BUILDING CAPACITY FOR PARTICIPANT-CENTERED RESEARCH IN HARM REDUCTION ORGANIZATIONS

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Background:
Research about harm reduction (HR) generates “evidence” used for policy and program development. However, not all evidence is valid, reliable, and relevant. Evidence deemed “higher quality” typically explicitly or implicitly excludes HR organizations and participants from the research process. This project built capacity for participant-focused research within a U.S. HR organization and developed guidance for programs as they consider research activities.

Approach:
Informed by the Patient-Centered Outcomes Research Institute’s (PCORI) supporting materials, we engaged with Researcher Stakeholders (RS) and Participant Stakeholders (PS) distributed among three cohorts each with 5-7 PS and 5-7 RS for 6-week sessions. PS members learned about basic research methods and RS learned about HR principles then we brought PS and RS together for 3 weekly sessions to discuss ideas and concerns about carrying out studies including HR participants as partners.

Analysis:
Notes, transcripts, and evaluation forms were reviewed each week for formative evaluation and to improve subsequent cohort sessions. These data were collated and reviewed for consistent themes with attention paid to barriers and facilitators to research, particularly participant centered approaches.

Results:
RS represented medical and social science specialties. Most had limited HR experience, one had lived experience, one had worked in HR organizations. Separate sessions for RS and PS prepared all for constructive interactions during 3 weekly combined sessions. PS presented research ideas, and concerns about participation. RS asked about recruitment, retention, and compensation. Together, stakeholders discussed informed consent and means to facilitate or avoid barriers to research participation and ongoing stakeholder engagement.

Conclusion:
HR participants are interested in and can be engaged to contribute meaningfully to the research process. Guidance for HRs includes considerations for financial and partnership models and concerns, protection of participants, and dissemination of results by means beneficial to researchers and HR organizations and participants.

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