Putting the Patient First in Patient and Community Engagement: The SPOR Evidence Alliance Initiative

Presenter: Dr. Andrea Tricco

Date: Thursday, April 25, 2024

SPOR Evidence Alliance

Alliance pour des données probantes de la SRAP

Strategy for Patient-Oriented Research

SPOR

Putting Patients First

ST. MICHAEL'S

UNITY HEALTH TORONTO

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.

Objectives

1. Describe the SPOR Evidence Alliance main activities.
2. Identify ways that patient partners can engage in research initiatives.
3. Explain ways that patient partners can collaborate with decision-makers on research projects coming from the community.

About the SPOR Evidence Alliance's Main Activities

About the SPOR Evidence Alliance

Funded by CIHR in 2017, the Strategy for Patient-Oriented Research (SPOR) Evidence Alliance is a pan-Canadian partnership between researchers, patients and the community, healthcare providers, and health system decision-makers to promote a learning health system in Canada.

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

Research Query Services

Demand-driven & context sensitive research

Training & Capacity-Building

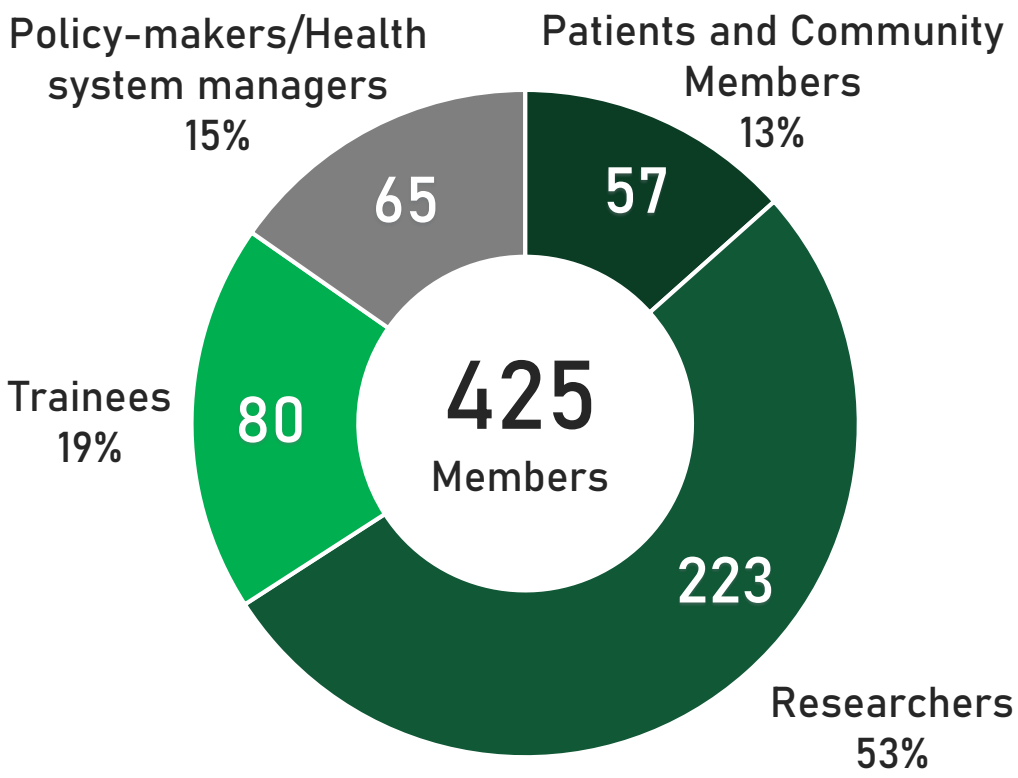
A culture of learning and innovation

Advancing Science

Increasing visibility and reach of Canadian health research

Membership

A diverse membership from across Canada and beyond contributing to a wealth of knowledge, expertise and experience to our initiative, with 36 specialized research teams and 400+ members across Canada and beyond.



Geographic Distribution

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

How the SPOR Evidence Alliance uses Co-Creation to Engage with Patient Partners and Other Partners from the Community

What is Co-Creation and its Relation to Knowledge Translation (KT)?

- *"The collaborative generation of knowledge by academics working alongside stakeholders from other sectors."*
- Spirit of co-creation is to invite multidisciplinary and diverse knowledge users as equal members of the research team to produce research alongside researchers and create a sense of ownership by everyone on the team.
- Two types of KT (or mobilization):
  1. End-of-grant KT– engage with your audience after the research is completed.
  2. Integrated KT– engage with your audience throughout the research process.
- Community-based participatory research related to integrated KT with the common aim to co-create knowledge that is the result of the researcher and knowledge user expertise.

Jull *et al. Implementation Science* (2017) 12:150
DOI 10.1186/s13012-017-0696-3

Implementation Science

DEBATE — Open Access

Community-based participatory research and integrated knowledge translation: advancing the co-creation of knowledge

Janet Jull[1*], Audrey Giles[2] and Ian D. Graham[1]

Abstract

Background: Better use of research evidence (one form of "knowledge") in health systems requires partnerships between researchers and those who contend with the real-world needs and constraints of health systems. Community-based participatory research (CBPR) and integrated knowledge translation (IKT) are research approaches that emphasize the importance of creating partnerships between researchers and the people for whom the research is ultimately meant to be of use ("knowledge users"). There exist poor understandings of the ways in which these approaches converge and diverge. Better understanding of the similarities and differences between CBPR and IKT will enable researchers to use these approaches appropriately and to leverage best practices and knowledge from each. The co-creation of knowledge conveys promise of significant social impacts, and further understandings of how to engage and involve knowledge users in research are needed.

Main text: We examine the histories and traditions of CBPR and IKT, as well as their points of convergence and divergence. We critically evaluate the ways in which both have the potential to contribute to the development and integration of knowledge in health systems. As distinct research traditions, the underlying drivers and rationale for CBPR and IKT have similarities and differences across the areas of motivation, social location, and ethics; nevertheless, the practices of CBPR and IKT converge upon a common aim: the co-creation of knowledge that is the result of knowledge user and researcher expertise. We argue that while CBPR and IKT both have the potential to contribute evidence to implementation science and practices for collaborative research, clarity for the purpose of the research—social change or application—is a critical feature in the selection of an appropriate collaborative approach to build knowledge.

Conclusion: CBPR and IKT bring distinct strengths to a common aim: to foster democratic processes in the co-creation of knowledge. As research approaches, they create opportunities to challenge assumptions about for whom, how, and what is defined as knowledge, and to develop and integrate research findings into health systems. When used appropriately, CBPR and IKT both have the potential to contribute to and advance implementation science about the conduct of collaborative health systems research.

Keywords: Community-based participatory research, Integrated knowledge translation, Engagement, Collaboration, Health systems, Co-creation, Knowledge, Implementation

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Greenhalgh T, Jackson C, Shaw S, Janamian T. Milbank Q 2016; Jull J, Giles A, Graham ID. Implement Sci. 2017; Grindell BMC Health Services Research, 2022.

Who can Researchers Co-Create with?

- End-users of the research
- Typically 3 categories: patient and community members, healthcare providers, policy-makers
- Goal is to engage all three categories in each research study!
- *Everyone receives co-authorship – researchers + patients and community members + policy-makers + healthcare providers*
- "Knowledge user" is more inclusive and culturally safe term than "stakeholder"
  - *"A knowledge user is defined as an individual who is likely to be able to use research results to make informed decisions about health policies, programs and/or practices"*

Healthcare provider

Policy-maker

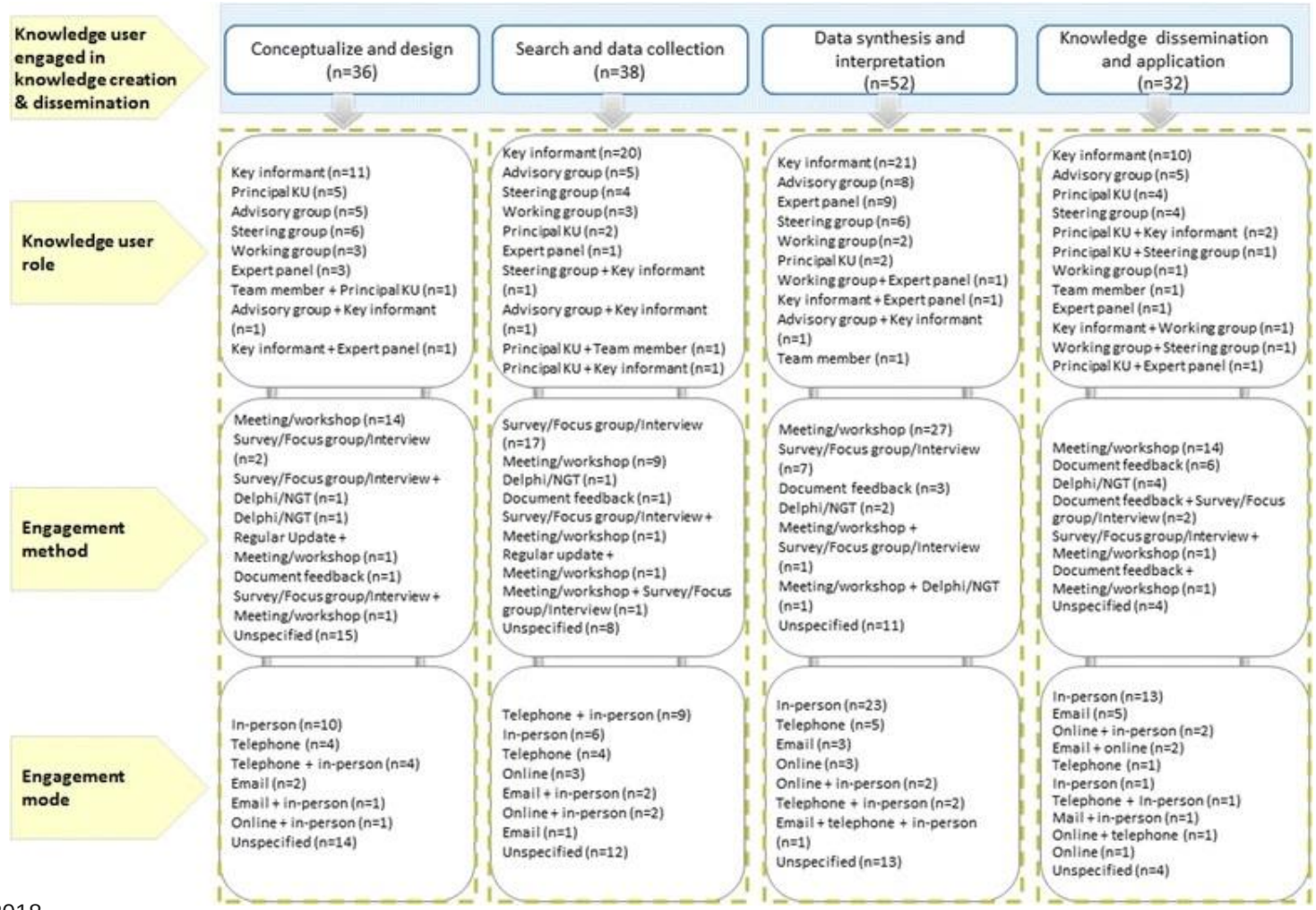
Pregnant Person

Educator

Consumer (e.g., patient partner)

Sharfstein JM, Milbank Quarterly. 2016.
Knowledge User Engagement: CIHR. Parry, D., Salsberg, J., Macaulay, A.C, (2019)

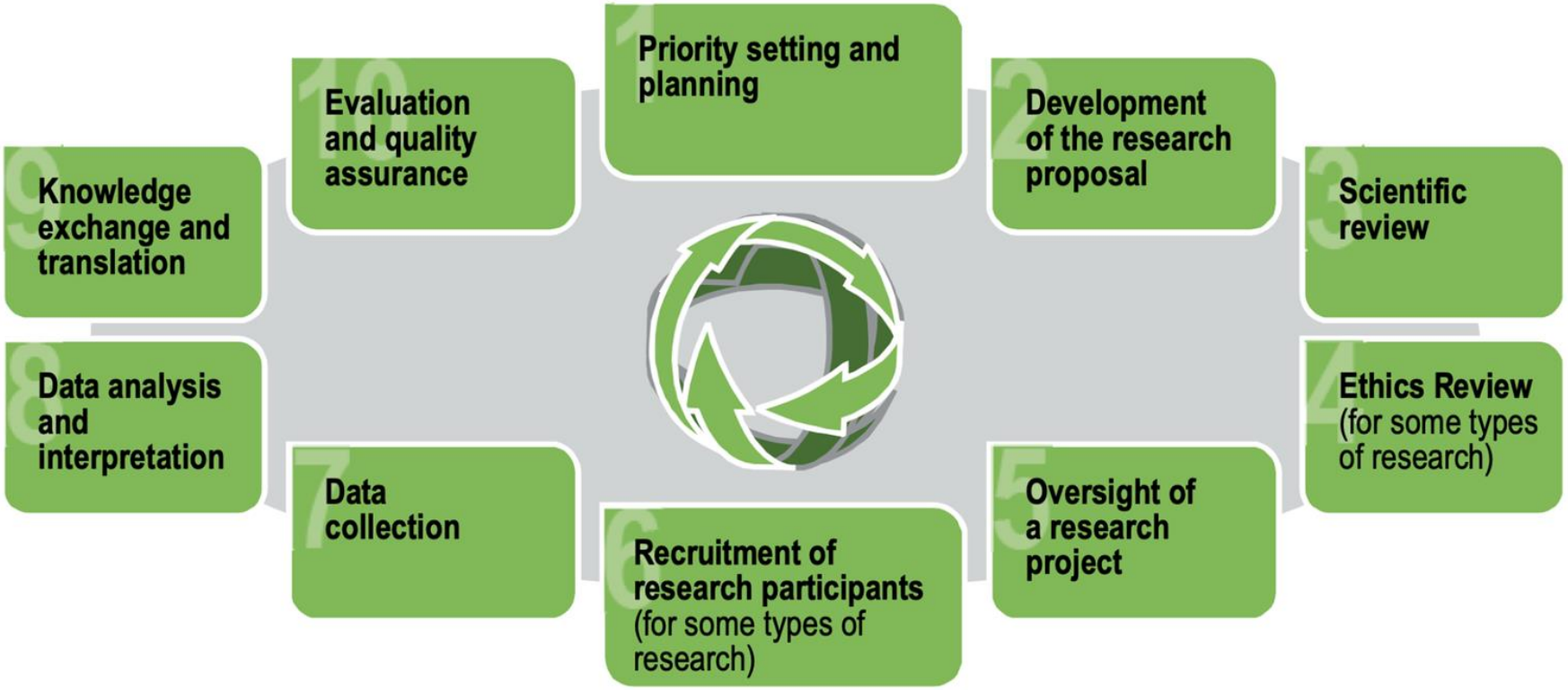
What are Ways to Engage Knowledge Users?



Tricco, Imp Sci, 2018

How Can we Co-Create Research?

Figure 3. Key stages in the research lifecycle



https://cihr-irsc.gc.ca/e/documents/ethics_guidance_partnerships-en.pdf

What are the Top 5 Barriers and Facilitators to Co-Creation in Knowledge Synthesis?

Tricco et al. Implementation Science (2018) 13:31
DOI 10.1186/s13012-018-0717-x

Implementation Science

RESEARCH Open Access

Engaging policy-makers, health system managers, and policy analysts in the knowledge synthesis process: a scoping review

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Abstract

Background: It is unclear how to engage a wide range of knowledge users in research. We aimed to map the evidence on engaging knowledge users with an emphasis on policy-makers, health system managers, and policy analysts in the knowledge synthesis process through a scoping review.

Methods: We used the Joanna Briggs Institute guidance for scoping reviews. Nine electronic databases (e.g., MEDLINE), two grey literature sources (e.g., OpenSIGLE), and reference lists of relevant systematic reviews were searched from 1996 to August 2016. We included any type of study describing strategies, barriers and facilitators, or assessing the impact of engaging policy-makers, health system managers, and policy analysts in the knowledge synthesis process. Screening and data abstraction were conducted by two reviewers independently with a third reviewer resolving discrepancies. Frequency and thematic analyses were conducted.

Results: After screening 8395 titles and abstracts followed by 394 full-texts, 84 unique documents and 7 companion reports fulfilled our eligibility criteria. All 84 documents were published in the last 10 years, and half were prepared in North America. The most common type of knowledge synthesis with knowledge user engagement was a systematic review (36%). The knowledge synthesis most commonly addressed an issue at the level of national healthcare system (48%) and focused on health services delivery (17%) in high-income countries (86%).
Policy-makers were the most common (64%) knowledge users, followed by healthcare professionals (49%) and government agencies as well as patients and caregivers (34%). Knowledge users were engaged in conceptualization and design (49%), literature search and data collection (52%), data synthesis and interpretation (71%), and knowledge dissemination and application (44%). Knowledge users were most commonly engaged as key informants through meetings and workshops as well as surveys, focus groups, and interviews either in-person or by telephone and emails. Knowledge user content expertise/awareness was a common facilitator (18%), while lack of time or opportunity to participate was a common barrier (12%).

Conclusions: Knowledge users were most commonly engaged during the data synthesis and interpretation phases of the knowledge synthesis conduct. Researchers should document and evaluate knowledge user engagement in knowledge synthesis.

(Continued on next page)

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Tricco A, Zarin W, Rios P, Imp Sci 2018

Factor reported (N=31 studies)	Seen as a Facilitator	Seen as a Barrier
Knowledge user expertise	16.7%	6.0%
Time	3.6%	10.7%
Early relationship-building	8.3%	0
Forums for interaction	7.1%	1.2%
Ongoing collaboration	4.8%	0

Based on experience, the biggest facilitator/barrier is communication!

Tips on Engaging with Knowledge Users

METHODOLOGY

Moving from consultation to co-creation with knowledge users in scoping reviews: guidance from the JBI Scoping Review Methodology Group

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ABSTRACT

Knowledge user consultation is often limited or omitted in the conduct of scoping reviews. Not including knowledge users within the conduct and reporting of scoping reviews could be due to a lack of guidance or understanding about what consultation requires and the subsequent benefits. Knowledge user engagement in evidence synthesis, including consultation approaches, has many associated benefits, including improved relevance of the research and better dissemination and implementation of research findings. Scoping reviews, however, have not been specifically focused on in terms of research into knowledge user consultation and evidence syntheses. In this paper, we will present JBI's guidance for knowledge user engagement in scoping reviews based on the expert opinion of the JBI Scoping Review Methodology Group. We offer specific guidance on how this can occur and provide information regarding how to report and evaluate knowledge user engagement within scoping reviews. We believe that scoping review authors should embed knowledge user engagement into all scoping reviews and strive towards a co-creation model.

Keywords: engagement; evidence synthesis; knowledge user; methodology; scoping reviews

JBI Evid Synth 2022; 20(4):969–979.

Introduction

Scoping reviews are a popular form of evidence synthesis.[1] They seek to map evidence in diverse fields, identify the types of evidence available, decipher potential knowledge gaps, and clarify key concepts or definitions within the literature.[2]

Scoping reviews allow for broad, hypothesis-generating research questions, highlighting where there is a need for future research or methodological improvement, or acting to underpin future systematic reviews.[1,2] Therefore, scoping reviews play an important role in reducing research waste, and the findings of scoping reviews can have implications for policy, practice and other decision-making processes.

There is an imperative for evidence syntheses to include knowledge users in health-related issues. Knowledge users are those invested in the production of research, and who may benefit or be impacted

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ACT, ZM, MDJP, CMG, HK, LA, PM, DP developed and reported the current, updated JBI guidance for scoping reviews.

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- Develop plan for engagement
- Ensure appropriate resources
- Provide capacity-building
- Develop recruitment strategy
- Consider barriers
- Create positive environment
- Show appropriate appreciation
- Report engagement transparently
- Evaluate engagement

Pollock D, Alexander L, Munn Z, JBI Evidence Synthesis 2022

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Why is Patient-Oriented Research Important?

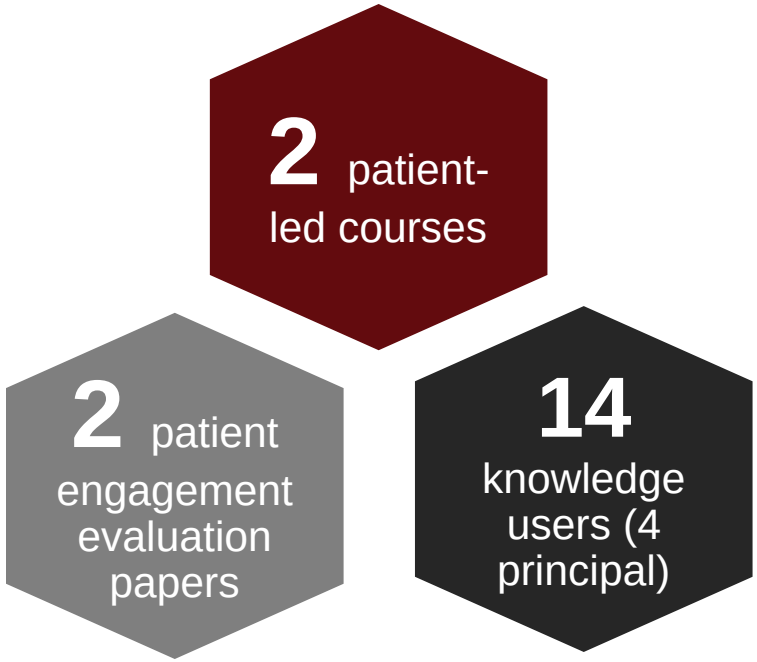
- Patient-oriented research: "*continuum of research that engages patients as partners, focusses on patient-centric priorities and improves patient outcomes individually and in communities such as vulnerable populations. …conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices*."
- 50% of patients do not get treatments of proven effectiveness.
- Up to 25% get care that is not needed or potentially harmful; this care is expensive.
  - In 2022, Canada spent approximately $331 billion on health care, or $8563 per person.
- Patients and clinicians have a right to expect that important health decisions are made on the basis of solid evidence.
- CIHR introduced SPOR in 2011 to improve health systems and practices and to ensure the right patient receives the right clinical intervention at the right time.

Why Should we Engage Patients and Community Members as Knowledge Users?

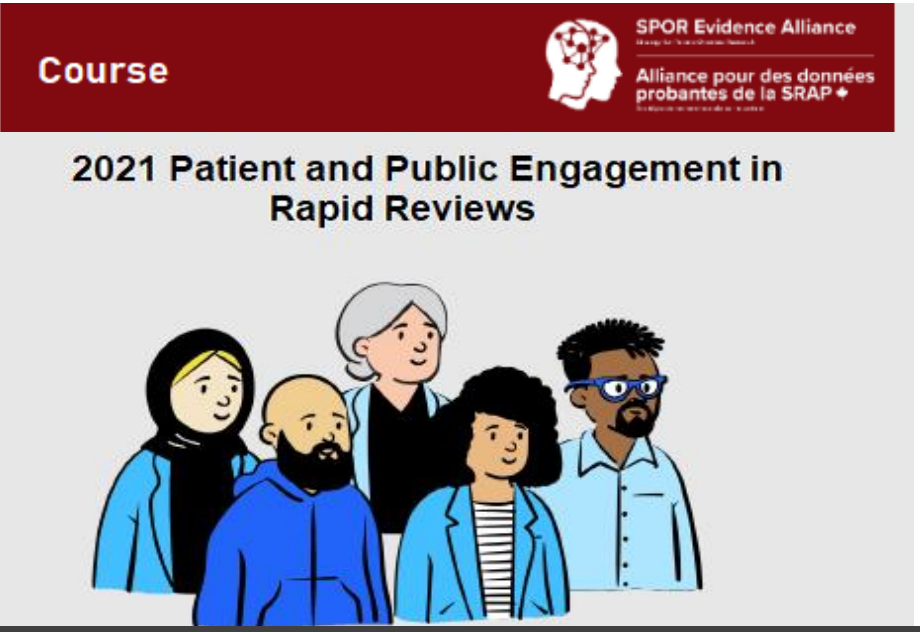
- Patient and community engagement in research involves inviting patients and members of the community as equal partners throughout the research process – including co-authorship!
- *"Nothing about us, without us."*
- Patients and community members:
  - are decision-makers,
  - have lived experiences that are unique, and
  - bring a different perspective to the priorities, goals/objectives, and research findings.
- Provides opportunities to engage patients' larger communities with the research.
- May lead to new research partnerships.
- Opportunities for trainees to learn.

How the SPOR Evidence Alliance Engages Patient Partners and Members of the Community

Patient and community partnership is integrated in research, leadership and governance



98	Patient and community members submitted health research topics, 23 fully funded co-led projects.
13	Patient and community committee members in the governance structure with 4 serving as co-chairs
24	Patient and community peer reviewers for annual seed grants and research priority-setting panel
338	Patient and community engagements across 100 research projects
700+	Patient and community learners



Co-building Patient and Community Capacity in Research

- Background:
  - Identified a need to include the perspectives of patients and community members in the research process, and that training would be necessary for meaningful engagement.
  - In collaboration with two experienced patient partners, SPOR Evidence Alliance co-developed and co-delivered two three-week courses over a span of 2 years.
- Goal:
  - Provide patient and community members with pragmatic tips and strategies to participate meaningfully in different knowledge synthesis projects.
- Course Feedback:
  - Overall, over 90% of the participants in both courses felt that the courses helped them achieve their learning goals and that their learning experience was valuable.

SPOR Evidence Alliance Resources

- Not only do we need to provide capacity-building to patients and community members, but also to the researchers.
- To ensure consistent product delivery, we have developed a series of templates and guidance documents for research teams:
  - https://sporevidencealliance.ca/resources-for-research-teams/
- To support meaningful patient and community co-leadership, we have compiled resources for patient-driven research teams:
  - https://sporevidencealliance.ca/patient-driven-research-resources/

Series of Papers on the SPOR Evidence Alliance

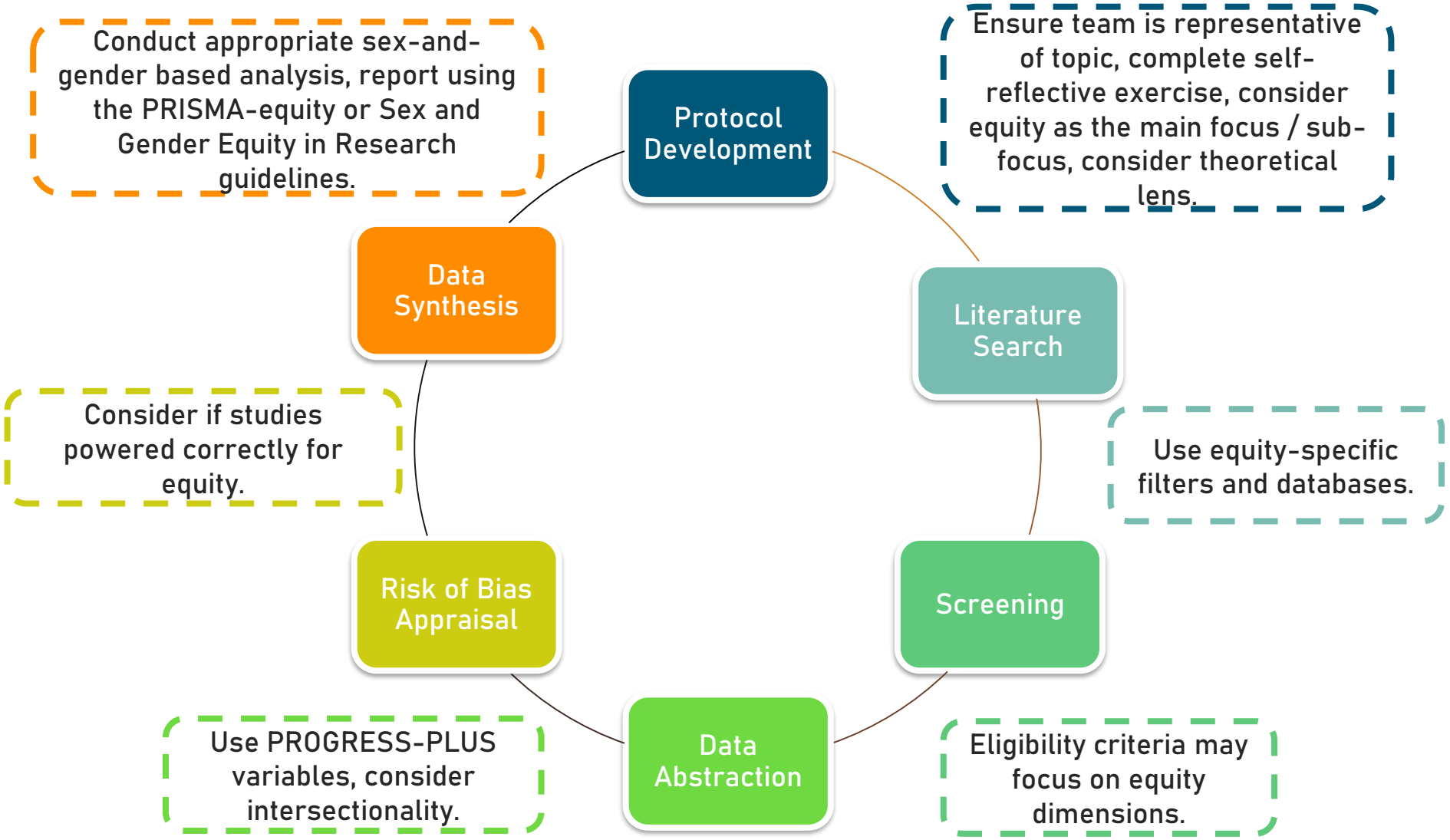
Why do we need to consider equity, diversity, and inclusion (EDI) in ALL our research projects?

- We are doing team-based science and including people with many diverse lived experiences.
- We are including researchers, research staff, trainees, patient partners, community members, healthcare providers, and policy-makers on each project.
- We need to create a safe (brave) space for people to contribute.
- We are here to improve patient outcomes.
- Our health system is plagued with health inequities.

Everything we do must be rooted in an EDI lens in research.

Williams, DR, Annu Rev Public Health, 2019

How can we Embed EDI in Knowledge Synthesis?

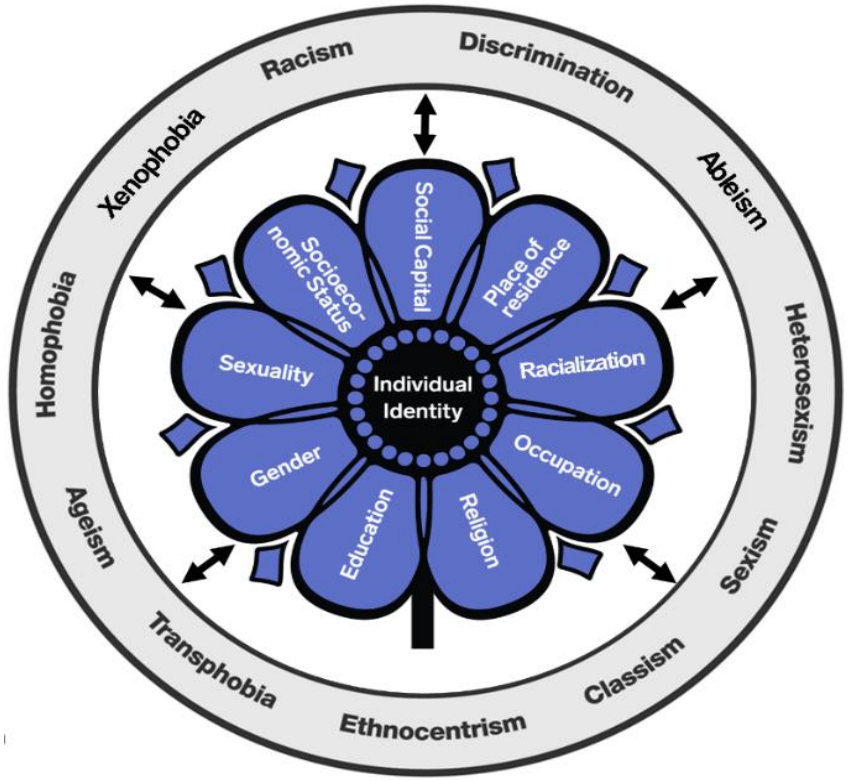


How can we root our research in (EDI) principles?

- Co-create EDI values/guiding principles with the team.
- Co-create terms of reference for the team.
- Co-create policies with the team (e.g., patient partner appreciation, COIs).

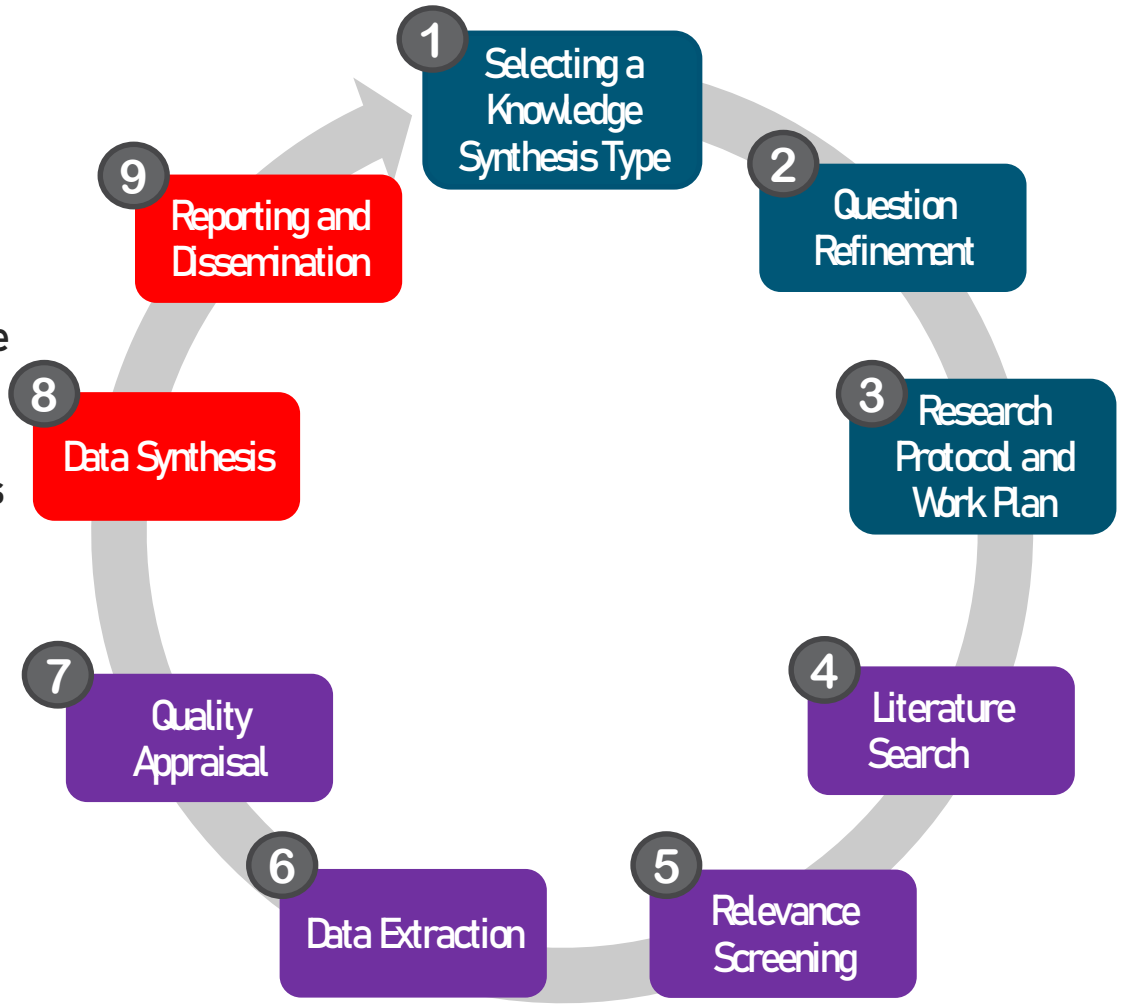
Complete a self-reflective exercise (not to be shared) to think about your:

- own lived experience,
- advantage or disadvantage, and
- position on the team.



https://sporevidencealliance.ca/about/governance-structure/
https://sporevidencealliance.ca/about/policies-procedures/
https://sporevidencealliance.ca/wp-content/uploads/2021/08/4.-SPOREA_Reflective-EDI-Exercise-UPDATED.pdf

Stages of a Knowledge Synthesis Patient and Community Members are Engaged



Idea Stage

1. Identify research gaps.
2. Prioritize health issues.
3. Identify important outcomes.
4. Co-develop or provide feedback on the protocol and work plan.

Research Conduct

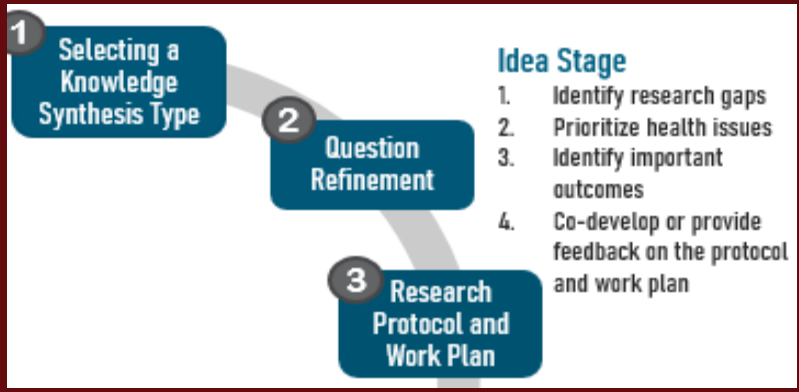
1. Recommend key papers.
2. Provide feedback on the study selection process.
3. Provide feedback on important outcomes to extract

Interpretation and Dissemination

1. Help contextualize and interpret findings.
2. Co-author reports and manuscripts.
3. Co-produce plain language summaries and infographics.

Engagement in Idea Stage

- Help develop or refine the research question for knowledge synthesis.
  - Participate in a priority-setting exercise to narrow down and identify important research gaps.
- Help define or refine the outcomes that the research should explore.
  - Suggest additional outcomes that would be of interest to patients, or selecting outcomes of greatest importance to patients.
- Provide input on how data is collected and synthesized.
  - Provide feedback on whether it is appropriate to group particular symptoms, treatments or health conditions together in the synthesis.

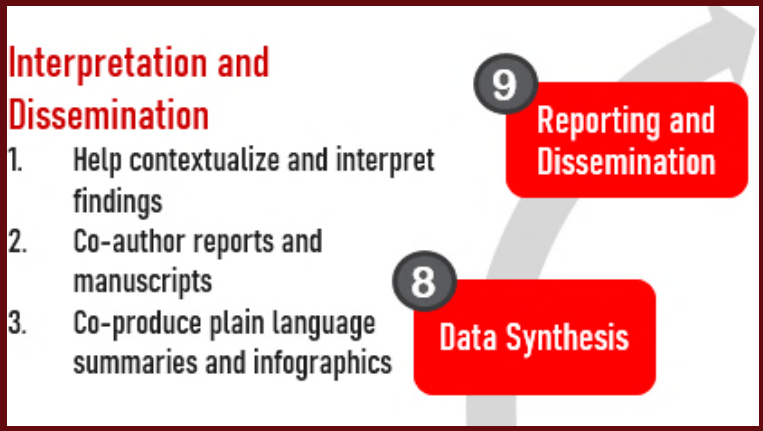


Engagement during Research Conduct

- Become a core member of the project team and support all steps of the research conduct.
- Provide feedback on key search terms and outcomes data to be collected.
- Provide input on screening questionnaire or eligibility criteria.
- Provide input on data abstraction form.
- Provide tools to use or interpreting risk of bias.
- If interested, supporting with screening and data extraction.

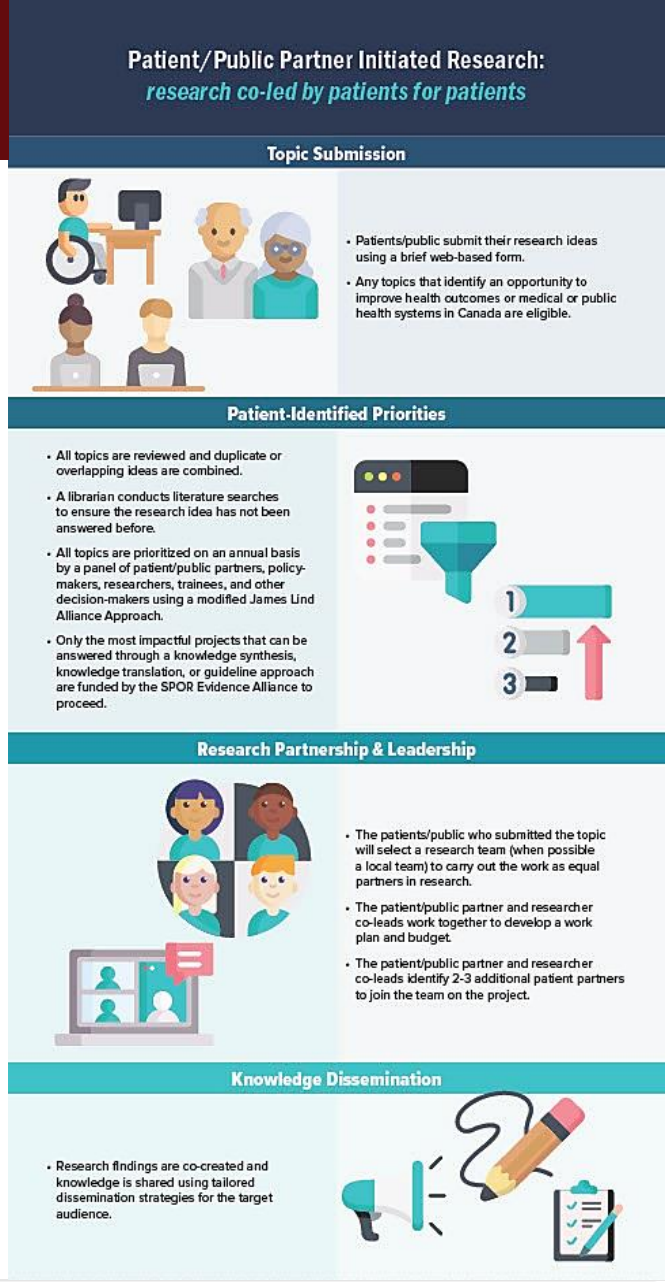
Engagement during Interpretation and Dissemination

- Provide feedback on a draft of the review results.
  - Provide specific feedback about whether you agree with how the results have been interpreted, or asked to give suggestions for what the key messages should be.
- Help develop the plain language summary of the research findings.
- Comment on the plans for sharing (disseminating) the research findings.
  - Make suggestions to help reach the general public, or particular population groups.
- Co-author the report or manuscript.
  - Co-authorship offered as per the recommendations of the International Committee of Medical Journal Editors.

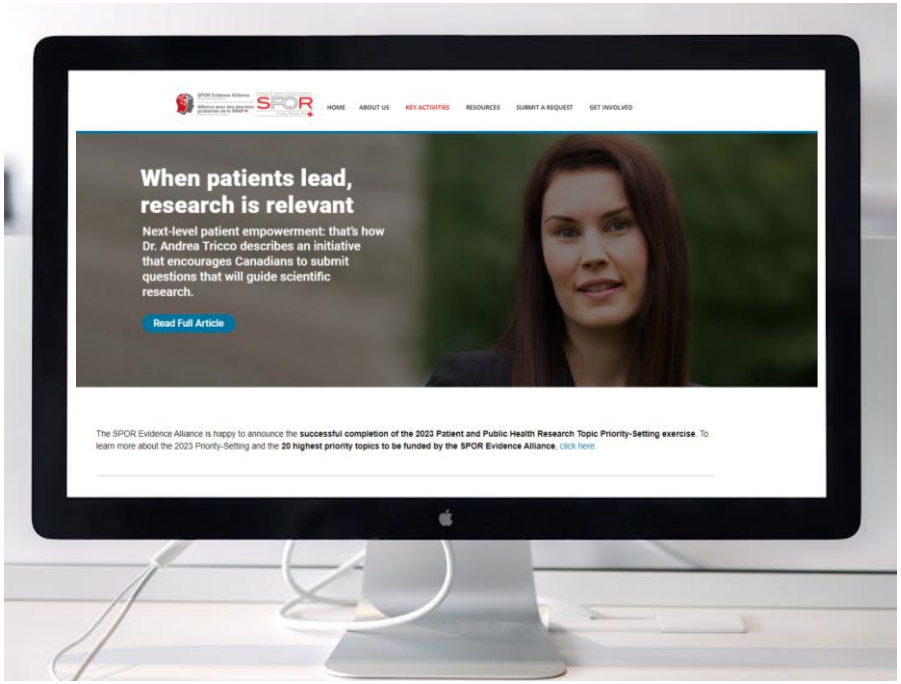


Patient-Driven Research Projects

- We invite health research topics from patients and community members that identify an opportunity to improve health outcomes or medical or public health systems.
- Our model has enabled a space for research curated for patients and community members by patients and community members.
- Enabled an environment for collaborative learning and mutual respect between researchers, policy-makers, health system decision-makers, and patients and community members in doing research.
- Highest-priority topics are identified through a ranking exercise and deliberative dialogue by a steering panel (patient partners, community members, and researchers/health system decision-makers) and developed into research projects.



Patient-Driven Research Projects



Details about the 23 patient-driven research projects are available on our website: https://sporevidencealliance.ca/patient-driven-research/

Testimonials

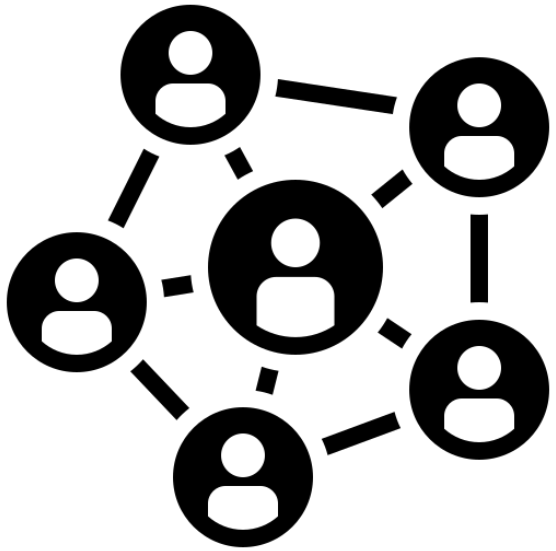
"[Patient partners] add heart and soul to the project"

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

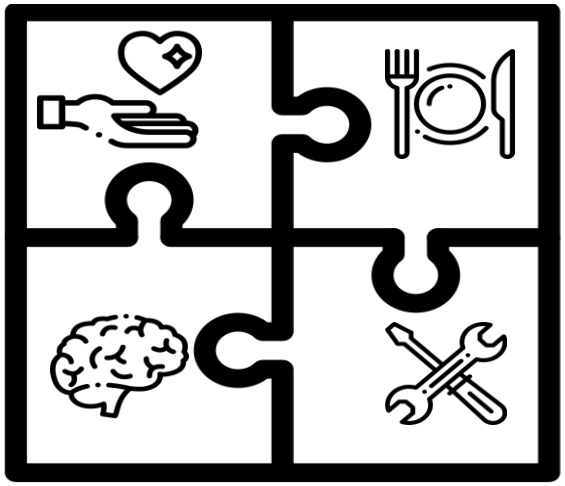
"It personalizes and humanizes the [research] process"

Communities of Practice (COPs) on Research Co-Leadership

- Formation of 5-6 COPs to support patient-driven research teams in research co-leadership.
  - Each COP will be led by expert members of the SPOR Evidence Alliance in patient-driven research.
- Objectives:
  1. Knowledge Sharing: Facilitate learning among members about patient-led research methodologies, ethics, and outcomes.
  2. Networking and Collaboration: Provide a platform for interaction among researchers, patients, and community knowledge users.
  3. Capacity and Skills Development: Enhance abilities in patient-driven research through structured support and shared resources.
  4. Advocacy: Promote the inclusion of patient-oriented principles in research funding and policy frameworks.

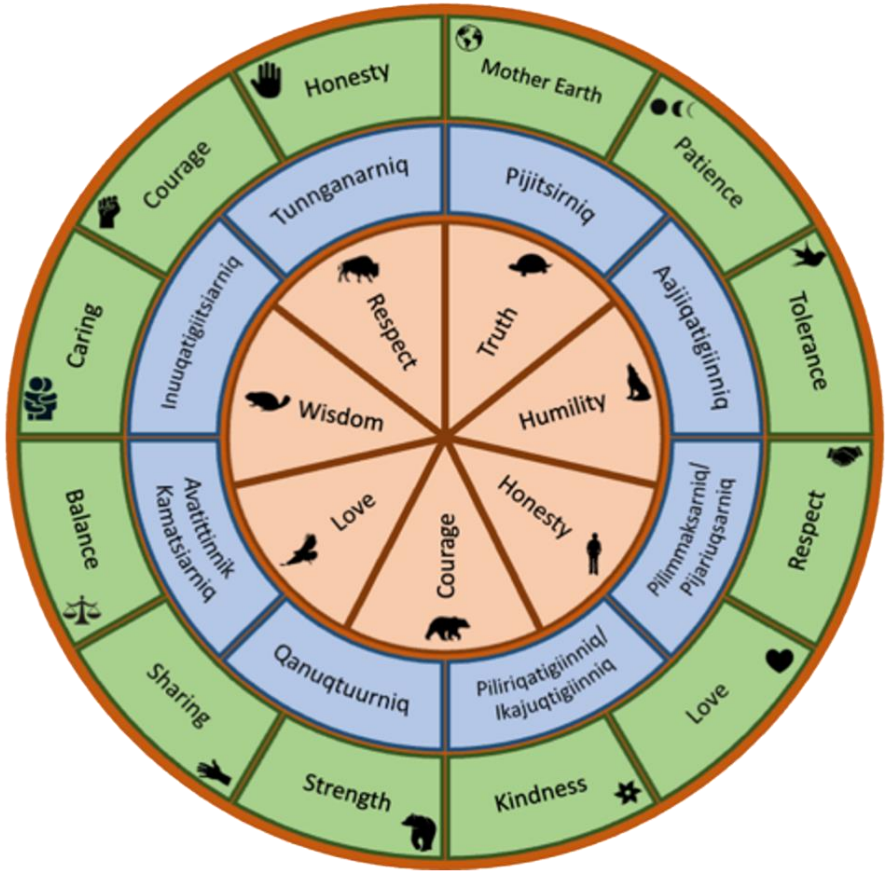


Indigenous Peoples Engagement



- Eight Indigenous community-driven projects supported ranging from roles of traditional healers in dementia care, colorectal cancer screening tools for Indigenous populations, and food and nutrition to promote brain health for Indigenous people across Canada, with a focus on food sovereignty and traditional foods across various regions.
- Dr. Angela Mashford-Pringle (co-PI) led a national dialogue on Indigenous data management plan attended by more than 250 learners.
- Dr. Jennifer Walker (co-I) and Dr. Janet Jull (co-I) have led several training and capacity development workshops and podcasts bringing together Indigenous knowledge holders to discuss Indigenous ways of gathering and synthesizing knowledge.

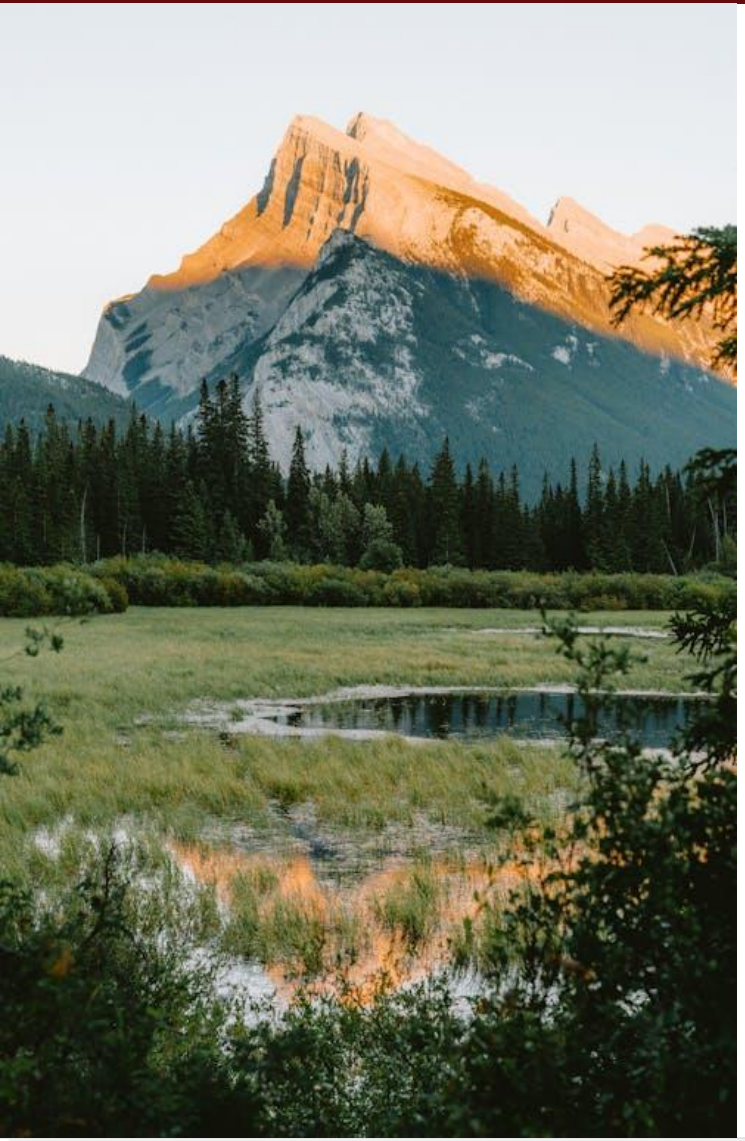
New Respect Online Cultural Safety Training



- A new training program offered to all SPOR Evidence Alliance members on New Respect Indigenous Cultural Safety by Angela Mashford-Pringle (co-PI).
- Course Objectives: Address systemic anti-Indigenous racism by providing content that both embeds Power, Privilege and Positionality (the 3 Ps) and prompts critical self-reflection throughout.
- More information on the training program available here: https://www.phesc.ca/indigenous

https://pubmed.ncbi.nlm.nih.gov/37217105/

Indigenous Land-Based Learning Program

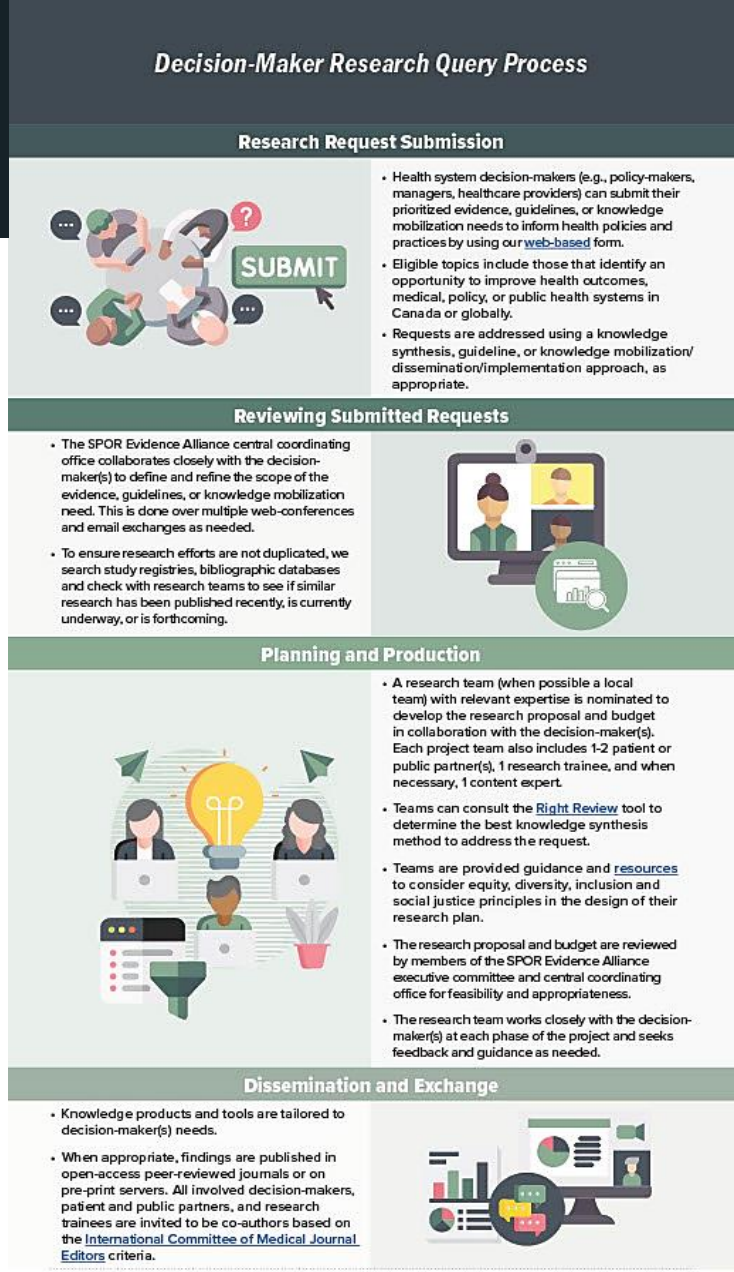


- Upcoming opportunity for SPOR Evidence Alliance members to participate in a 3-day land-based learning program.
- Emphasizes Indigenous ways of knowing, rooted in a profound connection to the Land and guided by the principle of reciprocity.
- Conversations will utilize the Land as a teacher, covering topics such as Indigenous research methods, colonization's impact, socio-political history, terminology, and power dynamics.
- Cultural safety and a strengths-based approach will be central, with participants encouraged to reflect on their learning journey.

How the SPOR Evidence Alliance Collaborates with Policy Decision-Makers on Research Projects Through the Research Query Services

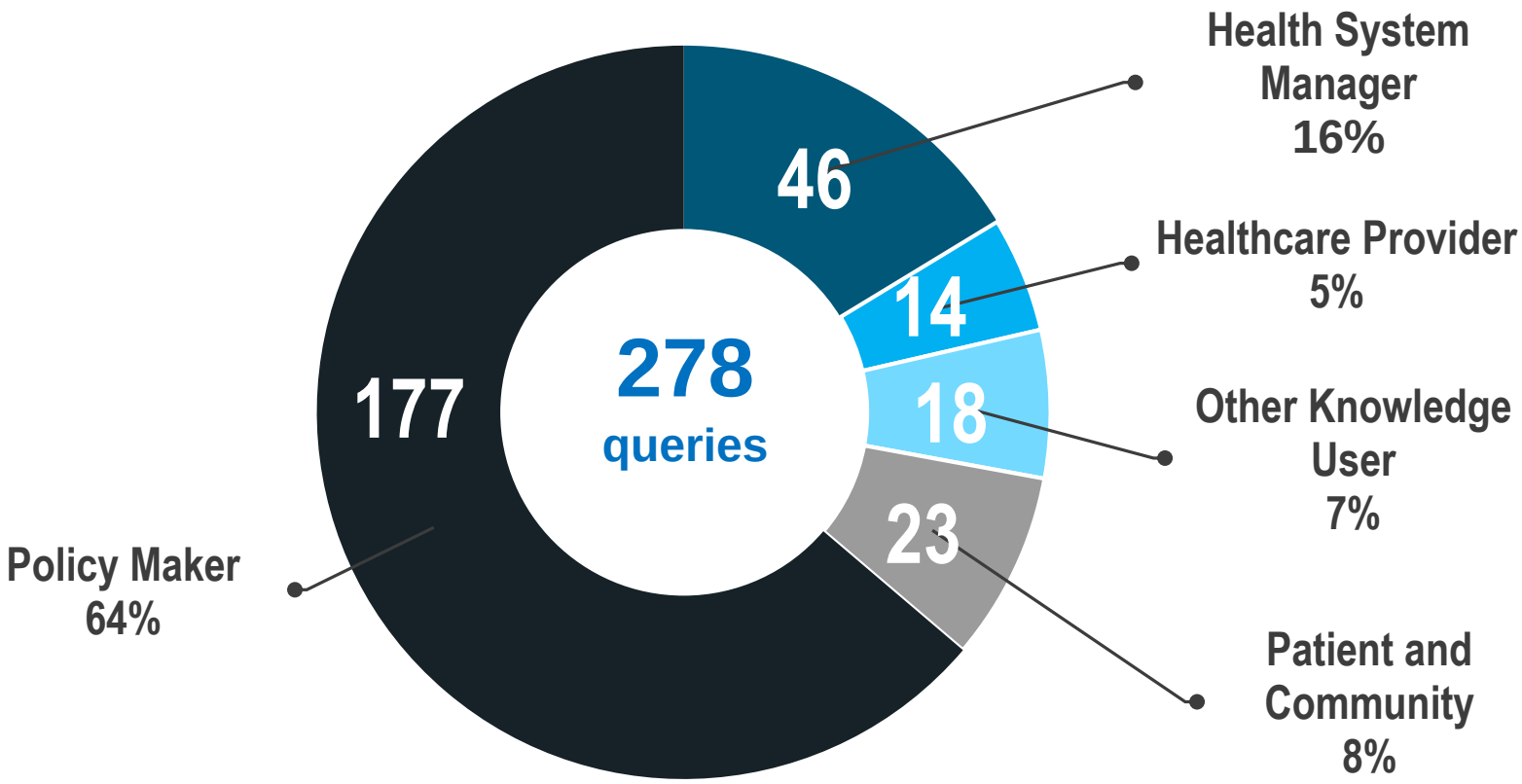
Health System Decision-Maker Query Process

- Research requests submitted by health system decision-maker(s).
- Research proposal developed by the research team and decision-maker(s).
- Teams are provided with capacity-building (e.g., patient engagement webinars), coaching, and resources (e.g., Right Review tool, AI enhanced tool for screening in reviews).
- Knowledge products and tools are tailored to the decision-maker(s) needs.
- Aim is to bring the patient/community voice closer to policy decision-making by including 1-2 patient/community members on each project as equal members.



Supporting Health System Decisions

Since 2018, we responded to 278 requests from 53 different organizations nationally and internationally.

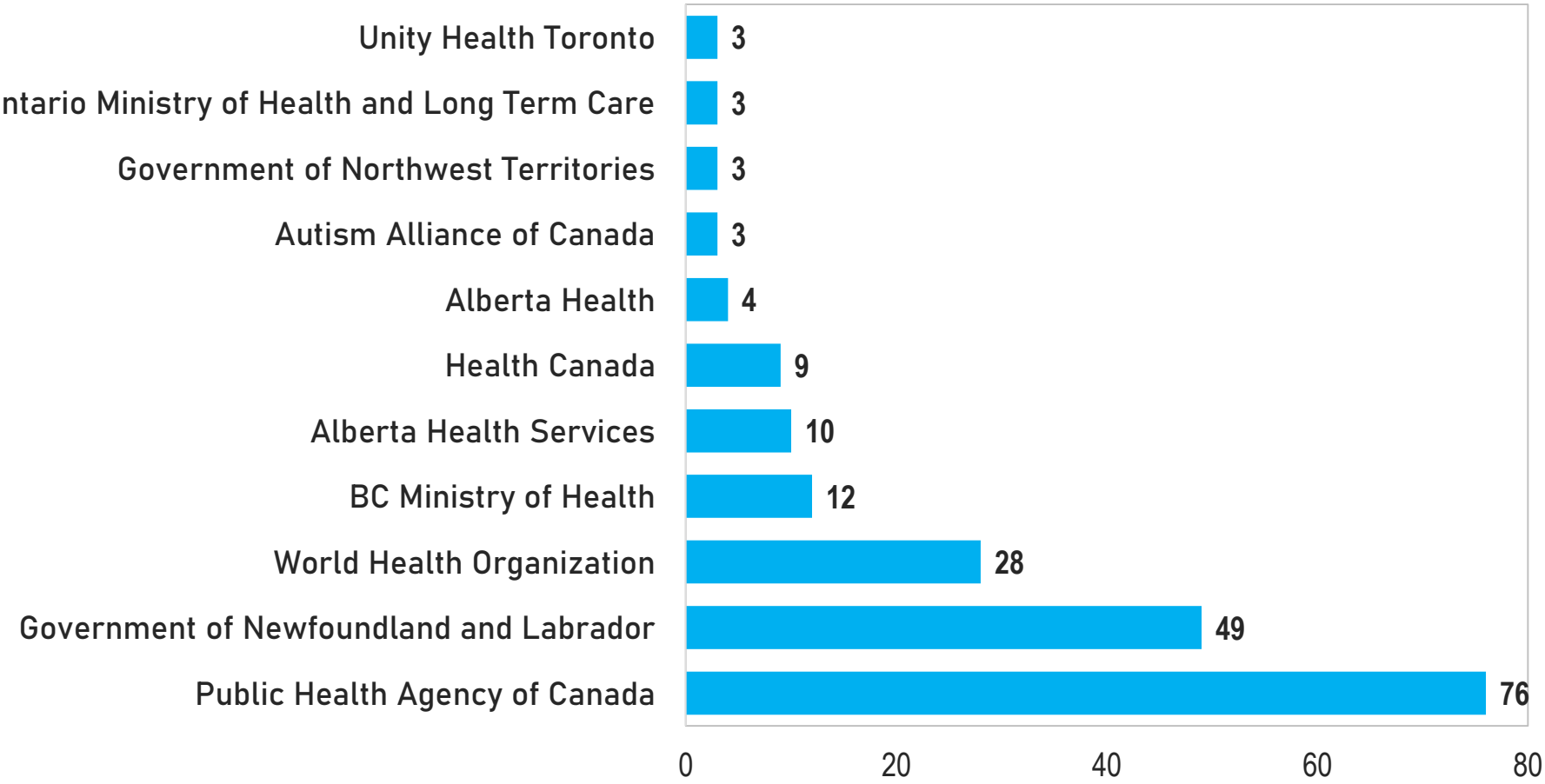


Range of decisions covered across 278 queries:

Products Disseminated

115	public health measures (e.g., infection prevention and control, surveillance, health promotion)
55	healthcare system arrangements (e.g., governance, delivery, financial)
48	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
16	economic and social responses (e.g., social gathering, economic impact)
4	health, public and/or organizational policies (e.g., legal, administrative)

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



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

Guideline 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 patients and community members, 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.

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 Bonet[4] · Etienne V. Langlois[5] · Robin Parker[6] · Heather Scott[7] · Janet Curran[2,3]

Guideline Impact Stories

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 Darvesh[1], Amruta Radhakrishnan[1], Chantelle C. Lachance[1], Vera Nincic[1], Jane P. Sharpe[1], Marco Ghassemi[1], Sharon E. Straus[1,2] and Andrea C. Tricco[1,3*]

World Health Organization

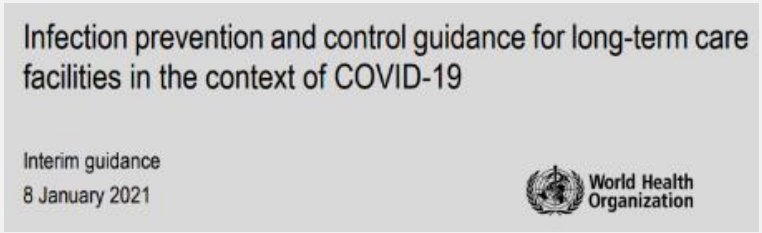
Home / Classifications / Frequently asked questions / Gaming disorder

Frequently Asked Questions

How is gaming disorder identified?

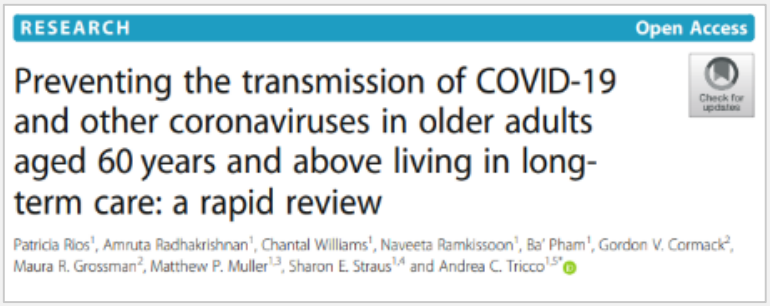
For gaming disorder to be diagnosed, the behaviour pattern must be severe enough that it results in significant impairment to a person's functioning in personal, family, social, educational, occupational or other important areas, and would normally have been evident for at least 12 months.

Guideline Impact Stories


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

Interim guidance
8 January 2021

World Health Organization


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 Rios[1], Amruta Radhakrishnan[1], Chantal Williams[1], Naveeta Ramkissoon[1], Ba' Pham[1], Gordon V. Cormack[2], Maura R. Grossman[2], Matthew P. Muller[1,3], Sharon E. Straus[1,4] and Andrea C. Tricco[1,5*]

Canadian Frailty Network

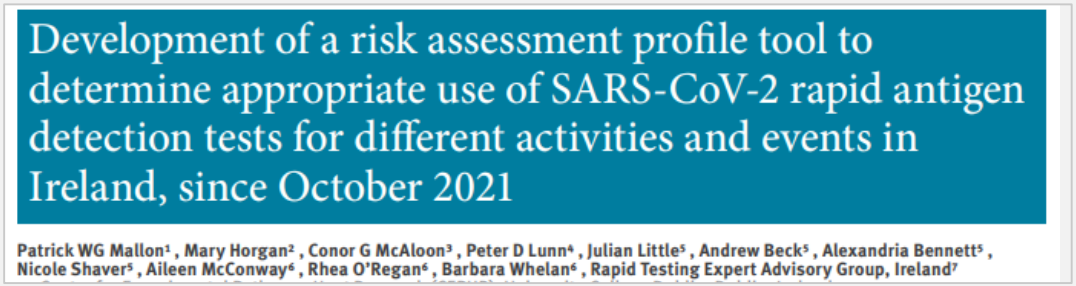
3. Infection prevention and control in long-term care homes (led by NPI Tricco): commissioned by the World Health Organization as the foundation for their first guideline at the onset of the pandemic, impacting approximately 5.9 million people residing in long-term care homes.

An update was commissioned by the Canadian Frailty Network and cited by the Organisation for Economic Co-operation and Development (OECD), Irish Department of Health, and Australian Department of Health.

Healthcare Decision-Making Impact Stories

In the past 5 years, 39 organizations requested our co-produced knowledge synthesis service; 179 unique projects were completed by 28 teams and engaging 76 trainees and 189 patient and community members, 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.



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 Mallon[1], Mary Horgan[2], Conor G McAloon[3], Peter D Lunn[4], Julian Little[5], Andrew Beck[5], Alexandria Bennett[5], Nicole Shaver[5], Aileen McConway[6], Rhea O'Regan[6], Barbara Whelan[6], Rapid Testing Expert Advisory Group, Ireland[7]

ESRI ECONOMIC & SOCIAL RESEARCH INSTITUTE

Healthcare Decision-Making Impact Stories

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

Autism Europe

Autism Alliance of Canada | Alliance canadienne de l'autisme

NIH National Institute of Mental Health

Healthcare Decision-Making Impact Stories

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 households in the Northwest Territories.

Government of Northwest Territories / Gouvernement des Territoires du Nord-Ouest

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 33 First Nation communities.

Sioux Lookout First Nations Health Authority

McMaster University

Healthcare Decision-Making Impact Stories

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

Knowledge User Statements

"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 WHO's 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 COVID-19 pandemic."

Etienne Langlois
WORLD HEALTH ORGANIZATION

"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

"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."

Leanne Gardiner
GOVERNMENT OF NORTHWEST TERRITORIES

"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

How the SPOR Evidence Alliance Trains the Next Generation of Scientists through Training and Capacity Development

Seed Grant Funding Competition

- 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

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SPOR
Putting Patients First
ST. MICHAEL'S
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Seed Grant Winners

2021

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

Ghazal Fazli
Post Doctoral Fellow, Unity Health Toronto

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

Nicole George
PhD Student, McGill University

2020

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

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

2019

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

Alexandra Korall
Post-Doctoral Fellow,
University of Manitoba

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

Lashanda Skerritt
MD-PhD Student, McGill University

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

Lisa Knisley Jones
PhD Student,
University Of Alberta

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

Amanda Wurz
Post-Doctoral Fellow,
University of Calgary

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Fellowships

Hosted 14 clinician research fellows for Evidence Synthesis Ireland to provide practical experience in co-producing demand-driven and context-sensitive knowledge synthesis for knowledge users.

EVIDENCE SYNTHESIS
IRELAND

Learning Opportunities

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

325
Learning opportunities

5,393
Learner engagements (**1,080** knowledge users)

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

256 Trainees engaged across **94** queries

46
Patient and community members trained in knowledge synthesis across **2** courses co-led with patient partners

8
Trainees/early career researchers awarded seed funds to advance science

SPOR Evidence Alliance
Alliance pour des données probantes de la SRAP
Strategy for Patient-Oriented Research SPOR Putting Patients First
ST. MICHAEL'S UNITY HEALTH TORONTO

Questions?

Special Thanks to the Central Coordinating Office!

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Research Assistant

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Jacqueline Sally So
Research Assistant *(casual)*

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www.sporevidencealliance.ca

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Thank you for being a great audience!

Andrea C. Tricco MSc, PhD

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Associate Professor, Dalla Lana School of Public Health & Institute of Health Policy, Management, and Evaluation, University of Toronto

Co-Director & Adjunct Associate Professor, Queen's Collaboration for Health Care Quality Joanna Briggs Institute Centre of Excellence, Queen's University

Tier 2 Canada Research Chair in Knowledge Synthesis

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