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Are you really doing "co-design"? Critical reflections when working with vulnerable populations

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Abstract

"Co-design" and associated terms such as "co-production" or "patient engagement", are increasingly common in the health research literature, due to an increased emphasis on the importance of ensuring that research related to service/systems development is meaningful to end-users. However, there continues to be a lack of clarity regarding the key principles and practices of co-design, and wide variation in the extent to which service users are meaningfully engaged in the process. These issues are particularly acute when end-users include populations who have significant health and healthcare disparities that are linked to a range of intersecting vulnerabilities (e.g., poverty, language barriers, age, disability, minority status, stigmatized conditions). The purpose of this paper is to prompt critical reflection on the nature of co-design research with vulnerable populations, including key issues to consider in the initial planning phases, the implementation process, and final outputs. Risks and tensions will be identified in each phase of the process, followed by a tool to foster reflexivity in co-design processes to address these issues.

Introduction

Over the last decade, co-design has emerged as a ubiquitous research and service/systems development approach across a myriad of health-oriented-disciplines including, but not limited to, health services,[1-4] quality improvement,[5] health technology development;[6,7] Indigenous health[8,9] and community-based health.[10] Application of co-design approaches are increasingly evident with populations who experience vulnerability due to social, economic and environmental barriers, from children,[6,11,12] through to older adults.[13-15] Researchers and practitioners within these disciplines have deployed co-design approaches across a range of settings, using various terms such as co-creation, co-production, co-research, experience-based co-design, human-centered design, technology co-design, participatory research, collaborative and community-based research.[16,17] The terms are linked to sets of core principles regarding the value of lived experience, collaboration, building on capabilities, and creativity.[16] Co-design, at a basic level, refers to application of user-centric research and service/systems development approaches in order to solve a particular problem or challenge.[18] However, co-design has also been described as a dynamic, creative approach to research that embraces partnership with community, and focuses on systems change and improving human experience.[16]

The increasing use of the term co-design and its associated methodologies has made it challenging to distinguish whether or not the term has been co-opted in such a way that sidesteps meaningful engagement with the original principles of co-design: distribution of power in research, amelioration of the human experience and positive societal impact. These issues are particularly acute when engaging populations who are 'vulnerable'; considering

vulnerability not as an individual characteristic, but as the result of social and systemic barriers (e.g., poverty, literacy, language barriers, and discrimination related to age, disability status, ethnicity/race, gender).

In this article, we critically discuss three questions, with a particular focus on research with vulnerable service users: 1) What is the epistemological starting point that is underpinning the decision to apply co-design processes and techniques? 2) How are co-design methodologies, planned, applied, and adapted while engaging in iterative "research through design" processes? 3) What type of post co-design outputs can be anticipated and created, and what will the manifest and latent impacts of these outputs be? The critical discussion which ensues places a particular emphasis on how power is conceptualized, deployed and received[19] within co-design processes aimed to ameliorate health services, products and experiences for vulnerable individuals and groups.

Where are you starting from?

Advancing effective and ethical co-design should start with critical reflection on the epistemological beliefs that are driving initiation of the process, including the 'mindset' of the co-design facilitators. Co-design should begin with critical and embodied reflexivity that attends to 1) ourselves – the subjective self or "I"; 2) our relationship with others – the intersubjective "we"; and 3) the systems in which we and others are embedded – the objective "it".[20]

The first point of reflection is internal; as a facilitator of co-design, it is important to consider the worldview, assumptions and values that you bring to the process. Co-design facilitators

need to embrace critical, reflexive practice, including development of a subjective, embodied understanding of their own standpoints and epistemological frameworks that will impact their relationships with others.[21] They need to be capable of improvising and taking other perspectives, and be willing to be transformed in the process.[22] These capabilities are cultivated through enhancing mindful awareness of, and working with the thoughts, emotions, perceptions, sensations, that arise as part of being in an interpersonal relationship.[23]

The second point of reflection is on your relationship with others who are engaged in the co-design. This includes attending to the effects that you have as a researcher, educator and/or practitioner at every step of the design process. It also involves a commitment to ongoing dialogue about various ways of knowing, the interrogation of power and privilege, and making the time and space to listen, share and co-create.[24] The humanity and multi-dimensionality of all participants must be respected and attended to with care, compassion, creativity and humility. Relationships require openness and vulnerability in the immediacy of human-to-human connection.[25]

The third and final point of reflection is on the system in which the co-design process will occur. There may be a clash of values since many organizations operate within a socio-political environment that privileges individualism over collectivism, self-sufficiency over collaboration, and scientific expertise over other ways of knowing based on lived experiences.[3,26] The fundamental principles of collaboration in co-design may be subverted in the drive for efficiency and top-down decision making. Critical awareness and resistance to these pressures

may be needed in order to find the time and space required for an authentic way of working together for social justice and change. Beginning a co-design project requires institutional support to ensure that there is a commitment to critical thinking, learning and change,[27] that diverse people are given an opportunity to participate,[28] and that sufficient resources (including funding and space) are provided.

What should you be doing?

Co-design has been described as both a philosophy and a method[27] that includes authentic and equitable collaboration between stakeholders in projects that are emergent, flexible, and iterative.[28] There are several specific approaches that have been used in the context of healthcare, including experience-based co-design (EBCD),[29,30] participatory research,[1,8] and user centred design.[31] Each approach has its own processes and tools, but there are several overarching issues to consider in optimizing the process of collaboration and design.

First, it is critical to include diverse people in the co-design process, including those with lived experience, those who deliver or implement a service or program, and other key stakeholders or influencers.[28] A noteworthy criticism of co-design specifically, and patient-oriented research generally, is that vulnerable populations may be excluded[32] or represented by 'super users' who do not reflect the typical population.[33] Super users are individuals who frequently contribute to research projects. They are often invited to participate since they are actively engaged, articulate, and clearly understand their role in the process. One of the dangers, however, is

that over time, socialization to their research role may desensitize them to the perspective of those experiencing greater disenfranchisement.[33] It takes time and effort to ensure representation from the important, but often unheard voices of communities who face many barriers to engagement.

When engaging groups from historically marginalized communities, sensitivity to power differentials and creative approaches may be needed to ensure a safe and inclusive space for collaboration. Invited spaces have been criticized for perpetuating marginalization and tokenism, since unexamined power imbalances may delegitimize forms of knowledge that depart from the status quo.[34] Principles and tools for engagement could include: a) formalizing agreements for shared leadership, decision making and ownership of knowledge; b) providing training and ongoing mentorship for new participants who may be uncomfortable and/or unfamiliar with the process; c) ensuring flexibility to account for differences and fluctuations in ability to participate; and d) establishing formal recognition for the value of service user input.[28,33,34] Richards and colleagues[35] present an insightful argument regarding compensation for service users in order to recognize vulnerability, promote equity, facilitate commitment, and remove barriers to participation. They suggest starting the conversation early to build relationships, negotiating a fair rate that addresses the needs of all parties, and establishing a formal agreement on roles and responsibilities in order to avoid the risk of tokenism.

Specific steps of co-design may vary depending upon the project, however, core processes include building trust, finding voice, sharing perspectives and creating a common vision for

change.[28] Arts-based tools and techniques can be incorporated to generate initial insights into stakeholder experiences, as well to foster creativity in designing solutions. Generative design strategies, as outlined by Sanders & Stappers,[31] emphasize the role of "doing" and "making' as alternate paths of expression that can evoke deeper insights and creative solutions. They highlight how a range of probes, generative toolkits and prototyping strategies can facilitate the co-design process, using creative tools such as video, storyboards, clay and even Lego to evoke insights and ideas that transcend what people might put into words. These strategies may be particularly effective to engage service users who may have difficulty with purely verbal interviews or focus group discussions (eg. recent immigrants, young children, older adults with dementia).

Rather than following a series of rigid steps, working with vulnerable populations requires following a set of core principles; "taking time to fully engage, listen for understanding and not move forward until participants or communities are ready".[28(p295)] One of the challenges for co-design facilitators is responding to pressures related to resource and time constraints that could compromise the process.[27]

What are your intended outputs?

In addition to how co-design is implemented, it is critical to examine outputs of the process. With its roots in design thinking and action research, co-design involves creating prototype solutions to address the priority problems or issues. Ultimately, the process should continue to

implementation and evaluation of the proposed solutions, with a commitment to ongoing collaboration in the process of change.[36,37] Without this movement to positive change, participants can become disempowered and even resentful, particularly with perpetuation of the status quo.

The specific outputs and outcomes of co-design are varied, but can occur on several levels, from individual to systems change. A survey of 59 EBCD projects in 6 countries found that most projects initially targeted small quality improvements, however the legacies of the co-design work had much larger impacts in terms of "deep changes in attitudes and behaviors".[30] Similarly, Palmer et al.[38] argue that while practical solutions are important, the skills gained by service users, family/caregivers and staff in negotiating new ways of advancing the future that they have helped to shape is even more significant. This can be particularly important for groups who have a history of fractured relations (eg. mental health service users), wherein new shared identities can be developed as the basis for a restructuring of future relationships.[39,40] These attitudinal and behavioural shifts are important in shifting culture within a service, and thereby improve the inter-personal dynamics of care,[41] including power sharing and enhanced communication between service professionals and users.[42] The ultimate hope is for positive, sustained change in health and/or social services through outputs of greater empathy, increased trust, shared commitment and advocacy.[38] The extent to which this occurs will depend on adopting and adhering to core principles and skilled facilitation.[28,43]

The way forward

The ubiquity of co-design as a strategy for health service and system reform, and the diversity in how it is defined, begs the question of whether there should be standards for implementation and evaluation, as well as critical reflection on the implications of doing this work with participants who experience a range of vulnerabilities.

As noted earlier, careful planning and critical reflection is needed to ensure that the process does not produce "token" service user involvement or further perpetuate inequities. A useful guidance document developed by INVOLVE[44] outlines key principles and strategies to consider in co-producing a research project. Also, guidelines for reporting on patient and public involvement in health and social care research (GRIPP2) have been proposed as a strategy to advance quality and transparency in co-design.[45] These guidelines are a helpful step toward consistency in language and reporting of co-design processes, outputs and outcomes, as well as a useful tool for generating critical reflection on the engagement of service users in research. The next steps are to create more specific questions to critically evaluate co-design projects stemming from the three overarching questions addressed in this article. Table 1 outlines a list of suggested sub-questions to consider, which reflect the high level of engagement expected throughout the entirety of a co-design project.

[Insert Table 1 about here]

Another key step forward will be more robust evaluation of co-design work, in terms of costs and benefits, quality improvement and wider systems impacts.[30] In their review of health-related co-design research, Slatterly and colleagues[18] echo the call for systematic research on the effectiveness of various co-design approaches and strategies. They emphasize that research should be theoretically informed, and build on implementation science principles that capture the context and complexity of the co-design process. Realist evaluation, therefore, is a promising approach, since it considers the impact of the context, as well as the mechanisms of change that shape project outcomes.[46] Realist evaluations are also based on a theory of change which can help to explicate the relationship between various dimensions of the co-design process and how they lead to change.[47]

In conclusion, it should be recognized that co-design can be a powerful tool to contest vulnerability through authentic collaboration in research and service / system design. Co-design is a philosophy and method that has the potential to empower people, both researchers and participants, service providers and service users, policy makers and community members. It must be recognized, however, that co-design is ultimately a relational process and as such, careful attention must be paid to ensuring that the process does not perpetuate inequities. The realities of fiscal and time constraints must be balanced with critical reflexivity and commitment to creating meaningful collaborative solutions.

Table 1 - A Tool to Foster Reflexivity in Co-Design with Vulnerable Populations

Where are you starting from?   1. What are your worldviews, assumptions and values relevant to the issue(s) or problem(s) you are trying to address? How open are you to being transformed by other worldviews?   2. How will you respectfully interact and compassionately attend to human diversity, and various ways of knowing?   3. How will you interrogate power and privilege?   4. How will you make time and space for sharing, dialogue and co-creation despite timelines and resource constraints?
What should you be doing?   1. How will you purposefully select a broad range of stakeholder perspectives and representatives? How do you define inclusive participation?   2. What tools, processes and techniques will you use to fully understand lived experiences, build rapport and foster trust within an environment of open and respectful dialogue?   ***3.*** How will you tap into tacit knowledge, creativity and shared meaning of diverse perspectives to co-create a shared vision for improvement?
What are your intended outputs?   1. How will you facilitate implementation of prototype solutions?   2. How will you foster commitment to change to minimize the risk of tokenistic engagement of vulnerable populations and perpetuating the status quo?

3. How will your co-design processes build capacity and forge new ways of communicating, and in doing so shift service cultures toward greater empathy, trust, shared commitment and advocacy?
4. How will you determine if your project has achieved the desired outcomes? Will these outcomes be sustainable?

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The increasing use of the term co-design and its associated methodologies has made it challenging to distinguish whether or not the term has been co-opted in such a way that sidesteps meaningful engagement with the original principles of co-design: distribution of power in research, amelioration of the human experience and positive societal impact. These issues are particularly acute when engaging populations who are 'vulnerable'; considering

vulnerability not as an individual characteristic, but as the result of social and systemic barriers (e.g., poverty, literacy, language barriers, and discrimination related to age, disability status, ethnicity/race, gender).

In this article, we critically discuss three questions, with a particular focus on research with vulnerable service users: 1) What is the epistemological starting point that is underpinning the decision to apply co-design processes and techniques? 2) How are co-design methodologies, planned, applied, and adapted while engaging in iterative "research through design" processes? 3) What type of post co-design outputs can be anticipated and created, and what will the manifest and latent impacts of these outputs be? These questions are based on synthesis of theoretical and practical writings about co-design from a range of disciplines, including engineering, business, health sciences, rehabilitation, and social sciences, as well as our own experiences as co-design researchers in these disciplines. Our standpoint as researchers is informed by reflections on our varied experiences in co-design with a range of communities, including families of children with disabilities, youth with mental health issues, newcomers, and older adults who are precariously housed. The critical discussion which ensues places a particular emphasis on how power is conceptualized, deployed and received[19] within co-design processes aimed to ameliorate health services, products and experiences for vulnerable individuals and groups.

Where are you starting from?

Advancing effective and ethical co-design should start with critical reflection on the epistemological beliefs that are driving initiation of the process, including the 'mindset' of the

co-design facilitators. Co-design should begin with critical and embodied reflexivity that attends to 1) ourselves – the subjective self or "I"; 2) our relationship with others – the intersubjective "we"; and 3) the systems in which we and others are embedded – the objective "it".[20]

The first point of reflection is internal; as a facilitator of co-design, it is important to consider the worldview, assumptions and values that you bring to the process. Co-design facilitators need to embrace critical, reflexive practice, including development of a subjective, embodied understanding of their own standpoints and epistemological frameworks that will impact their relationships with others.[21] They need to be capable of improvising and taking other perspectives, and be willing to be transformed in the process.[22] These capabilities are cultivated through enhancing mindful awareness of, and working with the thoughts, emotions, perceptions, sensations, that arise as part of being in an interpersonal relationship.[23]

The second point of reflection is on your relationship with others who are engaged in the co-design. This includes attending to the effects that you have as a researcher, educator and/or practitioner at every step of the design process. It also involves a commitment to ongoing dialogue about various ways of knowing, the interrogation of power and privilege, and making the time and space to listen, share and co-create.[24] The humanity and multi-dimensionality of all participants must be respected and attended to with care, compassion, creativity and humility. Relationships require openness and vulnerability in the immediacy of human-to-human connection.[25]

The third and final point of reflection is on the system in which the co-design process will occur. There may be a clash of values since many organizations operate within a socio-political environment that privileges individualism over collectivism, self-sufficiency over collaboration, and scientific expertise over other ways of knowing based on lived experiences.[3,26] The fundamental principles of collaboration in co-design may be subverted in the drive for efficiency and top-down decision making. Critical awareness and resistance to these pressures may be needed in order to find the time and space required for an authentic way of working together for social justice and change. Beginning a co-design project requires institutional support to ensure that there is a commitment to critical thinking, learning and change,[27] that diverse people are given an opportunity to participate,[28] and that sufficient resources (including funding and space) are provided.

What should you be doing?

Co-design has been described as both a philosophy and a method[27] that includes authentic and equitable collaboration between stakeholders in projects that are emergent, flexible, and iterative.[28] There are several specific approaches that have been used in the context of healthcare, including experience-based co-design (EBCD),[29,30] participatory research,[1,8] and user centred design.[31] Each approach has its own processes and tools, but there are several overarching issues to consider in optimizing the process of collaboration and design.

First, it is critical to include diverse people in the co-design process, including those with lived experience, those who deliver or implement a service or program, and other key stakeholders or influencers.[28] A noteworthy criticism of co-design specifically, and patient-oriented research generally, is that vulnerable populations may be excluded[32] or represented by 'super users' who do not reflect the typical population.[33] Super users are individuals who frequently contribute to research projects. They are often invited to participate since they are actively engaged, articulate, and clearly understand their role in the process. One of the dangers, however, is that over time, socialization to their research role may desensitize them to the perspective of those experiencing greater disenfranchisement.[33] It takes time and effort to ensure representation from the important, but often unheard voices of communities who face many barriers to engagement.

When engaging groups from historically marginalized communities, sensitivity to power differentials and creative approaches may be needed to ensure a safe and inclusive space for collaboration. Invited spaces have been criticized for perpetuating marginalization and tokenism, since unexamined power imbalances may delegitimize forms of knowledge that depart from the status quo.[34] Principles and tools for engagement could include: a) formalizing agreements for shared leadership, decision making and ownership of knowledge; b) providing training and ongoing mentorship for new participants who may be uncomfortable and/or unfamiliar with the process; c) ensuring flexibility to account for differences and fluctuations in ability to participate; and d) establishing formal recognition for the value of service user input.[28,33,34] Richards and colleagues[35] present an insightful argument regarding compensation

for service users in order to recognize vulnerability, promote equity, facilitate commitment, and remove barriers to participation. They suggest starting the conversation early to build relationships, negotiating a fair rate that addresses the needs of all parties, and establishing a formal agreement on roles and responsibilities in order to avoid the risk of tokenism.

Specific steps of co-design may vary depending upon the project, however, core processes include building trust, finding voice, sharing perspectives and creating a common vision for change.[28] Arts-based tools and techniques can be incorporated to generate initial insights into stakeholder experiences, as well to foster creativity in designing solutions. Generative design strategies, as outlined by Sanders & Stappers,[31] emphasize the role of "doing" and "making' as alternate paths of expression that can evoke deeper insights and creative solutions. They highlight how a range of probes, generative toolkits and prototyping strategies can facilitate the co-design process, using creative tools such as video, storyboards, clay and even Lego to evoke insights and ideas that transcend what people might put into words. These strategies may be particularly effective to engage service users who may have difficulty with purely verbal interviews or focus group discussions (eg. recent immigrants, young children, older adults with dementia).

Rather than following a series of rigid steps, working with vulnerable populations requires following a set of core principles; "taking time to fully engage, listen for understanding and not move forward until participants or communities are ready".[28(p295)] One of the challenges for co-

design facilitators is responding to pressures related to resource and time constraints that could compromise the process.[27]

What are your intended outputs?

In addition to how co-design is implemented, it is critical to examine outputs of the process. With its roots in design thinking and action research, co-design involves creating prototype solutions to address the priority problems or issues. Ultimately, the process should continue to implementation and evaluation of the proposed solutions, with a commitment to ongoing collaboration in the process of change.[36,37] Without this movement to positive change, participants can become disempowered and even resentful, particularly with perpetuation of the status quo.

The specific outputs and outcomes of co-design are varied, but can occur on several levels, from individual to systems change. A survey of 59 EBCD projects in 6 countries found that most projects initially targeted small quality improvements, however the legacies of the co-design work had much larger impacts in terms of "deep changes in attitudes and behaviors".[30] Similarly, Palmer et al.[38] argue that while practical solutions are important, the skills gained by service users, family/caregivers and staff in negotiating new ways of advancing the future that they have helped to shape is even more significant. This can be particularly important for groups who have a history of fractured relations (eg. mental health service users), wherein new shared identities can be developed as the basis for a restructuring of future relationships.[39,40]

These attitudinal and behavioural shifts are important in shifting culture within a service, and thereby improve the inter-personal dynamics of care,[41] including power sharing and enhanced communication between service professionals and users.[42] The ultimate hope is for positive, sustained change in health and/or social services through outputs of greater empathy, increased trust, shared commitment and advocacy.[38] The extent to which this occurs will depend on adopting and adhering to core principles and skilled facilitation.[28,43]

The way forward

The ubiquity of co-design as a strategy for health service and system reform, and the diversity in how it is defined, begs the question of whether there should be standards for implementation and evaluation, as well as critical reflection on the implications of doing this work with participants who experience a range of vulnerabilities.

As noted earlier, careful planning and critical reflection is needed to ensure that the process does not produce "token" service user involvement or further perpetuate inequities. A useful guidance document developed by INVOLVE[44] outlines key principles and strategies to consider in co-producing a research project. Also, guidelines for reporting on patient and public involvement in health and social care research (GRIPP2) have been proposed as a strategy to advance quality and transparency in co-design.[45] These guidelines are a helpful step toward consistency in language and reporting of co-design processes, outputs and outcomes, as well as a useful tool for generating critical reflection on the engagement of service users in research.

The next steps are to create more specific questions to critically evaluate co-design projects stemming from the three overarching questions addressed in this article. Table 1 outlines a list of suggested sub-questions to consider, which reflect the high level of engagement expected throughout the entirety of a co-design project. It should be noted that these questions are directed towards researchers and facilitators of co-design initiatives, as a tool to prompt reflexive analysis. Stakeholders who represent community partners and end users should also be engaged in dialogue about how to optimize the co-design process.

[Insert Table 1 about here]

Another key step forward will be more robust evaluation of co-design work, in terms of costs and benefits, quality improvement and wider systems impacts.[30] In their review of health-related co-design research, Slatterly and colleagues[18] echo the call for systematic research on the effectiveness of various co-design approaches and strategies. They emphasize that research should be theoretically informed, and build on implementation science principles that capture the context and complexity of the co-design process. Realist evaluation, therefore, is a promising approach, since it considers the impact of the context, as well as the mechanisms of change that shape project outcomes.[46] Realist evaluations are also based on a theory of change which can help to explicate the relationship between various dimensions of the co-design process and how they lead to change.[47]

In conclusion, it should be recognized that co-design can be a powerful tool to contest vulnerability through authentic collaboration in research and service / system design. Co-design is a philosophy and method that has the potential to empower people, both researchers and participants, service providers and service users, policy makers and community members. It must be recognized, however, that co-design is ultimately a relational process and as such, careful attention must be paid to ensuring that the process does not perpetuate inequities. The realities of fiscal and time constraints must be balanced with critical reflexivity and commitment to creating meaningful collaborative solutions.

Table 1 - A Tool to Foster Reflexivity in Co-Design with Vulnerable Populations

Where are you starting from?   1. What are your worldviews, assumptions and values relevant to the issue(s) or problem(s) you are trying to address? How open are you to being transformed by other worldviews?   2. How will you respectfully interact and compassionately attend to human diversity, and various ways of knowing?   3. How will you interrogate power and privilege?   4. How will you make time and space for sharing, dialogue and co-creation despite timelines and resource constraints?
What should you be doing?   1. How will you purposefully select a broad range of stakeholder perspectives and representatives? How do you define inclusive participation?   2. What tools, processes and techniques will you use to fully understand lived experiences, build rapport and foster trust within an environment of open and respectful dialogue?   ***3.*** How will you tap into tacit knowledge, creativity and shared meaning of diverse perspectives to co-create a shared vision for improvement?
What are your intended outputs?   1. How will you facilitate implementation of prototype solutions?   2. How will you foster commitment to change to minimize the risk of tokenistic engagement of vulnerable populations and perpetuating the status quo?

3. How will your co-design processes build capacity and forge new ways of communicating, and in doing so shift service cultures toward greater empathy, trust, shared commitment and advocacy?
4. How will you determine if your project has achieved the desired outcomes? Will these outcomes be sustainable?

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