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## Title

Patient partners' motivations and meanings for research engagement: A qualitative study

# Priority 1 (Research Category)

Patient engagement

## Presenters

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## Abstract

Context: Patient engagement in research refers to the meaningful and active involvement of patients and caregivers as co-researchers (patient partners). The interdisciplinary nature of patient engagement in primary care research inherently influences team dynamics. A shared understanding and respect for all team members' (including patient partners') backgrounds, motivations, and expectations is imperative to partnership.

Objective: To explore the motivations and meanings that patient partners attach to their role.

Study Design and Analysis: A qualitative study was co-designed and led with a patient partner, using semi-structured interviews. Analysis captured the voices of patient partners through a thematic analysis process.

Setting: Pan-Canadian.

Population Studied: Patient partners involved in a Canadian Institute of Health Research project funded through one of 13 Strategy for Patient-Oriented Research funding calls.

Intervention/Instrument: Semi-structured interviews were co-conducted virtually by a patient partner (RS) and academic researcher (AMC) and lasted 60-90 minutes. Open-ended interview questions were co-developed to address the research objective.

Outcome Measures: Participants': (a) reason(s) for becoming, and perceptions of the (b) definition, (c) purpose and/or value, and (d) roles and/or responsibilities of patient partners.

Results: Twelve (out of 15) individuals agreed to participate; 10 are women. Participants shared that although knowledge of living with a health condition and/or accessing health services provided the lived experience required to be a patient partner, they had other personal drivers motivating their decision and hopes for being co-researchers. Motivations included: altruism, professional background, personal

history, and desire for personal growth. While definitions of 'patient partner' varied, there was agreement that advancing our shared understanding of both the word 'patient' and the word 'partner', along with the underlying purpose(s), role(s) and responsibilities of patient partners is imperative.

Conclusions: Our findings advance insights into patient partners, which are relevant to primary care researchers and physicians. Researchers will benefit from taking the time to enhance their understanding of patient partners' hopes and motivations for partnering in research. An appreciation for what patient partners feel they have to offer and ultimately hope to accomplish nurtures positive team dynamics.