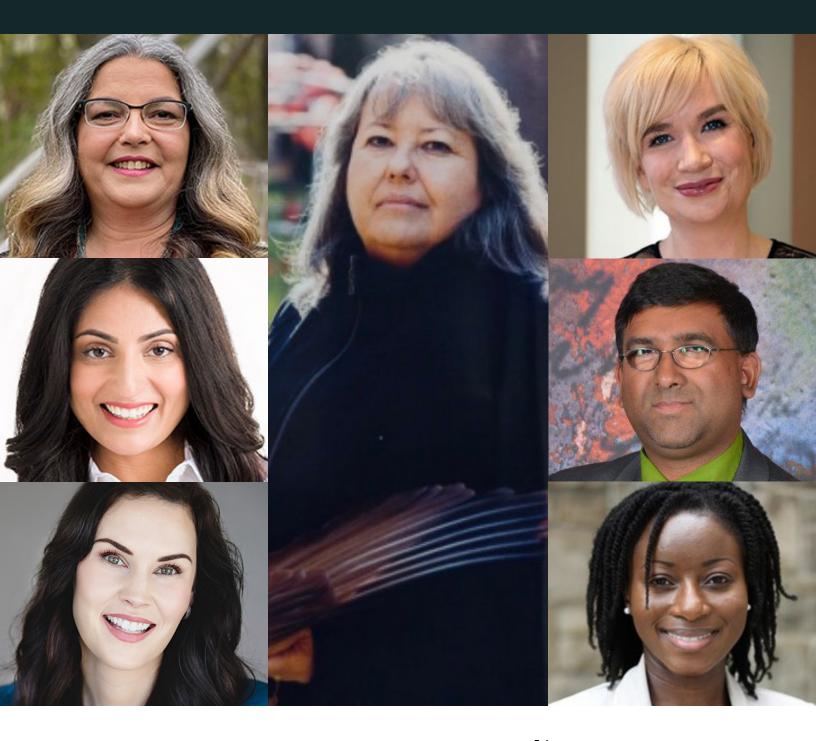
MEETING BOOK

2023 Annual General Meeting SPOR Evidence Alliance







Funding Acknowledgement

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

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Suggested citation:

SPOR Evidence Alliance (2024). 2023 Annual General Meeting Book. Toronto, ON: SPOR Evidence Alliance.

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Land Acknowledgement

The Central Coordinating Office of the SPOR Evidence Alliance is located on land now known as Toronto, derived from the Mohawk word Tkaronto. Toronto is the traditional territory of many groups, including the Mississaugas of the Credit and the Chippewa/ Ojibwe of the Anishnaabe Nations; the Haudenosaunee, and the Wendat. It is now home to many diverse First Nations, Inuit and Métis peoples. We also acknowledge that Toronto is covered by Treaty 13 signed with the Mississaugas of the Credit in 1787 and the Toronto Purchase, 1787, 1805 and 2010. It is also part of Dish with One Spoon Covenant territory of the Anishinaabe, Mississaugas and Haudenosaunee that connected them to share the territory and protect the land. By acknowledging the land, we acknowledge our treaty responsibilities in sharing this land and to the Indigenous people who have been the traditional caretakers of this land since time immemorial.

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. We recognize that Indigenous practices of health and well-being have been in place in this territory for over 10,000 years and are maintained to this day.



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Meeting Agenda



Dr. Andrea Tricco

Nominated Principal Investigator
SPOR Evidence Alliance
St. Michael's Hospital
Unity Health Toronto

12:00 PM to 12:05 PM (5 minutes) **Welcome and Land Acknowledgement**

Description

Dr. Tricco welcomed everyone to the 2023 SPOR Evidence Alliance Annual General Meeting.

The meeting commenced with a moment of self-reflection while a formal land acknowledgement was read.



Kahontakwas Diane Longboat

Elder – Senior Manager Strategic Initiatives, CAMH **12:05 PM to 12:20 PM** (15 minutes) **Opening Ceremony**

Description

Elder Diane Longboat opened the event with a prayer and blessing.



Dr. Andrea Tricco

Nominated Principal Investigator SPOR Evidence Alliance St. Michael's Hospital Unity Health Toronto **12:20 PM to 1:10 PM** (50 minutes)

The SPOR Evidence Alliance: Key Updates

Description

Dr. Tricco provided a snapshot of the key developments and successes of the SPOR Evidence Alliance on research, capacity-building, patient engagement and knowledge dissemination activities. An update on the sustainability and independent evaluation of the SPOR Evidence Alliance was also presented.



1:10 PM to 1:20 PM (10 minutes) Health Break



Ms. Carolyn Shimmin

Patient and Public Engagement Lead George & Fay Yee Centre for Healthcare Innovation, University of Manitoba 1:20 PM to 2:50 PM (90 minutes)

Trauma- and Resiliency-Informed Practice in Patient Engagement: A Primer for Researchers and Patient and Public Partners in Patient-Oriented Research

Description

An introduction to trauma- and resiliency-informed approaches in patient-oriented research was provided. This introduction was for researchers and patient and public partners involved in research to bring awareness and mindfulness on systems and structures that can amplify or re-create trauma among those who have past experiences of trauma.



2:50 PM to 3:00 PM (10 minutes)
Health Break



Dr. Angela Mashford-Pringle

(Moderator)
Assistant Professor
Dalla Lana School of Public Health
University of Toronto

3:00 PM to 4:15 PM (75 minutes) **Engaging with Communities Experiencing Health Inequities: Best Practices**

Description

A facilitated panel explored best practices related to engaging with communities that experience inequities in health. This facilitated discussion brought together different perspectives from individuals working closely with communities experiencing health inequities and how they engage people with lived experience from those communities in a meaningful way.

Engaging with Communities Experiencing Health Inequities: Best Practices (continued)



Dr. Deepa Singal

Scientific Director

Autism Alliance of Canada



Provincial Epidemiologist
Government of Prince Edward Island

Dr. Shamara Baidoobonso



Dr. Mahadeo Sukhai

Vice-President Research &
International Affairs and Chief
Accessibility Officer

Canadian National Institute for the
Blind (CNIB)



Kahontakwas Diane Longboat

Elder – Senior Manager Strategic Initiatives, CAMH **4:15 PM to 4:25 PM** (10 minutes) **Closing Ceremony**

Description

Elder Diane Longboat closed the event with a prayer and blessing.



Dr. Andrea Tricco

Nominated Principal Investigator SPOR Evidence Alliance St. Michael's Hospital Unity Health Toronto **4:25 PM to 4:30 PM** (5 minutes) **Closing Remarks**

Description

Dr. Tricco concluded the event with some final reflections and thoughts from the day.

Opening Ceremony





The 2023 Annual General Meeting welcomed Elder Kahontakwas Diane Longboat to open our meeting with her blessings and prayer.

Elder Kahontakwas Diane Longboat is a member of the Turtle Clan and Mohawk Nation at Six Nations Grand River Territory, Canada. She is a ceremonial leader, traditional teacher, and healer. She has served as Elder for the Centre for Addiction and Mental Health since January of 2013.

In First Nation, Métis, and Inuit communities, Elders are highly regarded figures as knowledge keepers who have attained a high degree of knowledge and understanding of their culture, traditional teachings, ceremonies, and healing practices.¹ They are recognized for their wisdom, stability, humour, sound judgment, and ability to provide appropriate advice and guidance on a particular matter.² They are leaders, teachers, role models, and mentors in their respective communities who sometimes provide the same functions as advisors, professors and doctors.³



Relationality also means reciprocity in which we only take what we need. But it also means responsibility to take care of those things that are on the earth."

The Ceremony

Dr. Andrea Tricco offered Elder Diane Longboat a traditional tobacco tie in the palm of her left hand to open the meeting and she accepted the offer. Elder Diane led a prayer to bless the meeting and the day.

Elder Diane shared the purpose of opening/closing ceremonies and her role to help make a connection to a high power. She thanked and honoured the Creator and Mother Earth for the opportunity to come together and discussed the creation stories that talk to about where we come from and the laws and codes that govern us.

Miigwetch to Elder Diane for imparting her wisdom with us.



We also take that time for inner reflection and renewal for ourselves. I want to say that these are important times for us for self-reflection."

https://www.oise.utoronto.ca/deepeningknowledge/Teacher_Resources/Curriculum_ Resources_(by_subjects)/Social_Sciences_and_Humanities/Elders.html

² https://www.ualberta.ca/provost/media-library/indigenous-files/elderprotocol.pdf

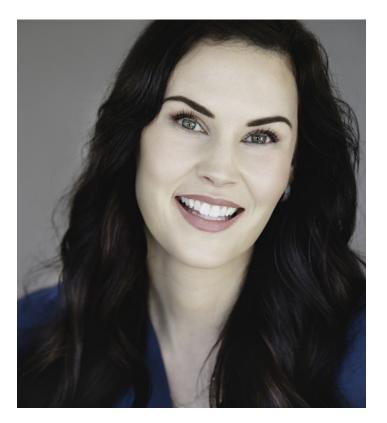
<u>a https://carleton.ca/indigenous/resources/guidelines-for-working-with-elders/</u>

A Warm Welcome



I want to self-reflect on my role here [as a white settler] on this land and what I can do personally to learn from and listen to Indigenous people across Canada, and especially how I personally can move towards reconciliation.

Dr. Andrea Tricco



Dr. Andrea Tricco

Nominated Principal Investigator, SPOR Evidence Alliance, St. Michael's Hospital, Unity Health Toronto

Dr. Andrea Tricco opened the 5th 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.

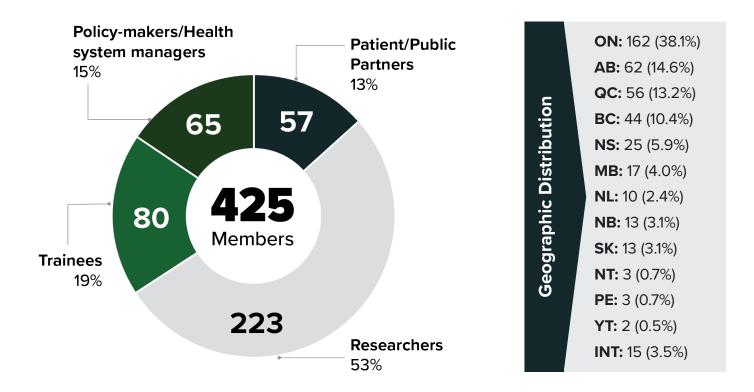
Meeting Attendee Land Acknowledgements



The SPOR Evidence Alliance: Key Updates

Membership

We opened our membership in February 2019. We have grown to over 36 specialized research teams and more than 400 members across Canada and beyond. Our members come from diverse geographical backgrounds and contribute to a wealth of knowledge, expertise, and experiences to our initiative.



ON – Ontario; AB – Alberta; QC – Quebec; BC – British Columbia; NS – Nova Scotia; MB – Manitoba; NL – Newfoundland and Labrador; NB – New Brunswick; SK – Saskatchewan; NT – Northwest Territories; PE – Prince Edward Island; YT – Yukon Territory; INT - International

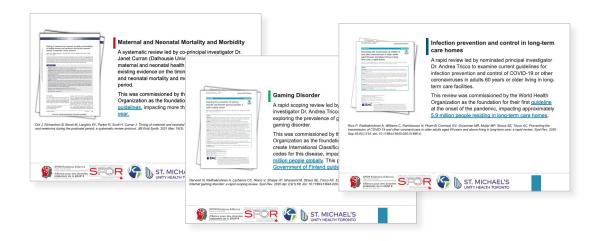
Research Query Services

We began receiving queries through our research query services in April 2018. Since 2018, we accepted **278 requests from 53 different organizations nationally and internationally to inform a range of decisions**.

To learn more about our research query services, please visit our website at <u>sporevidenceallience.ca</u>.

Impact stories

In the past 5 years, 21 organizations requested our co-produced guideline service, and we completed 41 unique projects engaging 46 trainees and 88 patient partners.



Our Impact: Healthcare Decision-Making Impact Stories

In the past 5 years, 39 organizations requested our co-produced knowledge synthesis service, and we completed 259 unique projects engaging 241 trainees and 270 patient partners.



Training and Capacity Development

Through training and capacity building, we aim to create a culture of learning and innovation that grows, supports, and sustains an environment for patient-oriented research using the SPOR Capacity Development Framework.

We led and supported 270 learning opportunities, with over 4,920 learner engagements.

270
Learning opportunities

4,920
Learner
engagements
(973 knowledge
users)

61Queries led by **24** early career researchers

256Trainees engaged across **94** queries

Patient/public partners trained in knowledge synthesis across 2 courses co-led with patient/public partners

Trainees/
early career
researchers
awarded seed
funds to advance
science

Seed Grant Funding

We awarded 8 trainees with seed grant funding to support methods projects at the conceptual stage. Our aim is to encourage a culture of learning, innovation, and advancements of science in the area of knowledge synthesis, guideline development, knowledge translation, and patient-oriented research.















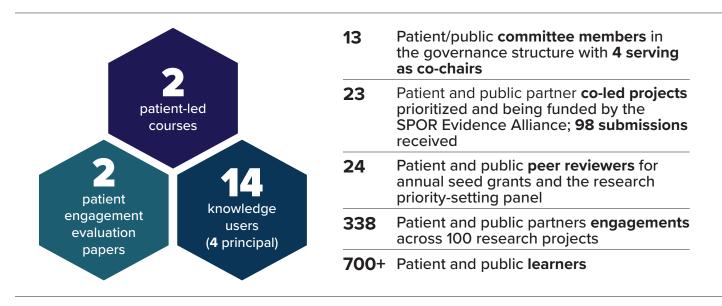


Seed grant winners from left to right: Ghazal Fazli (2021), Nicole George (2021), Richard Henry (2020), Jillian Macklin (2020), Alexandra Korall (2019), Lashanda Skerritt (2019), Lisa Knisley Jones (2019), and Amanda Wurz (2019).

Patient/Public Partner Engagement

"When patients lead, research is relevant"

Patient and public partnership is integrated in research, leadership, and governance. Our patient and public members bring a wealth of knowledge and experience that translates into purpose-driven research activities.



We partnered with two of our patient partners, <u>Janet Gunderson</u> and <u>Maureen Smith</u>, to co-develop courses in **rapid reviews and knowledge synthesis**.

- The 2021 Patient and Public Engagement in Rapid Reviews course was designed to provide
 patient and public partners with resources or tools they can use to meaningfully participate and
 collaborate in rapid review projects.
- The 2022 Patient and Public Engagement in Knowledge Synthesis course was designed to provide patient and public partners with foundational knowledge in knowledge synthesis and meaningful patient and public engagement in knowledge synthesis projects.

A total of 46 patient and public partners from across Canada participated in the courses.

Learners reported greater understanding of knowledge synthesis, rapid reviews, and patient and public partner engagement in knowledge synthesis after completion of the courses.



I am learning a lot in this course and it is helping build my confidence. I participated in one rapid review before the course and tended to downplay my contributions. This course is helping me understand my role as patient partner and to see the value of my contributions." — Patient Learner

2023 Patient and Public Partner Health Research Topic Priority Setting

- We are happy to announce the successful completion of the 2023 Patient and Public Health
 Research Topic Priority-Setting Exercise. We received 87 submissions with 63 unique topics, in
 English and French.
- A 15-member panel of patient and public partners, and knowledge users selected the top 20 health research topics using a <u>modified James Lind Alliance Priority-Setting Partnerships approach</u>.
- Visit our website for more information on the priority-setting exercise.

These carefully chosen topics are aimed at addressing current and pressing healthcare and health system gaps, aligning with our mission to prioritize issues of utmost importance to the community.

Administrative Updates

We have updated our <u>Conflicts of Interest (COI) Disclosure Policy</u>, with the aim to be **more inclusive** and accessible, incorporate a social justice, equity, diversity, inclusion+ lens, and provide guidance and clarity to end-users around COI reporting.

Our updates include:

- · Clarification on COI reporting requirements
- Elaboration on "How to Determine COI" with reflective questions based on roles
- COI management plan if a COI exists with the Nominated Principal Investigator or Executive Committee



The COI policy is very impressive. Really appreciated reading it and seeing the well thought out considerations."

Lisa Dolovich, Researcher



Kudos to the leadership of the SPOR Evidence Alliance for the recently approved 'Conflicts of Interest Disclosure Policy' - it provides the foundation for transparent processes to identify and address real, potential and perceived conflicts of interest for its members." – Alison Hoens, Patient Partner



I really like the reflective questions. I often struggle with filling out these forms. Great to have everything defined so clearly" – Maureen Smith, Patient Partner

Watch Dr. Tricco's full presentation here:

https://www.youtube.com/watch?v=9gtz4usxSBo

Trauma- and Resiliency-Informed Practice in Patient Engagement: A Primer for Researchers and Patient and Public Partners in Patient-Oriented Research



Ms. Carolyn Shimmin

Patient and Public Engagement Lead, George & Fay Yee Centre for Healthcare Innovation, University of Manitoba

Ms. Carolyn Shimmin presented a primer for researchers and patient and public partners to further their knowledge on trauma- and resiliency-informed engagement.

The primer addressed the following key topics:

- The definition, scope, and impacts of trauma at different levels, including individual, organizational, structural, and historical;
- The significance of trauma-informed engagement;
- The ways in which trauma-informed engagement can be put into practice; and
- The ways in which self-care can be integrated into your practice.

Carolyn emphasized the significance of trauma-informed awareness and approaches for fostering safe and inclusive spaces in health research collaboration and co-design. The audience highlighted that, although essential, trauma-informed engagements have the potential to inadvertently recreate trauma and elicit feelings of powerlessness.

The discussion delved into the distinctions between safety and comfort, highlighting that a safe environment empowers individuals to express themselves. Safeguarding this atmosphere requires the implementation of engagement strategies aimed at promptly addressing harmful speech, actions, and behaviours. These strategies should not only intervene but also model a supportive framework for those who may feel harmed.

Calling In and Calling Out

Calling in and calling out approaches can be used to interrupt bias:

Calling In

An invitation to a oneon-one or small group conversation to bring attention to harmful words or behaviour, including bias, prejudice, macroaggressions or discrimination.

An opportunity to explore deeper, make meaning together, and find a mutual sense of understanding.

How might the impact of your words or actions differ from your intent?

I'm curious. What was your intention when you said that?

Calling Out

Bringing public attention to an individual, group, or organization's harmful words or behaviours.

The need to interrupt the action or behaviour in order to prevent further harm.

It sounded like you said ______. Is that what you really meant?

That's not our culture here.
That's not our values.

I need you to know how that comment just landed with me.



Calling In and Calling Out (continued)

Calling someone in or out creates openings in the engagement for moments of pause, active listening, acknowledgment, and reflection, fostering opportunities to address and mend any harm.



"If you have developed guiding principles, you can even call people in during a group situation... because of the importance of leaning into uncomfortable conversations as well as relationship building." — Carolyn Shimmin



"When I know better, I do better. So that to me is where the accountability piece comes in and I can make a mistake but I want to be called in or out so I can examine it and learn."

Patient Partner

Key elements: Integrating trauma-informed engagement

The session further emphasized key elements of integrating trauma-informed engagement into practice:



Safety and Trust

- · Welcome introductions
- Adapt the physical and/or online space to accommodate patients and community members
- Provide clear and accessible information
- Ensure everyone understands confidentiality
- · Develop a crisis plan



Choice and Collaboration

- Offer choices to give back control to patients and community members
- Brainstorm strategies to address barriers to engagement and attendance
- Inquire about others who may be helpful to include in some aspects of the engagement



Bear Witness

- Listen and reflect on personal experiences and stories told by patients and community members
- Acknowledge effort and strength
- Offer appreciation and understanding
- Recognize successes



Empathy

- Actively listen to someone sharing a story, identify what feeling was going on with them, and reflect on your own personal experiences and stories
- Acknowledge strength and value of others



Boundaries

 Ensure everyone can maintain healthy interpersonal boundaries and can manage conflict appropriately

The session concluded by highlighting self-care strategies into practice, including grounding techniques, mindfulness-based stress reduction techniques, taking scheduled breaks, developing a debriefing plan, and setting realistic goals for yourself.

Resources



Helpful Resources

- Moving towards a more inclusive patient and public involvement in health research paradigm: The incorporation of a trauma-informed intersectional analysis
- Valuing All Voices: Refining a trauma-informed, intersectional and critical reflexive framework for patient engagement in health research using a qualitative descriptive approach
- Readiness to Engage Workbook: Questions for Research
 Teams & Partners to Consider when Planning and Evaluating
 Patient and Public Engagement
- The coin model of privilege and critical allyship: Implications for health
- Calling In and Calling Out Guide

Watch the full session here:

https://www.youtube.com/watch?v=-qWTOgxT7pY&ab_channel=KTProgram

Engaging with Communities Experiencing Health Inequities: Best Practices



Dr. Angela Mashford-Pringle (Moderator)

Assistant Professor, Dalla Lana School of Public Health, University of Toronto



Dr. Deepa SingalScientific Director,
Autism Alliance of
Canada



Dr. Mahadeo Sukhai

Vice-President Research & International Affairs and Chief Accessibility Officer, Canadian National Institute for the Blind (CNIB)



Dr. Shamara Baidoobonso

Provincial
Epidemiologist,
Government of Prince
Edward Island

Dr. Angela Mashford-Pringle, **Dr. Deepa Singal**, **Dr. Mahadeo Sukhai**, and **Dr. Shamara Baidoobonso** discussed their experiences in engaging with communities experiencing health inequities and shared best practices when conducting community-based research.

Here is a highlight of their discussion about their experiences doing community engagement research:

- Grappled with challenges of presenting their personal lived connections to the academic community while maintaining professionalism, but learned there is no such thing as scientific objectivity as everyone carries their own experiences and biases into their work.
- Witnessed how fractured and broken the health system is, and how difficult it is for individuals with less privilege to navigate these complex systems.
- Recognized the earned privilege of being in leadership roles and having influence within government organizations to advocate for and bring the voices of community to the fore.
- Through conducting community engagement research, they have become leaders, mentors, members, supporters and advocates for the communities they represent.
- Avoided being "helicopter researchers" and leaving after completing community-based research and continued to support their communities by the scope of the research.
- Cross-generational responsibility to cultivate the next generation of researchers to continue community-based research by providing capacity building and mentorship.
- Using research to empower communities and exploring how you can give a platform to communities to share their experiences.

Best Practices for Meaningful Community Engagement

They also shared some best practices to meaningful community engagement:

1. Use appropriate and respectful language

- Reflect upon how questions are posed to communities and whether they will come across as able-ist, disrespectful, or disingenuous.
- Provide respect for persons with lived experiences by addressing them using their preferred language (i.e., identity-first language or person-first language).

2. Allocate sufficient time for relationship building

• Relationship building with communities takes time in order to understand and prioritize the needs of community before the co-creation of a research proposal.

3. Involve communities throughout the entire research process

- Address community-identified knowledge gaps instead of researcher-identified knowledge gaps to ensure maximal impact to the community.
- If the community is not involved at each stage in the research process, it is not research that is by, with, and for the community.
- There is no way to respectfully or inclusively develop guidelines without persons with lived experience who are impacted by guidelines as part of the process.

4. Provide compensation for persons with lived experiences

- Compensation is not just an incentive for persons with lived experiences, but required for the contribution of their time and expertise.
- Collaborate with non-for-profits or charities who have the funding mechanisms to support persons with lived experiences without bureaucratic barriers that academic institutions have.

5. Acknowledge lived experience as expertise

- Traditionally, the term "expert" is based on the hierarchy of academic credentials, but it
 needs to be inclusive of persons with lived experience as they are experts of their daily, lived
 experiences.
- Offer capacity building or training for persons with lived experiences to learn jargon and terminology and bridge the gap between researchers and persons with lived experiences.

6. Reciprocity for the community

- Use research to empower communities and give communities members a platform to share their experiences.
- Cross-generational responsibility to cultivate the next generation of researchers to continue community-based research by providing capacity-building and mentorship opportunities.



[Community engagement] research is research that is with, by, and for persons with [lived experiences]" — Dr. Mahadeo Sukhai



Call to action for universities and funding agencies that are now seeing the value of [community engagement research]... to provide researchers with the resources, infrastructure support, and time to do this work well." – Dr. Deepa Singal



The benefits of community engaged research are beyond academic outputs and health improvements... it's the changes that take place in community." – Dr. Shamara Baidoobonso



Power, privilege, and positionality: We all have privilege to be able to sit here today... Your words, your actions, the things you purchase are power...lt's important to remember that every little thing you do as a person does to contribute to community engagement. To have more appropriate research, now and into the future, we need to look at the 7 generations. The 3 before us, our own, and the 3 coming up." — Dr. Angela Mashford-Pringle

Helpful Resources

- GIN Public Toolkit Patient and public involvement in guidelines
- Patient and public involvement in the development of clinical practice guidelines: a scoping review
- The effectiveness of community engagement in public health interventions for disadvantaged groups: a meta-analysis
- Narratives of community engagement: a systematic review-derived conceptual framework for public health interventions
- What do you mean by engagement? evaluating the use of community engagement in the design and implementation of chronic disease-based interventions for Indigenous populations scoping review
- Elements of Indigenous style (guide for writing by and about Indigenous Peoples)
- Recognition of knowledge translation practice in Canadian health sciences tenure and promotion:
 A content analysis of institutional policy documents

Watch the panel's full discussion here:

https://www.youtube.com/watch?v=oS90-hX4SxY

Closing Ceremony

Elder Diane closed the meeting and gave thanks to the Creator and Mother Earth for the opportunity to us to meet. She shared that our decisions and actions reverberate across the 7 generations to come.





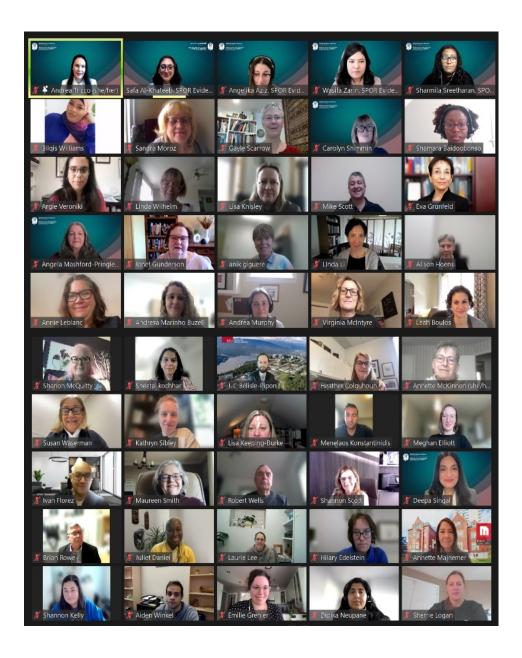
We ask that all of the people who have joined us here today, find their families well in that peace, [and] that they travel safely. Tomorrow morning when the sun rises, we will still be here together doing this great work. So with these words we give thanks for a beautiful day."

That's a wrap!

We are grateful to Elder Diane Longboat for her blessings, imparting her wisdom and performing the opening and closing ceremonies for the meeting.

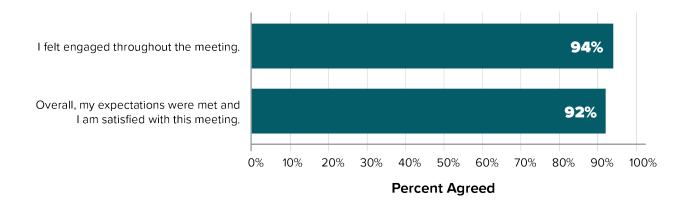
We would also like to thank our speakers Ms. Carolyn Shimmin, Dr. Angela Mashford-Pringle, Dr. Deepa Singal, Dr. Mahadeo Sukhai, Dr. Shamara Baidoobonso, and Dr. Andrea Tricco.

We are truly thankful to all meeting participants for their time, stimulating discussions, and ongoing collaboration and support of the SPOR Evidence Alliance.



Participant Feedback and Reflections from the 2023 Annual General Meeting

The survey for the 2023 Annual General Meeting was distributed to 113 attendees, garnering 40 responses from November 16 to December 14, 2023, resulting in a response rate of 35%.



Our meeting attendees shared their positive sentiments from the event, highlighting a remarkable level of satisfaction and active engagement. The insightful sessions led by our panel of presenters, coupled with the dynamic engagement throughout the event were key factors in fostering a positive and enriching experience among the valued members of our community.

Feedback from Meeting Attendees:



It was all interesting, engaging and informative, and the breaks were long and frequent enough that I could be engaged throughout the whole meeting."



Dr. Tricco and her team are incomparable and always high-level speakers, seamlessly organized, etc."



I really enjoyed learning about the unique experiences shared by the speakers and other participants. I also liked the welcoming and engaging atmosphere and respecting participant's' preferred level of engagement....needless to say this was a safe space."



I enjoyed the diversity of speakers and their authenticity."

Closing Remarks

Thank you for choosing to be with us today, and I hope that we can all reflect on our creation stories, and accept not only our beautiful differences, but also how we are all so alike"

- Dr. Andrea Tricco