ROUND 1: Patient-Driven Research Communities of Practice – Discussion Themes and Frequently Asked Questions

Preamble

The SPOR Evidence Alliance (hereafter Evidence Alliance) established six Communities of Practice (CoPs) consisting of 20 research teams to foster collaboration, facilitate knowledge sharing, and promote best practices in patient-driven research. During the months of May to July 2024, the CoPs met for the first time. These gatherings brought together co-leads involved in the 20 patient-driven research projects funded in 2023. The list of patient-driven research projects funded by the Evidence Alliance can be found on the Patient-Driven Research (opens in a new window) webpage.

This document summarizes common themes discussed, including facilitators and barriers encountered during their collaborative leadership in research. It also addresses frequently asked questions that arose during the initial meetings.

Context

The groups consisted of teams with varying levels of experience in patient and public partner co-leadership. Some teams had expertise in this area, while others were new to the co-leadership model despite having experience with patient and public partnership in research. It is important to remember that the **co-leadership approach will be unique to each team, as every co-lead brings their own unique knowledge, experience, and expertise.**

Thematic Summary of Discussions

Theme	Patient and Public Partner Co-Lead Perspective	Researcher Co-Lead Perspective
1. **Project Conceptualization and Design**	• Invest adequate time to discuss and refine the research question to ensure it accurately reflects the patient and public vision and perspectives. • Prefer flexibility in engagement terms, with some preferring advisory roles while others take on more research-related responsibilities.	• Need to align research design with real-world needs by incorporating patient and public insights. • The patient and public partner co-leads bring passion and enthusiasm to the projects and help contextualize the research framing.

Theme	Patient and Public Partner Co-Lead Perspective	Researcher Co-Lead Perspective
2. Recruitment and Engagement	• Ensure diverse viewpoints are included, enriching the research through broader perspectives.	• Able to leverage patient and public partner networks for recruitment and community engagement. • Increase the potential to expand the reach and inclusivity of the research through community connections.
3. Resource Sharing	• Emphasize the importance of research that can influence policy and decision-making.	• Learn from new resources brought by patient and public partner co-leads to guide project direction. • Gain important context and relevance for the research through patient-contributed resources.
4. Knowledge Mobilization	• Provide input to ensure knowledge mobilization events are accessible and tailored to participant needs. • Develop various formats for knowledge mobilization and identify key community partners.	• Leverage patient and public networks to identify knowledge users who would benefit most from the research findings. • Patient and public partner co-leads provide helpful guidance in tailoring the knowledge products and dissemination efforts for the target audience.

These themes highlight the valuable contributions of patient and public partner co-leads in shaping research projects and ensuring they are relevant, inclusive, and impactful.

Facilitators and Barriers Encountered

The teams discussed various **facilitators** encountered in their projects.

Facilitators	Patient and Public Partner Co-Lead Perspective	Researcher Co-Lead Perspective
1. **Effective Collaboration and Communication**	• Regular check-ins and informal communication channels help maintain accountability and fostered a sense of teamwork and commitment.	• Regular communication help maintain cohesion within the teams and enhanced the quality of the research.
2. **Meaningful Engagement and Relationship-Building**	• Invest time at the onset of the project to build trust and foster mutually respectful relationships, making patient and public partners feel valued and respected.	• Invest time for initial discussions to clarify the patient and public partners' roles, expectations, and preferences for engagement.
3. **Capacity Building and Learning Opportunities**	• Evidence Alliance courses on knowledge synthesis and patient and public engagement help provide foundational knowledge to allow for meaningful co-leadership.	• Learning modules and support provided by the Evidence Alliance help orient new staff to knowledge synthesis methodology.

The teams discussed various **barriers** encountered in their projects.

Barriers	Patient and Public Partner Co-Lead Perspective	Researcher Co-Lead Perspective
1. **Defining the Project Scope**	• Manage expectations and trust the research team's expertise in defining a feasible project scope, as aligning all perspectives while maintaining practical limits can be challenging.	• Balance patient and public partner co-leads' expectations with ensuring the project scope is achievable, as adequately addressing all perspectives within practical limits can be challenging.

Barriers	Patient and Public Partner Co-Lead Perspective	Researcher Co-Lead Perspective
2. Time Constraints	• Make time to identify and recruit partners who can contribute meaningfully to the project, as this can take longer than anticipated.	• Invest time early to build relationships and refine the scope, as meeting project milestone deadlines can be a challenge.
3. Funding Limitations	• Funding limitations can affect the ability to scale up knowledge dissemination efforts.	• Funding limitations can affect the ability to conduct more thorough and expansive knowledge syntheses.

Conclusion

The meetings underscored the value of meaningful engagement, relationship building, collaboration, shared learning, and advocacy for patient-oriented research principles. The discussions across the CoP meetings highlighted the significant contributions of patient and public partner co-leads in project design, feedback, recruitment, and knowledge mobilization.

Co-leads highlighted the benefits of the CoPs, including the opportunity to connect with other co-leads and learn about their projects, gain insights into the challenges and success of other groups engaged in patient-led research, and better understand how meaningful patient partnerships work, particularly in knowledge synthesis. Strategies for enhancing engagement and addressing challenges such as project timelines and accessibility of learning systems were examined.

As we move forward, the importance of continued support and advancement of the patient-driven projects remains a priority.

Frequently Asked Questions

1. **What is the purpose of the CoPs?**

   The CoPs were created to encourage collaboration, facilitate knowledge sharing, and promote best practices in patient driven research, with the goal of enhancing healthcare outcomes and advancing learning health systems. See the Terms of Reference (PDF, 537 KB) document for more information.

2. What led to the decision to implement the CoPs?

Co-leads from the patient-driven research projects funded in 2021 (our pilot year) shared feedback indicating that the teams would appreciate opportunities to connect and network with other teams to exchange perspectives and experiences.

3. Are patient and public partner co-leads compensated for their participation in the CoPs?

The time spent in the CoP related acitivites is already included for in the project budget and will be covered by the research project team. Each patient and public partner co-lead receives a $1,000 stipend from their project team to cover additional responsibilities, such as participating in the CoP. We expect up to three meetings throughout the project lifecycle – at the beginning, middle, and end – requiring an estimated 3 hours of total commitment. Additionally, co-leads were provided a $500 technology bonus to cover any out-of-pocket office expenses they may incur in their work.

4. What are the terms of engagement for the CoPs?

Each group can define their own terms of engagement without being limited to specific requirements. Groups can establish their preferences for scheduling meetings and communication methods, such as email or other informal channels.

5. Is protocol registration required?

It is important for patient and public partner co-leads to review and give feedback on the protocol before research teams formally register it on the database. All teams are strongly encouraged to register their protocols using platforms such as PROSPERO (opens in a new tab) or the Open Science Framework reviews (OSF) (opens in a new tab). However, please note that PROSPERO does not accept protocol registrations for scoping reviews.

6. Are there useful resources or tools for reporting patient/public engagement or health equity considerations in research?
- Teams are strongly encouraged to use the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) reporting checklist (opens in a new tab). The GRIPP2 reporting checklist is a structured tool for reporting of patient and public involvement in health and social care research.
- Teams should apply the PROGRESS-Plus (opens in a new tab) framework to identify characteristics that stratify health opportunities and outcomes.
- The 2023 Patient and Public Health Research Topic Orientation Meeting (PDF, 5.61 MB) document includes additional resources and tools for guidance on reporting of health equity considerations and patient and public engagement.

To facilitate resource sharing, a dedicated page on the SPOR Evidence Alliance website is available for patient-driven research resources (opens in a new tab). If you have any

additional resources to contribute or suggestions for future CoP meetings, please email them to the central coordinating office at SPOREA@smh.ca.

7. Is there any additional funding available to support knowledge mobilization events?

At this time, the SPOR Evidence Alliance does not have any funds to further support ongoing knowledge mobilization efforts. If you are aware of any funding opportunities, please email them to the central coordinating office at SPOREA@smh.ca and we will share it with all the teams.

8. When will the next meeting be scheduled?

The central coordinating office will reach out to facilitators to schedule the next meeting between October and November 2024.