

Submission Id: 2753

Title

Demonstrating the complexity of patient-partnered research in primary care: a snapshot of Patient-Partners

Priority 1 (Research Category)

Patient engagement

Presenters

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Abstract

Background: In Canada, we are still struggling to achieve the critical goal of enabling performant health care systems that moves research results to real-world impact particularly for primary care. To address this, we have created a primary care research network where patient partners are involved in all levels of decision making for governance, research, and innovation. For many researchers, however, it is unclear what primary care patient-partners 'brings to the table.' As the Pan-Canadian Patient Council of the Primary and Integrated Health Care Innovations Network, we wanted to provide insight into the richness of expertise and experience patient partners contribute.

Objectives: To provide an example of the characteristics, history and lived experience that patient-partners in a primary care research network represent and demonstrate the resource this presents.

Methods: As current council members, representing 10 provinces, we developed a survey of our demographics, personal history and experience in patient-oriented research using iterative, collaborative meetings. The answers to the questions provided "snapshots" for each of us. As a group, we worked with researchers to descriptively and thematically analyze the responses to provide insight and a description of primary care research patient partners.

Results: With 2 men and 8 women, we represented an average of 42.5 years of experience with health conditions (range 10-84 years) including cancer, genetic conditions, and multiple chronic diseases. On average, we worked with 4.7 different organizations each (range 2-9) on research topics covering the

spectrum of primary care. Many of us acted as mentors for researchers and trainees. All of us were innovators and influencers with demonstrated leadership skills. A need for more diversity in terms of age and underrepresented minorities was noted.

Conclusion: Diversity of life experience, extensive exposure to the health care system and strong engagement with multiple organizations for primary care research characterized us as patient-partners. This lived expertise represents a significant asset for researchers. This work should encourage researchers to starting thinking about how to include primary care patient-partners as a crucial resource in health research.