



Request for Proposals

Developing a 'white paper' on the 'ladder of engagement' concept from the patient perspective

Invitation

The Ontario SPOR SUPPORT Unit (OSSU) Patient Partnership Advisory Working Group (PPAWG) is soliciting proposals from organizations with demonstrated experience and sector knowledge to support the scoping and development of a patient-developed 'white paper' on the concept of the 'ladder of engagement' when viewed from a patient perspective. The successful organization is expected to work in conjunction with the PPAWG and the OSSU Coordinating to ensure a white paper that is patient-led, focused on patient needs, builds on existing evidence and speaks to multiple patient opinions.

Organizational Overview

Funded in 2013 for 5 years, the Ontario SPOR SUPPORT Unit (OSSU) collaboration includes 12 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, 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 PPAWG, 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

One ongoing challenge in patient-oriented research in Canada and beyond is the focus on patient engagement as a component of individual studies. One example of this is the concept of the 'ladder of engagement' – an approach to conceptualizing the role patients can play in research projects that underpins the internationally recognized IAP2 framework for engagement. The OSSU PPAWG have identified that there is an opportunity to look at this conceptual ladder from the point of view of patients, rather than projects, to investigate what partnering in research means from a patient perspective, rather than a project perspective.

The white paper would be conceptualized by the PPAWG, and written in accordance with their needs. The successful group/organization in this RFP work with a small steering committee of patient partners selected by the PPAWG.

Submitted proposals will outline the organization's track record and capacity to deliver on the scoping and development of the white paper over a 3-month timeframe (November 2017-February 2018).

Contractor requirements

To support the scoping and development of this community, the PPAWG is seeking a vendor with experience of working closely with patients and family members and with an understanding of the following issues:

- Patient engagement in research
- Relating evidence and experience in patient-oriented research
- Interviewing patients and caregivers
- Plain language writing of complex concepts

Interested vendors should provide details of their approach to scoping and developing white paper on the ladder of engagement concept in a short (3 page maximum proposal) to the PPAWG. The budget for this scoping and development is up to \$20,000. Work should be completed in a 3 month timeline.

The proposal should include:

1. description of the vendor (organization or individual) including relevant experience
2. proposed approach to scoping and developing the white paper, to include:
 - a. proposed approach to working with the PPAWG steering committee for the project
 - b. methodology for engaging evidence and experience in the development of the paper



3. budget and workplan for the approach

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

Key Considerations:

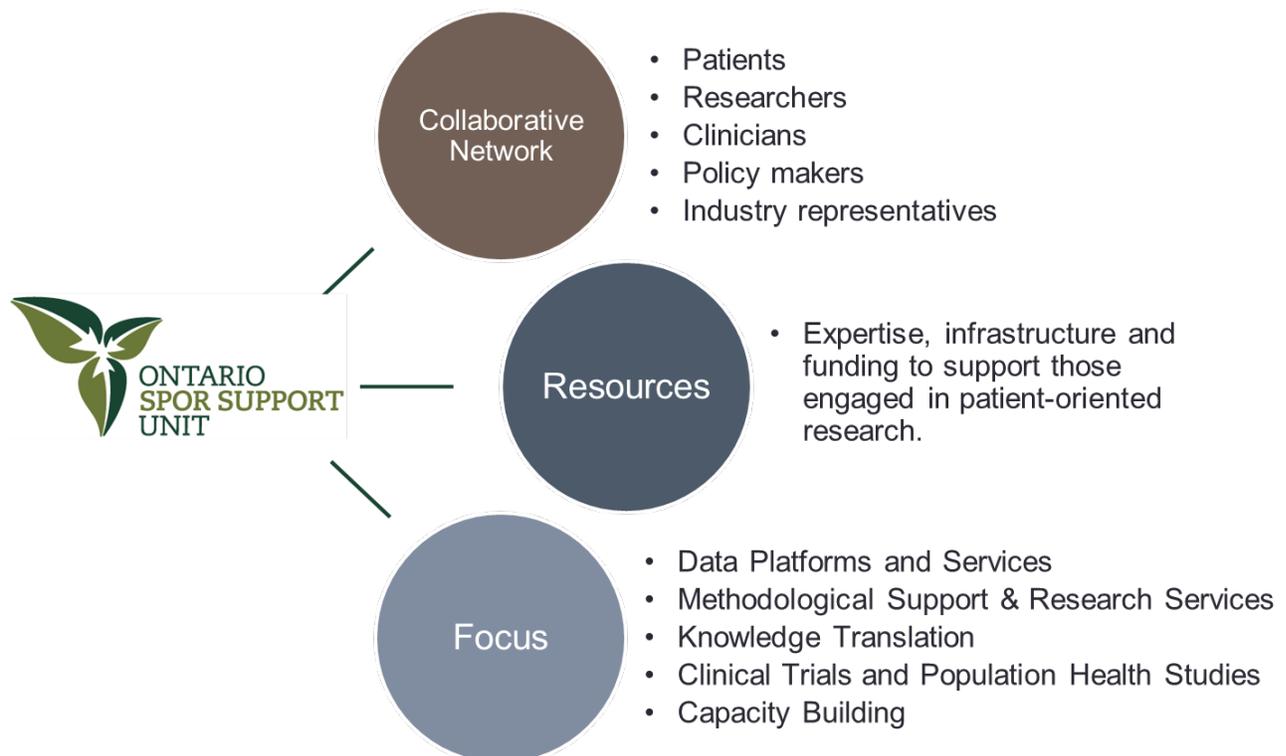
Proposals are to be submitted electronically to OSSU's PPAWG via the email OSSU@OSSU.ca by **5:00 pm** on **Wednesday, January 17, 2017**. Please include "PPAWG Ladder of Engagement White Paper Proposal" in the subject line. Questions regarding the RFP should be submitted to Eddy Nason (eddynason@ossu.ca) by 5:00 pm on Monday, January 8, 2017.

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

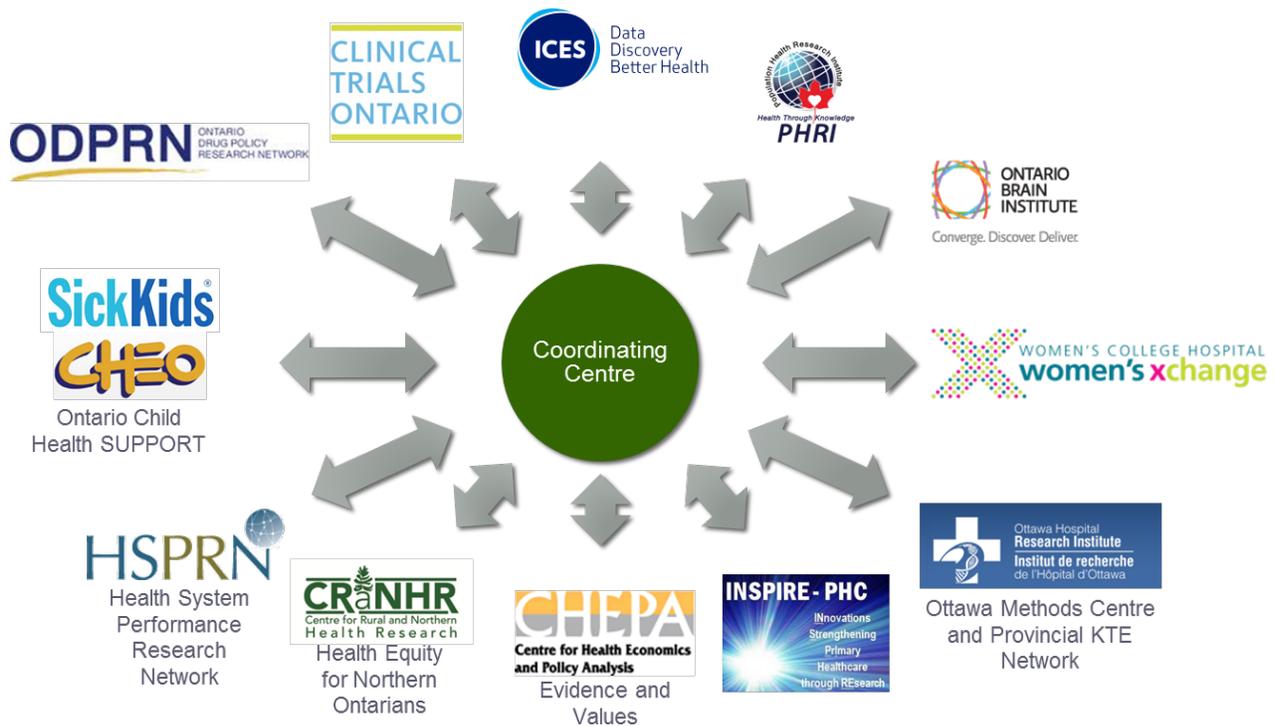


Figure 3. OSSU Working Groups

	Sex & Gender Issues	Francophone Issues	Indigenous Issues
Data Platforms	■	■	■
Pragmatic Trials	■	■	■
Capacity Building	■	■	■
Patient Partnership	■	■	■
Performance Measurement	■	■	■
Knowledge Translation & Exchange	■	■	■

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 both integrate 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.

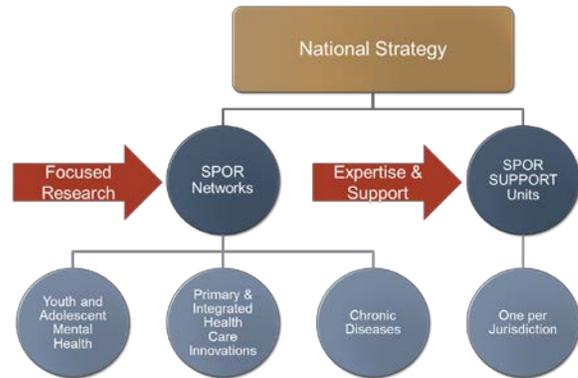


Figure 4. SPOR Components

Appendix B – IAP2 Spectrum

