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Addressing Ethical Challenges Related to Community and Patient Engagement in Health Research

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Article abstract

In this post-workshop summary, we describe three ethical challenges related to engaging people with lived experience as partners in health research. We share learnings and reflective prompts from our workshop delivered as part of the Canadian Bioethics Society Workshop and Community Forum held in May 2023.

ACTES DE COLLOQUE / CONFERENCE PROCEEDINGS

Addressing Ethical Challenges Related to Community and Patient Engagement in Health Research

CANADIAN BIOETHICS SOCIETY / SOCIÉTÉ CANADIENNE DE BIOÉTHIQUE
In collaboration with / En collaboration avec

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Résumé	Abstract
Dans ce résumé post-atelier, nous décrivons trois défis éthiques liés à l'engagement des personnes ayant une expérience vécue en tant que partenaires dans la recherche en santé. Nous partageons les enseignements et les pistes de réflexion tirés de l'atelier organisé dans le cadre de l'atelier et du forum communautaire de la Société canadienne de bioéthique, qui s'est tenu en mai 2023.	In this post-workshop summary, we describe three ethical challenges related to engaging people with lived experience as partners in health research. We share learnings and reflective prompts from our workshop delivered as part of the Canadian Bioethics Society Workshop and Community Forum held in May 2023.
Mots-clés	**Keywords**
engagement communautaire, engagement des patients, expérience vécue, recherche en santé, pouvoir, éthique	community engagement, patient engagement, lived experience, health research, power, ethics

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INTRODUCTION

In recent years, there has been growing recognition of the importance of engaging people with lived experience as partners in health research – and not merely as research participants (1). Community and patient engagement in research involves meaningful and active collaboration with people with lived experience of a health condition and intersecting identities throughout the research process, including study conceptualization, data analysis, and dissemination of findings. People with lived experience can be engaged on a continuum, ranging from consultation and advisory roles to equal partnerships, leadership, and decision-making roles.

When people with lived experience partner in research, it can enhance the appropriateness, quality, and potential impact of health research (2), and reflects a human rights-based approach wherein people are involved in research that relates to their lives (3). However, partnering in research also has the potential to create ethical harm to people with lived experience. In our workshop during the 2023 Canadian Bioethics Society Workshop and Community Forum, we explored three ethical challenges related to community and patient engagement in health research: 1) the power of language; 2) decision-making power; and 3) engaging with members of equity-deserving communities (groups that experience disadvantage and discrimination resulting in an unfair distribution of resources, opportunities, and power). Power, a common theme in engagement work, was interwoven throughout the ethical challenges we explored.

The intended audience for this workshop included researchers, trainees, and community members with an interest and/or experience in community and patient engagement in research. During the workshop, we discussed, as a group, potential mitigating strategies and participants' experiences with the ethical challenges raised.

CHALLENGE 1: THE POWER OF LANGUAGE

Language is a powerful tool that can profoundly shape the course of research. From formulating research questions and drafting recruitment materials to collecting and interpreting data, the words we use carry weight and influence. Language is especially relevant in the field of engagement. The terms or labels we commonly use such as 'patient', 'patient partner', 'patient advisor', 'service user researcher' and 'person with lived experience', all carry ethical implications. The terms chosen by researchers and institutions may not be inclusive or reflect individuals' complex and intersecting lived experiences. This limitation in linguistic inclusivity can inadvertently reinforce pre-existing power asymmetries between people with lived experience and other members of research teams (e.g., researchers and knowledge users).

Language also varies across research fields. For example, when engaging people with lived experience in the field of mental health, terminology lacks consistency and is heavily debated (4). Take, for instance, the term 'patient' and its use in mental health research. Although 'patient' is commonly used across medical settings, it is increasingly rejected in mental health research, among other fields, due to its reductionist nature and ties to the medical model, which often situates individuals in a

passive role within the health system (5,6). The term 'patient' is laden with implications related to historical and present oppressive practices in psychiatry, such as the stigma associated with psychiatric institutionalisation (5). As our linguistic choices reflect our attitudes, beliefs, values, and biases, it is critical to approach language in engagement with careful consideration and reflexive action.

Given that there is no "one size fits all" approach to language, direct dialogue with the people engaged in research is an ethical imperative and iterative process. We encourage research teams to initiate from the onset and continue ongoing conversations with people with lived experience to understand which terminology they prefer. Researchers should practice reflexivity by continuously reflecting on their assumptions, reassessing and adapting their terminology when necessary, and remaining mindful that preferences will vary even amongst people with lived experience (e.g., finding common ground when advisory group members disagree on language preferences). Standardizing language is important for clarity and research purposes, yet it should be carefully balanced with flexibility, and above all, respect for the preferences and safety of the people engaged in research.

Reflective questions:
- How do we identify what language to use to describe people with lived experience who participate as partners in research projects?
- How do we reconcile the benefits of using standardized language with flexibility to meet individuals' preferences and needs?

CHALLENGE 2: DECISION-MAKING POWER IN RESEARCH

In the context of patient or community-oriented research, it is important to think critically about who holds decision-making authority. What role do researchers, patient or community partners, healthcare organizations, and funders each play in shaping priorities and deciding what research is funded, receives institutional support, and is conducted? Often when people with lived experience are invited to participate as partners in research, research priorities and study approaches have already been chosen. This can lead to tokenism where individuals do not feel like they are able to make a meaningful contribution to a research project and are merely there to check a box (7).

It can be a meaningful exercise for research teams to reflect on how decision-making power is distributed at each stage of a research study. One way to interrogate how power is shared between study members as it relates to partnership initiation and priority setting is to use the typology of stakeholder engagement developed by Zimmerman and Concannon (7). This typology differentiates between project types based on how partnerships are initiated. Activities can be patient or public-initiated (e.g., public or patient movements, emancipatory research); partnership-initiated (e.g., community-based participatory research); or researcher-initiated (e.g., patient-partnered research) (8).

Our purpose in sharing this typology is not to suggest that one type of research activity or partnership type is necessarily better or worse than another. Instead, research teams should think critically about the goals they are looking to achieve and choose partnership approaches and corresponding research methods that help meet these goals. Having honest conversations with partners and collaborators to understand each other's goals is important for ensuring alignment. These discussions can be a starting point for ensuring the priorities of people with lived experience are meaningfully reflected in research.

Reflective questions:
- How do we reduce tokenism in community and patient engagement?
- How do we increase the decision-making power of people with lived experience within health research projects?

CHALLENGE 3: ENGAGEMENT WITH MEMBERS OF EQUITY-DESERVING COMMUNITIES

Researchers are increasingly recognizing the importance of engaging people with lived experience who reflect the diversity of communities served by health systems. However, for many individuals from marginalized communities, healthcare institutions have often been sites of discrimination or racism, rather than safe havens (9). Additionally, there is a well-documented history of abuse towards these communities within health research (10). People from equity-deserving communities have experienced historical harms and injustices in the name of research that continue to have long-lasting impacts on trust. Adopting engagement activities that reflect trauma-informed and anti-oppressive approaches can help ensure engagement activities are meaningful, tailored to intersecting identities, and do not create harm (11,12).

When engaging diversely, it is also important to ask whose voices are being amplified. What does meaningful engagement look like? There is a risk that a few voices might be taken to represent an entire community, which can lead to oversimplification or misrepresentation of diverse experiences and perspectives. A person with lived experience partnering on a research project cannot be expected to represent the perspectives and priorities of all individuals who are part of their shared communities.

The Canadian Coalition of Global Health Research Principles for Global Health Research address health inequities and champion human rights (13). Designed to steer researchers toward ethical and fairness-driven choices, they encompass six principles: 1) Practice humility; 2) Act on the causes of inequities; 3) Commit to the future; 4) Partner authentically; 5) Embrace

inclusion; and 6) Create shared benefits. These guidelines inspire researchers to pursue a more just approach to global health research and can serve as a framework for engaging with equity-deserving communities.

Reflective questions:
- What are trauma-informed and anti-oppressive practices that can increase the inclusivity of engagement practices?
- Among the Canadian Coalition for Global Health Research principles, which ones resonate with you?

POWER: A CROSS-CUTTING THEME

In this workshop, we discussed three common ethical challenges in community and patient engagement in health research. Power is a cross-cutting theme that connects all three issues. Addressing these key issues is integral to ensuring ethical practices throughout the engagement process. In so doing, we can work towards creating inclusive and respectful environments for community and patient engagement in health research, in turn increasing the influence of patient and community members on research outcomes.

GROUP DISCUSSION: UNPACKING ETHICAL CHALLENGES, STRATEGIES, AND ACTIONS

Towards the end of the workshop, it became timely to discuss questions that consolidate workshop learnings and identify proactive steps forward. We therefore posed the following three questions for participants to discuss:

1. Are there ethical challenges unique or specific to projects led by trainees and early career researchers?
2. What strategies can researchers and research teams use to minimize risks of ethical harm to community and patient partners?
3. What actions can funding agencies and research institutions take to support ethical community and patient engagement in research?

Workshop participants were highly engaged in these discussions. Interestingly, participants did not feel that there were ethical challenges unique or specific to projects led by trainees and early career researchers. Our rationale in asking this question was to explore how power relations shape the engagement activities of trainees and early career researchers who may have less autonomy and access to resources to support meaningful engagement with people with lived experience. Participants identified practical strategies informed by their own experiences and engagement activities. Strategies included initiating engagement activities as early as possible, co-authorship as an ethical standard, and communicating research findings to community members in ways that are tailored to them (e.g., community forum) rather than through traditional academic channels (e.g., peer-reviewed journals). Funding to support the often-invisible dimensions of engagement work, such as investing in interpersonal relationships is essential (14). We discussed the importance of researchers receiving support to navigate the complexities of engagement work; for instance, this might include clear and accessible guidelines for engagement and access to training opportunities.

Ultimately, the workshop discussions showcased that ethical issues inherent to engagement work are complex and multifaceted, much like a kaleidoscope, constantly shifting and unveiling new dimensions with each lived experience.

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