

Canada's Strategy for Patient-Oriented Research

Patient Engagement Framework at a Glance



Patients are at the Heart of SPOR

The term *patient* can mean different things to different people.



In the *Strategy for Patient-Oriented Research (SPOR)*, the term *patient* is defined as anyone who has personally lived the experience of a health issue as well as their informal caregivers, including family and friends.

Patient-oriented research engages patients as valued partners in the research process. It focuses on priorities that are identified by, and important to, patients. It involves patients, researchers, health care providers and others working together in collaboration.

SPOR aims to foster these collaborations in order to build a sustainable and equitable health care system – one that ultimately brings positive changes in the health of people living in Canada.

What Can Patients Contribute to Research?

There are different levels of engagement and a patient's role can vary according to the contributions they are prepared to offer.

Patients bring the knowledge they have gained through living with a condition or illness, as well as their experiences with treatments and the health care system. Their engagement can make the research more relevant, accountable and transparent. It increases the overall quality of the research and, as health care providers use research evidence in their practice, it increases the quality of health care.

The SPOR Patient Engagement Framework was developed with the help of patients, patient engagement experts, researchers, health care providers and other stakeholders. It outlines key opportunities for action and sets the stage for worthwhile collaborations throughout the research process.

Vision

Patients are active partners in health research that will lead to improved health outcomes and an enhanced health care system.

Objective

The Framework establishes key concepts, principles and areas for patient engagement to be adopted by all SPOR partners.

Core Areas for Engagement

- In all of SPOR's present and future endeavours, patients should be involved in **key governance structures and decision-making processes**.
- SPOR partners should **build capacity for patient engagement** by taking action to overcome the obstacles that prevent stakeholders from working together.
- SPOR partners are encouraged to **create tools and increase access to resources** that promote collaborations among researchers, patients, practitioners and decision-makers.

Guiding Principles

This Framework is built upon guiding principles that SPOR stakeholders will adhere to as they work to integrate patient engagement into research:

Inclusiveness: Patient engagement in research integrates a diversity of perspectives. The resulting research is reflective of their contribution.

Mutual Respect: Researchers, health care providers and patients acknowledge and value each other's expertise and experiential knowledge.

Co-Building: Patients, researchers and health care providers work together to identify problems and gaps, set priorities for research, and to produce and implement solutions.



Desired Outcomes of Patient Engagement



Inclusive mechanisms and processes



Respectful collaboration amongst patients, researchers and health care providers



Increased recognition of the value of patients' experiential knowledge



Research informed and co-directed by patients



Timely implementation of quality research

The complete Framework report can also be viewed at <http://www.cihr-irsc.gc.ca/e/48413.html>.

For more information on Canada's Strategy for Patient-Oriented Research, please go to <http://www.cihr-irsc.gc.ca/e/41204.html>.

Strategy for Patient-Oriented Research (SPOR)
 160 Elgin Street, 9th Floor
 Address Locator 4809A
 Ottawa, Ontario K1A 0W9 Canada
spor-srap@cihr-irsc.gc.ca

Also available on the Web in PDF and HTML formats
 © Her Majesty the Queen in Right of Canada (2015)

Cat. No: MR4-27/1-2015E-PDF
 ISBN: 978-0-660-02120-1