



ROUND 2: Patient-Driven Research Communities of Practice – Discussion Themes and Planning for Knowledge Mobilization

Introduction

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. From October to December 2024, the CoPs held their second round of meetings, bringing together co-leads and team members from the 2023 patient-driven research projects to reflect on their progress, challenges, and opportunities. The list of patient-driven research projects funded by the SPOR Evidence Alliance can be found on the [Patient-Driven Research webpage](#).

This document summarizes common themes discussed, including facilitators and barriers encountered during their collaborative leadership in research. It also provides an overview of core considerations and strategies for hosting knowledge mobilization or exchange events.

Summary of Discussions

Theme	Patient and Public Partner Co-Lead Perspective	Researcher Co-Lead Perspective
<p>1. Meaningful Co-Leadership, Relationship-Building and Team Collaboration</p>	<ul style="list-style-type: none"> • Foster an environment built on mutual respect and trust, allowing patient and public partners to share their perspectives, even if they differ. • Maintain ongoing communication, regular check-ins, and provide opportunities to work closely with the team to ensure that patient and public partners feel valued and engaged. • Offer structured team-building opportunities to strengthen collaboration and improve decision-making processes. • Clarify roles early on to prevent misunderstandings and ensure effective partnership. 	<ul style="list-style-type: none"> • Establish clear and honest communication and hold structured meetings or check-ins for role transparency and responsibilities to help prevent confusion. • Be patient and flexible as teams are navigating the evolving nature of patient-driven research, learning as they go. • Be open to being challenged, and unlearning established ways of thinking and doing research. • Set realistic timelines to accommodate patient and public partners' involvement.



Theme	Patient and Public Partner Co-Lead Perspective	Researcher Co-Lead Perspective
<p>2. Considerations for Engagement in Research Design and Methods</p>	<ul style="list-style-type: none"> • Take on research-related tasks such as advising on the review type, analyzing abstracts and articles, and contributing to report writing. • Ensure that research is tied to purpose and has an impact on practice to effectively support people. Patient and public partner co-leads have a meaningful impact on policy. 	<ul style="list-style-type: none"> • Ensure that the research questions remain true to the intent of the patient and public partner co-lead. This can involve re-defining or re-wording the research question. • Communicate research concepts and methods in a clear manner for members who wish to take on research-related tasks, regardless of their technical background or differing levels of experience in research. • Encourage flexibility in research design and methods by inviting input from patient and public partners, showing them that their contributions matter and integrating patient-oriented principles in research.
<p>3. Capacity-Building and Learning Opportunities</p>	<ul style="list-style-type: none"> • Tailored training, resources and capacity-building opportunities needed to help better understand complex research methods (e.g., risk of bias, quality appraisal), further facilitating empowerment and meaningful engagement. • Capacity-building courses offered by the SPOR Evidence Alliance are helpful in providing an overview of the knowledge synthesis process. • Call for resources and opportunities (e.g., funding initiatives), dedicated to sustaining the work of patient-driven research, with a focus on long-term community engagement efforts. 	<ul style="list-style-type: none"> • Encourage team members to develop foundational understanding of evidence synthesis, allowing everyone to effectively understand and interpret the findings. • Support patient and public partners and offer mentorship opportunities in the area of knowledge synthesis, particularly as research projects progress. • Facilitate collaborative learning by organizing group sessions where team members can review articles and abstracts together, discuss key insights, and address challenges.



Planning for Knowledge Mobilization

Importance of Knowledge Mobilization

Knowledge mobilization (KMb) is essential to ensure that research findings translate into meaningful actions that improve patient outcomes and inform future research. As the patient-driven research teams approach the completion of their projects, they are developing strategies to share their findings with key knowledge users such as policy-makers, patients, the public, healthcare professionals, and others. The 2023 patient-driven research teams have adopted a unique model, allowing teams to incorporate KMb events directly into their project, which is an aspect that is typically absent in traditional research.

Through discussions, teams emphasized the importance of the KMb events in facilitating sharing of knowledge, strengthening relationships with key partners, and shaping future research directions. Linking KMb efforts to real-world applications and ensuring that dissemination activities are purposeful and meaningful was highlighted.

Knowledge Mobilization Considerations and Strategies

1. Defining and Reaching Target Audiences

- **Engage in team discussions early on** to define the targeted audience for the event.
- **Consider the purpose of the event and how to communicate findings in a meaningful way**, once you have defined your audience.
 - For example, *“Is the aim of the event simply to communicate findings, or is it also to engage the audience in further interpreting and refining the findings?”*
- **When planning your event, consider the context of your research.** It is important to ensure events are inclusive and well-informed especially when addressing sensitive topics or engaging with vulnerable populations. Events may not be well-received by the audience if they are not thoughtfully planned with community input and a meaningful approach.
- **Ensure that results are relevant to *all* targeted audiences.** Research purpose and meaning can differ depending on your audience as what is meaningful to one group can be different to what is meaningful to another.

2. Fostering Meaningful Engagement and Collaboration with Key Partners

- **Focus on fostering and strengthening relationships with key partners early on.** Teams have leveraged existing community partnerships facilitated by patient and public partner co-leads due to their active role in community engagement and advocacy. Building meaningful relationships requires time and effort.
- **Ensure that diverse and equity-denied communities** are included in meetings and events. KMb events play a key role in fostering connections, facilitating networking, and bringing together partners for meaningful discussions.



- **Provide opportunities for the audience to provide feedback** during and after the event and encourage knowledge users to share their perspectives to help inform or refine research findings, fostering a collaborative process.
- **Interactive workshops, community forums, panel discussions, and presentations, featuring case studies and real-world examples can bring together key partners** (e.g., researchers, community representatives, patient and public partners, knowledge users, etc.) ensuring that findings are relevant, accessible, and well-informed.
- **Encourage flexibility in meeting design and formats**, as full-day events can pose barriers to specific groups. This can include separating the event across multiple days (e.g., 3-4 hour sessions) or hosting the event virtually or in a hybrid format (e.g., some components in-person and others virtually).

Navigating KMb Events with Limited Evidence

Even when research results are preliminary or limited, KMb events play a crucial role in fostering connections, facilitating discussions, promoting collaborative problem-solving, and helping to refine and interpret the findings. Patient-driven research teams identified the following key strategies to address instances where evidence is limited:

- **Frame the Event as an Ongoing Conversation:** Emphasize that research is evolving and the event is an opportunity for key partners to contribute insights rather than just receive findings.
- **Facilitate Expert Panels:** Invite experts, policymakers, patient and public partners, caregivers or practitioners to share perspectives on how emerging research aligns with existing knowledge and practice.
- **Interactive Brainstorming and Priority-Setting Sessions:** Engage participants in identifying pressing knowledge gaps and co-developing future research priorities and directions.
- **Communicate Scientific Uncertainty:** Develop infographics or plain-language summaries that explain what is known, what remains uncertain, and what steps are being taken to fill gaps.
- **Bridge Evidence Gaps with Patient and Community-Led Initiatives:** When academic research is still emerging, highlight grassroots or community-driven knowledge-sharing initiatives that offer valuable insights.
- **Networking Sessions:** Facilitate valuable connections between researchers, patient and public partners, and decision-makers to explore collaborations, share insights, and strengthen partnerships, especially when evidence is still developing.

Conclusion

Effective knowledge dissemination is fundamental to maximizing the impact of patient-driven research. By implementing strategic knowledge mobilization and exchange strategies, and embracing inclusive engagement approaches, teams can ensure their findings contribute to meaningful change. As teams move forward, continued discussions on best practices and new ways to communicate findings will further support the translation of research into real-world applications. For additional strategies tailored to different audiences, teams are encouraged to explore the **SPOR Evidence Alliance's [Menu of Dissemination Approaches \(PDF, 336 KB\)](#)**.