

Background and Context

The Ontario SPOR SUPPORT Unit (OSSU) has evolved as the foundation to catalyze equity-based patient-oriented research evidence and expertise in improving patient experiences, provider experiences, health outcomes and reduced costs in Ontario. The overarching goal of the Strategy for Patient Oriented Research (SPOR) is to translate research results into improved health outcomes for Canadians. OSSU is the first point of contact for stakeholders interested in learning more about support for patient-oriented research in Ontario and the gateway to other aspects of SPOR located in Ontario.

The legacy of OSSU's Phase I activity supports Ontario's developing evidence-informed learning health system in the current health system transformation and pandemic response. OSSU is moving into Phase II of its mandate with OSSU being an integral broker within the learning health system connecting evidence to practice through patient partnerships. In Phase II OSSU will continue to build a sustainable and responsive rapid-cycle learning patient-oriented research (POR) system in Ontario; catalyze Ontario's POR by providing infrastructure and supports for POR, including a focus on diversity, equity, and inclusion; and enhance research impacts of POR through the health system. OSSU's working groups serve as agents that ensure the impact of the OSSU is greater than the sum of the parts to advance the patient-oriented research agenda and infrastructure of patient inclusion in research in Ontario.

The Patient Partners Working Group (PPWG) aims to support and promote an overall strategy for engaging patients in the planning and conduct of research undertaken in Ontario.

Mandate

The work group mandate is to support the advancement of patient partner research with an emphasis on research infrastructure.

The specific terms of reference for the **Patient Partners Working Group (PPWG)** are:

1. To support and promote an overall strategy for engaging patients in the planning and conduct of research undertaken in Ontario through targeted activities.
2. To strengthen relationships with OSSU centres by sharing the support work that members are engaged in with their respective working groups.
3. To work with the OSSU stakeholders and groups to identify needs for patient representation in their membership and how best to represent the views and values of patients in their work.

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4. To oversee the development, approval, and conduct of specific projects as they relate to the mandate of the work group to advance the agenda of patient partner engagement.

The PPWG will document its own processes to prioritize and support qualitative or quantitative proposals developed within their working group. **Projects will usually be led by a sub-group of PPWG members (task groups) and will report back to the full group, unless the working group decides on an alternative structure.**

Membership and Decision Making

The PPWG will have:

- A Chair, who is also a member of the OSSU Operational Management Team (OMT);
- Patients/Caregivers;
- Researcher and non-researcher members;
- A representative from the OSSU Coordinating Centre

The Chair Emeritus of the PPWG will be invited to sit on the Funders Table Committee as a patient representative.

The PPWG will have 6-10 core members, with additional individuals providing input as appropriate. Participants become members through self-identification and/or nomination. The PPWG will meet as agreed on by all members, with a minimum of 6 meetings a year and with a minimum of 4 patient/caregiver partners in attendance. Patient/caregiver members will be offered a yearly honorarium and expenses pertaining to work group membership will be reimbursed upon review by OSSU.

Patient Partner Working Group members will have a three-year term of membership, with the option for an additional year at the conclusion of the initial three years. This additional year will be decided in conjunction with the member, OSSU and the Chair of the Working Group. Discretionary membership to go beyond the 4th year will be decided among the member, OSSU, and the Chair of the Working Group in accordance of the time of Phase II.

The PPWG Chair will serve for a tenure of 2 years with no option for renewal. Chairs must be existing members of the Working Group. The Chair's term is not dependent on their years of service as a member in the PPWG.

The PPWG will have 1-2 Vice-Chairs (depending on need and suitability). Vice-Chairs will serve for a period of 2 years with no option for renewal. The Vice-Chair will be invited to serve as Chair when the Chair's term has expired. It is expected that the

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Chair will work closely with the Vice-Chair to assist in preparedness and a smooth transition.

Working Groups, including task groups, have the authority to make decisions, initiate and perform projects/initiatives/targeted activities with consensus and support of OSSU according to OSSU's mandate. These may include but are not limited to: the creation and participation in webinars, podcasts, a reviewer on projects, and as a contributor and driver of special projects.

The activities of the PPWG will be supported by OSSU's Assistant Director. The Assistant Director will be responsible for administrative arrangements such as scheduling meetings; taking meeting minutes; circulating documents; and managing expenses.

These terms of reference are effective April 1, 2021 for the duration of OSSU PHASE II (March 30, 2026).