

The CIHR Ethics Policy Project: Patient Engagement in Research

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Outline

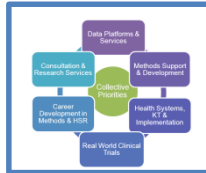
- Strategy for Patient-Oriented Research (SPOR)
- SPOR Patient Engagement Framework
- International context: Europe, North America
- CIHR Ethics Policy Project



Canada's Strategy for Patient-Oriented Research (SPOR)

- SPOR is a coalition of federal, provincial and territorial partners – all dedicated to the integration of research into care.
- The Canadian Institutes of Health Research (CIHR) has played a prominent role in the early stages of SPOR, but represents only one in a multitude of partners.

SPOR CORE ELEMENTS



Support for People and Patient-Oriented Research and Trials (SUPPORT) Units



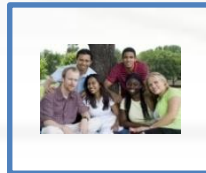
SPOR Networks



Capacity development



Improving the clinical trials environment



Patient engagement

PATIENT-ORIENTED RESEARCH

“a continuum of research that **engages patients as partners**, focuses on patient-identified priorities and improves patient outcomes”

↳ *SPOR Patient Engagement Framework, 2014*

Engaging patients across the continuum of research



“The international experience with engaging citizens and patients in research has shown that involving them early in the design of studies, ideally as early as at the planning stage, **leads to better results.**” (2012)



SPOR PATIENT ENGAGEMENT FRAMEWORK

GUIDING PRINCIPLES

Inclusiveness

Support

Mutual Respect

Co-building

VISION

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

Core areas for action:

- Governance and decision-making
- Capacity-building
- Tools
- Resources



INTERNATIONAL CONTEXT

INVOLVE (UK)

- Statement on patient and public involvement in research and research ethics committee review (2009)
- Resource document: examples of the impact of public involvement in the ethical design and conduct of research (2014)

Patient-Centred Outcomes Research Institute (PCORI) (US):

- Eager to develop a white paper on the ethics of patient engagement in research



CIHR Ethics Policy Project

Objective: to develop an ethics guide for researchers, patients and REBs when patients are co-partners in research.

Origin: The Working Group on Patient Engagement of the SPOR SUPPORT Units identified an emerging need to complement the SPOR Framework and TCPS 2 with ethics guidance on patient engagement in research, including active examples.



Project Origin:

Issues identified by SPOR SUPPORT Units

- Undue pressure on patients to participate
- Power imbalances
- Barriers to patient contribution and compensation
- Inadequate time and training provided to patients
- Lack of protection of personal information in sharing of research findings
- Inequitable sharing of benefits
- Respect for communication patterns favoured by patients
- Lack of involvement by REBs



Project Origin: Needs identified by SPOR SUPPORT Units

CIHR has a role in providing ethics leadership in PE in research

It would be great to have made-in-Canada guidelines/policies

The SPOR PE Framework provides some guidance, however it does not speak specifically to ethics

Active examples could be fleshed out regarding what meaningful engagement means

TCPS 2 should incorporate a section related to PE

REBs need additional education regarding the emerging circumstances of the patient-researcher

Something like the NHS framework would be more directly applicable (hands-on)



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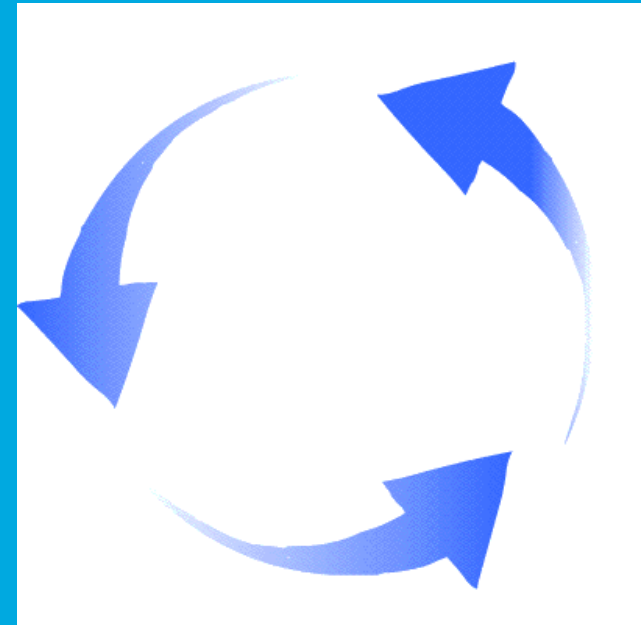
The CIHR Standing Committee on Ethics endorsed the project in December 2015.



CIHR Ethics Policy Project

Our Approach:

- Investigate and define the problem
- Create a Patient Engagement Ethics Working Group
- Consultation with key stakeholders at every stage of the project.



CIHR Ethics Policy Project

Initial consultation

- This is our first opportunity to receive initial feedback.
- We appreciate your interest.
- We also thank Michael and Don as our discussants.

