

Enabling the space and conditions for co-leadership in co-design: an evaluation of co-facilitator training for culturally and linguistically diverse consumers

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Key points

- Enacting co-leadership with consumers can widen participation and deepen engagement in co-design, especially with seldom-heard groups
- Training consumers, multilingual fieldworkers and researchers to co-facilitate co-design workshops is a way to effect co-leadership

Abstract

Objectives and importance of study: We report the evaluative findings from the first stage of a project designed to co-produce strategies which improve the safety of culturally and linguistically diverse (CALD) patients in cancer care. Co-leadership is developed via training and supporting consumers, multilingual fieldworkers and researchers to co-facilitate co-design. Our aim was to evaluate the training undertaken with CALD co-facilitators to prepare for co-leadership of the co-design process within the CanEngage project.

Study type and methods: A qualitative evaluation was conducted, consisting of semi-structured interviews with co-facilitators. Data were thematically analysed.

Results: Analysis of interviews with 12 co-facilitators generated three themes: creating the conditions for co-leadership; developing the space for connections during training; and readiness for co-design.

Conclusions: Providing opportunities for informal, social interactions during the training aided relationship-building among co-facilitators. The co-creation of terms of reference for the project encouraged a process of shared ownership and generated a path forward from the training to the upcoming co-design activities. We found that the recruitment process offered an initial forum to discuss the alignment of the motivations and expectations of those interested in becoming involved with the aims of the project and goals of the co-design.

Key points (cont)

- Providing opportunities for informal relationship-building, reflection on expectations and the co-creation of the terms of reference can aid these efforts

Introduction

Successful co-design is contingent upon fostering conditions conducive to the meaningful engagement of consumers, health service providers and other groups involved.^{1,2} Several factors can help to facilitate this, including: “research environment and receptive contexts; expectations and role clarity; support for participation and inclusive representation; commitment to the value of co-learning involving institutional leadership”.³ Optimal conditions often require multi-level investment (e.g. time and funding) and commitment from stakeholders, including health services leadership, from inception to implementation.¹ An obstacle to achieving authentic consumer participation in co-design is the lack of diversity of those involved⁴⁻⁶, especially of consumer groups who negotiate various dimensions of disempowerment and whose voices are seldom represented.^{7,8} For such communities, a range of challenges can impede involvement in co-design, ranging from stigma-related barriers to balancing participation-related burdens with other demands upon their time and energy.⁶ To our detriment, this can result in the contributions of diverse consumers being superficially ‘represented’ or altogether lost.^{4,5,9-11}

One approach to promoting equity and inclusion in the co-design process is the involvement of consumers as co-researchers, to effect co-leadership of the research.¹²⁻¹⁴ Consumer co-leadership involves consumers being equally involved in, and provided opportunity to, contribute to activities such as planning, managing and executing the co-design project.¹⁵ Given the challenges for the genuine representation and participation of seldom-heard groups in co-design^{4,7,9}, this is a promising approach. Co-leadership from the outset offers a means to reconfigure unequal power relationships that are often entrenched in research processes¹⁶, by inviting shared decision making about co-design and ownership of the process. Here, multiple forms of expertise, including that of lived experience are elevated and valued in guiding the research.¹⁷ Further, this facilitates a forum for ongoing reflection concerning the development of safe and supportive conditions for co-design with seldom-heard consumer groups.

Preparing consumers and multilingual fieldworkers for co-leadership of co-design workshops was one of two novel adaptations made to the experience-based design (EBCD) model that was employed in the CanEngage project, which is reported in full

elsewhere.¹⁸ The CanEngage project aims to co-design patient engagement strategies to enhance consumer engagement and safety for and in partnership with culturally and linguistically diverse (CALD) cancer service consumers in New South Wales (NSW) and Victoria (VIC).¹⁸ The CanEngage Co-Facilitator Network was established before embarking on the co-design workshops. Members include people with CALD backgrounds and multilingual fieldworkers who receive training to co-lead the planning and delivery of co-design workshops with the research team. Training and involving consumer co-facilitators in leading co-design can widen participation and deepen engagement in the co-design process but has not been formally evaluated. As such, there is much we can learn from co-facilitators’ experiences of their training and involvement in the research and the experiences of the academic research team in taking a co-leadership approach. In this paper, we aimed to evaluate the training undertaken with CALD co-facilitators to prepare for co-leadership of the co-design process within the CanEngage project.

Methods

Design

This was an exploratory qualitative study of the notion of being a co-facilitator and of the co-facilitator training provided. We used semi-structured interviews to generate rich data in which the participants narrated their experiences and reflected upon what those experiences meant for them.¹⁹ Details of the co-facilitator training are shown in Box 1.

Recruitment

Eligible participants were CanEngage project staff, Co-Facilitator Network members who included multilingual fieldworkers, and cancer services consumers who attended the co-facilitator training. There were a total of 13 participants. All potential participants were provided with study information and an invitation to participate via email. Recruitment was conducted by an academic researcher independent of CanEngage (ÉNS), and those who wanted to participate made direct contact with this researcher.

Box 1. Training workshop details

- A one-day training workshop was held, which could be attended in-person or online using a videoconferencing platform.
- Attendees were provided with a training pack containing information about the CanEngage project and supporting materials for each session.
- The content was underpinned by adult learning pedagogies and designed to ensure that co-facilitators were appropriately supported.
- The training was conducted over four sessions: 1) welcome and introduction; 2) patient engagement and safety in healthcare; 3) healthcare co-design; and 4 co-facilitator roles and activities.
- The content spanned current evidence, stories and lessons from previous co-design projects and an in-depth introduction to consumer participation in co-design in health research.
- The roles of consumer, multilingual fieldworker and researcher co-facilitators were discussed in the context of the CanEngage project.
- This event facilitated a forum for discussion, clarification and helped to cement an inclusive, collaborative context. This was delivered by two research team members (RH and ÉNS).
- The process of co-developing a terms-of-reference document for co-design group facilitation was started during the training.

Procedure

The interview questions were developed in consultation with the CanEngage consumer advisory committee and piloted with research team members. Interviews commenced once written consent was received, and consent was re-confirmed verbally at the outset of the interview (see Supplementary File 1 for interview guide, available from: <https://researchers.mq.edu.au/en/publications/enabling-the-space-and-conditions-for-co-leadership-in-co-design->). Interviews took place between July and August 2021 via video conferencing platform Zoom (San Jose, CA: Zoom Video Communications Inc) and on average, were 40 minutes in duration. All interviews were audio-recorded and transcribed verbatim, using station notation by a professional transcription agency. Participants had the opportunity to review and verify their transcripts. Data were de-identified and pseudonyms assigned.

Data analysis

An inductive thematic analysis of the interview data was undertaken by two experienced qualitative researchers (ÉNS and BNGE) independent of the CanEngage team.²⁰ The researchers independently familiarised themselves with the transcripts and undertook initial, preliminary

line-by-line coding of the text. Each researcher undertook an iterative process to develop preliminary themes separately, before meeting to review, discuss and agree on the themes. A further validation process was undertaken with three members of the CanEngage project team (BN, RH, NTT) in which the final themes were discussed and confirmed.²⁰ NVivo Pro software (version 12.6) was used to manage the data and facilitate the analysis.

Ethics

The study was approved by the Western Sydney Local Health District Human Research Ethics Committee in 2021 (2021/ETH00532).

Results

Of the 13 CanEngage Co-Facilitator Network members who were invited, 12 agreed to participate: six were consumers, two research team members, two multilingual fieldworkers, and two had dual roles as both research team members and multilingual fieldworkers (Table 1). Co-facilitators were proficient in one or more of the following languages: Bengali/Bangla, Burmese, English, Egyptian, Filipino/Tagalog, Gujarati, Hindi, Jordanian, Lebanese, Mandarin, Portuguese, Punjabi, Spanish, Sudanese Arabic, Syrian and Urdu.

Table 1. Deidentified summary of participants

Pseudonym (gender)	Role
Jin (Female)	Consumer
Goya (Female)	Consumer
Bella (Female)	Consumer
Róise (Female)	Consumer
Neela (Female)	Consumer
Ronit (Female)	Consumer
Joyce (Female)	Multilingual fieldworker
Hugh (Male)	Multilingual fieldworker
Blake (Male)	Researcher/Multilingual fieldworker
Isabel (Female)	Researcher/Multilingual fieldworker
Pippa (Female)	Researcher
Freya (Female)	Researcher

Three themes were developed following analysis of the interviews as shown in Figure 1 and described below.

Theme 1. Creating the conditions for co-leadership

The first theme describes how the process of developing the CanEngage Co-Facilitator Network was viewed as helping to establish a foundation for co-leadership in the project. Interviewees described how their motivations to become involved with the CanEngage project stemmed from their experiences with cancer services from the perspectives of patients, clinicians and supporting others accessing services. Common among these diverse experiences was a concern that CALD community members may not be accessing and/or receiving the optimal, full range of services relevant for them.

“So, they thought I would be good to join, that with my experience as a past cancer patient I’ll be able to help in that aspect, [...] I would love personally to step into solutions and find better options for those communities to access services.” (Bella)

“...it’s about my passion in approving holistic care for patients regardless of their background, regardless of the cultural background they’re coming from, and how to streamline a very Western healthcare that we have....” (Hugh)

Interviewees described how the Co-Facilitator Network recruitment process enabled discussions between potential co-facilitators and research team members about the scope of the work and expectations in advance of joining this network. Having the opportunity to clarify and discuss information about the aims of the co-design activity enabled individuals to consider whether their motivations and aspirations for the project were synergistic.

“Also, people [potential co-facilitators] are asking about [...] what is the project about and how can I contribute to this project.” (Isabel)

“...there were a couple [potential co-facilitators] who didn’t really fit the criteria, who didn’t actually meet what we were looking for. Or, in that conversation, we both came to that realisation, so when we chatted and realised they’re not quite a good fit.” (Freya)

“With these kinds of [co-design] projects that are meant to be developing something that benefits a system rather than tackles a problem, it’s a little bit of a different motivation that takes that.” (Pippa)

Theme 2: Developing the space for connections

The second theme describes how participants perceived the atmosphere and environment of the space in which the training was conducted and how this helped develop connections between co-facilitators during the sessions. The welcoming atmosphere was noted as important as it enabled openness and invited questions. A crucial part of this environment was the physical space and layout, especially the table arrangement – co-facilitators thought this contributed to this atmosphere and had a role in supporting the ease of interactions. For one participant who had not been able to locate the room easily, it was noted that their delayed arrival meant that they had less opportunity to learn about other members of the group.

“It’s a very good friendly environment. There’s scope for me to ask questions if I want.” (Ronit)

“I liked the room [...] like the round tables, everyone can talk to each other without any difficulty.” (Isabel)

“The way it was set up around the table – I would say it was a very good environment where everybody was able to ask questions without hesitation, and a good level of interaction.” (Joyce)

“I think we’d all had a chance at the beginning to introduce ourselves, and perhaps the ones that

Figure 1. Thematic findings



came a bit later [attendees who were delayed] may have felt a little at a disadvantage because they didn't know who we were." (Goya)

Most respondents recognised the importance of developing relationships through the training experience. As the first opportunity to bring co-facilitators together, the training process enabled them to build relationships and rapport they sought to sustain throughout the project lifecycle. Between-segment breaks were identified as important aspects of the training for relationship and rapport building.

"So those were the positives. I think for myself, having breaks, having refreshments, having the opportunity for them to speak, ask questions, or really actively involving them was good." (Blake)

The social spaces afforded by breaks in the training, such as the lunch break, were also described as providing forums for relationship-building and clarifying information with those leading the training. While online attendees reported being able to contribute to the training well during the formal components, it was these informal, social opportunities that they missed.

"What I really missed was the interaction with other members, which I wasn't able to do at all, basically because I'm online. So, all I can do is just listen to what they say and come in when I want to say something." (Bella)

"But I wasn't there for that bit, so I missed out. I was alone with my cup of tea. I think that's what makes it a place where people can ask their questions, and if the slides were too hard to understand, are we brave enough to go, I have no idea what you're talking about." (Freya)

Theme 3: Readiness for doing co-design

When reflecting on the training and their level of preparedness for co-design, interviewees discussed both the training content and the expertise of the network members and research team as a co-facilitation team. Interviewees described the information provided as accessible, holistic and informative; they knew what would happen when they entered into the co-design.

"All the information around what's going to happen, what it is and what are the expectations, that was well covered in the workshop." (Joyce)

"...the information was quite relevant, and I feel I understood throughout the process of the project and how the workshop consultation would happen and so forth." (Hugh)

"There was a good range of information presented in a way that covered all the points and allowed everybody to ask questions." (Goya)

Terms of reference (TORs) for the CanEngage project were collaboratively developed during the training. The TORs were designed to provide co-facilitators with a guide to co-design workshop facilitation. This included the role of co-facilitators, the scope and responsibilities of the research team members, and detailed agreement around how communications would occur between co-facilitators and the research team co-design members. A summary of the TORs components is included in Supplementary File 2, available from: <https://researchers.mq.edu.au/en/publications/enabling-the-space-and-conditions-for-co-leadership-in-co-design->.

"But just clarifying who are they [TORs] for, who's it for, what's it for, are people even familiar with the term, terms of reference, that sort of stuff I'm - people have been really good, and great ideas." (Freya)

Interviewees described their active contributions to developing the TORs to address their specific questions and preferences, including clarifying project roles and the language used in the document. Participants described their contributions on the day of the training and via email afterwards. Participants agreed that co-developing the TORs provided an opportunity to clarify and document specific ways of working and tailor ways of working in co-leadership of co-design that were relevant to the co-facilitators involved. This shared understanding of the role and its processes was seen to document and guide the co-design process.

"I think I did not find clear information about what a multilanguage field worker is supposed to do in that one, so I have put forward a suggestion to add some information on that one." (Joyce)

"The terms of reference has been good because it allowed us to quickly build the discussion into something actionable. That we can then action and as the co-design process actually comes about." (Pippa)

In looking towards the next project steps, co-facilitators reflected upon the ongoing impacts of the coronavirus 2019 (COVID-19) pandemic, especially requirements to work remotely. They suggested there was a need to consider alternative ways of proceeding. Consumer participants expressed uncertainty regarding conducting co-design sessions with CALD communities online.

"My concern is mainly because, if we are going to get the whole community to participate, a lot of them - [from] the people that I know and I work with, [...] they will not be able to speak openly as much as possible [when online]." (Róise)

"I'm just wondering how I'm going to deal with the whole thing if lots of the CALD communities now at this stage can't even access computers or they

don't have the knowledge of that technology in a way." (Bella)

Discussion

Our evaluation of co-design co-facilitator training to prepare consumers for co-leadership provides insights into the conditions that may support co-leadership. The opportunity to build rapport between researchers and consumer co-facilitators and among consumer co-facilitators was identified as important. Building rapport when working remotely was identified as a significant challenge for co-facilitators and a perceived challenge for co-design members from CALD backgrounds.

Co-design scholarship highlights the benefits of fostering a welcoming and inclusive environment.^{3,17} The physical spaces in which these interactions occur form an important element of this environment, especially in terms of accessibility and safety of spaces for those involved^{2,5}, but is often overlooked.^{2,5} Our findings indicate that the layout and physical characteristics of the environment can help participants feel comfortable contributing and asking questions and therefore merits greater attention. Further, opportunities for social interactions within and outside of the training schedule held benefits for relationship-building and information clarification. As such, these should be accounted for when planning these events. However, these opportunities may be more difficult to prepare for and promote in online/remote co-design venues.^{21,22} Those attending the training online raised the concern that they may have missed out on these social opportunities and has been identified as a critical challenge for researchers, consumers and other stakeholders who are adapting co-design projects to online/remote formats during the COVID-19 pandemic.^{21,22}

An absence of a shared understanding of project roles, aspirations and anticipated outcomes between those involved can inhibit meaningful participation and progress.^{4,6,13} The misalignment of expectations is a common challenge in co-design work, and strategies are needed to address this risk from the outset.^{9,17} Our findings suggest that the recruitment process offers a space for discussion and reflection about the alignment of individual motivations, what is involved, and the goals of the co-design. Given the lack of guidance concerning what should occur before the start of co-design^{3,4}, this finding identifies a process that could help anticipate and mitigate this potential challenge as part of early project activities.

The co-development of the TORs was identified as an approach valued by participants and one which enabled the explicit discussion and documentation of roles and expectations in the co-design process. There are several examples of projects in which the development of TORs form part of the co-design process.^{3,23,24} Still, there is little evaluation of this approach in the literature. Our analysis showed that co-facilitators were deeply engaged with

this process and actively contributed to this document. We would suggest that the development of TORs reflects the broader concept of co-leadership, which promotes shared ownership of the project going forward.¹⁴⁻¹⁶

In looking toward the next stage of the CanEngage project, co-facilitators expressed concern about the implications of the COVID-19 pandemic for starting co-design workshops. The possibility of shifting these workshops online was raised; a widely adopted approach in other types of research. Aside from the host of well-established factors that should be accounted for in adopting an online format (e.g. accessibility concerns), the nature and characteristics of approaches such as the EBCD model merits consideration. Promoting collaboration and support for co-designers to contribute is central to this approach, however, it may be more challenging to negotiate in online venues.^{21,22,25} These issues, along with co-designers' preferences and comfort with online engagement, will be critical points of consideration in advancing the project in the current context.

Limitations

The study data was generated from a limited participant pool, which may have shaped the findings. In some cases, co-facilitators occupied dual positions (i.e. as a multilingual fieldworker and researcher) or were involved in both the project and its evaluation. This affords the incorporation of insights from multiple perspectives and roles, but inevitably adds complexity to drawing conclusions from the findings and necessitates ongoing reflexivity in the project. Findings from qualitative research are not generalisable.

Conclusion

We note several lessons from this evaluation of the training of CALD co-facilitators to prepare for co-leadership of the co-design process of the CanEngage project, which may be useful for others. Firstly, in the recruitment and preparation for working in a co-leadership model, there is value in considering and reflecting on the alignment of the motivations and expectations of those interested in becoming involved with the project aims and the goals of the co-design process. Secondly, in developing training, it is beneficial to plan relationship-building opportunities and retain some flexibility to support these interactions. Thirdly, incorporating the co-creation of TORs for the project can deepen engagement and promote shared ownership and progression of the process. We consider the challenges of putting the theory and principles of co-design into practice to be an ongoing process of learning and adaptation, which will continue over the life of the CanEngage project.

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Peer review and provenance

Externally peer reviewed, invited.

Competing interests

None declared.

Author contributions

RH conceived of the project and contributed to the development of the study design. ÉNS was involved in data acquisition, and ÉNS and BNGE participated in the analysis process and produced the first draft of the paper. RH, AC, BN, KJ and NTT provided critical and substantial revisions to the manuscript. All authors read and approved the final manuscript.

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