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Title

Patient engagement works: Patient and researcher experiences of patient partnership in primary healthcare research

Priority 1 (Research Category)

Patient engagement

Presenters

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Abstract

Context: Health researchers are increasingly engaging patients and their families as partners in the research process, from inception to knowledge translation. The trend toward ‘patient-oriented’ research is encouraged by a growing view that studies which integrate the patient perspective will make better use of resources to produce more relevant evidence that can be more easily translated to clinical settings. While there is an emerging literature on best practices, challenges, and learnings related to patient engagement (PE), few studies consider the experiences of patient partners (PP) and researchers in the same project. This presentation will present PP and researcher experiences of PE, highlighting important similarities and differences and proposing recommendations. Objectives: To characterize PE experience from the perspective of researchers and PP working together on the same research program, PriCARE; to identify successes and challenges; to ascertain contributions of PE in health research. Study Design: Qualitative. Setting or Dataset: This study was conducted within the larger 5-province PriCARE study examining a nurse-led case management intervention for primary care patients with complex needs. Population studied: 22 members of the study team (7 PP, 8 coordinators, 2 co-investigators, 5 principal investigators). Methods: Data collection: In-depth interviews using guides co-created by researchers and PP covering topics such as PE-related training and knowledge, and reflections on PE processes and impact. Research assistants external to the PriCARE study conducted interviews, transcribed researcher interviews, and generated a summary of PP interviews. Analysis: Data were analyzed thematically using a coding framework that was co-developed with PP. Outcome Measures: Researcher and patient experiences of PE, PP contributions to health research. Results: All team members need PE training at the beginning of and throughout the research process. Evolving trust and flexibility helped team members to navigate different experiences and priorities. PP make integral

contributions to study and instrument design, data analysis, and knowledge translation. Clear expectations about the degree and nature of PE and team members' roles are critical. Conclusions: Meaningful PE requires patient-researcher partnership and clear expectation setting at the outset and throughout the research process, and ongoing flexibility to adapt.