



Request for Proposals

Mapping Patient Engagement in Research Activities in Organizations Across Ontario

Released October 22nd, 2018

Invitation

The Ontario SPOR SUPPORT Unit (OSSU) Patient Partners Working Group (PPWG) is soliciting proposals from applicants with demonstrated experience and sector knowledge to provide a provisional cataloguing of patient engagement in research activities in organizations across Ontario. The successful applicant is expected to work in conjunction with the PPWG and the OSSU Coordinating Centre to develop a catalogue of organizations in Ontario that currently have activities and policies in patient engagement, including a cataloguing of the patient partners experiences in those engagement processes.

Organizational Overview

Funded in 2013 for 5 years, the Ontario SPOR SUPPORT Unit (OSSU) collaboration includes 13 leading health research centres. It is supported by a Coordinating Centre which facilitates, connects and integrates activities across the network. Jointly funded by the Government of Ontario and the Canadian Institutes of Health Research (CIHR), the initiative engages patients, researchers, clinicians, policy makers, industry representatives and other health system professionals to implement Canada's Strategy for Patient-Oriented Research (SPOR) within Ontario.

With world-leading expertise in data access and analysis, methodological and research services, knowledge translation, clinical trials and capacity building, OSSU provides infrastructure, expertise and support to those engaged in patient-oriented research. It also promotes knowledge transfer and exchange of the latest research evidence to inform and implement more effective health policy and clinical practices throughout the province.

Key to the activities and strategy of OSSU is partnership with patients (broadly defined to include family members and carers as well as those with direct experience of the health care system). This partnership permeates all levels of OSSU and is overseen by the PPWG, a patient-led advisory group that identifies strategies and approaches to build a broader and more effective approach to patient partnership in health research in Ontario.

Further details on OSSU and SPOR are available in Appendix A and at www.ossu.ca.



Scope of the Work

Ontario has a large and complex health care and health research system, one which is increasingly becoming aware of the need to engage patients, caregivers and family members in their activities. Patient engagement in research is now a part of multiple types of organizations from large government groups (Ministry of Health Patient and Family Advisory Council, Health Quality Ontario, Cancer Care Ontario), to local delivery of research in health care settings (hospital family advisory groups, Local Health Integration Network Advisory Councils), to research groups and charities (University research groups, research charities).

Patient engagement in research is defined by SPOR as patients “becom[ing]... partners in the project and can be actively engaged in governance, priority setting, developing the research questions, ... performing certain parts of the research itself... [and] summariz[ing] or shar[ing] the results with target audiences.”

It is anticipated that the project will provide a simple-to-use catalogue of patient engagement in research across organizations in Ontario, although it is not intended to be exhaustive of all possible organizations that have a patient engagement aspect. Some examples of information on patient engagement that could form the skeleton of the catalogue are: 1) types of engagement (e.g. steering groups / decision making councils etc.), 2) forms of engagement (e.g. online), 3) areas of work (e.g. types of research, links to quality improvement, condition specific, work with diverse and underserved populations, etc.), and 4) potential key issues/things to learn from the groups. In addition to data collection from the organizations, it is expected that the contractor will speak with leading patient partners within organizations for their views on the engagement they have been involved with (in terms of strengths, weakness, opportunities for sharing practices, etc.). The project output is anticipated to be used by patient partners needing guidance on engagement at different organizations, health research organizations looking to identify similar groups involved with patient engagement, and research teams looking to identify organizations that have different approaches to engagement.

This work will be scoped by the contractor (academic or consultant) with guidance from the steering group in the Patient Partners Working Group, and then data collected and categorized by the contractor. The steering group for this will also likely include individuals from other organizations' patient partnership groups.

Submitted proposals will outline the applicant's track record and capacity to deliver on the mapping and cataloguing of patient engagement in research activities over a 6-month timeframe (March 2018 to September 2018).



Contractor requirements

To provide the cataloguing of patient engagement in research structures, activities and approaches, the PPWG is seeking a vendor with experience of working closely with patients and family members and with an understanding of the following:

- Patient engagement in research
- Developing systems for assessing and cataloguing complex information
- The Ontario health and health research system and its various components
- Interviewing patients and caregivers
- Plain language writing of complex concepts

Interested vendors should provide details of their approach to the mapping of patient engagement in research across Ontario organizations in a short proposal (5-page maximum) to the PPWG. The budget for this cataloguing project is up to \$60,000. Work should be completed in a 6-month timeline.

The proposal should include:

1. description of the vendor (organization or individual) including relevant experience
2. proposed approach to mapping patient engagement in research across Ontario organizations, to include:
 - a. proposed approach to working with the PPWG steering committee for the project
 - b. methodology for mapping patient engagement in research in Ontario organizations
 - c. approach to cataloguing patient engagement across Ontario organizations
 - d. approach to interviewing patient partners from Ontario organizations who have undertaken patient engagement in research approaches and activities
3. budget and workplan for the approach
4. the proposal may include appendices if necessary to clarify the approach

Bidders may collaborate to draw expertise from various organizations, but a single lead applicant should be identified on each submission.



Key Considerations:

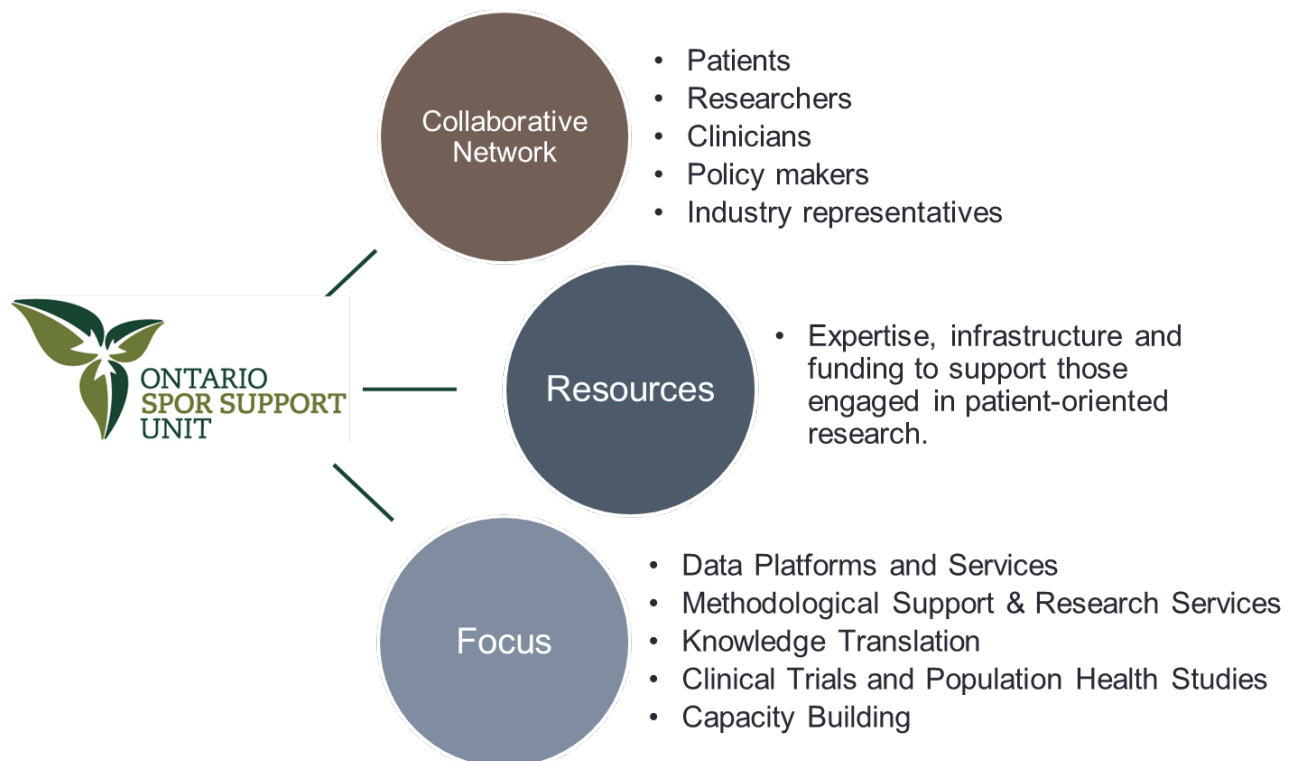
Proposals are to be submitted electronically to OSSU's PPWG via the email ossu@ossu.ca by **5:00 pm on Friday November 16th 2018**. Please include "PPWG Mapping Ontario Patient Engagement in Research Proposal" in the subject line. Questions regarding the RFP should be submitted to Eddy Nason (eddynason@ossu.ca) by 5.00pm Friday November 9th 2018.

Appendix A

OSSU Overview

OSSU brings together a diverse stakeholder group engaged with patient-oriented research in Ontario. With this group, OSSU leverages Ontario’s wealth of health research resources to align and build upon CIHR’s SPOR goals (Figure 1). Using this strategic approach allows OSSU to ensure that the existing high volume of excellent health research in the province gets realigned with the needs of the collaborative network of stakeholders in patient-oriented research in Ontario.

Figure 1. OSSU strategic approach



The OSSU is composed of a Coordinating Centre and 12 centres/networks with diverse expertise related to patient-oriented research and implementation (Figure 2). The majority of OSSU funding is directed to new activities at these 12 centres/networks, including supports and services that they will provide to other researchers, infrastructure/platform investments and capacity building initiatives.

Figure 2. OSSU Coordinating Centre and 12 Research Centres

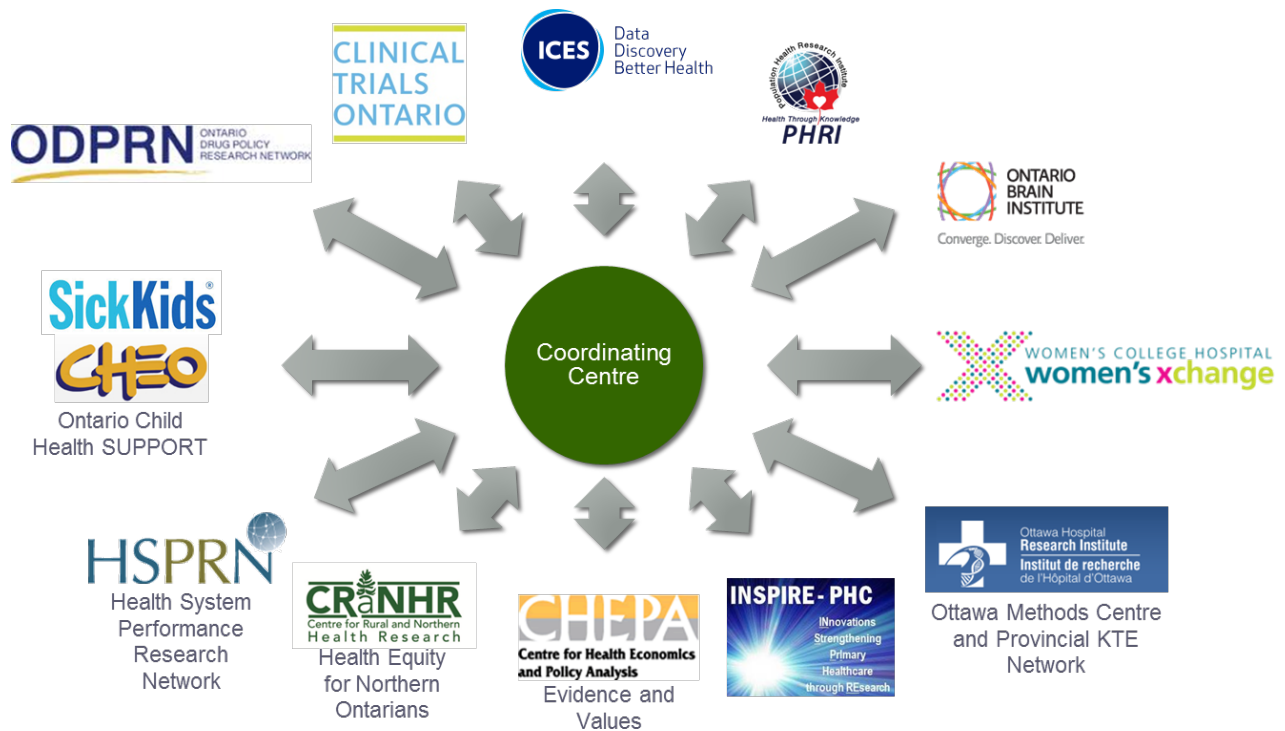
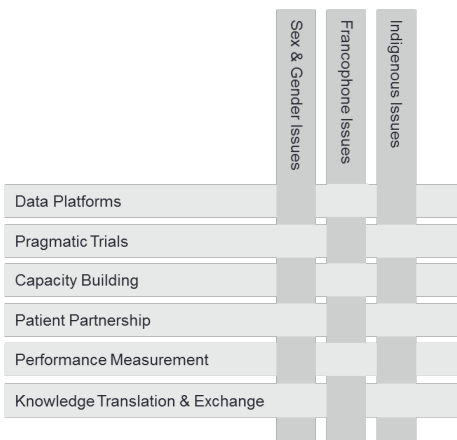


Figure 3. OSSU Working Groups



In addition to these 12 centres, OSSU has 9 cross-cutting working groups (6 aligned with the SPOR Support Unit priorities laid out by CIHR, and 3 aligning with Ontario POR priorities)(Figure 3).

In terms of research activity (as an illustration of how Ontario health research can utilize OSSU POR supports) OSSU has funded two demonstration projects beginning in 2013, one led by the Ontario Stroke Network (*Implementing Quality Based Procedures for stroke patients*), the second by Patients Canada (*Patient*



Partnership Principles and ER PROMs). In addition to these two demonstration projects, OSSU is funding a suite of IMPACT Awards - translational research projects that are Innovative, Measurable, Patient-oriented, Appropriate, Collaborative and Transformative (for details see <http://ossu.ca/impact-awards/>).

SPOR Overview

CIHR states that “**Canada's Strategy for Patient-Oriented Research (SPOR)** is about ensuring that the right patient receives the right intervention at the right time.” SPOR is a 5-year, joint federal, provincial, territorial initiative to foster:

- Evidence-informed health care with system-wide impact.
- Enhanced patient engagement and partnerships.
- Innovative collaboration among researchers, clinicians, patients, health system administrators, policy makers, health charities, industry, etc.
- An engaged coalition dedicated to the integration of research into care and the translation of research results into improved health outcomes.

For SPOR, patient-oriented research refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. In SPOR, ‘patient’ refers to individuals with personal experience of a health issue and informal caregivers, including family and friends.

SPOR as a whole is built on a number of principles (Box 1) that outline the way SPOR research should be funded, approached, practiced and assessed.

- Patients need to be involved in all aspects of the research to ensure questions and results are relevant and integrated into practice.
- Decision-makers and clinicians need to be involved throughout the entire research process to ensure integration into policy and practice.
- Funding is based on a 1:1 matching formula with non-federal government partners to ensure relevance and applicability.
- Effective patient-oriented research requires a multi-disciplinary approach.
- SPOR is focused on first-in-human (and beyond) research designed to be transformative in nature and improve patient outcomes and the effectiveness and efficiency of the health care system.
- SPOR is outcome driven and incorporates performance measurement and evaluation as integral components of the initiative.

Box 1. SPOR principles

SPOR is essentially comprised of two main components that integrate both patient engagement and training & mentoring activities as core components: SPOR Support Units and SPOR Networks (Figure 4).

Support Units: Provincial and/or regional centres providing support and expertise to those engaged in patient-oriented research.

SPOR Networks: National collaborations to generate research evidence and innovations designed to improve patient health and health care systems.

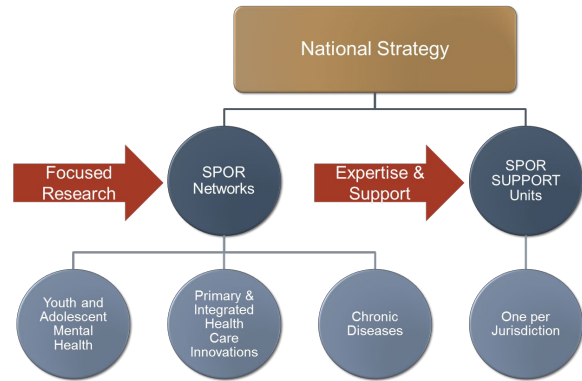


Figure 4. SPOR Components



Appendix B – Examples of Potential Organizations and Characteristics for Mapping Process

Organization	Sector	Patient engagement activities	Approaches to patient engagement	Patient partner perspectives
Health Quality Ontario	Government			
Cancer Care Ontario	Government			
Council of Academic Hospitals of Ontario	Hospital			
Local Health Integration Networks	Healthcare			
Ottawa Hospital Research Institute	Academic			
Holland Bloorview Children's Hospital	Hospital			
Ministry of Health and Long-Term Care Minister's Patient and Family Advisory Council	Government			
The Change Foundation	Charity			
Ontario Best Practices Research Initiative	Academic			
Arthritis Society Ontario	Charity			
<i>Other groups...</i>				