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A holistic wellbeing support system for young people experiencing early psychosis: Results of an experience-based co-design study

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Abstract

Young people experiencing early psychosis often face intertwined physical, psychological, and social challenges, yet support systems frequently remain fragmented and focused on a narrow range of clinical symptoms. This study aimed to co-design a culturally responsive system of health and wellbeing support for young people experiencing early psychosis in Aotearoa New Zealand. Using an experience-based co-design approach, the study moved through a pre-co-design phase, contextual inquiry and participatory design, product design, prototype testing, and final revision. Participants included rangatahi (young people) with lived experience of early psychosis, whānau (family), and early intervention and allied service providers.

Early co-design findings highlighted the importance of connectedness, hope and optimism, identity, meaning, empowerment, safety and security, addressing stigma, and support to "get the basics right" in everyday life. These insights were translated into a prototype support system comprising a 12-week health and wellbeing programme, residential trip, web-based app, voucher system, referral system, anti-stigma activities, and professional development for service providers. Prototype feedback suggested that these components were generally viewed as valuable and feasible, particularly the 12-week programme, voucher system, referral pathways, stigma-busting activities, and workforce development, although implementation barriers relating to time, staffing, and funding were consistently identified.

Findings suggest that young people experiencing early psychosis want holistic, relational, and empowering supports that extend beyond symptom management alone. Experience-based co-design offers a meaningful pathway for developing such supports, while also revealing the structural constraints that may limit implementation. The resulting framework provides a practical foundation for future delivery and evaluation of co-designed wellbeing supports in early psychosis services. The study was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12622001323718).

Keywords

Youth mental health, early intervention, co-design, psychosis, holistic wellbeing.

Introduction

Early psychosis occurs when someone first experiences symptoms of a psychotic disorder (Fisher et al., 2020). Symptoms such as emotional changes, social withdrawal, hallucinations, delusions, reduced self-efficacy and reduced motivation can disrupt everyday health behaviours, including sleep, eating and physical activity (Fusar-Poli et al., 2022; Hui et al., 2021). Distress may also lead to coping strategies with adverse effects, such as recreational drug use (Mueser & Gingerich, 2013), while antipsychotic medication can contribute to weight gain, sedation and reduced movement (Fisher et al., 2020). Together, these factors increase the likelihood of comorbid physical health conditions, particularly cardiometabolic conditions such as type II diabetes and cardiovascular disease (Hultsjö & Blomqvist, 2013). These risks can be compounded by diagnostic overshadowing, whereby physical symptoms are misattributed to psychosis, resulting in physical health concerns being minimised, overlooked, or left untreated (Molloy et al., 2021). Consequently, people experiencing psychosis have higher morbidity and a reduced life expectancy of 10–25 years compared with the general population (Coates et al., 2019).

First episodes of psychosis commonly occur during early adulthood, a critical period of developing and establishing identity, behaviour patterns, relationships, and future pathways. Alongside physical health risks, psychosis can disrupt education, employment, meaningful activities, social networks, cognitive and physical functioning, self-esteem, and identity (Ben-David & Kealy, 2020). However, with appropriate support, young people can reshape their identity with psychosis in ways that foster personal recovery and growth (Ben-David & Kealy, 2020). This highlights the need for comprehensive, recovery-oriented care that addresses physical, mental, and psychosocial wellbeing. Physical health support can reduce the metabolic side effects of antipsychotic medication and progression of physical health complications (Firth et al., 2018; Gates et al., 2015) while psychosocial interventions can support young people to build the skills, relationships and resources needed to live well over time.

Meaningful involvement of those with lived experience of early psychosis is essential to developing support systems that are acceptable, relevant, and responsive to the priorities of young people themselves. People experiencing early psychosis are experts in their own lives and describe empowerment as having agency in their care, meaningful relationships with clinicians and social networks, and feeling heard and

valued by services (Grealish et al., 2013; Grealish et al., 2017). Consistent with this, participation in care is associated with improved health outcomes among young people with serious mental health conditions (Walker & Child, 2008), while lifestyle interventions appear more successful when they support autonomy, competence, relatedness, peer support, choice and confidence (Firth et al., 2018; Hui et al., 2021; Vancampfort et al., 2016; Watkins et al., 2019). Meaningful involvement can also foster peer-support networks, build confidence and skills, address stigma, and challenge systemic barriers within mental health care (Jakobssen et al., 2023). In research, involving researchers with lived experience can deepen understandings of health and wellbeing in psychosis, strengthen relationships with participants, and enrich the ways in which data are captured and interpreted (Pitt et al., 2007; Hui et al., 2021). Empowerment, self-determination, and meaningful lived-experience involvement are therefore fundamental to the design of early intervention and research, not only as ethical principles, but as mechanisms that strengthen engagement, empowered health improvements, and recovery-oriented care. Experience-based co-design (EBCD) is a participatory action approach that positions people with lived experience not as research subjects, but as essential contributors to research and service development (Dent-Spargo, 2018). EBCD brings together service users, whānau, service providers and other stakeholders to identify priorities and design more responsive forms of support (Hui et al., 2021; Larkin et al., 2015). This approach is well aligned with early psychosis care, where empowerment, agency and meaningful participation are central to recovery and engagement. EBCD is increasingly used in the design and implementation of health and wellbeing services (Rolleston et al., 2022), yet this project represents the first known application of this approach with young adults experiencing early psychosis in Aotearoa New Zealand (Aotearoa hereafter) ([redacted author citation]).

Co-design also provides a mechanism for addressing health inequities and power differentials (Rolleston et al., 2022). Māori, as the Indigenous people of Aotearoa, experience higher rates of psychosis-related disorders, a pattern associated with longstanding systemic health inequities (Petrović-van der Deen, 2020). Te Tiriti o Waitangi, the founding constitutional document of Aotearoa, provides a basis for genuine partnership between Tangata Whenua and Tangata Tiriti (non-Māori allies of Te Tiriti o Waitangi), and for

privileging Māori voice, aspirations and rights within health research and service design. Accordingly, co-designed interventions in early psychosis should be responsive to the cultural values, priorities and needs of participants, whānau and communities.

This study aimed to co-design a culturally responsive system of health and wellbeing support for young people experiencing early psychosis, referred to hereafter as rangatahi whai ora. The study addressed two research questions: 1) What does a system of health and wellbeing support look like for rangatahi whai ora? 2) What components does such a system require, and what are the key considerations for implementation within the current health system?

Methods

The full protocol for this study has been reported elsewhere [redacted author citation]. Briefly, the study followed an EBCD process (Donetto et al., 2015) consisting of four phases: contextual inquiry and participatory design (understanding the context and devising initial solutions alongside service users); product design (adding service providers' perspectives); prototype as hypothesis (seeking service users' feedback and modifying as necessary); and final revision (see Figure 1). In addition, we included a preliminary 'pre-co-design' phase, during which a small group of rangatahi whai ora were consulted to guide the research team's understanding of a) how best to engage with their peers in this project, and b) their preferred methods to share the stories of their lived experiences. Each phase was directly informed by preceding phases. This study reports on the final methods for each phase alongside the outcomes under 'Results'.

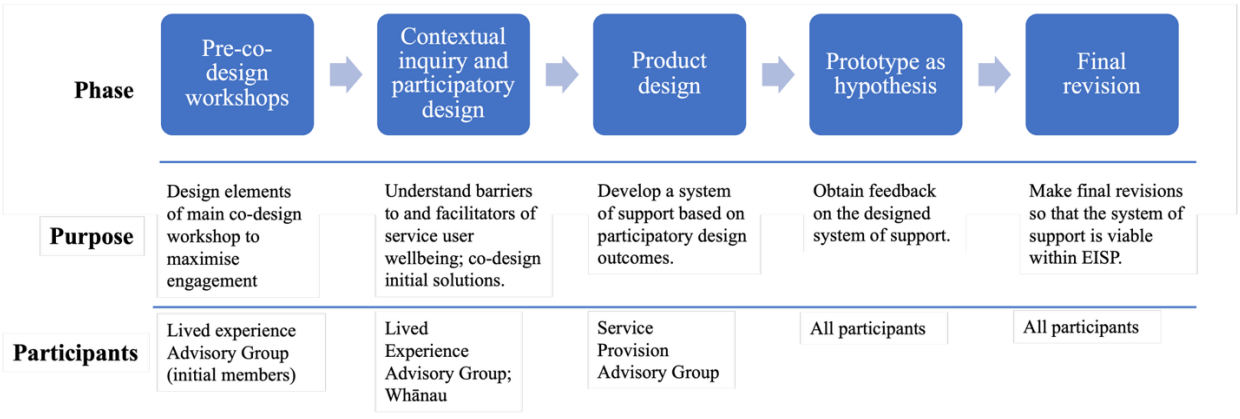


Fig. 1 Phases of the Te Hekenga Whaiora co-design process

The research team consisted of health promotion researchers, psychiatrists, clinical psychologists, and lived experience researchers. The study was approved by the University of Otago Health Ethics Committee (ref H22/048), underwent Māori consultation (in line with guidelines pertaining to research based in Aotearoa), and was registered with the Australian NZ Clinical Trials Registry (ACTRN12622001323718).

Participant Groups and Recruitment

All participants provided written informed consent to participate in the study, along with the option of changing their mind or retracting data pertaining to them at any point.

Lived Experience Advisory Group. This group consisted of rangatahi whai ora who were clients of Early Intervention Services in Psychosis (EISP) at the time of the study. Exclusion criteria stipulated that participants could not currently be experiencing an acute episode of psychosis. Participants were recruited through EISP networks in [redacted location]; posters were distributed throughout clinical spaces and case workers directly provided study information to potential participants.

Whānau. Perspectives of whānau (family members or support people of rangatahi whai ora) were also sought. Study information was shared via EISP email lists, posters, and lived experience advisory group members were asked to share it with those they considered whānau.

Service Provision Advisory Group. This group includes local EISP providers and adjacent service providers that worked alongside EISP. These participants were directly recruited through an EISP 'all staff' email list and the researchers' professional networks.

Data Collection and Analysis

Data types and data collection formats were flexible throughout the project, enabling us to respond to participant preference and availability throughout [(redacted author citation)]. For example, flexible, online surveys were offered to the service provision advisory group to accommodate clinical workload constraints.

Results

Participants

Throughout the co-design process, the Lived Experience Advisory Group comprised 12 participants who had been clients of EISP for up to six months. Two whānau members of rangatahi whai ora from the Lived Experience Advisory Group also participated. The Service Provision Advisory Group primarily consisted of EISP case workers, mental health nurses, and occupational therapists. See Table 1 for participant

demographics. Participation varied across the co-design process, where some group participants attended all phases while others only attended one. A breakdown of participation is provided for each phase.

Table 1. Participant demographics and/or characteristics

Participant group	**Demographics and/or characteristics**
Lived experience advisory group (*n*=12)	Gender 1. Male (*n*=6) 1. Female (*n*=5) 1. Prefer not to say (*n*=1) (Unselected options offered were 'Another gender, please specify'; 'Non-binary') Ethnicity (multiple responses allowed) 1. New Zealand European (*n*=7) 1. Māori (*n*=2) 1. Samoan (*n*=1) 1. Chinese (*n*=1) 1. MELAA (*n*=1) (Unselected options offered were 'Cook Islands Māori'; 'Tongan'; 'Niuean'; 'Indian'; 'Other, please specify'; 'Prefer not to say') Age 1. Mean 19.6 1. Range 17 to 24 years old Length of time in EISP 1. Mean: 5 months 1. Range: 3 to 24 weeks
Whānau members (*n=2*)	Gender 1. Male (*n*=1) 1. Female (*n*=1)
Service Provider Advisory Group (*n*=16)	EISP staff 1. Case worker (*n*=3) 1. Psychiatrist (*n*=1) 1. Service manager (*n*=1) 1. Occupational therapist (*n*=2) 1. Mental health nurse (*n*=2) 1. Clinical psychologist (*n*=2) 1. Social worker (*n*=3) Non-EISP staff 1. Local council health promotion (*n*=1)

	1. Mental health services pharmacist (*n*=1)

Phase 1: Pre-co-design

An in-person discussion with the Lived Experience Advisory Group (selected as first to respond to call; *n*=3) resulted in two key recommendations to maximise engagement with the co-design process: 1) Set remuneration for the Lived Experience Advisory Group in light of the lived experience expertise that rangatahi whai ora would bring (equivalent to NZ$25 per hour); 2) Provide alternative creative options for rangatahi whai ora to tell their stories (e.g., collages, drawings and other artistic outputs), alongside traditional written responses and recorded discussion to support participants to share their experiences on their terms and in their own ways.

Phase 2: Contextual Inquiry and Participatory Design

This phase consisted of a four-hour in-person workshop facilitated by two researchers with lived experience of psychosis and/or mental distress and was guided by a purpose-made illustrated framework ('Navigating the Puna', see [redacted author citation]). Participants included the Lived Experience Advisory Group (*n*=12) and whānau members (*n*=2). The contextual inquiry phase of the workshop focused on understanding the lived experiences of rangatahi whai ora and their whānau in leading (or supporting) healthy lives, including perceived barriers and enablers. Participants were also invited to suggest ways to address these barriers or strengthen identified enablers. Two participants who could not attend the workshop were interviewed separately by two members of the research team. Across the workshop and interviews, the data collected included various creative outputs (e.g., drawings, sculptures), written word, and spoken word (e.g., interviews, group discussion). Verbatim quotes from participants were noted from group discussions. Interviews were recorded and transcribed.

Following the workshop, the research team conducted a preliminary pragmatic thematic analysis of data. Here, 'pragmatic' refers to the use of rapid analysis to generate emerging themes and practical applications within a timely co-design process. Participants were emailed a copy of this analysis for feedback, with the proviso that non-response was taken as agreement with the analysis. No responses to this member-checking process were received.

Outcomes. A summary of the preliminary pragmatic thematic analysis can be seen in Table 2, and an illustrated graphic for these themes using direct participant quotes can be seen in Figure 2. Responses from the Lived Experience Advisory Group mapped strongly to the CHIME framework (Leamy et al. 2011), including themes of 'connectedness', 'hope and optimism', 'identity', 'meaning', and 'empowerment'. Additional themes and sub-themes of safety and security, getting the basics right (under empowerment), and addressing stigma were also identified. A full thematic analysis was subsequently undertaken, reported by [redacted author citation].

Table 2. Summary of themes from preliminary pragmatic thematic analysis with operational definitions

Theme	**Operational definition**	**Example quote**
Identity	Finding one's own identity within the diagnosis of psychosis, and/or reclaiming pre-diagnosis identities.	*There are side effects to medication… I was a different person before.*
Meaning	Finding meaning in the diagnosis of psychosis, through reframing the experience, following aspirations, or reconnecting to meaningful and value-driven activities.	*We all have dreams and aspirations, but if you've had psychosis, how much harder is it to believe that they're possible?*
Empowerment	Informed choice with regards to one's own healthcare, including education regarding medication options.	*I wish the system was co-operative, not authoritative.*
Safety and security	Feeling that there are spaces and places that offer safety and security (both physical and psychological), and which are accessible when needed.	*Mental health wards are just not safe spaces for us.*
Connectedness	Feeling connected to people: whānau, peers, alumni of early intervention services, and service providers.	*It's like finding a tribe.*
Getting the basics right	Receiving support for basic health behaviours such as physical activity, nutrition, living with medication.	*I try to get the basics right - eating, sleeping, moving, connecting, and enjoyable activities.*
Addressing stigma	De-mystifying psychosis and addressing common myths as a way of reducing both societal and internalised stigma.	*People experiencing psychosis are thought of as a threat, when in fact they are the most vulnerable.*
Hope and optimism	Experiencing hope and optimism of recovery or discovering ways of living with psychosis through shared experiences and increased understanding of psychosis.	*I thought that recovery was going to be about living without psychosis… now I aspire to having a life worth living in the presence of mental distress.*

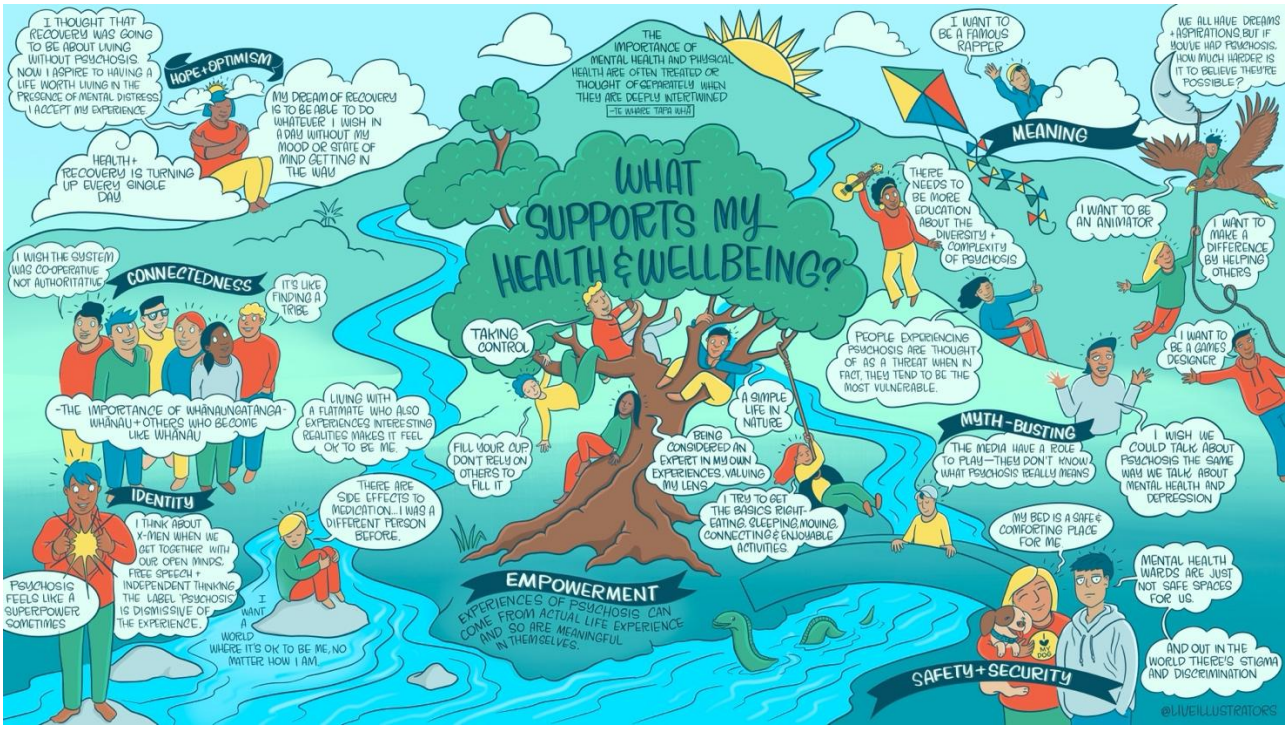


Fig. 2 Illustrated version of the preliminary pragmatic analysis

Phase 3: Product Design

This phase comprised a two-hour in-person workshop with the Service Provision Advisory Group (*n*=16), which included EISP staff (*n*=14) and adjacent service providers (local city council health promotion manager, *n*=1; mental health pharmacist, *n*=1). The themes from Phase 2 were presented to the group via PowerPoint presentation, including de-identified excerpts from the Lived Experience Advisory Group and whānau participants. Guided by each theme, the Service Provision Advisory Group provided feedback and further suggestions on how to support rangatahi whai ora. The result was a set of data walls, one associated with each theme (see Figure 3). Responses consisted of agreements with rangatahi whai ora experiences and suggestions, potential organisational partners, existing and new ways of supporting health and wellbeing, and potential barriers and enablers to these suggested supporting strategies. A summary of responses to themes can be seen in Table 3.

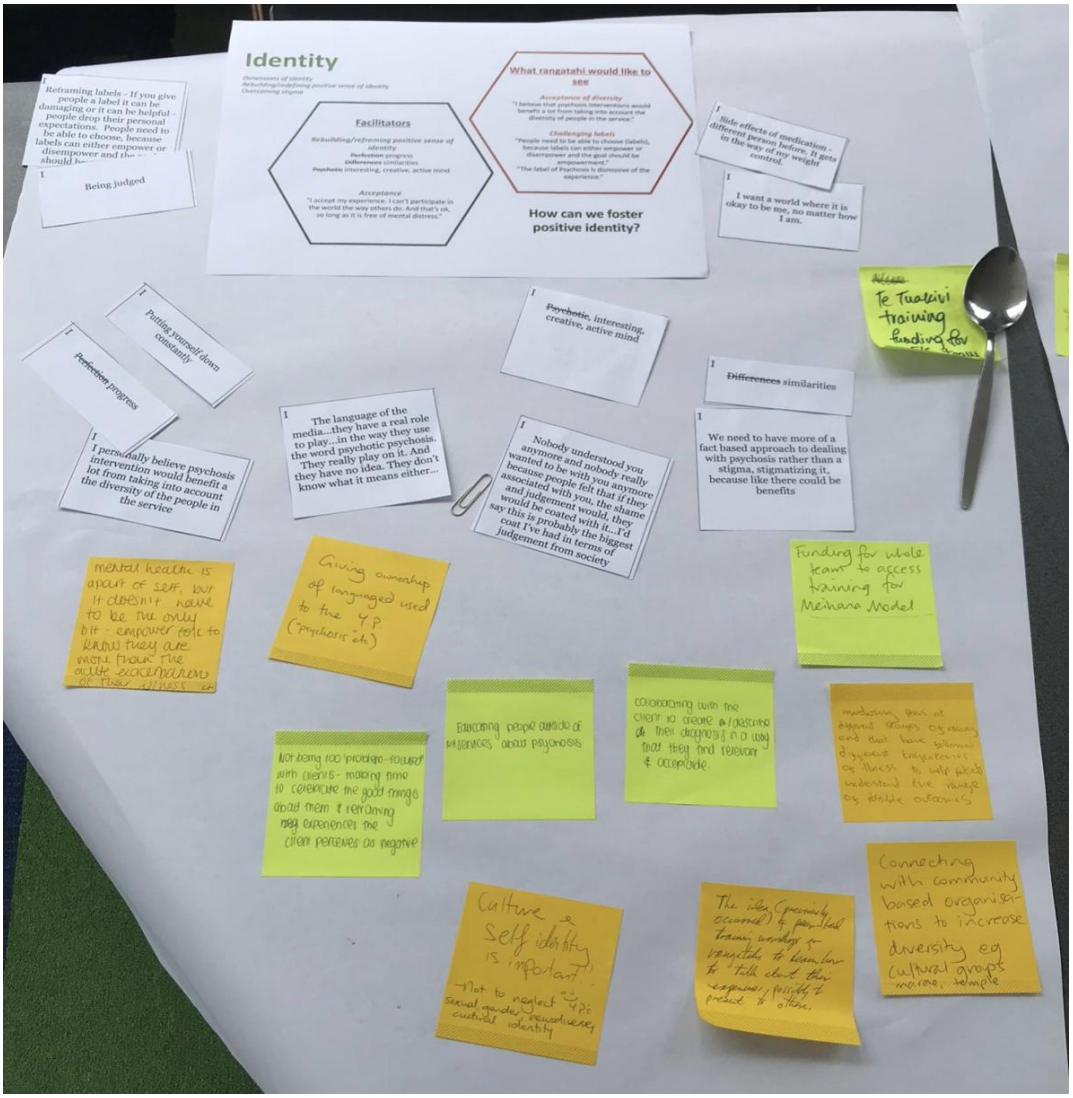


Fig.3 Example of data wall produced within the product design phase

Table 3. Summary of Service Provider Advisory Group responses to Lived Experience Advisory Group themes and additional suggestions

Lived Experience Advisory Group theme	**Summary of feedback**	**Service Provider Advisory Group responses (direct quotes)**
Identity	Psychosis does not define a person's identity	*Acknowledging and understanding that mental health is only a part of oneself and does not represent everything.* *Rangatahi whai ora should be empowered to know they are more than the acute symptoms of psychosis.* *Collaborate with rangatahi whai ora to describe their diagnosis in a way that they find relevant and acceptable to them.* *Culture and-self identity is important! Not to neglect*

		young person's sexual, gender, neurodiverse, cultural identity.
	Opportunities to connect to/explore cultural identity	*Connecting with community based organisations to increase diversity e.g., cultural group, marae, temples.*
	Reclaiming previous identity	*Importance of developing "roles" or gaining "roles" back that have been lost due to illness.*
Meaning	Supporting rangatahi whai ora with opportunities to reframe psychosis	*Reframing what psychosis means can be the catalyst for growth and change.* *Rangatahi whai ora should be given the opportunity to reframe what psychosis is and what it represents.* *Not being too 'problem-focused' with clients - making time to celebrate the good things about them and reframing experiences the client perceives as negative.*
	Finding a deeper meaning and understanding of psychosis	*Understanding how people experience psychosis -what it is saying on a deeper level - voice of self worth/self esteem? Versus clinical definitions.*
	Providing opportunities for mutual support and experience sharing	*Working out a system for enabling rangatahi to help other rangatahi, through sharing stories or experiences.* *Providing opportunities for clients to speak to others who have recovered or opportunities to hear others stories.*
	Supporting rangatahi to explore their own values and value-driven behaviours	*Supporting clients to identify what they value, then activities that align with these.* *Values work - how psychosis may have changed clients' values, how to live life according to values.* *Goal-setting to identify what is meaningful for whai ora.*
	Supporting opportunities for employment or other meaningful activities	*Finding activities for whai ora who aren't ready for study/employment.* *Coordinated liaison with a volunteer network.*
Safety and security	Support cultural safety	*Culturally and rainbow safe spaces.*
	Provide a space safe from the outside	*Providing places in which rangatahi whai ora can escape the noise of the outside world (e.g., sensory rooms).*
	Medical safety	*Dedicated specialised staff (e.g., depot nurse).* *Honouring privacy and confidentiality regulations.*
	Support whānau to create safe spaces	*Ensure whānau are supported themselves and in supporting rangatahi whai ora (e.g., Workfirst family therapy).*
Empowerment	Create opportunities for expression	*Offer opportunities for creative expression (dance, improv, music).*
		Empowerment through activity. Stay connected with sporting activities, so that people with less confidence can be supported to do this.

	Empowerment through knowledge	*Empowerment through knowledge - health education in understandable language, simplified medication language for ease of understanding for both rangatahi whai ora and whānau.* *Individualised education for clients.* *Support nutritional knowledge and practice (e.g., Garden to table, Seeds to Feeds).* *More information of the different courses of illness and outcomes and the chance of each outcome depending of personal risks/background choices.* *Workshops that empower rangatahi whai ora to learn how to talk about and share their experiences with others.*
	Provide opportunities for leadership	*Peer-led outdoor specific groups.*
	Provide autonomy in own healthcare	*Supporting advocacy, (even when under MHA).* *Provide medication options - compare side effect profiles and efficacy of different antipsychotics and let patients have choice.* *Having a choice around case managers.* *Acknowledging the current situation of rangatahi whai ora; validation and collaborative recovery plans.* *More information of the different courses of illness and outcomes and the chance of each outcome depending of personal risks/background choices.* *Offer manageable choices where possible (e.g., appointment times).*
Connectedness	General connection	*Supporting rangatahi whai ora to understand that they aren't alone.*
	Connectedness to service providers	*Consistent relationships with service providers.*
	Connectedness to other peers	*EISP community get-togethers to connect with others who have similar lived experiences - past and present.* *Bringing in previous EISP clients to speak with existing clients.* *Creating a warm, safe space for sharing. Includes online spaces - social media can be a cesspit, so offer an alternative online space that is accepting.*
	Opportunities for cultural connection	*Inclusion of cultural aspects. Maoritanga + other cultures.*
	Opportunities for whānau connection	*Helping whai ora reconnect with family members.* *Whānau-friendly events - time to all come together, have*

		fun and connect.
	Connection to similar others	*Groups for people at different stages of recovery/different comorbidities e.g. people with Autism Spectrum Disorder, people in remission. So they can identify more with others' shared experiences*.
	Connection to local communities	*Signposting and actively connecting rangatahi whai ora to local community agencies and opportunities (e.g., community snorkelling, foraging walks) and actively support when necessary*.
Hope and optimism	Provide stories of hope	*Make stories or narratives from others about their recovery available to rangatahi whai ora and the wider EISP team*. *Inviting peers at different stages of recovery and that have followed different trajectories of illness to help patients understand the range of possible outcomes*.
Addressing stigma	General	*Educate people outside of services about psychosis - wider society, whānau*.
Getting the basics right	Take a holistic approach (avoid diagnostic overshadowing)	*A need for holistic approaches to health and treatment*.
	Signposting opportunities to be active	*Provision of Leisure Card - listen to the community and provide - this could look like anything that gets young people active and playing sport*. *More liaison and/or referrals with external service providers (e.g., family workers, physical activity providers)*.
	Acknowledging and supporting through challenges	*Supporting rangatahi whai ora through unpredictable shifts in motivation*. *Understanding that life has bumps and challenges - everyone experiences them even if they present differently we all need to learn tools to manage our challenges*.
	Supporting health knowledge	*Support nutritional knowledge and practice (e.g., Garden to table approaches)*.

Following the workshop, the research team collated all participant data from Phases 2 and 3 to identify potential components and produce a prototype system of support for the health and wellbeing of rangatahi whai ora. Hierarchical nesting (see Figure 4) was used to systematically ensure that every piece of participant data was considered and - where feasible and appropriate - included in the prototype system. The

main themes from the Lived Experience Advisory Group were placed at the top of the hierarchy, with their data becoming more specific further down the hierarchy. Support strategies suggested by both advisory groups were mapped to the hierarchy using letter codes to ensure the main themes that participants identified as important to health and wellbeing were represented. The strategies were then translated to form the support system components.

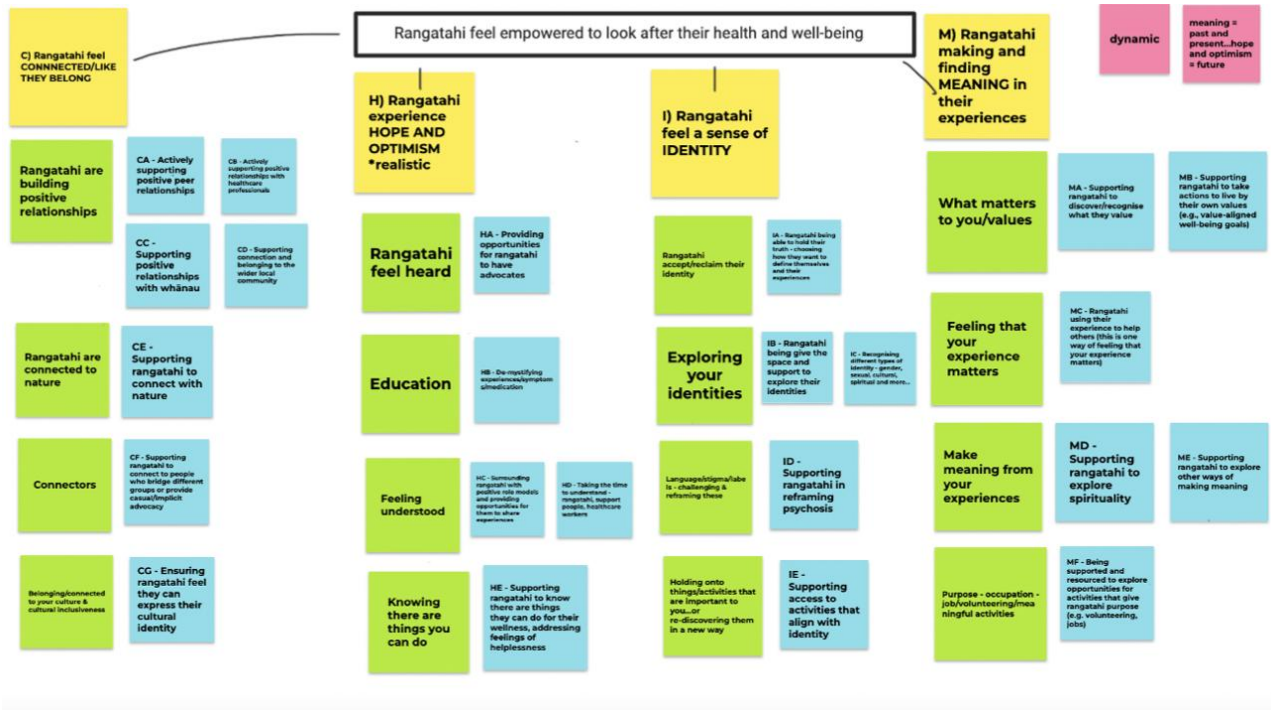


Fig.4 Example of hierarchical nesting model

Outcomes: The resulting system consisted of six components: a 12-week health and wellbeing programme (including aspects to improve health knowledge); a residential trip; a web-based application that provides clear, relevant, and relatable information regarding various aspects of psychosis (e.g., medication); a voucher system for local community activities and cafes (to share experiences with friends and family); a referral system (to other service providers); stigma-busting activities (e.g., social media or poster campaigns); and professional development for EISP providers and adjacent service providers in supporting rangatahi whai ora (e.g., in physical activity, nutrition, or smoking cessation). Table 4 shows how each component may be used to achieve the desired outcomes.

Table 4. Mapping sought-after features/processes onto components

Process	Relevant component	Rationale

The need for empowerment and collaborative healthcare	Programme	Supporting autonomy through choice in specific programme components.
	Anti-stigma campaign	Empowerment through re-framing psychosis and identity; empowering others through lived experience.
	Voucher system	Supporting autonomy to explore local community.
	Web-based app	Improving access to information and therefore increasing potential for informed decision-making).
Finding identity	Programme	Supporting identity discovery or re-discovery through various programme components (e.g., creative endeavours, sport and recreation).
	Web-based app	Providing a platform for sharing lived experience stories that support relatability.
Understanding psychosis	Programme	Support understanding of psychosis through educational elements of programme (e.g., medication) and shared experiences and peer-to-peer support while on the programme.
	Web-based app	Providing clear, accessible, and relatable information about psychosis.
Getting the basics right	Referral system	Supporting communication and referrals amongst allied health and aligned health professionals .
	Programme	Embedding lifestyle medicine principles in a holistic wellbeing programme that addresses positive health behaviours (e.g., physical activity, nutrition).
	Professional development	Addressing competence of service staff to support rangatahi whai ora in positive health behaviours.
	Web-based app	Providing accurate and relevant information to rangatahi whai ora related to psychosis.
Access to resources	Voucher system	Providing support for access to spaces and places that support wellbeing and social connection.
	Referral system	Providing access to health professionals beyond EISP.
	Web-based app	Providing accurate and relevant information

		to rangatahi whai ora related to psychosis.
Whakawhanaungatanga (building relationships)	Programme	Providing opportunities for face-to-face connections within a programme with a shared purpose (i.e., promoting positive health behaviours).
	Web-based app	Providing a way to connect to peers in a digital space and share experiences and stories.
	Voucher system	Providing opportunities for face-to-face connections with peers away from clinical spaces or home situations.
Holistic approach	Programme	Delivering programme activities that address a wide range of wellbeing outcomes, including mental health, physical health, social health. Based on the Māori model of health and wellbeing 'Te Whare Tapa Whā' [a].
Making space for young people	Programme	Creating spaces and activities that are led by rangatahi whai ora themselves, and on their terms (e.g., providing choice around whānau involvement).

[a] Te Whare Tapa Whā is a leading Māori health and wellbeing model (Durie, 1998). The model compares human health to a traditional Māori meeting house (or wharenui), which requires four strong pillars or walls to stand tall. In a health sense, these are: physical health, mental health, spiritual health, and social health.

Phase 4: Prototype as hypothesis

Participants for this phase included the Lived Experience Advisory Group (*n* = 10), whānau members (*n* = 1), and the Service Provision Advisory Group (*n* = 14). For the former two groups, visually engaging pen and paper surveys were used to obtain feedback on the individual components comprising the prototype system of support (see Figure 5). Rangatahi whai ora were supported to complete this survey alongside staff at EISP (e.g., case workers, occupational therapists) during regularly scheduled clinical appointments.

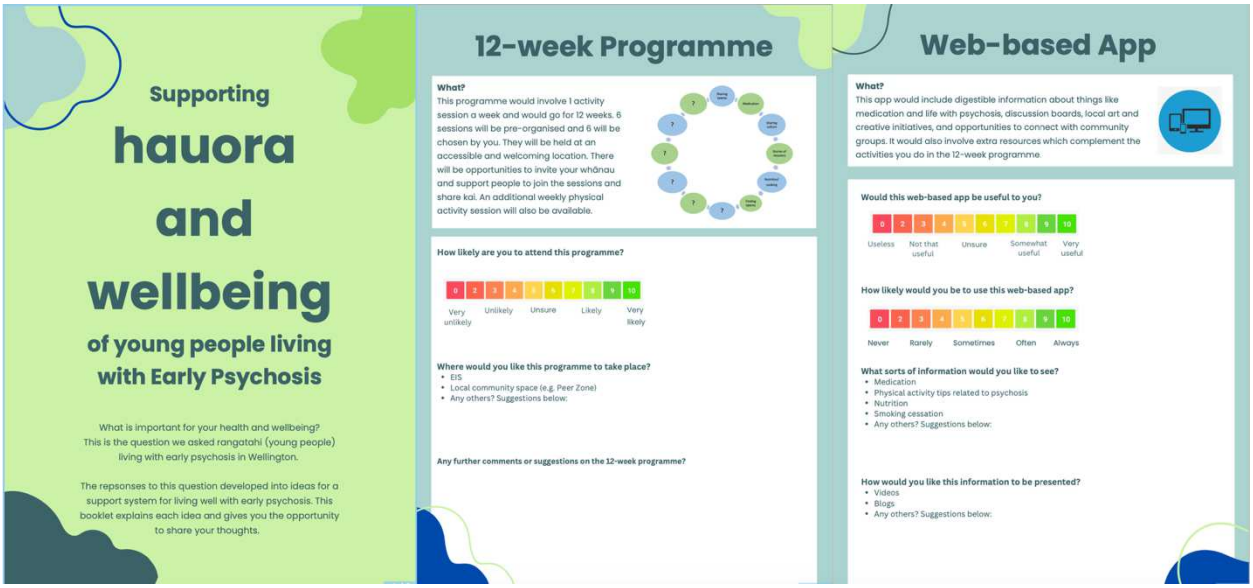


Fig. 5 Engaging surveys for rangatahi whai ora

The Service Provision Advisory Group was asked to complete online surveys, with short and long (reflective) versions offered to maximise response rates given reported time constraints among service providers. The short version consisted of multiple-choice answers (5 minutes), whereas the longer version consisted of rating scales and open text responses for reflective responses (15-20 minutes). For each survey format, a brief written description of each component was included, followed by component-specific questions. Question wording also differed according to whether it was the rangatahi whai ora or service provider survey, and these questions are included in the results tables for both groups of participants (Table S1 and Table S2, respectively).

Outcomes

12-week health and wellbeing programme

Rangatahi whai ora and whānau indicated they would be moderately likely to attend a 12-week programme (6.6 out of 10). In terms of possible programme location(s), the Lived Experience Advisory Group suggested the EISP facilities, community spaces, and green spaces (reflecting the earlier lived experience narrative of nature-based experiences supporting wellbeing, [redacted author citation]). They also specified the need for whakawhanaungatanga opportunities (building relationships), and sessions that emphasised interaction, fun, and enjoyment.

From the perspective of the Service Provision Advisory Group, the programme was perceived as having high value for rangatahi whai ora (9.3 out of 10) and seen as moderately feasible (6.4 out of 10). Lack of time, funding, and personnel were identified as key barriers, alongside difficulties engaging with rangatahi whai ora. Service providers noted that some similar components already existed in early intervention service models, including a fortnightly physical activity group within EISP with approximately 10 regular attendees (out of 125 rangatahi whai ora in this service). However, such activities were not provided on a weekly basis and did not explicitly address health knowledge. We also note that the physical activity group was not mentioned by our Lived Experience Advisory Group, leading to the assumption that these participants did not generally engage with it. Other community-based activity groups were also identified but were not specific to rangatahi whai ora living with psychosis. It was also noted that in other geographical areas of Aotearoa - specifically Tāmaki Makaurau (Auckland) - there were health and wellbeing programmes like the suggested prototype. Such geographical differences are an artefact of the decentralised and localised mental health system in Aotearoa (which, since 2022, has undergone a wide-ranging restructure towards a centralised system). In addition, an existing whānau-specific workshop was also identified, but generally whānau options seemed to be sporadic or disconnected.

Residential trip

The Lived Experience Advisory Group responded favourably to the residential trip component, particularly if it was to be integrated into the 12-week programme. A variety of locations were suggested, some arguably more realistic and sustainable (e.g., local green spaces, marae) than others (e.g., long-distance overseas trips). Suggested durations ranged from three days to two weeks, and suggested activities were varied, including exploring local places of interest, nature-based activities and other forms of active recreation (e.g., nature walks, fishing, camping, bowling, horse riding, sports). An important caveat to such activities was that they should be adapted to the individuals undertaking them, particularly in relation to energy levels given medication side effects. Social connection was emphasised, including spending time with others and 'team-building' activities. Opportunities for creative expression through arts (e.g., painting, drama games) and sharing kai (food) were also seen as important factors.

From the perspective of the service provision advisory group, the trip was seen as both feasible (7.0) and of value (8.8), with the barriers being time, money, and resources. Location was also a key consideration – being close enough to home to allow participants to leave if they experienced discomfort or at least the provision of a safe space (reflecting the 'safety and security' theme from the lived experience narratives; [redacted author citation]).

Web-based app

The Lived Experience Advisory Group reported that the app would be moderately useful (6.2 out of 10) and were moderately likely to use it (5.8 out of 10). Various types of information were requested regarding psychosis in terms of causes, prognosis, and medication. Recovery stories, wellbeing tips, links to support groups, and health behaviour information (e.g., physical activity, nutrition, smoking cessation) were also sought. Suggested formats for this information were videos, written articles, interactive games, or facilitated connection to others.

The Service Provision Advisory Group reported high levels of feasibility (7.0 out of 10) and value (8.3 out of 10) for the web-based app. It was noted that some websites already exist, including a website previously co-produced with rangatahi whai ora (www.talkingminds.co.nz); however, this site lacked interactive content. Funding and time constraints were identified as potential barriers, particularly for website maintenance. One participant also noted lack of internet access as a potential barrier, although low-cost data plans are available for some communities within Aotearoa, and data charges are often waived for selected health-related websites and apps.

Voucher system

The Lived Experience Advisory Group reported that the voucher system would be very useful to them (8.1 out of 10), and requested a range of voucher types, including: sport and active recreation, local places of interest (e.g., ecosanctuary), arts (movies, bookshops), clothing, equipment, food and drink (e.g., cafes), and public transport.

For the service provision advisory group, the voucher booklet was seen as highly feasible (7.7 out of 10) and highly valuable (9.2 out of 10), and that nothing like this exists currently. No barriers were reported.

Participants did state that for the voucher system to work, there needs to be a focus on inclusivity in terms of culture and identity (e.g., Māori, Pasifika, and Rainbow identities). It was pointed out that if delivered and utilised in the correct way, the voucher system could encourage autonomy, community, structure, meaning, and engagement.

Referral system

Of the Lived Experience Advisory Group, four reported being referred to an external organisation and eight reported no prior referrals. Among those referred, such supports were rated as very useful (8.6 out of 10), and included youth alcohol and drug counselling services and wellbeing workshops. Specific requests included Traditional Māori healing ('rongoā'), health behaviour support (e.g., personal trainer, smoking cessation), sexual health and family planning, financial guidance, and identity-aligned support groups (e.g., neurodiverse, rainbow community).

The Service Provision Advisory Group deemed the referral system as highly feasible (8.2 out of 10) and highly valued (8.2 out of 10) noting that it already exists to some degree but with some caveats. Existing referrals included to regional sports trusts, local art studios for creative expression, and active recreation opportunities. However, barriers to the referral system included rangatahi whai ora engagement, long delays between referral and uptake, an outdated record of available services, and funding. It was also noted that referred-to services required an understanding of challenges faced by rangatahi whai ora, including fluctuating motivation and medication side effects that may result in missed appointments, and to exercise leniency for non-attendance, which has not always been the case (e.g., referral cancellation for missed appointments). In addition, referrals often relied on a single person in the referred-to service, meaning that these connections could be lost if that person left the organisation.

Stigma-busting activities

The Lived Experience Advisory Group rated the stigma-busting activities to be very useful (7.2 out of 10) and suggested formats included videos and visual images, written word, ads in public spaces, advocacy and protests, seminars, and myth-busting. It was stated that these activities should be led or co-led by

people with lived experience of psychosis ('Real people, real stories, real data to give clear simple messages').

The Service Provision Advisory Group deemed this component as highly feasible (8.8 out of 10) and extremely valuable (9.7 out of 10), noting existing work addressing mental illness stigma, including advocacy by organisations such as Noku te Ao (Like Minds) and EISP staff supporting the employment of rangatahi whai ora. Various ways of addressing stigma were suggested, including whānau education, peer involvement in service design, employment support, and public awareness campaigns. This variety of suggestions reflects the reported need to address stigma at both individual (internalised) and societal levels.

Professional development

As the only participants responding to questions on professional development, the Service Provision Advisory Group rated this component as highly feasible (8.4 out of 10) and extremely valuable (9.5 out of 10). However, they identified significant barriers including time constraints, competing service demands, limited resources, and challenges keeping abreast with best practice. High staff turnover was also noted as a barrier to sustaining professional development, notwithstanding inductions for incoming new staff members.

Existing professional development opportunities were highlighted, including occupational training, workshops, and refresher courses on topics such as working with consumers, families, Māori, and Rainbow communities. Some staff reported development through attending youth forums and conferences expanding their professional networks and community connections, while informal in-house knowledge and skill sharing was also recognised as an important source of development. Desired areas for professional development included cultural safety; working with whānau; practical psychology skills; dual diagnosis, substance abuse disorders, and trauma; medication knowledge, understanding psychosis and the brain; health behaviour change; adventure-based activities; general mental health; assertive case management; and working with adolescents.

In additional comments, participants noted a lack of regular updates on recent advances in psychosis research and practice, noting these should form a standard component of professional development for psychologists, psychiatrists, and other clinicians.

We acknowledge many of these components overlap. From a pragmatic perspective, the distinction between categories is less important than ensuring the activities are delivered. Indeed, overlapping activities may therefore offer multiple benefits, providing a cost-effective approach for resource-constrained health services.

Phase 5: Final revision

The system components were disseminated at a final revision seminar attended by mental health service providers, community support, service users, and whānau. Each component was accompanied by a description and displayed using diagrams and text on flip-chart paper, alongside a summary of the feedback from previous rounds and the resulting responses (see Supplementary Material 4). Participants were invited to suggest further revisions through an opt-in feedback process and were informed that, if none were proposed, the system should be finalised. No such revisions were offered, indicating that the previous rounds had sufficiently captured participants' ideas.

Discussion

This study co-designed a system of support for rangatahi whai ora as they navigate early psychosis. The findings indicate that service users, whānau, and service providers valued a system that extends beyond symptom-focused care to include a regular wellbeing programme, opportunities for social connection, improved referral pathways and inter-service networking, continued professional development, and explicit efforts to address stigma associated with psychosis. Participants viewed these components as meaningful and broadly feasible, while also identifying important barriers to implementation, particularly time, workforce capacity, funding, and the resources required to sustain cross-sector collaboration.

The need for holistic support

Physical health disparities among people experiencing psychosis are well established, and a range of approaches has been proposed to address these disparities. However, focusing on physical health alone risks further compartmentalising wellbeing, particularly when physical health is measured primarily through biomedical markers such as weight or body mass index. For young people experiencing early psychosis, these markers may be important but insufficient, especially when rapid weight gain and metabolic disruption may be strongly shaped by antipsychotic medication. In this context, early indicators of meaningful change

may also include engagement, trust, enjoyment, autonomy, confidence, and willingness to re-engage with health-promoting activities.

The findings therefore support a broader understanding of health and wellbeing. Holistic approaches are consistent with Indigenous models of health in Aotearoa, including Te Whare Tapa Whā (Durie, 2001), Te Wheke (Pere, 1988), and Ngaruroro (Johnson et al., 2024), which emphasise the interconnection of physical, emotional, spiritual, whānau, relational, and environmental dimensions of wellbeing. Participants' priorities reflected this broader orientation. They identified the importance of connection, identity, autonomy, cultural responsiveness, stigma reduction, and everyday health practices, suggesting that physical health promotion in early psychosis is more likely to be meaningful and sustainable when embedded within a wider system of psychosocial and relational support.

Co-design, engagement, and culturally responsive care

The study also reinforces the value of co-design as a starting point for developing acceptable and meaningful support for rangatahi whai ora. If young people do not engage with a programme, even highly efficacious intervention components are unlikely to have real-world or sustained impact. Co-design can help maximise buy-in from both service users and service providers by ensuring that supports are shaped by the priorities, experiences, and constraints of those expected to use and deliver them (Donetto et al., 2015). In this study, co-design helped shift the focus from what services assume young people need to what rangatahi whai ora, whānau, and providers identify as useful, realistic, and important.

In Aotearoa, co-design also has equity implications. Culturally responsive and whānau-centred approaches are central to improving the relevance and acceptability of services for Māori rangatahi whai ora and whānau. The inclusion of holistic health models to interpret findings does not make this a kaupapa Māori study; rather, it highlights the need for early psychosis support to be responsive to the cultural contexts in which rangatahi whai ora live. Future work should continue to strengthen Māori guidance, whānau engagement, and Māori-led interpretation where Māori data and aspirations are involved.

Implementation and sustainability

Although the co-designed components were valued, the findings also highlight the resource-intensive nature of meaningful co-design and implementation. Time, funding, workload capacity, and service

constraints were identified as major barriers. These constraints are not incidental; they shape whether co-designed support can move from aspiration to practice. Asking service users and whānau what they want from services without the capacity to respond risks reinforcing mistrust or consultation fatigue. Implementation therefore requires a balance of ambition and pragmatism: services need mechanisms for listening and responding to lived experience, but these mechanisms must be matched by organisational commitment, resourcing, workforce capacity, and cross-sector partnerships.

These findings point to the need for a core set of co-design and implementation principles that can be adapted to different service contexts. For some services, a full experience-based co-design process may be unrealistic. However, less resource-intensive approaches can still create meaningful opportunities for service users and whānau to shape service development, provided these approaches are transparent, purposeful, and linked to action. Existing co-design literature offers useful guidance in this regard (Donetto et al., 2015; Vargas et al., 2022), but further work is needed to understand how these principles can be applied in early psychosis services where workforce pressure, clinical risk, and resource constraints are substantial.

Strengths and limitations

A key strength of this study was its flexible and pragmatic approach to data collection. Participants were able to contribute in ways that suited their preferences, needs, and availability, particularly the lived experience advisory group. Offering multiple methods of participation including in-person creative workshops, interviews, online surveys, and pen-and-paper surveys enabled a broader range of perspectives to be included than would likely have been captured through a single method. Although resource-intensive, this flexibility generated rich data that reflected participants' experiences, priorities, and practical concerns.

Several limitations should also be noted. Despite efforts to maximise recruitment and engagement through relationship-building and flexible participation options, some key groups were under-represented. Only a small number of whānau participants were recruited, and psychiatrist participation was limited. Whānau recruitment relied primarily on the EISP, which may have constrained participation, particularly where whānau had limited or negative prior engagement with clinical services. Future studies should consider more community-based recruitment strategies that do not rely solely on clinical service pathways. Psychiatrist participation was also limited by workload pressures and the realities of clinical service delivery.

Feedback from the EISP indicated that high caseloads and stretched resources left limited time for engagement in research beyond day-to-day clinical responsibilities. In addition, the rotational structure of psychiatric training in Aotearoa means that registrars may spend relatively short periods within a given service, limiting opportunities to build sustained relationships with service users. This aligns with previous findings from our team that rangatahi whai ora can find it difficult to build relationships with psychiatrists when clinical continuity is disrupted by rotation [redacted citation]. Finally, this was a highly localised co-design study conducted in the [redacted location]. The findings should not be treated as statistically generalisable to all early psychosis services. However, the principles, components, and implementation considerations may be transferable to other early psychosis and youth mental health contexts, particularly where services are seeking to develop more holistic, participatory, and culturally responsive forms of support.

Future directions

The next step is to deliver and evaluate the co-designed components, beginning with those identified as highest priority and most feasible. At the time of writing, this process has begun through the delivery and evaluation of a 12-week holistic wellbeing programme informed by the current study. Further work is required to evaluate the acceptability, feasibility, implementation requirements, and outcomes of this programme, alongside other components of the proposed support system.

Implementation science and systems thinking offer useful approaches for this next phase. Rather than evaluating only individual-level outcomes, future research should examine service fit, workforce capacity, inter-service referral pathways, partnership readiness, resourcing, and sustainability. A local network of health and wellbeing promotion organisations may also support implementation by enabling psychosis-specific adaptations of existing wellbeing, activity, and community programmes. Over time, such work could contribute to a broader implementation framework for holistic early psychosis support across Aotearoa.

Taken together, these findings suggest that supporting young people experiencing early psychosis requires more than symptom-focused clinical care. Participants prioritised forms of support that were relational, holistic, and grounded in everyday life, including opportunities for connection, autonomy, cultural

responsiveness, stigma reduction, and health-promoting practices. The Te Hekenga Whaiora co-design process translated these priorities into a practical system of support that was viewed as meaningful by service users, whānau, and providers, while also making visible the structural conditions required for implementation. As such, this study contributes an empirically grounded framework for community mental health service development in early psychosis.

Conclusion

This study demonstrates the value of co-design for developing holistic, contextually relevant support for rangatahi whai ora experiencing early psychosis. Participants identified priorities that extended beyond symptom reduction to include connection, identity, meaning, empowerment, safety, stigma reduction, and everyday health and wellbeing practices. These priorities were translated into a practical system of support that was viewed as meaningful by rangatahi whai ora, whānau, and service providers.

The findings also highlight that co-design alone is insufficient without the conditions required for implementation. Workforce capacity, time, funding, service coordination, and cross-sector partnerships will shape whether holistic early psychosis support can be sustained in practice. Te Hekenga Whaiora therefore provides both a co-designed model of support and an empirical foundation for future implementation and evaluation within community mental health settings in Aotearoa.

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Data availability statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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