

A COMPASS for Navigating Relationships in Co-Production Processes Involving Vulnerable Populations

Gillian Mulvale, Ashleigh Miatello, Jenn Green, Maxwell Tran, Christina Roussakis & Alison Mulvale

To cite this article: Gillian Mulvale, Ashleigh Miatello, Jenn Green, Maxwell Tran, Christina Roussakis & Alison Mulvale (2021): A COMPASS for Navigating Relationships in Co-Production Processes Involving Vulnerable Populations, International Journal of Public Administration, DOI: [10.1080/01900692.2021.1903500](https://doi.org/10.1080/01900692.2021.1903500)

To link to this article: <https://doi.org/10.1080/01900692.2021.1903500>



© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC.



Published online: 06 Apr 2021.



Submit your article to this journal [↗](#)



View related articles [↗](#)



View Crossmark data [↗](#)

A COMPASS for Navigating Relationships in Co-Production Processes Involving Vulnerable Populations

Gillian Mulvale^a, Ashleigh Miatello^b, Jenn Green^a, Maxwell Tran^c, Christina Roussakis^d, and Alison Mulvale^{a,e}

^aDeGroote School of Business, McMaster University, Burlington, Ontario, Canada; ^bHealth Policy PhD Program, McMaster University, Hamilton, Ontario, Canada; ^cFaculty of Medicine MD Program, University of Toronto, Toronto, Ontario, Canada; ^dFaculty of Law, University of Toronto, Toronto, Ontario, Canada; ^eToronto branch, Canadian Mental Health Association, Toronto, Ontario, Canada

ABSTRACT

When it comes to engaging vulnerable populations in co-production, power imbalances across stakeholder groups can create methodological challenges. A thoughtful, planned, and responsive approach is needed to prepare vulnerable participants to fully engage in co-production processes. Data from key informant interviews (n = 16) and author reflections on three Experience-based co-design (EBCD) studies involving youth (16–25 years) with mental health issues in Ontario Canada, were analyzed. Four overarching themes and 12 subthemes were identified, and heuristic tools (a relational COMPASS and MAPS directions) were developed to assist researchers in navigating vulnerability, power and relational issues in co-production processes involving vulnerable populations.

KEYWORDS

Co-production; experience-based co-design; child and youth mental health; vulnerable populations; relational safety; power

Introduction

Policy makers and governments in many countries increasingly call for co-production of public service improvements in areas such as health, social services, housing, and employment (McGeachie & Power, 2017; Osborne et al., 2016; United Nations Human Rights Council, 2017). However, special attention to process is needed to ensure effective co-production of public services when involving vulnerable groups. Although the term vulnerability is contested (Katz et al., 2019), it is used here to describe groups facing social and structural barriers to full participation in health services and co-production activities (Grabovschi et al., 2013). In the policy literature the interests of these groups are sometimes referred to as repressed because they are unlikely to be served due to existing institutional structures (Alford, 1977). Excluding or involving these groups in a tokenistic manner in co-production activities may unintentionally reinforce existing power imbalances that exacerbate their vulnerability (Iedema et al., 2010; Osborne et al., 2016).

With origins dating back to the policing and civil rights movements in the United States in the 1970s, the co-production concept has had a resurgence in recent years, particularly in areas of health and social policy reform (Palmer et al., 2018). Co-production is defined as “the provision of services through regular,

long-term relationships between professionalized service providers (in any sector) and service users or other members of the community, where all parties make substantial resource contributions” (Bovaird, 2007, p. 847). The approach is founded on the belief that service providers and service users each have unique understanding and knowledge to contribute to the planning, design and implementation of service improvements (Realpe & Wallace, 2010). To operationalize and benefit from this belief, it is essential that all participants have the opportunity to meaningfully contribute and have their voices heard.

In the health and social care context, experience-based co-design (EBCD) (Bate & Robert, 2006, 2007; Donetto et al., 2014) can be one element of a co-production approach that places lived experience at the centre of co-design and co-production practice. In EBCD, the research team¹ establishes processes whereby patients work collaboratively with family members or other caregivers (hereafter referred to as caregivers), and service provider staff to improve public services by translating the experiences of these groups into tangible service redesign (Bate & Robert, 2006, 2007). Since its introduction in 2006, applications of EBCD have expanded rapidly across a wide range of health, social care and other public service contexts (Tsianakas et al., 2012). A toolkit that outlines key steps in the EBCD

CONTACT Gillian Mulvale  mulvale@mcmaster.ca  Health Policy and Management, DeGroote School of Business and Center for Health Economics and Policy Analysis (CHEPA), 4350 South Service Road, Burlington, ON L7L 4X5, Canada.

© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC.

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

process points to complex issues that may arise when using EBCD with potentially vulnerable groups, especially when preparing them for and supporting them through the co-design stage (Point of Care Foundation, n.d.). While some helpful suggestions are made, there is a gap in understanding how the research team can position itself in regard to power imbalances across the full array of participants in EBCD processes.

To address this gap, this research explores the role of the research team in navigating power imbalances among participants in co-production processes involving vulnerable groups based on key informant interviews and experience conducting three EBCD studies involving youth with mental health issues. Lessons learned from designing and conducting EBCD processes with this group are illustrative of the relational dynamics between the research team and the various participants and how processes can be structured to address power imbalances across the various perspectives involved. We present two heuristic tools that can be used to anticipate and navigate anticipated and unexpected relational challenges that may arise from power imbalances in co-production processes involving vulnerable populations and describe their application in an EBCD process in the youth mental health context in Ontario.

Theoretical underpinnings

The theoretical foundations for the study relate to vulnerability, power, and relationships in co-production and co-design processes, as well as issues of power when co-designing in the youth mental health context. Key concepts from the literature are briefly reviewed here as a basis for this research.

Structural vulnerability in health care

Structural vulnerability arises from one's location in a hierarchical social order that is embedded in diverse networks of power relationships and effects (Bourgois et al., 2017). For example, the structural vulnerability of patients in the health care context arises when their location in society's overlapping and mutually reinforcing power hierarchies arising from socioeconomic, racial and cultural considerations and institutional and policy-level statuses (e.g., immigration status or labour force participation) constrain their ability to access healthcare and pursue healthy lifestyles (Bourgois et al., 2017). Furthermore, patients and caregivers who are able to access services may experience structural vulnerability in interactions with health providers arising from informational asymmetry (Bennett & Irwin,

1997). This can be exacerbated in the mental health context if patients are judged to lack capacity or insight (Morant et al., 2015), and may also occur with older adults and other vulnerable populations. Alford describes the tendency for health care systems to resist reform as deriving in part from the embeddedness of dominant (health care professional), challenging (health care managers seeking reform) and repressed (the public, patients and families) interests arising from existing institutional and social structures (Alford, 1977).

Social interactions and power in co-production and co-design

Consistent with these notions of structural vulnerability, Farr (2018) observes that a complex set of psychological, social, cultural, and institutional interactions that influence power relations among participants must be managed and co-ordinated in co-production and co-design processes. The "social interactions, the people involved and the structures" within which co-production and co-design processes are set all influence "... whether co-production may empower participants, or, conversely, embed existing power inequalities" (Farr, 2018, p. 628). When such power imbalances are addressed, social interactions in co-production processes can facilitate shared understandings, and in turn lead to changes in people, cultures or structures through "the collective power that can emerge through the human ability to act together" (Farr, 2018, p. 628), while building a sense of collective ownership (Bradwell & Marr, 2008).

Relational processes and reflexivity

However, the mere adoption of co-production or co-design techniques is not enough to guarantee that power will be equalized between participants (Dimopoulos-Bick et al., 2018). Instead, "constant critical reflective practice and dialogue" is required "to facilitate relational processes that can empower and enable, and challenge dominating relations and practices" (Farr, 2018, p. 641) rather than perpetuating inequities (Moll et al., 2020). The research team must adopt principles of reflexivity and humility, and give constant consideration to power sharing and their own positionality in relation to others at each moment of every interaction when working with structurally vulnerable groups to avoid "dangers seen, unseen and unforeseen." (Milner, 2007; Moll et al., 2020). Without this vigilance throughout the process, there is a risk that inequitable partnerships and low trust between professionals and service users could not only lead to missed opportunities but also co-destruction of value (Dudau et al., 2019; Steen et al., 2018).

Research team as catalyst for collective power

This theoretical backdrop suggests that the relationship of the research team to all other groups in the co-production and co-design process is of paramount consideration to overcome the sense of mutual powerlessness reportedly felt by service users and service providers in quality improvement circles in mental health (Broer et al., 2012). A strong relationship between the research team and service users (youth and caregivers in the youth mental health context) is important to ensure that service users do not set aside their own best interests and well-being (Cribb & Gewirtz, 2012) and that service providers understand their role is to be an equal player rather than a leader of the process. Similarly, a relationship with managers of the staff at the various organizations involved is needed to ensure they will become champions for and remain committed to the process so as to challenge existing practices where appropriate (Dimopoulos-Bick et al., 2018). We propose that while each of these power relationships must be brokered, the research team must also bring all three groups together to achieve the sense of collective power suggested above, which is needed to advance improvements.

The concepts of vulnerability, power, and relational processes are explored together as the conceptual foundation for this paper's examination of the role of the research team in navigating relationships among participants in co-design processes in the youth mental health context. Contextual background is next provided to ground the analysis.

Co-design in youth mental health context

The mental health consumer-survivor movement has long recognized the potential vulnerability of mental health consumers due to stigma (Stuart et al., 2012) and power imbalances arising from legislation through which people could be detained and treated against their will (Ning, 2010; United Nations Human Rights Council, 2017). Structural factors such as rigid age cut-offs and discontinuities in services between child and adult sectors, health factors such as the high risk of onset of serious mental illness, and social factors such as key developmental life transitions to adulthood (Davidson & Cappelli, 2011; Singh, 2009) contribute to further vulnerability for transitional age (16 to 25 years) youth with mental health issues (hereafter referred to as youth). Youth from ethno-racialized groups and other diverse populations may face additional challenges at this time (Garcia et al., 2012).

Advocates call for involvement of people with lived experience in mental health service design and policy-making as part of a recovery orientation (Freeze & Walker Davis, 1997; Ning, 2010; Piat & Sabetti, 2012). In the mental health context, co-design, which can be an element of broader co-production of services, has been recognized as a promising approach to improving and potentially transforming public services (Larkin et al., 2015; Palmer et al., 2018). However, a long history of power imbalances between mental health service users (patients and caregivers) and service providers may challenge effective collaboration and co-working (Mulvale et al., 2007). Further relational challenges exist in EBCD processes aimed at improving transition experiences in health and social services across child and adult sectors, such as the involvement of many organizations with different statutory age cut-offs, governance and funding streams, and professionals with diverse training.

Materials and methods

The purpose of this research was to explore how to prepare and empower youth with mental health issues to effectively participate in EBCD processes, and to understand the role of the research team in navigating relationships and attending to issues of power among the various participants. Drawing on theories of vulnerability, power, and relational processes, analytic principles consistent with constructivist grounded theory (Charmaz, 2006) were applied to analyze key informant interviews and reflections on experiences conducting three EBCD studies in the youth mental health space.

Data sources

Key informant interviews

The literature offered insights about participant preparation and general engagement processes, but a deeper understanding was necessary to navigate the anticipated relational challenges arising from feelings of vulnerability and power imbalances characteristic of the youth mental health context. We initially sought key informants with experience in conducting EBCD processes involving youth to participate in telephone interviews; however, there was a paucity of experts with expertise in both EBCD processes and youth mental health. Instead, informants who could contribute knowledge of either EBCD or youth engagement were interviewed to draw on their collective expertise in successive rounds of interviews. and snowball sampling was used to identify additional informants with experience in EBCD or similar design approaches involving other vulnerable

populations. Interviews were conducted during January and February 2016. A total of 20 informants were invited to participate and 16 (8 researchers, 5 engagement experts, 2 facilitators, 1 designer) from five countries (Canada, Sweden, United Kingdom, Australia, New Zealand) agreed to participate. Youth themselves were not included as key informants, as the focus was on experiences of those conducting rather than participating in co-design and other participatory processes. Sampling continued until no new insights were gained and no new themes emerged (Charmaz, 2006; Miles et al., 2014).

We invited potential informants via standardized recruitment email, letter of information, and consent form. A semi-structured interview guide was used to facilitate consistency of main themes pertaining to experiences preparing participants for co-design or other participatory processes, with probing around the theoretical concepts drawn from the literature, as well as questions tailored to the expertise of each informant. The interviews lasted between 30 and 60 minutes, and were audio recorded and transcribed verbatim.

Researcher reflections

Authors participated in reflective meetings to discuss unanticipated relational challenges following each of three EBCD projects involving health and related services for transitional age youth that were held between November 2016 and June 2019 (Mulvale et al., 2019). Reflections were triangulated with source material (project-related email correspondence with participants), and with accounts of similar relational challenges by researchers and participants at an international symposium on co-production and co-design with vulnerable populations (Mulvale et al., 2019) to inform this paper.

Data analysis and management

Initial coding was done independently by two authors (MT, CR). An inductive approach to coding was used, closely reflecting the data and using in-vivo codes where possible (Charmaz, 2006; Miles et al., 2014). Analysis of interview data began during weekly team meetings when the authors discussed the emerging codes until agreement was reached. Data analysis was iterative, occurring concurrently with data collection. When new ideas were identified in the data or during team discussions, they were checked against the existing data and categories (Birks et al., 2019; Charmaz, 2006). Fortnightly team meetings were held between January and August 2016 until no new categories, relationships or insights were identified (Charmaz, 2006). Four authors (GM, AM, CR, MT) participated in focused and axial coding to identify

categories in the data (Charmaz, 2006), summarizing these data using a table, and subsequently all authors met to discuss the categories, and the relationships between them.

Following each experience in conducting EBCD, the authors returned to the data to refine the themes with emerging insights from unanticipated relational challenges that occurred. A key struggle was capturing what was heard during the interviews about planning for relational considerations that were predictable at each phase of the EBCD processes, with the unpredictability of relational challenges that arose unexpectedly in the youth mental health context. Two authors (GM, AM) returned to this question at various points, which deepened the researchers' learning about co-design/co-production involving vulnerable populations and enabled these findings to crystallize (Ellingson, 2009). While key informant data is central to this analysis, the formulation of the findings is also shaped by the researchers' expanding expertise in EBCD practice involving youth with mental health issues as a vulnerable population. Following reviewer suggestions, the experiences of conducting one such EBCD process to improve transitions from child to adult mental health services involving multiple health and social service organizations in the Hamilton region of Ontario, Canada are used to illustrate the application of the tools that were developed in this analysis (COMPASS, MAPS). This EBCD process involved identifying touch-points through individual interviews, focus groups by perspective (youth, caregiver, and service providers) and prototyping improvements at a co-design event involving all perspectives (Mulvale et al., 2019).

Ethics approval for this study was provided by the Hamilton Integrated Research Ethics Board, project #15-059. Alphanumeric codes were assigned to each key informant to protect participants' identities (e.g., KI6 refers to key informant 6). Data were managed using NVivo 11.0 software.

Findings

The study findings are organized in a COMPASS heuristic tool (Figure 1), which serves as a guide for researchers to navigate the relational dimensions of an EBCD journey where issues of power are at play. The tool presents four major themes that outline relational processes that the research team must navigate considering power imbalances inherent in co-production processes involving vulnerable populations. These major themes for CO-production are presented in the four quadrants of the COMPASS tool respectively: supporting Managers, preparing Participants, building Affinity, and fostering Sensitivity throughout the process to create relational

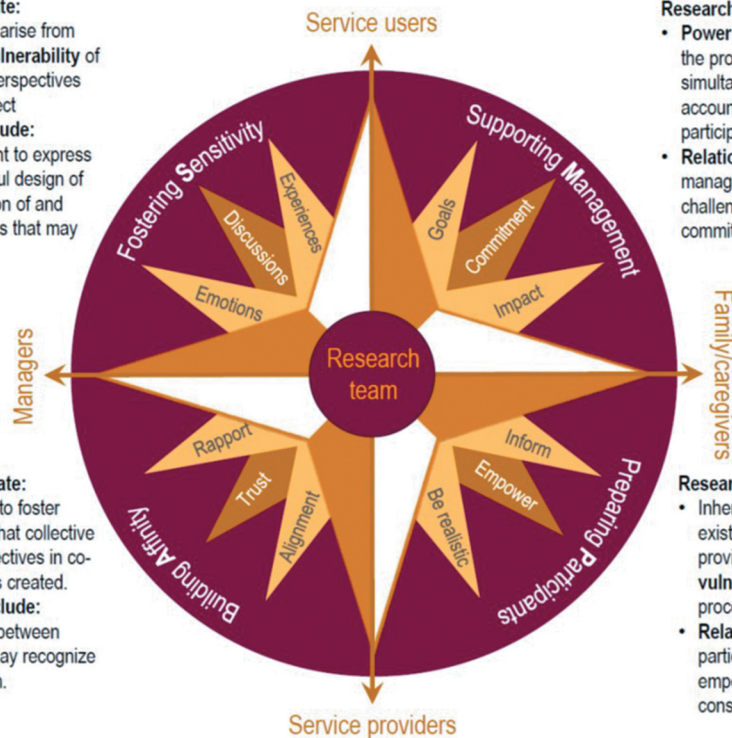
Role of the research team: The research team plays a pivotal role in navigating multiple vulnerabilities and empowering all participants at every stage of the unfolding process, to establish a relationally safe environment within which collective power can fuel co-design.

Research team must navigate:

- The potential for conflict to arise from **power imbalances** and **vulnerability** of different participants and perspectives over the course of the project
- **Relational processes include:** Creating a safe environment to express experiences, through careful design of discussions, and anticipation of and support for difficult emotions that may be expressed.

Research team must navigate:

- **Embracing vulnerability** to foster mutual understanding so that collective power that bridges perspectives in co-designing improvements is created.
- **Relational processes include:** Building rapport and trust between participants so that they may recognize the alignment among them.



Research team must navigate:

- **Power** held by managers to authorize, support the process, and implement outcomes, and their simultaneous **vulnerability** given their accountability to leadership while not participating in co-design activities.
- **Relational processes include:** Understanding managers' goals, conveying potential challenges, visibly establishing their commitment, and demonstrating impact.

Research team must navigate:

- **Inherent structural power imbalances** that exist across youth, caregivers and service providers, and recognize that all groups feel **vulnerable** in advance of co-design processes.
- **Relational processes include:** Informing participants of what to expect, which empowers them while working within realistic constraints.

Figure 1. A COMPASS for relational safety in co-design/production.

Safety. The central role of the research team is indicated by their placement at the centre of the COMPASS. The floating directional arrows indicate that the research team must be constantly attentive and reposition itself with respect to emerging power dynamics across the various groups while navigating these processes. The textbox beside each quadrant in [Figure 1](#) describes the key relational considerations arising from power and vulnerability, and how the COMPASS helps in their navigation. Subthemes within each quadrant support these relational processes, and are further elaborated with detailed 'directions' for researchers under the same quadrant headings (supporting Managers, building Affinity, preparing Participants, and fostering Sensitivity) in the MAPS tool ([Figure 2](#)). In the description below, each quadrant of the COMPASS and MAPS tools is discussed in turn, providing first an overview of the phase of the EBCD process, the power and vulnerability considerations and the relational objectives of the research team; followed by the major themes from the interviews; and then by illustrative examples from experiences with EBCD processes involving youth with mental health issues.

North-East quadrant: supporting managers

The north-east quadrant of [Figure 1](#), which corresponds to the initial planning phase, focuses on navigating relationships between the research team and managers of the organizations involved in the co-design. From a power perspective, the research team has to navigate the power that managers have to determine whether the project occurs and continues, and whether co-designed solutions will be implemented, while facilitating a grass-roots improvement process. The themes in this quadrant recognize the power imbalance between managers and the research team, making the research team vulnerable to management support, while simultaneously asking managers to have faith in a co-design process that they themselves do not participate in and so renders them vulnerable as well.

Key informants elaborated that the research team must recognize that undertaking an EBCD process is "risky" for managers [KI3] because it entails voicing people's experiences, both good and bad, and allowing them to suggest solutions. It is therefore important that the research team fully understand managers' goals for the process and be honest with managers that

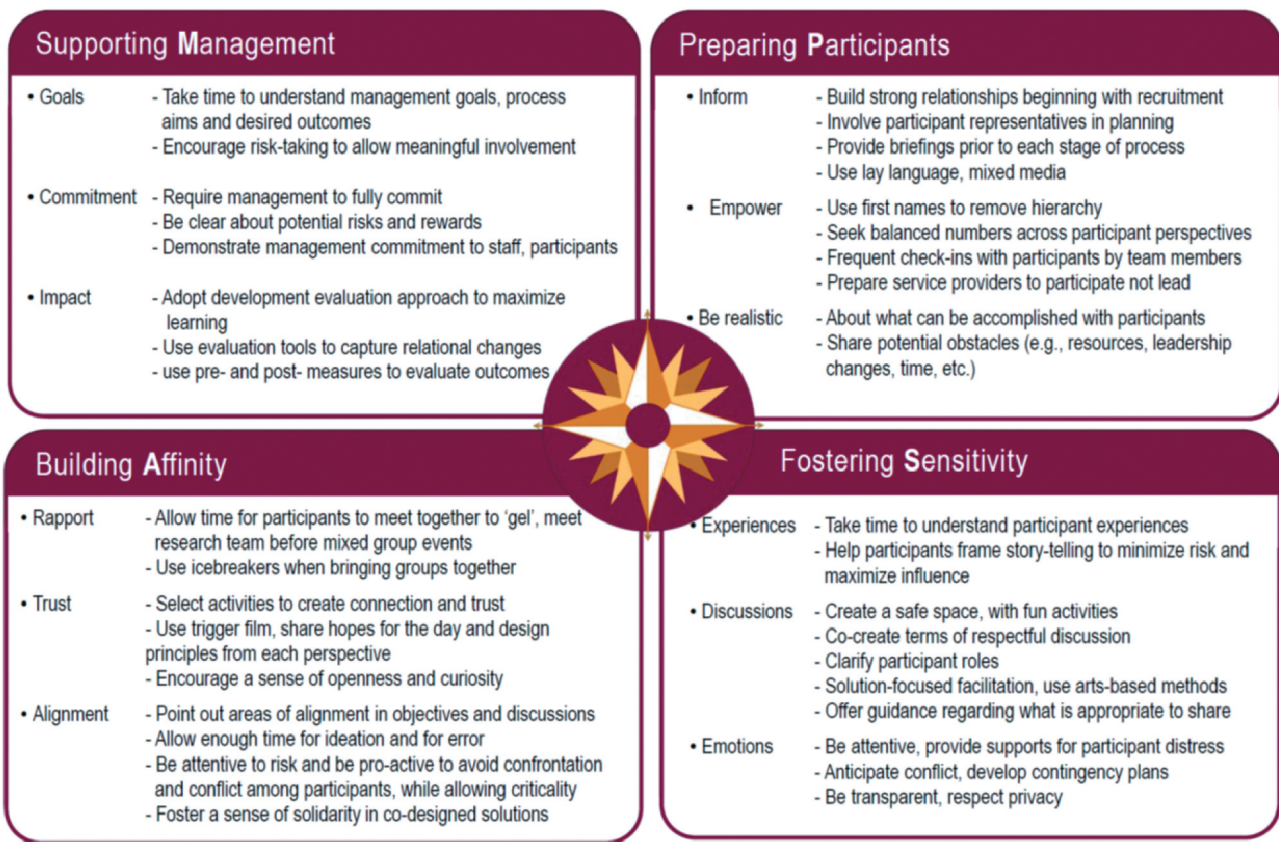


Figure 2. MAPS as directions to realize COMPASS strategies.

challenges are likely to arise by explaining “... this is pioneering. Some things are going to work; some things are not”, and asking them, “Do you want to be a pioneer ... ?” [KI3] This transparency helps in “building trust – trust in the managers, getting them to trust you.” [KI4] The research team should help demonstrate to managers that despite the risk there is potential benefit and make “... sure that they want to do it, and not to underestimate what’s going to happen.” [KI3] This **commitment** by managers to the process “warts and all” [KI3] should be so strong that they “... chase you as the researcher/designer” [KI1] rather than the other way around, and should be made visible to clients, caregivers, and staff throughout the process. Early attention to developing evaluation frameworks that demonstrate **impact** can help managers make and sustain this commitment and later support advocacy efforts by managers to encourage senior organizational and system leaders to fund the co-designed improvements that emerge from the process.

In our own experience, many face-to-face meetings with different managers in the cross-organizational context of child to adult mental health service transitions were required to understand their **goals** and secure their support in recruiting youth, caregivers, and service

provider participants. A key challenge emerged when one manager wanted to attend the co-design event as an observer and was disappointed to learn that this would threaten power relationships. The manager was visibly uncomfortable; however, the research team explained this as respectfully as possible, and was able to proceed with the event. Although this COMPASS/MAPS quadrant called for securing **commitment** upfront to implement outcomes, this proved untenable in our context, because eventual co-designed improvements were expected to span multiple organizations. Forcing commitment at this stage could have derailed the process, so the focus was on building strong relations with managers at each organization to maintain their ongoing support, and establishing evaluation measures for each phase of the co-design process to demonstrate **impact** that could later support implementation.

South-East quadrant – preparing participants

Once management support is secured, the second COMPASS quadrant focuses on the relationship the research team must develop with participants during the recruitment phase, as they remove barriers to participation and prepare participants for their roles in the EBCD processes. This involves navigating inherent

power imbalances across youth (with the double stigma of age and diagnosis of mental illness), caregivers (who are vulnerable to exclusion from the care process as youth move to the adult system), and service providers (who while typically in a position of structural power in the healthcare system, may feel vulnerable to criticism during co-design processes). The aim is for each group to feel they have important knowledge to contribute to co-design activities through professional or lived experience, while being realistic about what can be accomplished.

As one informant explained, the best way to prepare vulnerable groups, is through a warm, respectful approach, recognizing that some people will feel more comfortable being well prepared, whereas “... other people will be quite spontaneous.” [KI6] Personalized invitation letters can be used to **inform** participants of logistical details: the event purpose, who the other participants are, and the roles expected of them, including their equal status in the process (Boyko et al., 2012). A mix of media (e.g., websites, written materials, videos, information leaflets) that can appeal to different learning styles can be used to give all participants a common background. Rather than more formalized training, the objective is to support people “to participate in, as active, open and honest way as they can” and to optimize the conditions “... for them to be engaged with the process and share their true experiences.” [KI3] During this phase it is also important to **empower** vulnerable groups, inviting them to take on roles such as co-researcher, peer engager or facilitator (Larkin et al., 2015; Tollyfield, 2014). Having separate meetings of each group initially enables people to become comfortable sharing their experiences among others with similar perspectives, building solidarity and developing a powerful collective voice as “my story” becomes “our story.” [KI7] The research team must also prepare service providers to take on a role of equal participants, rather than leaders in these discussions, and to reassure them that the goal is not to “investigate what went wrong, but to try and get touch points for re-design.” [KI4] The aim is for all participant groups to feel highly engaged and empowered by the end of these meetings. At the same time, the research team must help participants to have **realistic** expectations for improvement, given resource and time constraints, while not quelling their enthusiasm. One informant suggested transparently explaining, “‘Look, this isn’t the ideal way of doing it, but these are the parameters we’ve got’ ...” [KI1] to avoid feelings of betrayal among vulnerable participants if the ideas generated are not implemented immediately.

In our experience, the **inform** process began during recruitment, wherein the Research Coordinator’s engaging style while presenting information about the study helped to build strong relationships between the research team and individual participants, which later proved instrumental in navigating relational challenges that arose during co-design activities. Using texting rather than phone or email as a communication style was a powerful way to connect with youth, demonstrating a youth-centred approach to the project. Similarly, sending taxis rather than traditional bus tokens helped youth realize that their input was valued by the team and facilitated their attendance. The separate focus groups proved to be highly effective as a way to **empower** participants: Youth shifted from initial apprehensiveness to conversing freely as they built upon each other’s ideas during the experience mapping exercise; caregiver participants became such strong allies that they were disappointed to leave and joked that the researchers could go home, but they would like to stay and continue to talk; and service providers dropped initial wariness of each other and of the process, and shared mutual frustrations with systemic barriers that hampered their efforts to support effective service transitions.

South-West quadrant – building affinity

The third quadrant of the COMPASS is focused on helping participants with often widely divergent perspectives build mutual affinity and shift each group away from its own sense of vulnerability and toward recognizing their collective power as they co-design solutions together. The role of the research team is to create co-design processes that foster this mutual understanding, helping participants recognize their common objectives, while navigating the potential for conflicts to arise.

According to key informants, one approach is to take time to bring participants together “to have them gel a bit,” building **rapport** and minimizing potential “storming”, before officially working together in co-design activities [KI4]. An informal gathering where people can “come and hang out” can allow them to get to know each other as individuals [KI9]. This can be “grounding” [KI2] and can convey that the “project [is] about relationships ... and worth investing in,” rather than “just another study” [KI9]. If a prior face-to-face meeting is not possible, an online dialogue space can enable people to exchange ideas prior to the first mixed group meeting [KI4]. Once everyone is brought together, processes must engender **trust** in the research team and in the whole group. “Everyone has to trust [the researcher] in the middle, and you have to feel that you

have some connection with [the participants].” [KI4] Having participants share their hopes at the start of the co-design event can help to make common objectives visible, initiating the process of bringing perspectives into **alignment**. An informant elaborated that “They . . . [have to] have each other’s back, where they sort of feel that they have some solidarity.” [KI4] Facilitators can set the tone of discussions, by encouraging participants to have “an abundance of curiosity” [KI6] and pointing out areas of agreement as they arise, while maintaining an environment in which everyone feels comfortable sharing their perspectives. Using arts-based methods in group interactions can help people step out of traditional modes of interacting. These approaches were described as being “. . . like going to art school. They look a mess, they’re creative, but actually they get things done.” [KI4]

In our EBCD experience working with youth with mental health issues, there was an unanticipated threat to developing **rapport** across groups that arose when trying to schedule the co-design event. A weekend event was proposed to accommodate school and work schedules for youth and caregivers; however, any event outside work hours was a ‘non-starter’ for service provider participants. Caregivers protested that service providers did not appear sincere in their commitment to keep the experiences of caregivers and youth as the central focus of the co-design process, undermining both groups’ **trust**. The research team navigated this impasse by scheduling the event on a school holiday to facilitate youth participation, and by doubling the honorarium rate for caregivers to help pay for extra childcare or lost income. The concerned caregivers appreciated the willingness of the research team to go the extra mile to engage youth and caregivers given the constraints that service providers were experiencing, which re-established their trust in the process. The event was launched with an ice-breaker activity, followed by viewing the trigger film of experiences from different perspectives (Point of Care Foundation, n.d.) and discussing the design principles that were essential from each perspective. These processes helped to foster mutual understanding and respect for each group’s perspectives, helping them recognize **alignment** in their objectives for the co-design activities. As the co-design activities such as visual prototyping unfolded in small group work, participants began to have fun with the process, recognizing their collective power in contributing to co-designing improvements and how working together they could better advocate for their implementation.

North-West quadrant: fostering sensitivity

The final COMPASS quadrant focuses on the need for the research team to maintain sensitivity when bringing

mixed groups together during all EBCD phases, but especially when working with other groups during the co-design activities, when participants initially feel most vulnerable. Prior relationship building and understanding of each participant’s experiences pays off during this phase, by helping the research team attend to sensitivity in sharing experiences, in structuring and facilitating discussions, and responding to expressions of strong emotions that may occur.

Key informants pointed to the importance of the research team coaching participants about what types of **experiences** to share to foster receptivity among other perspectives and minimize potential post-sharing regret. This means being attentive to emotions and any negative preconceptions that may arise, for example, due to stigma. Informants also stressed the importance of setting expectations for the tone of **discussions** and ensuring that different groups do not dominate. In the mental health context, the research team must recognize the risk of conflict, wherein some participants will “. . . go into attack mode quite quickly . . .” [KI4]. As one informant described it there is “. . . a very fractured, factionalized kind of history between mental health service users and service providers, which I think is just different in cancer care or other [conditions].” [KI4] The research team play an essential role as facilitators in ensuring that different perspectives are aired, but that the process remains one of “. . . participatory empowered co-design, not one side or the other telling each other what to do.” [KI5] One key informant described the co-design process as being “like a UN peace negotiation” and that facilitators may need to occasionally intervene to encourage more collaboration and understanding of each other’s experiences in order to create change, stating, “That’s all part of being this type of designer. Are you up for that?” [KI4] The research team can also avoid confrontations where tenuous relationships are known to exist, by seating people with difficult prior history at different tables and by creating contingency plans to quickly switch to a different activity or strategy should conflicts arise. Informants also recommended sensitivity to strong **emotions** that may surface because some participants may still be receiving treatment, while others may find it triggering to share traumatic experiences from their past. Suggested strategies include creating a ‘comfort agreement’ at the outset of co-design events to set the tone for discussions, having a quiet room where participants can discreetly disengage to regroup, and having a clinician available in the event of distress (Point of Care Foundation, n.d.). It is also recommended that the research team be proactive by respectfully checking-in with participants following interviews, focus groups and the co-design events to encourage

help-seeking if required. Sensitivity also means respectfully sharing information about how the results will be used and shared, member checking findings at every stage and being clear that while every effort will be made to maintain confidentiality, the research team will follow legal reporting requirements if a situation of risk should arise. [KI7]

While **sensitivity** was an ongoing preoccupation in our experience, it notably came into play several days prior to the co-design event, when a service provider raised concerns about attending the same event as a former client. The research team suggested this be discussed with the youth to gauge their comfort level. The youth was comfortable attending, if they did not work with the service provider in the small group activities, which was discreetly arranged by the research team. The research team and participants co-created a ‘comfort agreement’ at the start of the co-design event to set the tone of **discussions** and posted it as a visual reminder should overly critical opinions be expressed, and remained vigilant to any emergent signs of potential disrespect or conflict among participants. Adopting a ‘carousel’ approach to co-design discussions allowed each group to build confidence co-designing with others of the same perspective, before asking them to co-design in mixed groups (Mulvale et al., 2020). Several participants took advantage of the ‘chill out’ room (whose name was suggested by youth) at various points in the proceedings to process difficult **emotions** that arose, and in some cases had such a strong rapport with the research team that they asked a member to accompany them. This was accommodated by having back up facilitators in place for every facilitation role. Knowing these supports were available helped youth and caregivers fully open up to depth of experience while maintaining relational safety. At one point, a youth began experiencing symptoms arising from a recent medication change and required medical attention. The team had arranged to have a clinician in the role of main facilitator, with a backup facilitator available if required. This enabled the clinician to discreetly step out of the facilitator role and accompany the youth to visit a health care provider, as the event continued without interruption from the perspective of other participants. The youth returned to the event following treatment and was safely transported home by taxi afterwards. The research team followed up the next day with this and other participants who had shown signs of distress at different points.

Discussion

This analysis reveals that the research team plays a pivotal role in navigating multiple vulnerabilities and

empowering participants at every stage of the unfolding process to establish a relationally safe environment within which collective power can fuel co-design. This in-depth description of the complex role of the research team contributes to both the theory and practice of co-design and co-production with vulnerable groups.

From a theoretical perspective, the themes identified build on and expand those identified in the literature by separating out the essential facilitating role of the research team in navigating vulnerability, power, and relational dynamics between the players involved in and across the phases of an EBCD process. The findings make clear the fluid nature of power and vulnerability often considered structurally embedded, and how power imbalances can shift across participant groups during and within co-design processes. Themes from the key informant interviews and our own experience suggest that groups who traditionally hold structural power such as service providers and managers are reported to feel vulnerable during co-design processes. Similarly, participants who are typically considered structurally vulnerable, can become empowered through sharing their experiences and actively participating as equal partners in improving public services. This power through sharing lived experience is supported in the co-design and co-production as well as the mental health literature (De Vecchi et al., 2016).

The findings also suggest that co-production and co-design processes can be a microcosm through which to challenge the interplay of dominant, challenging, and repressed interests arising from societal structures that are typically highly resistant to change (Alford, 1977). The EBCD process offers an opportunity for traditionally repressed patient and caregiver interests to be heard in co-designing health system improvements without requiring the “enormous political and organizational energies” that repressed structural interests must normally summon “to offset the intrinsic disadvantages of their situation” in policy-making (Alford, 1977, p. 16). The theory that underscores the COMPASS and MAPS tools recognizes the unique opportunity for the research team to navigate and monitor power shifts over the course of the co-design process; first empowering repressed interests and challenging the role and power of dominant interests during the focus groups to set the stage for more equalized power during co-design processes. This emerging theory points to the need for the research team to be ever-vigilant and responsive in their support for processes that can lead to opportunities for reform, while being transparent to participants about the risks involved and bearing in mind the goals of managers to maintain their support for EBCD as an improvement process.

From a practice perspective, the COMPASS and MAPS tools bring theories about vulnerability, power, and relational processes together into a unified framework that can complement existing EBCD and quality improvement toolkits, going beyond simply enumerating the procedural elements of the process (i.e. informing management, inviting participants, hosting events) to support reflexivity on the part of the practitioner to the inherent vulnerabilities and power dynamics between the participant groups, and between the participants and the research team throughout all phases of EBCD processes. This relational component can be likened to the ‘art’ of co-design that requires a shift in mindset from simply adhering to steps in a process. By attending to what could happen and why at different stages, these tools provide guidance about how to prepare proactively in anticipating relational challenges arising from vulnerability and power imbalances and to respond effectively to unanticipated challenges that arise.

Support for each of the COMPASS quadrants can be found in the literature. For example, Sanders and Stappers (2008, p. 9) explain that “Co-designing threatens the existing power structures” by requiring that control be relinquished by managers and given to potential customers, consumers or end-users. Similarly, the literature supports many of the participant preparation elements, such as advanced information-sharing (Blomgren Bingham et al., 2005; Bohman, 1998; Montesanti et al., 2017), the importance of own group processes prior to mixed group work (Point of Care Foundation, n.d.), and creating a co-design context where all voices are equally valued. The literature also supports opportunities for participants to get to know each other outside their traditional roles (Callander et al., 2011), and sharing values statements for each group to help them to take risks and trust each other (Bovaird, 2007).

As the research team navigates these relationships, sensitivity plays out through every stage of the unfolding process. Profound listening to experience, empathetically yet simultaneously recognizing the inherent strength of each group of participants is an antecedent to fulsome dialogue and creative brainstorming. Sensitivity must also allow for criticality in co-design and co-production to avoid recreating existing structures and power imbalances (Bovaird, 2007). Rather than always ensuring pleasant interactions, co-design requires the research team to be prepared for the sharing of a wide range of feelings and experiences (Akama et al., 2018). When involving youth with mental health issues, researchers must be careful not to project their concerns, and instead empower participants by adopting

a strengths-based approach. In this way the research team must both embrace and contest participants’ vulnerability. This duality means that supports for vulnerable participants such as the presence of a chill room and/or a clinician must be clearly made known, but participants should be able to access them discreetly if required. This places a particular burden on the research team, in trying to manage relationships and be all things to all people. It requires attentiveness and skill (Adams et al., 2013; Tsianakas et al., 2012), working on ‘many levels’ simultaneously to ensure both the outcomes and processes work as desired, while being responsive to emergent relational challenges, power and vulnerability. While it may not be feasible to attend to every element captured in these tools in practice, the overarching message is that researchers must remain vigilant to issues of power and potential relational clashes when working with vulnerable populations that can arise quite suddenly, and be prepared to navigate the process if thrown off course.

This paper is subject to a number of limitations. First, the interviews are grounded in recollections of a mix of experts in co-design, some of whom had experience with vulnerable populations and others with deliberative processes involving youth with mental health issues because informants from EBCD studies involving youth with mental health issues could not be identified at the time of the interviews. The risk of recall bias was minimized by triangulating findings with the broader literature. Participants were recruited through researchers’ networks and literature, and although sampling continued until no new themes emerged, it is possible that there are important insights that were not captured here. Given our focus on perspectives of practitioners and researchers, youth perspectives on preparation for co-design activities, and how relational challenges should be navigated are not captured. In addition, differences in context such as organizational structures that may have influenced key informants’ experiences of co-production involving vulnerable groups were not explored, which may have yielded additional insights for researchers conducting co-design or co-production activities. The MAPS detailed directions reflect the focus on EBCD processes involving youth with mental health issues; additional challenges may exist when working with different vulnerable populations. Finally, the usefulness of the COMPASS and MAPS tools has not been validated in practice. Future work should examine whether using the COMPASS and MAPS results in meaningful change in conducting co-design or co-production processes, and should include all stakeholder perspectives (youth, caregivers, service providers, managers, researchers). Future studies can also examine the

relevance of the COMPASS and MAPS directions to co-production involving different vulnerable populations, within single organizations and in cross-organizational contexts and their utility in planning for, conducting and evaluating co-design and co-production processes.

Conclusion

When working in the context of vulnerable populations, such as youth with mental health issues, co-production and co-design processes must do more than provide background information or training to prepare participants. Experts suggest that enduring attention by the research team to relational considerations arising from power imbalances among groups is paramount to provide relational safety for all participants when involving vulnerable populations. The COMPASS and MAPS heuristic tools can assist researchers in navigating relationships among service users, service providers, caregivers, and managers in co-design and co-production processes. Future work is needed to assess whether use of the COMPASS and MAPS tools enhances the quality and effectiveness of co-production and co-design processes.

Note

1. Although we use the term research team, this could be a team of designers, public administrators or whomever is organizing a co-production process.

Acknowledgments

The views expressed in this manuscript are the views of the authors and should not be taken to represent the views of the Government of Ontario. We would like to acknowledge and thank the key informants for sharing their insights and experience.

Funding

This work was supported by an Ontario Early Researcher Award #ER13-09-203.

ORCID

Gillian Mulvale  <http://orcid.org/0000-0003-0546-6910>

References

Adams, M., Maben, J., & Robert, G. (2013). *Improving patient-centred care through experience-based co-design*

(EBCD): An evaluation of the sustainability and spread of EBCD in a cancer centre. London: King's College. <https://www.kcl.ac.uk/nmpc/research/nnru/publications/reports/improving-pcc-through-ebcd-report.pdf>

- Akama, Y., Pink, S., & Aumartojo, S. (2018). *Uncertainty and possibility: New approaches to future making in design anthropology*. Bloomsbury.
- Alford, R. (1977). Health care reform and structural interests. In *Health care politics* (pp. 9–21). University of Chicago Press.
- Bate, P., & Robert, G. (2006). Experience-based design: From redesigning the system around the patient to co-designing services with the patient. *Quality and Safety in Health Care*, 15(5), 4. <https://doi.org/10.1136/qshc.2005.016527>
- Bate, P., & Robert, G. (2007). *Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design*. Radcliffe publishing.
- Bennett, K. C., & Irwin, H. (1997). Shifting the emphasis to “patient as central”: Sea change or ripple on the pond? *Health Communication*, 9(1), 83–93. https://doi.org/10.1207/s15327027hc0901_7
- Birks, M., Hoare, K., & Mills, J. (2019). Grounded theory: The FAQs. *International Journal of Qualitative Methods*, 18, 1–7. <https://doi.org/10.1177/1609406919882535>
- Blomgren Bingham, J., O’Leary, R., & Nabatchi, T. (2005). The new governance: Practices and processes for stakeholder and citizen participation in the work of government. *Public Administration Review*, 65(5), 11. <https://doi.org/10.1111/j.1540-6210.2005.00482.x>
- Bohman, J. (1998). The coming of age of deliberative democracy. *Journal of Political Philosophy*, 6(4), 24. <https://doi.org/10.1111/1467-9760.00061>
- Bourgois, P., Holmes, S. M., Sue, K., & Quesada, J. (2017). Structural vulnerability: Operationalizing the concept to address health disparities in clinical care. *Academic Medicine*, 92(3), 299–307. <https://dx.doi.org/10.1097%2FACM.0000000000001294>
- Bovaird, T. (2007). Beyond engagement and participation: User and community coproduction of public services. *Public Administration Review*, 67(5), 846–860. <https://doi.org/10.113.109.182>
- Boyko, J., Lavis, J., Abelson, J., Dobbins, M., & Carter, N. (2012). *Deliberative dialogues as a mechanism for knowledge translation and exchange in health systems decision-making*. *Social Science & Medicine*, 75(11), 1938–1945. <https://doi.org/10.1016/j.socscimed.2012.06.016>
- Bradwell, P., & Marr, S. (2008). *Making the most of collaboration. An international survey of public service co-design*.
- Broer, T., Nieboer, A. P., & Bal, R. (2012). Mutual powerlessness in client participation practices in mental health care. *Health Expectations*, 17(2), 208–219. <https://doi.org/10.1111/j.1369-7625.2011.00748.x>
- Callander, R., Ning, L., Crowley, A., Childs, B., Brisbane, P., & Salter, T. (2011). Consumers and carers as partners in mental health research: Reflections on the experience of two project teams in Victoria, Australia. *International Journal of Mental Health Nursing*, 20(4), 263–273. <https://doi.org/10.1111/j.1447-0349.2010.00731.x>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Sage Publications Ltd.
- Cribb, A., & Gewirtz, S. (2012). New welfare ethics and the remaking of moral identities in an era of user involvement.

- Globalisation, Societies and Education*, 10(4), 507–517. <https://www.tandfonline.com/action/showCitFormats?doi=10.1080/14767724.2012.735155>
- Davidson, S., & Cappelli, M. (2011). *We've got growing up to do: Transitioning from child and adolescent mental health services to adult mental health services*. Ottawa: Ontario Centre of Excellence for Child and Youth Mental Health.
- De Vecchi, N., Kenny, A., Dickson-Swift, V., & Kidd, S. (2016). How digital storytelling is used in mental health A scoping review. *International Journal of Mental Health Nursing*, 25(3), 183–193. <https://doi.org/10.1111/inm.12206>
- Dimopoulos-Bick, T., Dawda, P., Maher, L., Verma, R., & Palmer, V. (2018). Experience-based co-design tackling common challenges. *Journal of Health Design*, 3(1), 86–93. <https://doi.org/10.21853/JHD.2018.46>
- Donetto, S., Tsianakas, V., & Robert, G. (2014). *Using experience-based co-design (EBCD) to improve the quality of healthcare: Mapping where we are now and establishing future directions*. King's College.
- Dudau, A., Glennon, R., & Vershuere, B. (2019). Following the yellow brick road? (Dis)enchantment with co-design, co-production and value creation in public services. *Public Management Review*, 21(11), 1577–1594. <https://doi.org/10.1080/14719037.2019.1653604>
- Ellingson, L. L. (2009). *Engaging crystallization in qualitative research: An introduction*. SAGE Publications Inc.
- Farr, M. (2018). Power dynamics and collaborative mechanisms in co-production and co-design processes. *Critical Social Policy*, 38(4), 623–644. <https://doi.org/10.1177/0261018317747444g/10.1177/02610183177474>
- Freeze, F., & Walker Davis, W. (1997). The consumer-survivor movement, recovery, and consumer professionals. *Professional Psychology: Research and Practice*, 28(3), 2.
- Garcia, A. R., Pecora, P. J., Harachi, T., & Aisenberg, E. (2012). Institutional predictors of developmental outcomes among racially diverse foster care alumni. *American Journal of Orthopsychiatry*, 82(4), 573–584. <https://doi.org/10.1111/j.1939-0025.2012.01181.x>
- Grabovschi, C., Loignon, C., & Fortin, M. (2013). Mapping the concept of vulnerability related to health care disparities: A scoping review. *BMC Health Services Research*, 13(94), 1–11. <https://doi.org/10.1186/1472-6963-13-94>
- Iedema, R., Merrick, E., Piper, D., Britton, K., Gray, J., Verma, R., & Manning, N. (2010). Codesigning as a discursive practice in emergency health services: The architecture of deliberation. *The Journal of Applied Behavioral Sciences*, 46(1), 73–91. <https://doi.org/10.1177/0021886309357544>
- Katz, A., Hardy, B.-J., Firestone, M., Lofters, A., & Morton-Ninomiya, M. (2019). Vagueness, power and public health: Use of 'vulnerable' in public health literature. *Critical Public Health*, 30(5), 601–611. <https://doi.org/10.1080/09581596.2019.1656800>
- Larkin, M., Boeden, Z., & Newton, E. (2015). On the brink of genuinely collaborative care: Experience-based co-design in mental health. *Qualitative Health Research*, 25(11), 1463–1476. <https://doi.org/10.1177/1049732315576494>
- McGeachie, M., & Power, G. (2017). *Co-production in Scotland – A policy overview*. Scottish Co-Production Network. <http://www.coproductionscotland.org.uk/resources/co-production-in-scotland-a-policy-overview/>
- Miles, M.B., A.M. Huberman, and J. Saldana. (2014). *Qualitative data analysis: A methods sourcebook*. 3rd ed, 2004. Thousand Oaks, California: Sage Publications Ltd.
- Milner, H. R. (2007). Race, culture, and researcher positionality: Working through dangers seen, unseen, and unforeseen. *Educational Researcher*, 36(7), 388–400. <https://doi.org/10.3102/0013189X07309471>
- Moll, S., Wyndham-West, M., Mulvale, G., Park, S., Buettgen, A., Phoenix, M., Fleisig, R., & Bruce, E. (2020). Are you really doing 'codesign'? Critical reflections when working with vulnerable populations. *BMJ Open*, 10(11), e038339. <https://doi.org/doi:10.1136/bmjopen-2020-038339>
- Montesanti, S. R., Abelson, J., Lavis, J. N., & Dunn, J. R. (2017). Enabling the participation of marginalized populations: Case studies from a health service organization in Ontario, Canada. *Health Promotion International*, 32(4), 636–649. <https://doi.org/10.1093/heapro/dav118>
- Morant, N., Kaminskiy, E., & Ramon, S. (2015). Shared decision making for psychiatric medication management: Beyond the micro-social. *Health Expectations*, 19(5), 1002–1014. <https://doi.org/10.1111/hex.12392>
- Mulvale, G., Abelson, J., & Goering, P. (2007). Mental Health Service Delivery in Ontario Canada: How do Policy Legacies Shape Prospects for Reform? *Health Economics, Policy and Law*, 2(4), 363–389. <https://doi.org/10.1017/S1744133107004318>
- Mulvale, G., Green, J., Miatello, A., Cassidy, A., & Martens, T. (2020). Finding harmony within dissonance: Engaging patients, family/caregivers and service providers in research to fundamentally restructure relationships through integrative dynamics. *Health Expectations*. <https://doi.org/10.1111/hex.13063>
- Mulvale, G., Moll, S., Miatello, A., Murray-Leung, L., Rogerson, K., & Sassi, R. (2019). Co-designing Services for Youth With Mental Health Issues: Novel Elicitation Approaches. *International Journal of Qualitative Methods*, 18(13).
- Mulvale, G., Moll, S., Miatello, A., Robert, G., Larkin, M., Palmer, V. J., . . . Girling, M. (2019). Codesigning health and other public services with vulnerable and disadvantaged populations: Insights from an international collaboration. *Health Expectations*, 14.
- Ning, L. (2010). Building a 'user driven' mental health system. *Advances in Mental Health*, 9(2), 112–115. <https://doi.org/10.5172/jamh.9.2.112>
- Osborne, S., Radnor, Z., & Stokosch, K. (2016). Co-production and the co-creation of value in public services. *Public Management Review*, 18(5), 14. <https://doi.org/10.1080/14719037.2015.1111927>
- Palmer, V., Weavell, W., Callander, R., Piper, D., Richard, L., Maher, L., Boyd, H., Herrman, H., Furler, J., Gunn, J., & Iedema, R. (2018). The participatory zeitgeist: an explanatory theoretical model of change in an era of coproduction and codesign in healthcare improvement. *Medical Humanities*, 45, 247–257. *Published Online First*. <https://doi.org/10.1136/medhum-2017-011398>
- Piat, M., & Sabetti, J. (2012). Recovery in Canada: Toward social equality. *International Review of Psychiatry*, 21(1), 9. <https://doi.org/10.3109/09540261.2012.655712>
- Point of Care Foundation. (n.d.). *EBCD: Experience-based co-design toolkit*. London, UK: Point of Care Foundation.

- <https://www.pointofcarefoundation.org.uk/resource/experience-based-co-design-ebcd-toolkit/>
- Realpe, A., & Wallace, L. (2010). *What is co-production?* London, UK: The Health Foundation.
- Sanders, E. B.-N., & Stappers, P. J. (2008). Co-creation and the new landscapes of design. *CoDesign*, 4(1), 5–18. <https://doi.org/10.1080/15710880701875068>
- Singh, S. (2009). Transition of care from child to adult mental health services: The great divide. *Current Opinion in Psychiatry*, 22(4), 4. <https://doi.org/10.1097/YCO.0b013e32832c9221>
- Steen, T., Brandsen, T., & Vershuere, B. (2018). The dark side of co-creation and co-production seven evils. In T. Brandsen, T. Steen, & B. Vershuere (Eds.), *Co-production and co-creation engaging citizens in public services* (pp. 284–293). Routledge.
- Stuart, H., Arboleda-Florez, J., & Sartorius, N. (2012). *Paradigms lost: Fighting stigma and the lessons learned*. Oxford University Press.
- Tollyfield, R. (2014). Facilitating an accelerated experience-based co-design project. *British Journal of Nursing*, 23(3), 5.
- Tsianakas, V., Robert, G., Maben, J., Richardson, A., Dale, C., & Wiseman, T. (2012). Implementing patient-centred cancer care: Using experience-based co-design to improve patient experience in breast and lung cancer services. *Supportive Care in Cancer*, 20(11), 8. <https://doi.org/10.1007/s00520-012-1470-3>
- United Nations Human Rights Council. (2017). *Report of the special rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*. United Nations General Assembly.