

# 5 - Patient and Public Involvement in Research: Why and How?

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## **Background:**

Patient and public involvement in research (PPIR) is increasingly advocated to improve the quality, validity, generalizability, dissemination and implementation of research studies. Appearing over 20 years ago, PPIR is becoming a requirement in most aspects of the research cycle: from planning studies and obtaining research funding to managing projects, publishing and disseminating findings. Patient and public involvement in data collection and analysis remains rare. PPIR seems particularly relevant in the context of research studies aiming to promote patient engagement in healthcare.

## **The aim of the workshop:**

This workshop aims to: 1) outline the true benefits of PPIR, 2) establish guiding principles for the successful involvement of patients and the public, 3) avoid common pitfalls and barriers to successful collaboration, 4) provide examples from successful PPIR, and 5) understand how best to plan and design patient and public involvement for your project (including data collection and analysis).

## **Target audience:**

All researchers and other stakeholders (patients, caregivers, health professionals) with an interest in:

- Patient and public involvement in research;
- Involving patient and the public in research for the first time;
- Increasing the extent to which they engage patients and the public;
- Maximizing the impact of patient and public involvement.

## **Learning objectives and methods:**

Objective 1: Understand how to maximize the impact and success of patient and public involvement in research (including data collection and analysis)

Objective 2: Explore multiple ways to operationalize patient and public involvement in research through examples provided by patient associates (actively involved in data collection) and the Director of Public and Patient Engagement at PCORI

Objective 3: Determine how best to plan and design appropriate patient and public involvement for your project.

This workshop will be led by two patient associates (patients who are actively engaged in conducting research). They are currently involved in recruitment and data collection for a randomized controlled trial of breast cancer patient decision aids. Facilitation and support will be provided by the Director of Public and Patient Engagement at PCORI, and health services researchers. Short didactic sessions will be combined with small group discussions.