for co-produced research — if the participants really do become 'co-researchers' (or the term they prefer, such as contributor), then really they should also be named on all outputs. This challenges how authorship currently works, as well as the expectation of confidentiality, and the expectations of what someone will have done to be named as an author. There is generally a hierarchy to the order of authors as well, which contradicts co-production efforts to share power. By co-producing knowledge, the notion of who owns knowledge or research is challenged.

Focussing on individual ownership can be a tension with collaborative, relational approaches like co-production. Employment opportunities, promotions and qualifications such as PhDs all require individuals to claim ownership or responsibility of projects or research, or at least parts of them. Stating such claims is really uncomfortable — it feels like chopping projects into pieces, and in the process, can lose some of the nuance and complexity of a project. When new knowledge is created by the interactions in a process, not just the parts, how can an individual claim ownership of an interaction? Even using the split between core project team and contributor can suggest (or reinforce) that the core project team has more claim to ownership of the project and its outputs — but the core project team is still a collaboration, so it remains in tension with academia's prioritisation of individuality.

An aim of Care-full Co-production was to create a library of research questions — with the possibility of sharing these questions with other people (e.g. those best suited to exploring particular questions). This also challenges the academic focus on individuality, as generally, research questions are considered intellectual property and held onto by the researchers themselves. Sharing research questions needs to include ethical considerations, and maintain a connection to where the questions originated — not for ownership's sake, but to respect and acknowledge the people whose experiences shaped the development of the questions.

Neoliberal

The neoliberal universities of today prioritise the production of quickly produced quantities of outputs over longer or slower quality engagements, and encourage competitiveness rather than collaboration (Zielke et al., 2023). They situate themselves as the producer and holder of knowledges in a way that is often exclusionary (Duggan, 2021). Design, and its methods such as design thinking, which allows for the fast creation and implementation of solutions to various situations, has therefore helped reinforce the valuing of productivity (Tonkinwise, 2017). As Stern and Siegelbaum (2019) said, "contemporary design is not merely an outcome of or response to neoliberalism but also an important contributing factor in its articulation and implementation" (pp. 265-266). Co-production research can provide a way for academics, communities, and experts of lived experience to challenge not only the production of knowledge but also the dissemination of knowledge (Bell & Pahl, 2018). However, this requires intentional actions and choices to resist the faster-paced and output-churning expectations. Without a specific critical approach, such as a feminist praxis, to share power and value relationships, co-production could be implemented with a scientific positivist epistemology (Turnhout et al., 2020) — though this would not be considered co-production as has been developed and defined in this thesis.

Speed and productivity expectations of neoliberalism are at odds with the principles of co-production, which require a more flexible timeline, pace and taking time to build relationships. The outputs and impacts of co-production are not always tangible or measurable in the way that universities are used to, which can result in

co-production being questioned as to whether it even 'counts' as productive research (M. Parsons et al., 2016). This reiterates Pain et al.'s (2015) call for evaluating the success and impact of co-production projects in different ways — to provide universities with ways of understanding this without using the current post-positive ways of showing validity and legitimacy (Durose et al., 2022; Goodkind et al., 2023).

How does funding impact co-production?

While we were fortunate to have generous funding for The Co-production Project, and therefore Care-full Co-production, and few restrictions, there were still some constraints. Like most funding options, the funding for our project was for a set timeframe, which limited how long the project would have resources available. This generosity and relative freedom made it possible for us to follow co-production principles from the beginning. Often to be able to gain project funding a certain amount of the work is needed to be decided and planned in order to be included in a grant application — to be able to co-produce these aspects could mean asking contributors to donate their time and expertise, without knowing if the project would get funded and therefore progress (Bell & Pahl, 2018; Pain et al., 2015). It would also be difficult to provide the support and resources needed (e.g. hospitality and transport) for contributors to be involved in co-producing a project from the start if there is no funding for that early phase. There has been an increase in universities and other funding bodies providing 'seed funding' to use for this planning phase of a project, which will help reduce some of these challenges. Oliver et al. (2019), when commenting on the 'dark side' of co-production in health research, suggest that the economic and professional burden of co-production is high, such as delayed funding or publications that can impact reputations or the success of other opportunities. They suggest that because of the impacts of these burdens, co-production research is often left to those in precarious or more junior academic positions to carry out without the necessary resources to do 'good' research. Williams et al. (2020) critique this, asking why co-production is not being adequately funded or supported from the outset. They argue that the unequal burden of co-production is due to systemic inequities within academia rather than being a negative of co-production itself. This supports the argument that co-production will do best when it is considered for a project from the beginning rather than being an addition later on in the project.

Funding can add constraints to a project if the funding source's values are not aligned with the project's values or those of the researchers and contributors (Williams et al., 2020). For The Co-production Project, we were fortunate that Te Pūnaha Matatini's values supported what we had in mind, and when the core project team co-constructed a set of project values (as shared in Aotearoa Waters, p. 61, and Appendix 6, p. 364), Te Pūnaha Matatini's values were incorporated into the final set of project values. From this perspective, the funding timeline was one of the ways that the string bag contained the octopus.

What ways do procedural ethics contain and constrain projects?

Consideration of ethics in design research is relatively recent, especially, as design researcher Janet Kelly (2018) writes, in a formal way — though from my observations it is increasing and discussions are deepening. From the string bag perspective, procedural or academic ethics are the main ethical considerations influencing how the academic systems impact a co-production project. While they can be (and often are) discussed as distinct types of ethics, separate from other forms, such as 'everyday ethics' and ethics of care, in practice, they are all intertwined and influence each other. In the conference paper I co-authored with Anna Brown (2024), we described them as Head and Heart ethics, and how there can be tension between these. It also signals the embodied nature of ethical decisions, with our bodies and senses contributing to the decisions researchers make throughout a project (Sand et al., 2024).

While in other countries participatory research does not always need ethics approval (Locock & Boaz, 2019), within universities in Aotearoa we do. This generally includes completing a detailed form and gaining the approval of an ethics committee (though for lower risk situations, there is a shorter process). Ethics committees focus on clarity of outcomes and outputs, and anonymity and confidentiality, and mostly focus on the safety of individuals rather than communities (Muller & Brown, 2024). As mentioned previously, the ethics application process created a conundrum for how to get this project started, as we needed approval to be able to recruit contributors, but needed a plan, which we couldn't create without contributors. The timing of ethics committee meetings for approving applications, as well as how long that part of the process can take, can have a significant impact on the project timeline. This can be factored in to a certain extent, but more flexibility in this process could really help co-production projects. While completing the application form with its specific questions and character limits helped clarify and refine the project, it also felt quite restrictive and reductive.

Haverkamp (2021) discusses these procedural ethics as being masculine or cognitive ethics of concern and justice, in contrast to feminist and Indigenous ethics of care. The ethics of concern show up in the focus on anonymity or confidentiality, and how this must be preserved at all stages of the research. For a relational project such as The Co-production Project, this is less of a focus, as the aim is to build and prioritise relationships with those who become contributors in the project. It is also limited by the 'kitchen table' approach to conversations, where multiple contributors are involved in each conversation, meaning confidentiality is somewhat lost. This process of making contributors' identities confidential is not always wanted by the contributors themselves — they want to stay attached to their stories and the experiences they share. A contributor highlighted this when they responded to the prompt "What could valuing your contributions look like?" with "want to be me — my name to be used — not just a number" (as seen in Figure 109).

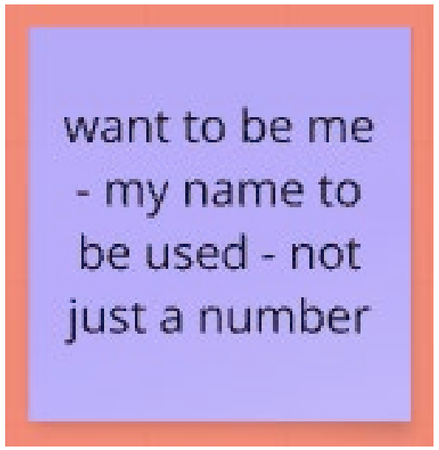


Figure 109: The String Bag part of the metaphor, with the threads labeled to show what makes up the bag.

Confidentiality is further blurred by the notion that contributors are co-researchers rather than participants, with them starting as participants when they were first recruited but then transitioning to co-researchers as the project progressed — though there was no clearly demarcated transition point.

Procedural ethics can feel like a specific task carried out at the beginning of a project, but ethical considerations do not stop with the application (and receiving ethics approval) — they are a continual action throughout the project, and may continue past the end of the project if publications or other outputs happen later. Ethical considerations, particularly the questions found in ethics applications, can facilitate thinking about power imbalances and how to minimise risks of harm and coercion, but they can also be constrained by the string bag threads of the highly controlled and hierarchical structures of academia.

How can university systems be challenging?

Different academic institutes or organisations will have their own systems and processes that may influence co-production projects in various ways. The ones that had the biggest influence for us — where Care-full Co-production, or *The Ethical Octopus*, felt constrained by the string bag — were the way we were able to compensate or show our appreciation for people's contributions in a tangible way, and the paperwork that is required as part of the recruitment process (the information sheet and consent form). What follows is a discussion of the challenges and considerations raised by these.

Koha

Koha is a Māori concept meaning: "(noun) gift, present, offering, donation, contribution — especially one maintaining social relationships and has connotations of reciprocity" (Te Aka Māori Dictionary, n.d.). This concept is commonly used as a way of valuing people's contributions in situations where they are not paid employees (or similar). What the koha is, or what the monetary value is, is often influenced by the amount that university staff members can approve, and is sometimes constrained by tax rules, such as when the amount or type of koha becomes a 'fringe benefit' issue.

The koha amount isn't solely calculated as an hourly rate or other 'time equals value' approach, but due to this, it can result in an amount that is too low to appropriately show appreciation for people's contributions in a co-production context. These contributions are made up of not only time but also mental and emotional labour in coordinating attending sessions, as well as involvement in the actual sessions. In co-production projects, their contributions also include their expertise of lived experiences. As Filipe et al., (2017) commented:

> Commonly held notions of participation and co-production as voluntary acts that are unpaid (or paid below market value) should be reassessed in favour of a more substantive notion of co-production as a form of collaboration toward social justice, inclusion, and economic solidarity. (p. 4)

For co-production research projects, the difference between being a participant and a co-researcher can be a bit fuzzy when some people are paid to be part of the project (e.g. the core project team) and others (e.g. contributors) are not.

The form in which a koha is given also needs to be considered. Frequently, it is given as a supermarket voucher, but ideally, contributors would be given a choice of what suits them best — either cash or a voucher not restricted to a specific retailer, or to choose which retailer it is for. Offering choice can create additional labour for the core project team and needs to be factored into the team's capacity (Kidd et al., 2021). For Care-full Co-production, we started out offering a choice of supermarket or petrol vouchers, but as contributors either had no preference and only chose supermarket vouchers, we moved to only giving supermarket vouchers. We did need to ensure that we were giving a voucher for a retailer that was in the location where the contributors lived.

We also had some security concerns about posting out supermarket vouchers to those who had participated online since we could not hand the vouchers over in person. A solution was found using an option to email the voucher to contributors — this mostly worked well, however, it required a level of technical ability that not everyone had. One participant struggled with this option, and as they were not very concerned about receiving the koha themselves, I offered them the option to donate their koha to a charity of their choice. I had anticipated this to be a straightforward

process; however, the university payment systems made this more difficult and would have resulted in more labour for the contributor, which defeated the purpose of this option. We found a short-term workaround for this one-off situation, but it was not ideal and was a moment when we felt constrained by the string bag/university processes.

Purchasing the physical supermarket vouchers was also not as simple as one might expect as neither the supermarket nor the university systems were set up for easily buying bulk vouchers — core project team members either needed to use their own money and then wait potentially a month or more to be reimbursed (which is not possible for everyone) or the one team member with a university credit card had to make all the purchases, which added additional logistics and labour to the process. It can also be quite uncomfortable to hold up a supermarket checkout while they load 20+ vouchers with the correct amounts and then walk out carrying about $3000 worth of vouchers. On the other hand, however, the vouchers (and especially the amount) were very appreciated by recipients, as one said:

> "the koha was much appreciated too! This has helped my family's food shop this week."

Recruitment paperwork

The forms required for research projects, such as information sheets and consent forms, can feel constraining for projects that are doing research differently, like co-production. The intent of the forms is not in question. However, the requirements of what is included can feel restrictive. The number of things that need to be covered can make it difficult to keep the forms short enough for people to read them. We provided the forms in advance so our contributors could take their time reading them, but that does place additional labour on them. Frequently our contributors had not read the forms before attending one of our engagement sessions, so we had to allow time in the schedule for understanding the information — we would happily summarise the forms verbally, but we also had to be prepared for people to want to read it all, and people read at varying speeds so it could take longer than anticipated for this to be completed. It was also difficult to meet the university's requirements and, at the same time, have the information sheet and consent form written in everyday language. Exploring alternative ways to present this information (e.g. using images) would be beneficial to try in the future.

Having someone sign a consent form can reinforce the inherent power asymmetries between academic researchers and those joining the project from outside the university. With co-production aiming to share power and reduce power asymmetries, the consent form coming so early in the project (and potentially early in the relationship development) can hinder this aim. A core project team member reflected after one of the sessions that

> "The consent form process was quite long, and felt uncomfortable starting with something so formal before we'd been through the actual relationship building phase."

I found our way of handling the tension between relationship building and completing the paperwork resulted in a tendency to try to distance ourselves from the consent form — saying things such as "the university requires it" or "it's part of the ethics process" — as if we were separate from those requirements and processes. On reflection, considering the options of verbal consent or investigating if we could use an email response instead of a signed consent form might have led to better ways to reduce the impacts of this power imbalance.

Summary and provocations

This chapter has highlighted how aspects of academia, funding, ethics and university systems can be both constraining and containing for a co-production project. Systemic changes are slow, so in general we had to rely on short-term workarounds — although now that the constraining elements have been identified, more thought could be given to how to make lasting changes. Reflecting on three years of experience and understanding what co-production can look like has given a different perspective on the challenges faced — more confidence to sit with the uncertainty, and more ideas of how to work within the constraints or ideas for reducing the constraints. Like in a lot of contexts, if we set the systems up to support those with the most needs, everyone benefits — so considering how to improve academic and funding systems and processes could be beneficial for all research. Taking an octopus' perspective and their ability to get out of small spaces, we can look for the hopeful spaces where we can reduce constraints or move beyond the confining elements of the university.

The provocations that make up the String Bag are:

- How is academia containing and constraining?
- How does funding impact co-production?
- What ways do procedural ethics contain and constrain projects?
- How can university systems be challenging?

Horizon:
Concluding Thoughts

Horizon:
Concluding thoughts

Having used the structure of ‘the octopus in a string bag’ to explore and discuss the understanding of co-production that has been developed through this research, it is now time to look to the horizon. A short recap of how co-production was researched through the case study follows. I have then presented the key findings and their implications — this is the ‘ending’ of the story as it were, bringing all the entangled threads together through some concluding statements. Acknowledgement of possible limitations to this research are explained, and then a look to the future, with suggestions of possible next steps for research, women’s health and co-production. Hopefully, this move from the micro and macro of the project, to future perspectives, leaves you thinking, pondering and imagining — while you enjoy a ‘cuppa’.

Research recap

Women’s health

In the Aotearoa Waters (chapter) I outlined how we explored co-production through the case study of women’s health. We spent time building the conditions for the project, including the core project team getting to know each other, and making connections with others working in this space. Language choices were discussed and made, along with deciding who we wanted to include in the project. Following this, we initiated our Cuppa & Cake sessions, a co-discovery process to build an understanding of what women’s health means to women across Aotearoa New Zealand. Taking care with venue choices and hosting decisions, we created informal environments where our contributors felt cared for, included, and safe to share their thoughts and experiences. Through seventeen engagement sessions across the motu, in Wellington, Auckland, Online, Queenstown, Christchurch and Invercargill, we had conversations with 89 women with many different, as well as shared, experiences. These conversations were heartfelt, vulnerable, generous, supportive and thought-provoking. Having space, time and places to share and learn with each other was inspiring and empowering, with many women wishing for more opportunities like this.

The core project team synthesised and summarised the transcripts from the Cuppa & Cake sessions, settling on ten themes to communicate the commonalities across the conversations. We then presented these to the contributors in a series of online sessions. We heard that presenting these themes in a grid display enforced an unintentional hierarchy and removed the interconnectedness of the themes. The conversation also included considering how we might all work together going forward, what would be of interest, and what the women would like to be ‘called’. We had thought that using the term ‘co-researcher’ would be appreciated, and a way to reduce power asymmetries. However, this term did not sit right, and in the end, ‘contributor’ was settled on.

Following the summary sessions, we used an online survey to gather information from the contributors about their preferences for ways of working, their motivations and what they were interested in exploring. This provided valuable feedback and insights and led to the creation of The Octopus, the project’s monthly newsletter, as well as Contributor Clusters. The Contributor Clusters were intended as a way for contributors to explore topics of interest in smaller groups and collaboratively develop a deeper understanding of the topic to feed into research question development. We had an online cluster and a place-based cluster in Queenstown. While these were interesting, the Contributor Clusters didn’t end up progressing the way we envisioned, and our next steps changed.

We then moved on to our Research Questions Development phase, with online and in-person sessions. Using an activity where contributors added ‘question parts’ and ‘content words’ together to create questions, we collaboratively developed over 100 research questions about women’s health. There was also a simple task where contributors drew around their hand, and then responded to the prompt “When it comes to women’s health in Aotearoa New Zealand, something I’d like to see is….” The responses to these prompts were included in the refinement process of the research questions. The research questions were then made available for everyone to interact with on the online platform ‘Padlet’, allowing those who had not been in the sessions to add their input. Through several iterative processes, the core project team worked with the research questions, grouping, summarising, sorting and then refining the questions down to a smaller group of 34.

We drew the project to a close with a series of three celebration events in Wellington, Christchurch and Queenstown. These were a way of sharing what we had learnt, created and developed back to the women in the project, and to share the project with friends, family and anyone else who we or the contributors thought might be interested. We presented all the hand photos and hand-drawn hands as a wall display, and attendees at the events could also draw their own hand to add to the collection. Contributors were also invited to share their reflections on being involved in the project. It was a beautiful way to softly close this chapter of the project, while maintaining relationships we hope last beyond the project.

Co-production

From a critically reflexive perspective, I documented and recorded what we did in order to explore co-production through this case study. I took a multi-dimensional approach to consider the micro, meso and macro details of the project in a transdisciplinary way. I participated in the project, working with the core project team and the contributors to construct engagement sessions, experiences, new knowledges and the project's outputs. Through this situated and participatory ethnographic approach, I expanded the metaphor of the 'octopus in a string bag' into the structure of this thesis. Using the octopus as a framework to demonstrate the non-linearity and complexity of co-production, with each chapter offering prompts for consideration with the aim of assisting the application of *The Ethical Octopus* to other contexts. The Head of the octopus covered 'co-productioning' — looking at how it is a robust research approach, barriers and challenges and what success might look like. Following this came the eight arms: Building the Conditions; Care; Power; Prioritising Relationships; Temporality; Language; Reflexivity & Reflectivity; and Participatory Design Approaches. Blending theory with examples from the case study, these chapters aimed to provide 'practice-able' ideas and understanding, in order to support future researchers and practitioners to have a positive experience applying co-production in their spaces.

Key findings and significance

Women's health

While what we learnt about women's health is not the main focus of this process-oriented thesis, it is worth sharing the high-level findings, as they can not be completely detached from what has been learnt about co-production. The women involved in the project really benefited from having time and space to have conversations with others about health. I think we all hope our research will be of benefit to those involved, but to actually have the benefit of participating acknowledged at the time is quite rewarding. Many of the women commented as they left engagement sessions how much they'd enjoyed the conversation — even when the topics of those conversations had been difficult and emotional. Through these conversations, women found validation, solidarity, experienced being heard, and learnt from others.

Women are keen and eager to be involved in research about women's health, and co-production is an engaging and suitable way to include them. They want to see an increase in research into health that includes more women in general, and research that focusses on health issues that are experienced predominantly by women. Improving health care and health knowledge, so that other women and future generations have better experiences, is a motivating factor for why they want to be involved. The questions they developed in the Care-Full Co-production project

were big, complex and often systems focussed — they concentrated on making things better for everyone. Focussing on such high-level issues was not surprising, as through the conversations we had, we saw that women's health is more than just the health of the individual; it also includes the health of those around them. Improving research and, therefore, health care for women will contribute to improving health within their communities as well. Collaboratively creating research questions is a relevant and important way to improve the impacts and benefits of future research.

Co-production

Having come to the end of the project, and now the thesis, I still consider the definition I started with to be appropriate: co-production describes an approach to research in which communities, organisations or groups who are meant to benefit from — or who otherwise will be affected by — the research become partners in formulating, designing, carrying out, analysing, and reporting the research (Chambers et al., 2021; Durose et al., 2022; Pain et al., 2015; Willyard et al., 2018). However, I argue to expand the principles of co-production from the original four — share power; prioritise relationships; build capability; and use participatory means — to six principles with the addition of: elevate lived experiences; and embed an ethics of care. I believe explicitly stating these final two principles will assist with avoiding the tokenistic application of co-production and increase focus on everyone involved having a positive and beneficial experience. These additions are particularly important in the bicultural context of Aotearoa to help overcome Pākehā Paralysis and to develop non-colonial participatory methods. However, I assert they would be appropriate, and possibly necessary, in other contexts as well. With reference to the discussion on the development of co-production (in the Ocean chapter), expanding the key principles to these six principles ties together the two historical strands of development (public service development and participatory design), giving a form of co-production that embraces its design roots along with its science applications, and strengthening its ability to facilitate transdisciplinary research.

For most of the project, I had the lingering feeling that co-production was more than a method, a framework, a concept, an approach or even a methodology. I repeatedly tried to understand where co-production might fit, and what I could use to make it easier to classify it. I was left with the impression that much of the confusion about 'what' co-production is and how to define it came down to this classification. When we think of something as a framework or methodology, we often look for clear descriptions, and potentially instructions for how to 'use' it — these have been missing, blurry or interchangeable with other terms. Following some attempts to explain my work using complex systems thinking and language, and some generous conversations with other scholars, I (somewhat) untangled my thoughts. I conclude this research by taking a stand that co-production is actually an ethico-onto-epistemology. Phenomenologist Małgorzata Kowalcze (2022) explains that physicist Karen Baraad coined this term to highlight that ethics, ontology and epistemology cannot be separated — they are entwined and entangled when

it comes to knowledge production. Co-production is, at its heart, about the ethics involved with what we know and how we know it. Whatever the outputs aimed for, co-production produces new transdisciplinary knowledge through what its processes create and how its processes are experienced. As Block (2024) writes "it makes more sense to do science in a transdisciplinary and applied way, going beyond a pure quest for knowledge for its own sake" (p. 3). I would expand this to include all research, not solely science.

With co-production as an ethico-onto-epistemology, we are not left looking for an instruction manual as such, because co-production becomes a guide to define mindsets and decision-making. With this classification of co-production, the concept of epistemic care would be important. Described by Block (2024), epistemic care is about tending to the inequalities found between different knowledges, and recognising the efforts needed to value different ways of knowing in the same way that academic knowledge is valued. Using Haverkamp's (2021) term 'engaged research', this additional layer of caring would slide projects along the participatory continuum from participatory research to engaged research, reflecting contributors roles and input as more than simply participating.

The intention with *The Ethical Octopus*, and the consideration prompts within each part of the octopus, is to provide a way of transforming the knowledge shared in this thesis into an actionable aid that can be applied in other settings. These prompts could also form part of an evaluation process — considering answers to the questions as part of building and planning the project, and then checking in with the questions and answers along the way to see if new things need considering or tending to. Especially for those starting out, *The Ethical Octopus* may provide some scaffolding to support people through the discomfort of the process. While not a prescriptive instruction list, it could make it easier to get started. As the aim of this research was to specifically look at co-production within an Aotearoa New Zealand context, some aspects may need reinterpreting for different applications, such as interaction rituals for developing relationships. However, sharing *More Than a Name Tag* overseas and being interviewed by an Australian university radio station show there is applicability and interest for some of these approaches to be employed in other contexts.

People in the project

Research, and especially reflexive and relational research, also results in changes in the 'researchers' themselves. While I can't account for the rest of the core project team, I can share some of the ways I'm aware I've changed. Through the reflexive practices, interrogating my assumptions and reading such a wide range of content, I have expanded my knowledge and understanding of inclusive and accessible practices — along with the additional embodied knowledge of needing to accommodate myself. Understanding inclusion and accessibility in a way that includes neurodiversity and chronic health conditions, as well as disabilities, had me considering the experiences we developed more broadly and paying attention to the details more. It also drew my attention to how difficult it can be to balance all the

options within the constraints of a project — and how frustrating it can be to have the best of intentions but not be able to turn them into change and action.

Through opportunities afforded me by joining the Te Pūnaha Matatini community, along with connections and experiences within Care-full Co-production, I have been able to deepen my understanding of Te Tiriti of Waitangi and tikanga (the Māori system of values and practices, Te Aka Māori Dictionary, n.d.) as well as become more aware of my Pākehā worldview. My hope is that this growth will at least help me identify when Pākehā Paralysis is happening and encourage bravery in pushing past this. Mostly, it reminds me how much I have to learn and unlearn.

Through practising and exploring co-production, I have necessarily expanded my knowledge — in transdisciplinary and academic ways. Block (2024) writes:

> In order to avoid more epistemological loss in the future, we need, according to Interviewee 3, scholars who understand that a transformation of scholarship is necessary and that such a process of change will also change them, the scholars. This change will significantly affect their epistemological view of the world and the (implicit) prejudices embedded in it, the influence of which should not be underestimated. (p. 9)

I hope I am on my way to being such a scholar and practitioner.

Limitations

With a broad focus on women's health and developing research questions about women's health, the people who were involved in the project were the right people at the right time. However, there were some groups of people and lived experiences that we heard from less or not at all. These include: younger women, disabled people, migrants, Pacific peoples, queer people, and intersex, trans and non-binary folk. In an ideal world, we would have more time and funding to intentionally build connections with these communities in order to include their experiences in the project and the research questions we created.

Being fortunate to have generous funding with a generous timeline gave us a 'blank slate' that is unlikely to be available to most co-production projects. We have likened this project to doing co-production 'in a petri dish' or a 'test kitchen' where results and experiences in the 'real world' will be different. The practical and actionable approach of this thesis and *The Ethical Octopus* help address this though, as the octopus can be picked up and taken to a new body of water (context) to be applied.

Similarly, sharing power and decision-making as much as one might like is difficult when the project originates from the university. Ideally, power would be equal or the project actually led by the community (as long as they want to), but that is hard to achieve within the academic and funding systems we operate within.

As Block (2024) writes "In the end, the epistemological framework of the academic researchers constitutes the epistemic corset. This means that a dialogue on equal terms remains an ideal that by definition cannot be reached despite, or because of, empowerment strategies" (p. 7). Working within the existing structures will often reproduce the status quo, even if there are intentional efforts to change or disrupt the way things are. Additionally, having an awareness of the risk of reinforcing the status quo and the impact this can have on the knowledges created throughout a co-production project is an important aspect of being truly committed to the principles of co-production (Block, 2024). While awareness alone won't ensure change, it is the first step in mitigating this risk.

Future steps and research

Women's health

For the women's health aspect, there are so many future research opportunities. For a start, we have 34 research questions waiting to be explored — either by sharing with other researchers (possibly by publication, the project website or through our connections) for them to progress, or through finding funding options that would allow The Co-production Project team to continue working on some. An appropriate next step would be to share the findings and outputs from this project with health professionals and build relationships with those who might be interested in investigating some of the research questions together. I think it would be very powerful to exhibit the hand-drawn hands as a display where health professionals could see them — the hands share people's thoughts and ideas in a much more emotive and engaging way than a written report would.

Another area that could be developed would be continuing the conversations and research questions with the people whom we did not get to talk with (those listed in the limitations section), and to expand the scope to include trans, non-binary and gender affirming care. To do this, we would need to look for invitations via existing relationships and, through this, ideally find people from these communities to lead the conversations.

Co-production

For this particular research project, I believe there is an opportunity (as well as a responsibility to those involved) to share this work with wider audiences. Following the principles of co-production, this would ideally include having contributors as co-authors and co-presenters. It could be easy to focus on this myself with the core project team, but the risk then is that contributors' voices are diluted, and the knowledge shared via publications or presentations becomes primarily focussed on academic ways of knowing.

There is also an opportunity to advocate for changes within the 'string bag' — to create longer-term change within university systems and processes. This could include collaborating with ethics committees to develop flexibility with the ethics processes that would accommodate co-production more easily, and expand options for providing information for contributors to make informed choices and give consent using methods that are less reliant on the written word, and support relationship building.

To expand the research and understanding of co-production itself, future research could delve further into the theoretical similarities and differences of the different approaches to research — Participatory Action Research, Community Participatory Action Research, Co-operative Inquiry, etc. Exploring this further with the aim of clarifying how the approaches differ from each other could help future researchers to decide what circumstances each approach is most suitable for, and be able to explain why one option was chosen over the others.

Block (2024) argues that the collaborative knowledge production that co-production (as described in this thesis) aims for, if achieved, would actually be better phrased as 'co-constitution'. They claim that co-production approaches "perpetuate the hegemonic supremacy of modern Western onto-epistemology instead of creating conditions for curiously engaging with other onto-epistemologies so as to be able to have a dialogue among equals." (p10). Adding a new 'co-' word to the collection could add to the messiness, but a lot of my frustration around the interchangeable use of co-words might be reduced if we had a different term for the ethico-onto-epistemology as explored in this thesis. Maybe moving away from using 'co-production' would increase our clarity and understanding.

Last words

A lot of what has been discussed in this thesis feels ordinary, 'general knowledge' or as some call it 'the mundane', like it is obvious for everyone but maybe it's just that way for me, because acts of care have become a part of everyday life for me, and my background learning in psychology and sociology has primed me to notice the everyday, micro acts of humans. Also, it's often this 'everyday-ness' of things that has us failing to discuss these things overtly, leading to them being invisible, overlooked or taken for granted. It is through the micro-details that we can come to understand the macro layers.

And in the words of a contributor:

> "I am a big fan of this project and how you have managed it and engaged with whānau."

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Appendices

Appendix 1: Ethics

Appendix 2: Participant recruitment

Appendix 3: Cuppa & Cake sessions

Appendix 4: Summary documents

Appendix 5: Research question development

Appendix 6: Project Values

Appendix 7: Project outputs

Appendix 8: Email example

Full ethics application
#SOB22/64 approved 10/02/2023

TE KUNENGA KI PŪREHUROA | MASSEY UNIVERSITY
UNIVERSITY OF NEW ZEALAND

10/02/2023

Dear: Anjuli Muller

Re: Ethics Application - SOB 22/64 - The Co-Production Project: Exploring co-production research methods through the subject of women's health in Aotearoa NZ — Phase 1 (Discovery)

Thank you for the above application that was considered by the Massey University Human Ethics Committee:

Ohu Matatika 3 at their meeting held on **Thursday, 1 December 2022**

On behalf of the Committee I am pleased to advise you that the ethics of your application are approved.

Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics, Graduate Research School and Ethics
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand
E humanethics@massey.ac.nz; animalethics@massey.ac.nz
www.massey.ac.nz/research/ethics

Amendment One

Gmail Anjuli Muller <anjulicmuller@gmail.com>

HEC: Southern B Application SOB 22/64 - Amendment One Approved
1 message

Patsy Broad <P.L.Broad@massey.ac.nz> Tue, Sep 5, 2023 at 10:00 AM
To: Anjuli Muller <anjulicmuller@gmail.com>
Cc: Anna Brown <A.E.Brown@massey.ac.nz>, Faith Kane <F.Kane@massey.ac.nz>

Minor Amendment to a previously approved application

SOB 22/64 The co-production project: Exploring co-production research methods through the subject of women's health in Aotearoa NZ – Phase 1

Anjuli Muller (HEC: Southern B Application 22/64)

Department: College of Creative Arts

Supervisor: Prof Anna Brown, A/Prof Faith Kane, Miss Jean Donaldson, Miss Eleanor McGechie

Approved: 5 September 2023

Thank you for your email dated 18 and 23 September 2023 outlining the change you wish to make to the above application.

The change has been approved and noted, as follows:

1. Two supplementary workshops to be held in September as an opportunity to share learnings from the discovery phase with participants (open to those who took part in the focus group discussions earlier in 2023). Note: This provides an additional opportunity for participants to contribute to the research and the direction the project will take.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee. If over time, more than one request to change the application is received, the Chair may request a new application.

Ngā mihi

Patsy

Patsy Broad I Team Leader, Research Ethics I Research and Enterprise

Massey University I Private Bag 11 222 I Palmerston North 4442 I New Zealand I DDI 06 951 6840 or ext 83840

Low risk notification
#4000026681 approved 14/09/2022

TE KUNENGA | MASSEY
KI PŪREHUROA | UNIVERSITY
UNIVERSITY OF NEW ZEALAND

14/09/2022

Dear: Anjuli Muller

Re: Low Risk Notification - 4000026681 - Exploring co-production & participatory public engagement through the subject of women's health in Aotearoa NZ

Thank you for submitting a low risk notification for your research/teaching/evaluation.

This email is to acknowledge receipt of the low risk notification and to inform you that the details of your project have been recorded in our database for inclusion in the annual reports to the Health Research Council Ethics Committee (HRCEC) and the Massey University Research Committee (URC).

You may proceed with your research, though it is advisable to provide a couple of weeks before commencing, as all low risk notifications are checked for completeness and clarity by a Research Ethics Advisor. You may be contacted if your application is incomplete and/or further clarification is required.

The low risk notification for this project is valid for a maximum of three years.

Please notify me if situations subsequently occur which cause you to reconsider your initial ethical analysis.

If a sponsoring organisation, funding authority (e.g., the Health Research Council) or a journal require evidence of ethical approval from a Human Ethics Committee (with an approval number), you need to complete a full Massey University Human Ethics application to be reviewed and approved by one of our Human Ethics Committees. Applications must be submitted and approved prior to the commencement of the research.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact the Research Ethics Office, email humanethics@massey.ac.nz. "

Please include the following statement on all public documents (e.g., information sheet, consent form) related to your project:

> ***This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.***
>
> ***If you have any concerns about the ethical conduct of this research that you want to raise with someone other than the researcher(s), please contact Massey University Human Ethics by email: humanethics@massey.ac.nz.***

I wish you all the best in your research, teaching or evaluation activities and appreciate your thoughtful consideration of ethics principles and practices.

Ngā mihi nui,

Professor Craig Johnson
Chair, Human Ethics Chairs' Committee and Director (Research Ethics)

Research Ethics, Graduate Research School and Ethics
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand
E humanethics@massey.ac.nz; animalethics@massey.ac.nz
www.massey.ac.nz/research/ethics

Low risk notification
#4000028204 approved 26/09/2023

TE KUNENGA | MASSEY
KI PŪREHUROA | UNIVERSITY
UNIVERSITY OF NEW ZEALAND

26/09/2023

Dear: Anjuli Muller

Re: Low Risk Notification - 4000028204 - The Co-Production Project: Exploring co-production research methods through the subject of women's health in Aotearoa NZ — Co-planning Survey

Thank you for submitting a low risk notification for your research/teaching/evaluation.

This email is to acknowledge receipt of the low risk notification and to inform you that the details of your project have been recorded in our database for inclusion in the annual reports to the Health Research Council Ethics Committee (HRCEC) and the Massey University Research Committee (URC).

You may proceed with your research, though it is advisable to provide a couple of weeks before commencing, as all low risk notifications are checked for completeness and clarity by a Research Ethics Advisor. You may be contacted if your application is incomplete and/or further clarification is required.

The low risk notification for this project is valid for a maximum of three years.

Please notify me if situations subsequently occur which cause you to reconsider your initial ethical analysis.

If a sponsoring organisation, funding authority (e.g., the Health Research Council) or a journal require evidence of ethical approval from a Human Ethics Committee (with an approval number), you need to complete a full Massey University Human Ethics application to be reviewed and approved by one of our Human Ethics Committees. Applications must be submitted and approved prior to the commencement of the research.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact the Research Ethics Office, email humanethics@massey.ac.nz. "

Please include the following statement on all public documents (e.g., information sheet, consent form) related to your project:

> ***This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.***
>
> ***If you have any concerns about the ethical conduct of this research that you want to raise with someone other than the researcher(s), please contact Massey University Human Ethics by email: humanethics@massey.ac.nz.***

I wish you all the best in your research, teaching or evaluation activities and appreciate your thoughtful consideration of ethics principles and practices.

Ngā mihi nui,

Professor Tracy Riley
Acting Chair, Research Ethics Chair's Committee

Research Ethics, Graduate Research School and Ethics
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand
E humanethics@massey.ac.nz; animalethics@massey.ac.nz
www.massey.ac.nz/research/ethics

Low risk notification

#4000028282 approved 19/10/2023

TE KUNENGA KI PŪREHUROA | MASSEY UNIVERSITY
UNIVERSITY OF NEW ZEALAND

19/10/2023

Dear: Anjuli Muller

Re: Low Risk Notification - 4000028282 - The Co-Production Project: Exploring co-production research methods through the subject of women's health in Aotearoa NZ — Phase 3

Thank you for submitting a low risk notification for your research/teaching/evaluation.

This email is to acknowledge receipt of the low risk notification and to inform you that the details of your project have been recorded in our database for inclusion in the annual reports to the Health Research Council Ethics Committee (HRCEC) and the Massey University Research Committee (URC).

You may proceed with your research, though it is advisable to provide a couple of weeks before commencing, as all low risk notifications are checked for completeness and clarity by a Research Ethics Advisor. You may be contacted if your application is incomplete and/or further clarification is required.

The low risk notification for this project is valid for a maximum of three years.

Please notify me if situations subsequently occur which cause you to reconsider your initial ethical analysis.

If a sponsoring organisation, funding authority (e.g., the Health Research Council) or a journal require evidence of ethical approval from a Human Ethics Committee (with an approval number), you need to complete a full Massey University Human Ethics application to be reviewed and approved by one of our Human Ethics Committees. Applications must be submitted and approved prior to the commencement of the research.

Please note that travel undertaken by students must be approved by the supervisor and the relevant Pro Vice-Chancellor and be in accordance with the Policy and Procedures for Course-Related Student Travel Overseas. In addition, the supervisor must advise the University's Insurance Officer.

If you have any concerns about the conduct of this research that you want to raise with someone other than the researcher(s), please contact the Research Ethics Office, email humanethics@massey.ac.nz. "

Please include the following statement on all public documents (e.g., information sheet, consent form) related to your project:

> ***This project has been evaluated by peer review and judged to be low risk. Consequently, it has not been reviewed by one of the University's Human Ethics Committees. The researcher(s) named above are responsible for the ethical conduct of this research.***
>
> ***If you have any concerns about the ethical conduct of this research that you want to raise with someone other than the researcher(s), please contact Massey University Human Ethics by email: humanethics@massey.ac.nz.***

I wish you all the best in your research, teaching or evaluation activities and appreciate your thoughtful consideration of ethics principles and practices.

Ngā mihi nui,

Professor Tracy Riley
Acting Chair, Research Ethics Chair's Committee

Research Ethics, Graduate Research School and Ethics
Massey University, Private Bag 11 222, Palmerston North, 4442, New Zealand
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www.massey.ac.nz/research/ethics

Participant Information Sheet
Page 1

Participant Information Sheet
Page 2

The Co-Production Project

INFORMATION SHEET AND INVITATION TO PARTICIPATE

Researcher(s) Introduction
Kia ora, my name is Anjuli Muller (she/her), and I'm PhD student in Design at Massey University of New Zealand. I joined Good Bitches Baking as a volunteer in 2016 and in 2019 took over the sole paid role, National Operations Coordinator. I grew this role into General Manager in 2021, and held it until I left in early 2022 and started my PhD. My PhD is exploring the use of a participatory research method, co-production, in Aotearoa/New Zealand through the exploratory topic of women's health.

Project Description and Invitation
The Co-Production Project is a collaboration between Te Pūnaha Matatini (an academic Centre of Research Excellence) and Toi Āria: Design for Public Good — a research unit in the College of Creative Arts, Massey University. It is using women's health as an exploratory topic to develop better understanding of co-production research methods in Aotearoa New Zealand.

Co-production is a research approach where the communities who are meant to benefit from research become partners in the research process. It puts people at the heart of research and aims to balance out the power dynamics between those involved. This project explores the use of co-production research as a way of broadening our understanding of the topic of women's health, and learning what needs there are in this area. In this first discovery phase we aim to connect with a wide range of women and listen to their thoughts and ideas on women's health through focus group discussions. Participants in this discovery phase will contribute to our foundation of understanding which will help us plan the future phases of the project. Participants may benefit from learning about what projects are happening in this space and by being part of a kind, considerate and inclusive focus groups, people may benefit from positive relationships and interactions, increased social connectedness and the wellbeing benefits that come with these.

Participant Identification and Recruitment
- We invite any past or present GBB volunteer who self-identifies as a woman to participate in this phase of the Co-production Project.
- If you're reading this Information Sheet, you may have seen our video in the GBB Kindness Times e-letter. Any GBB Volunteer (past or present) who is 16 or over and a fluent English speaker is invited to participate.
- We aim to recruit up to 100 women to be involved in focus group discussions across the motu. We want to hear from the broadest possible range of voices. These focus groups will be held in person or online, depending on participants' preferences.
- It is possible that we will receive interest from more people than we can speak to. In this case we may not be able to include everyone who is interested in participating. Anyone we are unable to involve will be notified directly using their preferred method of communication.
- People who participate in a focus group discussion will be gifted their choice of a $100 supermarket or petrol voucher as a token of our appreciation.
- Discussions held in these focus groups may be uncomfortable and sharing stories may surface difficult or emotional memories.
- Generally a focus group will be made up of participants from the same GBB Chapter so there is a possibility that some participants in the focus groups may know each other — if this will impact your participation please discuss with the researcher/s.
- Choosing to participate or not in this project will not have any impact on your volunteering role with GBB.
- To register your interest, complete **this Google form before 28 February 2023**. Your name and contact details will only be collected to enable us to coordinate your participation and will then be deleted. After this date we will contact you via your preferred contact method to answer any questions you may have and to discuss participation. By using Google Docs you accept that each time you use a Google product or service it captures a bit of the information —your browsing habits, search queries, location, device types, voice, etc and stores it for its commercial and research uses.

Project Procedures
- We're asking volunteer participants to take part in the research and share their views in a relaxed focus group conversation that will last up to 90 minutes. The researcher(s) will ask some general questions around what the words 'women's health' mean to participants, invite them to share experiences and ask about their needs and preferences in the sphere of health
- We'll take notes, but any views expressed will be reported anonymously and no information will be reported in a way that would identify a particular participant.
- Prior to their participation in a focus group, potential participants will be given a consent form to confirm their desire to participate
- If all participants agree, the focus group will be audio-recorded. Once again, this will only take place with specific consent. All participants will have the right to leave the focus group after it has started or at any time if they are not comfortable with the discussion.
- If a participant does not agree to either audio-recording or note taking they will be unable to participate in the focus groups.
- The conversation will be led by Toi Āria researchers
- Participants will have access to the details of a named Counsellor/Wellbeing Support Person if they would like further support after taking part in the focus groups. Details will be provided by researchers at the focus group sessions. Alternatively participants can contact Lifeline Aotearoa by calling 0800 LIFELINE (0800 543 354) or sending a text to HELP (4357).

Data Management
- The data collected from these interviews will be stored on a password protected Massey University server in a folder accessible only to Toi Āria Professor Anna Brown and PhD Candidate Anjuli Muller.
- Participant identity (as captured on the consent forms) will be stored separately from the focus group data in a way that will not allow re-identification.
- Focus group data, transcriptions and consent forms will be kept for two years and then deleted.
- The focus group data collected and used in reporting will not be attributed to participants as individuals. Things that are said may be used in reporting but not in a way that can be linked to any individual.
- Participants will receive a project summary if requested.

Participant's Rights
You are under no obligation to accept this invitation. If you decide to participate, you have the right to:
- decline to answer any particular question;
- withdraw from the study before the focus group begins;
- ask any questions about the study at any time before and during participation;
- provide information on the understanding that your name will not be used unless you give permission to the researcher;
- be given access to a summary of the project findings when it is concluded;
- ask for the recorder to be turned off at any time during the focus/discussion groups.

Project Contacts
If you would like any further information, please email Anjuli.Muller.1@uni.massey.ac.nz or project supervisor Anna Brown, A.E.Brown@massey.ac.nz

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application SOB 22/64. If you have any concerns about the conduct of this research, please contact Dr Gerald Harrison, Chair, Massey University Human Ethics Committee: Southern B, telephone 06 356 9099 x 83570, email humanethicsouthb@massey.ac.nz.

Participant Consent Form

FOCUS GROUP PARTICIPANT CONSENT FORM

The Co-Production Project

I have read, or have had read to me, and I understand the Information Sheet attached as Appendix 1.
I have had the details of the study explained to me, my questions have been answered to my satisfaction, and I understand that I may ask further questions at any time. I have been given sufficient time to consider whether to participate in this study and I understand participation is voluntary and that I may withdraw from the study at any time.

☐ I understand that I have an obligation to respect the privacy of the other members of the group by not disclosing any personal information that they share during our discussion.

☐ I understand that all the information I provide will be kept confidential to the extent permitted by law, and the names of all people in the study will be kept confidential by the researcher.

Note: There are limits on confidentiality as there are no formal sanctions on other group participants from disclosing your involvement, identity or what you say to others in the focus group. There are risks in taking part in focus group research and taking part assumes that you are willing to assume those risks.

☐ I understand that due to the nature of focus group discussions, if I withdraw from the study after contributing to a discussion, my contributions may not be withdrawn from the data if they would impact the context of other participants' statements.

☐ I give permission for any worksheets completed during the focus groups to be photographed.

☐ I consent for the research team to make an audio recording and transcript of this focus group.
I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research. The transcript will not provide any identifiable information. If I do not consent to the audio recording, the researchers will instead take written notes throughout the focus group.

☐ I agree to participate in the focus group under the conditions set out in the Information Sheet attached as Appendix 1.

Declaration by Participant:

I _____ hereby consent to take part in this study.
(print full name)

Signature: _____

Date: _____

Cuppa & Cake' runsheet

GBB Focus Group Kōrero Guide

Focus Group Purpose

- Building our foundation of understanding of the topic of women's health
- Learning about needs in this area, as expressed by participants
- Gathering information that helps us plan the next phase of the project

Focus Group Aims

i) to connect with a wide range of women
ii) listen to their thoughts and ideas on women's health
iii) establish their interest in ongoing participation in the co-production research
iv) everyone has a chance to feel listened to

Roles
Facilitator - (F), Researchers - (R), Host - (H)

Materials
Sticky notes, pens, big paper, drinks & cake, water, tissues, Zine/Name Tag sheets, Info sheets and Consent Forms

Welcome 15' (F/R)	Welcome - thanks and appreciation - option of opening karakia - host venue details & emergency info - information sheet/consent form check Introduction - to people and project (F) - intro to team present and our roles, timing/overview of the session (in 2 parts) - kitchen table frame - a conversation about our health and experiences as women - confirmation of the reason for/background to the kōrero (R) Consent, comfort & kawa for the session (F) - recording/notes & confidentiality - agency in participation at all times, no consequences if you decide not to participate - encouragement to speak freely; you are the experts in your own lives and experiences - an open conversation, no wrong answers, sharing the good and the bad - support each other, share the time and the space, take care of others' stories - break around half way through - intro Zine & invitation to doodle/colour in All in the Room - introduce yourself: something that would allow people with visual impairments to 'see' you + something that you LOVE doing (nb no job titles etc) - F/R models this
Name Tag 30-40'	Intro - 5' - First exercise - going a bit deeper on who we are, our identities and experiences. Show paper, fold and add name at top of white side - hold up to demo 'behind the name tag' concept. WHITE SIDE 1: face value

	- One piece of info per box. Anything you tend to quickly share in a situation like this eg where you live, where you're from, about your family, what do you do for work & play... Pause for white side completion - 1' BLUE SIDE: hidden depth - things that you might not necessarily/usually stick on a 'name tag', but you consider are a key part of your identity - things that make you YOU - eg socio-economic background/ethnic/gender/sexuality identity, politics, religion, significant achievements/experiences/challenges - particularly relating to health/your body/your experience of being a woman - highlight that there will be no requirement to share these Complete tags - 5' Round of re-introductions/responses to the activity - 10'-20' - what would you like to add to your introduction - particularly given we're here to talk about our experiences as women, and women's health? - if there's nothing else you'd like to share about yourself, what was it like doing that exercise? - share as much or as little as you want Elicit further conversation/story sharing around emerging topics - 10'-20' - invite expansions as appropriate - with option of a yes/no/not right now response - ensure everyone has had an opportunity to contribute equally - other prompt Qs: what are you noticing about how health/body/our experiences as women is part of this conversation? How much do you think our health/wellbeing experiences contribute to who we 'are' in the world?
Break 5'	Tea, coffee, loo, stretch, more cake etc - prep paper sticky note space in centre of table
Sticky Notes	Checking back in - 5'

20'-30'	- what's it like talking about our health together? What are you noticing about this conversation so far? What's it feel like? What's present? What's missing? What's surprising you? 'Women's Health': where we are - 10-15' - collective brainstorm with sticky notes. What do you think of when you hear the words 'women's health'? What does that phrase mean to you? What do you understand by it? What does it encompass? - one idea per post it note, no wrong answers - 5' to consider - group adds notes to shared space in middle of table - invite conversation, further enquiry, clustering of notes etc eg 'could you say more about...? 'Women's Health': where we'd like to be - 10-15' (may not be required depending on conversation so far) - repeat exercise above - with 'best future state' prompts - What words/phrases would you like to be there? What do you hope a future definition might encompass? What else is important in conversations about women's health? What would 'good' women's health look like? - Invite comments/Qs from (R)
Closing 10'	Next steps and appreciation - outline next steps for process - and opportunities for future involvement (R) - thank for time, knowledge and expertise and offer koha - invite a closing remark from everyone: anything you'd like to say to us, or each other? Or haven't said and wanted to say? - option of closing karakia

Supplementary Question Ideas
- What do you wish others knew about women's health?
- Describe an interaction (positive and/or negative) with health professionals that has made an impact on you.
- What are your priorities and /or values in relation to health?
- What is your understanding of/how do you define health and wellbeing?

‘Cuppa & Cake’ reflection document

Focus Group Purpose

- Building our foundation of understanding of the topic of women’s health
- Learning about needs in this area, as expressed by participants
- Gathering information that helps us plan the next phase of the project

Focus Group Aims

i) to connect with a wide range of women
ii) listen to their thoughts and ideas on women’s health
iii) establish their interest in ongoing participation in the co-production research
iv) everyone has a chance to feel listened to

Wellington March 2023

Group 1: 12.30 — 2pm 3 people
Group 2: 5.30 — 7pm 4 people

Hannah

Room and set up was perfect. Private, closed and circle around a table.

Warm welcome from the beginning. Helpful to have clear roles/responsibilities re who is doing what so as not to overwhelm arriving participants.

Small, intimate groups with the two of us holding felt great - division of F and R roles felt comfortable.

Taking time on the set up and framing is useful - and getting paperwork out of the way before ‘beginning’.

Name Tag worked well - prompts in Zine would be helpful? When discussing the blue side, a more ‘vulnerable’ share from F or R is helpful to model, but important to do this with care so as to avoid any sense of pressure on participants. As helpful to discuss the ‘thought process’ of what to include/not include.

Two parts with a break feels like a good structure
i) set up, intros, Name Tag and personal stories (Heart)
ii) ‘Women’s Health’ concept analysis and discussion (Head)
Different type of energy in two sections

How do we explain and/or delineate our roles as facilitators/researchers - and active participants/contributors? Are there any tensions or challenges we need to explore? Or guidelines we should consider?

What’s our plan for any conflict/emergence of difficult experience in the workshops?

12.30-2pm 3 people
Different age groups, deep, lovely, warm conversation - miscarriage conversation, hormones - thoughtful and felt like it could have gone deeper, and gone on longer.

5.30-7pm 4 people
Lighter conversation - closer range of ages than 1 (20s-40s) - several people who knew each other prior to workshop. More on equity side of health? More ‘heady’ than first session.

Anjuli

Seemed to flow really easily from section to section (with facilitation)

Timing felt like a good length - long enough to have decent conversations, but finishing before people have got bored/run out of things to share. People left with a bit of a feeling that they’d like to keep chatting.

I could do with being more clear in my head what I’m going to cover at the beginning.

Maybe worth explaining a bit about our roles in the session - that we’ll participate a bit too….and good to demonstrate this early to help develop a conversational feel, and set the tone/example (but without putting pressure on anyone including ourselves to share)

Encourage people to eat cake earlier.

Be clear about the purpose of the zine & that it’s for them to keep.

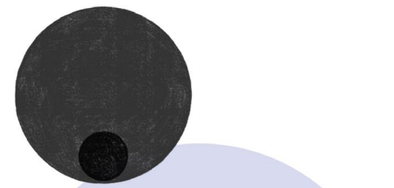
Name tag intro was really well received & worked as a comfortable transition from arriving/sharing names to a deeper conversation.

Re-looking at the aims, I need to ask directly for an indication if anyone might be interested in ongoing participation, rather than just explaining we’ll be doing that recruitment in the future.

Group 1: Gentle, thoughtful & caring conversation. Quite open and reflective. Shared experiences of miscarriage & conceiving. One person made a comment about not thinking trans health should be included in women’s health as they are different experiences.

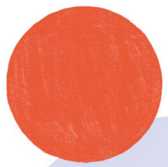
Group 2: Louder group, more jokes and swearing. Still included vulnerable sharing. One person mentioned women’s health includes all women. Post-it-note session was more higher level/theoretical thinking - eg talking about power structures

10 Themes in Word Bubbles



The 'untalked about'

grief
bleeding
guilt
self-esteem
loneliness
bodily fluids
leaking
incontinence
loss
shame
difficulty
sadness
discharge
discomfort
embarrassment



Big life experiences

heart attack
pregnancy
parenting
stroke
chronic conditions
childbirth
infertility
infant loss
cancer
death

Social and cultural narratives

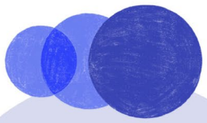
discrimination
patriarchy
pressures
expectations
social norms
power imbalances
racism

Other people

positive relationships
peer learning
inter-relational
caring for others
sharing experiences
inter-dependent
intergenerational

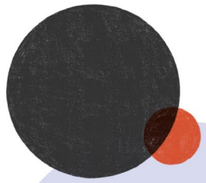
Education and knowledge

navigation
health literacy
online
Dr Google
multiple sources
confusion
deprofessionalisation



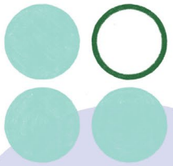
Different stages of life

how our bodies and needs change
puberty
managing fertility
perimenopause
later life
menopause
ageing
having/not having children



Interacting with the health system

attitudes
constraint
access
navigating systems
scarcity
continuity of care
appointment times



Autonomy, choice and self-determination

respect
listening
research
self-advocacy
navigation
choice

Everyday wellness

thriving
holistic
nutrition
fitness
sleep
wellbeing
exercise

Hormones and emotions

menopause
feelings
balance
emotions
cycles
imbalance
HRT
hormones
mental health
understanding

Summary document
(that we sent to contributors)

The Co-production Project
Summary

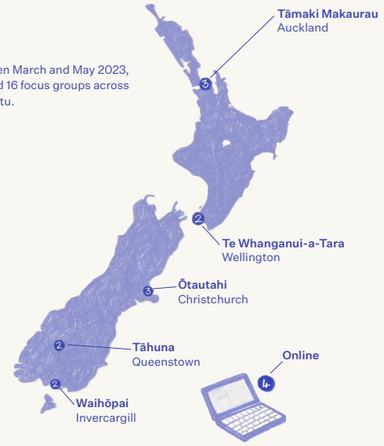
Co-discovery phase summary

In total we heard from 61 women.
Ages approximately early 20s — early 80s.
No other demographic data was collected.

Focus group format

The 'Cuppa & Cake' focus group sessions were based on the idea of sitting round a kitchen table having a chat. We loosely structured the conversations around the Name Tag activity (often included stories from the heart), and a sticky note brainstorm (the 'heady' thinking) on the topic of Women's Health. Each conversation was very different — led by the people and stories in the room.

Between March and May 2023, we held 16 focus groups across the motu.



Te Pūnaha Matatini Data • Knowledge • Insight
TOI ĀRIA DESIGN FOR PUBLIC GOOD
MASSEY UNIVERSITY TE KUNENGA KI PŪREHUROA UNIVERSITY OF NEW ZEALAND

Synthesis findings
Common themes

The following themes we've identified from across the focus group transcripts, may not fully capture the depth and breadth of the emotions that accompanied the stories we heard from the women in these focus groups. Beyond the following themes, from the experiences women shared, we heard about resilience, strength, pain, friendships, endurance and joy. We heard that women deal with a lot, carry a lot, survive a lot, care a lot and love a lot.

The 'un-talked about'
Women's health includes much that is difficult to comfortably discuss. Physical experiences are often messy and uncomfortable; social norms lead to feelings of shame, guilt and embarrassment. There continues to be significant ongoing stigma attached to mental distress, body image and self-esteem.

Big life experiences
Health is as much about the big life experiences as it is about everyday wellness. For many women this relates to experiences with fertility and childbearing, including pregnancy, birth, infant loss and not being a parent. Chronic health conditions and dealing with major and terminal illness are always a huge part of any conversation about health.

Social and cultural narratives
Women's health does not exist in a vacuum. Social and gender norms and expectations play a key role in defining how women experience the world. The dominance of the Western cultural lens must be acknowledged, alongside a health system built around compartmentalisation. Age, gender, body shape, skin colour, physical abilities and neurological function all have an impact on women's experiences — discrimination is rife.

Other people
Women's health is not just the health of an individual — it is embedded in relationships. Caring for others is a big part of many women's lives and individual health is often connected to the health of the wider family or whānau. Intergenerational relationships are important for informal learning — more opportunities for women to share stories together about common conditions and experiences would be beneficial. Positive familial relationships and friendships are vital for women's wellbeing.

Education and knowledge
Health is a complex field to understand and navigate, and the sources of information are many and varied. Women learn a lot about their bodies and how to care for them at every stage of life from each other, and from the internet. However, reliable information can be hard to access — not least because there is limited research pertaining to women's bodies and experiences of healthcare. Accessing professional advice can also be difficult and the advice can vary in quality. Women want high quality health education that is easy to access and understand for everybody.

Different stages of life
Bodies change as they age, and our questions, needs and preoccupations change. For a lot of women, and for much of our lives many of these relate to menstruation, reproduction and childbearing. Improving health literacy here, as well as for other life stages and experiences is critically important for better women's health.

Synthesis findings
Common themes (continued)

Interacting with the health system
There is a huge diversity of experience when it comes to women's interactions with the health system. Access remains a challenge for many, and experiences can be frustrating and demeaning. Women wish for continuity of care but rarely experience it. Economic and temporal constraints are affecting the quality of healthcare most people can access.

Autonomy, choice and self-determination
Many women don't feel heard or listened to when it comes to their health concerns. The perceived role of 'The Doctor' has changed over time, along with greater access to information for many. This is enabling self-advocacy for many women — but not for everyone. The need to navigate multiple options can also lead to choice being experienced as a burden.

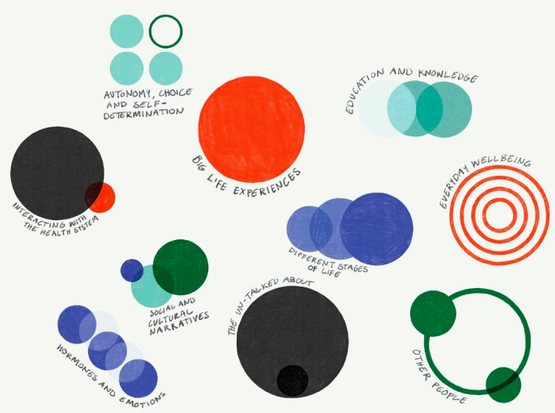
Everyday wellbeing
Every day wellbeing — nutrition, sleep, exercise and mental wellbeing — plays an important role in health at all stages of life. The factors that contribute to a person's ability to thrive and flourish are many and complex — not all of which lie within the domain of personal control and influence. Women are eager to know more, and support each other more in everyday functional health.

Hormones and emotions
Hormones, hormonal cycles and the emotions they produce have a huge impact on women's experience of health and wellbeing. Better integration of felt experience and making more space for this element of life in a female body is necessary for more holistic healthcare.

Where we went next
Summary sessions

In September 2023 we held 2 online summary sessions and a handful of individual conversations, to share with you the ten topics we came up with to reflect what you shared in the 'Cuppa & Cake' sessions. We also discussed ways we could continue working together and people's preferences for what to be 'called' (e.g. co-researcher, collaborator, contributor), showing more comfort with being 'called' a contributor.

We heard that having these as ten separate topics simplified things and lost the interconnectedness and complexity. We talked about them being more like a solar system, with some topics closer together, or orbiting around another and all linked in some way.



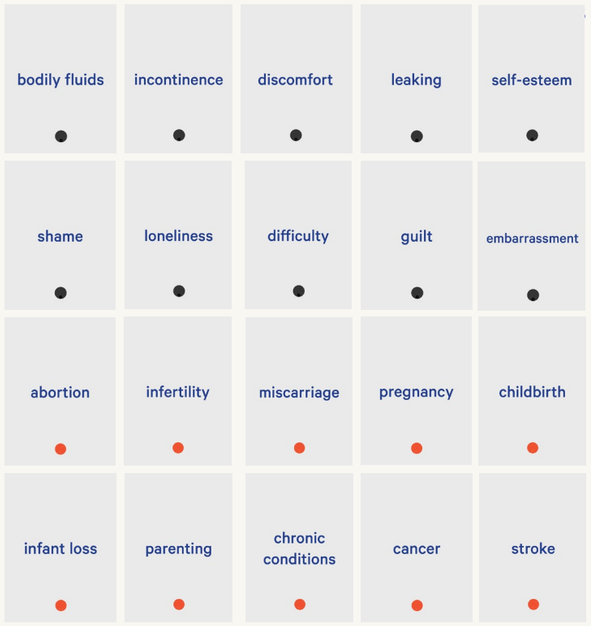
Cluster sessions

We held our first 'Cluster' Sessions in November 2023 — one in person in Queenstown and one online. These sessions were a conversation around what topics might be of most interest (with the online session starting from The Untalked About) and how we might explore them further.

What's up next
Research question development session preparation

Building on these earlier sessions, next we're hosting some sessions to develop research questions about women's health that women think are a priority.

In advance of these sessions, please take time to look at the 'cards' below and choose 3–5 that you might have questions about, or that you have strong feelings towards.



All 100 Research Questions

Padlet

The Co-production Project 5/09/2024

Women's Health Research Question Generator

Welcome! Have a read through the questions below. As you do so, click on the heart icon under any that feel particularly important or compelling for you. If you'd like to tell us why - or suggest an improvement to the question, write a note in the Add Comment section. These comments will be anonymous. We think this will take about 10 — 15 mins so grab a cuppa and take your time.

THE CO-PRODUCTION PROJECT 5/15/24 12:25AM

How can we explore attitudes of health professionals so that women are empowered to better understand their health?

♡ 6 💬 1

> **Anonymous** 6/14/24 3:08AM
> Maybe reword - How can we enhance health professionals attitudes to be more empowering for women's health?

THE CO-PRODUCTION PROJECT 5/15/24 12:24AM

How could the medical centres change the system so that patients have a choice of time to discuss (& have doctors listen)? Eg 20mins instead of 15mins

♡ 5 💬 2

> **Anonymous** 5/22/24 3:37AM
> what are the barriers to medical centres creating longer appointments?

> **Anonymous** 7/1/24 12:05AM
> Could there be additional time added automatically for disabled or chronically ill people?

THE CO-PRODUCTION PROJECT 5/15/24 12:24AM

Who might empower the ageing population to live fuller and worthwhile lives and find the funding for this?

♡ 3 💬 1

> **Anonymous** 6/14/24 3:24AM
> Links to lifestage education?

THE CO-PRODUCTION PROJECT 5/15/24 12:29AM

How might we develop understanding and access for more people around weight issues?

♡ 2 💬 4

> **Anonymous** 6/14/24 3:16AM
> Access to what?

> **Anonymous** 7/3/24 9:10AM
> I think there is so much to unpack here and what is meant by weight issues could be very different for different people. I'm really interested in how weight impacts healthcare received and weight based discrimination.

> **Careful Orca** 9/23/24 10:58AM
> Need to train more professionals. It's a political

> **Careful Orca** 9/23/24 11:08AM
> Issue is there needs to be a change of GDP which won't allow our borrowing to increase so there is enough money to actually pay for health requirements necessary. It's a political problem!

THE CO-PRODUCTION PROJECT 5/15/24 12:26AM

How can we educate women from a young age on best practices throughout their menstrual cycle?

♡ 0 💬 1

> **Anonymous** 6/14/24 3:22AM
> This links to life stage education?

THE CO-PRODUCTION PROJECT 5/15/24 12:26AM

How can we educate and empower women about postnatal changes to optimise their health post baby?

♡ 2 💬 1

> **Anonymous** 6/14/24 3:23AM
> Links to lifestage education?

THE CO-PRODUCTION PROJECT 5/15/24 12:26AM

How can we teach women about lifestyle choices to improve/impact health (with more options than just the GP)?

♡ 3 💬 1

> **The Co-production Project** 7/16/24 11:18PM
> I like the emphasis on HOW can we teach ... I think that people often do know what we should be doing (at an informational level) but experience difficulties as we try to integrate positive changes into our lives. So for me it's not just about 'teaching information' > but more about how we might support women to develop 'ketes of knowledge' that they can then embody/enact in their own contexts.

THE CO-PRODUCTION PROJECT 5/15/24 12:26AM

How might we help GP's be more empathetic towards women's health?

♡ 0 💬 1

> **Anonymous** 6/16/24 12:25AM
> This is quite a bias question, assuming all GP's are not empathetic, similar to listening question. This possibly links back to initial education question, ensuring medical professionals alike are getting the education they need to support women well.

THE CO-PRODUCTION PROJECT 5/15/24 12:26AM

How can we support younger women's education on hormones and cycles?

♡ 9 💬 3

> **Anonymous** 6/14/24 3:24AM
> Links to lifestage education?

> **Anonymous** 6/16/24 12:02AM
> This needs to be explored from multiple angles, content, training for kaiako etc.

> **Anonymous** 6/17/24 4:13AM
> I certainly feel this is still lacking in sexuality/health curriculum. The focus is more on how to manage bleeding, and sex education. Young women need to understand the massive impact hormones play throughout life stages.

THE CO-PRODUCTION PROJECT 5/15/24 12:30AM

How do medical professionals become more accepting of indigenous practices?

♡ 4 💬 2

> **Anonymous** 5/22/24 3:37AM
> This would be one of my top 3 questions here

> **Anonymous** 6/14/24 3:24AM
> I think this links to some other questions around rongoa etc

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THE CO-PRODUCTION PROJECT 5/15/24 12:33AM

How might we enable more participation in social activities?

♡ 1 💬 1

> **Anonymous** 6/17/24 3:20AM
> Have widely advertised open-days, with a warm welcome for first-timers.

THE CO-PRODUCTION PROJECT 5/15/24 12:23AM

Who might advocate for women's access to health screening (mammograms etc)?

♡ 4 💬 1

> **The Co-production Project** 7/16/24 11:22PM
> Although important, I would argue looking further upstream is more important, e.g prevention (lifestyle) medicine with a focus on women, their hormones and the complexities of what this needs to look like. Focusing more on prevention, with the options for screening still available.

THE CO-PRODUCTION PROJECT 5/9/24 3:42AM

How can we redesign health services so that women feel more comfortable and safe within them?

♡ 4 💬 0

THE CO-PRODUCTION PROJECT 5/9/24 3:42AM

How could healthcare providers learn to listen well to women?

♡ 4 💬 2

> **Anonymous** 6/14/24 3:18AM
> I think this links to the question about GPs being more aware/sensitive to women's health

> **Anonymous** 6/16/24 12:41AM
> Very similar to a question above.

THE CO-PRODUCTION PROJECT 5/9/24 3:41AM

How can we advocate for women's health being taught in schools and education institutions?

♡ 9 💬 1

> **Anonymous** 6/14/24 4:37AM
> Teach young people to say "my [period/ breasts/ vulva] typically looks like..... but lately....". So often we get asked "how are your periods?' to which the obvious answer is "fine"- just because it's usual or normal for you doesn't mean it's right!

THE CO-PRODUCTION PROJECT 5/9/24 3:40AM

What needs to be put in place to bring down some of the barriers eg transport costs or childcare

♡ 5 💬 1

> **The Co-production Project** 7/16/24 11:16PM
> For me, this question would need more detail what kind of barriers are meant or included. Are we talking barriers to access HC, barriers in interactions with doctors and HCW or barriers to medication etc. If you wanted to keep the question at this broad level, I'd rephrase it: what are the barriers for women to receive medical care and how can these be overcome?

THE CO-PRODUCTION PROJECT 5/15/24 12:24AM

How can older people manage their information, now that we have so many inputs hammering us (email, WhatsApp, social media, phone messaging etc)?

♡ 1 💬 0

THE CO-PRODUCTION PROJECT 5/9/24 3:40AM

How might we create more forums where people feel safe to share their health challenges, and to support each other to address them?

♡ 4 💬 0

THE CO-PRODUCTION PROJECT 5/15/24 12:25AM

How do we find out if we need to take vitamins and supplements (and at what age, not one that's recommended for all ages)?

♡ 0 💬 2

> **Anonymous** 7/3/24 9:17AM

> How do we better regulate supplement advertising and claims so people don't get conned into spending big money on loads of products they don't need

> **The Co-production Project** 7/16/24 11:15PM
> This question is not relevant to me. I think the answer depends very much on your personal health circumstances and a recommendation cannot be made as a general rule, especially as some supplements can interfere with medication you may be on. I would think this is a question for your GP or trusted pharmacist who has access to your medication/medical record.

THE CO-PRODUCTION PROJECT 5/15/24 12:34AM

How do we create more opportunities for ALL women to access support from other women?

♡ 4 💬 1

> **The Co-production Project** 7/16/24 11:20PM
> I personally feel a strong connection with this one, as much of my research is related to 'peer support'.

THE CO-PRODUCTION PROJECT 5/9/24 3:39AM

How might we rig the algorithms? (eg Dr Google)

♡ 1 💬 5

> **Anonymous** 5/24/24 1:14AM
> Rig them to do what?

> **Anonymous** 6/16/24 12:16AM
> Agree with comment, unsure what this question means.

> **Anonymous** 6/30/24 11:58PM
> This is particularly pertinent now that it's a lot harder to tell what is real with the advent of AI

> **Anonymous** 7/3/24 8:57AM
> Love the outside the box rebel thinking in this one!

> **The Co-production Project** 7/16/24 11:22PM
> This questions doesn't quite make sense to me. What are we trying to rig? I would say we actually want to create a deeper form of knowledge and information sharing? How might we ensure informative information about women's health is part of the algorithms? Also, with the uptake of AI, I think algorithms may start to not be the bigger issue.

THE CO-PRODUCTION PROJECT 5/9/24 3:37AM

How might we create more information that's reliable and relevant to women in Aotearoa?

♡ 2 💬 1

> **Anonymous** 6/14/24 3:05AM
> It think this is very similar to the increasing education question - could be linked?

THE CO-PRODUCTION PROJECT 5/9/24 3:35AM

How might we better enable health professionals to understand pain experienced by women?

♡ 6 💬 0

THE CO-PRODUCTION PROJECT 5/15/24 12:28AM

How do we celebrate our whare tāngata?

♡ 0 💬 0

THE CO-PRODUCTION PROJECT 5/15/24 12:23AM

How can we develop resources to enable women to better understand how to navigate the health system?

♡ 0 💬 1

> **Careful Orca** 9/23/24 11:56AM
> I feel all of these questions end up being a political choice. We now have a govt that is governing to try and stop all the progress made during the Labour/ Green govt legislation and empowering women/ gender issues. There was hope and intelligent evidence based research and decisions

> making great strides in highly qualified Ayesha Verrall. Now we have a puppet robot weak cold uncaring minister in Shane Rheti . Aotearoa is rapidly going backwards. These important questions will never we considered until this dreadful coalition govt is voted out.

THE CO-PRODUCTION PROJECT 5/9/24 3:35AM

What would an increase in wāhine Māori health professionals do to elevate better access for more women to health care?

♡ 7 ◯ 1

> **Anonymous** 7/3/24 9:14AM
> And how can we enable that increase

THE CO-PRODUCTION PROJECT 5/9/24 3:35AM

How could we expand education about hormones to improve our understanding of women's health?

♡ 7 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:31AM

How could we improve sexual health education and services access for young women, including those in rural or remote areas of Aotearoa NZ?

♡ 9 ◯ 1

> **Anonymous** 7/1/24 12:06AM
> Mobile units, telehealth, more readily accessible high speed internet, education on how telehealth works etc

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THE CO-PRODUCTION PROJECT 5/9/24 3:35AM

How might we explore the importance of autonomy in gynaecological care?

♡ 0 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:36AM

How could health professionals develop their patient's understanding of procedures to enable and support autonomy?

♡ 0 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:36AM

Who might provide accurate content/information about women's health to/for women?

♡ 1 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:36AM

How might we vet the information that is found online?

♡ 5 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:37AM

Where might we go to better access information?

♡ 0 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:37AM

How might we empower women with education and choices to make personally informed choices?

♡ 4 ◯ 2

> **Anonymous** 7/3/24 8:54AM
> It feels like this one needs a little rewording to make it easier to understand, maybe it could simply finish after the first choices?

> **The Co-production Project** 7/16/24 11:20PM
> This question is important – but I feel it needs more 'refining' to clarify what is being asked. It's a bit confused/ing currently ....

THE CO-PRODUCTION PROJECT 5/9/24 3:38AM

How can we increase our autonomy around decision making?

♡ 0 ◯ 1

> **Anonymous** 7/1/24 12:01AM
> And how do we include those who are viewed as being unable to make decisions due to their "ability"

THE CO-PRODUCTION PROJECT 5/9/24 3:38AM

How can we increase education to improve women's knowledge/understanding of different stages of life?

♡ 6 ◯ 1

> **Anonymous** 6/14/24 3:04AM
> I think this is essential. Not sure about 'increasing' education - I would like to see a focus on enhancing relevant information and access to it in equitable ways

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THE CO-PRODUCTION PROJECT 5/9/24 3:38AM

How might health professionals better support the autonomy of women's health decisions?

♡ 2 ◯ 1

> **The Co-production Project** 7/16/24 11:27PM
> *Health professionals have the perspective of their own life experiences unless they are educated and informed about the needs of women. Better support would come from training, and in particular male professionals need to dialogue with women to understand that we know our own bodies best and have the biggest vested interest!! I am often intimidated and compliant, much to my own disgust. Education, education, education – and confidence in our own knowledge – can we be seen as equal partners in decision-making?*

THE CO-PRODUCTION PROJECT 5/9/24 3:39AM

How could we improve education (of the medical system) so that more women/wāhine Māori can advocate for their health?

♡ 2 ◯ 1

> **Anonymous** 5/24/24 1:03AM
> I think this question would be stronger with a tweak to the wording - 'education within the medical system'?

THE CO-PRODUCTION PROJECT 5/9/24 3:39AM

How could women be supported to navigate into, through and between supports and services so that they can be connected and access health-optimising 'spaces'?

♡ 2 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:40AM

What would feeling less guilty look like for women?

♡ 2 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:40AM

What would a wider forum/audience where women can advocate for each other look like?

♡ 1 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:40AM

How can women be supported and empowered to better advocate for their needs and preferences?

♡ 3 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:41AM

What can be done (i.e. technologies/ products design) to deal with the smells related to body leakage (e.g. urine)?

♡ 3 ◯ 1

> **roxboroughpt** 6/17/24 9:50AM
> I avoid buying pads that are for incontinence; less embarrassment to buy sanitary pads

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THE CO-PRODUCTION PROJECT 5/9/24 3:42AM

Could story-telling / story-listening be a tool to support women's wellbeing?

♡ 2 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:42AM

How could an intergenerational approach support wāhine to live well across the whole of their lives?

♡ 7 ◯ 1

> **The Co-production Project** 7/16/24 11:17PM
> This is a really interesting question – and I think under-researched and/or understood (in the health space anyway).

THE CO-PRODUCTION PROJECT 5/9/24 3:42AM

How might we help children better understand and respond to what's happening in their bodies so they can approach healthcare in a better way?

♡ 3 ◯ 2

> **Anonymous** 6/14/24 3:19AM
> Seems this links to the question about awareness of different stages of life?

> **Careful Orca** 9/23/24 10:34AM
> The statistics read that the majority of voters are the older bracket and those who own their own home. What worries me more is empowering the young to vote! Those who feel there's no point! Never owning a home Climate Breakdown job opportunities leaders helping the rich get richer! These are highest statistics for women/ her/she /they.

THE CO-PRODUCTION PROJECT 5/9/24 3:42AM

How can women be supported to live well with long-term chronic health conditions?

♡ 4 ◯ 2

> **Careful Orca** 9/23/24 10:16AM
> Women leadership in health roles and lobbying MPs

> **Careful Orca** 9/23/24 10:18AM
> Again nutrition and health taught as compulsory in schools.

THE CO-PRODUCTION PROJECT 5/9/24 3:43AM

How can women be kept safer in their own homes?

♡ 3 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:30AM

How could initial training and education in the field of medicine improve outcomes for women's health in Aotearoa NZ?

♡ 4 ◯ 4

> **Anonymous** 5/24/24 1:09AM
> Curious about what might need to change in this 'initial training and education' - does this need input from someone who works in this area?

> **Anonymous** 6/15/24 11:57PM
> In response to the commenter, in initial training there is little/no consideration of the diverse gender needs, so think it is an important consideration in terms of advocating for and ensuring women health needs are front and centre for practitioners.

> **Anonymous** 6/17/24 3:13AM
> Anonymous.I think that everyone's needs should be front and centre for practitioners, and to meet these needs they must listen!

> **Careful Orca** 9/23/24 10:13AM
> Can there be a professional fact checker for mis/ disinformation ?

THE CO-PRODUCTION PROJECT 5/15/24 12:22AM

To what extent can equity of access be promoted by those in power?

♡ 1 ◯ 1

> **The Co-production Project** 7/16/24 11:26PM
> *I am not sure what is meant by those in power. The Government, Te Whatu Ora, District Areas or G.P's. I truly believe equity of access to be an issue. Of course funding is crucial. Maybe the results of your project can be used to inform those in power, all of us can lobby for this issue. Empowering women to fight for their rights could improve equity of access, but in general society is NOT equal, health access is part of that.*

THE CO-PRODUCTION PROJECT 5/9/24 3:41AM

What would a health system that approaches wellbeing holistically look like?

♡ 5 ◯ 1

> **Anonymous** 7/1/24 12:00AM
> https://www.healthhubqld.com.au/about/

THE CO-PRODUCTION PROJECT 5/9/24 3:41AM

What might a health system designed by women for women look like in Aotearoa NZ?

♡ 7 ◯ 1

> **Anonymous** 6/17/24 4:10AM
> I really like this question because it allows us to re-think everything, and it opens up space to see what priorities arise.

THE CO-PRODUCTION PROJECT 5/9/24 3:41AM

How can we achieve equitable access to treatment across the entire healthcare system across the country so it doesn't matter where you live or whether you've got private health insurance or not?

♡ 11 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:37AM

How can the health system be better equipped to support health care for those experiencing gender transition/for trans people?

♡ 6 ◯ 1

> **Anonymous** 7/1/24 12:08AM
> More surgeons and specialists

THE CO-PRODUCTION PROJECT 5/9/24 3:40AM

What might a health system centred around hormones/wellbeing/etc look like?

♡ 3 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:39AM

How could society (attitudes, expectations, actions) be influenced to improve health and wellbeing outcomes for women?

♡ 1 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:39AM

What would an enabling society (attitudes, expectations, actions) look like for women?

♡ 5 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:37AM

How do we address the imbalance around research relating to women?

♡ 11 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:38AM

How might we increase research into chronic conditions (eg PCOS and Endometriosis)?

♡ 5 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:38AM

How might we create/grow the volume of more female specific research?

♡ 9 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:36AM

How might we create a health DIAS? (Disability information and support)

♡ 1 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:37AM

How can we address the inequities in health access?

♡ 9 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:36AM

How might health professionals develop gynaecological care/information for disabled women that reflects the UNCRDP and the enabling good lives principles alongside Te

Tiriti? (United Nations Convention on the Rights of Persons with Disabilities)

♡ 8 ◯ 2

> **Anonymous** 6/14/24 3:22AM
> This seems important - I suspect very overlooked

> **The Co-production Project** 7/16/24 11:12PM
> This is a very important question and one could probably extend its scope beyond just gynaecological care. It should probably include training modules right from the start (medical school). Would chronic illness fall under disability?

THE CO-PRODUCTION PROJECT 5/9/24 3:35AM

How could we adopt a whānau or multigenerational health support system in an indigenous lens? (eg red tent etc)

♡ 2 ◯ 1

> **Anonymous** 5/24/24 1:06AM
> 'Red Tent' reference needs some explanation (or to be left out - I think the question relatively clear without it, although I think a better preposition would be 'through'

THE CO-PRODUCTION PROJECT 5/9/24 3:34AM

What would an autonomous health system look like?

♡ 0 ◯ 0

THE CO-PRODUCTION PROJECT 5/9/24 3:34AM

To what extent { } increase access so that women's health care (e.g. menopause specialist GPs) are affordable and included as a general practice health need?

♡ 3 ◯ 2

> **Anonymous** 6/14/24 3:10AM
> I'm not sure if it needs to be in general practice, but sure needs to be more accessible

> **Anonymous** 6/16/24 12:00AM
> in response to the commenter, GP is the most commonly visited and engaged with area for the general population so would argue it is a good space for this to be explored.

THE CO-PRODUCTION PROJECT 5/9/24 3:32AM

How might we increase government funding so that some of our ideas can be implemented?

♡ 4 ◯ 1

> **The Co-production Project** 7/16/24 11:25PM
> This is a good question, but would need some strong sub questions to inform what the 'ideas' are. A more practical and direct question, maybe in itself a sub question to a bigger questions.

THE CO-PRODUCTION PROJECT 5/9/24 3:32AM

How might the healthcare system address intimate partner violence and providing support for affected women in Aotearoa NZ?

♡ 6 ◯ 1

> **The Co-production Project** 7/16/24 11:28PM
> *This is a big ask for healthcare. Reporting suspected violence and being vigilant is essential, though difficult with privacy issues. My niece found support from Women's Refuge. Once again women need to be empowered not to put up with violence. So, more funding for help agencies – it is a social issue as well as a healthcare one. We all need to play a part in speaking up if we have suspicions. If they are unfounded, so be it.*

THE CO-PRODUCTION PROJECT 5/9/24 3:29AM

How could the medical system integrate nutritional education into routine care for women to help them make informed choices about their unique health needs?

♡ 8 ◯ 2

> **Anonymous** 6/17/24 4:08AM
> understanding the link between diet and hormones is vital, and lacking. this would really empower women.

> **Careful Orca** 9/23/24 10:01AM
> As a Home Economics teacher this was most important to raise this education as just as important a status as the three R's

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THE CO-PRODUCTION PROJECT 5/9/24 3:30AM

What policies and regulations could be implemented at the national and local levels to incentivise food retailers to offer a wider selection of nutritious options and promote healthier food environments for women?

♡ 4 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:23AM

Who might influence adequate government funding for women's health?

♡ 5 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:23AM

Who will raise awareness of ageing and realise that this demographic will soon be in the majority of voters?

♡ 4 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:23AM

How can we connect different parts of the health system to share information for better outcomes or decreased wait times/recovery times?

♡ 6 ◯ 1

> **Anonymous** 7/1/24 12:07AM
> Having a national database that covers all medical/allied health services? But this raises significant confidentiality concerns...

THE CO-PRODUCTION PROJECT 5/15/24 12:24AM

What would make medical professionals more able to listen?

♡ 2 ◯ 1

> **Anonymous** 6/16/24 12:22AM
> This is quite a bias question, assuming all medical professionals don't listen. Possibly the question is "what would make medical examinations safe spaces for all health conditions to be explored seriously?"

THE CO-PRODUCTION PROJECT 5/15/24 12:24AM

Who might enable lifelong respect for individuals?

♡ 0 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:25AM

How could the health system listen to older people and acknowledge that they/we are living longer & support them to stay healthy?

♡ 6 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:25AM

How might we create information about women's health that everyone can understand?

♡ 6 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:25AM

How could we design health care systems that empower/allows everyone to participate if needed?

♡ 4 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:26AM

What type of education can be put in place to teach about optimising health?

♡ 4 ◯ 1

> **Anonymous** 6/30/24 11:57PM
> and how is can it be accessible to all people

THE CO-PRODUCTION PROJECT 5/15/24 12:28AM

How might we enable more access to rōngoa and 'alternative' remedies in our health system?

♡ 7 ◯ 1

> **Anonymous** 6/14/24 3:11AM
> I think this is a Te Tiriti responsiveness obligation - should be much more available

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THE CO-PRODUCTION PROJECT 5/15/24 12:28AM

How do we get our young people to look at careers in health?

♡ 3 ◯ 1

> **Anonymous** 7/1/24 4:25AM
> Make them appealing - remove barriers to study and ensure good salary expectations once graduated

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THE CO-PRODUCTION PROJECT 5/15/24 12:28AM

How might we make it easier to access information around weight issues?

♡ 1 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:28AM

How do we teach mātauranga knowledge to non-Māori professionals?

♡ 7 ◯ 1

> **The Co-production Project** 7/16/24 11:29PM
> *Another important challenge. This knowledge would support those most at risk in an acceptable forum/way. Physical and non- physical values need to be understood and the positive and negative aspects explored. As a Pakeha I tend to rely on Science and so do non-Maori professionals I guess. The only way to understand Matauranga knowledge is to rely on tangata whenua to teach and guide us. Again! Funding for Hui where knowledge is shared is crucial.*

THE CO-PRODUCTION PROJECT 5/15/24 12:29AM

How do we teach our rangatahi/help them be more involved in our natural environment?

♡ 0 ◯ 1

> **The Co-production Project** 7/16/24 11:25PM
> This question also confused me. What is the natural environment? Does this mean how do we get them to be outdoors more? And why? If this is the case, again I would focus the question more towards lifestyle medicine. "How can be support our rangatahi to be more aware of lifestyle

> medicine, and the impact our choices about how we live impact on our body?"

THE CO-PRODUCTION PROJECT 5/15/24 12:29AM

How might we strengthen intergenerational connections?

♡ 6 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:29AM

How might we decolonise our support systems?

♡ 1 ◯ 2

> **Anonymous** 5/24/24 1:09AM
> I am curious about this but I'm not sure what 'support systems' means in this context

> **Anonymous** 6/14/24 3:07AM
> Same as above

THE CO-PRODUCTION PROJECT 5/15/24 12:29AM

How might healthcare services be combined in one place?

♡ 4 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:30AM

How do hospitals become more inclusive of indigenous practices?

♡ 3 ◯ 1

> **Anonymous** 6/14/24 3:16AM
> This potentially links to the question around rongoa? More inclusion in all areas of health - not just hospitals?

THE CO-PRODUCTION PROJECT 5/15/24 12:30AM

How do we create more choices for people in healthcare decision making?

♡ 1 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:30AM

How might we bring down barriers when we are trying to move forward?

♡ 0 ◯ 2

> **Anonymous** 5/24/24 1:11AM
> Which barriers? To what?

> **The Co-production Project** 7/16/24 11:14PM
> For me, this question would need more detail what kind of barriers are meant or included. Are we talking barriers to access HC, barriers in interactions with doctors and HCW or barriers to medication etc. If you wanted to keep the question at this broad level, I'd rephrase it: what are the barriers for women to receive medical care and how can these be overcome?

THE CO-PRODUCTION PROJECT 5/15/24 12:30AM

How might we decrease dependency on medication for mental health?

♡ 1 ◯ 3

> **Anonymous** 5/27/24 9:12PM
> This one comes across as suggesting medication isn't a good thing for mental health. Do we have any evidence of this? On the flip side there is research that has shown medication has had positive outcomes for people with mental health conditions, in conjunction with other mental health tools. What do we mean by 'dependency' here?

> **Anonymous** 6/14/24 3:13AM
> I agree with the comment above - medication does have it's place

> **Anonymous** 6/16/24 12:33AM
> This questions possibly links with the more lifestyle medicine questions above. Something along the lines of "how can we suppo knowledge in lifestyle medicine so women have options for non-medication routes for a range of purposes?"

THE CO-PRODUCTION PROJECT 5/15/24 12:31AM

How might we destigmatise mental health in our health system?

♡ 6 ◯ 1

> **Careful Orca** 9/23/24 10:10AM
> I suppose more female leaders health professionals who can acknowledge female pain

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THE CO-PRODUCTION PROJECT 5/15/24 12:32AM

How do we accept that mental illness is only part of you — it is not who you are?

♡ 1 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:33AM

How might we stop diagnoses being weaponised against us?

♡ 1 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:33AM

How do we bring down the costs of accessing healthcare?

♡ 7 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:33AM

How might we rebalance our lives in the digital world?

♡ 0 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:33AM

How might we better resource mental health support for rangatahi?

♡ 9 ◯ 0

THE CO-PRODUCTION PROJECT 5/15/24 12:34AM

How might we adapt to our changing society? e.g. digital technology

♡ 1 ◯ 0

Refined List of Research Question

Padlet

The Co-production Project 7/31/2024

Women's Health Research Question Generator

A short list of research questions created by women, about women's health.

THE CO-PRODUCTION PROJECT 7/31/24 11:27PM

How might we strengthen intergenerational connections in order to improve women's health issues?

0

THE CO-PRODUCTION PROJECT 7/31/24 11:28PM

How might we better understand the supports women need to live well with long-term or chronic health conditions?

0

THE CO-PRODUCTION PROJECT 7/31/24 11:29PM

How might we use technology or product design to improve the options available to deal with smells related to body leakage?

0

THE CO-PRODUCTION PROJECT 7/31/24 11:33PM

How could we adopt a whānau or multigenerational health support system through an indigenous lens?

OR: How could we adopt a whānau or multigenerational health support system **with** an indigenous lens?

0

THE CO-PRODUCTION PROJECT 7/31/24 11:36PM

How might we destigmatise women's mental health in our health system?

1

> **The Co-production Project** 7/31/24 11:36PM
> How might we better resource mental health support for taitamāhine?

THE CO-PRODUCTION PROJECT 7/31/24 11:39PM

How might women be supported to navigate into, through and between health services so they have better access to health-optimising spaces?

This includes looking at how health service providers can share information about patients in order to decrease wait times and improve health outcomes.

0

THE CO-PRODUCTION PROJECT 7/31/24 11:42PM

How might policy and systems design be developed and implemented in order to improve equity of access to healthcare?

0

THE CO-PRODUCTION PROJECT 7/31/24 11:44PM

What are the barriers to medical centres creating longer or varied appointment times in order to meet patients needs?

0

THE CO-PRODUCTION PROJECT 7/31/24 11:44PM

What are the barriers for women to receive medical care and how can these be overcome?

0

THE CO-PRODUCTION PROJECT 7/31/24 11:48PM

How might we create more spaces and places for women to safely share their experiences in order to improve self- and peer-advocacy and support?

Could story-telling and story-listening be a tool to support women's wellbeing?

0

THE CO-PRODUCTION PROJECT 7/31/24 11:54PM

How can we redesign health services so that women feel comfortable and safe within them?

0

THE CO-PRODUCTION PROJECT 7/31/24 11:59PM

What might be needed to ensure health professionals have the support and resources to increase women's experiences of feeling heard, trusted and validated so that women receive the care they need?

1

> **The Co-production Project** 8/2/24 2:51AM
> Sub Question: How might healthcare providers learn to listen well to women?

THE CO-PRODUCTION PROJECT 8/1/24 12:02AM

What attitudinal shifts are needed in health care and medical education to include and accept indigenous practices throughout the health system?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:05AM

How can we enhance health professionals attitudes to be more empowering for women's health?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:06AM

How can the health system be better equipped to support health care for those experiencing gender transition and trans people?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:06AM

How might we enable more access to rōngoa and 'alternative' remedies in our health system?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:07AM

How might increasing the number of wāhine Māori health professionals increase the benefits to women accessing health care?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:08AM

How could the medical system integrate nutritional education into routine care for women to help them make informed choices about their unique health needs?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:08AM

How might we create more information that's reliable and relevant to women in Aotearoa?

1

> **TCP Christchurch Event** 9/24/24 7:00AM
> How do we rebuild trust in health professionals as a point of truth?

THE CO-PRODUCTION PROJECT 8/1/24 12:09AM

What might a health system designed by women for women look like in Aotearoa NZ?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:11AM

How might we support women to develop 'ketes of knowledge' that they can then embody/enact in their own contexts that is accompanied by a health system that approaches wellbeing holistically?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:14AM

How could we design health care systems so that women have agency and autonomy throughout?

1

> **The Co-production Project** 8/1/24 12:15AM
> Sub Question: How might we explore the importance of autonomy in gynaecological care?

THE CO-PRODUCTION PROJECT 8/1/24 12:24AM

How might we increase equitable access to relevant information in order to improve women's knowledge and understanding of different life stages?

2

> **The Co-production Project** 8/1/24 12:25AM
> Sub Question: How can we educate and empower women about postnatal changes in order to optimise their health post baby?

> **The Co-production Project** 8/1/24 12:26AM
> Sub Question: How could the health system acknowledge older people are living longer, listen to them more and support them to stay healthy at all ages?

THE CO-PRODUCTION PROJECT 8/1/24 12:28AM

How might we increase research into chronic conditions impacting women (eg PCOS and Endometriosis)?

1

> **TCP Christchurch Event** 9/24/24 7:14AM
> This. And more generally, how can we incentivise, celebrate and FUND (the longer term, better) impactful research led by diverse researchers and knowledge holders on health issues that matter

---

THE CO-PRODUCTION PROJECT 8/1/24 12:29AM

How might we better enable health professionals to understand pain experienced by women?

1

> **TCP Wellington Event** 8/29/24 7:08AM
> Thisssss!!!

THE CO-PRODUCTION PROJECT 8/1/24 12:30AM

How might we achieve equitable access to treatment across the entire healthcare system throughout the country so it doesn't matter where you live or whether you have private health insurance or not?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:32AM

How might we build better education provisions to support younger women's access to relevant information and services about women's health, hormones and sexual health?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:34AM

How might the healthcare system address intimate partner violence and providing support for affected women in Aotearoa NZ?

0

THE CO-PRODUCTION PROJECT 8/1/24 12:35AM

How do we teach mātauranga knowledge to non-Māori health professionals?

0

THE CO-PRODUCTION PROJECT 8/1/24 10:14PM

How might health professionals develop women's health care and information for disable women that reflects the UNCRDP and enabling good lives principles alongside Te Tiriti?

UNCRDP = United Nations Conventions on the Rights of Persons with Disabilities

1

> **The Co-production Project** 8/1/24 10:15PM
> Sub Question: How might we create a health Disability Information Advisory Service?

THE CO-PRODUCTION PROJECT 8/2/24 2:52AM

How might we empower women and provide therewith agency and choice in their health decision making?

3

> **The Co-production Project** 8/2/24 2:52AM
> Sub Question: How might health professionals better support the autonomy of women in making heath decisions?

> **The Co-production Project** 8/2/24 2:53AM
> Sub Question: How could we improve education within the medical system so that more women/wāhine Māori can advocate for their health?

> **TCP Christchurch Event** 9/24/24 6:31AM
> How can we create space in the system to educate and inform so that empowerment involves knowledge and confidence?

THE CO-PRODUCTION PROJECT 8/2/24 2:56AM

What are the impacts of AI in relation to women's health?

(This might also include algorithms)

1

> TCP Christchurch Event 9/24/24 7:22AM
> How do we mitigate biases to train AI to be tailor to women 's health?

THE CO-PRODUCTION PROJECT 8/2/24 3:06AM

How might we increase understanding of how weight impacts the healthcare received and weight based discrimination?

0

THE CO-PRODUCTION PROJECT 8/2/24 3:11AM

How might we increase access to specific women's healthcare services so they are affordable and included as part of primary care services (GPs)?

An example a specific women's healthcare service are GPs who are menopause specialists.

1

> TCP Christchurch Event 9/24/24 8:07AM
> Yes to this, and with practitioners who are comfortable asking women how they are coping really, and encourage us to not just put up with discomfort as if it's part of ageing and we mustn't complain

Co-production Project Values and Expectations

Welcome to the co-production project team

By co-production, we mean an approach to research in which communities who are meant to benefit from — or who otherwise will be affected by — the research become partners in formulating, designing, carrying out, analysing, and reporting the research. It aims to balance out the power dynamics between those considered 'experts' and those the research aims to support to ensure their voices are listened to and that they benefit from the project's outcomes.

Co-production is underpinned by respect, equality, learning and kindness, and relies heavily on positive relationships and effective communication. These principles understandably provide the core foundation to this team's way of operating.

When you join this team we expect you to read this document, and follow these guidelines. If something needs clarifying, or you think something needs adding/ changing, please talk to Anna.
For more information on the project and timeline please see the appendices.

Please email Anjuli anjuli.muller.1@uni.massey.ac to acknowledge having read this document, and consent to being part of the research outputs.

Philosophy and Values

Manaakitanga

He aroha whakatō, he aroha puta mai.
If kindness is sown then kindness you shall receive.

- We are responsible for our actions, and how we interpret the actions of others. Everyone is doing their best with their particular set of circumstances, so we ask you to strive to show kindness to others and yourself. By kindness we mean: a behaviour marked by ethical characteristics, a pleasant disposition, and concern and consideration for others, not in return for anything or for the advantage of the helper (definition from Wikipedia).
- Aim to take kind actions, be empathetic, think kind thoughts and avoid making assumptions.
- Avoid gossip, or teasing, belittling or ignoring others — what you think of as funny might not be funny to the receiver.
- When able, include and check in on others, you never know what someone else might be experiencing and that interaction might be just what they need to get them through a rough day or week.

- Showing others caring, kindness and warmth.
- As part of the TPM team we have a commitment to promoting Kindness in Science. The Kindness in Science movement currently defines Kindness in Science as a fierce commitment to deliberate and sustained action to create a science system that is right and just. For more info please check out this website.

Inquisitive Spirit

- This project is new in so many different ways, so some things will work and some things won't.
- Be supportive of trying new things — failures are learning opportunities.
- Be willing to try new things and open to new ideas.
- A lot of this project is being determined as we go along, so be flexible to changing plans and directions if the current information indicates it is needed.
- Be curious

Equality

- Everyone has different skills, knowledge and experience to contribute to the team and project.
- Everyone's contributions are valued.
- We have a non/low hierarchical approach to working as a team — everyone's input is important.

Pono

- Truth
- Genuineness

Tika

- Doing the [right] thing
- Reciprocity

Tapu

- Acknowledges the intrinsic value of each and every person and thing
- Mana maintaining – responsibility to recognise and return mana within relationships.
- Behaving according to this principle.

To do [some] good

- There are always unseen consequences to our work
- How do we define what is 'good'
- Creating work that aims to make the world a better place

Community centred

- Our work reaches further than 'human-centred design'
- Everyone's experience is informed and influenced by the things and people around them

Inclusive

- Using a holistic approach to design
- Recognising the intersections of everyone's different identities
- Respectful and open to everyone's different experiences in the world

Lived Experience

- Being the voice of lived experience
- Acknowledging that our work is directly connected to the lives and experiences of real people

Expectations and Responsibilities

Everyone's responsibilities:

- Be kind. Be mindful of how your actions will impact others. Don't jump to conclusions. Do kind things.
- Strive to be positive, proactive, and productive.
- Ask others if you need help. Think about who might have the most knowledge about what you need help with. If you have too many tasks to get done, talk with Anna about ways to reprioritise them or if it's possible to delegate some.
- Help others out if they need help - offer even if they don't ask, not everyone has learnt to ask for help yet. Help others, and you can expect others to help you when you need it.
- It's ok to make mistakes. We've all made them. If you do make a mistake, you should tell Anna (or a relevant team member). We admit our mistakes, and then we correct them and move on.

» If you're sick, stay home and take care of yourself (whether it is Covid19 or another sickness). It's important you get better, but it's also important that you don't make other team members sick - especially as we don't know who might have an increased risk of long term and/or severe impacts from an illness. Let someone know that you won't be coming to work, so we don't start to worry about you.

» You are expected to manage your time to get your work done. You're also expected to take breaks and have your holidays. Make sure the rest of the team know if you will be uncontactable for more than a day or two.

» Document everything in a way that makes sense not just to you. File documents in the appropriate Google Drive folder so it's easy for others to find them when needed - make sure you haven't accidentally saved them in 'My Drive' instead.

» No academic misconduct. It is never ok to plagiarise, tamper with data, make up data, omit data, or fudge results in any way. We have a responsibility to everyone else involved in the research to treat their knowledge and experience with respect and care.

» Respect everyone who is involved in the project - including their culture, their religion (or lack thereof), their beliefs, their sexual orientation. Respect that people work in different ways, and may have different needs for support and success.

» If you're struggling, tell someone. Your health and happiness are important. This team looks out for the well-being of all its members. We are here to help. It's ok to go through hard patches (we all do), and you shouldn't feel shy about asking for help or just venting.

» Tension, hostility or conflict can make it hard for a team to work together well. If this is happening, something needs to be done about this promptly. Either talk to the person/ people involved, or if you're not comfortable doing so directly, discuss the situation with Anna. Also let Anna know, even if it has been resolved.

» Have a life outside of the project, take care of your mental and physical health, and don't ever feel bad for taking time off work.

Issue #2 of *'The Octopus'* newsletter

View this email in your browser

The Octopus

The Co-production Project Newsletter

Issue #2 — 6 December 2023

Welcome to the second issue of *The Octopus*

Wow the past month definitely flew by as this time of year tends to do. It was great to catch up with some of you again, and to welcome some new contributors to the project. It really feels like things are coming together, and with the input we've received from you we have some great ideas for what to explore next with you in the New Year.

It's been mentioned before, but we'd really like to reiterate how grateful we are for your tolerance of the discomfort of an unknown research method. We know it's not easy without a clear path to follow and we really appreciate your contributions and continued involvement. It's always a joy for us seeing who turns up to sessions, and getting to know you all a bit more.

We really would like to 'co-produce' this newsletter with you — so we're looking for more of your thoughts and suggestions. What would you like to see or learn? What will make *The Octopus* the one newsletter you always open…?

Let us know here.

Project progress

November sped by, finishing off with a few great conversations with some of you which was really enjoyable.

- Debbie, who participated in one of our Tāhuna Queenstown 'Cuppa & Cake' sessions back in May, invited us back to have a conversation with a group of wāhine Māori about women's health. On November 23rd, we had a 'Kai & Kōrero' session with 21 wāhine. It was a generous and emotional conversation, with many experiences shared and waiata sung. We're looking forward to continuing the conversation.
- While in Queenstown, we had a follow up chat with three of you who we'd met in May — our 'Queenstown Cluster'. We got to know each other a bit more, talked through areas of interest within women's health, and tentatively started coming up with ideas for next steps. Those of you Queenstown folk, who didn't make it, keep an eye out for upcoming invitations to be involved as and when you can.
- We also started our first 'Online Cluster', loosely focused on 'the untalked about'. Another really insightful conversation ending with a tentative next step which we'll move towards in the New Year.

Asks and invitations

We'll be in touch in the New Year with our next invitations. But if you have enthusiasm for a cluster to start around a particular topic or in a particular location, do let us know.

One of the first sessions in the New Year will be an ideas generation workshop where we want to create the first 100 questions for this project. You can start thinking about your top "How might we…" questions!

The people in the project

Kia ora, I'm Jean.
I'm an illustrator and designer working at Toi Āria.

How do you take your coffee/tea?
I will always be found drinking an iced latte with oat milk and one sugar.

What's your favourite cake?
Definitely coffee cake.

What's the most daring thing you've ever done?
Back when I used to do rock climbing I did a 50 metre abseil down a cliff face.

What's a favourite go-to joke?
Knock knock
Who's there?
Yoda lady
Yoda lady who?
Stop yodelling!!

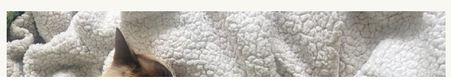
What was one of the scariest moments of your life?
Maybe being woken up by the Kaikōura earthquake in Wellington.

Do you put your right leg or left leg in your pants first?
Left leg first!

What's a song you always have to skip?
Closer by the Chainsmokers.

What's a movie you've watched multiple times?
Booksmart, my favourite movie!

Tell us about any pets you have
My whānau has two beautiful burmese cats, Billy and Ivy.



Bookclub

Book
Divergent Minds by Jenara Nerenberg
Recommended by Anjuli — *"Great for broadening our understanding and empathy for other people's way of being in the world. Highlights the lack of research into Autism, HSP & ADHD in women. Also provides suggestions for creating spaces that are more inclusive for neurodiversity."*

Quick Read
"The Friendship Problem" by Rosie Spinks

Podcast
Getting Better - A Year in the Life of a Māori Medical Student — doctor and award-winning writer Emma Espiner (Ngāti Tukorehe, Ngāti Porou) travels to the front lines of healthcare in New Zealand, where life and death decisions are made every day and where the statistics clearly show Māori are suffering: Māori die younger, get chronic illnesses earlier and receive less care than non-Māori.
Recommended by Tania Roxborogh (a Co-production Project contributor)

Read, heard or seen something recently about women or women's health that's made you stop and think? Or that you wish more people knew?
Let us know here.

Sound of the month

This month Hannah has been listening to Tiny Ruins.
According to Spotify, Hannah spent 551 minutes listening to them this year!

Got a tune, or a sound that helps you feel good that you'd like to share with others? Let us know here.

Did you know?

Did you know that up to 1 in 3 people who menstruate experience abnormal uterine bleeding!

'Abnormal' isn't always a useful term to describe period experiences, here's a video that shows different levels of blood loss during a period.

What have you learned recently about health, a health condition or women's bodies that's made you think? Or helped you understand something better?
Let us know here.

In your words

"In the process of sharing information and memories with other members of the group it sparked thoughts of how we had similar experiences and yet in other ways quite different experiences and a privilege that they were willing to share."

If you would like to write something for us — about your experience of being in the research project so far, or something health related (not specifically an experience you've had) — please let us know.

Finally…

We hope you all have a gentle summer season — with some time for rest and moments of laughter. We look forward to reconnecting in February.

Meri Kirihimete,
The Co-production Core Team

The Co-production Project has been founded on

The Co-production project is funded by
Te Pūnaha Matatini
Complexity is at our heart

And brought to you by the team at
TOI ĀRIA
MASSEY UNIVERSITY
UNIVERSITY OF NEW ZEALAND

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Figure 110: The Octopus newsletter – Issue 2
Find all 14 issues of The Octopus here:
https://docs.google.com/document/d/1FapqN7ar9aqAkKiG6GVd4J-WxGm4Y-6VRrQIXQ2YhqY/edit?usp=sharing

Figure 67

Kia ora [redacted]

Thank you for continuing to be part of The Co-production Project. If you're reading this, you've made an important contribution to the project already — and we have one more thing to ask of you.

One of the aims of this project has been to co-produce research questions about women's health that are a priority for women in Aotearoa. So far, we've created 102 questions — and now we're focused on refining and prioritising them. We'd really value your input at this stage in the process. We are looking for input from at least 20 women (hopefully more!) and there are two ways you can provide this:

If you have 5 minutes:

We are asking each woman who's been involved with the project so far to consider a random selection of 4 of the questions we've generated. Please have a look at the questions below and let us know how they land for you. Do these questions feel important to you? What might make them even better? Any other thoughts or comments?

— What needs to be put in place to bring down some of the barriers eg transport costs or childcare
— How might health professionals develop gynaecological care/information for disabled women that reflects the UNCRDP and the enabling good lives principles alongside Te Tiriti? (United Nations Convention on the Rights of Persons with Disabilities)
— How might we bring down barriers when we are trying to move forward?
— How do we find out if we need to take vitamins and supplements (and at what age, not one that's recommended for all ages)?

If you have 10-15 minutes:
If you have a bit more time, or would like to see all the questions we've gathered so far, take a look at this online board. You can 'like' or comment on any or all of the questions according to your interest. It should be reasonably clear how to do this, but please let us know if you'd like any help at all. To those of you who have already shared your thoughts with us on the board, thank you. Do feel free to add more comments if you have them.

If neither of these options work for you but you'd still like to contribute, please let us know. You can reply to this email — or respond via this quick form. For example, we're happy to post you a set of questions if looking at things on a computer is not your cup of tea.

Thanks once again — we really appreciate your time and contributions.

Ngā mihi nui,
The Co-production Project team