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.