Strengthening Review and Publication of Participatory Mental Health Research to Promote Empowerment and Prevent Co-optation

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As reviewers, editors, and researchers with lived experience of mental health challenges, addiction, and/or psychosocial distress/disability, the authors have struggled to find an adequate way to address inappropriate or misleading use of the term "participatory methods" to describe research that involves people with lived experience in only a superficial or tokenistic manner. The authors of this article have found that, in their experience, editors or other reviewers often appear to give authors extensive leeway on claims of participatory methods that more accurately reflect tokenism or superficial involvement. The problem of co-optation is described,

examples from the authors' experiences are given, the potential harms arising from co-optation are articulated, and a series of concrete actions that journal editors, reviewers, and authors can take to preserve the core intent of participatory approaches are offered. The authors conclude with a call to action: the mental health field must ensure that power imbalances that sustain epistemic injustice against people with lived experience are not worsened by poorly conducted or reported studies or by tokenistic participatory methods.

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As lived experience and service user researchers and activists, we want to draw attention to what we see as a common and problematic practice in the scientific literature, namely, the (deliberate or inadvertent) inaccurate use of terms related to participatory research. (We use the term "lived experience" to be consistent with previous literature, although "living experience" may be a more accurate term for some of us because it denotes ongoing experience.) A recent e-mail discussion within our international collaborative, Advancing User/Survivor Capacity and Leadership in Research, revealed that many of us who identify as lived experience researchers and advocates (i.e., mental health researchers or advocates who have the experience of serious mental health/substance use problems and/or trauma) have repeatedly seen the terms "participatory research" and "stakeholder involvement" used in scholarly works in ways that appear to be less than robust. Often, these works offer little clarity or transparency about who was involved, the nature of involvement, and the degree of influence of stakeholders. As reviewers, we often see that authors of articles that claim to have "lived experience leadership" or coproduction relegate coauthors who are service users to middle author slots after our single-blind peer review. Perhaps most concerning are our experiences of hidden authorship. Many in our small community have coauthored research articles that specifically sought to include lived

experience voices, only to withdraw our authorship or participation because of concerns that our involvement represented tokenism and ultimately had the potential for greater harm than good. However, we have never seen a case where this uncomfortable backstory (i.e., a lived experience academic or advocate refusing to attach their name to a work because of these ethical concerns) was made visible in published articles. A few stakeholder activists have published critical narratives of their experiences with participatory

HIGHLIGHTS

- Scholarly articles often describe research methods as participatory, even when the level of involvement of people with lived experience of mental health challenges is minimal.

- Stakeholder involvement that is described as participatory but more accurately reflects tokenism risks co-optation of the values and principles of stakeholder groups.

- The authors present concrete suggestions for researchers, reviewers, and editors to strengthen review and editorial processes for participatory research.

research that describe their side of the story and expose uncomfortable truths (1, 2).

These misleading practices are problematic for several reasons. Participatory approaches not only are vital to ensure that research is directly relevant to a target community but also involve methodologies rooted in deeper value systems, including cross-culturalism, social justice, and equity (3–7). Although specific participatory approaches differ, an overarching theme in participatory mental health services research is the importance of empowering marginalized voices so that a less oppressive mental health care system can be built. Therefore, publishing tokenistic research—in which people with lived experience had minimal to no direct control over project decision making or interpretation of findings—and describing it as participatory can be understood as reenacting what many people with lived experience have faced within the health care system: the systematic erasure of their/our own voices as sources of knowledge and meaning (8). This has been referred to as "epistemic injustice": the devaluation of a knower's knowledge because of biases about who is credible or structural practices that drive how knowledge is collected (9).

PARTICIPATORY RESEARCH AND ITS CO-OPTATION

Participatory methods comprise a constellation of related approaches aimed at increasing the involvement and leadership of relevant communities or stakeholders (often described as "people with lived experience"). These traditions have developed and evolved worldwide, including community-based participatory research in North America; coproduction in the United Kingdom, European Union, and Australia; the "Southern School" of participatory action research in Latin America and other parts of the Global South; and participatory development in resource-limited settings (10–14). Within this body of literature, researchers, activists from target communities, and their allies have repeatedly raised concerns about the risks of inaccurately labeling research as "participatory" when what took place more accurately represents tokenism, co-optation, or very superficial levels of involvement (5). Concerns focus on the extent to which participatory research projects are able to create defined roles for stakeholders in decision making and the interpretation of findings. This gap in practice is outlined clearly in recent global public health research discussions of the marginalization of lived experience voices from the Global South (15–17). Service user– or survivor-led research, implemented most strongly in the United Kingdom, has long held that leadership and control over research decisions are fundamental to more emancipatory research (5, 18).

In an effort to articulate and delineate levels and types of participation, researchers and organizations have developed continuum models of participation that are based on the work of Arnstein (19) and others. Multiple frameworks are available to help researchers and policy makers define and evaluate participatory work, including the International Association for Public Participation's spectrum of public participation, the 4Pi national involvement standards in the United Kingdom, and the GRIPP2 involvement reporting checklist (20–22). Disability justice principles also stress the need for representation through a critical disability lens that refocuses power on those most affected by the research (23).

Although the particulars of different participatory research models vary, most proponents would agree that participatory research is not an either/or proposition (i.e., participation vs. no participation). Instead, leaders in this space are likely to focus on the importance of transparency and ongoing efforts to move toward greater and more meaningful collaboration (24). Ideally, study authors should clearly delineate how robust the participation was and include clear acknowledgment when stakeholders were involved in only minimal ways. At the same time, researchers should continuously work to acknowledge power imbalances and take concrete steps toward greater stakeholder empowerment (24, 25). These ideals suggest that checklists and involvement continuum rubrics may be most helpful as reminders of the details or distinctions of participatory research that authors should report, not as "fidelity" metrics. Indeed, specific participatory methodologies are less our concern than are the risks of overstating the levels of involvement and/or lived experience control and decision making.

When transparency is lacking, invocations of "participatory" methods can function as a form of co-optation. As explained by Penney and Prescott (8), co-optation can occur in two ways: when dominant groups "absorb or neutralize" less dominant or marginalized groups by adopting their terms, weakening them, removing them from their political implications, and using them in ways other than originally intended; and when dominant groups "selective[ly] embrace" (8) aspects of a marginalized group's agenda in a way that ultimately dilutes and undermines the marginalized group's original goals. Thus, by deploying terms such as "participatory methods" when stakeholders had no direct influence on or control over project decision making, the scientific literature can present an appearance of extensive and meaningful lived experience or service user involvement that belies the truth.

Such misrepresentations, in turn, risk seriously undermining service user/lived experience–driven efforts to truly lead or colead (and design or codesign) the research that affects them—if participatory research is viewed as common in the literature, then why does anything need to change (25, 26)? Overall, it may appear that past injustices—epistemic, clinical, and structural—have been overcome, when in fact we are experiencing, at best, modest changes in lived experience contributions to project leadership and decision making. In some areas, the effects of co-opting participatory research have already been recognized, and attempts have been made to address them; for example, in Indigenous health research contexts in Canada, participatory research is

BOX 1. Examples of co-optation in research

- Describing as "coproduced" an intervention or assessment tool that is developed entirely by researchers without lived experience and is afterward refined through service user involvement
- Describing studies as "participatory" when involvement of those with lived experience was limited to assistance with data collection or intervention adaptation, without involvement in the research process itself (in these cases, the tokenistic "advisory" role is often claimed to count as participation, for example, crowdsourced data collection ["citizen science"] described as participatory even when end users are not included in the research design)
- Conflating research participants with stakeholders who are involved in the planning or conduct of research (e.g., a project described as having "stakeholder involvement" when the only "stakeholder" role is to use, for instance, an app-based intervention while serving as a participant in a research study)

- Referring to the fact that some coauthors have lived experience but, when pressed by reviewers, failing to articulate details about their role in the research
- Adding lived experience coauthors to a submitted manuscript only after being questioned by the reviewer or editor
- Describing specific aspects of "stakeholder involvement" only when asked to do so by the reviewer. In cases such as these, we have found that the degree of lived experience representation is usually overstated (e.g., authors of a review of interventions to improve service user mental health may lump together various stakeholder groups and rate their participation equally, even when no service users were included as stakeholders in a particular study)
- Failing to discuss the lack of meaningful service user involvement in the project as a limitation of the study

sometimes subject to review using formal and informal ethics guidelines to counter the discriminatory legacy of colonialism (27). However, in guidelines for the ethics or evaluation of participatory research, specific guidance for peer reviewers is not included.

EXAMPLES FROM OUR EXPERIENCE AS REVIEWERS AND EDITORS

Against this backdrop, members of our lived experience research community reflect regularly on the instances of co-optation that we have seen as peer reviewers, educators, advocates, and clinicians (Box 1).

A common theme found in what might be described as mislabeled, tokenistic, or co-opted participatory research is its directionality; that is, researchers without lived experience define the research question, construct the assessment tool or intervention, and only then bring in persons with lived experience to confirm their findings or comment on their intervention or assessment tool. In these cases, the generative process of the research begins with academic researchers before involving persons with lived experience, who may suggest, but are not actually given the power to make, meaningful changes. We argue that more robust participatory research designs should instead begin with the ideas, insights, and creativity of persons with lived experience.

We also want to underscore the ethical dilemmas, frustration, and distress that can result from these review processes. Unlike the identification of statistical problems or garden-variety questions about study design that arise during review, the personal, social, and political nature of concerns about the inaccurate deployment of participatory research can provoke ethical and existential distress, frustration, and anger among lived experience reviewers. We often find ourselves to be the only reviewers with both expertise in participatory methods and experience of disability

or distress (or both) and the only reviewers who push for greater transparency and acknowledgment of these serious limitations. Concerns about inadequately reported claims of participation often seem to be taken less seriously than concerns about significant statistical, qualitative, or design problems, leaving reviewers who raise concerns about participation with the feeling that their expertise and perspectives are not respected or supported. For many of us, this feeling echoes our experiences not only within academia but often in mental health care systems and in other institutions with which we may have been involved. In this sense, the scientific or intellectual labor involved in the peer review process is often compounded by significant and potentially detrimental emotional labor for lived experience researchers and advocates (28–30).

From a social justice perspective, when researchers misuse the term "participatory research," the likelihood of oppression continues, and then cultural, social, economic, and other types of marginalization are propagated. Only through addressing power hierarchies and moving to genuinely center the voices of those to whom the research applies through inclusion in leadership and decision making (rather than just paying lip service to participatory ideals) can we expect participatory methods to become truly participatory. Moreover, consistent invocation of the term "participatory research" to describe only superficial forms of inclusion risks eventually remaking what participation means in practice—normalizing tokenism or involvement with little real power.

SUGGESTED PRACTICES FOR ENSURING ACCOUNTABILITY TO PARTICIPATORY GOALS

Many organizations, workgroups, and journals have developed guidelines for strengthening the scientific rigor of reporting in various types or characteristics of research, including systematic reviews (31), qualitative research (32),

BOX 2. Strategies journal editors can use to address possible co-optation

- Diversify editorial boards, editors, and reviewers and explicitly include researchers with direct lived experience of major areas the journal covers (e.g., current or former users of mental health services, peer support leaders, and those with the conditions under investigation such as schizophrenia, opioid use, and others), especially researchers from intersecting racialized and other marginalized communities. This approach would be aided by developing training and resources to support peer review by community stakeholders who may lack formal academic training.
- Amplify the perspectives of reviewers who call attention to potential tokenism, superficiality, or lack of transparency. Emphasizing the importance of reviewer concerns about stakeholder involvement improves fidelity to participatory practices and helps to redress power imbalances.

- Develop (or adopt) training and resources to strengthen reporting on lived experience researcher/stakeholder involvement in participatory research outputs. Rubrics may be especially useful to reviewers as they evaluate the level and quality of participatory approaches while conducting their reviews.
- Promote a universal editorial policy requiring that some (or all) manuscripts include a short lived experience commentary, highlighting areas of long-standing concern among advocates and activists (e.g., police involvement, involuntary hospitalization). Examples of this practice can be found in articles related to the review of the U.K. Mental Health Act 1983, conducted by the National Institute for Health Research's Mental Health Policy Research Unit (42).

clinical trial design (33), and race-ethnicity of participants (34). To our knowledge, however, no psychiatry or mental health services research journal has offered explicit guidance for editors and reviewers on how to determine the rigor and merit of participatory mental health research.

Ensuring that participatory methods are not co-opted in mental health research requires a concerted and multidisciplinary approach spanning research and educational activities, roles, and practices. Actors in multiple roles must first learn about and understand the power imbalances that underlie the need for participatory research; without such sensitivity, it is too easy to mistake tokenism for real (emancipatory) change (35–37). We outline some areas in which scholarly reviewers and others can act to ensure that participatory methods are truly participatory.

Journal Editors

The first step is an active response by journal editors. An active response by editors strengthens a journal's quality of peer review and returns the focus of participatory research to the power imbalance, thereby preventing further harm to persons with lived experience. Such a response is especially important for mental health research, where inequities in lived experience inclusion and support are well established (38–41). One approach to addressing inequities is to invite lived experience commentaries on articles accepted for publication. Examples of this practice can be found in articles related to the review of the Mental Health Act 1983 (42). Active responses by journal editors can be modeled and implemented in a variety of ways (Box 2).

Reviewers

Reviewers are the next line of defense in ensuring that reporting of participatory methods is robust. Reviewers should not be afraid to point out or ask questions about involvement that appears to be tokenistic. If participatory methods (or similar terms such as "coproduction" or

"patient and public involvement," etc.) are claimed but sufficient detail is not provided, then reviewers should ask for clarification. Where details are lacking, reviewers should ask specific questions (Box 3).

Reviewers should also carefully examine reflexivity statements, particularly for the first and senior authors, to determine how positionality or identities (which might include direct experience of the topic investigated) influenced project design and interpretation of findings. Reviewers can always suggest a more detailed supplemental file if the word count limits of the journal will not allow sufficient detail.

For reviewers without an academic background or who have little experience reviewing manuscripts, we recommend taking advantage of several particularly useful peer review functions (Box 4).

Authors

Ultimately, it is the responsibility of authors to clearly and accurately describe participatory methods. Before beginning to write, authors should critically reflect on the harms of published research that misrepresents the level or influence of stakeholder involvement. For example, as researchers and authors, we may have wanted to be at the top of Arnstein's ladder (19), but were we able to achieve that? We suggest that authors reflect on and report several details of participation (Box 5).

LIVED EXPERIENCE REFLECTION, LIMITATIONS, AND FUTURE GOALS

The authors of this article are individuals with experience of psychosis/schizophrenia, bipolar disorder, depression, addictions, Madness, trauma, and other invisible disabilities. We have experienced the welfare system, disability benefits, subsidized housing, poverty, and/or colonialism. Many of us have also supported family members experiencing significant mental health and substance use challenges. Some of us

BOX 3. Questions reviewers can ask during peer review to address possible co-optation

- How many stakeholders were involved, how were they identified, and what were their specific roles?
- How and at what point in the project were stakeholders involved in core project decision making (vs. advisory or consultative functions)?
- What were the specific participatory processes and what roles did individuals with lived experience have (e.g., advisory board member, community coresearcher, team leader,

member of the core research team, research support staff, etc.)?
- What was the nature of diversity among lived experience stakeholders (e.g., race-ethnicity, class, cultural background, etc.)?
- To what extent were those involved in the project explicitly selected to reflect the diverse needs and concerns of the target population, and, if selected, how were such selections made?

are/identify as people of color, queer, and/or belonging to minoritized religious groups. Yet, some of us also have experiences or identities that reflect privilege: Whiteness, being cisgender and/or heterosexual, identification with majority religious or gender groups, being based in the Global North, having the ability to conduct research and advocacy, and, importantly, having a voice in the privileged arena of academia. Collectively, we have worked for research projects in the roles of "lived experience adviser," "coresearcher," research student, postdoctoral and doctoral faculty member, and contract researcher.

During this collaboration and after drafting this article, we realized that we, too, had a responsibility to ensure diverse perspectives in collaborative efforts within our group. We discussed our lived experiences within the author team and agreed that we lacked collaborators from the Global South; therefore, our concerns prioritize those tied to linguistic and geopolitical privilege. As we then reflected, our marginalization in some areas (e.g., as people with the lived experience of mental health challenges, addiction, and/or psychosocial distress/disability) does not guard against privilege and power in others. However, rather than invite another author to the team after our manuscript was jointly written and midway through revisions, which would reflect the very type of tokenistic participation discussed earlier, we decided instead to practice transparency and acknowledge this to be a limitation of our article. Future collaborations

within our organization will be able to take advantage of a formalized workflow to help ensure greater diversity at project conception.

We also acknowledge the embeddedness of this article as a factor in its narrower focus—namely, the concept for this article arose within an e-mail group in which broader issues of co-optation and disempowerment within and outside research are regularly discussed. Anger and frustration with the state of research (and participatory policy and program development) are often conveyed, shared, discussed, and lamented on. Many of us have been part of projects—as consultants, assistants, and even coinvestigators—in which lived experience has been painfully tokenized. Our positions, in general, are not neutral and are born from the experience of disempowerment in contexts ostensibly designed to be emancipatory.

CONCLUSIONS

Our article aims to center the core goal of participatory approaches: democratization of research through inclusion, influence, and empowerment of people with lived experience. These goals are undermined by inaccurate labeling or co-optation of the term "participatory research," which creates a veneer of meaningful participation that cracks on closer inspection. It may seem innocuous to allow editorial flexibility in descriptions of participatory research;

BOX 4. Recommendations for novice reviewers

- Ask for further clarification from authors until the extent of stakeholder involvement is clear. Note that everything a reviewer asks for needs to be addressed by the authors, whether in the manuscript or privately in a response-to-reviewers letter, in which authors can clarify participatory processes or provide context in direct response to reviewer comments.
- Share concerns freely and honestly. Sometimes, reviewers outside academia or novice reviewers might feel insecure or uncertain about their concerns or questions, but peer review is most often blind (i.e., anonymous), and it is the reviewer's role to ask for more details when necessary.
- When in doubt about what to say and what not to say to the authors, add notes for the editor. Most journals allow

reviewers to make private comments to editors in addition to their review, allowing reviewers to convey their concerns and uncertainties only to editors.
- Understand informational supplements to published articles. Most journals now have an option that allows authors to submit supplementary details or data that will not fit within a standard printed article. It is perfectly legitimate to ask authors to include additional information as a supplement, such as greater detail regarding participatory processes, level of inclusion, and relative influence of lived experience collaborators (e.g., what changed about the research as a result of having lived experience collaborators).

BOX 5. Reporting suggestions for authors

- The type and level of stakeholder involvement, the diversity of stakeholders involved, whether stakeholders were compensated for their involvement, the degree of control stakeholders had over decision making, and specific roles stakeholders played in the research (e.g., design, coding, interpretation, and manuscript writing)
- If necessary, any reduced levels of stakeholder involvement or withdrawal from the project by lived experience stakeholders, and how these losses might have affected the interpretation of findings and the relevance to the target community (which could be added to the limitations section of the manuscript)
- Explicit reflexivity statements that meaningfully address how power differentials in relationships between those with and those without lived experience may have affected project decision making and interpretation of findings

- Consideration, in the reflexivity statement, of the diversity and politics of who was involved and why. Many groups and experiential intersections remain seriously underrepresented in psychiatric research, including Indigenous communities, individuals with histories of intersecting system involvement (e.g., criminal justice, homelessness, child welfare, public benefits, and immigration and asylum), and minority racial-ethnic, cultural, and gender identities. Authors should consider how and whether research processes fostered involvement of these underrepresented groups
- Within funded research projects, authors may also consider asking the journal editor whether it would be possible to commission a short lived-experience commentary to better include the voices of people with lived experience (see examples in the review of the U.K. Mental Health Act 1983 [42])

however, widespread claims of participatory practices without adequate transparency may contribute to further reifying epistemic inequities and perpetuating exclusion of the deeper insights, knowledge, and demands of the people our research aims to serve. We all have a responsibility to strive toward these goals and must not lose sight of them in the rush to publish.

Importantly, robust participatory research is incredibly difficult. Participation should be challenging work, involving the joining of different and often conflicting views and experiences (43, 44). There must be space for perspectives that might cause discomfort and disagreement. Trusting relationships must be built with individuals and groups who have experienced intersectional layers of oppression and disempowerment (45, 46). Hierarchies and privileges of those in academia must be acknowledged and discussed. It takes time and resources to build these relationships and to ensure that the voices of people with lived experience are not overshadowed by those of academic researchers who need to answer to funders, institutions, and deadlines. The goal of this process is not to achieve perfection but to be transparent and honest about limitations and challenges, even as we continually try to strengthen methods and capacity. Our goal for this article is to open a conversation and to further the capacity and commitment of editors, reviewers, and authors to promote accuracy and transparency in descriptions of every form of participatory research. Insisting on fidelity to reporting not only strengthens scientific practice, but also is a form of activism and a way for people with lived experience and allies to work together to ensure all voices are heard.

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