HHS Public Access

Author manuscript

Aust N Z J Public Health. Author manuscript; available in PMC 2023 February 17.

Published in final edited form as:

Aust N Z J Public Health. 2022 February ; 46(1): 56–61. doi:10.1111/1753-6405.13187.

Assessing youth empowerment and co-design to advance Pasifika health: a qualitative research study in New Zealand

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Abstract

Objectives: The Pasifika Prediabetes Youth Empowerment Programme (PPYEP) was a community-based research project that aimed to investigate empowerment and co-design modules to build the capacity of Pasifika youth to develop community interventions for preventing prediabetes.

Methods: This paper reports findings from a formative evaluation process of the programme using thematic analysis. It emphasises the adoption, perceptions and application of empowerment and co-design based on the youth and community providers' experiences.

Results: We found that the programme fostered a safe space, increased youth's knowledge about health and healthy lifestyles, developed their leadership and social change capacities, and provided a tool to develop and refine culturally centred prediabetes-prevention programmes. These themes emerged non-linearly and synergistically throughout the programme.

Conclusions: Our research emphasises that empowerment and co-design are complementary in building youth capacity in community-based partnerships in health promotion.

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The authors have stated they have no conflicts of interest.

Implications for public health: Empowerment and co-design are effective tools to develop and implement culturally tailored health promotion programmes for Pasifika peoples. Future research is needed to explore the programme within different Pasifika contexts, health issues and Indigenous groups.

Keywords

youth empowerment; co-design; community-based research; Pasifika health

Current health statistics for Pasifika peoples, both island-born and New Zealand-born Pacific peoples, demonstrate a clear need for innovative approaches to develop health interventions. Pasifika peoples are disproportionately represented for nearly all non-communicable diseases (NCDs), with obesity (body mass index [BMI] >30kg/m^2), prediabetes and type 2 diabetes mellitus (T2DM), among the worst.[1,2] People with prediabetes have a 41.3% probability of developing T2DM within 7.5 years[2] and T2DM is more common in people with obesity (14.2%) compared to normal-weight groups (2.4%). There is a host of health, economic and social burdens associated with obesity and prediabetes, and T2DM and Pasifika peoples are overrepresented for all conditions compared to all other ethnic groups, with onset occurring earlier, and rising.[3]

Existing research demonstrates that lifestyle interventions can effectively improve NCDs,[4] aligning to the global shift towards holistic health outlined in the Ottawa Charter (1986). Empowerment-based interventions, defined as interventions aimed to build capacity, redistribute power and educate people, consistently demonstrate promise in health promotion among peoples that experience marginalisation.[5,6] They take a health-enhancing approach and often address broader determinants of health and have been described as a mechanism for social change.[7,8] For youth (individuals aged 15–24 years old), empowerment programmes include a series of educational and development workshops that build knowledge and skillset capacities, focus on leadership, self-efficacy and self-esteem, and motivate youth to engage with their communities.[9,10] Previous research demonstrates that youth empowerment programmes are a promising approach to educate, inspire, and develop the public health capacities of youth[11] and are gaining attention in Pasifika health promotion. In the most recent Pasifika health and wellbeing strategic action, *'Ola Manuia'*,[12] one of the nine key focus areas is to "empower Pacific peoples with the knowledge and skills to manage their own and their families' health and wellbeing" (p. 27). Emerging research by Firestone et al.[13,14] showed that empowerment programmes have the potential to build leadership capacities and that Pasifika youth bring unique insight into community health. Their research concluded that there was potential to modify the tested empowerment-based programme to incorporate a method to translate empowerment outcomes into the community and build health promotion interventions with youth at the forefront, and they tested in this research a co-design approach.

Co-design is an innovative, interdisciplinary approach to develop, test, and implement innovative systems, programmes, tools or products.[15] It takes a bottom-up approach to collaboratively develop initiatives with stakeholders that would have been traditionally underrepresented or not included in designing and implementing the intervention. Co-design

has demonstrated success with young people to initiate community change,[16] as well as within Pasifika communities,[17,18] because co-design approaches often develop social change initiatives to address important issues that are relevant to peoples lived experiences.

This study/research aims to assess how co-design can be effectively embedded in interventions with an empowerment framework. To date, empowerment and co-design have not been in a formal research setting and this is the first paper that evaluates empowerment and co-design together as one entity.

Methods

This research employed a Community-Based Participatory Research (CBPR) methodology and qualitative design to develop and embed an original model of co-design within an intervention focused on empowering youth to adopt healthy lifestyles and deliver the intervention, titled 'Pasifika Prediabetes Youth Empowerment Programme' (PPYEP). The PPYEP is a partnership between researchers at Massey University and two Pasifika community health service providers, one in an urban and the other in a rural location in New Zealand. The community service organisations herein referred to as the 'community partners' hired a community research facilitator who led the PPYEP with three research assistants from Massey University and guidance from the PIs. CBPR aligns with the call for public health to better integrate research and practice, increase community involvement, partnerships, and organisation, include more holistic, partnership-based research methods, and account for cultural provisions of ethnic-specific communities.[6] The PPYEP research methodology and programme modules were adapted to each Pasifika context with input from the communities. The Fonofale model[19] provided the Pasifika framework and guided how the modules incorporated Pasifika language, values and beliefs. The methods of co-design aligned with CBPR because they are both human/community-centred and focus on relationships, building capacity and developing social action plans that are specific, relevant and community-driven.

The final programme sample (N=29/41, 71% retention) included Pasifika youth aged 15–24 years from both communities as described in Table 1. The community partners led the recruitment and engagement strategy, utilising their existing relationships with schools, churches and youth organisations to recruit participants. The community facilitators read and signed the consent forms with the youth (aged 18 years or older) and their families (for those youth aged 16 or 17 years), including consent to publish data without personal identification of individual participants.

Programme development

The programme contained seven empowerment modules and five co-design modules, referred to as the 'model of co-design' (n=12 modules). The empowerment modules focused on increasing youth's leadership capacities and knowledge and skills about health; they were largely retained from the pilot youth empowerment programme[13] and refined with the community partners. The model of co-design contained five experiential modules, typifying steps to build relationships among community partners, explore the root causes of prediabetes, and ideate, refine and test community health interventions. The model

of co-design was largely informed by existing literature on youth-based co-design in health[17,18,20,21] and input from our partners. The key module was titled 'Gifts + Issue = Change,' a participatory brainstorming exercise to ideate community and individual strengths (i.e. gifts), explore the root cause of health disparities in each community (i.e. issues) and envision how the youth can initiate change through designing and delivering community interventions (i.e. change). A description of the co-designed interventions and the implementation evaluation has been recently published and is outside the scope of this paper.[22]

Formative evaluation approaches

Formative evaluation aligned with CBPR and co-design, allowing us to assess youth and community understanding, utilising their voices. By empowering all players to reflect and articulate their experiences, the formative evaluation methods overcome concerns regarding objectivity versus subjectivity, positionality, voice and community-embeddedness. The youth participants completed weekly open-ended evaluation surveys after each module containing two open-ended questions about key learnings and outcomes from each module, offering one-sentence to one-paragraph responses as the programme progressed. Completion rate varied by each workshop as participation changed from 41 youth to 29. The community partners and the research team also debriefed each module to discuss uptake and adoption. Two semi-structured focus group discussions (FGDs) were conducted and audiotaped, one in each community, six months after the programme finished. Each two-hour session contained questions on knowledge, behavioural changes, and key learnings from the program, as well as challenges experienced during the programme and changes for the future. FGDs are a culturally appropriate method of data collection for peoples that value collectivism. FGDs draw parallels to *talanoa*, a Pasifika way of sharing ideas or collective discourse, that trace back to Tongan, Samoan or Fijian roots. The community research facilitator and community partner CEOs completed a 60-minute key informant interview five months after the programme. Each semi-structured interview elicited insight on how the programme went from an operational perspective, as well as recommendations for the future. The interviews lasted between 45 and 60 minutes and were audiotaped.

All data (FGD, survey questions, interviews) were transcribed and underwent deductive thematic analysis, informed by the six steps of Braun and Clarke,[23] using NVivo 12 software by three researchers at Massey University. The codes and common themes from each set of data were merged and refined. Thematic analysis occurred until all data reached saturation, referring to the point where there was no other information or justification of higher-level concepts and definitions for each theme, following processes outlined by Braun and Clarke.[23] The data were analysed for latent meaning and validated by the community partners. The transcripts and non-exhaustive thematic analyses were shared with the youth participants, community research facilitators and community partners for interpretation, commentary and member validation.

Results

The thematic analysis results fall within three categories based on the formative evaluation foci: adoption, perceptions and application.

Adoption

Two themes emerged for the adoption of the programme: knowledge about health and healthy lifestyles and leadership and social change capacities (Table 2).

Theme 1: Knowledge about health and healthy lifestyles—The programme increased the youth's awareness about the Fonofale Model of Pasifika health,[19] a traditional conceptualisation of health that incorporates mental, spiritual, and environmental pillars in addition to physical health. The participants conceptualised the Fonofale to their community contexts and emphasised the intersectionality between mental wellness and obesity, prediabetes and T2DM for Pasifika peoples. The empowerment modules also familiarised youth with complex health terminology on cardiovascular health, diet, and diabetes aetiology. Youth explored the past and present health environments for Pasifika people and deepened their critical thinking skills as they conceptualised and contemplated the health realities of their communities. They also acknowledged that prediabetes disproportionately affects Pasifika peoples and corroborated that prediabetes is a critical issue to improve within their communities.

Theme 2: Leadership and social change capacities—Leadership and social change capacities described the youth's strengths and capacities to engage with their communities and initiate social action plans. The youth broadened their conceptualisations to consider leadership as a process rather than a position and generated a list of values of effective leadership: collectivism, teamwork, inclusivity, honesty, love, humility, integrity, commitment and initiative. The youth identified their own leadership style based on a leadership model incorporated within the youth empowerment programme (YEP) that contains four common leadership types. The youth were able to describe the qualities, strengths and weaknesses of their particular style and acknowledged that leadership styles are situational according to the context and environment. Overall, the youth left the programme with a deepened awareness about their own strengths as well as their collective, or group, capacities and capabilities, and how to build effective teams. The youth also built practical social change and leadership skills including initiative, communication, teamwork and design-thinking that were demonstrated throughout the entire empowerment modules and during the model of co-design.

Perceptions

One theme emerged for the perceptions of the programme: harnessing youth insight into community change (Table 3).

Theme 3: Harnessing youth insight into community change—The model of co-design modules encouraged the youth to be social determinants of health experts as they identified the underlying causes of prediabetes specific to their communities. It required

the participants to build upon their knowledge of Pasifika health acquired within the empowerment component of the programme and synthesise it with their personal views and experiences. The youth identified that, from their lens, environmental, social and cultural aspects, mental health, and lack of knowledge were the key determinants of prediabetes for Pasifika peoples. The groups developed seven different preliminary community intervention ideas that were later refined within the model of co-design. The programme also encouraged dialogical opportunities for youth to share their insights and concerns about affecting change. They considered the systems that perpetuate health inequalities to broaden the scope of their community intervention ideas and target the underlying root causes of prediabetes, as opposed to the symptoms.

Application

Two themes emerged for programme application: building a safe space and refining the community interventions (Table 4).

Theme 4: Building a safe space—The model of co-design modules developed a safe space among the youth and for the community partners and research team, defined as a collaborative, values-based foundation for the programme. These modules substantiated that for co-design to occur, all stakeholders must identify a relational foundation in which to operate. One programme module involved the youth in creating the vision for their own safe space, encouraging self-determination, building connection and increasing engagement. This encouraged relationships to form, a highlight of the programme for many youth. Both community partners described that the model also established and upheld relationships that encouraged accountability, respect and trust. They remarked that the programme encouraged a mindset shift from their organisations to trust that they were valued within the process, differing from their previous experience in co-design research.

Theme 5: Refining the community interventions—The co-design modules facilitated a process to refine each preliminary intervention idea and provided a practical ‘how’ to implement the community interventions. One of the modules, titled, *Gift + Issue = Change,* took a strength-based approach to utilise their capacities and competencies (i.e. gifts) and motivated them to be creative as they envisioned how to improve upon the underlying causes of prediabetes (i.e. issues) and generate community intervention ideas (i.e. change). The model of co-design capitalised on community resources and allies and provided a roadmap for implementation. It also provided an opportunity for the community partners to make suggestions on how to make the interventions culturally relevant, upholding CBPR objectives and principles. Both groups co-designed and later implemented similar interventions that targeted working age Pasifika adults (aged 25–44 years) to increase physical activity and health literacy. The youth applied the process of co-design other community social action projects outside of the PPYEP and provided examples of engaging in their schools, churches and families.

Discussion

The tested programme demonstrated that co-design is an important addition to empowerment frameworks. The use of co-design offered a practical tool to embody multidimensional conceptualisations of empowerment through, as proposed by scholars like Freire,[24] Wallerstein and Bernstein[7] and Zimmerman.[10] The empowerment component developed healthy lifestyles, social change and leadership abilities, and the co-design component deepened these skills as the youth applied them to co-design the community interventions.

Our analysis demonstrates that the themes were intersectional, as successful programme adoption, perceptions and application evolved interdependently and strengthened outcomes synergistically. The safe space established a strong relational foundation that encouraged the youth to engage in the programme, strengthening the adoption of knowledge and leadership and social change skills. The need for safe spaces supported the youth's personal development and self-awareness of their leadership styles and capacities. Knowledge of the self draws upon work by youth development psychologist Kegan (1982), who described that the processes of becoming self-aware allow individuals to examine their previous ways of being and reorient themselves in a position to make a change.[25] It connects to seminal empowerment scholar, Freire's, original conceptualisation of empowerment theory that one must have "consciousness" of their situation and, therefore, be equipped to change it.[24] The programme concurrently developed these strengths, which, cumulatively, situated youth in a position to initiate change, corroborating that safe spaces and collaborative environments are essential for youth to initiate meaningful change.[26]

Second, our research determined that Pasifika youth are critical of their realities and bring unique insight into community health and community change-making processes. There is a growing body of literature on youth empowerment suggesting that harnessing the passion and creativity of youth offers the opportunity to accelerate the progress of community change,[27] and our program modules offered a practical tool to develop skills and translate them into action. The knowledge that youth acquired about healthy lifestyles, leadership and social change underpinned their ability to contribute to effective co-design and ensured that the interventions addressed relevant issues for their communities. In our study, youth provided new perspectives on intervention approaches, participant recruitment and how to engage families in health promotion efforts, and directed the co-design intervention development and delivery. It was empowering for the youth to have their voice and leadership skills contribute to bettering the health of their communities. They brought perspectives that are often absent from processes in health promotion that do not account for the cultural contexts and lived experiences of marginalisation and socioeconomic constraints.[28]

The youth and community partners also remarked that after participating in the programme, their youth voice as a younger generation is stronger. This was achieved through youth seeking leadership roles and initiating social action plans within their schools, churches and families. The youth claimed that their leadership potential is more valued by their communities and that the programme contributed to a more progressive conceptualisation of

leadership, accessible to all participants, that was encouraged by the community partners as the programme progressed. Traditionally within Pasifika communities, positionality and governance are central to both the socio-political organisation of society and family settings, often influencing how Pasifika communities make decisions and function as a collective.[29] Empowering young leaders to perceive themselves and to be perceived by the community as influencers of social change shifts leadership from being hierarchical to a process that youth can participate in. This is important, because the Pasifika population is young and growing in comparison to all other ethnicities in New Zealand, and building a strong foundation of young Pasifika leaders could improve the future of Pasifika health and wellbeing. This research corroborates with other youth empowerment programmes that changing cultural norms and expectations regarding youth participation contests the communities' perception of youth and provides more opportunities for youth to practise leadership in other community affairs.[30]

Synergising youth empowerment and co-design

One module emerged as the seminal link between the empowerment component and the model of co-design, *Gift + Issue = Change*. The 'gifts' component instructed the youth to compile their leadership and healthy lifestyle skills developed both within and outside of the programme. As a group, they determined how these skillsets can be used to improve health issues in their communities. It took a strengths-based approach, rooted in the youth's passions and interests. This is important because when youth participants are invited to ideate their collective strengths in co-design, there is often greater innovation of the co-designed product[31] and the youth participants' self-efficacy, in turn, increases too.[8] No models of co-design to date, however, have simultaneously increased the capacity and capabilities of participants (i.e. the empowerment modules of the PPYEP). The 'issues' component ensured that the co-design process addressed community-specific issues. The module encouraged the co-designed interventions to reach beyond one specific risk behaviour of prediabetes (i.e. poor nutrition) and used the youth's strong understanding of the social-cultural barriers and enablers of healthy lifestyles for their communities accrued throughout the empowerment modules. Lastly, the 'change' component encouraged youth to innovate ideas that adjourned their 'gift' and 'issue' that were strengths-based, culturally relevant and community-targeted. This is novel because it aligns with theoretical and empirical aims of empowerment[5,7,10,32] and co-design[15-18] approaches to health promotion in a structured, youth-based approach that accounts for the lived experiences and realities health specific to each community. It corroborates with the pilot research that youth have passion and skillsets to initiate community change[13] and fulfils the 'what' and 'how' that the model of co-design employed to develop successful interventions.

Strengths of the model of co-design

This model differed from the conventional NCD prevention approach that targets one specific, predetermined risk behaviour, and garnered important insights into how best to engage youth and community partners on changing health behaviours. Many existing interventions in health use 'co-design' as a theoretical base, however, they do not provide a specific method or develop any prototype to activate meaningful change.

Our model verifies that public health initiatives garner success when they are determined by individuals within communities to address relevant, community-specific needs.[30] It suggests that social change initiatives must incorporate self-determination for the participating communities to identify health issues and priorities. This is often termed as 'community individualisation', describing how co-design processes target specific problems, relevant to the lives of those involved.[12] Within a Pasifika research setting, community individualisation must encompass cultural provisions and beliefs[17,18] and this model provided opportunities to account for the unique realities of each community context. Second, this model corroborated the notion that youth can critically assess health issues and bring unique insight into social change discussions. Incorporating opportunities for youth-led dialogue and discussions reverses traditional age-dependent power-hierarchies within social change efforts and confirms that Pasifika youth are critical of their social realities and bring a unique perspective to social change processes.[13,14] Providing opportunities for youth participation also increased the youth's ownership of the co-design process and established a strong foundation for youth engagement during the implementation phase.

Research limitations

This research was subject to volunteer sample selection bias and there were differences between participants and the broader population of Pasifika youth, limiting our ability to extrapolate our findings to all Pasifika youth. This research was also subject to attrition bias because only those participants retained in the programme completed the programme evaluation. Accounting for attrition bias is a complicated task within YEPs, and it is often omitted from research methods and discussions. This research postulates, however, that attrition bias did not influence the credibility of the results because our findings underwent member validation, we reached high programme retention (71%) compared to other programmes with similar structure,[33,34] and the themes were validated by the community partners, reaching saturation.

Conclusions

This research confirmed that together, youth empowerment and the model of co-design are an effective approach to inspire and equip Pasifika youth to lead change projects in their communities. Our findings highlight the perceptions, adoption, and application of the programme from the youth and community partner's perspectives of hosting and participating in the programme. Overall, the programme increased the youth's knowledge about health and leadership and social change capacities, and co-design offered a practical model to translate empowerment outcomes into community change. The *Gift + Issue = Change* module provided a seminal 'link' between the empowerment component and the model of co-design. It harnessed the youth's capacities and capabilities, explored the root cause of prediabetes for Pasifika, and encouraged the youth to ideate ways to affect them. Future research could involve testing the programme among different samples of Pasifika youth, modifying the programme to focus on other health and social issues, and embedding it within other Indigenous and marginalised populations within and outside of New Zealand.

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Table 1:

Programme participant description and demographics .

	Started programme (n)			Retained N (%)		
	Total	**Tokoroa**	**Henderson**	**Total**	**Tokoroa**	**Henderson**
	41	18	23	29 (70.73)	14 (77.77)	15 (65.22)
Gender						
Male	12	5	7	7 (58.33)	3 (60.00)	4 (57.14)
Female	29	13	16	22 (75.86)	11 (84.61)	11 (68.75)
Ethnicity						
Cook Island	16	16	0	12 (75.00)	12 (75.00)	0
Samoan	7	1	6	6 (85.71)	1 (100)	5 (83.33)
Tokelauan	1	1	0	1 (100.00)	1 (100)	0
Tongan	12	0	12	8 (66.67)	0	8 (66.67)
Tuvaluan	5	0	5	2 (40.0.0)	0	2 (40.0)
Age						
Mean	17.29	16.11	18.17	17.03	16.03	17.78

Table 2:

Programme adoption theme quotations.

Theme	Quotation
Increasing knowledge about healthy lifestyles	Youth: “I learned more in-depth about diabetes/ prediabetes and how it affects the body.”
	Youth: “It was important to breakdown the issue of prediabetes and to look at the problem from afar to start action planning. We got a better understanding of why it exists.”
	Youth: “Mentality is so important to be healthy: a healthy heart equals a healthy body equals a healthy mind.”
	Youth: “…[we] learned things in a way that we could understand but also think ‘why for our Pasifika peoples’ is this here?’…”
Building leadership and social change capacity	Youth: “I learnt about the leadership skills that I never knew I had and how to use everyone’s skills.”
	Youth: “With Pasifika old school, traditional ways, there is a closed-minded view of leadership. Now, we are all leaders.”
	(Community research facilitator): “They [the youth] left the programme having a better understanding of their capabilities as a community.”
	(Community partner CEO): “You know, our future looks even brighter because we have this grouping of really impassioned, keen, and still young and youthful in outlook. It may not come to them in 5 years, but at some point, in their lives, they are going to recall that ‘no, this is the way we are meant to do it.’ Because of the really strong foundational base of values and a vision.”

Aust N Z J Public Health. Author manuscript; available in PMC 2023 February 17.

Table 3:

Programme perceptions theme quotations.

Theme	Quotation
Harnessing youth's insight into community change	Youth: "I was able to learn about prediabetes and the whole story rather than just saying 'that's prediabetes, and it's what leads to diabetes.' It taught me that it's avoidable and how to prevent it."
	Youth: "… when you know we are capable of doing, you know how we can solve it, and in what kind of way."
	Youth: "Our voice now as a younger generation and as a Pacific community is stronger. Back then, I don't reckon it was valued. I think it was more 'I'm older, so you should listen.' But like now, it is just like our youth's voices are so important."

Table 4:

Programme application theme quotations.

Theme	Quotation
Building a safe space	Youth: “What I looked forward to, was seeing everyone again. I really like the bond that we created, but also just journeying with everyone.
	(Community partner, CEO): “And just the whole bond of friendship and relationship that has developed through the programme- it holds them much more in good standing for the future than anything else that I believe that could have happened within the community to continue a legacy of health.”
	(Community partner, CEO): “The other part that I like [about the relationship] is that we can hold each other accountable and challenge- so that the relationship is really honest and upfront. It gives you a higher level of engagement because of that trust and that responsibility that partners have. It has been a significant mindset shift because we have been conditioned to be “done to” not “done with”- and so this has been a change ourselves to accept that kind of approach. It’s the best fit for this space.”
Refining the community interventions	Youth: “What I will take away from the PPYEP programme is the action plan because that is the main part of the programme for me; it is the way that we help others prevent prediabetes. I have learned a lot of skills that I will enter into my skills kit. I have also learned the intervention model as a whole and then the implementation process into our communities.”
	(Community partner, CEO): “The programme allowed for the mutual understanding about the space that we were going to work in and allowed a higher level of flexibility to suit the needs of the community and where we are at.”