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Introduction

An important goal of Canada’s Strategy for Patient-Oriented Research (SPOR) is for patients, researchers, health care providers and decision-makers to actively collaborate to build a sustainable, accessible and equitable health care system and bring positive changes in the health of people living in Canada. Since patients are at the heart of SPOR, they must be involved as much and as meaningfully as possible in order for health research to be more responsive to the needs of Canadians.

If patient-oriented research is intended to focus on priorities that are important to patients and produce information that is truly taken up and used to improve health care practice, therapies and policies, a strong foundation for ensuring successful collaboration must be laid. SPOR’s National Steering Committee has requested that a Patient Engagement (PE) Framework be developed that will outline key opportunities for action, setting the stage for worthwhile collaborations in the identification of health research priorities as well as in the design and conduct of research projects.

A consultative process was undertaken to develop this PE Framework. A workshop held in Ottawa on January 9th brought together a cross-representation of Canadian patients and patient engagement experts, serving as a pivotal step in the process to identify patients’ aspirations for engagement in SPOR. Since that time, CIHR has presented the draft to SUPPORT Unit leads, the SPOR Working Group, and the SPOR National Steering Committee for validation and further input. It will be shared with SPOR stakeholders so that there is a common understanding and alignment of goals for patient engagement.

It is important to note that this Framework will be a living document and it will be re-evaluated as the various components of SPOR are implemented.

Vision

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

Objective

The SPOR Patient Engagement Framework is designed to establish key concepts, principles and areas for patient engagement to be adopted by all SPOR partners.
Definitions

It is crucial that key concepts and terms are defined to develop a common understanding across SPOR. We recognize there may be no catch-all term that fits everyone; the word ‘patient’, for example, is meant as inclusive but may initially evoke a range of meanings or limitations depending on the audience. Even so, the following definitions serve to clarify and establish terminology used throughout this document and SPOR.

Patient:
An overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.

Patient Engagement:
Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context patient-oriented research may also engage people who bring the collective voice of specific, affected communities.

Patient-Oriented Research:
Patient-oriented research refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices.

SPOR Partner:
Are key stakeholders collaborating in patient-oriented research, such as the SUPPORT Unit jurisdictional leads for each province and territory, patients, researchers, policy makers, decision-makers, health organizations, provincial/territorial health authorities, academic institutions, charities and the pharmaceutical sector.

*Patient-oriented research is ultimately aimed at achieving benefits that matter to patients:*

- Improved health
- Improved access to the health care system
- The right treatment at the right time
- Being an active and informed partner in health care
- Quality of life that is tied to patient-oriented outcomes
- Make a contribution to improving the cost effectiveness of the health care system
What can patients contribute and why it is needed?

Patients bring the perspective as ‘experts’ from their unique experience and knowledge gained through living with a condition or illness, as well as their experiences with treatments and the health care system. Involvement of patients in research increases its quality and, as health care providers utilize research evidence in their practice, increases the quality of care. ‘Engaging patients in health care research makes (investments in) research more accountable and transparent, provides new insights that could lead to innovative discoveries, and ensures that research is relevant to patients concerns. 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.’1 By encouraging a diversity of patients to tell their stories, new themes may emerge to guide research. Patients gain many benefits through their involvement including increased confidence and master new skills, access to information they can understand and use, and a feeling of accomplishment from contributing to research relevant to their needs.

Patient Engagement in SPOR

Patient engagement means fostering a climate in which researchers, health care providers, decision-makers and policy-makers understand the value of patient involvement and patients see the value of these interactions.

Engaging patients is an integral component in the development and implementation of all elements of SPOR such as, but not limited to, SUPPORT Units and Networks. As such, stakeholder (patients, researchers, health care providers and decision-makers) uptake on orientation and engagement tools is imperative to the success of the model.

Patients’ roles vary according to the contributions a patient is prepared to offer; however, the bar needs to be raised to allow jurisdictions to push the boundaries on the potential to build their capacity to engage patients in truly innovative roles and models of patient engagement. The patient perspective is integrated into every step of the research process including developing research questions, defining research objectives, collecting data and evaluating results. Some patients have the readiness to contribute as full members of research teams while others may bring a range of expertise such as in ethics or as knowledge brokers. Other patients bring the collective voice of specific, affected communities. Their knowledge and expertise offers insights about people who are unable to communicate on their own behalf.

The meaningful involvement of patients can include the following roles:

- As research committee members, planning, designing and guiding the project as it progresses. This involvement in decision-making processes and in bringing forward priority issues for research is integral to patient-oriented research.

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1 Methods for Involving Patients in Topic Generation for Patient-Centered Comparative Effectiveness Research, An International Perspective (2012), p.8
As competent patient engagement researchers. “They have mastered the specific research skills and know how to engage other patients, capture and articulate their ideas, support these ideas with valid research, and bring them to the table.”

As contributors to identifying the right research question, study design, recruitment, data collection, and analysis of findings. Patients can also have a role in reviewing stories to identify common threads/relevant themes. This ensures that the outcomes important to patients are supported and measured.

As supporters of participant-friendly research studies, improving access to patients via peer networks and accessing difficult-to-reach patients and groups.

Guiding Principles

Patient engagement in research will improve the relevance of the research and improve its translation into policy and practice, contribute to more effective health services and products, and ultimately, improve the quality of life of Canadians and result in a strengthened Canadian health care system. Underpinning this Framework are guiding principles to which SPOR partners will adhere in pursuing the goal of integrating patient engagement into research:

**Inclusiveness:** Patient engagement in research integrates a diversity of patient perspectives and research is reflective of their contribution – i.e., patients are bringing their lives into this.

**Support:** Adequate support and flexibility are provided to patient participants to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training, and education. Support also implies financial compensation for their involvement.

**Mutual Respect:** Researchers, practitioners and patients acknowledge and value each other’s expertise and experiential knowledge.

**Co-Build:** Patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions.

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2 http://webapps2.ucalgary.ca/~crds/greymattersinaction/docs/AHS%20Patients%20Matter%20Progress%20Report%20April%202015%202013.pdf
Core Areas for Engagement

1. Patient Engagement in Governance and Decision-Making

To achieve the vision of patients as active partners in health research, it is imperative that patients are involved in key governance structures and decision-making processes in all of SPOR’s present and future core elements. There needs to be a commitment to engage patients in decision-making, in peer review and in priority setting committees. A principle-based approach for patient representation on boards/committees is needed to clarify roles and expectations and to ensure that those who are impacted by the direction of research have a say (i.e., nothing about us without us). The following are non-exclusive examples crucial to integrating patient engagement into SPOR’s foundational structures: i. SPOR National Steering Committee: Patients need to be adequately represented on this committee; ii. SUPPORT Units: Each SUPPORT Unit will develop and implement a patient engagement plan which includes patient participation in governance and decision-making processes. SUPPORT Units will track and report on results of patient engagement activities in their jurisdiction; iii. SPOR Research Networks: Networks will create a process for patients, citizens and community stakeholders to be actively involved in research governance and as active participants in the research itself.

2. Capacity Building for Patient Engagement

To achieve an active collaboration between patients and researchers, health care providers and decision-makers for patient-oriented research, a change in culture must happen. Capacity development in SPOR focuses on approaches to overcoming the obstacles that inhibit these stakeholders from realizing PE objectives. It also focuses on enhancing their abilities so that measurable and sustainable results are achieved. What actions can support researchers, health care providers and decision-makers to engage patients and to see the benefits of PE? What needs to be in place so that patients are willing to participate in producing and using health research?

A variety of areas have been identified in which mechanisms are needed to address different audiences:

- Identify research funding mechanisms which will support SPOR to meaningfully engage patients in patient-oriented research;
- Integrate patient engagement into training strategies, including with research/trainees/interns and opportunities for patients;
- Adopt a partnership approach to build capacity for patient engagement by leveraging the existing work and expertise of other organizations/networks, including training and evaluation models in the health care context;
- Support patients to share in the responsibility of engaging/reaching out to under-represented groups as well as mentor other patients; and
3. Tools and Resources

The creation of tools and access to resources is encouraged in order to implement research collaborations among researchers, patients, practitioners and decision-makers:

- Create a pool of patient participants: a cross-section of participation with representatives from diverse populations in different geographic, socioeconomic and cultural contexts who also reflect gender and age representation;
- Provide education, orientation, and training for patients, researchers, health care providers and decision-makers so that they can work and communicate meaningfully and efficiently;
- Share best practices on a range of engagement approaches and role definitions in order to meet the needs of a variety of patients, population and age groups;
- Support researchers to identify and engage under-represented patient groups; and
- Support patients in their efforts to engage/reach out to under-represented groups.

Evaluation of Patient Engagement in SPOR

The consultation workshop sought input from patients and patient engagement experts on their desired outcomes for patient engagement.

- Inclusive mechanisms and processes are created;
- Capacity for respectful collaboration is established amongst patients, researchers and health care providers;
- The experiential knowledge of patients is valued as evidence as part of the research process;
- Research is informed and co-directed by patients; and
- Everyone shares the goal of timely implementation of quality research.

Appendix 2 expands on these outcome statements which were described as ‘conditions for success’ by the patient representatives who participated at the Patient Engagement Workshop on January 9, 2014.

The above outcomes will be used in the development of patient engagement performance indicators and integrated within the overall SPOR Performance Measurement Strategy. These indicators are currently in development as CIHR is consulting with other organizations with experience in evaluation of patient engagement programs. Both the scan and consultation processes will inform the development of patient engagement performance indicators.
Appendix 1: PE Framework Dashboard

VISION

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

OBJECTIVE

The SPOR Patient Engagement Framework is designed to establish key concepts, principles and areas for patient engagement to be adopted by all SPOR partners.

**DESIRED OUTCOMES OF PATIENT ENGAGEMENT**

- Inclusive mechanisms and processes are created
- Respectful collaboration is established amongst patients, researchers and health care providers
- The experiential knowledge of patients is valued as evidence as part of the research process
- Research is informed and co-directed by patients
- Common goal of timely implementation of quality research

**GUIDING PRINCIPLES**

Underpinning this Framework are guiding principles to which SPOR partners will adhere in pursuing the goal of integrating patient engagement into research.

- Inclusiveness
- Support
- Mutual Respect
- Co-building
Appendix 2: What does Success Look Like?

These conditions for success are derived from the SPOR Patient Engagement consultation workshop that took place on January 9, 2014.

Successful patient engagement includes the following:

i. **Inclusive Mechanisms and Processes**: Patient involvement at all levels is a desired aspiration that also means shared leadership and decision-making processes in which patients are co-building with researchers, practitioners and other decision-makers in collaborative research teams. There is also opportunity for peer to peer recruitment and engagement. (Patient-led research is supported).

ii. **Multi-Way Capacity Building**: This ensures that the capacities of patients, researchers, and health care providers are being developed in order to work effectively together. There is support for creating safe environments that promote honest interactions, cultural competence, training and education.

iii. **Multi-Way Communication and Collaboration**: A safe environment of mutual respect is fostered and is characterized by honest conversations that inform and involve people.

iv. **Experiential Knowledge Valued as Evidence**: Experiential knowledge of patients, families and caregivers is mobilized and translated.

v. **Patient-Informed and Directed Research**: Research approaches engage patients in collaborative methods and the research is inclusive of a range of patients. Recognition is given to a diversity of patients’ needs and expectations through a range of roles.

vi. **A Shared Sense of Purpose**: All participants work together towards the goal of timely improvements to the quality of research driven by patient-oriented outcomes. Mechanisms are in place for a continuous feedback loop in which the results of patient-oriented research are communicated back to patients.