

Welcome to the 2023 Annual General Meeting!

The 5th Annual General Meeting of the SPOR Evidence Alliance

November 16, 2023 12:00 PM - 4:30 PM EST









Meeting Chair

Andrea C. Tricco MSc, PhD is a scientist and director of the Knowledge Synthesis Team in the Knowledge Translation Program at St. Michael's Hospital of Unity Health Toronto. She is an Associate Professor at the University of Toronto in the Dalla Lana School of Public Health & Institute of Health Policy, Management, and Evaluation. She is also Co-Director & Adjunct Associate Professor for the Queen's Collaboration for Health Care Quality, Joanna Briggs Institute Centre of Excellence at Queen's University. Her research program focuses on advancing the science of knowledge synthesis and responding to information needs of decision-makers (including policymakers, healthcare providers, and patients) through knowledge synthesis. Andrea currently holds a Tier 2 Canada Research Chair in Knowledge Synthesis.









Land Acknowledgement

The SPOR Evidence Alliance Central Coordinating Office is located on land now known as Tkaronto (Toronto). Tkaronto 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 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.









Opening and Closing Ceremony Etiquette

- During the ceremony, we will take down the slide deck so we are all in gallery mode on Zoom.
- Please turn on your camera, if you feel comfortable doing so.
- Maintain a respectful posture and etiquette:
 - Remove your hat if you are wearing one.
 - Bow your head and place your hands at your side or clasp them in front of you.
 - No talking, texting, or taking phone calls during the ceremonies.
 - Be present in the moment.
- As the listener, you are being entrusted with knowledge by Elder Kahontakwas Diane Longboat.









Opening Ceremony



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





The SPOR Evidence Alliance: Key Updates



Dr. Andrea Tricco is the nominated principal investigator of the SPOR Evidence Alliance. She is based at the St. Michael's Hospital, where she is the director of the Knowledge Synthesis Team. She is an Associate Professor at the University of Toronto in the Dalla Lana School of Public Health & Institute of Health Policy, Management, and Evaluation.





ABOUT US

The SPOR Evidence Alliance is a Canada-wide partnership between:









Researchers

Patients and the Public Healthcare Providers Health System Decision-Makers

Jointly funded by the Canadian Institutes of Health Research and 41 funding partners from public and not-for-profit sectors to create a collaborative research environment.

OUR MISSION

To promote a Canadian health system that is increasingly informed and continuously improved using scientific evidence.

OUR APPROACH



Our work is guided by evidence-informed methods to ensure the highest standards in research practice



Our research environment promotes inclusiveness, respect and collaboration



Our research is conducted with decision-makers (including patients) who use and are impacted by the findings











KEY ACTIVITIES



Research Query Services

We have researchers across Canada with diverse expertise to respond to decision-maker research needs



Training and Skills Development

We offer a range of courses and workshops to support and grow researchers and decision-makers who use research findings



Ideas and Innovation

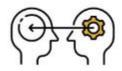
We promote and advance the use of scientific knowledge



Knowledge Synthesis



Clinical Practice Guidelines



Knowledge Translation

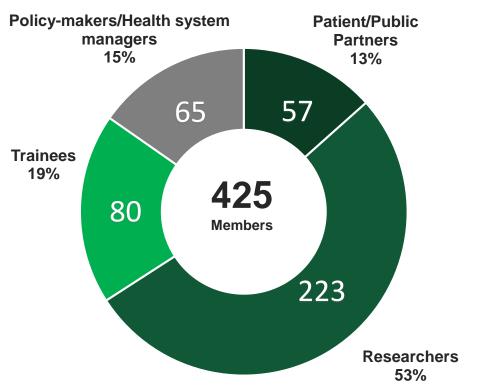






SPOR Evidence Alliance Membership

36 specialized research teams and 400+ members across Canada and beyond contributing to a wealth of knowledge, expertise and experiences to our initiative.



ON: 162 (38.1%)
AB: 62 (14.6%)
QC: 56 (13.2%)
BC: 44 (10.4%)
NS: 25 (5.9%)
MB: 17 (4.0%)
NL: 10 (2.4%)
NB: 13 (3.1%)
SK: 13 (3.1%)
NT: 3 (0.7%)
PE: 3 (0.7%)
YT: 2 (0.5%)

INT: 15 (3.5%)

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









Geographic Distribution

British Columbia

Query teams: 4 Researchers: 17 Trainees: 10

Patient/public members: 13 Knowledge Users: 6 Questions addressed: 14

Yukon

Query teams: 1 Researchers: 1 Trainees: 0

Patient/public members: 1 Knowledge Users: 0 Questions addressed: 0

NWT

Query teams: 0 Researchers: 0 Trainees: 0

Patient/public members: 0 Knowledge Users: 4 Questions addressed: 3

Patient/public members: 8 Knowledge Users:13 Questions addressed: 10

Query teams: 3

Trainees: 21

Researchers: 22

Quebec

Newfoundland

Query teams: 1 Researchers: 7 Trainees: 0

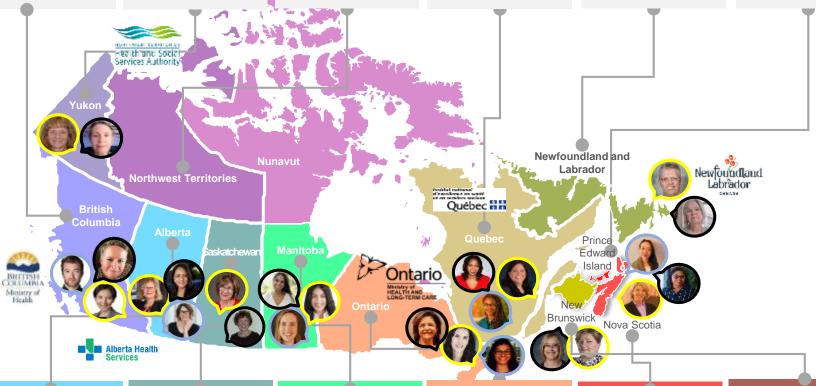
Patient/public members: 1 Knowledge Users: 3

Questions addressed: 49

PFI

Query teams: 0 Researchers: 1 Trainees: 1

Patient/public members: 1 Knowledge Users: 1 Questions addressed: 49



Alberta

Query teams: 2 Researchers: 33 Trainees: 11

Patient/public members: 6 Knowledge Users: 12 Questions addressed: 13

Saskatchewan

Query teams: 0 Researchers: 5 Trainees:0 Patient/public members: 4 Knowledge Users:4 Questions addressed: 0

Manitoba

Query teams: 2 Researchers: 13 Trainees: 2 Patient/public members: 1 Knowledge Users:1

Questions addressed: 1

Ontario

Query teams: 19 Researchers: 93 Trainees: 26

Patient/public members: 18 Knowledge Users: 24 Questions addressed: 14

Nova Scotia

Query teams: 4 Researchers: 17 Trainees: 6 Patient/public members: 1

Knowledge Users: 3 Questions addressed: 2

New Brunswick

Query teams: 0 Researchers: 4 Trainees: 3

Patient/public members: 2 Knowledge Users: 4 Questions addressed: 2

Research Query Services

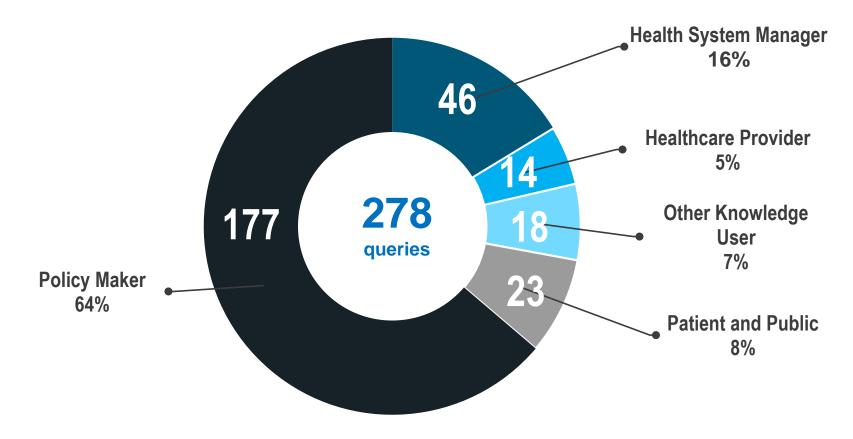






Supporting Health System Decisions

Since 2018, 278 requests accepted from 53 different organizations nationally and internationally to inform pressing health challenges.







Range of Decisions Covered across 278 Queries



Range of decisions informed:

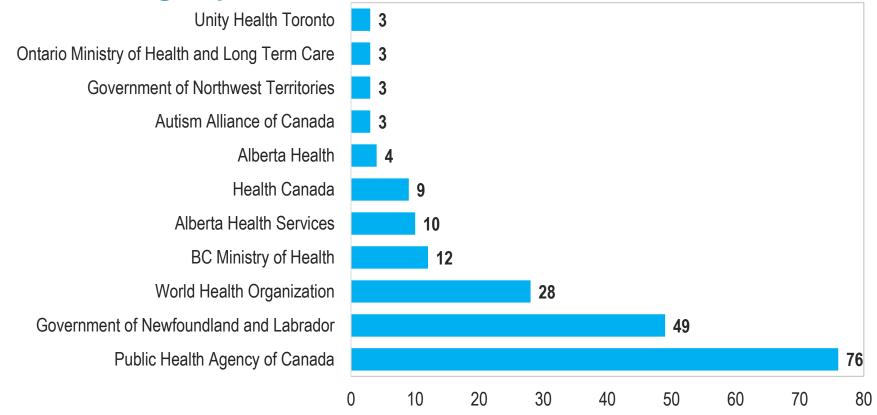
- 115 public-health measures (e.g., infection prevention and control, surveillance, health promotion)
- healthcare system arrangements (e.g., governance, delivery, financial)
- clinical management or guidelines (e.g., symptom management, treatment)
- 21 public health system arrangements (e.g., governance, delivery, financial, partnerships, communication)
- 19 knowledge exchange and mobilization
- economic and social responses (e.g., social gathering, economic impact)
- 4 health, public and/or organizational policies (e.g., legal, administrative)





Supporting Health System Decisions (cont.)

Repeat services from diverse local, provincial, national and international groups*



*Note: All international requests (e.g., WHO) were funded by that organization



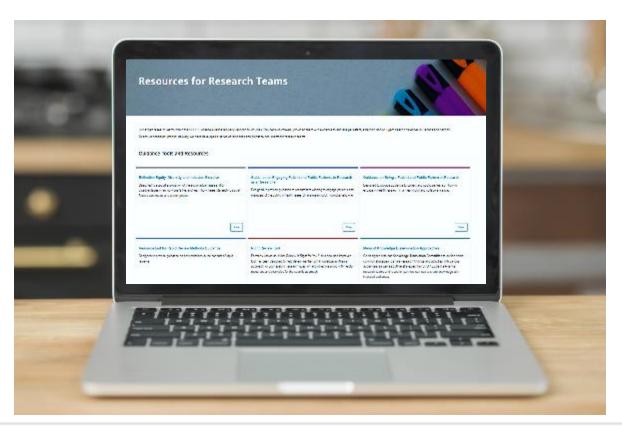






SPOR Evidence Alliance Resources

- To ensure consistent product delivery, we have developed a series of templates and guidance documents for our research teams.
 - https://sporevidencealliance.ca/resources-for-research-teams/







Guidelines impact stories

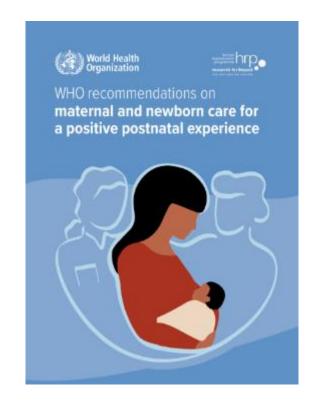
In the past 5 years, 21 organizations requested our co-produced guideline service; 41 unique projects were completed by 14 teams and engaging 46 trainees and 88 patient partners, positioning Canada as a leader in the development of guidelines.

1. Maternal and neonatal health (led by co-PI Curran, Dalhousie University): commissioned by the World Health Organization as the foundation of their international guidelines, impacting more than 140 million births per year.

SYSTEMATIC REVIEW PROTOCOL

Timing of maternal and neonatal mortality and morbidity in healthy women and newborns during the postnatal period: a systematic review protocol

Justine Dol^{1,2} • Brianna Richardson^{2,3} • Mercedes Bonet⁴ • Etienne V. Langlois⁵ • Robin Parker⁶ • Heather Scott⁷ • Janet Curran^{2,3}









Guidelines impact stories (cont.)

2. Gaming disorder (led by NPI Tricco, University of Toronto): commissioned by the World Health Organization as the foundation for their guideline to create International Classification of Disease (ICD) codes for this disease, impacting approximately 60 million people globally. ICD codes are used internationally to ensure data can be used across countries to monitor and compare disease morbidity and mortality. This project was cited in the Government of Finland guideline.



RESEARCH

Open Access

Exploring the prevalence of gaming disorder and Internet gaming disorder: a rapid scoping review



Nazia Darvesh¹, Amruta Radhakrishnan¹, Chantelle C. Lachance¹, Vera Nincic¹, Jane P. Sharpe¹, Marco Ghassemi¹, Sharon E. Straus^{1,2} and Andrea C. Tricco^{1,3*}





Home / Classifications / Frequently asked questions / Gaming disorder

Frequently Asked Questions

How is gaming disorder identified?

For gaming disorder to be diagnosed, the behaviour pattern must be severe enough that it results in significant impairment to a person's functioning in personal, family, social, educational, occupational or other important areas, and would normally have been evident for at least 12 months.









Guidelines impact stories (cont.)

3. Infection prevention and control in long-term care homes (led by NPI Tricco): commissioned by the World Health Organization as the foundation for their first guideline at the onset of the pandemic, impacting approximately 5.9 million people residing in long-term care homes.

An update was commissioned by the <u>Canadian Frailty Network</u> and cited in the <u>Organisation for Economic Co-operation and Development policy</u>, <u>Irish Department of Health report</u>, and <u>Australian Department of Health guidance</u>.

RESEARCH

Open Access

Preventing the transmission of COVID-19 and other coronaviruses in older adults aged 60 years and above living in long-term care: a rapid review



Patricia Rios¹, Amruta Radhakrishnan¹, Chantal Williams¹, Naveeta Ramkissoon¹, Ba' Pham¹, Gordon V. Cormack², Maura R. Grossman², Matthew P. Muller^{1,3}, Sharon E. Straus^{1,4} and Andrea C. Tricco^{1,5}*

Infection prevention and control guidance for long-term care facilities in the context of COVID-19

Interim guidance 8 January 2021













In the past 5 years, **39 organizations** requested our co-produced knowledge synthesis service; **259 unique projects** were completed by **35 teams**, engaging **241 trainees and 270 patient partners**, positioning Canada as a leader in knowledge synthesis and knowledge translation.

1. Risk assessment for COVID (led by co-I Little): commissioned by the Irish Department of Health for their COVID strategy and used in decision-making by the Economic and Social Research Institute of Ireland, impacting approximately 5 million people in Ireland.

RAPID COMMUNICATION

Development of a risk assessment profile tool to determine appropriate use of SARS-CoV-2 rapid antigen detection tests for different activities and events in Ireland, since October 2021



Patrick WG Mallon¹, Mary Horgan², Conor G McAloon³, Peter D Lunn⁴, Julian Little⁵, Andrew Beck⁵, Alexandria Bennett⁵, Nicole Shaver⁵, Aileen McConway⁶, Rhea O'Regan⁶, Barbara Whelan⁶, Rapid Testing Expert Advisory Group, Ireland⁷









2. Global policy analysis of autism strategies (led by co-I Singal, University of Manitoba): commissioned by the Autism Alliance of Canada to inform the first ever national Canadian autism strategy for Public Health Agency Canada, Autism Europe, National Institute of Mental Health of the United States, and Government of Malta Autism Advisory Council, impacting approximately 380,000 Canadians living with autism and millions more internationally.









Public Health Agency of Canada Agence de la santé publique du Canada









3. Family violence interventions (led by previous co-PI Moffitt, Aurora College): commissioned by the Government of the Northwest Territories for decisions related to 15,000/15.000 households in the Northwest Territories.



A comprehensive approach to prevent and address family violence in northern, remote, and primarily indigenous communities









4. Indigenous colorectal screening programs (led by co-I Walker, McMaster University): commissioned by Sioux Lookout First Nations Health Authority for decisions on <u>33 First Nation communities</u>.









22

5. Workplace Violence in Emergency Departments (led by co-I Hamilton, Arthritis Research Canada): commissioned by Unity Health Toronto.



Evidence-Based Approaches to Mitigate Workplace Violence From Patients and Visitors in Emergency Departments: A Rapid Review

Chantelle Recsky, Melissa Moynihan, Giovanna Maranghi, Orla M. Smith, Elliot PausJenssen, Priscille-Nice Sanon, Sharon M. Provost, Clayon B. Hamilton

"I am proud that our work is now in print, and available to emergency departments working to create safer spaces for staff and for patients."

- Orla Smith







Client Statements

Here is what our service users have to say...

"The technical assistance centre (TAC) from the SPOR Evidence Alliance was essential in leading the development and implementation of the Embedding Rapid Reviews in Health Systems Decision–Making (ERA) initiative, a capacity strengthening program funded by the WHOs Alliance for Health Policy and Systems Research. They successfully supported the establishment of rapid review platforms in four low-and-middle income countries, namely in India, Georgia, Malaysia, and Zimbabwe. This in turn equipped the platforms to respond to numerous policymaker requests for rapid evidence syntheses to support health system and policy decision—making in their countries, particularly during the COMD-19 pandemic."

Etienne Langlois

WORLD HEALTH ORGANIZATION

"The collaboration with SPOR [Evidence Alliance] for the community engagement piece actually moved our work one step further by validating the research. I want to especially recognize the care the team took to not just meet their ethical obligations as far as their research license, but in carefully managing their interaction with community members in a culturally safe way, explicitly putting the needs of community participants ahead of any research goal."

Leanna Gardiner

GOVERNMENT OF NORTHWEST TERRITORIES

"Working with the SPOR Evidence Alliance Team has been a great experience. Clinicians in the emergency department face rising levels of violence, and finding effective solutions to mitigate this issue were challenged. Based on the advice of a trusted colleague, I connected with the team and the rest is history! Through multiple meetings, we refined our question and our approach. Patient and family advisors were engaged to provide a needed perspective. I am proud that our work is now in print, and available to emergency departments working to create safer spaces for staff and for patients."

Orla Smith
UNITY HEALTH TORONTO

"Infoway is committed to ensuring that digital health initiatives in Canada are built upon the best possible evidence. This literature will help Infoway and its partners to understand the current and future potential impacts of e-prescribing on opioids and controlled substances. It can inform our actions as we expand and optimize the service, and the complementary initiatives of governments seeking to reduce the negative impacts of opioids."

Simon Hagens

CANADA HEALTH INFOWAY

Our impact

- The SPOR Evidence Alliance publication on methodological challenges of rapid reviews during COVID-19 was cited by the Robert Koch Institut of Germany and the Australian living guidelines on COVID initiative.
 - The Brazilian Ministry of Health, National Health Service of the United Kingdom, and the International Public Policy Observatory have invited talks by the SPOR Evidence Alliance to inform their rapid response services.
 - The SPOR Evidence Alliance also led an interactive workshop and webinar for decision-makers in Public Agency of Canada and Health Canada.





Journal of Clinical Epidemiology

Journal of Clinical Epstemology 126 (2020) 177-187

COVID-19 ARTICLES

Rapid review methods more challenging during COVID-19: commentary with a focus on 8 knowledge synthesis steps

Andrea C. Tricco^{a,b,c,*}, Chantelle M. Garritty^a, Leah Boulos^c, Craig Lockwood^{c,*}, Michael Wilson^{b,k,j}, Jessie McGowan^k, Michael McCaul[†], Brian Hutton^a, Fiona Clement^a, Nicole Mittmann^{c,p,q}, Declan Devane^c, Etienne V. Langlois^c, Ahmed M. Abou-Setta[†], Catherine Houghton^a, Claire Glenton^a, Shannon E. Kelly^{a,k}, Vivian A. Welch^{a,j}, Annie LeBlanc^c, George A. Wells^{a,k}, Ba^c Pham^a, Simon Lewin^{a,k}, Sharon E. Straus^{a,a,b}

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Conflict of interest ACT, J.M., and G.W. are associate edition and S.E.S. in on the editorial board for the Journal of Clinical Epidemiology; none were incolord with the new review of this article or decision to only. and provides consulturely to Cricheaus Response. S.L. in the Joint Coordinating Editor of Codenne Effective Practice and Organization of Care (EPOC) and Casin of the Grossmance Group of the Global Editories Synthesis Institute (GESI), E.L.V., A.A.S., V.W., B.F., S.K., C.H., M.W., N.M., C.G., L.B., F.C., C.L., M.M., A.L., and D.D. have an competing intensit to declare.

* Corresponding suffor: Knowledge Translation Program, Li Ka Shing:









To learn more about our query services, visit our website at sporevidencealliance.ca



Decision-Maker Research Query Process

Research Request Submission



- Health system decision-makers (e.g., policy-makers, managers, healthcare providers) can submit their prioritized evidence, guideline, or knowledge mobilization needs to inform health policies and practices by using our web-based form available in both English and French.
- Eligible topics include those that identify an opportunity to improve health outcomes, medical, health policy, or public health systems in Canada or globally.
- Requests are addressed using a knowledge synthesis, guideline, or knowledge mobilization/dissemination/implementation approach, as appropriate.

Reviewing Submitted Requests

- The SPOR Evidence Alliance central coordinating office collaborates closely with the decisionmaker(s) to define and refine the scope of their evidence, guideline, or knowledge mobilization needs. This is done through focused conversations held via web conferences and email.
- To ensure research efforts are not duplicated, we search study registries, bibliographic databases and check with our research teams to see if similar research has been published recently, is currently underway, or is forthcoming.



Planning and Production



- A research team (when possible a local team) with relevant expertise is nominated to develop the research proposal and budget in collaboration with the decision-maker(s). Each project team also includes 1-2 patient or public partner(s), 1 research trainee, and 1 content expert (as needed).
- Teams can consult the <u>Right Review</u> tool to determine the best knowledge synthesis method(s) to address the request.
- Teams are provided guidance and resources to consider equity, diversity, inclusion and social justice principles in the design of their research plan.
- The research proposal and budget are reviewed by members of the SPOR Evidence Alliance executive committee and central coordinating office for feasibility and appropriateness.
- The research team works closely with the decisionmaker(s) at each phase of the project and seeks feedback and guidance as needed.

Dissemination and Exchange

- Knowledge products and tools are produced and tailored to decision-maker(s) needs.
- When appropriate, findings are published in open-access peer-reviewed journals or on pre-print servers. All involved decision-makers, patient and public partners, and research trainees are invited to be co-authors based on the <u>International Committee of Medical Journal</u> Editors criteria.



Training and Capacity Development









Learning Opportunities

We create a culture of learning and innovation that grows, supports, and sustains an environment for patient-oriented research using the SPOR Capacity Development Framework.

270

Learning opportunities

4,920 Learner engagements (973 knowledge users)

61

Queries led by **24** early career researchers

256 Traineesengaged across94 queries

46

Patient/public partners trained in knowledge synthesis across

2 courses co-led with patient/public partners

8

Trainees/early career researchers awarded seed funds to advance science









Seed Grant Opportunity

- Seed grant funding aims to encourage a culture of learning, innovation, and advancement of science in the areas of knowledge synthesis, guideline development, knowledge translation, and patient-oriented research by funding methods projects at the conceptual stage.
- Supporting doctoral students, post-doctoral fellows or early career researchers at a Canadian institution.
- Funds Available: \$10,000 per award
- Eight awards granted since 2019 on the following themes:

2019-2020	2020-2021	2021-2022
Advancing the Science of Patient Engagement in Research	Advancing the Science of Guideline Development with Patient Partnership	Knowledge Dissemination and Implementation with Patient Partnership Using an Equity, Diversity, Inclusion and Social Justice Lens

 2024 seed grant completion will focus on Advancing Indigenous Ways of Knowing and Doing Research.







29

Seed Grant Winners



"Nothing about us, without us": The need for trauma-informed intersectional analysis of diabetes risk during COVID-19 through patient and public engagement

Ghazal FazliPost Doctoral Fellow, Unity Health Toronto



Incorporation of recommendations for gender-diverse people in clinical practice guidelines: A review of traditionally sex-binary guidelines and recommendations

Richard Henry
Post Doctoral Fellow, McGill University



Engaging patient and public partners in a scoping review on the practice and science of James Lind Alliance Priority Setting Partnerships





Exploring predictors of women's overall satisfaction with their HIV care

2021

2020

2019

Lashanda Skerritt MD-PhD Student, McGill University



Community partnerships for chronic pain management: An equity, diversity and social justice lens

Nicole George
PhD Student, McGill University



Exploring multiple perspectives on how patients can and should be involved in the development of guidelines for patient engagement in artificial intelligence (AI) health research

Jillian Macklin
MD-PhD Student, University of Toronto



Engaging Métis citizens in Manitoba in the development of child health resources





Co-creating inhospital physical activity programming to enhance health for children during treatment for cancer

Amanda Wurz
Post-Doctoral Fellow,
University of Calgary









Fellowships

In partnership with Evidence Synthesis Ireland, we have hosted and mentored 11 clinician research trainees on knowledge synthesis projects.

Fellow Name	Fellow Affiliation	Review Title	Review Supervisor
Dr. Jennifer Fortune	Postdoctoral Fellow, Royal College of Surgeons in Ireland	The Relationship Between Social Isolation and Falls in Older Adults: A Scoping Review	Dr. Andrea Tricco
Dr. Orna Fennelly	Postdoctoral Fellow, NUIG	Implementation of Artificial Intelligence in Healthcare: A Scoping Review	Dr. Andrea Tricco
Dr. Gary Mitchell	Registered Nurse Lecturer, Queen's University Belfast	Interventions For Social Isolation In Older Adults Who Have Experienced A Fall: A Systematic Review	Dr. Andrea Tricco
Dr. Aoige Egan	Endocrinologist, Mayo Clinic	Rapid review on the effects of recreational cannabis use in patients with diabetes	Dr. Andrea Tricco
Dr. Jennifer McSharry	Chartered Health Psychologist and Lecturer, School of Psychology, NUIG	Scoping Review on Knowledge Acquisition Assimilation and Use at the Organizational Level	Dr. Andrea Tricco
Dr. Margarita Corry	Registered Nurse Teacher, Trinity College Dublin	Comparative Effectiveness Of Influenza Vaccines In Adults 65 Years Of Age And Older: A Systematic Review And Network Meta-Analysis	Dr. Andrea Tricco









Fellowships (cont.)

Fellow Name	Fellow Affiliation	Review Title	Review Supervisor
Dr. Olga Cleary	Primary Care Development Officer, Health Service Executive	Exploring the Existence of Gender Inequity with an Intersectionality Lens in Academic Health Care, Health Sciences and Health Policy and Interventions to Optimise Gender Equity	Dr. Andrea Tricco
Dr. Bearach Reynolds	Infectious Diseases Specialist, MPH student	COVID-19 Variants Of Concern – A Rapid Scoping Review And Living Evidence Synthesis	Dr. Janet Curran Dr. Andrea Tricco
Dr. Daragh Bradshaw	Researcher, University of Limerick	Methods for deriving prediction intervals in meta-analysis and network meta-analysis and enhancing their clinical readability and uptake: A scoping review	Dr. Jennifer Watt Dr. Andrea Tricco
Dr. Aileen Conway	Specialist Registrar, Infectious Diseases, St Vincent's University Hospital, Dublin	A suite of rapid, living evidence syntheses with the University of Ottawa, for the Irish Dept. of Health Expert Advisory Group on Rapid Testing (RTEAG)	Dr. Julian Little
Dr. Rhea O'Regan	Infectious Diseases specialist	A suite of rapid, living evidence syntheses with the University of Ottawa, for the Irish Dept. of Health Expert Advisory Group on Rapid Testing (RTEAG)	Dr. Julian Little









Patient Engagement

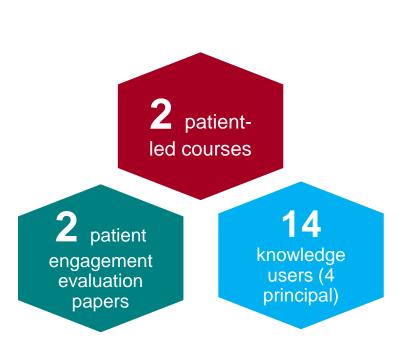






Patient and Public Engagement

Patient partnership is integrated in research, leadership and governance



Patient and public **committee members** in the governance structure with **4 serving as co- chairs**

Patient/Public Partner co-led projects
 prioritized and being funded by the SPOR
 Evidence Alliance; 98 submissions received

Patient and public **peer reviewers** for annual seed grants and research priority-setting panel

Patient and public partners **engagements** across 100 research projects

700+ Patient and public learners







Patient/Public Partner Initiated Research: research co-led by patients for patients

Topic Submission



- Patients/public submit their research ideas using a brief web-based form.
- Any topics that identify an opportunity to improve health outcomes or medical or public health systems in Canada are eligible.

Patient-Identified Priorities

- All topics are reviewed and duplicate or overlapping ideas are combined.
- A librarian conducts literature searches to ensure the research idea has not been answered before.
- All topics are prioritized on an annual basis by a panel of patient/public partners, policymakers, researchers, trainees, and other decision-makers using a modified James Und Alliance Approach.
- Only the most impactful projects that can be answered through a knowledge synthesis, knowledge translation, or guideline approach are funded by the SPOR Evidence Alliance to proceed



Research Partnership & Leadership



- The patients/public who submitted the topic will select a research team (when possible a local team) to carry out the work as equal partners in research.
- The patient/public partner and researcher co-leads work together to develop a work plan and budget.
- The patient/public partner and researcher co-leads identify 2-3 additional patient partners to join the team on the project.

Knowledge Dissemination

 Research findings are co-created and knowledge is shared using tailored dissemination strategies for the target audience.



2023 Patient/Public Topic Priority-Setting

- We received 87 submissions with 63 unique topics (English and French) for the 2023 Patient and Public Health Topic Priority-Setting.
- Topic scoping searches and feasibility assessments were conducted to assess and avoid duplication of research.
- A 15-member panel of patient/public partners and knowledge users selected the top 20 topics using a modified James Lind Alliance Priority-Setting Partnerships approach. Visit our website for more: https://sporevidencealliance.ca/key-activities/2023-priority-setting-exercise/
- Top 20 topics are being funded by the SPOR Evidence Alliance and co-led by patient/publicpartners.
- Patient partners are provided with capacity-building, resources, and guidance.









Impact of Patient/Public Co-led Projects

- Our model has enabled a space for research curated for patients/public by patients/public.
- We have enabled an environment for collaborative learning and mutual respect between researchers and patients/public in doing research.

"[Patient partners] add heart and soul to the project"

"It challenges the research code book and encourages collaborative learning"

"It personalizes and humanizes the [research] process"

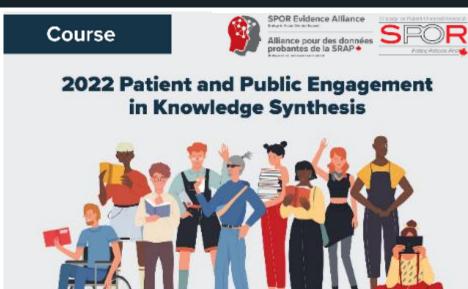






Two Patient Co-led Courses for Patients





From an idea to 2 courses: Co-building patient and public capacity in research with Janet Gunderson and Maureen Smith

- 46 patient and public learners from across Canada.
- Graduates of these learning events have subsequently collaborated on 33+ demand-driven research projects.

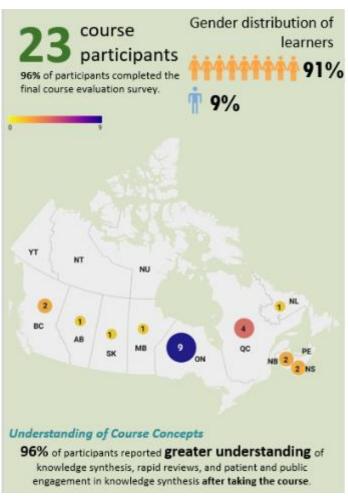




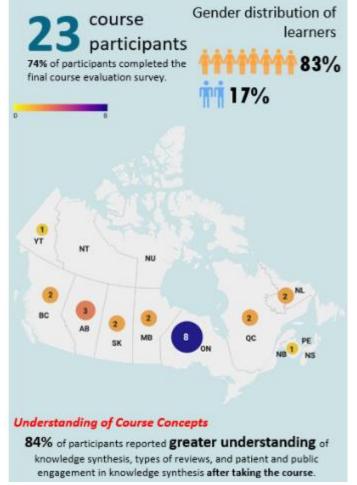


Our Learners

2021 Course



2022 Course











Administrative Updates









Goal: Use of more inclusive and accessible terminology and language, incorporating a social justice, equity, diversity, inclusion+ lens, and provide clarity and guidance to end-users around COI reporting (e.g., include examples).

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 members of the Executive Committee.





Feedback on our Updated COI Disclosure Policy

"The COI policy is very impressive. Really appreciated reading it and seeing the well thought out considerations." "I really like the reflective questions. I often struggle with filling out these forms. Great to have everything defined so clearly"

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

Maureen Smith

PATIENT PARTNER





CIHR Directed-Funding Renewal (2024 – 2026)

2-year directed funding renewal opportunity

- Application submitted: October 3, 2023
- Notice of Decision: December 19, 2023

Welcomed and appointed:

- Co-Pls: Dr. Angela Mashford-Pringle, Dr. Christine (Tina)
 Fahim, Dr. Christine Cassidy, and Dr. Kathryn Sibley
- Principal KU: Beverly Pomeroy

Appointed new champions:

- Indigenous Research Champion: Dr. Angela Mashford-Pringle
- Sex and Gender-Based Analyses (SGBA+) Chairs: Dr. Nicole Doria, Dr. Kathryn Sibley
- Equity, Diversity and Inclusion (EDI) Chairs: Beverly Pomeroy,
 Huda Shah, Dr. Shamara Baidoobonso, Dr. Clayon Hamilton











Our Renewed Objectives

With this renewal, we will:

- Enhance our focus on sex and gender based analysis and equity, diversity, and inclusion.
- 2. Facilitate 20 community-centered queries through pre-existing and new partnerships (e.g., Black/South-East Asian community).
- 3. Support Indigenous community projects (e.g., Talking Circles on Data Sovereignty principles in KS, fund 2 Indigenous-led methods projects through our seed grant competition).
- 4. Amplify French language services (e.g., >5 queries for French-speaking KUs, publish our website in French).
- 5. Complete 20 new KU-driven research queries.
- 6. Create 80 knowledge products from 20 community-based and 20 KU-driven queries.
- Establish linkages wherein gaps exist geographically across Canada and globally.
- 8. Offer 60 training events, provide 35 learners with opportunities to engage in a research query, and engage 25 patient/public partners and 25 policy-makers in the research queries.









SPOR Evidence Alliance Evaluation



Spindle Strategy Corp was selected to conduct the evaluation of the Governance and Research Query Services of the SPOR Evidence Alliance.

Evaluation Design Phase

Refine and validate logic model and evaluation framework

Data Gathering Phase

Data collection through document review, conduct survey and interviews with SPOR EA key informants

Data Analysis and Report Generation Phase

Generate results, impact stories, and recommendations



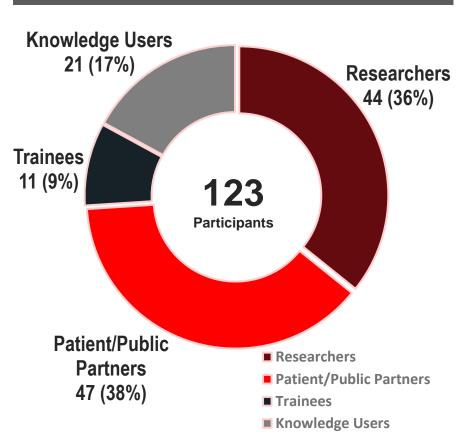




SPOR Evidence Alliance Evaluation – Status Update

Breakdown of survey respondents





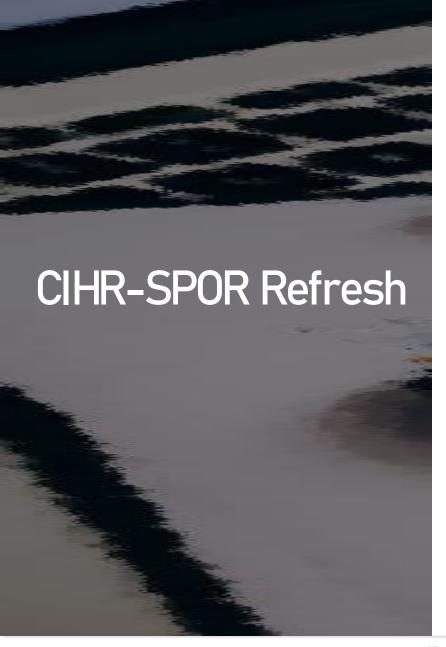
1:1 consults completed

5 Focus group consults with 37 participants have been completed









- The Strategy for Patient-Oriented Research (SPOR) was launched in 2011 to embed people with lived and living experience into all stages of the research process
- SPOR completed and shared the results of their second evaluation, covering the period of 2016-17 to 2020-21.
- Given the evolving landscape, SPOR is undergoing a Refresh process to define a renewed approach that builds on successes to date while reflecting evolving patient, community, partner, and health systems priorities.







Seven Key Themes for the SPOR Refresh

The Refresh will focus on the following themes:

- 1. Strengths and challenges for the SPOR program overall
- 2. Important trends and emerging needs of the future
- Delivering on Truth and Reconciliation Commission (TRC) Calls to Action and accelerating First Nations, Inuit, and Métis (Indigenous) self-determination in health research through SPOR
- 4. Strengthening equity, diversity, and inclusion, anti-racism, and accessibility (EDIA) in patient engagement and patient-oriented research
- 5. Building capacity and partnering for excellence in patient-oriented research
- Strengthening collaboration with policy and health system decision-makers to increase research impact
- 7. Strengthening SPOR's Governance

We will be reaching out to our members in early 2024 for your input to inform the SPOR Refresh.









Upcoming Events and Engagements

- SPOR Refresh engagement in the first quarter of 2024
- Patient Appreciation Policy update in the first quarter on 2024
- Seed Grant in the summer of 2024
- Community Engagement course in the fall of 2024
- SPOR Evidence Alliance evaluation at the end of 2024
- Sustainability workshop in early 2025







Closing Ceremony



Elder Kahontakwas Diane Longboat





Special Thanks



Wasifa Zarin



Sharmila Sreetharan



Safa Al-Khateeb



Angelika Aziz



Kahontakwas Diane Longboat



Carolyn Shimmin



Angela Mashford-Pringle



Deepa Singal



Shamara Baidoobonso



Mahadeo Sukhai

Closing Remarks

- We would like to thank you all for your ongoing collaboration and support of the SPOR Evidence Alliance.
- The many successes realized since our inception could not have been possible without all of your hard work and dedication.
- As we look to the future of the SPOR Evidence Alliance, we look forward to our continued collaboration and hitting all our future milestones.
- We will be circulating a survey. Please fill it out and let us know how we did.







Funding Acknowledgement

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SPOREA@smh.ca

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