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Title

Best practices to engage community members with lived experience in community based participatory research: A Scoping Review

Priority 1 (Research Category)

Systematic review, meta-analysis, or scoping review

Presenters

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Abstract

Context: Community-based participatory research (CBPR) is a collaborative research approach that equally engages researchers and community stakeholders throughout the research process. Community advisory boards (CABs) can effectively integrate individuals with lived experience and community organizations into the research process to align the work with community priorities.

Objective: We sought to: (1) explore best practices for the recruitment and engagement of people with lived experiences on CABs; and (2) identify the scope of literature on minimizing power dynamics between organizations and community members with lived experience who work on CABs together.

Study Design and Analysis: This scoping review follows the Arksey and O'Malley methodological framework. Two researchers independently screened texts using Covidence software. Final texts were uploaded into NVIVO, and thematic analysis was applied in three phases: open coding; axial coding; and abstraction. Extracted data was recorded and presented in tabular formats and/or graphical summaries, with descriptive overviews.

Dataset: Search strategies were completed in Embase, Medline and PsychINFO. Grey literature references and reference lists of included articles published between Jan. 1, 1990, and Mar. 30, 2023, were considered.

Population Studied: The scoping review aims to inform on how CBPR projects integrate people with lived experience onto CABs.

Outcome measures: Best practices for recruitment and engagement of individuals with lived experience on CABs, and minimization of power imbalances on CABs, identified from thematic analysis.

Results: 53 papers were included in the final analysis. Recruitment was reported in 39 papers, exploring challenges such as tokenization. Successful engagement was explored in 44 papers, highlighting best practices such as culturally grounded leadership, appropriate compensation, and bi-directional capacity building. Overcoming barriers such as mistrust, accessibility, and alienation from the scientific process were highlighted as key steps to minimize power differentials on CABs.

Conclusions: To successfully establish CABs with individuals with lived experience, it is essential to ground all stages of the work in community priorities. Dedication of resources to relationship building and capacity building, upon a foundation of mutual respect, is essential to CAB success. Further research is needed to demonstrate the practicality of proposed best pr

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