Observations and recommendations for conducting research in partnership with people with lived experience of homelessness

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This commentary addresses the urgent need for responsible research practices when conducting research on populations of people with lived experiences of homelessness. Recognising the marginalisation of this group by scientific investigators in both societies, this commentary seeks to address the ethical considerations, consent processes, and community engagement necessary to conduct meaningful and respectful investigative research in this population. By summarising basic approaches that prioritise data collection, participation and engagement, this piece aims to promote a deeper understanding of the unique challenges faced by people with lived experience of homelessness and the responsibilities of researchers choosing to work on this topic.

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People with lived experience of homelessness (PWLH) are some of the most marginalised and stigmatised populations in the world. Decades of research conducted by governments, non-profit organisations and universities have outlined both the upstream factors, events or circumstances that contribute to people becoming homeless, as well as the downstream health and social implications of living unhoused. By identifying and clarifying the social and environmental causes and consequences of homelessness, research like this is essential for informing public policy and improving social services. As important as this research is, working in and among PWLH has a unique set of ethical challenges. Factors such as undiagnosed mental illness, experiences of discrimination, social vulnerability, unaddressed trauma, substance use disorders, pernicious housing policy and limited personal freedom complicate the research landscape. This commentary outlines a set of recommendations based on the importance of adopting research methodologies such as community-based participatory research (CBPR), which respect the dignity and autonomy of people experiencing homelessness as a means to conduct research in a way that best informs social services and public policy.

Understanding the context

Inadequate shelter or living unhoused is one of the most important determinants of health.[1] Individuals experiencing homelessness represent a broad swath of the population, yet their numbers reflect a disproportionate level of mental health and substance use conditions compared with the general population.[2] In many ways, PWLH exist in a precarious balance between resilience and desperation.[3] While these differences vary by country and geographic region, research describing large health disparities between PWLH and the general population shows high rates of disease prevalence, severity and acuity.[4] In addition to health disparities, there are social and behavioural disparities that further contribute to the vulnerability and status of PWLH.[5] Research is one of the principle strategies to understanding and guiding effective practices to support PWLH. To develop impactful policies and practices, it is necessary to understand the context of working with PWLH and explore strategies for meaningful engagement. Here, I will discuss strategies for engaging PWLH, based on my own research in the two locations in the US—one urban and one rural. Doing this work respectfully and supportively means ensuring that participation is voluntary and informed, and that research in this population is not probative or extractive but supportive and collaborative. There are core elements of methods grounded in CBPR.[6,7]

People experiencing homelessness experience remarkable health challenges. Mortality rates for people experiencing homelessness are four times greater than the general population.[8] Physical illnesses associated with homelessness include malnutrition,[9] chronic pain,[10] skin diseases,[11] oral health,[12] pneumonia,[13] asthma and chronic obstructive pulmonary disease,[14] as well as infectious diseases such as tuberculosis, hepatitis C virus, HIV and AIDS.[1,15,16] Substance use and chemical dependency occur at higher rates in the homeless population.[17] Limited access to primary and preventive health services among people experiencing homelessness shows later-stage diagnoses of disease and higher occurrence of preventable hospitalisations.[18,19]

Mental illness and substance use disorder

The high prevalence of concomitant mental health and substance use disorder among PWLH impacts their ability to find and maintain steady employment, navigate their daily lives and establish consistent and safe behaviours. Mental illness affects one in four adults in the US.[20] In many cases, people with PWLH also have a disproportionate level of exposure to violence and abuse that contributes to a prolonged sense of isolation and vulnerability. This contributes to perceived social exclusion and heightened anxiety, which often promotes coping strategies associated with substance use and basic survival.[21,22]

Privacy concerns

In my role as a health services researcher, I have observed and listened to stories from people with housing insecurity describing their rational fears regarding data sharing and government surveillance. In the US, many people who live on the streets fear government intervention and oversight. For them, living on the streets is associated with a constant fear of being searched, asked to vacate a location or having their belongings stolen. In urban settings, privacy concerns may be linked with city policies attempting to keep the streets safe and clear to reduce the amount of public drug use and paraphernalia.[23] Yet, people who live on the street, like the general population, are not monolithic in their behaviour, ways of thinking or health status. To generalise this population would be a mistake.

Over the course of my research exploring how PWLH rate their health, one of the most deterministic factors mentioned was having time to recover and a safe space. Many describe their lives as a constant struggle, lived minute by minute and day by day. Under these conditions, there is little time to plan or develop strategies for the future, as immediate needs for shelter and food take priority. For people living moment to moment, finding shelter or a place to rest can be a welcomed break from the constant fear and anxiety of living on the street. Yet, despite the benefits of finding a room at a shelter, the conditions of many shelters are poor. People who have spent time in shelters report feeling unsafe, living under constant pressure and being routinely exposed to drug use.[3]

Under these conditions, it is reasonable that people living on the streets might be suspicious of university-based researchers or public health professionals asking them questions. What may appear as a necessary question about the use of a smartphone for access to health-related information could be perceived as probing into someone's social habits or personal choices. In another case, where a researcher may want to audio or video record an interview, perceived use of these approaches may elicit deep fear and anxiety in participants. In such cases, a researcher's well-intentioned desire to 'capture the authentic participant's voice' may be seen as intrusive and exploitative. What seems to be consistent among PWLH is their tendency to fiercely protect their own 'things' or 'property'. Where daily intrusions into personal space and freedom are normalised, researchers need to consider what additional questions or perceived intrusions might trigger in this population.

While no single approach may find generalisability across geographic or cultural landscapes, the following section explores the necessity of implementing thoughtful and intentional measures to protect the confidentiality and privacy of research participants.

Applying a community based participatory approach

One of the most widely supported methods for developing impactful and ethical standards of research in vulnerable communities is known as CBPR. The origins of this method were fashioned by Brazilian educator and social activist Paolo Freire, whose widely cited work *Pedagogy of the Oppressed*[24] emphasised how education could serve as a political tool to give voice to vulnerable and oppressed groups. While his influence has impacted social justice in medical education,[25] healthcare[26] and public and community health education,[27] one of the practical applications of his methods is CBPR.[28,29]

In addition to its social advocacy foundation, CBPR has a deep commitment to partnering with communities, which is fundamental to its purpose. This means that research conducted within the CBPR framework must prioritise sharing power and decision-making with community members. This 'levelling', as many have called it, refers to how researchers engage with communities and work to develop habits or management practices that ensure both the researcher and community are on the same level throughout the process. When initiating a project using CBPR, all team members should recognise the expectations inherent to collaborating with communities, which include:

(1) Sharing decision-making with community members;
(2) Committing to communicating clearly and effectively at all stages of the process (replacing academic jargon with plain language);
(3) Conducting preparatory work to translate technical or theoretical constructs into practical terms.

Implementing a CBPR framework into a community research project requires forming a team that is prepared to integrate the following nine principles of CBPR into their methodology:[30]

(1) Community is the unit of identity: define the community by its social construct, whether as a neighbourhood, cultural group, ethnic group or affinity group.
(2) Projects build on the strengths of a community, however defined.
(3) Supports collaboration and partnership across all phases of the research project.
(4) Power-sharing with all stakeholders.
(5) Embraces co-learning and capacity building with all partners or stakeholders.
(6) Achieves a balance between knowledge generation and intervention for the mutual benefit of all partners or stakeholders.

Table 1. Integrated CBPR principles with examples from research on people experiencing homelessness

Principles	CBPR construct	Practical example of working with people experiencing homelessness
Principles 1 and 2	Leveraging an asset-based model with members of the homeless community as the focus	Examine the health impact of city policy on people with lived experience of homelessness and ensure that members of the community validate experiences.
Principles 3 and 4	Shared leadership and decision-making across stakeholders from project initiation to completion	Establish a routine for agenda setting, meeting schedules, and roles. Ensure stakeholders and partners share leadership and acknowledge their roles. This means giving people with lived experience key roles in leadership and research.
Principles 5	Shared learning and capacity building are built into planning and process	Planning events or interventions must have goals for idea generation and objectives for updating/improving current practices or processes (e.g. planning events should include representatives from all stakeholder groups, and routine check-ins to verify value for long-term maintenance).
Principles 6 and 7	Interventions or community output should benefit all parties and address the local context from multiple levels	When creating something new (artefact) or developing ideas in the community, people with lived experience should verify the value of the artefact for their community, and how it best positions them to achieve their broader goals as a community.
Principles 8 and 9	Create a sustainable process and one that routinely updates/informs the broader community	In addition to managing routine planning meetings, any new work, processes, or findings should be routinely updated through shared community events like a community open house or symposium (e.g. it is always good to have people with lived experience participate in dissemination).

CBPR = community-based participatory research.

(7) Focuses on local relevance of the health problem, applies an ecological perspective and attends to multiple determinants of health.
(8) Applies an iterative approach to learning and design with attention to dissemination to all partners or stakeholders.
(9) Establishes long-term research processes with sustainability as the goal.

This list of principles should guide any partnership process but should not be the sole factor for determining what matters most to communities or their stakeholders. The process for building and sustaining partnerships for research must be designed in collaboration, where members of each stakeholder group have a chance to contribute.

Implementing CBPR concepts into routine engagement strategies

There are substantive barriers to achieving the goal of implementing CBPR processes when working with PWLH. One of the most important processes that needs to be addressed before any work is started is building relationships and identifying key stakeholders in the community. A central goal of CBPR is to build iterative and sustainable partnership processes. To do this effectively, it is important to consider and make a clear list of who your stakeholders are and what their roles will be.

Building sustainable and mutually beneficial relationships with stakeholders

When working with PWLH you need to determine who your partners are going to be. These partners can be non-profit organisations, presumably a group that has capacity in the community already. These could also be private or government groups who conduct work in the community of interest. For example, a private medical clinic that does health screenings in the homeless community. This could also be a government or religious group that routinely conducts or provides services in the community such as a public health community vaccine clinic or a local church organisation that holds bi-monthly community meetings to empower PWLH. Building these relationships and establishing strategic processes to engage partners is neither simple nor quick. Fostering these kinds of partnerships takes commitment and dedication. Examples of this level of commitment from academic or medical partners might be allocating a percentage of time to meetings or research. This work may not resemble typical research tasks, as it often includes reserving meeting locations, ordering catering, coordinating student involvement, planning events or meetings and summarising processes for dissemination, not publication.

Conducting research involving PWLH

As described earlier, PWLH often cite having a lack of autonomy in their day-to-day interactions. Given these perceptions, researchers who are interested in working with this population must rely on their partners and relationships with existing organisations to demonstrate purpose and vision. Once a research team has an established community-based partner, it is their job to inform and empower community members about the benefits of doing this work. Here are a few guiding strategies to support conducting research involving PWLH:

(1) Recruit (hire/include) individuals from the community to serve as members of the research team.
(2) Create an advisory board or team to routinely meet and review research or programme processes.
(3) Compensate individuals for their professional time and effort.
(4) Build processes into the research that involve community members taking leadership roles and research responsibilities.

Ethical considerations for research

Informed consent

The complexity of informed consent is magnified in this context. It is crucial to simplify consent forms, as these forms are required by most institutional review boards to determine whether research involves human subjects. Conducting informed consent with PLWH may heighten previously noted privacy concerns, making clear communication essential. Applying multiple communication strategies to ensure participants fully understand their rights and the study's nature is crucial.

Multiple communication strategies

Multiple communication strategies can be used for informed consent including paper-based forms with checkboxes that participants can mark to indicate whether or not they understand, reading consent documents aloud to participants and obtaining their verbal consent or assent and providing a short video that explains the research and consent process. These strategies will ensure effective communication, which is essential for conducting ethical research. They involve using clear, jargon-free language and diverse means of communication to accommodate the varied literacy levels and cognitive states of PWLH.

In addition to the above steps for guiding informed consent, another effective strategy is to leverage team members with lived experience of homelessness in the research team. These individuals can review and practise filling out forms or other processes before public use, helping to identify areas where language or procedures may need to be applied for clarity and accessibility.

Suggestions for a methodological framework based on CBPR

Designing the study

One of the many research/professional roles in any study is determining the right design or method. Determining the right research methods—qualitative or quantitative—must consider the sensitivities and challenges specific to people experiencing homelessness. Most studies employing CBPR methods have used the following strategies:

(1) **Community workshops** – This is an excellent method for collecting data in partnership with a community interested in creating, collecting ideas and/or designing practices or policies. For example, a series of workshops could be held every Friday of the month, where community members are invited to participate in an event planned with food, providing an opportunity to share ideas or gather feedback on concepts in a group setting.

(2) **Community-based project symposiums** – This is an effective way to support the dissemination of information collected from workshops or other strategies with the community. The use of community member panels, which include PWLH alongside content experts, provides a valuable platform to share views. Symposia are also a useful way for members of the community to engage directly with professionals, policy-makers, key leaders and decision-makers in a practical way.

(3) **Community-led listening sessions** – These are much shorter in duration and can be monitored or facilitated by a partnership between researchers and community members. These are effective tools for eliciting direct reactions from community members related to new policies, programmes or initiatives.

(5) **Focus groups and/or individual interviews** – Considered a more research-focused method, these qualitative approaches to gathering data are highly effective when teams require detailed and nuanced responses to specific questions. Such questions may relate to personal experiences, beliefs, knowledge or attitudes about certain concepts or phenomena in the community. One example might be having a focus group to understand ways groups of men who experience homelessness seek care for health-related concerns. These types of questions lend themselves to the use of an interview guide or focus group guide.

(5) **Community-based surveys or questionnaires** – This type of approach is almost purely for research or data-gathering purposes. CBPR surveys could be used to collect broad perspectives from a large number of constituents; however, these approaches tend to be less personal and may discourage engagement. When surveys are seen or needed as necessary instruments for data collection, one way to apply a CBPR approach is to elicit community feedback on the survey questions and on their analysis with members of the community.

Participant recruitment and engagement

When you consider applying any of these methods in a community, it is useful to consider how you plan to recruit participants. Strategies for ethically recruiting and maintaining engagement with participants will emphasise the importance of building trust and respecting the personal circumstances of each individual. One method might be to partner with an existing organisation that already works with members of the homeless community to spread the word and assist with the process of recruitment. Having a partner organisation guide the recruitment process helps ensure the right amount of buy-in, which is necessary for establishing and verifying trust. Another approach would be to recruit directly from community events, where members of the research team can engage with the community, present the research or the project and address any questions. This direct interaction allows researchers to explain the project details including incentives, time, commitment and use of the data.

Transparent data collection and analysis

Any CBPR project will require some type of data collection. This is necessary for several research and practice-based efforts to improve service delivery or gather meaningful feedback to understand/evaluate current policies or practices aimed at the community. What becomes paramount under these conditions is transparency. Any partnership must be prepared to explain how and why specific data are being collected, how personal or private data will be used and how participants will have access to them. Given all the concerns raised, it should be obvious that data collection and analysis strategies must be conducted with utmost respect for participants. This requires building data collection strategies that ensure accuracy without compromising the dignity or confidentiality of the individuals involved. Key procedures to achieve this include:

(1) **Sharing data and information collected with community members and teams**. One example might be from within a workshop or symposium. At the start of any event, the research team (with members of the community) can introduce themselves and the work by presenting an overview of the progress to date and sharing any key findings and updates with the community.

(2) **Building in dissemination processes as part of the data collection strategy**. Integrating dissemination processes into a CPBR project can involve having the research team request that a community partner provide a brief overview of the project at the outset of any formal data collection. This approach ensures that participants receive a verbal or paper-based update as part of any formal workshop, focus group or interview.

(3) **Giving and receiving feedback to community members regarding the data collected and the process used to gather data** – One example of this would be using a technique called member-checking. As part of a formal data-gathering strategy, member checking involves first organising data and findings in an understandable way to a broad range of community members. Next, the summarised data is formally brought to the community to elicit their feedback and reflection. Essentially, the research team would be looking to understand: (1) are the data realistic; (2) do they reflect your experiences; (3) are there things missing and (4) what else needs to be asked.

Conclusion

The goal of this commentary was to provide a discussion and framework for applying CBPR in a way that respects the dignity and autonomy of PWLH. Traditional research strategies are limited, in their design and purpose, to meet the unique ethical challenges presented by this population, such as mental illness, substance use and dependency as well as social vulnerabilities. By employing a CBPR approach, researchers and public health professionals can ensure that their work is not only informative but also ethically responsible. CBPR emphasises the importance of informed consent, privacy and collaborative decision-making, which are essential for engaging PWLH in a manner that respects their lived experiences.

CBPR's commitment to partnership, shared power and effective communication fosters a research environment that is transparent, sustainable and ethically robust. By integrating the community's voice and expertise at every stage of the research process, CBPR not only enhances the validity and relevance of the research but also ensures that the benefits of the research are equitably distributed. As this commentary argues, the application of CBPR helps to build trust, empower communities and create lasting, positive impacts on public policy and social services for PWLH.

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