Frequently Asked Questions

What does the patient/public partner co-leadership role look like?

Patient/public partner co-leads play a central role in guiding the research direction through the lens of their lived experiences at every stage of the research process. The scope and level of engagement of their roles can vary depending on the responsibilities the partners are prepared to take on. Prior to initiating the project, it is essential for patient/public partner co-leads to engage in thorough discussions with the research team to establish terms of engagement that resonate with their individual interests, expertise, experience, and availability.

We recommend that patient/public partner co-leads are engaged in the following capacity:

- Providing subject matter expertise through lived experience, if applicable
- Co-developing the research question, work plan and budget with careful consideration for the anticipated time commitment from the patient/public partner co-lead
- Providing input on the search terms being used to develop the search strategy, study selection criteria, data abstract form, data analysis and presentation plan
- Co-authoring all dissemination products (e.g., manuscript, plain language summaries)

Tasks such as performing literature screening, extracting data, assessing risk of bias or running data analysis are responsibilities of the research staff on the team. However, patient/public partner co-leads can be involved in the pilot phases of the screening and data extraction steps (i.e., testing the screening and data extraction questionnaires on a small sample of studies) if they wish, but are not required to.

What if I do not agree with the proposed work plan?

We always encourage open and respectful communication within the team. If there is a misalignment between opinions and ideas, we recommend having an open dialogue to build consensus. For some tips, check out these resources:

- Guidance on Engaging Patient and Public Partners in Research as a Researcher
- Guidance on Being a Patient and Public Partner in Research

What is the compensation policy for patient/public partner co-leads?

Patient/public partners are compensated at an hourly rate of **$40**. Additionally, there is a $1000 stipend offered for each patient/public partner co-lead (i.e., partners who submitted the research topic). **Any additional patient/public partners added will be in a support role and are not eligible for the additional $1000 stipend.**

Please ensure that the project budget allocates sufficient funds for meaningful engagement, co-leadership and partnership. **Research teams are responsible for monitoring and managing their research expenses, including disbursing payments for patient/public honoraria.**

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How much time and budget should be dedicated to the patient/public co-lead(s)? Is there an established framework for this?

Data from our pilot projects indicate that patient/public partner co-leads contributed 150-200 hours to the project. We hope the additional stipend should cover any unanticipated hours that the patient/partner co-lead(s) may contribute in the project lifecycle.

Will there be financial assistance for equipment/technological support (e.g., access to institutional library access, computer hardware, etc.)?

The SPOR Evidence Alliance central coordinating office is currently exploring provisions for offering equipment/technological support for patient/public partner co-leads. We will provide details as information becomes available.

Is the inclusion of a second patient/public partner a requirement? What role and responsibilities does the second patient/public partner have?

For teams with one patient/public partner co-lead, it is highly encouraged to add a second patient/public partner in a support role. Having a support patient/public partner can bring diverse perspectives and avoid tokenism. The second patient/public partner is **not a co-lead,** and will take on an advisory role providing feedback at the project planning stage (work plan and protocol development), results interpretation, and development of plain language summary stages.

For more information, please access our **Patient and Public Partner Engagement in Research document**, which includes key terminology, overview of how patient/public partners can be engaged, and roles for patient/public partners.

Who is responsible for the recruitment of additional patient/public partners?

Both the patient/public partner and research co-leads can discuss who they believe will be a meaningful addition. If you have pre-existing relationships with designated patient/public partners, please feel free to include them in the project in a **supportive and/or advisory capacity.**

The SPOR Evidence Alliance can also assist in recruiting a patient/public partner with relevant lived experience for the research topic. If you need assistance, please complete the **patient and public engagement intake form** and send it to the central coordinating office.

Can funding be carried on past the deadline (e.g. fees related to knowledge translation and dissemination)?

At this time, the funding term will conclude on **March 31, 2025**. In the event that a no-cost extension becomes necessary, we will evaluate each request on a case-by-case basis.

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Where can I access templates and guidance documents for this project?

Templates (e.g., workplan and budget template), guidance documents and forms are available on the SPOR Evidence Alliance **resources webpage.**

What happens after the work plan and budget is submitted?

Once the work plan and budget are submitted to the central coordinating office, a member of the team will confirm receipt.

The work plan and budget will be reviewed by an expert in knowledge synthesis and patient/public engagement and by a member of the central coordinating office. We anticipate that this will take 3 weeks from the date that the work plan and budget are submitted. If additional revisions are required, you will have 1 week to review and update your work plan and budget accordingly.

Who can I reach out to if I have concerns regarding this process?

The central coordinating office is available to answer any questions or concerns about the process. Please feel free to reach out via email at SPOREA@smh.ca.