

# Meaningful patient-oriented research: Working together on a collaborative multi-provincial study

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# What we want to talk about today

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Building meaningful collaborative relationships

## What is patient oriented research?

The Canadian Institute for Health Research (CIHR) defines patient engagement in research as:

*“an approach that involves meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation”*



# ENHANCING RESEARCH THROUGH MEANINGFUL ENGAGEMENT WITH PATIENT PARTNERS



## LEARNINGS

AUTHENTIC AND IMPACTFUL PATIENT PARTNERSHIP EVOLVES WITH CULTURE OF OPENNESS AND INVESTMENT OF TIME AND EFFORT.

CO-DEVELOPMENT IS BENEFICIAL TO RESEARCH AND REQUIRES HARMONIZING RESEARCH STANDARDS WITH THE LIVED EXPERIENCE OF PATIENT PARTNERS.

## OUTCOMES

- INTEGRATED KNOWLEDGE
- UNDERSTANDING
- VALIDITY
- CLARITY
- LEARNINGS
- SUSTAINABILITY
- PATIENT RELEVANCE



# Benefits of patient-oriented research

Patient perspective improves research

Opportunity to learn new skills, including from each other



Opportunity to collaborate on presentations, papers, and qualitative research

New ideas, resources, and information to share

# Project background

- Case management in primary care for frequent users of healthcare services with chronic diseases and complex care needs.
- Funded by CIHR SPOR
- Led by Dr. Catherine Hudon at the University of Sherbrooke, with Dr. Shelley Doucet as the lead for New Brunswick.
- Involves the implementation and evaluation of a nurse led case management intervention in primary care clinics in QC, NB, NFL, SK, and NS for people with chronic conditions and complex care needs.
- Case management is a collaborative approach to plan, facilitate, and coordinate care to meet individual/patient and family healthcare needs.



Researchers and patient partners work together on all areas of this project as a research team



Patient partners work locally with the research team, while also coming together as a full team across provinces



This project has spanned over multiple years. Team members have come onto the project at different times, including some turnover

# Project Background

## Patient and researcher experiences of patient engagement in primary care health care research: A participatory qualitative study

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### Abstract

**Background:** Studies have highlighted common challenges and barriers to patient engagement in research, but most were based on patient partners' or academic researchers' experiences. A better understanding of how both groups differentially experience their partnership could help identify strategies to improve collaboration in patient engagement research.

**Aim:** This study aimed to describe and compare patient partners' and academic researchers' experiences in patient engagement research.

**Methods:** Based on a participatory approach, a descriptive qualitative study was conducted with patient partners and academic researchers who are involved in the PriCARE research programme in primary health care to examine their experience of patient engagement. Individual semi-structured interviews with patient partners ( $n = 7$ ) and academic researchers ( $n = 15$ ) were conducted. Academic researchers'

Experience  
working  
together as a  
team



# Experience working together as a team

As a team, we have worked together on a variety of activities, at both the provincial level and with the full team, such as:

- ❖ Attend full team meetings together, with patient partners as co-chairs
- ❖ Training case managers/other patient partners
- ❖ Reviewing qualitative data and tools
- ❖ Reviewing and co-publishing articles
- ❖ Knowledge translation activities

# Strategies for patient engagement in qualitative analysis



Determining interest



Training and  
resources



Planning



Adjusting the analysis  
process

# An example of patient engagement in a qualitative study

- Discussed interest
- Planning
- Co-developed a codebook
- Research assistants used the codebook to analyze interviews
- Summary table
- Meeting to validate findings



# Strategies for meaningful engagement



STRONG  
ORIENTATION



REGULAR CHECK-  
INS



TEAM MEETINGS



OPEN RESPECTFUL  
ENVIRONMENT



OPPORTUNITIES  
FOR SHARING



QUESTIONS?

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