PCR198

Engaging Patients in the 10-Step Framework for Continuous Engagement: Challenges and Recommendations

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Background

- The purpose of the community-engaged research (CEnR) is to enable consideration of community health priorities, promote equity throughout the research process, and share the process, resources, and products associated with the research between researchers and communities.
- There are ethical challenges in CEnR that hinder true patient and community engagement.

Study Aim

- Describe the challenges that patients may encounter at each stage of the 10-step framework for continuous engagement
- Propose recommendations to promote health equity and more authentic partnerships between patients and researchers

Methods

- We identified challenges at each step of the framework through a literature review.
- We proposed a VALUE (Valued -Authentic -Literate - Understood - Empowered) approach to assess and resolve challenges related to patient engagement.
- Valued refers to the importance given to the patient's experience;
- Authentic suggests that the engagement is not tokenistic;
- Literate refers to the patient's and the researcher's knowledge in clinical research;
- Understood relates to the researcher's level of understanding of the patient's needs and vice versa;
- Empowered refers to actions taken to strengthen the partnership and the patient's ability to solve problems related to patient engagement.
- Patients and researchers should be accountable to each other as they go through each step of the VALUE approach to ensure full engagement of partnership members during the assessment and resolution process.

Principal Findings

VALUE RECOMMENDATIONS

VALUED: The experience, preferences and needs of community members must be valued, i.e., at each step, community members must have their propositions drawn from their experiences .

AUTHENTICITY : Patient engagement should be supported by authenticity. Authenticity helps build relationships based on trust. Authenticity allows patients involved to exchange honestly about the advantages and disadvantages of research on the part of the academic.

LITERATE : Literacy is a process where academics evaluate their knowledge of the experiences, needs, and preferences of community members and where community members assess their knowledge on research process.

UNDERSTOOD : Understood marks a mutual assessment of how well shared propositions match the expectations of each party in order to resolve or prevent challenges that may cause harms to both the community and academics.

EMPOWERED : Empowerment is a mechanism that allows communities to have an active role in every step of the process. Empowerment should promote shared decision making between academics and community members.

CHALLENGES RELATED TO THE 10-STEP FRAMEWORK

Step	Topic Solicitation	Prioritization	Framing the question	Selection of comparators and outcomes	Creation of conceptual framework	Analysis plan	Data collection	Reviewing and interpreting results	Translation	Dissemination
Challenges	Researcher's ignorance of patients' values and preferences	Community members' lack of confidence	Researcher's lack of flexibility	Experience sharing bias due to the proximity of control and experimental groups in small group studies	Lack of research training for community members	Low research literacy of community members	Community members' privacy concerns	Lack of communication between researchers and community members	Unavailability of meaningful and valid results limiting community benefits	Results contributing to stigmatize and stereotyping the community
Examples	The researcher chooses the subject and only solicits members of the community who share the same research interests	Community members may feel that they are incompetent to talk about research priorities because of the complexity and technicality that accompanies the process	The researcher lacks flexibility to accommodate community input for defining or designing the research question because he is obligated to deliver the promised objectives and work plan to the funder	In a study, control participants hear about participants' experiences in the music therapy sessions, and they feel resentful for not having been assigned to that group.	Community members who have not been trained in research may not fully grasp the nuances of methods, theory, and study design	The challenge for the survey researcher is to explain complex and not-so complex statistical analytical concepts and procedures in a "friendly" manner with limited technical jargon and without oversimplifying complex relationships.	Participants questioning of need for certain data and hesitating to consent to videotaping of home out of concern for invasion of privacy and questions about how recordings will be used	Lack of communication about study results between researchers and community members may happen	Meaningful and valid results at both the community and participant level may not be available for years and community benefit is not concrete	Disseminated results may stigmatize or further stereotype a community. Research results may not clearly benefit a community.

Conclusions

The challenges and recommendations help to advance the science of patient engagement and the vision of health equity.

Policy/Practice Implications

Future research should focus on interventions that engage community members, community organizations, and researchers to address these challenges related to the 10-step framework for continuous engagement to build trusted partnerships.

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