

AMERSA Workshop

Workshop Title:

Should There Be a Price of Admission? People with Lived Experience as Partners in Addiction Research and Policy

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Workshop Category:

Research, Education, Clinical Practice, Community Action

Audience:

Researchers, clinicians, trainees, community partners, peer recovery specialists, program administrators, and policymakers involved in substance use research and care

Background (≤250 words):

Participation of people with lived experience (PWLE) of substance use has become an increasingly recognized priority in addiction research and practice, reflecting broader movements toward patient-centered, community-participatory, and equity-driven science. PWLE bring critical insights that can improve research and clinical practice relevance, feasibility, reach, and impact. However, meaningful (i.e., input has impact) integration of PWLE into research and clinical oversight roles (i.e., advisory boards) remains inconsistent and often poorly defined. Key questions persist: What constitutes adequate preparation or “qualification” for participation? What supports are necessary (if any) to ensure equitable and meaningful participation? Are current expectations for training, professionalism, or compensation aligned with ethical and inclusive practices—or do they create unintended barriers?

This workshop will critically examine the implicit and explicit “price of admission” for PWLE participation in oversight role in addiction research and clinical practice. Drawing on emerging practices and real-world examples from NIH funded research projects and the National Coalition to Liberate Methadone, the session will explore tensions between institutional norms and community realities, including issues of power, stigma, compensation, meritocracy, and role legitimacy. Participants will engage with practical and ethical considerations, including how to structure advisory roles, how of those with no research or oversight experience, what training or onboarding is appropriate, and how to distinguish between supportive preparation and exclusionary gatekeeping. By fostering dialogue across stakeholders, this workshop aims to identify actionable strategies to promote authentic, equitable, inclusive, and sustainable partnerships with PWLE in addiction research.

Learning Objectives:

1. Identify key barriers and facilitators to engaging people with lived experience as partners in the oversight of addiction research and clinical practice.
2. Critically examine assumptions about meritocracy, training, qualifications, and professionalism for PWLE participation.

3. Apply ethical and practical frameworks to develop inclusive and equitable engagement strategies, inclusive of those with limited prior oversight experience.

Content and Methods (≤500 words):

This 90-minute interactive workshop will use a combination of panel discussion, small-group breakout sessions, and facilitated large-group dialogue.

- **Breakout Groups (10 min):** Icebreaker, introductions, and share experiences with utilizing people with lived experiences as advisors and/or experience with CAB
- **Panel Discussion (30 minutes):** A multidisciplinary panel—including individuals with lived experience, researchers, and clinicians—will present diverse perspectives on engaging PWLE as research partners, utilizing previous and active clinical trials, community advisory boards, and the National Coalition to Liberate Methadone as examples. Topics will include expectations for participation, training needs, compensation, and challenges in team integration. Panelist will discuss potential strategies and novel interventions needed to overcome barriers based on prior successes and failures. The tradeoffs of qualification and training requirements based on prior work will be reviewed. This will include how social vulnerabilities and survivorship bias (i.e., the “compliant” patient gets invited to join) may intersect with a lack of prior oversight experience. Strategies reviewed will aim to ensure representation in decision making across the continuum of patient vulnerability and be resilient to changes in participant availability. Exploring the use of outreach strategies – transportation stipends, childcare support, flexible scheduling, remote participation, overrepresentation of key groups – will be explored to include people in decision making who are new to research/treatment or less stable. For participation of those hesitant to engage, the need to create community partnerships with outside organizations trusted by people who use drugs – such as harm reduction organizations and drug users’ unions will be reviewed.
- **Breakout Groups (30 minutes):** Participants will work through case-based scenarios that highlight common dilemmas (e.g., determining necessity of qualifications, addressing stigma within research teams, navigating compensation and institutional policies). Groups will identify barriers and propose solutions.
- **Large Group Discussion (20 minutes):** Facilitated discussion of breakout group scenarios. Further discussion to synthesize learning points, sharing what questions and answers individuals will bring back to their institutions and personal work for ethical and effective engagement of PWLE.

Impact / Dissemination Potential (≤200 words):

This workshop will equip participants with practical frameworks and strategies to improve the integration of people with lived experience as participants in addiction research and clinical practice. By addressing common challenges and ethical tensions, participants will be prepared to implement more inclusive and effective engagement practices within their own institutions.

Materials, including case scenarios and facilitation guides, can be adapted for use in research and clinical practice advisory board development and institutional capacity-building efforts.

Participants will be encouraged to share these approaches within their organizations, fostering broader cultural change toward equitable partnership with PWLE.

By promoting authentic engagement, this workshop supports improved research relevance, enhanced trust, and more effective translation of findings into practice, ultimately contributing to better outcomes in substance use care.