

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

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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.

Objective: To provide insight on the characteristics of a pan-Canadian council of patient-partners in a primary care research network.

Methods

- As current council members, we developed a survey of our demographics and experience in patient-oriented research.
- Answers to the questions provided “snapshots” for each of us.
- These were descriptively and thematically analyzed to provide a description of primary care research patient-partners.

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



Summary

We represent 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 have worked with 4.7 different organizations (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.

This lived expertise represents a significant asset for researchers. This work should encourage researchers to include primary care patient-partners as a crucial resource.

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