Critical Public Health

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/ccph20

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To cite this article: Lori E. Ross, Merrick Pilling, Jijian Voronka, Kendra-Ann Pitt, Elizabeth McLean, Carole King, Yogendra Shakya, Kinnon R. MacKinnon, Charmaine C. Williams, Carol Strike & Adrian Guta (20 Oct 2023): ‘I will play this tokenistic game, I just want something useful for my community’: experiences of and resistance to harms of peer research, Critical Public Health, DOI: 10.1080/09581596.2023.2268822

To link to this article: https://doi.org/10.1080/09581596.2023.2268822

CRITICAL PUBLIC HEALTH
https://doi.org/10.1080/09581596.2023.2268822

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‘I will play this tokenistic game, I just want something useful for my community’: experiences of and resistance to harms of peer research

Lori E. Ross[a], Merrick Pilling[a*], Jijian Voronka[b**], Kendra-Ann Pitt[a***], Elizabeth McLean[a****], Carole King[a], Yogendra Shakya[c*****], Kinnon R. MacKinnon[a******], Charmaine C. Williams[d], Carol Strike[a] and Adrian Guta[b]

[a]Dalla Lana School of Public Health, University of Toronto, Toronto, Canada; [b]School of Social Work, University of Windsor, Windsor, Canada; [c]Access Alliance Multicultural Health and Community Services, Toronto, Canada; [d]Factor-Inwentash Faculty of Social Work, University of Toronto, Toronto, Canada

ABSTRACT

Hiring peer researchers – individuals with lived experience of the phenomenon under study – is an increasingly popular practice. However, little research has examined experiences of peer research from the perspectives of peer researchers themselves. In this paper, we report on data from a participatory, qualitative research project focused on four intersecting communities often engaged in peer research: mental health service user/consumer/survivor; people who use drugs; racialized; and trans/non-binary communities. In total, 34 individuals who had worked as peer researchers participated in semi-structured interviews. Transcripts and interviewer reflections were analyzed using a participatory approach. Many participants reported exposure to intersecting forms of systemic oppression (racism, transphobia, ableism, and classism, among others) and disparagement of their identities and lived experiences, both from other members of the research team and from the broader institutions in which they were working. Peer researchers described being required to perform academic professionalism, while simultaneously representing communities that were explicitly or implicitly denigrated in the course of their work. Practices of resistance to these harms were evident throughout the interviews, and participants often made strategic decisions to permit themselves to be tokenized, out of the expectation of promised benefits to their communities. However, additional harms were often experienced when these benefits were not realized. These findings point towards the need for a more reflexive and critical approach to the use of peer research.

ARTICLE HISTORY
Received 11 January 2023
Accepted 3 October 2023

KEYWORDS
Participatory research; peer research; qualitative research; inclusion

Introduction

For over two decades, there has been a movement towards increased community engagement and participation in many domains of social life, including research (Reynolds & Sariola, 2018; Truman &

CONTACT Lori E. Ross l.ross@utoronto.ca

*Present Address: School of Disability Studies at Toronto Metropolitan University, Canada.
**Present Address: Interdisciplinary and Critical Studies, University of Windsor, Canada.
***Present Address: Faculty of Social Sciences at the University of the West Indies.
****Present Address: Centre on Drug Policy Evaluation, Canada.
*****Present Address: Global Equity Matters Institute, Canada.
******Present Address: School of Social Work at York University, Canada.

Raine, 2001). As part of this, a growing practice in many studies has been to hire community members as peer researchers (PRs), research staff whose lived experience of the phenomenon under study is considered essential to their eligibility for the position (Roche et al., 2010). Although particularly characteristic of participatory research methods (e.g. Bell et al., 2021; Israel et al., 1998), paying individuals to engage in the research process on the basis of their lived experience is now a common practice across a wide range of studies concerned with community engagement, such as patient-oriented research (e.g. Boechler et al., 2021).

Prior to this move, if communities were engaged at all, it would typically be via involving community organizations and/or members in an advisory capacity and on only an occasional basis. The PR model seeks to deepen participation of the target community by hiring members as staff and/or research team members, ideally increasing the depth and level of community engagement in the work. Involvement of PRs is thus intended as an epistemological intervention to shift power in the knowledge production process to be more equitable, and on a more concrete level, to enhance the quality of research by facilitating access to hard-to-reach populations and by providing insider knowledge and analysis about the topic under study (Bell et al., 2021, ch.1; Roche et al., 2010). The engagement of PRs is argued to benefit communities through processes of capacity building (Logie et al., 2012) whereby individuals who have gained research skills can go on to use them for benefit to themselves and their communities. Further, the PR process is hoped to result in research that is more reflective of community needs, and thus more impactful for the target community.

Despite these intended benefits, little empirical research has examined the process, context, and outcomes for PRs of their research involvement (Guta et al., 2013; Roche et al., 2010; Voronka, 2019). Exceptions come from two domains in which communities have long histories of resisting the research enterprise and biomedicine more generally. First, there is scholarship by survivor researchers, i.e. individuals with lived experience of the mental health system, as well as scholarship generated from the emerging field of Mad Studies, which interrogates experiences of inclusion in mental health research (Groot et al., 2022; Heney & Poleykett, 2021; Johnston, 2019; Tseris et al., 2022). Second, there is literature examining PRs experiences in HIV research (e.g. Rhodes et al., 2010; Roy & Cain, 2001), a field with a long history of community advocacy for engagement (Wright, 2013). Collectively, this research illuminates the tensions inherent in roles that require both authentic connections to marginalized communities and performance of a professionalized work role (Voronka, 2019), alongside institutionalized barriers that limit the possibilities for community engagement (Heney & Poleykett, 2021).

In this paper, we build on this scholarship by offering analysis from an empirical study that explored experiences of PR engagement across communities of study with a variety of different relationships to the research enterprise. Specifically, our project utilized a participatory, qualitative design to investigate experiences of PRs from four intersecting communities: trans and non-binary; racialized; mental health service user/consumer/survivor; and people who use drugs. The objectives of our study were to: a) examine how PRs experience processes of inclusion; b) determine how PRs experience benefit and/or harms from their involvement in research; and c) identify similarities and differences in experiences of inclusion, benefit and harm between the four communities of interest. In this paper, we focus on an analysis of the harms of PR practices described across all four communities of study. We take this focus given that a) experience of harm was a prominent theme in our data; and b) little published research on PR has examined the potential harms of this practice of inclusion.

Theoretical approach

Our work aligns with critical theory emphasizing the emancipatory potential of the knowledge production process, including diverse traditions and scholars such as Freire (2017) and hooks (1994). We further engage with work of critical scholars across disciplines who have been rethinking what inclusion and diversity practices produce for those who are being included (Ahmed, 2012;

Voronka, 2016). As Ahmed (2012) notes on the basis of her interrogation of 'diversity work' in institutions; 'the very promise of inclusion can be the concealment and thus extension of exclusion' (p. 183) due to shallow frameworks that serve to silence dissent or limit inclusion to those who do not question dominating structures of power. Our work brings together this scholarship with perspectives aligned with crip theory (McRuer, 2006; Schalk, 2018) and disability justice (Mingus, 2011; Piepzna-Samarasinha, 2018; Sins Invalid, 2015). This scholarly and activist thinking draws our attention to the limited gains that can come from simply including those who have previously been excluded into oppressive systems, without working for fundamental changes to those systems. Drawing on these perspectives, our primary objective is to critically examine the harms associated with peer inclusion in research from the perspective of PRs and trace them back to their structural causes, while simultaneously attending to resistance to these harmful practices of inclusion.

Methods

This qualitative study was grounded in a participatory approach. The investigators in the study collectively had many decades of experience with peer research as taken up within all four communities of interest, both from the perspective of employees hired as PRs and as academic investigators leading projects that employed PRs. On the basis of this experience, we implemented research practices that reflected our commitment to participatory principles, and particularly those connected to redistribution of power over the knowledge production process, through all aspects of the study. These included: involvement of co-investigators and research staff with lived experience of working as PRs within our communities of interest; development of principles of collaboration; and involvement of PR team members in processes of recruitment, data collection, data analysis, and knowledge translation (further detailed in Ross et al., 2024). The study included an autoethnographic component wherein both PR and academic team members recorded their reflections on the research process; these findings are reported elsewhere (Ross et al., 2024; Voronka & King, 2023). The study received approval from the Health Sciences Research Ethics Board at the University of Toronto (Protocol 34811).

Research participants were 34 individuals who, in the 10 years prior, had held a paid research position that required lived experience with one or more of the four communities of interest. Recruitment was through electronic and hard copy distribution of flyers. Wording on the flyer described the study as 'a community-based project that aims to understand how PRs experience their involvement in research with four different communities' and invited individuals who 'were paid to work on a research project for which your lived experience was a requirement for the job' to contact study staff by telephone or email. Interested participants were screened by telephone to establish eligibility for study inclusion, collect sociodemographic characteristics, and ascertain a brief description of the individual's PR experience. This information was used to inform sampling on the basis of both individual- and research-related factors, to ensure representation of participants across a range of sociodemographic characteristics (e.g. age, race, gender) and a variety of research experiences (e.g. studies led by academic vs. community-based principal investigators; studies involving a range of methodologies and research tasks). Participant characteristics are provided in Table 1.

Data were collected via in person, semi-structured interviews approximately one hour in length, co-facilitated by one academic and one PR member of the research team, in a private space at the University of Toronto. Interviews followed a semi-structured guide which included questions querying: a) characteristics of their PR position (purpose, how and why they got involved, roles and responsibilities, hours of work and compensation); b) experiences on the projects (training and support, relationships with other research team members, accommodations and safety, power relationships on the research team); c) benefits and harms (how they felt about the project, personal benefits, benefits to other PRs, negative consequences, any impacts on identity, community or personal life); and d) recommendations for academics, organizations, and community members

Table 1. Sociodemographic characteristics of participants ($N = 34$).

	n (%)
Identifies as a person who uses drugs	
- Yes	20 (58.8%)
- No	13 (38.2%)
- No response	1 (2.9%)
Identifies as consumer/survivor/mental health service user (%)	
- Yes	27 (79.4%)
- No	6 (17.7%)
- No response	1 (2.9%)
Gender (%) (could select multiple options)	
- Cisgender woman	10 (29.4%)
- Trans woman/trans feminine	4 (11.8%)
- Cisgender man	6 (17.7%)
- Trans man/trans masculine	2 (5.9%)
- Non-binary	6 (17.7%)
- No response	7 (20.6%)
Sexual Identity (%) (could select multiple options)	
- Heterosexual/straight	11 (32.4%)
- Gay	1 (2.9%)
- Bisexual/pansexual	9 (26.5%)
- Asexual	1 (2.9%)
- Queer	8 (23.5%)
- Unlabeled	3 (8.8%)
- No response	3 (8.8%)
Identifies as racialized (%)	
- Yes (could select multiple options)	21 (61.8%)
○ Black African/Caribbean	9 (26.5%)
○ East Asian	3 (8.8%)
○ Indigenous	6 (17.7%)
○ Latinx	2 (5.9%)
○ South or Southeast Asian	3 (8.8%)
○ Mixed race (participant-defined)	2 (5.9%)
- No	12 (35.3%)
- No response	1 (2.9%)
Age Range (%)	
- 18–29	9 (26.5%)
- 30–49	12 (35.3%)
- 50–64	8 (23.5%)
- 65+	2 (5.9%)
- No response	3 (8.8%)

related to peer research. Analysis for this paper drew from data elicited in response to the question about harms (i.e. ‘Looking back on your experiences, do you think your involvement in this research had any negative consequences for you?’) alongside relevant data elicited throughout the rest of the interview guide (e.g. from questions about experiences on the projects).

Immediately following the interview, the co-facilitators discussed their experiences of conducting the interview; both the interviews and reflections were audio recorded, transcribed verbatim, and analyzed. Briefly, the analytic approach entailed iterative engagement with the data to identify codes, categories, and ultimately themes. In order to integrate a participatory approach into this process, we began by having several members of the team notate a few transcripts that the study coordinator and PR staff felt reflected key ideas, upon which we collaboratively developed an initial coding framework. Two members of the team (including one academic and one PR staff) then independently coded all transcripts according to this framework. Discrepancies were resolved through discussion, with a principle of inclusive coding (i.e. unless a code had been applied in error, both coders’ analyses were included). NVivo software was used to assist in data management.

To address this paper’s research question, the first author closely analyzed the data that had been included in the ‘harms’ node of the coding framework, which included any harms experienced while working as a PR, either explicitly described by the participant or perceived by the analysts. Working with these data, and with reference to full transcripts for context, the first author identified subthemes which were verified and developed through discussion with two of the authors who were particularly close to the data and relevant theoretical frameworks (MP, JV), and subsequently with the entire author team.

Results

We identified three major themes: the harms of requiring respectability, intersectional experience as 'negative value', and the harm of no benefit. Woven throughout were stories of 'resistance and opposition' (Costa et al., 2012), wherein participants took strategic action to protect themselves from, or alternatively, expose themselves to these harms for the benefit of themselves or their communities. Consistent with our theoretical framework, in our analysis we pay close attention to the role of structural factors as they operate in relation to both harms and resistance. In presenting our findings, we include supporting quotations identified by participant number. We deliberately do not include any demographic or other contextual information, since doing so could make participants easily recognizable to their managers and co-workers, potentially jeopardizing opportunities for future PR employment.

The harms of respectability: valued and denigrated identities

> I think what affected me was understanding more viscerally the way institutional power works (p. 10).

Pervasive throughout nearly all of the interviews were accounts of being called upon to represent identities and experiences that were valued in principle, but in practice were explicitly or implicitly denigrated in the course of the research work. Consistent with the work of Voronka (2019), PRs in this study were expected to perform denigrated identities in ways that were deemed to be both authentic (i.e. to represent the communities under study) and respectable (i.e. align with their professionalized role in an academic space). The notion of respectability is imbued with systemic forms of oppression (racism, transphobia, ableism, and classism, among others) that participants encountered in interactions with other members of the research team and the broader institutions in which PRs were working. Participants were expected to perform respectability according to hegemonic norms regarding professional behaviour, and represent their communities in circumscribed ways that PRs often experienced as tokenizing or degrading:

> To be completely frank I think it was mostly optics. Like [PI] wanted this openly trans woman . . . So I think a part of [PI] was like, 'wow, look how progressive I am, I have this visibly trans person on my team who is, you know, leading the project', even though I was a tiny person on it, like I had nothing to do with it [laughs]. So I think a lot of it was optics really (p. 22).

PRs described being treated differently than non-peer staff in ways that implied they were less respectable and therefore less valued than their co-workers who did not have (or did not disclose) lived experience:

> It wasn't really very comfortable . . . I was left with the sense that they thought they [investigators] were better than all of us [PRs], better than me (p. 13).

In another example, one participant described her experience getting access to the building in which she worked:

> Participant: Back then we [PRs] didn't have fobs at all. That was a problem that we had back then is that we weren't being treated very well . . . We recently got fobs for the building, we had to fight for them –

> Interviewer 1: When I worked at [the same site], I had a locker but I didn't have a key to the locker room, so yeah, I just felt like a kid every day. And when it was time to go home, I had to find someone and interrupt them from what they were doing to get my coat.

Participants were expected to bring in their lived experiences of marginalization (as poor, homeless, and/or living with a mental health issue, for example), while being censured if they did not consistently behave in the 'respectable' ways expected in academic spaces. For example, one participant's supervisor threatened to fire them for coming to work five minutes late, and the participant felt this was at odds with the principles of a peer program that was supposed to be sensitive to the structural challenges that PRs face:

> I came late to a few meetings. But it wasn't on purpose. I'm still trying to get familiar with the rhythm of things . . . the peer program is for people who are just getting back into it. So many of us, even though we might seem very intelligent, doesn't necessarily mean that we're all together. You can have brilliant people but hey, in my case it was depression and post trauma, suicidal tendencies. So it doesn't mean that I have it all together and from what I understood the peer program is about that (p. 26).

PRs were expected to be professional – sometimes even credentialed – but not to comment on aspects of the research that were seen as outside their expertise:

> They look to me to have a perspective, like they don't really think I'm going to comment on things outside of a perspective . . . They wouldn't expect me to comment on the quality of the analysis independent of my peer point of view. So, I can say I've worked in mental health as a researcher, but I just don't feel like people take it in. Like once I'm identified as a peer, I feel like that's my primary identity (p. 21).

For many participants, the constant struggle to be perceived as respectable, alongside the discrimination it exposed them to, took a significant toll:

> I feel it deep inside me this pathologization, sanism, where I'm like, every choice I'm making, I'm wondering are people thinking that I'm making that choice because they see me as a mentally ill person? (p. 10).

> I think for a lot of young, racialized women in particular, those kinds of experience are cumulative, and the impact that it can have in just destroying and decimating your self-esteem and self-worth as a researcher . . . there's always this nagging feeling at the back of your mind that if you say no, or you hesitate, it's a question of your competence. It's immediately a question of your intelligence. It's immediately a question of like, are you up to it? (p. 34).

Intersectional lived experience as "negative value": the harms of devaluing intersectional identities

> I get asked to come in because of my HIV experience. Then they find out that I'm a substance user, or I've been incarcerated . . . I've just added another value, let's call it that. And to them, a negative value (p. 33).

Study participants embodied the inherent intersections among race, gender, mental health and drug use (together with other systems of social stratification such as class, sexual orientation, and (dis) ability). Drawing on Hill Collins (1990) work, racism, (cis)sexism, sanism and other forms of oppression acted in a mutually reinforcing *matrix of domination* to determine participants' experiences. That is, for those participants who experienced discrimination in the course of their work as a PR (the majority of the sample), at times the discrimination was directly tied to the specific identity expected to be mobilized in participants' work. For participants who were also impacted by other systems of oppression, however, the discrimination was often targeted there:

> Many of the people involved were cis, and so like I feel like there was missing this lens of like intersectionality of like, this is not only like cis queer men, masculine identified folks. But trans, non-binary, all of these things . . . Sometimes [research team members] would make jokes about vaginas, stuff like that. Things that were sort of like, considering all men, thinking all men have penises or something like that. That was their assumption (p. 18).

As in this quote, some participants attributed their experiences of discrimination and marginalization to the research team's lack of intersectional understanding of their communities; that is, their lack of appreciation that these various aspects of participants' identities were inherently interconnected:

> Sometimes I felt like [the research team] understood what transphobia was, but then they didn't understand what like, poverty was, or what classism was. As someone who lived in poverty most of my life, I would have to explain more what people would see as trans things, it was really just like, no, this is poverty things. If trans people are more likely to live in poverty, these are some of their experiences because of that poverty (p. 30).

The experiences described by participants may also reflect implicit assumptions about the communities under study, as filtered through a lens of respectability. As Voronka (2019) has described, PRs 'are only invited in by respectability' (p. 8) and as noted above, are thus expected to behave in ways seen as appropriate to the professionalized context. However, when intersectional experiences render PRs to be perceived as less than model members of their communities that respectability is jeopardized:

> [While involved in a study that required a cellphone] I was punched in the face and my phone got stolen ... I never claimed any of [the costs to replace it] because they looked at it as my fault ... '[Name] you did wrong, we have to be careful with you and sensitive information. What if some of it was on your phone?...We can't trust [name] because [my] phone keeps getting stolen'. ... They could not understand fully when something affects like a- [pause] somebody like myself, right? (p. 23).

While this participant does not expand on what was meant by 'somebody like myself', we can speculate that it might encompass identifying as a gay, multiracial, HIV-positive immigrant with limited formal education and experience of poverty, drug use, and mental health issues – a combination that may call respectability into question. Another participant, who in the excerpt above described being reprimanded for lateness, describes being held to a both higher standard (e.g. being reprimanded for minor issues) and to a lower standard (e.g. surprise when they accomplished what they considered to be basic tasks) than were their white counterparts:

> It's like, what, a Black guy being [a researcher]? And it's like, yeah, we exist ... you're not used to seeing a Black guy being so prolific ... doing a good job, doing things that you're just not used to seeing except for in a rap video ... I got my [institutional ID] badge, I signed up online, and [supervisor] was like, 'What? Really? Well great!' But it was always that, I always got that (p. 26).

As in this example, participants often felt essentialized by other members of their research team: acknowledged for aspects of their identity seen as relevant to the research, while other components were ignored or disparaged. In this way, participants perceived that some aspects of their lived experience were considered more respectable than others; some were invited or obliged to be put on display, while others had 'negative value' and needed to be made invisible.

"A lot of struggle for not much gain": the harm of no benefit

> I'm left with a bit of bitterness about that project to be honest, because I did so much work on that project, I did almost everything except write the final papers ... I've seen nothing from that project. I've seen no benefit to me in any way, professionally or career wise. And also, I don't know what has happened with that work ... what's changed? I see nothing (p. 3).

Prominent in the interviews were instances where PRs endured the harms described in the first two themes – typically in order to see the promised benefits to themselves and their communities – but these benefits were never realized. This was summarized in one interview reflection as 'a lot of struggle for not much gain'. (Reflection 22). For example, when asked if they had personally benefited from their PR position, they replied:

> The project is like a year long project but also [with] so many issues unaddressed. So it kinda feels like I'm not really moving forward or developing anything or gaining anything from it (p. 11).

Participants also expressed doubts about community benefits of their labour:

> While I was in it, I was like, this is amazing. This is the best thing ever. But now that I look back on the work . . . am I really helping? With doing this work? Or am I just kind of supporting the portfolio of the PI?. . . just kind of a weird feeling in terms of, is the work that I did then actually benefitting anyone now? . . . Or is this more of the PI needed 6 papers each year in order to advance their career, so I just helped advance their career but I didn't really help the community? (p. 27).

The harm of there being no benefit was not a universal experience: some participants felt that there were benefits at the personal or community level. But among those who expressed concern about the lack of positive outcomes, many articulated this as not simply a neutral absence of benefit, but rather as a harm associated with their involvement in research:

> Well, it's always a disappointment . . . I participated in a lot of more specific studies around maybe being racialized or you know what I mean, or whatever that looks like. And nothing's ever been done. . .You've been trusting people to really support you and to make those changes, right? Cause hey, what's better than an ally?. . . But then when allies turn around and make it about them, or make it about – or add to what the conversation has always been, you know what I mean. It really just is disheartening, this betrayal to a community (p. 17).

Experiences such as these left participants questioning whether research teams were truly invested in social justice for their communities, and with complex feelings about who was benefiting from their labour. When asked if she thought she was doing her community a service by being involved in her research project, one participant shared:

> I mean, in some ways yes, because I can now go back and like, warn people about the way it's so insidious, because you don't really know what kind of prejudice you're gonna experience when you walk into that building and when you do your work there as a person with lived experience (p. 10).

Similarly, when asked about benefits of being involved in PR, another participant stated:

> Through those processes you learn something too, you know what I mean? And I think it made me learn for the next [research project] . . . what questions do I want to ask? Making sure that I'm not being tokenized, is this real? And maybe seeing, you know, the validity or like, is this really gonna change something? (p. 17).

Stories of resistance and opposition

> I can't focus on 'you should have done more before this', [I] just focus on, 'what can I do now?' So, okay, I'm here. You have the trans expert. I will play this tokenistic game, I just want something useful for my community (p. 30).

Costa et al. (2012) have called on researchers who work with the stories of people with 'lived experience' to 'complicate what we are listening for: to listen . . . more for stories of resistance and opposition' (p. 96). PRs who participated in this research were not simply acted upon by research teams and institutions; rather, they made strategic choices to allow themselves to be tokenized under some circumstances but not others, pushing back when it felt necessary or safe to do so and, as in the examples above, sharing their learning with others in their communities.

Some participants chose to make formal complaints, as was the case for a white, non-binary participant whose work organizing a community event was not acknowledged when it was abruptly cancelled. For others, the time and emotional labour involved in making a complaint, coupled with a sense that it would have no impact, led them to decide against taking such action. This was the case for an Indigenous participant who experienced racism in her PR work:

> I was thinking, oh, I'm gonna go to the human rights, I'm gonna go over [supervisor's] head you know? As I started to get better [recover from the mental health impacts of a racist incident] I had to let it go because it's – it's like hitting a wall, too. You know what I mean? Cause it's like, okay, am I gonna – pick your battles (p. 1).

Formal complaints were only one approach to resistance: participants also described strategies they developed to make difficult working conditions more tolerable. Many of these aimed to minimize exposure to discrimination, such as ‘flying under the radar’ (not drawing unwanted attention to stigmatized identities), communicating with other team members via email rather than in person, and reducing the number of hours worked. One participant described drawing on previous negative PR experience to pre-emptively address common challenges of PR roles at the time of negotiating the contract:

> Contracts were prepared and drafted but [in the past] I would just sign on the dotted line, you know?. . . So now when it comes to me be involved [in research] and the work is – especially because so much of my work is working with communities that can easily trigger me and re-traumatize me, I negotiate when it comes to my supervision – mental health support. I negotiate transportation because sometimes because of the nature of the work I was doing when it comes to recruitment it requires you to go to so many different locations . . . I would have a discussion based on the draft contract of what I felt was missing (p. 16).

Participants also engaged in negotiation and resistance at the organizational level. For example, one participant resisted the Board of the organization at which he was employed in response to their efforts to replace community members with professionals:

> So, the new chair of the Board was saying, ‘oh, well we’re all community members’. And we’re saying, no, it’s people with lived experience, right? And not all of you have lived experience . . . They eliminated our honorarium for the community members. They voted to eliminate the honorarium so they thought that would get rid of us all, you know? If we don’t give them money, they won’t come! (laughs) But it didn’t work. We still kept coming . . . then I got the remark from the new chair of the Board saying that I should consider myself lucky that I live in Canada, that if I were living in some other country I’d be in much worse shape. And I said, you know, that made my decision. I resign (p. 8).

For some participants, their very involvement in PR was an act of resistance: they did the work with the goal of preventing researchers from further harming their communities:

> As a community member I felt like sometimes I really had to put up a fight. To actually bring the perspectives of the community into the work (p. 22).

> There were many times when I wanted to step away, but I chose to continue because I thought that it was important to get my voice in there (p. 2).

Discussion

The data in this paper illustrate the harms that may be enacted when people are invited into research on the basis of lived experience. These harms centre on the impacts of being required to represent denigrated identities in a research space where systemic oppressions remain un- or insufficiently mitigated. Although we cannot know the intentions of the research teams who employed the participants in this study, we expect that many drew on PR practices in an attempt to mitigate power imbalances inherent in the research process or deepen involvement of members of community in a paid capacity. However, our findings indicate that the larger context of respectability requirements acting in concert with racism, ableism, classism and other forms of oppression predetermines various aspects of the research environment, and consequently, the capacity of project leaders to mitigate potential harms may be constrained.

Our work contributes to a growing body of research that has explored the potential harms and complexities of peer research (e.g. MacKinnon et al., 2021; Thulien et al., 2022) and that has examined the impacts of imperatives to engage communities, patients, and publics in other domains of social life (e.g. Papoulias & Callard, 2022). We extend this work by hearing from a diverse group of PRs employed in a variety of research projects, enabling us to identify parallels across communities and areas of study, and to highlight the resistance work of these communities.

Limitations

This study has limitations that should be borne in mind. Although PRs in this study were involved in the first round of data analysis and some contributed to this manuscript, we were not able to fully engage them throughout the analysis process because the grant (and therefore their contracts) had ended. Although common in participatory research, and tied to the impacts of neoliberalism (e.g. inadequate funding and supports for participatory research; Guta et al., 2013; MacKinnon et al., 2021; Ross et al., 2024), this likely contributes to the very harms we have detailed. Many participants were engaged in PR through broader peer work (e.g. as peer support workers) and at times it was difficult to separate their experiences of research from other peer experiences, given these often took place within the same spaces. This may suggest that our findings are also applicable to other peer contexts, although additional research is required to confirm this. Finally, our work centred the experiences of PRs and thus we cannot know the intentions of other research team members.

Our findings point towards the need for more cautious and critical utilization of peer research. Collectively, we have diverse opinions about how this is best accomplished, ranging from approaches to improvement (e.g. internal evaluations of participatory projects, a PR bill of rights, education for teams and institutions) through to a move away from peer research to explore alternative mechanisms for addressing the power-sharing goals of participatory and other community-engaged research methods. This is not to undervalue the benefits that PRs bring to research: we are aware that this study both benefited from PR labour (e.g. in creating conditions for PRs to share critical details that they likely otherwise would not have disclosed) and enacted some of the harms we describe (i.e. as a consequence of working in the neoliberal academy where systemic oppressions are active; Ross et al., 2024). This was despite our team's attempts to adhere to participatory research practices intended to mitigate power imbalances, such as the inclusion of people with lived experience in the conception, design and execution of the project.

We do not wish to undermine the agency of PRs to make decisions about their involvement in research; our data show that communities are well aware of these harms and respond strategically. However, we call on research teams and institutions to proactively and reflexively anticipate and be accountable for these harms, lest our research practices should reproduce the power relationships they are intended to disrupt. As aptly summarized by one of our team members:

> If you're not at some point going to accept people's lived experience and their knowledge acquired thereof as having some sort of equivalency to textbook knowledge, then all this peer stuff is just a way to get cheap fucking labour. That's all it is. (Reflections 9)

Acknowledgements

We wish to acknowledge the essential contributions of PEERS project staff and participants to this manuscript. Stella Schneckenburger provided administrative support in the preparation of the manuscript.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This manuscript draws on research supported by the Social Sciences and Humanities Research Council of Canada.

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