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Title

Engaging the “Just Right” Patient in Research

Priority 1 (Research Category)

Participatory research

Presenters

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Abstract

Context: Engaging patients and community members in research has gained momentum and funding support over the past 2 decades. Long standing participatory research groups may provide a valuable example of patient and community member characteristics associated with successful engagement efforts.

Objective: Identify patient and community member characteristics associated with successful engaged and participatory research.

Study Design and Analysis: Five groups with varying lengths of patient and community member engagement conducted guided conversations about how to identify the “just right” patient for their research engagement efforts. Lists of characteristics were created and refined by the groups. Group lists were compiled, cleaned, and organized around common elements.

Setting: The group conversations began with the long-standing Community Advisory Council of the High Plains Research Network in rural Colorado. Additional group conversations were held in a rural Montana Community Transformation Training, the Colorado Research Network (CaReNet) Patient Partners Research Council, a Boot Camp Translation Facilitator Training, and the NAPCRG Patient and Clinician Engagement (PaCE) Program.

Results: Groups identified a broad set of characteristics they believe are necessary and desirable for successful participatory and patient engagement efforts. The groups reported that not everyone must have all of these, but overall, these characteristics are important to long-term relational engagement. Motivation for initial engagement and reasons to stay engaged were important considerations. Some

characteristics are innate, some deal with experience, and others relate to logistical issues. Curiosity, willingness to listen, basic health care knowledge, experience in the community, time to commit to the research activities, ability to travel, no singular personal agenda, sense of humor, a sense of purpose to their engagement work, ability to think outside themselves, put themselves in others' shoes, ability to speak humbly about their own experience and expertise.

Conclusions: Actively engaged community members were able to identify characteristics they believe are important for participatory and patient engaged research. Next steps will include identifying the characteristics of the just-right researcher.