

# 2022 Annual General Meeting Book



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**Suggested citation:**

SPOR Evidence Alliance (2022). 2022 Annual General Meeting Book. Toronto, ON: SPOR Evidence Alliance.



**SPOR Evidence Alliance**  
Strategy for Patient-Oriented Research

**Alliance pour des données probantes de la SRAP** 🇨🇦  
Stratégie de recherche axée sur le patient

## Funding Acknowledgement

The Strategy for Patient-Oriented Research (SPOR) Evidence Alliance is supported by the Canadian Institutes of Health Research (CIHR) under Canada's SPOR Initiative, and the generosity of **41 partners from public and not-for-profit sectors** across Canada who provided cash or in-kind support.

## Disclaimer

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# Land Acknowledgement

The Central Coordinating Office of the SPOR Evidence Alliance is located on land now known as Tkaronto (Toronto). Tkaronto is the traditional territory of many groups, including the Huron-Wendat and Petun Nations, Mississaugas of the Credit and the Chippewa/Ojibwe of the Anishnaabe Nations; and the Haudenosaunee.

Tkaronto is covered by Treaty 13 with the Mississaugas of the Credit and The Dish with One Spoon treaty between the Anishinaabe, Mississaugas and Haudenosaunee that connected them to share the territory and protect the land. All Indigenous Nations and peoples, Europeans and newcomers, have been invited into this treaty in the spirit of peace, friendship and respect.

We would like to honour the Elders and Knowledge Keepers, both past and present, and are committed to continuing to learn and respect the history and culture of the communities that have come before and presently reside here.

We acknowledge the harms of the past and present, and we dedicate ourselves to work with and listen to First Nations, Inuit and Métis communities in the spirit of reconciliation and partnership. We are grateful to have this opportunity to work on this land, and commit to caring for this land.

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# Meeting Agenda

Time	Agenda Items	Speakers/Moderators
12:00 p.m. – 12:10 p.m. (10 minutes)	<b>Welcome to the SPOR Evidence Alliance Annual General Meeting</b>	Dr. Andrea Tricco
12:10 p.m. – 13:00 p.m. (50 minutes)	<b>The SPOR Evidence Alliance: 5 Years in Review</b>	Dr. Andrea Tricco
13:00 p.m. – 13:10 p.m. (10 minutes)	Health Break	
13:10 p.m. – 14:10 p.m. (60 minutes)	<b>Fireside Chat: Patient/Public Partner Driven Research with Partnership and Co-Leadership</b>  <i>Project Title: Trauma-informed Care Practices to Support Caregivers of Children with Severe Illness: A Systematic Review</i>  <i>Project Title: Supporting Patient and Public Partners in Writing of Lay Summaries of Scientific Evidence in Healthcare: A Scoping Review</i>  <i>Project Title: The Effectiveness of Alternatives to Institutional Care for Older People with On-going Complex Care Needs: A Systematic Review</i>	Dr. Andrea Tricco  Bev Pomeroy Dr. Lindsay Jibb  JoAnne Mosel Dr. Heather Colquhoun  Elliot PausJenssen Dr. Elaine Moody
14:10 p.m. – 14:20 p.m. (10 minutes)	Health Break	
14:20 p.m. – 15:10 p.m. (50 minutes)	<b>Patient-Oriented Research in Canada: Where We are Now</b>	Dr. Tammy Clifford
15:10 p.m. – 15:20 p.m. (10 minutes)	Health Break	
15:20 p.m. – 16:05 p.m. (45 minutes)	<b>Breakout Session: Let's Connect</b>	Breakout Rooms
16:20 p.m. – 16:30 p.m. (10 minutes)	<b>Closing Remarks</b>	Dr. Andrea Tricco

# A Warm Welcome



**Dr. Andrea Tricco**

*Scientist and Director,  
Knowledge Translation Program  
St. Michael's Hospital, Unity Health Toronto*

Dr. Andrea Tricco opened the 4th Annual General Meeting of the SPOR Evidence Alliance by inviting participants to take a moment of silence to reflect upon the land they work and live on from coast to coast, and to share their personal land acknowledgements in the chat box.

"I would like to acknowledge I am an uninvited settler person on the shared, traditional, ancestral, and unceded territories of the Snuneymuxw (snuh-nay-moe) territory also known as Gabriola Island. Snuneymuxw (snuh-nay-moe) territory encompasses one of the most productive and resource rich areas at the heart of the Salish Sea. I honor the elders of today and those who have come before us."

"I am an uninvited settler and am grateful to live, work, and play...on the traditional ancestral unceded territory of the Stó:lō people."

"Queen's University is situated on traditional Anishinaabe and Haudenosaunee Territory. I am grateful to be able to learn, live and play on these lands, and committed to work with my Indigenous colleagues toward reconciliation and social justice."

"I respectfully acknowledge that Ottawa is built on un-ceded Algonquin Anishinabe territory. The peoples of the Algonquin Anishinabe Nation have lived on this territory for millennia. Their culture and presence have nurtured and continue to nurture this land."

"I acknowledge that I live, work, and play on the beautiful traditional territories of the people of Treaty 7 in S. Alberta. Calgary is also home to the Métis Nation of Alberta, region 3."

"I am a settler, respectfully joining from Saskatoon, Treaty 6 territory of the Cree, Salteaux, Dakota nations and homeland of the Métis."

# SPOR Evidence Alliance: 5 Years in Review

This presentation provided a snapshot of the SPOR Evidence Alliance's research training, patient and public engagement and knowledge dissemination activities over the 5 years since inception.

A summary of key milestones is given below.



**2017**  
**SPOR Evidence Alliance is funded.**  
CIHR awarded a 5-year operating grant towards our mission to facilitate learning health systems that are increasingly informed and improved using up-to-date health research evidence.

**2018**  
**SPOR Evidence Alliance goes live.**  
Research query service was launched, an asset map of Canadian guideline developers was published, and governance structure was established.

**2019**  
**Training and Patient Engagement**  
Inaugural annual seed grant competition went live, patient and public partner appreciation policy was released, patient and public topic submission portal opened, and membership registration application was released.

**2020**  
**COVID-19 Response**  
Established a rapid response model to support decision-maker evidence needs, cross-collaboration established nationally and internationally, and training resources prepared for research teams.

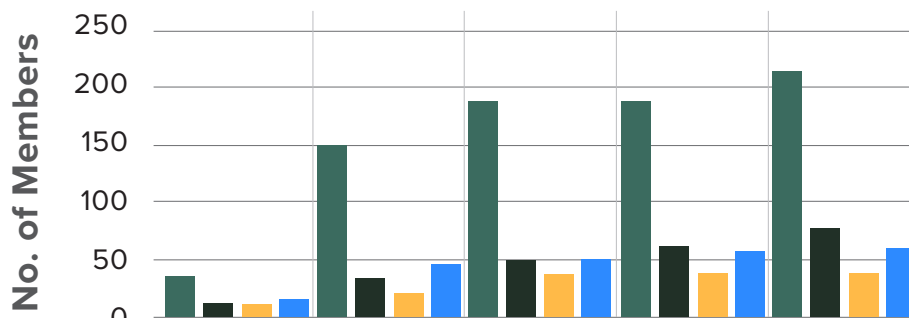
**2021**  
**Patient- and Public-Driven Research**  
Course on rapid reviews developed for patient and public partners with patient and public partners, and 3 patient- and public-driven research projects funded.

**2022**  
**Advancing Science and Renewal**  
A collection of four papers on the SPOR Evidence Alliance was published in the FACETS journal, and CIHR funding renewed for 18 months.

## Membership

We opened our membership in February 2019. We have grown from 35 researchers, 12 trainees, 11 patient and public partners and 15 knowledge users to 213 researchers, 77 trainees, 38 patient and public partners and 60 knowledge users.

### SPOR Evidence Alliance Membership Since Inception



	2017 - 2018	2018 - 2019	2019 - 2020	2020 - 2021	2021 - 2022
● Researcher	35	150	187	186	213
■ Trainee	12	33	49	61	77
🟡 Patient and Public Partner	11	21	37	38	38
▲ Knowledge User	15	46	51	57	60

● Researcher ■ Trainee 🟡 Patient and Public Partner ▲ Knowledge User

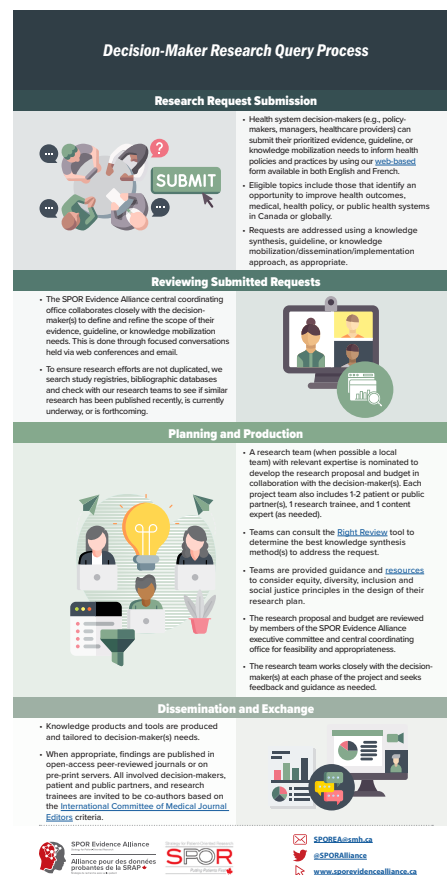
## Research Query Services

We exceeded our goal of responding to 100 queries from decision-makers over the duration of the 5-year CIHR funding period.

Our co-creation model resulted in 194+ decision-maker engagements and 180+ patient and public partnerships.

Throughout the pandemic, we partnered with [COVID-END](#) to support requests for rapid and living reviews. 46 requests were received, with rapid timelines, varying from 5-10 days.

We completed our first patient and public topic priority-setting process in 2021 and have funded 3 patient- and public-driven research projects that are currently ongoing.





## Training and Capacity Development

**We led or supported 148 learning opportunities with over 3,300 learners.**

We awarded 8 trainees with seed grant funding to support methods projects at the conceptual stage.



Seed grant winners from left to right: Nicole George (2021), Ghazal Fazli (2021), Richard Henry (2020), Jillian Macklin (2020), Alexandra Korall (2019), Lashanda Skerritt (2019), Lisa Knisley Jones (2019), Amanda Wurz (2019)

**A course on rapid reviews for patient and public partners, co-developed with patient and public partners...**



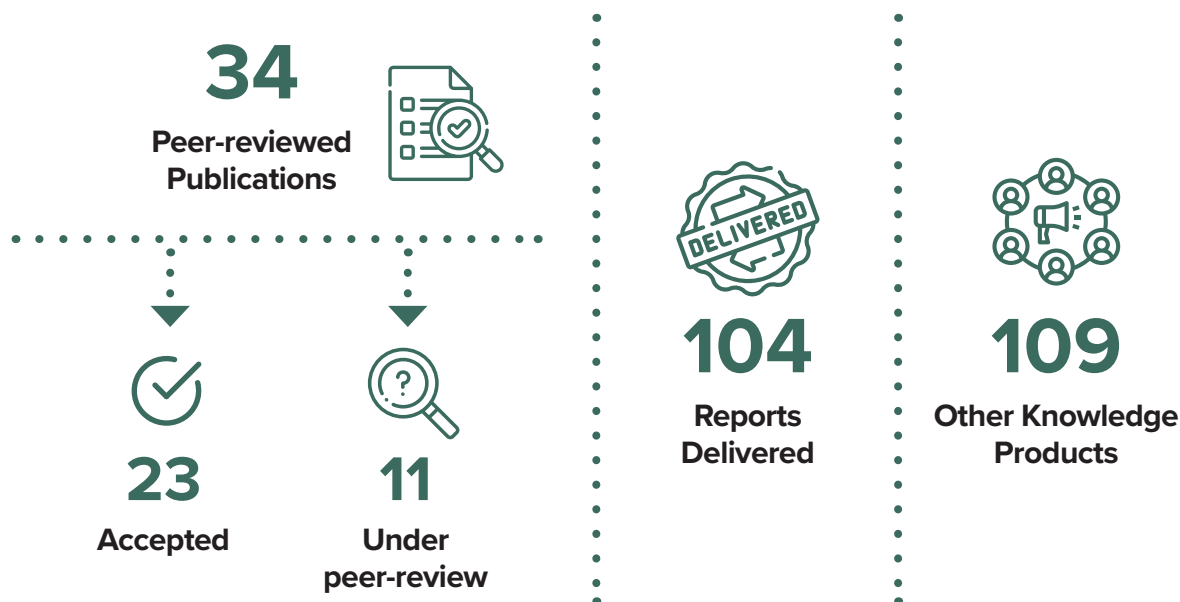
Course developers from left to right: Janet Gunderson, Maureen Smith, Andrea Tricco, Wasifa Zarin, Sabrina Chaudhry, Sinit Michael, Fariha Mosaddeque

In partnership with co-Principal Knowledge Users Maureen Smith and Janet Gunderson, a 3-week course was developed to inform patient and public partners of the rapid review process and how they can engage with the research process.

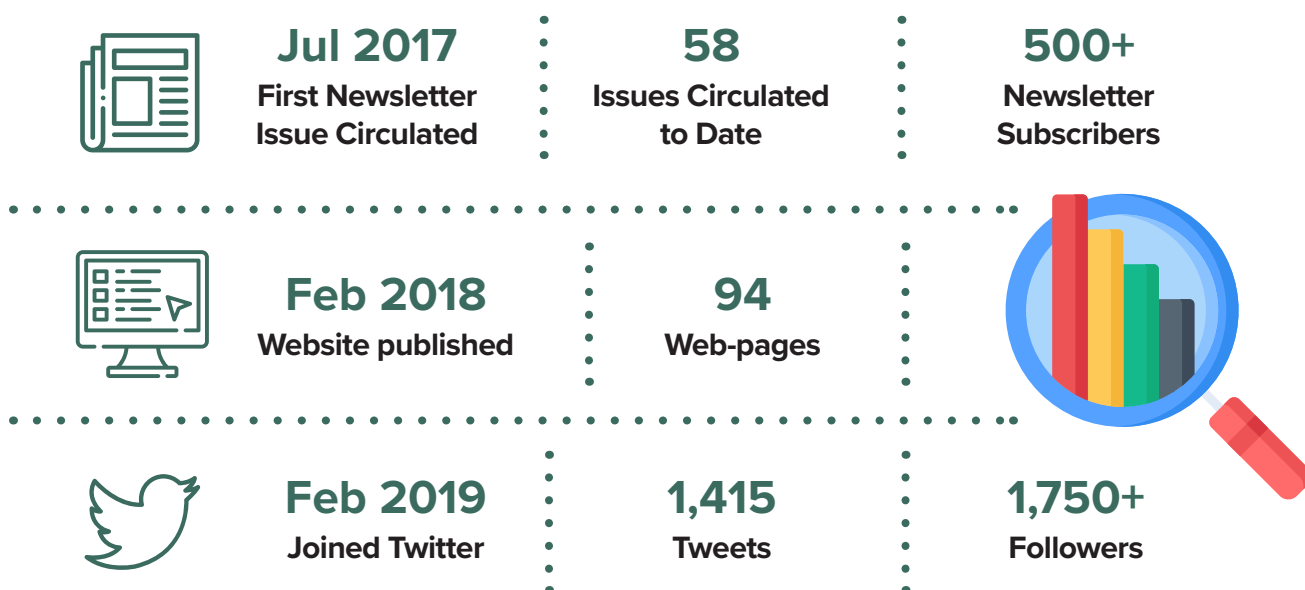
**To date, all 24 graduates were matched to at least one project, in pairs, across 18 projects since June 2021.**

## Training and Capacity Development

The research findings from the research queries have been disseminated in the following forms to reach a broader audience:



The SPOR Evidence Alliance primarily utilizes newsletters, our website, Twitter, and scientific journals and conferences to disseminate information.



*Peer-reviewed papers:* 4-paper special collection published in the FACETS journal, 5 upcoming papers related to Indigenous people's engagement, COVID-19 response, patient and public partner engagement and topic prioritization in the SPOR Evidence Alliance.



# Fireside Chat: Patient/Public Partner Driven Research with Partnership and Co-Leadership



**JoAnne Mosel**  
*Patient Partner*  
SPOR Evidence Alliance



**Beverley Pomeroy**  
*Patient Partner*  
SPOR Evidence Alliance



**Elliot PausJenssen**  
*Patient Partner*  
SPOR Evidence Alliance



**Dr. Heather Colquhoun**  
*Assistant Professor*  
University of Toronto



**Dr. Lindsay Jibb**  
*Scientist*  
The Hospital for Sick Children (SickKids)



**Dr. Elaine Moody**  
*Assistant Professor*  
Dalhousie University

Bev Pomeroy, Elaine Moody, Elliot PausJenssen, Heather Colquhoun, JoAnne Mosel, and Lindsay Jibb discussed the patient- and public-driven research queries they are currently co-leading. Andrea Tricco moderated the conversation and guided the group through five questions.

Bev, Elliot and JoAnne shared personal stories detailing why these topics were important to them, what inspired them to submit the topic to the SPOR Evidence Alliance and subsequently get involved in co-developing the research project. The group discussed the rewards and challenges of co-leadership, their team communication practices, how to create and maintain brave spaces, and advice for anyone wishing to pursue a similar co-partnership model. They highlighted the importance and feasibility of engaging patient and public partners at any level of research.

Read more about the research projects here:

<https://sporevidencealliance.ca/patient-driven-research/>

Watch the full discussion here:

<https://youtu.be/EcFISU7bddE>



Here is a highlight of their discussion themed around challenging the unspoken traditional research “code book”:

- Countering the researcher code book involves revisiting common communication practices, changing one’s mindset towards the research process, and being open to learning along the way.
- Challenging traditional funding frameworks and timelines are necessary to allow hard to reach populations to be accommodated, heard, and appreciated in a safe and meaningful way, as it takes time to build trust and respect.



**“(Co-leadership) is very different than your classic researcher, PI (principal investigator) leadership and the way researchers work... we have this sort of code... there’s no manual, it’s not written anywhere, but we know it. I’ve never had that so challenged. I’m trying to forget that code book and do a new code book.”**

*Heather Colquhoun*

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They highlighted the importance of humanizing and personalizing the process:

- With the recognition of how personal this research is to the patient and public partner co-leads, it was important to slow down and think about the relationships within the team to keep the research personal.
- One team mentioned that they created a list of values, so co-leads and team members have a foundation to follow. This list of values is a living list that is frequently and continually updated.
- The researcher must take the time and effort to make sure the patient and public partner knows their value in the research process.
- Make a point of identifying and prioritizing ways of making the research process fun and enjoyable for all team members.



**“One of the things that has come out of this [co-leadership], particularly doing a review, which is the most academic of academic pursuits, is personalizing and humanizing the process.”**

*Elaine Moody*



**“My team LOVES this project. I can barely pull them away to do other projects, because they all really want to get going on this and they’re so excited. I think that comes from this personalization, this heart and soul that this project has.”**

*Lindsay Jibb*

They discussed maintaining open, clear and timely communication practices:

- Clear expectations of co-leads and team members should be discussed.
- An initial meeting should occur between co-leads to get to know each other and understand why they would like to do this project.
- Meetings should be consistent with set times, but can be less structured to discuss key concepts and to facilitate an open discussion.
- For patient and public partner co-leads, individual meetings with team members without the research co-lead may help facilitate confidence building.
- Being humble and listening intently can help create a brave space and facilitate projects moving forward.



**“(On creating a brave space) incorporating self-compassion, self-reflection, activating resiliency, this idea around post-traumatic growth... we think about activating resiliency, it’s around what is the care and connectedness that we bring together as a team, what does it look like for Lindsay and her team and vice versa, what do I need to feel cared for and connected in this project...”**

*Bev Pomeroy*

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The session concluded with the speakers highlighting the continual learning process that occurs from each other:

- The mentorship helped foster learning about the research process and about one’s self.
- Being open to the contribution of the patient and public partner co-lead at all and any stage can help strengthen the research.
- It is an ongoing learning experience, in which co-leadership is a skill we must all learn to continually develop.



**“Gurus in patient engagement often talk about the vulnerabilities of patient partners... and the power imbalance ...I think it’s important for confidence building to have your own team [to lead].”**

*JoAnne Mosel*



**“Co-leadership requires commitment and it is a skill that all of us need to develop. It is something that all of us need to work on. We may start off in one way, but as we develop we may take a different path. Be open to that.”**

*Elliot PausJenssen*

# Patient-Oriented Research in Canada: Where We are Now



**Dr. Tammy Clifford**

*Vice-President Research –  
Learning Health System, CIHR*

Dr. Tammy Clifford presented on the past, present and future of patient-oriented research (POR) at CIHR, outlining the journey of SPOR in Canada from its inception to future expectations and prospects included in the CIHR Strategic Plan, 2021-2031.

The presentation opened with the [CIHR Mandate](#): “to excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge **and** its translation into improved health for Canadians, more effective health services and products and strengthened health care systems”, which was revisited throughout the presentation to highlight its alignment with SPOR.

Dr. Clifford explained that the creation of SPOR stemmed from the need to bridge the research to practice continuum, closing the gap between research and policy decision-makers/patients and public to improve health outcomes and ensure a sustainable healthcare system.

The SPOR journey began in 2011 and developed over the past decade.

Watch Dr. Clifford’s full presentation here:

<https://youtu.be/VfobqV3-zmU>

## The SPOR Journey



In 2021, CIHR released its [Strategic Plan 2021-2031](#) to provide priority setting direction for the next decade. While concerns were expressed with a 10-year plan, the desire was to have a generational impact on the trajectory of the health of the country. There is room available in the plan to allow for flexibility to reprioritize and redirect resources on short notice to respond to emerging issues. The 6 priorities are:



<sup>1</sup>Clifford, T. (2022). *Patient-Oriented Research at CIHR – Past, Present, and Future* [PowerPoint]. <https://sporevidencealliance.ca/wp-content/uploads/2022/07/Clifford-SPOR-EA-June-29-2022.pdf>



While the term patient-oriented does not appear in the Strategic Plan, it does not mean it was not considered; in fact, it is foundational to the implementation of the Strategic Plan. “Integrate evidence in health decisions” was chosen to increase the inclusivity of the reach and scope of patient-oriented research (POR). Similarly, SPOR can be seen throughout the Strategic Plan and POR is being integrated into CIHR across its institutes and programs.

Learning Health Systems (LHS) and POR aim to address the two valleys of death that occur in translational research: the translation of laboratory discoveries to humans and the translation of evidence to policy and practice. Startling statistics highlight the significant need to bridge these gaps.

**Similarly, it is estimated that 85% of research is wasted, generally because it asks the wrong questions, is badly designed, not published or poorly reported.**

Dr. Clifford suggested a LHS approach, where patients and public are involved at the beginning and throughout the process, can help address some of the research waste issues.

CIHR has several programs and initiatives to support LHS and POR throughout the country, including SPOR, [Health System Impact Fellowship](#), [knowledge-to-action cycle](#), [Open Science](#) and the [Gender-Based Analysis Plus tool](#). As led by Dr. Clifford, the expansion of the LHS portfolio will enable collaboration, coordination and capacity development across existing and new initiatives to support knowledge mobilization and evidence integration with the goal of enabling effective and efficient health systems.

Findings from the first SPOR evaluation demonstrated an alignment with international trends, the right elements and activities to address areas in need of support for POR and evidence-informed health care and exceptional knowledge user and public engagement. SPOR Evidence Alliance has been a key resource in supporting evidence informed decision making, especially as COVID-19 emerged and through the collaboration with [COVID-END](#).

SPOR’s second evaluation will be used to inform program improvement and decision making related to SPOR’s future direction, planning and sustainability, as well as the refresh of the SPOR Strategy document, as part of the CIHR Strategic Plan 2021–2031. To close the presentation, Dr. Clifford highlighted the opportunities for POR, beyond SPOR, particularly the [Centre for Research on Pandemic Preparedness and Health Emergencies](#), Knowledge Mobilization initiatives, [Clinical Trial Funds](#) and continued collaboration with [Pan-Canadian Health Data Strategy](#).

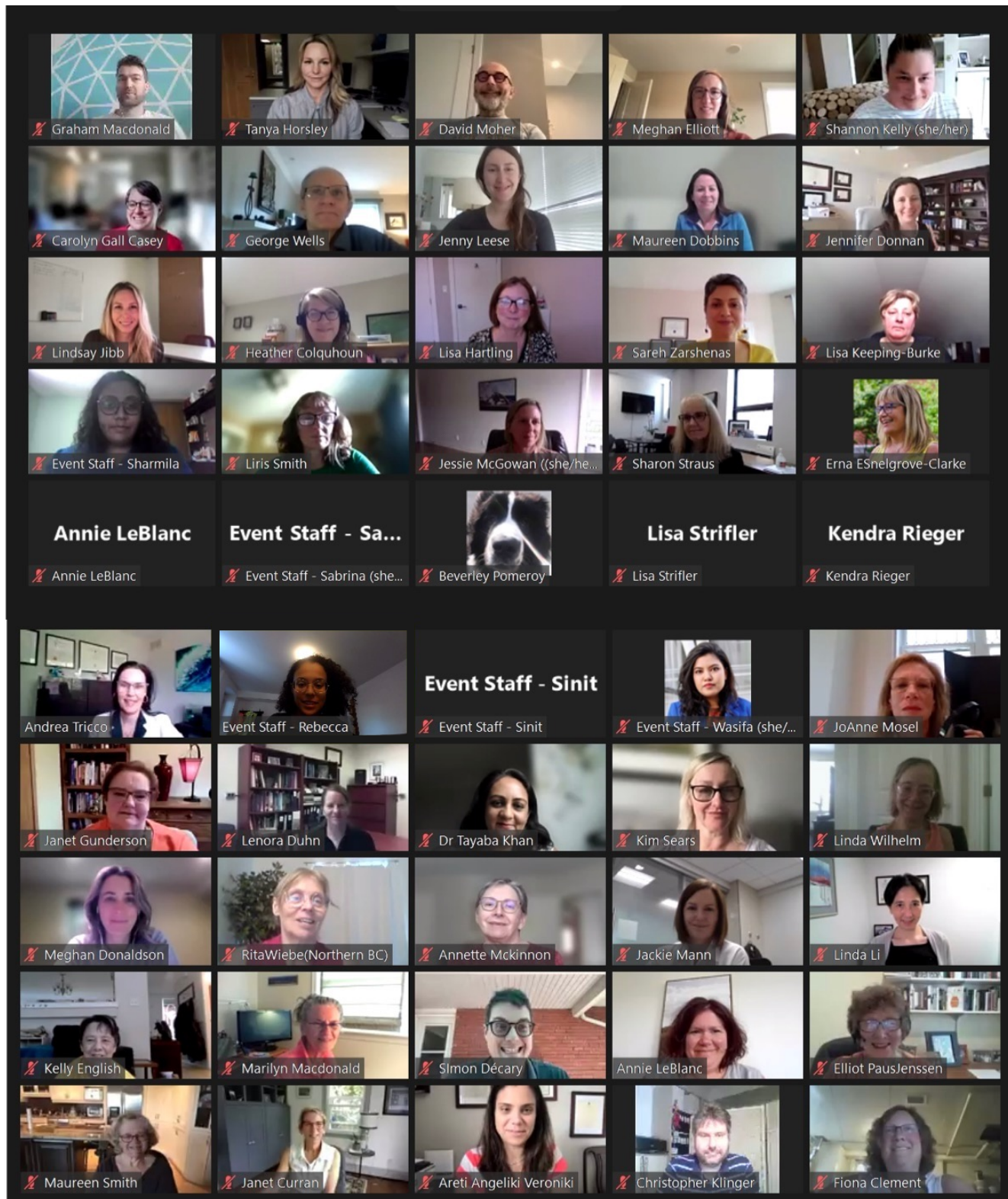
# Breakout Session: Let's Connect

Governance members met within their committees for 45 minutes to reflect on the meeting proceedings and discuss committee-specific priorities. Investigators, patient and public partners, and knowledge users who were not members of governance met in a breakout space for networking.



<https://www.freepik.com/vectors/remote-team> Remote team vector created by storyset - [www.freepik.com](https://www.freepik.com)

# That's a wrap!





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**“Thank you so much (to everyone) for your  
commitment, for everything that you’ve done and for  
everything that we have been working on together”**

*Dr. Andrea Tricco*

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