



ROUND 3: 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 May to July 2025, the CoPs held their third and last 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 reflections on facilitators and barriers to co-leadership in research, as well as takeaways from knowledge mobilization (KMb) events. It also outlines key considerations and strategies for planning and hosting effective KMb or knowledge exchange events.

Summary of Facilitators and Barriers to Co-Leadership Research

Teams reflected on their co-leadership experiences and noted that the Evidence Alliance's patient-driven research initiative represented the first meaningful opportunity for patient/public partners to submit and lead research projects rooted in their lived experiences. This marked a significant shift after years of unsuccessful attempts to engage traditional research bodies with patient- and public-initiated topics.

The following table summarizes facilitators and barriers that teams experienced during their co-leadership:

Theme	Facilitators	Barriers
Shared Leadership & Decision-Making	<ul style="list-style-type: none">• Shared leadership gave patient/public partners a sense of ownership and validation.• Clear roles and responsibilities allowed meaningful contribution and recognition.• Researchers gained lived experience insights that complemented academic approaches and supported equitable collaboration.• Dedicate sufficient time to planning, identifying, and refining the research question(s) as a team.	<ul style="list-style-type: none">• Patient/public partners were sometimes unsure about decision-making authority.• Concerns about tokenism when leadership roles were unclear.• Researchers struggled to balance shared leadership with research requirements and defining equitable decision-making processes.



	<ul style="list-style-type: none"> Embed opportunities for patient partner feedback throughout the entire project cycle. 	
Meaningful Communication, Engagement & Team Dynamics	<ul style="list-style-type: none"> Open dialogue, respectful discussions, and regular updates built trust and inclusion. Structured communication, role definitions, and shared project tools maintained coordination and transparency. Weekly updates and check-ins kept teams informed and engaged. Engaging a range of roles and disciplines including researchers, patient and public partners, clinicians, and steering panels enriched collaboration and perspectives. 	<ul style="list-style-type: none"> Patient/public partners felt left out when updates were inconsistent. Unclear expectations caused confusion. Researchers had difficulty maintaining consistent communication with large or busy teams, and unclear task division slowed progress. Limited opportunities to meet as a team regularly, with teams expressing a strong desire for more in-person meetings to strengthen relationships and enhance collaboration.
Capacity Building, Training and Resource Sharing	<ul style="list-style-type: none"> Training and ongoing engagement improved patient/public partners' research literacy, confidence, and ability to contribute meaningfully. Access to shared documents, living records, and administrative support enabled full participation. Researchers reinforced skills in mentorship, team training, and adapting research processes to patient/public partner needs. Patient and public partners highlighted the generosity of researchers in slowing down and creating opportunities for others to acquire knowledge, skills, and experience. 	<ul style="list-style-type: none"> Patient/public partners expressed a need for accessible training and resources for evidence synthesis methodology. Researchers found that training can be limited by funding and capacity restrictions. Explaining knowledge synthesis methods in a simple and accessible way was challenging, which sometimes led to gaps in understanding between researchers and patient/public partners.
Time & Workload Management	<ul style="list-style-type: none"> Sharing power improved team collaboration and mutual respect. Flexible structures and iterative approaches allowed projects to remain relevant and engagement to continue over time. Adjustments in process helped maintain engagement despite unexpected challenges. 	<ul style="list-style-type: none"> Shifts in project scope sometimes caused misalignment between expectations and deliverables. Extra workload in training, mentoring, and communication sometimes competed with other academic demands. Researchers often relied on structured research models,



	<ul style="list-style-type: none">• Efforts to balance workloads helped reduce risk of burnout.• Flexible timelines allowed integration of patient/public priorities.	applying the same methodology across projects. While this provided consistency, it limited adaptability to the unique perspectives and lived experiences of patient and public partners. Teams emphasized the importance of adjusting research processes to accommodate diverse contributions and ensure that each project reflected the priorities of its members.
Equitable and Inclusive Considerations	<ul style="list-style-type: none">• Iterative approaches ensured research questions stayed relevant.• Respect for lived experience and opportunities to lead promoted equity.• Researchers adapted outputs to reflect real-world contexts.• Teams created safe spaces for open dialogue and sharing lived experiences.• Acknowledging emotional challenges validated contributions and promoted trust.• Structured discussions on power dynamics improved equity in participation.	<ul style="list-style-type: none">• Emotional strain discussing sensitive topics without adequate support.• Challenge to recruit multiple patient partners with relevant lived experience, especially on niche or sensitive topics.• Virtual participation difficulties, tech or accessibility barriers.• Researchers acknowledged emotional burden but often lacked strategies to mitigate it, with logistical challenges complicating participation.

Knowledge Mobilization Events and Lessons Learned

Strengths and Takeaways from Knowledge Mobilization Events

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 reached or neared the completion of their projects, they implemented 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 adopted a unique model by incorporating KMb events directly into their projects, an element that is often absent in traditional research models.

KMb events were consistently highlighted as a critical component of the patient-driven research projects. They created opportunities for meaningful dialogue among patient/public partners, researchers, community members, and policy makers, fostering community connections and validating the value of patient-driven work. Even when projects yielded limited or preliminary results, KMb events



fostered connections, encouraged collaborative problem solving, and helped refine and interpret findings.

The teams shared the following takeaways:

1. **Amplification of the Patient/Public Voice:** KMb events provided patient/public partners with meaningful opportunities to share their perspectives and increase visibility for patient-led research. Participation in these events validated their contributions, reinforced the value of lived experience in shaping research outcomes, and demonstrated how patient-led insights could influence project directions. Patient/public partners reported that contributing to presentations, roundtables, and workshops enhanced their sense of ownership and confidence in research engagement.
2. **Engagement Strategies:** Successful KMb events employed interactive formats including workshops, roundtables, café scientifiques, and plain language summaries, which facilitated meaningful engagement with diverse audiences such as community members, clinicians, and decision-makers. Early identification of target audiences, ongoing communication, and tailored presentations were critical for ensuring relevance, maximizing reach, and promoting the practical utility of findings. It was also important to remain mindful of the specific populations represented by patient/public partners and to consider potential barriers to participation, ensuring that engagement approaches were inclusive and accessible.
3. **Capacity-Building Opportunities:** Participation in KMb events strengthened patient/public partners' research literacy, advocacy skills, and confidence in contributing to evidence synthesis and dissemination. Similarly, researchers reported that collaborating with patient/public partners enhanced their ability to communicate findings in accessible ways, adapt knowledge translation strategies, and mentor co-leads.
4. **Building Connections and Networks:** Events facilitated collaboration among patient/public partners, researchers, and other knowledge users, fostering both professional and community networks and strengthened relationships that extended beyond individual projects. These networks supported knowledge sharing, collaboration on future projects, and the development of stronger community networks.
5. **Policy and Practice Outcomes:** Teams observed that KMb events could generate tangible outcomes and real-world impact even when research results did not fully meet expectations. Some discussions led to immediate policy changes, while other events sparked partnerships or pilot initiatives. These outcomes reinforced the value of patient/public engagement in translating evidence into actionable solutions.
6. **Logistical Insights:** Virtual and hybrid event formats expanded participation but required careful planning to ensure accessibility, effective engagement, and meaningful interaction. Holding KMb events in collaboration with relevant larger conferences or community events also proved effective, as it resulted in larger attendance from target groups and enhanced overall reach.



Next Steps

- Teams are required to submit their final project report or publication upon completion, which will be published on their project webpage.
- Teams must also submit a plain language summary, ideally prepared by the patient/public partner co-lead(s). Templates for these reports and publications can be accessed [here](#).
- If supplemental funding was received for a KMb event, teams must complete a post-KMb event evaluation form, which can be found [here \(DOC, 95 KB\)](#).
- If a no-cost extension was provided beyond March 31, 2025, teams must submit a final completed Form 300 to report on the usage of any remaining funds by April 30, 2026.
- An external evaluation will be conducted by the Team for Implementation, Evaluation, and Sustainability team at Unity Health Toronto. This evaluation will launch in Fall 2025, and project teams and co-leads will be contacted regarding participation in interviews, surveys, and sharing relevant project materials.
- Planning is underway for an end-of-grant knowledge translation event, and details will be shared via email as they become available.