

FULL-LENGTH ARTICLES

Creating Research Partnerships With People With Traumatic Brain Injury From Underserved and Made-Marginalized Communities: The Need for Accommodations and Trauma-and Violence-Informed Dialogue

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Background

Involving persons with lived experience (PLEx) as research partners is increasingly recognized as valuable in health and social sciences, particularly where behavioral and social determinants intersect with health. Unique considerations arise when partnering with PLEx from underserved, marginalized, and trauma-affected communities. Traumatic brain injury (TBI) co-occurs with other health and social inequities; populations experiencing trauma, poverty, and systemic violence carry greater TBI burden and poorer outcomes, yet are underrepresented as research participants and especially as research partners. Meaningful inclusion of these communities is needed to center their voices in research questions and design, however researchers require guidance on the intersectional impacts of TBI, trauma, poverty, and mental health, and on how to operationalize equitable partnerships that accommodate these realities.

Objective

To identify barriers and facilitators to engaging individuals with TBI from underserved and marginalized communities as research partners, and to generate concrete recommendations to mitigate barriers and promote accessible, trauma-informed partnerships.

Methods

We conducted a partnered qualitative study. Demographic information was collected from consented participants with histories of TBI, trauma, and marginalization. Two virtual focus groups were held using questions co-developed with a research partner with lived experience. Focus group topics included the perceived need for research partnerships with PLEx of brain injury and marginalization; required accommodations and accessibility measures; and preferred practices for addressing power imbalances and fostering safety and

genuine partnerships. Sessions were recorded, transcribed, and analyzed using thematic analysis to identify patterns, themes, and subthemes. From identified themes, we developed specific recommendations for researchers.

Results

Ten individuals consented; five attended focus groups despite repeated reminders, with non-attendance attributed to memory, organizational challenges, and unstable life circumstances—illustrating practical barriers to engagement. Analysis yielded three principal themes: (1) Need for Trauma- and Violence-Informed Dialogue — emphasizing recognition of trauma histories, sensitive communication, and practices that avoid re-traumatization; (2) Research Collaboration and Partnerships — underscoring the importance of shared decision-making, power redistribution, meaningful roles, compensatory practices, and sustained relationship-building; and (3) Need for Accommodations and Accessibility — detailing flexible scheduling, multiple communication modalities, memory and cognitive supports, and practical assistance (e.g., transportation, technology). From these themes, we derived eleven actionable recommendations for researchers to consider when designing and implementing partnerships with PLEx of brain injury and trauma.

Conclusions

Partnering with PLEx represents a paradigm shift capable of informing systemic change in healthcare and research. Engaging PLEx of brain injury from underserved and marginalized communities can deepen understanding of their complex needs and support more equitable access to care and rehabilitation. Implementing trauma- and violence-informed approaches alongside concrete accommodations can enable accessible, meaningful, and ethical research partnerships.

Introduction

The concept and merit of involving persons with lived experience (PLEx) as partners in research is increasingly well recognized, particularly in fields of health and social sciences where complex behavioral and social factors intersect with health and well-being (Price et al., 2022; Tutton & Barker, 2019). Research partnerships extend beyond PLEx research participation whereby PLEx are actively engaged as collaborators throughout the research process (e.g., setting priorities and identifying research questions, designing studies, collecting/interpreting data, and disseminating findings), rather than only as study participants or subjects (Canadian Institutes of Health Research, 2014).

This expanding appreciation for the value of lived experiences in research partnerships reflects an evolving paradigm shift towards more inclusive and participatory methods, with the ultimate aim of transforming health and intersecting social systems and practice. This not only enhances the ecological validity of research, but is also relevant and transformative from the perspective of health outcomes and thus, social (and societal) well-being. However, unique considerations must be applied when partnering with

persons with lived experience in research, especially those from communities who are underserved and made-marginalized, and thus may be considered as ‘hard to engage’ (Liao et al., 2025). For purposes of this study, we have chosen to utilize the terms underserved and made-marginalized, recognizing that systemic societal and structural barriers can create marginalization, and limit access to services and research engagement (Badesha et al., 2026; Katz et al., 2020; Wiseman-Hakes et al., 2023).

Within the field of public health, it is also well known that among underserved and made-marginalized communities, there exist co-morbidities with other significant health conditions, such as traumatic brain injury (TBI). TBI is defined as an alteration in brain function or other evidence of brain pathology, caused by an external force (Menon et al., 2010). It is recognized as a global public health issue that is the leading cause of death and disability worldwide (Huang et al., 2024; Menon et al., 2010). There is widespread recognition that a history of traumatic brain injury (TBI) is associated with increased risk of a range of adverse lifelong brain health outcomes, and other long-lasting health consequences (Ayton et al., 2024; Scholten et al., 2016). However, the impact of TBI extends well beyond physical health and has a bi-directional relationship with the social determinants of health (Centers for Disease Control and Prevention, 2023; Dams O’Connor et al., 2014; Taylor et al., 2024).

The lifetime prevalence of traumatic brain injury (TBI) of all severities (mild to severe) in the general population is estimated to be around 8.5% to 12% globally (James et al., 2018; Karamian et al., 2025; Nguyen et al., 2016). Nevertheless, significant disparities exist among populations that sustain TBIs, with a greater burden and poorer outcomes associated with those who experience health inequities, lower socioeconomic status and are from communities who are often considered as underserved (Durand et al., 2017; Haag et al., 2022; Manoranjan et al., 2022; Moynan & McMillan, 2018; St. Ivany & Schminkey, 2016; Stubbs et al., 2020; Wiseman-Hakes et al., 2023). Furthermore, having a TBI often leads to reduced access to the social determinants of health (Centers for Disease Control and Prevention, 2023; Dams O’Connor et al., 2014; Taylor et al., 2024), and given that among certain populations who are frequently underserved, the prevalence of TBI is disproportionately high, this perpetuates a cycle of inequity. These communities include (but are not limited to) those who are precariously housed or experiencing homelessness, who have experienced violence and abuse, and are involved with the criminal-legal system (Wiseman-Hakes et al., 2020, 2023).

In contrast to the prevalence of TBI among the general population, the prevalence (of any severity) among individuals experiencing homelessness has been reported as 53.1%, (Stubbs et al., 2020) at least 75% for survivors of intimate partner violence (IPV) (Haag et al., 2022; Manoranjan et al., 2022; St. Ivany & Schminkey, 2016), and at least 80% among individuals experiencing incarceration (Durand et al., 2017; Moynan & McMillan, 2018).

Moreover, given that many of these injuries are the result of physical assault and violence, these are communities who have also experienced complex psychological trauma in addition to their TBIs (Schwarzbold et al., 2008; Wiseman-Hakes et al., 2020, 2023). These communities are not mutually exclusive, and many intersectionalities exist (Wiseman-Hakes et al., 2023).

There is also limited representation of these communities in traumatic brain injury care and rehabilitation research both as participants and even less so, as research partners. Consequently, there is a lack of understanding regarding the care and rehabilitation needs and priorities of these communities. Further, their TBI sequelae are often superimposed upon the neurobiological impacts of trauma on the brain and behaviour, with high prevalences of co-morbid mental health issues including Post Traumatic Stress Disorder (PTSD), depression and anxiety (Schwarzbold et al., 2008), chronic pain, as well as social and health inequities, which add additional complexities (Wiseman-Hakes et al., 2023).

Historically, these are the individuals with multiple co-morbidities and challenges who are excluded from research as they are the 'outliers' with mental health and behavioural challenges. They are not included due to the typical exclusion criteria of; history of psychiatric illness, substance use or prior incidence of TBI, or other neurological disorder. Thus, published rehabilitation research is generally not applicable to these individuals.

While there exists a body of literature which addresses how to engage individuals with experience of trauma as research participants (Alessi & Kahn, 2023; Edelman, 2023; Liao et al., 2025; Maas et al., 2017; Working Group of the Knowledge Hub Community of Practice, n.d.), there is limited literature on how to engage them as partners in research (Jumarali et al., 2021). Currently, little is known about the factors that hinder and/or promote the autonomous involvement of people with TBI from made-marginalized and underserved communities as partners in the research process. There is a paucity of research which aims to understand and address their unique and complex care and rehabilitation needs, particularly as recent evidence suggests that many feel unseen and that their needs are not met by current traditional medical practices (Hoepner & Keegan, 2023; Wiseman-Hakes et al., 2023; Wiseman-Hakes, Riess, et al., 2025). This is of particular importance as their lack of access to care that addresses the cognitive, communication, emotional-behavioural, and physical sequelae of TBI perpetuates the cycle of marginalization (Wiseman-Hakes et al., 2023). Further, the co-occurring conditions of PTSD and other mental health complexities are important considerations for research involvement (Wiseman-Hakes, Albin, et al., 2025; Wiseman-Hakes et al., 2023). These factors must be addressed in order for rehabilitation to be meaningful and successful and to address intersectionalities such as trauma and precarious housing. This is critical as most of these individuals do not receive adequate care or any rehabilitation, let alone specialized rehabilitation services. This results in significant social and financial costs to the individual and society.

There exists a great need to involve key interest holders (Akl et al., 2024) with TBI from these communities as partners in the development and conduct of research to ensure their voices are centered in the research questions, research design and interpretation of research findings. This is necessary to inform best practices (Maas et al., 2017). However, many barriers to these partnerships exist currently, and to mitigate these, researchers need to understand the intersectional impact of TBI, trauma, poverty, and mental health challenges that may contribute to or act as barriers. Moreover, researchers need guidance on how best to operationalize these partnerships in ways that accommodate for these intersectionalities and mitigate barriers.

Thus, the **aims** of this qualitative research study were to: a) understand from the perspectives of interest holders with lived experience, the barriers and facilitators to engaging individuals with TBI from these underserved and often, made-marginalized communities as partners in research, and b) to develop specific recommendations for knowledge translation to mitigate these barriers. Data from this study is necessary to understand barriers to research engagement and partnerships, to inform researchers, healthcare providers and healthcare policy regarding factors which may facilitate the development of research processes to optimize outcomes for these individuals.

Findings from this study can also provide a framework for researchers to advance the development of co-creation and engagement of individuals with lived experience as partners in research with the ultimate aim of informing research that is meaningful, relevant and addresses the unique needs for rehabilitation practice, clinical care, and continuity of care among these underserved communities.

Methods

This qualitative study was reviewed and approved by the University Health Network Research Ethics Board REB# 23-5229, with a secondary review and approval by the Community Research Ethics Board of Ontario (CREO) #317.

This study was co-created in partnership with an individual with lived experience of brain injury (acquired and traumatic) and experience of being underserved and made-marginalized. The study was developed and conducted collaboratively between University Health Network-Toronto Rehabilitation Institute and the Compassionate Justice Fund (The Compassionate Justice Fund [CJF], n.d.) in partnership with the Ontario Brain Injury Association (The Ontario Brain Injury Association [OBIA], n.d.). The CJF is to our knowledge, the only program in Canada whose mandate is to bridge a critical gap in funding and access to rehabilitation services for people who have sustained a TBI through means of violence, abuse, intimate partner violence, and those who have experienced precarious housing, and who have not had any prior access to rehabilitation or access to other funding for services. The CJF supports individuals age 16 and above who live in Ontario Canada.

The methodology for this study was informed by a Trauma and Violence Informed Care (TVIC) approach. TVIC is a framework for understanding and responding to individuals who have experienced trauma and violence. It recognizes the widespread impact of trauma, and goes beyond trauma informed care (TIC) to consider not just what happened to the individual, but what is happening systemically in their environment (Isobel, 2025; Wiseman-Hakes, Riess, et al., 2025).

This manuscript was prepared in accordance with the consolidated criteria for reporting qualitative research (COREQ) (Tong et al., 2007).

Research Team and Positionality

The research team for this study has well-established relationships with individuals from these communities and was therefore well-situated to work collaboratively to understand the barriers, identify facilitators, and develop best practices for the engagement of underserved and made-marginalized individuals with TBI in research. The team included one person with lived experience of TBI as a research co-creator (RCC). Several members of the research team have an established history of research co-creation with persons with lived experience (Wiseman-Hakes et al., 2020; Wiseman-Hakes et al., 2025).

Further, the principal investigator (PI) (CWH) is a registered speech language pathologist with expertise in the cognitive and communication disorders associated with traumatic (and acquired) brain injury and trauma. She did not provide any clinical treatment to any of the participants, however had an in-depth understanding of their challenges. Together with the research team, considerations were given to the types of accommodations and trauma informed approaches that would facilitate participation.

Research Governance: Research Co-Creator

To ensure our research was reflective of the needs of persons with lived experience, we engaged a research co-creator (RCC) as a key member of the research team. The RCC had worked previously with the PI (CWH) on another co-creation project where they are co-authors of a book chapter and accompanying video, regarding provision of culturally responsive and trauma-informed services for adults with acquired neurogenic communication disorders (Wiseman-Hakes et al, 2025). Their collaboration and partnership were developed through many months of relationship building, navigating a significant history of the RCC's trauma and building trust. Based on this experience, the PI invited the RCC to be a co-creator partner on this study. The RCC had also been supported in accessing trauma-informed brain injury services through the CJF, and their sole source of income is through a government disability support program. They have experience of precarious housing and food insecurity. They identify as Non-binary Trans "Neuroqueer" (Mental Health America, n.d.) grounded in core values of Transnational Anti-Colorism, Anti-Black Racism, and praxis of Decolonial Transcultural Communications, with their adulthood shaped by 20 years

Table 1. Summary of the role of the Research Co-creator within the research process

Research Stage	Research Co-Creator Involved?	Notes
Development of Research Questions	Yes	NA
Preparing of Grant Application	Yes	The RCC consulted throughout the writing of the grant and was considered as a person with lived experience partner by the granting agency
Background Literature Review	No	The RCC provided their lived experience and their work as an advocate for others with lived experience that was consistent with reviewed literature
Development of Qualitative Methodology	Not directly	The RCC is not a trained researcher and was not familiar with qualitative methods. However, the concepts of qualitative research were discussed and the RCC was in full agreement regarding the use of group interviews.
Development of Interview Questions	Yes	The questions were developed in partnership with the RCC.
Development of Accommodations	Yes	The accommodations were developed in partnership with the RCC and the PI. The RCC made the suggestion of developing and sending a welcome video in advance of the group interviews and sending the questions in advance to accommodate for slow processing.
Conducting Group Interviews	No	NA
Review of transcripts and coding	No	The RCC has a history of brain injury with resulting slow processing, and challenges with reading lengthy documents
Developing themes	Yes	The RCC was an integral partner in developing the themes based on the codes and supporting quotes
Developing recommendations	Yes	The RCC was an integral partner in the development of recommendations.
Writing of Manuscript	No	The RCC reviewed and provided suggestions as appropriate.

lived experience of ABI (including mTBI and ABI). Recently, they were accepted into the Asian American Justice and Innovation Lab (*Asian American Justice Innovation Lab*, n.d.) Formations" leadership mentorship program and will begin leading their own community lab centred on "Language Justice" rooting into the Sins Invalid framework of "Disability Justice" (Sins Invalid, n.d.). The RCC was involved across the research process from being a co-investigator on the grant application that supported the project to the development of the final recommendations.

The researcher's identity, credentials and positionality were shared with participants through a welcome video (see methods) that was sent to participants in advance of the focus group-semi structured interview(s).

As participants had already been provided support through the CJF, they were assured that their involvement in the study would not impact their future relationship to the CJF in any way.

Theoretical Frameworks

A *Community-Based Participatory Research (CBPR)* (Collins et al., 2018) was used as the overarching framework to inform this qualitative study. CBPR emphasizes partnership between researchers and community members throughout the research process. CBPR involves sharing power and decision-making, ensuring that the community's knowledge and input shape

the research questions, methods, and outcomes. CBPR is an approach that fosters trust and sustainability within the community (Collins et al., 2018; Kidd & Kral, 2005).

In keeping with this framework, this study was co-created in partnership with the RCC who has lived experience of brain injury (traumatic and acquired) and psychological/emotional trauma who identifies as being from a made-marginalized and underserved community.

We also applied an *Inclusion and Diversity Framework* to our research, which actively seeks to include underrepresented groups (Lignou et al., 2024). This framework is of particular importance as there is a paucity of research as well as clinical practice guidelines inclusive of persons with lived experience of brain injuries (both traumatic; TBI and acquired; ABI, specifically through attempted strangulation during acts of intimate partner violence) as well as trauma and experiences of being made- marginalized. This framework can involve specific outreach strategies, culturally competent research practices, and provide resources that ensure all participants can engage meaningfully (Lignou et al., 2024).

Participant Selection

Participants were recruited through the Compassionate Justice Fund (CJF, 2026). The CJF's mandate is to address gaps in funding and access to rehabilitation for individuals in Ontario Canada who have experienced traumatic brain injury related to violence, abuse, intimate partner violence, or precarious housing and who lack access to other rehabilitation funding or services.

Sampling: All individuals who met the above inclusion criteria and had applied for the fund since inception (January 2021) were considered eligible to participate in this study. Recruitment occurred over the period from November 2023 to March 2024.

Method of Approach: A study information flyer using simplified language to accommodate for any cognitive-communication challenges, was posted on the "Participate in Research" section of the CJF website. Prospective participants (i.e., all those who had applied to the CJF) were sent a study information flyer by email and informed that they would be contacted by email to discuss the study, ascertain potential interest and gain verbal consent. Prospective participants had the option to reply to the initial email with a 'I prefer not to be contacted'. If an individual did not reply, it was assumed that they agreed to be contacted. Persons without an available email or invalid email were called directly. Consent was obtained verbally to reduce barriers to participation; i.e., most eligible participants only had access to a phone, and did not have access to a computer, printer or scanner.

Sample Size: Seventy-eight individuals were eligible for this study. Ten consented to participate however only 5 participated.

Non- Participation: Although 78 individuals were eligible for this study, challenges with working with individuals from these communities were encountered. As stated above, all individuals who had applied to the CJF

from 2021- 2024 were considered eligible. Eleven individuals had insufficient contact information, and an additional 14 could not be contacted (e.g., incorrect contact information). Five did not meet the eligibility criteria despite having applied to the CJF. Ten declined to participate. Of the 38 remaining eligible participants, recruitment for this study was unfortunately capped after 13 individuals verbally expressed interest in participating, due to the funding limitations of the grant for honorariums.

Three individuals agreed to be contacted but did not consent. Reasons given for lack of consent included:

- Still incarcerated or recently released
- Lives were too chaotic (e.g., unstably housed, poverty, mental health challenges)
- Consent form was too long, complex and onerous (consent done verbally)
- Feeling of lack of safety or trust
- Scheduling issues.

Five individuals consented but did not participate despite being contacted several times in advance with reminders; challenges with memory and organization were given as reasons. Every effort was made to accommodate those who wanted to participate within the confines of the time limitations of the grant. One individual expressed their frustration and disappointment with themselves for not participating.

Institutional Barriers: It is important to recognize that despite efforts and commitment by organizations to involve persons with lived experience (PLeX) as partners in research, barriers also exist at institutional levels. We were fortunate to be the first grant allocated by the funding agency. However, there were many organizational complexities experienced by our research team notwithstanding the support of the funding agency team and the PI's Research Institute, which revealed the need for institutional infrastructure and clear guidelines to be in place prior to research commencement. For example, within our grant budget, funds were allocated to pay the research co-creator an honorarium for their expertise and contributions. This study was conducted in Canada, and the Canada Revenue Agency stipulates that any honorarium greater than \$500 is taxable income. However, this impacts those receiving honorariums whose income source is through government programs, is limited, and which leaves individuals living below the poverty line. This was the case with our research co-creator. The grant was spread over two years, and to receive the honorarium, they were required to complete a number of forms (each year of the grant) that would be submitted to the Disability Payment Agency, declaring this additional money. The amount of the honorarium would have impacted their disability income. Moreover, our

co-creator, like many people with brain injuries, has challenges with slow processing, organization and was overwhelmed by the multitude of forms to complete which became a barrier to their participation. It took several months of institutional ‘back and forth’ before we came up with a solution.

Accommodations and Trauma and Violence Informed: Given that participants had a history of brain injury and associated cognitive and communication challenges as well as history of trauma, the research team made every effort to make participation in the study accessible and safe. This is consistent with an ***Inclusivity and Diversity Framework***, whereby the researchers do their best to ensure all participants can engage meaningfully. The following accommodations were put in place.

1. The language for the information flyer, consent phone call and demographic interview was simplified to accommodate for cognitive and communication challenges subsequent to the TBIs. (Note that we were unable to accommodate the length or language of the consent form as this was dictated by the Research Institute’s Research Ethics Board).
2. A welcome video was created and sent in advance to consented participants. The purpose of this short video (recorded using Zoom) was to;
 - a. Introduce the principal investigator (CWH) and the research assistant (MF); thank and welcome participants; and share some of their personal information to facilitate a feeling of comfort and safety.
 - b. Provide relevant background information and (research) vocabulary and explanations.
 - c. Reiterate the rationale for the research and why their participation was of value and importance.
 - d. Explain the research procedure to mitigate any uncertainty or concerns.
3. Questions for the semi-structured group interviews were sent a week in advance to allow participants time to review and reflect on the questions and think of and/or write down their responses (should they choose to, and to accommodate slow processing time).
4. Participants were invited to email the research assistant in advance of the focus groups if they had any questions that required clarification or concerns. No participants identified any questions or concerns.

5. Electronic Communication including the secure Microsoft Teams link and instructions were sent to participants a week in advance.
6. To accommodate for memory and organizational challenges, the research assistant assisted with accommodations regarding scheduling of the interview groups, and then followed up with email and phone reminders the day before scheduled interview groups.
7. At the onset, participants were verbally reminded that the focus group was a safe place and they should feel comfortable to share with support and without judgement.
8. Microsoft Teams transcription was used both as a transcription methodology and so that participants could read live captions to aid in processing and comprehension as needed.
9. Harm Protocol: Participants were advised that should they feel upset at any time during the focus group, they could pause or stop their participation and would be offered the opportunity to debrief with a study team member, who was the community support person for the CJF and OBIA and who was a person in training to become a psychotherapist. The majority of participants knew this team member as she supported the intake and case coordination for all CJF recipients.

Data Collection

Data were collected across three time points: First, as all participants had previously applied to the CJF, demographic data provided on their intake forms was utilized (with consent). Additional demographic information was collected during a telephone-based interview with author MF, following the consent process. (See [Table 1](#) for Demographic Information).

Two, online semi-structured focus group discussions of approximately 1.5 hours in length were conducted through a secure Microsoft Teams Platform. The first group had 4 participants and the second group only had one, as others who had consented and agreed to participate in the second group did not attend (reasons described above). To ensure consistency and support analytic rigor, a parallel approach between the first and second interviews was applied using the same questions and the same or similar probes. As described above, the questions were sent to all consented participants a week in advance of the interviews so that they could reflect on and consider their responses in advance if they chose to do so.

Interview Guide

The questions for the interview guide were co-developed with the RCC with lived experience. They were also informed by the PIs understanding of the types of considerations and accommodations that are typically needed by people with brain injuries and associated cognitive and communication disorders and experience of trauma. Focus group questions addressed the following areas:

- a. Desire and need for research partnerships with PLEx of brain injury and experiences of being made-marginalized.
- b. Need for accommodations and accessibility and what that should involve.
- c. Best (desired) practices for mitigating power imbalances, creating a feeling of safety and partnership.

Analysis

A qualitative methodology (Kim et al., 2017; Sandelowski, 2010), specifically, thematic analysis (Ahmed et al., 2025; Braun & Clarke, 2022), was determined as the best approach to explore the research aim: barriers and facilitators to involving persons with lived experience of brain injury and trauma from underserved and made-marginalized communities as partners in research. Thematic analysis is both iterative and reflexive, whereby the researchers actively engage with the data and acknowledge their own theoretical positioning and biases throughout the process (Ahmed et al., 2025; Braun & Clarke, 2022).

Setting

Focus group discussions were recorded using the Microsoft Teams recording function, and notes were taken during the discussions by the research assistant (MF). Focus group discussions were transcribed using the Microsoft Teams transcription function. Data were analyzed using thematic analysis, guided by the framework and procedures developed by Braun and Clarke in 2006 and updated in 2022 (Braun & Clarke, 2022).

Data Analysis

The process of analysis began with two of the authors MF and CWH reviewing the Microsoft Teams transcripts individually, and familiarizing themselves with the data, along with a review of the notes taken by MF during the interviews. Transcripts and notes were analyzed using a thematic approach and initial descriptive codes were developed. Researcher triangulation through continuous discussion and reflection helped ensure an enhanced and iterative understanding and interpretation of the data, identification of emerging themes, patterns and subthemes across transcripts, as well as clarifying context and nuances to ensure that interpretations and

codes were grounded in the participants' experiences. The analysis involved prolonged engagement with the data, presentation and discussion of data and ongoing review of transcripts.

We continued to compare and contrast codes until a final coding scheme was developed. Finally, we maintained a detailed audit trail, including minutes of our debriefing discussions, and a record of our evolving thematic code map, to ensure transparency of the analysis.

The research co-creator reviewed and agreed with the final themes and subthemes.

Positionality was also an important component as the researchers, including the co-creator with lived experience, were from different disciplines and backgrounds, with differing areas of expertise. These include those with expertise in TBI and ABI (CWH, MF, FIM, RW), communication, cognition and trauma (CWH) brain injury rehabilitation (MF, CWH), violence, racism and intersectionality (RR), mental health and trauma (CWH, MIF, FIM), intimate partner violence (CWH, RW, RR) substance use (MIF) and criminal legal system (CWH, FIM) and the social determinants of health (CWH, MF, FIM).

Member Checking: While member checking is a typical step in qualitative research, it was not conducted due to the logistical constraints in recontacting participants following data collection.

Findings

Description of Sample: Demographics

The final sample of 5 was comprised of males and females. Due to small cell counts, specific numbers were not reported for all variables. Of note, 100% had experienced adverse childhood events, and 100% had co-morbid mental health challenges.

Self- Report of Post Injury Challenges

Of note, 80% of participants reported challenges with communication, mood and pain since their injuries, and 75% reported challenges with cognition, mood and managing their emotions. As reported in [Table 2](#), none of the participants had received previous support or therapy for any of these issues.

Themes

Three overarching themes were identified with associated subthemes and supporting quotes to inform accessible and meaningful participation as collaborators in the research process and best practices in developing research partnerships. The themes align closely with core Community-Based Participatory Research (CBPR) principles and point to specific adaptations necessary to actualize the principles. It is noteworthy that many of the themes reflected participants' prior experiences within the healthcare system that are also documented in the literature (Hoepner & Keegan, 2023).

Table 2. Demographics

Demographic Variable	Description **
Total number of consented participants	10
Total number of actual participants	5
Sex	Males and females
Gender Identity	Women, men, non-binary-gender fluid
Number of Diagnosed TBIs	Range 1-2, and unsure
~ Mean Age at first TBI	20 (mean) 15.9 (SD)
Undiagnosed TBIs	Yes (N= 2)
Causes of TBI	Motor Vehicle Crash (MVC) Fall Intimate Partner Violence (IPV) Sport Physical abuse/assault (other than IPV)
Loss of Consciousness	N=5, 100%
Went to ER	N=4, 80%
Admitted to Hospital	N=3, 60%
Received medical/rehabilitation care and support prior to involvement with CJF	No=4, Yes = 1
Geographic Location	Urban (n = 3), Rural (n = 2)
Experience of Substance Use	N= 3, (in the past)
Experience of Mental Health Condition (previously or current)	N=5, 100%
Experience of Adverse Childhood Events	N=5, 100%
Level of Education	N= 5, 100% some or completed undergraduate studies
Experience of Food Insecurity since injury(ies)	N= 3 (in the past) 60%
Experience of Unstable Housing or Homelessness since injury(ies)	N=4 80% (includes previously and current)
Experience of Criminal Justice System Involvement since injury (ies), (as both victim and/or committed an offense)	N=4 80% (includes previously and current)
Primary Income Source	Disability (majority), FT employment (N=1)

** Given small cell counts, exact numbers are not reported for some variables for purposes of confidentiality: Data are provided only for the 5 who participated rather than for the 10 who consented.

The first theme, **Need for Trauma and Violence Informed Dialogue**, included four subthemes: 1) Considerations for language use-language matters, 2) The types of questions that are asked, 3) How questions are asked and 4) Humanize the relationship.

Participants collectively identified that researchers need to use safe, non-judgemental discourse and facilitate collaborative partnerships that are considerate of participants' "cultural, sexual, and spiritual identity and also need to consider how these factors interrelate". Participants emphasized that this also relates to other equity-based considerations such as level of education, health literacy, experiences of racism, sexism and systemic violence. Participants highlighted that 'researchers need to understand that a history of trauma may influence their ability to participate in research as well as to receive responsive care'. Specifically, they stated that "dialogue needs to be thoughtful and intentional" (P2, P3, P5)), to avoid triggering and or re-harming. Participants felt strongly that researchers (and research staff)

Table 3. Self-Report of Post Injury Challenges

Self-reported Post Injury Challenge	Number (/5)	Percentage
Communication	4	80%
Thinking/ Cognitive Abilities	3	75%
Mood	3	75%
Managing Emotions	3	75%
Physical Issues	2	40%
Organizing Myself	2	40%
Accessing the Community	3	75%
Independence in the Community	2	40%
Using Technology	2	40%
Mobility	2	40%
Pain	4	80%
Sleep Disturbances	4	80%
Other (unspecified)	1	20%

require additional training and experience in trauma (and violence) informed care (P5), particularly for instances where individuals are required/invited to speak about personal experiences and when completing consent forms. They further emphasized that certain questions may be invasive, and that “asking sensitive questions requires the use of sensitive language”. Participants highlighted the need for researchers to understand (and assume) that potential collaborators/participants/people from these communities are likely to have experienced trauma or prejudice for any variety of reasons and that researchers must respect that and operate appropriately (using trauma and violence informed dialogue and practices). They also clearly emphasized the need to “humanize the relationship” between research and research partners with lived experience, to mitigate power dynamics and for researchers to share something of themselves on a personal level to demonstrate mutual respect and vulnerability, illustrated by the following;

“A priority is humanizing the relationship first to have relational safety and comfort. And by that, I mean personal sharing at the beginning, I know that might not seem professional or what, but I think to bring you can only kind of come meet each other before the work happens by knowing each other better and understanding”. (P2)

“This form of relational intimacy, I think this offers, because if we don’t know if the other person, it’s about safety, but it allows honest sharing [...] and can give someone courage to speak up if there isn’t balance if they trust the person they are working with. And it is safe to speak up, because if the person’s partner is safe, they can be an anchor if something comes up that is triggering or, or if they need a need like an accessibility need”. (P5)

One participant shared their experience about having to live with a brain injury and dealing with systemic violence in healthcare and healthcare research.

“Overcoming brain injury is one thing, but overcoming inhumane treatment or violence or general feelings from the the overall group [...] well then I must get over that as well” (P1)

Others emphasized the need for non-violent, trauma informed and anti-oppressive communication practices.

“I notice umm that in terms of, maybe communication styles that are nonviolent. That could be subtle, but this awareness for words and communication style are better practices.” (P4)

“ensuring that umm with umm anti oppressive language is uh within the communication and awareness within like racially marginalized folks likewise with gender and gender diverse and the the rest, but particularly with trauma and violence and precarious housing, because of how in the different that particular trauma and traumas need extra trauma responsivity and sensitivity.” (P4)

Participants also expressed the need for researchers to clearly and overtly state that the research environment and collaboration would be a ‘safe place’ and ‘without prejudice’.

“So I think it’s good to know that you’re that we are in a safe space and maybe just those words without prejudice would help me.” (P2)

The second theme, **Research Collaboration and Research Partnerships** elucidated participants’ strong belief that people with lived experience of brain injury and who are from underserved and made-marginalized communities want to and should participate as partners in research. This is necessary to develop research questions and protocols that are inclusive of these communities and which can a) *advance knowledge and understanding of experiences* and most importantly, b) *create solutions that are sensitive to the intersectionality of brain injury, trauma, equity issues and access to the social determinants of health and well-being, that can address the inequities and gaps in care.*

They further stated that they felt these types of collaborative research partnerships were opportunities for them to ‘advocate for others’ and ‘give back’.

“We should collaborate and see the research data collection, because of course we’re there. We’re the ones with no filters. We’re the ones telling you all the things you need to know.” (P3)

“Well, I have brain injury since childhood so all my life I’ve been excluded, you know? So inclusive is the only word I like.” (P1)

“We’re honest and we’re gonna speak what we what our needs are and what we feel like might be (and often is) neglected (in research).” (P3)

Another participant expressed the need for researchers to ensure that research opportunities and research partnerships are more widely publicized to increase participation. They stated that,

“You need to get the word out so that more applicants can participate because you’re only getting a small amount of people who have brain injuries when there’s a wide group.” (P5)

“Getting more people to weigh in on the topic, you do get a more wide -ranging perception.” (P2)

Participants also expressed that they should be involved in several stages of the research process; 1) Development of the research question, 2) Development of the methods and 3) where possible and appropriate, depending on the type of data, be involved in the interpretation of the data and its’ implications. However, participants agreed that the *study design stage is the most important stage for their collaboration and partnership*. They further stated that *when advertising research and research partnership opportunities, researchers should clearly state that accommodations and accessibility will be provided*. (see next theme).

The third and final theme **Need for Accommodations and Accessibility** highlights a key area for research involvement and partnership. As theme 2 clearly identified, individuals with lived experience of brain injury with experience of marginalization and who are from underserved communities do want to be involved as partners in research, and they feel strongly that they have a voice and insights to offer. However, in order for theme 2 to be operationalized, researchers need to be cognizant of and sensitive to existing cognitive, communication, energy and fatigue, pain, sensory sensitivity and mental health challenges and constraints and associated needs for accessibility and accommodations.

Participants also stated that researchers need to understand that

“These factors/limitations/challenges can come and go and change or be invisible throughout the course of the research.” (P2, P3, P5, Paraphrased as expressed by all three participants).

“Researchers need to continually work to foster an embodied “felt-sense of safety” with us as research partners to accommodate for our slowed processing and ease of overwhelm and fatigue, so we [research partners] may stay within the “window of rest/digest” rather than triggering outside of their “window of tolerance” [overwhelm/shutdown]”. (P5)

Participants provided insights on and suggestions for a number of concrete accommodations that researchers could implement in order to promote collaborative research partnerships. They emphasized that researchers need to be conscious of participants’ “existing limitations and [needs for] accessibility” and to “appreciate and address these needs to facilitate an accessible and safe collaborative process”. (P1, P4).

These include considerations for the timing and duration of meetings; most participants requested accommodations for energy and fatigue levels; many are less ‘functional’ in the early morning and later afternoon. Thus, conversations regarding the best times to hold meetings was a recommendation. Participants also suggested that research meetings be no longer than one hour or at most one and a half hours in duration due to issues such as screen sensitivity, fatigue, challenges with sustained attention, and slowed processing. Participants also stated that whenever possible, researchers provide written materials in advance of meetings (ideally one week) to accommodate for challenges with reading, comprehension and slow processing. Allowances for increased response time in meetings and support and recognition that participants may have challenges with word finding and expressing what they want to say. Participants also clearly stated their awareness that they would need to ‘push themselves’ from an energy and processing perspective to participate as partners in research, but felt they could manage with built-in accommodations (and understanding), recognizing they may experience increased pain and fatigue afterward.

The following quotes illustrate participants experiences of having to push themselves while living with an invisible disability that can present differently from day to day.

“I push myself fairly regularly and hard to accomplish tasks that maybe they are even, you know, beyond what I should be.” (P2)

“People who have to learn about their limitation or restriction and and and and tell other because people cannot tell by looking you know so but but also it takes a long time for for people who need you to find out their limitation instead of to be a super person which is normal.” (P1)

“I need the extra time because I notice for every task, I try to accomplish any I wanna need to put more effort and I need to put extra time especially to learn and to master something may have difficulty understanding what I said or read.” (P3)

“I can know something really well today and then maybe two days from now I’m thinking I don’t know how to do this [...] So I’m saying that these symptoms are sometimes better, sometimes worse [...] I think the overwhelming part of it is that you just don’t know which day is gonna be.” (P2)

Researcher Reflections

The process for both participants, RCCs, and researchers is challenging and requires a lot of care and consideration and would benefit from better funding and organizational support. However, despite the financial limitations associated with a small grant and the numerous challenges associated with this type of work, this study was a labour love for all those involved. We were honoured by the trust of our participants and their passion and commitment to research partnerships and equitable advocacy. The personal experiences of the research team and engagement with participants served only to reinforce our commitment to equity, advocacy, and the need for research partnerships that truly reflect the voice and needs of persons with lived experience. The partnership with the RCC was critical to this project. The RCC and the PI have a long-standing relationship of mutual respect, trust and learning, and the PI is deeply grateful for the privilege of collaboration and the experiences of co-creation and partnership.

Research Co-Creator Reflections

The RCC shared the following comments in writing:

"As promised, here are my offerings of phrasing for the recommendations we spoke about....I am SO sorry for my last-minute-ness because I had positioned my brain/lens from another context experience.

With that in mind, I want to share with you I think this research and the recommendations are deeply thoughtful, considerate, and is evident rooted to honouring the participants in the study and to the co-creation and research partnerships that are so badly needed !!! Thank you for truly seeing me and taking the time to know me beyond my ‘pathology’".

Discussion

Inclusion of individuals with lived experience as partners in research is an evolving paradigm shift in research practice, however there is a paucity of evidence regarding the need for guidelines and recommendations for researchers on how to operationalize this partnership, particularly for individuals with complex histories including experience of trauma such as those with brain injury from underserved and made-marginalized communities (Wiseman-Hakes et al., 2020, 2023; Wiseman-Hakes et al., 2025). This study helps to bridge this knowledge gap by contributing

survivor led recommendations and guidelines from these individuals. Our findings from this co-partnered research highlight the barriers that limit access to services and research participation for these communities and underscore the deep interconnection between brain injury, trauma, and marginalization with exclusion from relevant research, healthcare exclusion, and systemic inequities. Furthermore, our findings validate CBPR as the appropriate framework, suggesting that concrete, actionable trauma and cognitive-communication aware accommodations including accessible and trauma-and-violence informed communication, trauma-and violence-informed procedures, explicit power-sharing and humanizing of relationships, and long-term capacity-building are necessary to make CBPR genuinely inclusive and effective for this population. Our study findings also clearly elucidate that individuals from these communities want to participate as partners in research, that their voices are important and relevant to address gaps in understanding and care, and that there are concrete ways in which researchers can facilitate participation. This can help to address the significant gaps in research to ensure it is inclusive of these individuals, which in turn can help to mitigate the gaps in access to care.

Our findings highlight that systemic challenges and institutional barriers, combined with a lack of trauma- and violence- informed training and poor application of these principles by researchers, as well as an insufficient understanding of the need for accommodations and equitable accessibility, continue to create significant obstacles to CBPR partnerships.

Furthermore, there is a need for the process of engaging RCCs and PLEx from underserved and made-marginalized communities to become easier and more streamlined from a research-organizational standpoint. This study describes the organizational and logistical challenges for all involved parties that create barriers for researchers and RCCs to initiate and effectively engage PLEx in this type of research. We hope that organizations will apply the findings of this study to inform future practices to create and integrate better structures that seek to mitigate these challenges as best as possible and support researchers, RCCs, and participants in conducting similar and needed research. The lessons learned during this research suggest that there are concrete opportunities and facilitators to reform research principles and practice that can mitigate these barriers.

Recommendations for Involving Persons with Lived Experience as Partners in Research

Based on our study findings and in collaboration with the RCC, we provide the following recommendations for researchers (and research institutions) aiming to include individuals with brain injury who are from underserved and made-marginalized communities in research. Researchers and research institutions should:

1. Engage in ongoing dialogue with research partners with lived experience, as well as engage in critical reflection and intentional action.
2. Study and apply principles of trauma-and-violence informed care when partnering with individuals with history of trauma.
3. Learn about the cognitive, communicative, physical and emotional challenges often experienced by individuals with brain injury, and ensure that concrete, personalized accommodations are put in place (e.g., but not limited to: timing and duration of meetings, sending materials in advance, use of slower and more simplified means of communication, provision of glossary of terms as needed).
4. Ask research partners what types of accommodations they need (and provide them!).
5. Mitigate any power imbalances and promote authentic researcher-partner relationships based on trust and respect.
6. “Express gratitude and humanize the relationship/partnership”.
7. Ensure language/dialogue and all materials are informed by TVIC principles as well as considerate of the common cognitive-communication challenges typically experienced by those with brain injuries: **Language matters**.
8. Work with community partners to ensure research partnership opportunities are widely disseminated to persons with lived experience.
9. Partner with persons with lived experience to identify relevant and meaningful research questions and engage them in the study design and methodology (at the very least).
10. Look to the Healthcare Excellence Canada Supporting Patient Engagement in Action framework for further information and resources (Healthcare Excellence Canada, n.d.).
11. The final recommendation is for institutional ethics board which should consider weighing the balance between the need for comprehensive and transparent consent forms with the cognitive burden associated (and thus, a barrier to participation) with the complex language and lengthy consent forms that are traditionally utilized.

Additional Recommendations

The following recommendations did not come from participants, rather they emerged from the research team's experience while conducting the research, and are important considerations.

1. Clarify any tax or other financial implications for administration of honorariums in advance of the study.
2. Provide support as needed to research partners with lived experience in completing forms regarding their honoraria.
3. Be prepared to adapt and respond as researchers, to the needs of participants throughout the study process as required, which may include offering or referring participants to community resources.

Strengths and Limitations

To the best of our knowledge, this is the first study to examine the barriers and facilitators to research engagement as partners in research for individuals with brain injury from underserved and made-marginalized communities and to provide specific recommendations from participants with lived experience. This provides researchers with concrete considerations and actionable items that can assist them in the application of sustainable Community Based Participatory Research Partnerships. Our findings have the potential to inform the adoption of guidelines for future research partnerships, through the provision of accommodations as well as accessible, and trauma-and-violence informed research principles and practices. An additional strength of this study was the inclusion of a research partner with lived experience, who contributed extensively to the methodology and interpretation of the research findings. A further strength was the implementation of accommodations and trauma and violence informed principles across the study and in every participant interaction. Participants expressed their gratitude for their involvement and how much it meant to them to be able to provide their voice and experiences on this important topic, and to advocate for others.

Our study is limited by the small sample size, and it is unlikely that we achieved data saturation; this is however, reflective of the immense challenges associated with conducting research with persons from these communities. Further, our inclusion of reasons for non-participation offers valuable information and considerations for further research. Additionally, despite the small sample, the research team, including the research partner with lived experience, carefully co-created the questions for the focus groups to gain maximum relevant information, and there was considerable synergy among participant responses.

Conclusions

Partnering with persons with lived experience in research using a Community Based Participatory Research Framework is an emerging paradigm shift that has the potential to inform systemic change in healthcare and society. Specifically, it can inform our understanding of the unique and complex needs of persons with lived experience of brain injury from made-marginalized and underserved communities and thus inform more equitable access to care and rehabilitation.

This paper highlights the need to embed a trauma-and-violence informed approach in research partnerships as well as the need to provide accommodations for cognitive-communication and physical-sensory challenges, to promote accessible and meaningful partnerships. It is our hope that the findings and lessons learned from this study will contribute to enhanced engagement and research partnerships, and contribute to better health outcomes and thus, social (and societal) well-being.

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