



SPOR 
Strategy for Patient-Oriented Research
**EVIDENCE
ALLIANCE**

Strategy for Patient-Oriented Research
SPOR
Putting Patients First 

Winnipeg



2019 ANNUAL GENERAL MEETING BOOK

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MEETING AGENDA

Time	Agenda Items	Speakers
8:00 – 9:00	Breakfast and Networking	
9:00 – 9:05	Welcome & Introduction Dr. Tricco welcomes everyone to the meeting and introduces Indigenous Knowledge Holder Sherry Copenace	Dr. Andrea Tricco
9:05 – 9:30	Opening Ceremony Knowledge Holder Copenace welcomes everyone to traditional lands and opens the day with a ceremony	Knowledge Holder Sherry Copenace
9:30 – 11:00	Patient Engagement in Research In this interactive session, co-authors of the Patient Engagement In Research (PEIR) Plan discuss how to meaningfully engage patients in the research enterprise	Ms. Annette McKinnon Ms. Kelly English Ms. Shanon McQuitty Ms. Jenny Leese Dr. Linda Li
11:00 – 11:10	Health Break	
11:10 – 12:00	Panel Discussion: Producing High Quality Evidence for Decision-Maker Needs Each panelist presents their work for 5 minutes followed by a 2-minute question and answer (Q&A) period The final 20 minutes will consist of a moderated panel discussion & general Q&A	(Moderator) Dr. Andrea Tricco (Panelists) Dr. Ahmed Abou-Setta Dr. Annie LeBlanc Dr. Pertice Moffitt Dr. Sharon Straus
12:00 – 13:00	Lunch and Networking	
13:00 – 13:45	Alliance Progress Update Dr. Tricco provides a progress update on the Alliance	Dr. Andrea Tricco
13:45 – 14:45	Understanding KT Priorities of the Alliance Dr. Colquhoun presents aggregate results from the KT Priorities Survey Dr. Baidoobonso and Dr. Small facilitate a moderated group discussion	(Presenter) Dr. Heather Colquhoun (Moderators) Dr. Shamara Baidoobonso Dr. Sandra Small
14:45 – 15:00	Health Break	
15:00 – 15:30	Core Competencies and Mentorship Program Ms. Donnan presents on behalf of the Core Competencies Working Group Dr. Desroches presents on behalf of the Mentorship Working Group	Ms. Jennifer Donnan Dr. Sophie Desroches
15:30 – 16:30	Strategic Discussion: Grant Opportunities and Publications on the Alliance Dr. Tricco and Dr. Straus facilitate a discussion on collaboration opportunities in future grants and publications on the Alliance	Dr. Andrea Tricco Dr. Sharon Straus
16:30 – 17:00	Next Steps and Closing Remarks Dr. Tricco discusses next steps and closes the meeting	Dr. Andrea Tricco



TERRITORY ACKNOWLEDGEMENT FOR WINNIPEG

We would like to acknowledge that the land we are on today, which we now call the city of Winnipeg, is the ancestral land of the Anishinaabeg, Dakota, and Ininiwak, and the homeland of the Métis.

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

We respect the treaty of this land, Treaty 1. We acknowledge the harms and mistakes of the past and present, and we dedicate ourselves to move forward in partnership with First Nations, Inuit and Métis communities in the spirit of reconciliation and collaboration.

We recognize and are grateful to have this opportunity to conduct the work of the SPOR Evidence Alliance on this land, and we encourage all of the participants here today to consider and reflect on our places on this land.

OPENING CEREMONY

The 2019 Annual General Meeting welcomed **Knowledge Holder Sherry Copenace** to open the day.

Born and raised in the Ojibway community of Onigaming, Indigenous Knowledge Holder Sherry Copenace is known for her experience in Indigenous social services and her devotion to Anishinaabe traditions. She speaks her original Language-Ojibway and has great love for the Land, Waters and Peoples. She holds a Masters in Social Work and holds the title of Indigenous Knowledge Holder at the University of Manitoba.

Since 2011, Indigenous Knowledge Holder Copenace has organized Makooskewin-Anishinaabe young women coming of age teachings and ceremonies. She is part of a Grandmothers Circle in Kenora and at Nanaandawewigamig. She helps at Anishinaabe Teaching and Sacred Lodges. She is a board member at Wijiidiwag Ikwewag and Animikii Ozozon Family Services and has over 25 years of experience working in Indigenous social services.

The Ceremony^{1,2}

- Knowledge Holder Copenace led a smudging ceremony to start the day
- Smudging is a tradition of many First Nations and Métis, which involves the burning of one or more sacred medicines gathered from the earth to purify the air, mind, spirit, and emotions
- The four sacred medicines are tobacco, sage, cedar, and sweetgrass



1. <https://www.ictinc.ca/blog/a-definition-of-smudging>

2. <http://ofl.ca/wp-content/uploads/OFL-Guidelines-for-Indigenous-Smudge-Ceremony.pdf>

PATIENT ENGAGEMENT IN RESEARCH

Dr. Linda Li led a panel discussion on patient engagement in research with three patient partners (Kelly English, Annette McKinnon, and Shanon McQuitty) and a doctoral student (Jenny Leese).

Ms. Jenny Leese shared important findings uncovered from the first qualitative study her research group led to understand patient perceptions of meaningful engagement.

Three main themes were observed:

1. **Being heard**

- Demonstration of mutual respect in interactions with researchers

2. **Co-building social relations**

- Informal space to acknowledge others beyond project-specific role

3. **“Adding another spinning plate to an already busy life”**

- Risks of negative physical and emotional impacts



Resources

Leese J, Macdonald G1, Kerr S, Gulka L, Hoens AM, Lum W, Tran BC, Townsend AF2, Li LC. ‘Adding another spinning plate to an already busy life’. Benefits and risks in patient partner-researcher relationships: a qualitative study of patient partners’ experiences in a Canadian health research setting. *BMJ Open*. doi: 10.1136/bmjopen-2018-022154.

Tran BC, Leese J (Co-Primary Authors), MacDonald G, Gulka L, Hoens A, Kerr S, Lum W, Li LC. It is about us! Patient engagement in health research. Richmond, Canada: Arthritis Research Canada; 2016.



Dr. Linda Li provided an overview of the Patient Engagement in Research (PEIR) Framework. This framework was developed to facilitate a conversation between researchers and patient partners to develop a high quality partnership.

1. **Procedural Requirements:** process to facilitate involvement of patient partners in a research project
2. **Research Environment:** team/organizational culture that facilitates inclusion and openness in the patient-researcher relationship
3. **Team Interaction:** research team's communication style, preferences, and practice
4. **Convenience:** providing choice and accessibility, including adequate time to engage, and the flexibility to choose how and when to contribute
5. **Contributions:** roles of and tasks assumed by patient partners
6. **Support:** opportunities and resources, financial support and knowledge/skill development, that are essential to facilitate individuals' engagement as patient partners
7. **Feel Valued:** ensure that patient partners feel welcome and equally important on the research team
8. **Benefits:** the perceived benefits of being a patient partner

Resource:

Hamilton C, Hoens A, Backman C, English K, McKinnon A, McQuitty S, Li L. [Workbook to guide the development of a Patient Engagement In Research \(PEIR\)](#). Richmond, Canada: Arthritis Research Canada; 2018.

PANEL DISCUSSION:

PRODUCING HIGH QUALITY EVIDENCE FOR DECISION-MAKERS

A panel of Alliance investigators spoke about their experiences and lessons learned in conducting research for health system decision-makers in an integrated knowledge translation and patient-oriented research environment.



Ahmed Abou-Setta MD, PhD

Dr. Ahmed Abou-Setta is an Assistant Professor and Director of the Knowledge Synthesis Platform at The George and Fay Yee Centre for Healthcare Innovation, University of Manitoba. He has published over 100 peer-reviewed studies and his work has been cited over 2000 times by colleagues. His areas of research expertise include clinical epidemiological research methods, methods for evaluation of the quality of data from clinical trials, the meta-analysis of trial data, and methods for utilizing indirect evidence.



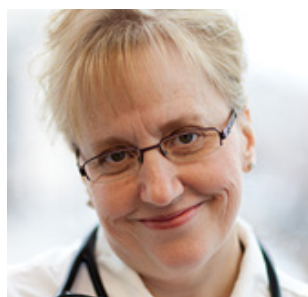
Annie LeBlanc, PhD

Dr. Annie LeBlanc is a clinical epidemiologist, Associate Professor in the Department of Family and Emergency Medicine, Faculty of Medicine, Laval University. Dr. LeBlanc's research centers around the translation of comparative effectiveness research into practice through the design, evaluation, implementation, and sustainability of patient-centered interventions and their impact on patient important outcomes.



Pertice Moffitt, PhD

Dr. Pertice Moffitt is a Manager and Instructor in the Health Research Programs at Aurora Research Institute of Aurora College in Yellowknife. Dr. Moffitt's research on women's health has addressed a range of topics including breastfeeding and mothering, quality of life of older adults, intimate partner violence and rural and remote nursing. She is experienced in a variety of research methods including fourth generation evaluation, ethnography, grounded theory and photovoice.



Sharon E. Straus, MD, MSc

Dr. Sharon Straus is a geriatrician and clinical epidemiologist. She is the Director of the Knowledge Translation Program and Physician-in-Chief, St. Michael's Hospital; Director, Division of Geriatric Medicine; Vice Chair, & Professor, Department of Medicine, University of Toronto. She holds a Tier 1 Canada Research Chair in Knowledge Translation and Quality of Care and has authored more than 400 publications and 3 textbooks in evidence-based medicine, knowledge translation and mentorship.

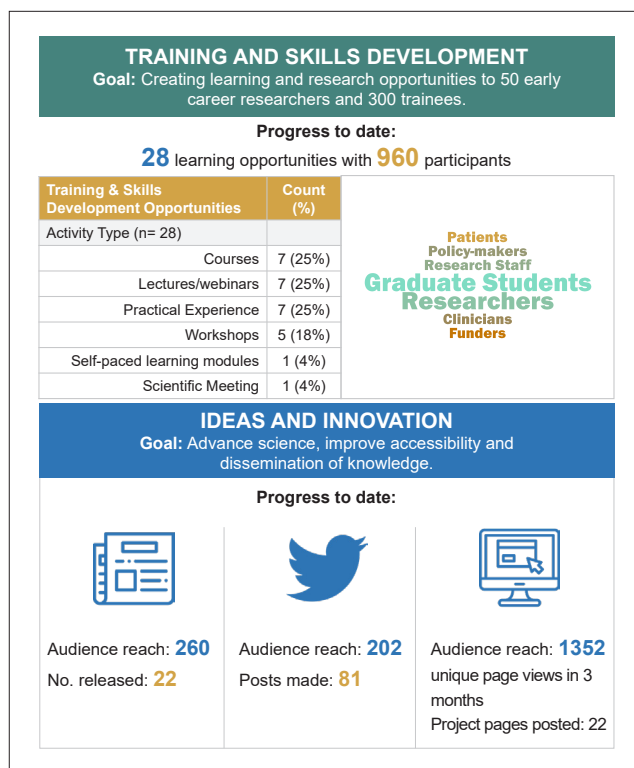
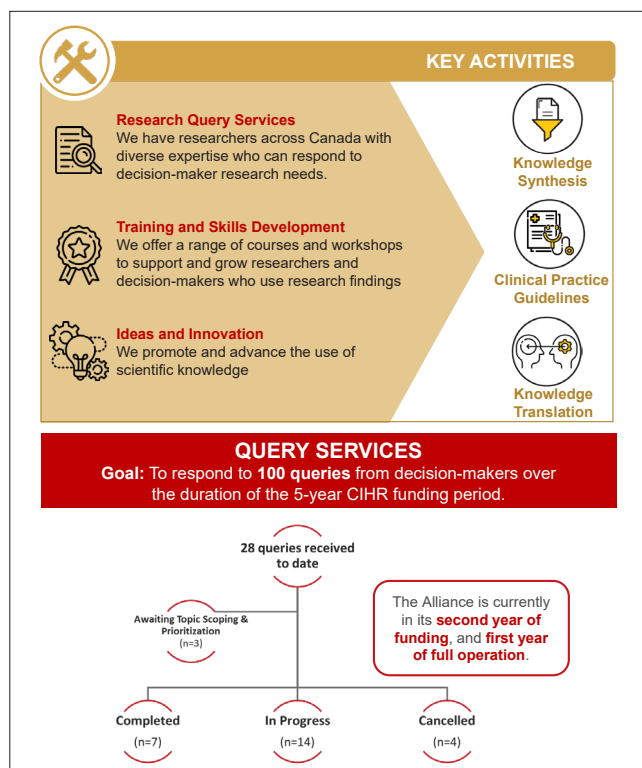


Lessons Learned

- Patient engagement strategy takes time to properly develop and implement
- As the number of interventions/comparators increase, so does the difficulty in identifying how best to present all the comparisons to patient partners and decision-makers
- Clarifying the needs, roles and expectations of the knowledge users is critical
- Important to tailor the deliverables based on knowledge user needs
- Being knowledgeable of cultural context and procedural mechanisms when working with Indigenous communities
- Providing honorariums based on established rates of your organization is important
- Managing expectations of the knowledge users
- Being mindful and careful of the context in which the information will be used when tailoring key messages and recommendations

2018-2019 PROGRESS UPDATE OF THE ALLIANCE

Dr. Tricco provided an update on the successes and new developments of the Alliance.



UNDERSTANDING KT PRIORITIES OF THE ALLIANCE

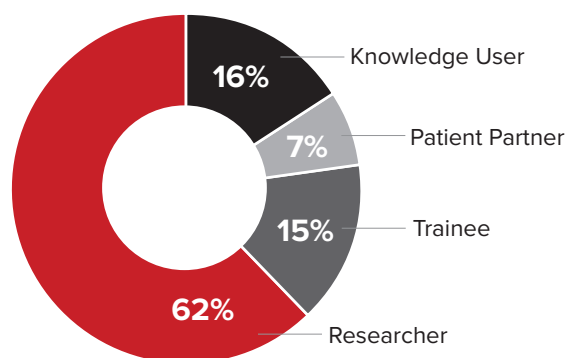
Dr. Heather Colquhoun presented on themes that emerged from the Knowledge Translation Priorities Survey that was administered 4 weeks before the meeting. **Dr. Shamara Baidooobonso** and **Dr. Sandra Small** moderated a group discussion to understand the themes.

Survey Objective: To understand the Alliance’s dissemination and Knowledge Translation (KT)-related capacity-building priorities

Survey Approach: A brief ranking survey was administered to all 188 Alliance members at the time. A representative sample of 82 participants have completed the survey (44% response rate).

SURVEY RESPONDENT CHARACTERISTICS

Respondent Membership Type



Respondent’s work closely aligns with...

- **Research** – 43%
- **Education** – 19%
- **Clinical practice** – 14%
- **Policy-making** – 9%
- **Community health and promotion** – 6%

Ranking of dissemination priorities

Top ranked...

- Inform practice change
- Raise awareness
- Inform policy change



INTENDED GOALS

Top ranked...

- Policy-makers
- Health service providers
- Patient and public



TARGET AUDIENCE

Top ranked...

- Tailored infographics
- Journal publications
- Plain language summaries



PRIORITY STRATEGIES

Top ranked...

- Increase knowledge of KT practice
- Increase knowledge of patient and stakeholder engagement
- Promote use of KT approaches

Top ranked...

- Alliance researchers
- Alliance knowledge users
- Alliance patient partners
- Alliance trainees

Top ranked...

- Inventory of KT resources
- 1-on-1 coaching on KT practice
- Manual on KT practice

Ranking of KT capacity building priorities

Discussions on Dissemination

- Additional audience suggested:
 - Raising awareness amongst **researchers**
 - Establishing relationship with **media channels**
 - Maintaining ongoing communication with research **funders**
- Strategies/activities:
 - The intensity and types of activities will differ for each audience
 - Set some guidelines and checklists that recommend the minimum set of dissemination products that should be developed at the conclusion of each project
 - It was clarified that the KT Committee plays an advisory role in the Alliance and will not be responsible for undertaking the activities
 - The Annual Report was identified as a key dissemination product to bring awareness about the Alliance and the outputs
- Need a way to measure the reach and impact of the products

Discussions on KT-Related Capacity Building

- KT resource repository:
 - Many raised concerns about resources required for ongoing maintenance and update of such a database
 - Development of such a database is also time-consuming and resource intensive
- KT manual:
 - The Patient-Centered Outcomes Research Institute (PCORI) manual was recommended as an example
 - Some questioned if we need to recreate a manual when many are already in existence
 - It was recommended that a series of case examples might be more useful



CORE COMPETENCY DEVELOPMENT

Objective:

- To establish a set of core competencies that outline the expected skills of someone working in knowledge translation, knowledge synthesis and patient oriented research.
- These competencies will support training and mentoring activities within the alliance.

Approach:

- Research focused and focuses on three unique sciences
- Goal is to develop competencies for researchers, trainees, patients and knowledge user, but **started with researchers and trainees**

Discussions:

- What are we advocates of?
 - Evidence-informed decision-making
 - Our guiding principles: collegiality, collaboration, diversity, inclusiveness, co-creation of research, openness
- How should competencies be used for the Alliance?
 - Need to step back and consider the purpose of competencies if we are not creating a curriculum
 - Could be used as a self-assessment tool
 - Experience of working on projects is more effective way to learn than simply taking a course and getting a certificate
- The Fellowship Program of the Evidence Synthesis Ireland was briefly described as a reference:
 - Fellows must develop a list of skills while working on a knowledge synthesis project being led by a mentor
 - Fellows also take a self-paced online module and meet with the mentor one-on-one
 - We could offer something similar through the Alliance, where:
 - ☐ Simple checklist of competencies must be acquired
 - ☐ Principal investigators or co-investigators can act as mentors
 - ☐ Give them access to any existing learning modules (e.g., Systematic Reviews course), have them participate in an Alliance project, and provide certificate at the end
 - ☐ Need to consider having competencies tailored to patient partners

MENTORSHIP PROGRAM

Objective: to develop a mentorship program for members of the Alliance

Approach: several documents on current mentorship programs were reviewed:

Program Host	Resources
The College of Family Physicians of Canada	Mentorship Program Guide <ul style="list-style-type: none">To foster networking opportunities between novice and experienced professionals
Diabetes Action Canada	Early Career Investigator Mentorship Award <ul style="list-style-type: none">To foster networking and collaboration opportunities
Canadian Frailty Network	Interdisciplinary Fellowship Program <ul style="list-style-type: none">Mentorship embedded as part of the fellowship program
University of Calgary	Academic Leadership Mentorship Program <ul style="list-style-type: none">To grow new academic leaders in their role
O'Brien Institute for Public Health	The O'Brien Institute for Public Health Mentorship Program <ul style="list-style-type: none">To foster career development in academic researchers

Discussions:

- Mentorship in Academic Medicine book co-authored by Dr. Sharon Straus was recommended as an additional resource
- Reporting requirements and paperwork for the participants should be kept efficient and not redundant and burdensome
- Embedding mentorship within various capacity-building activities was suggested
- Need to establish formal contract between mentors and mentees that clearly defines roles and expectations as well as provides terms on data ownership and protection of intellectual property
- Mentorship can also take form of mutual 2-way/multi-way capacity building
 - Example: Drug Safety and Effectiveness Network (DSEN) approach where government educates the researchers on drug safety regulation and the researcher provides education on study methods



GRANT OPPORTUNITIES

Suggested Topics:

- Methods papers advancing science of knowledge synthesis, clinical practice guidelines patient engagement, and knowledge translation
- The 2-way capacity-building framework of the Alliance (scientists and knowledge users)
- Building capacity for uptake and use of evidence in environments that do not currently have the infrastructure
- Studying the Alliance from a social science perspective

Suggested Funding Sources:

- Provincial health departments, non-governmental organization, PCORI, Ontario Impact awards, other SPOR entities, health organizations, Ministries of Health
- Avoid double-dipping with CIHR
- Avoid industry; noted that we could consider pharma for non-drug research like project about patient portal, but would need to be cautious

Fostering Collaboration:

- Provide generic letters of support for relevant projects
- Ensure we avoid duplication of other SPOR entities
- Make a clear pathway so patients can find you if they want to get involved
- Consider access to capacity building resources when requesting funding
- Spread awareness at conferences
- Researchers can send their research/grant idea to Alliance if they want to put out a call for collaborators

PUBLICATIONS

Suggested Topics:

- Engaging patients in the conduct of knowledge synthesis
- Evaluation of patient engagement efforts and discussing successes/barriers
- Overall vision of Alliance and what success looks like
- Comparison of different national issues and what gaps are being filled
- Recommendations to local stakeholders and how they can contribute
- Series of accessible papers with lay summary of who we are and what our goals are → can help with knowledge user engagement
- Illustrating knowledge user perspective of working with the Alliance on queries
- Paper on impact of all Alliance queries so far
- Consider non-academic publications → lay summaries of terms like knowledge synthesis, knowledge translations, patient-oriented research, and clinical practice guidelines

Defining the Purpose:

- Need to consider goal of publications
- Is the goal to promote the Alliance or generate evidence?
- If promotion of the Alliance is the goal, consider reaching out to André Picard to write an article

Suggested Journals:

- CMAJ open, Systematic Reviews, BMJ, Implementation Science

Fostering Collaboration:

- Suggest that each committee take on a publication
- Series of papers with original visionaries of the Alliance



THAT'S A WRAP!

We are grateful to **Knowledge Holder Sherry Copenace** for her time and for performing the opening ceremony for the meeting.

We would also like to extend special thanks to **Natalie Rodriguez** from the DEVOTION Network at the Children's Hospital Research Institute of Manitoba for her support in liaising with Knowledge Holder Sherry Copenace.

We are also grateful to **Mercy-Anne Magundayao** from the George and Fay Yee Centre for Healthcare Innovation for photography and supporting the social media coverage for the day.

Finally, we are truly thankful to all meeting participants for travelling from far and near to attend the meeting in-person or tuning in remotely. Their expertise and experiences around the table stimulated constructive and open discussions on the Alliance progress and future directions.



