

The background of the entire page is a photograph of several people holding hands in a circle on a sandy beach. The image is slightly blurred and has a warm, golden-brown color palette. A large, semi-transparent red rectangle is overlaid on the left side of the image, containing the title and other text.

ANNUAL REPORT 2017-2018

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www.sporevidencealliance.ca



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

Strategy for Patient-Oriented Research
SPOR
Putting Patients First 

Acknowledgements

The SPOR Evidence Alliance is supported by the Canadian Institutes of Health Research ([CIHR](#)) under Canada's Strategy for Patient-Oriented Research ([SPOR](#)) initiative, and the generosity of partners from [41 public agencies and organizations](#) across Canada who have made cash or in-kind contributions.

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Message from the Nominated Principal Investigator



The SPOR Evidence Alliance (hereafter, the Alliance) is a new initiative that has been in operation since September 2017 following a competitive grant success. Our operations have been made possible by a 5-year non-renewable grant from Canadian Institutes of Health Research (CIHR) under Canada's Strategy for Patient-Oriented Research (SPOR) initiative, and the generosity of partners from 41 public agencies and organizations.

The Alliance was established in response to the gaps and inefficiencies identified in the initial SPOR Strategy¹ document released by CIHR. The document, published in August 2011, called for a concerted, well-resourced, and collective approach to enhancing the Canadian capacity to develop, disseminate and uptake systematic reviews and clinical practice guidelines. We are privileged to have this unique opportunity to support decision-makers across Canada with their knowledge needs to improve the care and lives of Canadians.

Our commitment is to achieve the triple aims of improving patient experience of care, health of populations, and cost efficiency by supporting access to high-quality information that is timely and easy to use for decision-makers.

This report will provide you with a brief overview of the Alliance's core functions and achievements over the past year. In its first year of operations, the Alliance worked on laying down the administrative foundations for this Canada-wide initiative.

Some of our successes included:

- Setting up the 6 focused committees of the governance structure, while ensuring inclusive and diverse member representation including patient partners, researchers, trainees, and knowledge users
- Branding our Alliance with a new name (formerly named REACH network), logo, and visual identity following consultation with our members
- Recruiting and training new staff, and establishing the central coordinating office to manage the day-to-day operations of the Alliance
- Launching the Alliance website along with the online query submission platform
- Launching and branding the release of monthly newsletters
- Developing and publishing a report on the Asset Map of Canadian Clinical Practice Guidelines
- Starting to establish many new and important collaborations and partnerships
- Developing the stakeholder and patient partner engagement plan in consultation with patient partners, knowledge users, researchers and trainees
- Starting to refine and develop the capacity-building plan
- Developing a strategy to expand the membership of the Alliance with a streamlined and systematic new member recruitment plan
- Beginning work on 10 knowledge-user initiated research queries

We are proud of how far we've come in our first year, while embracing the challenges that come with establishing a national initiative. We thank you for your continued support and for being a part of our journey. Our work is just beginning, and we have exciting times ahead, as we roll out our core activities across Canada.

With regards,

A handwritten signature in black ink that reads "Andrea Tricco".

Andrea C. Tricco MSc, PhD

¹CIHR. Canada's Strategy for Patient-Oriented Research. Available from <http://www.cihr-irsc.gc.ca/e/44000.html#a4.4.6>

Our Vision

To create a rapid learning health system where patients receive the right intervention at the right time, by supporting access to high-quality information that is timely and easy to use for decision-makers and improving the triple aims – patient experience of care, health of populations, and cost efficiency.

1. Preamble

This report has been prepared to share our overall 1-year progress update with the public and the members of the Alliance. It is also intended to provide an update to the CIHR, funding partners and other stakeholders who share our Vision and Goals.

We welcome you to join us in reviewing our journey to date along with the challenges and successes met along the way.

2. About the Alliance

The Alliance is a Canada-wide network of researchers, research trainees, patient partners, healthcare providers, policy makers, and other decision-making bodies who have come together to improve the Canadian health system by achieving the triple aims – patient experience of care, health of populations, and cost efficiency. Launched in September 2017, the Alliance acts as a national coordinating centre to support decision-maker needs in knowledge synthesis, clinical practice guidelines development, and knowledge translation.

2.1 Five-Year Strategic Goals

1	Provide timely evidence-based answers to decision- maker knowledge needs
2	Meaningfully involve patients, partners and decision makers in research process
3	Reduce duplication and redundancies in research through Canada-wide coordination
4	Offer training and mentorship opportunities to patient partners, decision makers and research trainees
5	Increase the visibility and update of Canadian research
6	Make research more visible and easier to obtain by making research findings freely available
7	Collaborate with the SUPPORT Units and SPOR Networks
8	Advance the science of knowledge synthesis, clinical practice guidelines, knowledge translation, and patient-oriented research



Charlene Soobiah, PhD (c)

Institute for Health Policy, Management & Evaluation (IHPME), University of Toronto

I am a PhD candidate at the Institute for Health Policy, Management & Evaluation (IHPME) at the University of Toronto and a graduate student in the Knowledge Translation Program at St. Michael's Hospital. My dissertation focuses on evaluating the effectiveness of geriatrician-led care models and seeks to identify optimal care models to improve health outcomes. To address this we conducted a systematic review and used an integrated knowledge translation approach, where different knowledge users such as patients, caregivers, geriatricians and policymakers were engaged in the conduct of the review. Through my research, I have learned that engaging patients in research is a spectrum and what approach you take should be based on what is meaningful to your patient partners as well as the project.

2.2 Our Core Functions



2.2.1 Research Query Services

The Alliance responds to knowledge user needs for knowledge synthesis, clinical practice guidelines, and knowledge translation through an online central intake process. Query service requests are accepted from policy makers, health system managers, healthcare providers, patients, and other knowledge users across Canada to support their research priorities.

The Alliance fosters an integrated knowledge translation environment for all its research activities, whereby knowledge users and relevant stakeholders (including patient partners when appropriate) are engaged throughout the research conduct.

The Alliance accepts research queries in both English and French.

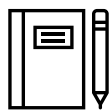


2.2.2 Knowledge Translation and Implementation

The Alliance will develop a comprehensive knowledge translation (KT) strategy to communicate and disseminate all knowledge and research products created by its researchers, research trainees in partnership with patient partners and other knowledge users.

Monthly newsletters are released to widely disseminate news of current Alliance activities and developments.

To provide an asset map of Canadian clinical practice guidelines, a report has been published and a searchable online database is being created.



2.2.3 Training and Mentorship

The Alliance hopes to **build capacity and train the next generation of researchers** in knowledge synthesis, clinical practice guideline development, knowledge translation, in a culture of patient-oriented research and integrated knowledge translation.

The Alliance has **three education streams** targeting graduate level trainees and post-doctoral fellows, researchers and research staff, as well as patient partners and knowledge users.

There will also be funding opportunities to provide salary support to research trainees and seed grants to support innovation and advancement of research methods.

**Detailed updates on each of the core functions are provided in later sections of the report.*

2.3 Our Membership

The Alliance is built on a culture of inclusiveness and provides a supportive environment that fosters collaboration, and shared decision-making. Our diverse membership is comprised of 111 researchers, 42 knowledge users, 14 research trainees and 12 patient partners from across Canada.

Twelve principal investigators and 62 co-investigators bring a range of expertise in our four core research areas: knowledge synthesis, clinical practice guideline development, and knowledge translation. The aim is to leverage their skills and expertise in a patient-oriented research environment.

2.4 Governance and Central Coordinating Office

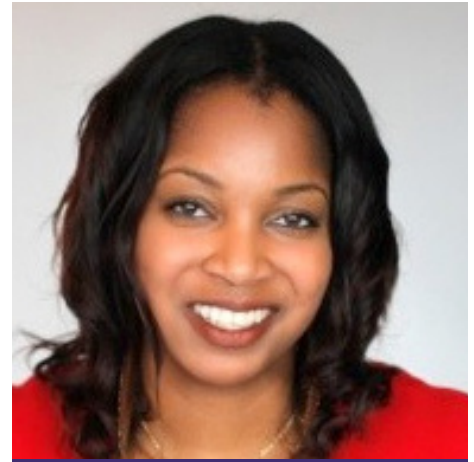
2.4.1 Governance

The Alliance has oversight from six committees to ensure progress towards its vision and goals are on track. Each committee has clearly defined roles and responsibilities described in their Terms of Reference. Committees are responsible for annually reviewing and revising their Terms of Reference as appropriate.

Knowledge-users, research trainees and patient partners have reserved seats in each of the committees. The seats across the 6 committees are 92% (76/83) filled and currently consist of 9 patient partners, 12 trainees, 14 knowledge users, and 34 researchers. The remaining seats will be filled as new patient partners join the Alliance.



PATIENT PARTNER



Priscille-Nice Sanon

Quelle belle première année au sein de l'Alliance ce fut! J'ai eu le privilège d'agir à titre de délégué lors de la conférence pancanadienne sur la recherche axée sur le patient organiser par les instituts de recherche en santé du Canada. J'ai pu en compagnie de Mme Annette Mckinnon et Dr. Andrea Tricco. Nous avons présenté aux patients, chercheurs, décideurs ainsi que les gestionnaires les services de l'Alliance via le kiosque durant l'ensemble de la conférence. Cette conférence fut riche en information, mais surtout en histoire, histoire de personne dont la vie a été changée par l'approche que le recherche axée sur le patient fait concrètement.

Les plénières étaient touchantes et à la fois remplies d'éléments concrets que les patients tout autant que les chercheurs pouvaient en retirer. Cette conférence fut aussi l'occasion de faire le lien avec les patients partenaires des quatre coins du Canada et d'avoir des conversations intéressantes et de leur donner un intérêt de devenir membre de l'alliance et de participer à la création d'un système de santé à apprentissage rapide dans lequel les patients reçoivent les bons soins au bon moment, en favorisant l'accès à des informations de haute qualité, rapide et facile à utiliser pour les décideurs.

Committee	Oversight	Members
International Advisory Committee	Provide guidance on strategic direction and sustainability of the Alliance	Brian Mittman (co-chair) Nancy Baxter (co-chair) Ahmet Metin Gulmezoglu Brett Thombs Eva Grunfeld Lesley Stewart Matthew Page Pamela Valentine Paul Glasziou Rosemary Wilson Shannon McQuitty
Steering Committee	Provide recommendations on key operations and leadership on direction (including priorities and milestones) of the Alliance	Annie LeBlanc (co-chair) Minnie Downey (co-chair) Priscille-Nice Sanon (co-chair) Alison Hoens Andrea Tricco Beverley Temple Carolyn Gall Casey Cheryl Koehn Christina Godfrey Heather Colquhoun Jeremiah Hwee Linda Wilhelm Sharon Straus Sophie Desroches
Executive Committee	Oversee key operations and monitor ongoing progress towards objectives of the Alliance	Andrea Tricco (chair) David Moher Fiona Clement Ivan Florez Janet Curran Jenny Leese Jullian MacLean Kim Sears Linda Li Rachel Rodin Suzanne Morin
Partnerships Committee	Oversee and monitor patient partner and stakeholder engagement activities of the Alliance	Peter Oxland (co-chair) Tanya Horsley (co-chair) Ahmed Abou-Setta Charlene Soobiah Irfan Dhalla Janet Martin Kelly Mrklas Kim Critchley Lyn-Miin Alikhan Martha Paynter

Committee	Oversight	Members
Training Committee	Oversee and monitor training and capacity-building initiatives of the Alliance	Sophie Desroches (co-chair) Zahra Goodarzi (co-chair) Kelly English (co-chair) Amy Outcshoorn Chantelle Lachance Cliff Lindeman Jennifer Donnan Leah Boulos Lisa Keeping-Burke Lisa Strifler Marilyn Macdonald Meghan Elliott Wanrudee Isaranuwachai
Knowledge Translation Committee	Oversee and monitor knowledge translation activities for new knowledge and research products developed by the Alliance	Cheryl Koehn (co-chair) Heather Colquhoun (co-chair) Ahmed Abou-Setta Annette McKinnon Christopher Klinger Elliot PausJenssen Erna Snelgrove-Clarke Graham Macdonald Ian Graham Jennifer Watt Jessie McGowan Kelly Mrklas Lynn Klein Pertice Moffitt Sandra Small Shamara Baidooonso



Jeremiah Hwee, PhD, MSc

Postdoctoral Fellow

Institute for Better Health, Trillium Health Partners

Health System Performance Research Network, University of Toronto

I was very excited after I learned I would be part of the SPOR Evidence Alliance as a trainee. As a junior researcher, being a part of the Steering Committee has been a great learning experience. I've participated in providing shared strategic leadership that includes setting priorities and milestones, discussions on policies and processes for intellectual property, and defining terms of reference. More importantly, I had the opportunity to engage with decision-makers, patient advocates, knowledge users and other researchers to learn about what is important to them. This ensures the research outputs are relevant to patients and enhances the uptake of new evidence-based knowledge and practice to improve patient care and outcomes. These experiences are important in developing my skills as an independent researcher and I will certainly apply what I've learned to future projects. I look forward to my continued involvement with the SPOR Evidence Alliance.

2.4.2 Central Coordinating Office

The central coordinating office is based within the Knowledge Translation Program at the Li Ka Shing Knowledge Institute of St. Michael's Hospital. This team manages and executes the day-to-day operations of the Alliance, including all business transactions, query intake, tracking all activities, contracts and agreements, reporting to the CIHR and other stakeholders. The office also supports all logistical and administrative needs of the governance and the core activities of the Alliance.

3. Progress Updates

3.1 Administrative

3.1.1 Branding

Our pan-Canadian alliance of researchers, research trainees and patient partners and knowledge users was branded with a new name, SPOR Evidence Alliance (formerly, REACH Network) soon after being funded by the CIHR. All 179 members were engaged to submit suggestions for a name that they felt represented our purpose. All members were then invited to participate in two rounds of online voting to select their preferred name from the list of suggestions. The Evidence Alliance was selected by majority vote. A trained graphics designer then helped conceptualize the visual identity of the Alliance. Three potential logo concepts were considered by the Alliance members in two rounds of online voting to select the final logo based on the majority vote.

3.1.2 Relationship Building

The Alliance has met with all 9 SUPPORT Units across Canada (either in-person or via web-conferences) to build our partnership and to strategize on opportunities for collaborations. The Alliance also presented to a few SPOR Councils and Working Groups to spread the word about our establishment, vision and goals. We have begun connecting with SPOR Networks, and will continue to do so in the 2019 to ensure coordinated and concerted efforts towards our shared goals and activities.

3.1.3 Member Expansion

The Alliance hopes to expand its membership in 2019 through active recruitment, with special emphasis on expanding patient partner representation within the Alliance. A New Member Intake Policy has been drafted by the Central Coordinating Office and is currently being reviewed by both the Steering and Partnerships Committees.

3.2 Research Query Services

The Alliance began accepting research queries in April 2018 and has received 10 research queries to date. All of the queries received are for knowledge syntheses to inform policy decisions, clinical practice guidelines or decision tools by decision-makers at the international (n=1), national (n=5), and provincial (n=4) level. A summary of received queries is provided in the table below.

Table 1. Summary of Knowledge User Initiated Research Queries

Query #	Organization Name	Request Type	Research Topic	Query Purpose	Response Type
Query 01-18	The Society of Obstetricians and Gynaecologists of Canada	Knowledge Synthesis	Chronic Pain in Pregnancy	Evidence base for guideline on chronic pain in pregnancy	Rapid (3-6 mos)
Query 02-18	Health Canada	Knowledge Synthesis	Knowledge acquisition, assimilation and use at the organizational level (absorptive capacity)	Evidence base to inform program design, program implementation, performance measurement and evaluation	Standard (12 mos)
Query 03-18	Quebec Ministry of Health and Social Services	Knowledge Synthesis	Extended Scope of Practice in Family Medicine	Evidence base to inform a tool to encourage the adoption of extended scope of practice among family medicine clinicians	Rapid (3 mos)
Query 04-18	Laval University	Knowledge Synthesis	Self-Management of Chronic Pain	Inform development of improved self-management programs for chronic pain	Standard (12 mos)
Query 05-18	Diabetes Action Canada - SPOR Network in Diabetes and its Related Complications	Knowledge Synthesis	Early Detection and Management of Diabetes Complications	Inform the implementation report of the National Diabetes Strategy being presented to the federal government	Rapid (3-6 mos)

Query #	Organization Name	Request Type	Research Topic	Query Purpose	Response Type
Query 06-18	AlterGo	Knowledge Synthesis	Promotion of Physical Activities for children with disabilities	Inform a policy brief to be presented to policy makers in Quebec (at municipal, regional and provincial levels) to lobby for inclusion of leisure activities for children with disabilities in Quebec policy	Rapid (3 mos)
Query 07-18	Government of the Northwest Territories	Knowledge Synthesis	Family Violence in northern communities	To advance the work of GNWT towards prevention and reduction of, as well as healing from family violence in the NWT.	Rapid (3 mos)
Query 08-18	University of Ottawa	Knowledge Synthesis	Military Injury Gender Disparities	To inform development of mitigation strategies that aim to reduce vulnerability to injury while upholding gender-free fitness standards.	Rapid (3-6 mos)
Query 09-18	WHO	Knowledge Synthesis	Gaming Disorder	To inform inclusion of gaming disorder in the 11th Revision of the International Classification of Diseases (ICD-11)	Rapid (3-6 mos)
Query 10-18	Diabetes Canada	Knowledge Synthesis	Cannabis use in patients with diabetes	To inform a position statement to be disseminated to the medical and scientific community	Rapid (3 mos)



3.3 Knowledge Translation and Implementation Science

3.3.1 Launch of the Website and Media Activities

The Alliance launched its website as a central platform to promote its services (including research service requests) and facilitate communication and opportunities for collaboration across the Alliance and beyond. It features the online query intake form where patients, policy makers, health system managers, healthcare professionals and other knowledge users can submit their research needs in either English or French through a central intake process. All promotional and media updates are also shared through the website.

The Alliance also began releasing monthly newsletters to provide regular updates to all the members. The Alliance has issued 15 newsletters since July 2017, which are all available on our website (<https://sporevidencealliance.ca/newsroom/newsletter/>). The Alliance also made an official media release to announce our grant success, as well as our vision and goals.

3.3.2 Asset Map of Canadian Clinical Practice Guidelines

To map Canadian developers of clinical practice guidelines, a report including over 1100 open-access clinical practice guidelines that have been developed either at the local, provincial or national level were profiled. The aim was to demonstrate the strengths and capacity of Canadian developers of clinical practice guidelines, and identify opportunities to advance the science of guideline development, as well as opportunities for future collaborations. The report has been used to develop an online searchable database. The database will be updated on an ongoing basis to provide up-to-date and easy to access information on existing and current guidelines and help reduce redundancies and duplication of efforts in guideline development.

PATIENT PARTNER



Linda Wilhelm

Canadian Arthritis Patient Alliance

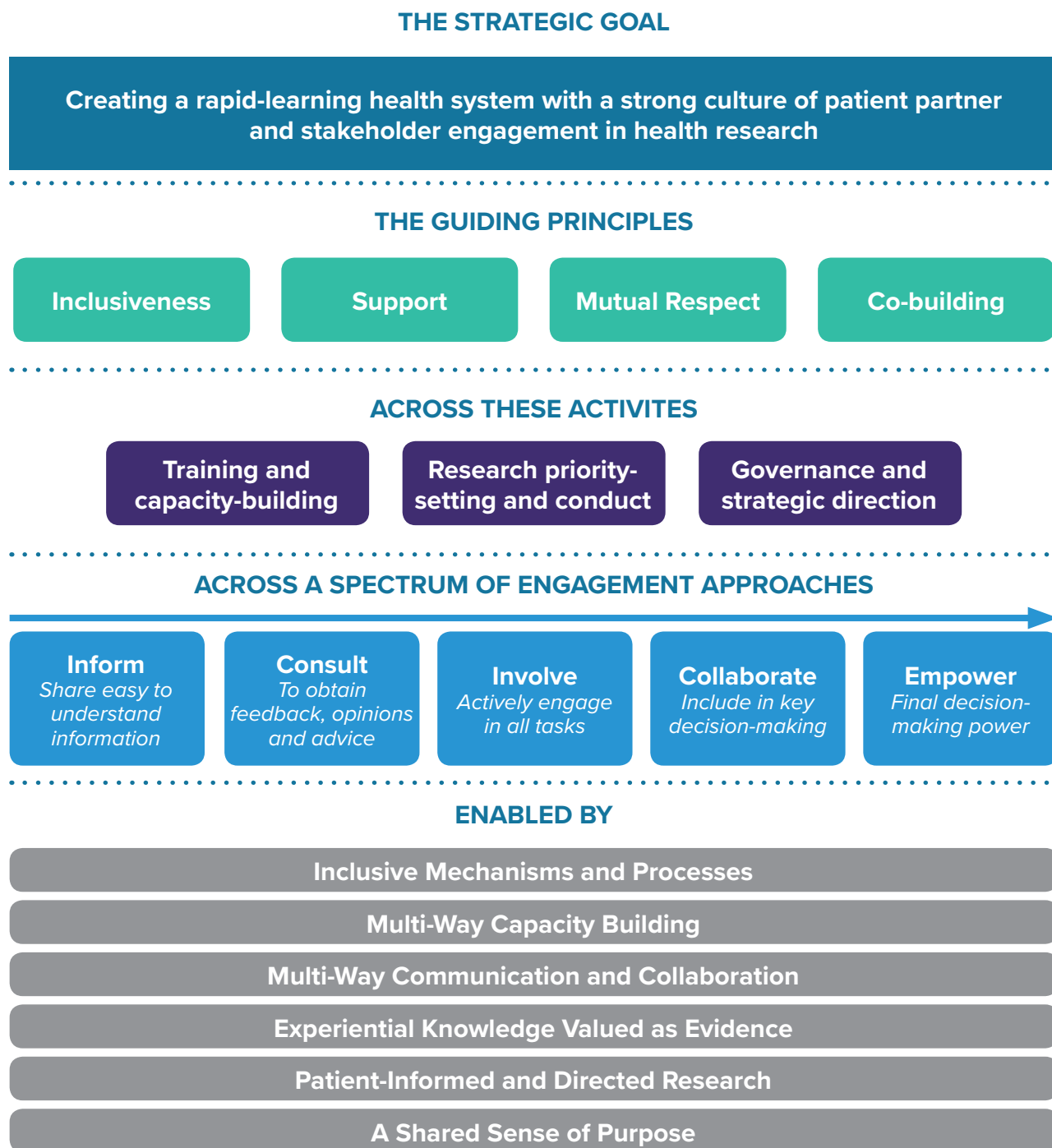
It was exciting, as a patient who has been involved in research for many years to be asked to collaborate on the grant application to CIHR SPOR for an Evidence Alliance Network. When the grant was funded we immediately began looking for additional patient partners to become involved in this research network that would begin synthesizing knowledge to improve health for Canadians. The governance structure has patient partners as members on all network committees, with a patient and a researcher co-leading the evaluation of patient engagement in the work. Much of the work to date has been setting up the structure and network policies; patients have been integral in the process often bringing in their experience with other networks to reduce duplication such as the patient compensation model that was co-developed by the other networks and their patient partners. With the network now receiving queries I am looking forward to getting to work and seeing how patients can have an impact the research and expanding on the roles we currently play as well as assisting with the knowledge translation to improve the uptake into the health care system.

3.3.3 Patient Partner Engagement Strategy

The Alliance has an inclusive patient and stakeholder engagement strategy to foster a culture of patient-oriented research and integrated knowledge translation, where patients and other knowledge users are involved in all aspects of research.

The strategy has been drafted by the Central Coordinating Office and is being reviewed by the Steering Committee and Partnerships Committee. A summary of the engagement strategy has been visualized in an infographic below.

Figure 1. SPOR Evidence Alliance Patient Partner Engagement Strategy

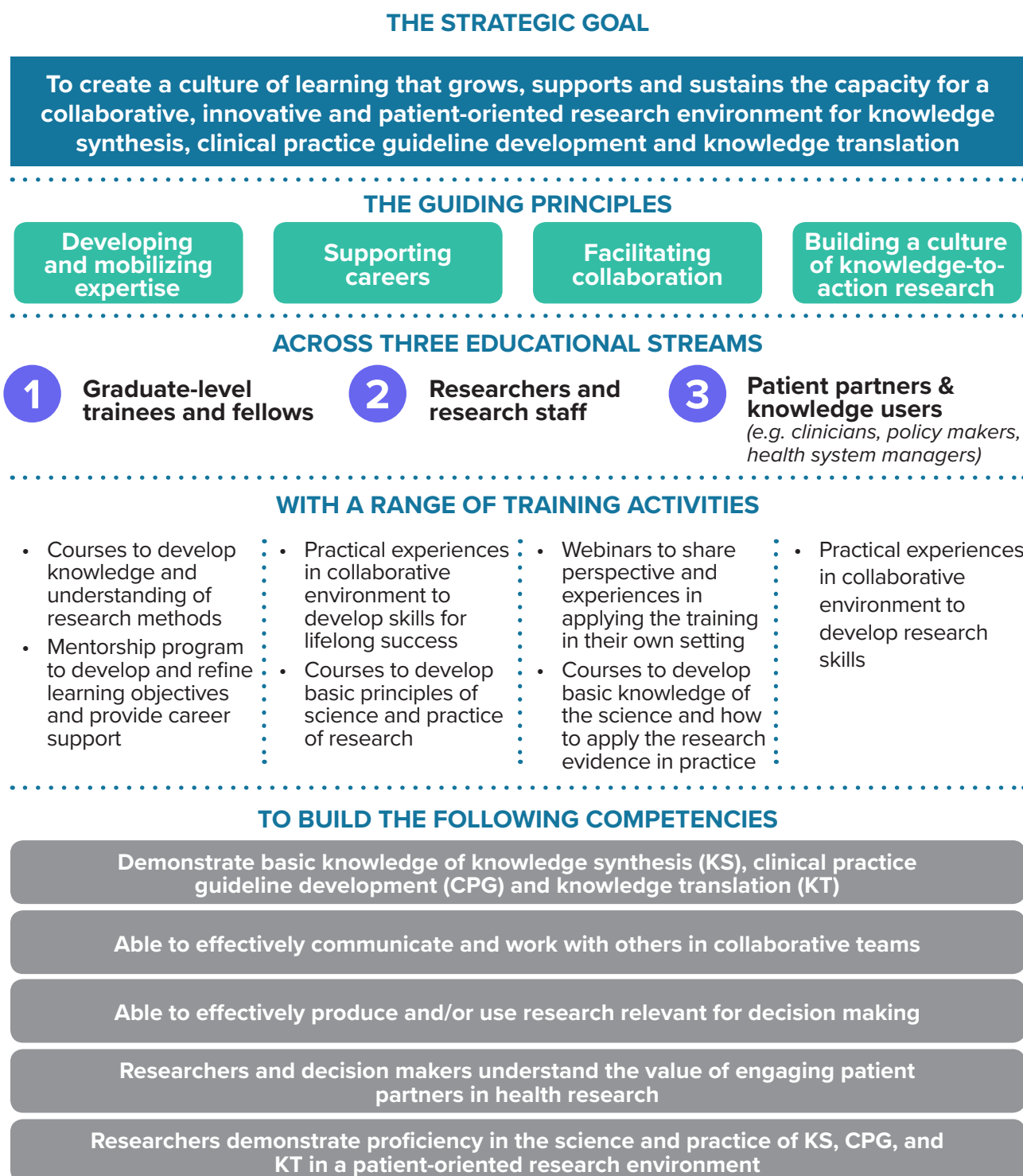


3.4 Training and Mentorship

The Alliance is committed to train the next generation of researchers in knowledge synthesis, clinical practice guideline development, and knowledge translation in a culture of patient-oriented research and integrated knowledge translation.

The **Capacity-Building and Training Strategy** has been developed and is being reviewed by the Training Committee. A working group has been created to develop core competencies for the training strategy. Most of our training initiatives will be launched in 2019.

Figure 2. SPOR Evidence Alliance Capacity Development Strategy





Annette McKinnon

Being part of the Evidence Alliance at the SPOR Summit this year was exciting. I had never attended the SPOR Summit though my interest in the Strategy for Patient Oriented Research began years ago.

One of the presentations I attended that showed me how patients fit into the Strategy for Patient Oriented Research Summit, was a panel titled Patient Partners' Perspectives on Engagement and Impact. It included fellow-patient Linda Wilhelm describing her involvement with the SPOR Evidence Alliance as a member of the Steering Committee.

Learning more about the ways that the six national SPOR networks and the Ontario SPOR Support Unit partner with patients made me think more about the benefits of this engagement to patients, research and to the health system.

Priscille Nice-Sanon is another patient with the EA and I was happy to meet her, and to talk to her and Dr. Andrea Tricco at the booth that the Evidence Alliance had at the Summit where people were able to connect and find out more about the work of the Alliance.

4. Our Partners

4.1 Our Sponsors

The SPOR Evidence Alliance is made possible by a five-year grant from the Canadian Institutes of Health Research (CIHR) under Canada's Strategy for Patient-Oriented Research (SPOR) Initiative, and the generosity of sponsors from 41 public agencies and organizations across Canada who have made cash or in-kind contributions.



4.2 Our Supporters

The SPOR Evidence Alliance is thankful for the ongoing collaborations from members of **52 Canadian and international public agencies and organizations** who have provided letters of support.

SPOR Entities



Research Alliance and Institutions



Government Institutions



Post-Secondary Institutions



Health Institutions and Organizations



Healthcare Professional Colleges and Societies



Publishing Institutions



Kelly English

Imagine a world where health care researchers all have patients on their research teams. Imagine a world where you know what to do on a research team. Now imagine that the surveys asked to patients and the research results are understandable to most patients even with a lower reading level.

That is why I joined the SPOR evidence Alliance Training committee.

I feel by being involved in the training aspects of the trainees and the patients; we will have patients that are not intimidated by the process of research and feel they can participate to their fullest ability. Researchers will know what patients can do on their teams. Furthermore, patients can be involved from start to finish on a research team. We have so much to contribute.

SPOR Alliance is giving me this opportunity. I am involved in finding some courses that patients across Canada can take to increase their knowledge and make them comfortable around the process. In return, the researchers will have patients who are eager to contribute to research as an engaged patient.

Isn't that what we all want?

PATIENT PARTNER



Peter Oxland

Over the past 5+ years, I have spent much time and energy encouraging the inclusion of the patient and family member voice as an important stakeholder who is meaningfully involved in helping to enhance healthcare.

I feel privileged to have worked with very talented and professional scientific research teams on many research projects, with different roles such as grant writing, committees and working groups, conducting qualitative research, results dissemination, etc.

I have witnessed the significant focus scientific research teams have on obtaining new research grants, conducting the research, and achieving publication success, learning that the latter is a very important academic requirement.

On the other hand, I have become troubled with (from 'my lens') the limited focus and success in taking research results (existing & newly-created) and using them to inform and implement front-line change.

I ask myself... 'Why do research unless there is a plan to use the results to make changes in care that enhance the health and well-being of Canadians?'

I find the Evidence Alliance's Five-Year Strategic Goals thoughtful and inspiring, and encourage everyone involved to use these when considering activities. Significant progress can be made in more effectively using research-created evidence to help inform and implement changes in care, to improve the health and well-being of Canadians.

TRAINEE



Kelly Mrklas, PhD (c)

KT/Implementation Scientist at Alberta Health Services & Hiking Enthusiast

I am fortunate to wear several hats with the Evidence Alliance – as a knowledge user/applied health services researcher working in a learning health care organization, and as a health services research stream PhD candidate.

My days are spent dwelling in the (fascinating!) grey space between knowledge and action - so it is no coincidence that the SPOR Evidence Alliance feels like home to me!

What does the Evidence Alliance mean to me and what benefit does it bring to my daily work?

In my mind, the word that best describes the Alliance is 'consolidation' - in the form of expertise in synthesis and translation, patient engagement and empowerment, and in the form of service delivery that optimizes the uptake and use of evidence into the daily work of health care providers, decision makers, leaders and policy makers across Canada.

The 'secret sauce' of the Evidence Alliance lies in the fact that it is several magnitudes bigger, than the sum of its parts. It is still early days for the Alliance and there is much work to be done. But to me, the Alliance is a portal to better quality: decision making, knowledge and translation products, as well as patient, provider, and healthcare systems outcomes.

The SPOR Evidence Alliance is an aspiration becoming reality and is admirable in its determination to take on the hardest of challenges and forge new paths and ways of creating and using evidence together.