

# Foundations in Patient-Oriented Research

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## Course Description:

This course is designed to give patients a foundational understanding of the research enterprise. It is equally intended to help equip patients, researchers and other stakeholders (i.e., care providers and system decision-makers) with the skills necessary to engage meaningfully in a variety of roles, including: governance, peer review or other committee work, priority-setting, and the conduct of patient-oriented research and to foster the attitudes essential to the formation and development of genuine partnerships.

The course is intended to enable participants to:

- acquire foundational knowledge about health research to allow them to become full-fledged members of a research team;
- build mutually beneficial partnerships for conducting patient oriented research; and
- work as a team to carry-out patient-oriented research and produce quality scientific knowledge in a given health-related field.

We use **patient** is an overarching term inclusive of those with lived experience of the health care system and their informal caregivers such as family and friends. Some people prefer terms such as “people with lived experience”, “client” or “consumer” and we encourage you to substitute whichever term resonates most for you.

## Pre-requisites:

This course is open to anyone who is a patient and who is currently either involved with a researcher, research body or network, or clinical network or in communication about potential involvement. This could be direct communication or through a patient group/network. It is also open to researchers and other stakeholders such as, care providers and system decision-makers who are interested in learning about working in partnership with patients in health research.

## Module 1: Patient-Oriented Research

The goal of this module is to give participants an understanding of patient-oriented research and provide an opportunity for them to assess how they may wish to become engaged. This module would be suitable for patients, researchers and all other stakeholders – including care providers and system decision-makers – who want to know more about patient-oriented research.

### Learning Outcomes:

Upon completion of this module, participants will be able to:

- Define patient-oriented research and describe how it is different from more traditional health research
- Articulate why it is beneficial to involve patients in health research
- Describe the various roles that patients can meaningfully and actively play in health research, including governance, priority setting, peer review and other committee work, and the conduct of research itself
- Identify the kinds of roles that they are interested in
- Identify future learning needs related to those roles
- Assess the unique strengths that patients may bring, not only as patients but through their other personal, educational and professional experiences
- Describe the various levels of engagement as outlined by the International Association of Public Participation (IAP2)
- Appreciate the guiding principles that underpin patient engagement in health research: inclusiveness, support, mutual respect and co-building.
- Describe examples of ways patients have been involved in patient oriented research
- Outline the practical considerations for engaging patients as partners in health research – e.g. compensation, incentives and rewards, culturally and socially safe environments
- Compare patient-reported outcome measures and patient-reported experience measures with measures traditionally used in health research
- Appreciate the value of personal stories and how they contribute to a better understanding of the needs, values and preferences of patients

### **Patient-oriented research:**

Research that engages patients as partners and focuses on patient-identified priorities. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve health care systems and practices.

## Module 2: Fundamentals of Health Research in Canada

The goal of this module is to provide patients and other non-researchers (e.g. care providers and system decision-makers) with the necessary contextual knowledge to enable them to participate in various roles related to the health research enterprise including governance, committee work, peer review, and the conduct of research itself.

*“As my knowledge about health research in Canada grew, it gave me confidence and helped me to feel that I really could participate meaningfully and actively in the various roles I was interested in taking on.” – Patient Partner*

### Learning Outcomes:

Upon completion of this module, participants will be able to:

- Describe the purpose of health research
- Describe who typically conducts health research studies and the traditional role of patients as study subjects
- Describe the diversity of health research topics and studies
- Develop an awareness of different research designs and methodologies
- Describe the stages of a research study
- Describe the role of the Canadian Institutes of Health Research and other health research funders
- Describe the characteristics of a good research question using the FINER acronym (feasible, interesting, novel, ethical and relevant)
- Describe the ethical considerations for health research and how ethical practices are assured
- Describe the peer review process
- Define knowledge translation/knowledge exchange

## Module 3: Building Partnerships and Consolidating Teams

The goals of this module are to enable patients and researchers to build a mutually beneficial partnership for conducting patient-oriented research and to provide them with tools to enable them to work together as they go through the stages of team development.

### Learning Outcomes:

Upon completion of this module, participants will be able to:

- Explain Tuckman’s five stages of team development (forming, storming, norming, performing and dissolving) and, together, develop strategies to work through each of the stages
- Understand how to put the guiding principles for patient-oriented research into action: *inclusiveness, support, mutual respect, and co-design* (SPOR Patient Engagement Framework)
- Act on usual obstacles for partnership
  - Understand
    - How roles and responsibilities are viewed differently through the lenses of culture, class, gender, etc.
    - How people’s confidence and ability to use their voice can be undermined
    - How our current system can impede partnership
    - How to leverage experience-based knowledge within a team
    - How learning and leadership styles have to be taken into account to adjust partnership dynamics
  - Identify tools
    - Learn about different ways to support team work
    - Learn effective decision-making models/processes for partnership
- Frame and plan team actions with McGill University Center for Excellence in Patient and Public Partnership’s co-building model

*“It’s important for every team member to show mutual respect for the competence and experience that each person brings to the table.” – Workshop Participant*