

2018 SPOR EVIDENCE ALLIANCE ANNUAL GENERAL MEETING BOOK

A summary report of the meeting
discussions and presentations

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SPOR 
Strategy for Patient-Oriented Research
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ALLIANCE**

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Acknowledgements

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For questions about this report, please contact:

SPOR Evidence Alliance
Central Coordinating Office

Email: SPOREA@smh.ca

2018 SPOR Evidence Alliance Annual General Meeting

WEDNESDAY, 7 NOVEMBER 2018

8:30 a.m. to 5:00 p.m.

LOCATION

Pantages Hotel
Conference Hall 1 & 2
200 Victoria St, Toronto, Ontario

[View on Google Maps](#)

Meeting Purpose

The purpose of this meeting is to review the Alliance's progress to date and strategize on next steps, growth, and sustainability.

| Time | Agenda Items | Speakers |
|-------------|---|-------------------------------|
| 8:00-8:30 | Breakfast and Networking | |
| 8:30-9:00 | Welcome and Introduction | Andrea Tricco |
| 9:00-9:50 | Report on Progress and Impact of the Alliance | Wasifa Zarin Sonia Thomas |
| 9:50-10:05 | Refreshment Break | |
| 10:05-12:00 | Panel Presentations on Patient-Oriented Research <ul style="list-style-type: none">• Mini Presentations by Researchers, Trainees, Patient Partners and Knowledge Users | <i>Speaker bios enclosed.</i> |
| 12:00-13:00 | Lunch and Networking | |
| 13:00-15:00 | Committee Breakout Session <ul style="list-style-type: none">• Reviewing Committee Progress to Date• Developing Action Plan for the Upcoming Year | |
| 15:00-15:15 | Refreshment Break | |
| 15:15-16:45 | Large Group Discussion <ul style="list-style-type: none">• Each Committee to Present on Key Updates and Action Plan• Open Discussion & Feedback | |
| 16:45-17:00 | Next Steps and Closing Remarks | Andrea Tricco |

Participant List

| Name | Primary Affiliation |
|------------------------|---|
| Ahmed Abou-Setta | University of Manitoba, Manitoba SPOR SUPPORT Unit |
| Lyn-Miin Alikhan | L. Miin Alikhan Advisory Services |
| Shamara Baidoobonso | Government of Prince Edward Island |
| Nancy Baxter | University of Toronto, St. Michael's Hospital, Cancer Care Ontario |
| Carolyn Gall Casey | Diabetes Canada |
| Wai-Hin Chan | St. Michael's Hospital |
| Heather Colquhoun | University of Toronto |
| Caroline Susan Corbett | University of Calgary |
| Kim Critchley | Government of Prince Edward Island |
| Janet Curran | Dalhousie University |
| Sophie Desroches | Laval University |
| Irfan Dhalla | Health Quality Ontario, St. Michael's Hospital |
| Jennifer Donnan | Memorial University of Newfoundland |
| Minnie Downey | BC SUPPORT Unit |
| Zahra Goodarzi | University of Calgary |
| Alison Hoens | University of British Columbia |
| Tanya Horsley | Royal College of Physicians and Surgeons, University of Ottawa, Society for Academic Continuing Medical Education |
| Jeremiah Hwee | University of Toronto |
| Lisa Keeping-Burke | University of New Brunswick, Queen's University, Canadian Council of Cardiovascular Nurses |
| Lynn Klein | Covenant Health |
| Christopher Klinger | University of Toronto |
| Cheryl Koehn | Arthritis Consumer Experts |
| Chantelle Lachance | Canadian Agency for Drugs and Technologies in Health (CADTH) |
| Annie LeBlanc | Laval University |
| Jenny Leese | University of British Columbia |
| Linda Li | University of British Columbia, Arthritis Research Canada, BC SUPPORT Unit |
| Marilyn Macdonald | Dalhousie University |
| Graham Macdonald | Arthritis Research Canada |
| Janet Martin | University of Western |
| Jessie McGowan | University of Ottawa |
| Annette McKinnon | Arthritis Patients Advisory Board (APAB) of Arthritis Research Canada |

| Name | Primary Affiliation |
|-----------------------|--|
| Shanon McQuitty | Arthritis Patients Advisory Board (APAB) of Arthritis Research Canada |
| Brian Mittman | Kaiser Permanente Southern California Dept. of Research and Evaluation |
| Pertice Moffitt | Aurora College |
| David Moher | Ottawa Hospital Research Centre, Stanford University |
| Suzanne Morin | McGill University, Osteoporosis Canada |
| Kelly Mrklas | Alberta Health Services |
| Amy Outcshoorn | The College of Family Physicians of Canada |
| Peter Oxland | Alberta Health Services, Alberta SPOR SUPPORT Unit |
| Martha Paynter | Dalhousie University |
| Rachel Rodin | Public Health Agency of Canada |
| Priscille-Nice Sanon | Quebec SPOR SUPPORT Unit |
| Kim Sears | Queens University, University of Adelaide |
| Sandra Small | Memorial University |
| Erna Snelgrove-Clarke | Dalhousie University |
| Charlene Soobiah | University of Toronto |
| Lesley Stewart | University of York |
| Sharon Straus | University of Toronto, St. Michael's Hospital |
| Beverly Temple | University of Manitoba |
| Brett Thombs | Canadian Task Force on Preventive Health Care, McGill University |
| Andrea Tricco | St. Michael's Hospital |
| Jennifer Watt | University of Toronto, St. Michael's Hospital |
| Linda Wilhelm | The Canadian Arthritis Patient Alliance |
| Rosemary Wilson | Queen's University |

SPOR Evidence Alliance Central Coordinating Office

| Name | Primary Affiliation |
|----------------|------------------------|
| Shameemah Khan | St. Michael's Hospital |
| Sinit Michael | St. Michael's Hospital |
| Sonia Thomas | St. Michael's Hospital |
| Wasifa Zarin | St. Michael's Hospital |

Minutes

1. Call to order and welcome

Andrea Tricco welcomes members to the inaugural SPOR Evidence Alliance Annual General Meeting.

2. Report on Progress and Impact of the Alliance

Wasifa Zarin and Sonia Thomas presented a slide deck on the Alliance's progress to date, outlining its 1-year journey and key developments.

The full report on our 2017-2018 progress has been published on the Alliance website and can be found [here](#).

All members then engaged in a round-table discussion touching on the following points:

- The indigenous subcommittee has been put on hold to carefully build relationship with a culturally sensitive approach
- We will work on publishing papers on the Alliance in 2019
- Linda Li (Director, Arthritis, Joint Health & Knowledge Translation Research Program) and her PhD student, Graham Macdonald, are also studying the methods of patient engagement in research
- Once our New Member Application goes live in 2019, we will also focus on recruiting more patient partners to the Alliance
- Difference between a systematic review approach and a rapid review approach were outlined and the following resources were mentioned:
 - Tricco AC, Langlois EV, Straus SE, editors. Rapid reviews to strengthen health policy and systems: a practical guide. Geneva: World Health Organization; 2017. Licence: CC BY-NC-SA 3.0 IGO. Available <https://www.who.int/alliance-hpsr/resources/publications/rapid-review-guide/en/>

3. REFRESHMENT BREAK



4. Panel Presentations on experiences with Patient-Oriented Research

Panel A: Erna Snelgrove-Clarke, Annette McKinnon, Martha Paynter, and Ahmed Abou-Setta

Presenter bio and slide decks for this panel can be found in [Appendix A](#).

Key discussion points included:

- More resources and training in doing patient-oriented research is needed
 - The Knowledge Translation Program at St. Michael's Hospital has an online course ([Partners in Research](#)) that has been co-developed by patient partners and researchers. Every term, a few seats are offered free of charge to the Alliance trainees.
 - A course on patient-oriented research will soon be offered by the Waterloo University and the University of Western Ontario
- Some facilitators to meaningfully engaging patient partners included:
 - Schedule meetings outside of work hours to avoid accruing potential income loss
 - Offering fair compensation for participation
 - Providing other necessary support to facilitate engagement which may include, but not limited to, proving childcare, reimbursing any expenses incurred, removing geographic barrier by offering remote access, etc.

Panel B: Peter Oxland, Jennifer Donnan, Suzanne Morin, and Charlene Soobiah

Presenter bio and slide decks for this panel can be found in [Appendix B](#).

Key discussion points included:

- Some tips on improving communications were shared:
 - Important to articulate what their engagement entails, when it begins and ends
 - Could create a formal agreement that stipulates the start date and the end date of their involvement
- Having published literature and documents on lessons learned from patient engagement can help advance our approach to patient-oriented research

Panel C: Pertice Moffit, Christopher Klinger, Elliot PausJenssen, and Annie LeBlanc

Presenter bio and slide decks for this panel can be found in [Appendix C](#).

Key discussion points included:

- Important to seek and understand what is important for the patients when conducting research related to healthcare
- Need more culturally sensitive health policies for the indigenous communities

Panel D: Brian Mittman, Jennifer Watt, Sophie Desroches, and Kelly Mrklas

Presenter bio and slide decks for this panel can be found in [Appendix D](#).

Key discussion points included:

- How to recruit diverse group of patient partners in research?
 - Conduct focus groups with under-privileged and vulnerable populations to learn of their barriers to participate and how we can support them
 - Use language that is accessible and easily understandable by all and avoid use of technical terms and jargons
- Patients need to be given their own voice in research
 - Researchers should support, but not become the voice of patients during research

5. LUNCH AND NETWORKING



6. Committee Breakout Session

Each of the six committees was given protected time to review their committee's progress to date and develop an action plan for the year 2019.

A summary of each committee's progress update can be found in [Appendix E](#).

7. REFRESHMENT BREAK

8. Large Group Discussion

Following a period of breakout sessions, each committee reported back to the plenary group with a summary of their breakout discussions.

| International Advisory Committee | |
|--|--|
| <i>Mandate: To provide guidance on strategic direction and sustainability of the Alliance</i> | |
| Brian Mittman (co-chair) <i>Kaiser Permanente Southern California Dept. of Research and Evaluation, Los Angeles, USA</i> | Nancy Baxter (co-chair) <i>University of Toronto, St. Michael's Hospital, ON</i> |
| Ahmet Metin Gulmezoglu <i>World Health Organization, Geneva, Switzerland</i> | Brett Thombs <i>Canadian Task Force on Preventive Health Care, McGill University, QC</i> |
| Eva Grunfeld <i>University of Toronto, Cancer Care Ontario, Ontario Institute of Cancer Research, ON</i> | Lesley Stewart <i>University of York, UK</i> |
| Matthew Page <i>Cochrane Australia, Monash, Australia</i> | Paul Glasziou <i>Bond University, Queensland, Australia</i> |
| Pamela Valentine <i>Alberta Innovates, AB</i> | Rosemary Wilson <i>Queen's University, ON</i> |
| Shannon McQuitty <i>Arthritis Patients Advisory Board (APAB) of Arthritis Research Canada, BC</i> | |

International Advisory Committee (IAC) presented the following:

- Members in attendance recommended that the committee meet every 6 months via web-conference/ teleconference, as opposed to once a year in-person
- Requested to receive quarterly reports (i.e., every 3 months) from the Steering Committee to track activity of the Alliance
- Advised that the Alliance should work with the end goals in mind and think about what is needed to be able to achieve them
- Recommended refining the Alliance vision statement further
- Recommended refining the specific 5-year goals include explicit measurable outcomes that relate back to the overall vision statement
- Suggested that the Alliance consider having mission statements
- Alliance should aim to become a broker between guideline developers and knowledge synthesis producers
- Requested clarification on who the stakeholders and knowledge users of the Alliance are
- Highlighted the importance of considering evaluation strategies

| Steering Committee | |
|--|---|
| <i>Mandate: To provide recommendations on key operations and leadership on direction (including priorities and milestones) of the Alliance</i> | |
| Annie LeBlanc (co-chair) <i>Laval University, Quebec SPOR SUPPORT Unit, QC</i> | Minnie Downey (co-chair) <i>BC SUPPORT Unit, BC</i> |
| Priscille-Nice Sanon (co-chair) <i>Laval University, QC</i> | |
| Alison Hoens <i>Arthritis Patient Advisory, BC</i> | Andrea Tricco <i>St. Michael's Hospital, Li Ka Shing Knowledge Institute, ON</i> |
| Beverley Temple <i>University of Manitoba, MB</i> | Carolyn Gall Casey <i>Diabetes Canada, ON</i> |
| Cheryl Koehn <i>Arthritis Consumer Experts, BC</i> | Christina Godfrey <i>Queen's University, ON</i> |
| Heather Colquhoun <i>University of Toronto, ON</i> | Jeremiah Hwee <i>Institute for Better Health, Trillium Health Partners</i> |
| Linda Wilhelm <i>The Canadian Arthritis Patient Alliance, SPOR Network CPN, NB</i> | Sharon Straus <i>St. Michael's Hospital, Li Ka Shing Knowledge Institute, Ontario SPOR SUPPORT Unit, ON</i> |
| Sophie Desroches <i>Laval University, QC</i> | Tanya Horsley <i>Royal College of Physicians and Surgeons, ON</i> |

Steering Committee (SC) reported the following:

- Decided that one member from the committee will be delegated the responsibility of reporting back to the IAC
- Requested that the Central Coordinating Office set up a dashboard that can aid in reporting
- Recommended strategic meeting schedules to allow them to meet once the committees under their oversight have met
- Requested high level budget reports for ongoing monitoring of Alliance activities
- Will facilitate relationship building between the Alliance and the SPOR SUPPORT Units
- Recommended that the Alliance formalizes its communications and marketing plan and expands beyond its immediate stakeholder group

| Executive Committee | |
|---|--|
| <i>Mandate: To oversee key operations and monitor ongoing progress towards objectives of the Alliance</i> | |
| Andrea Tricco (chair) <i>St. Michael's Hospital, Li Ka Shing Knowledge Institute, ON</i> | |
| David Moher <i>Ottawa Hospital Research Institute, Ontario SPOR SUPPORT Unit, ON</i> | Fiona Clement <i>University of Calgary, AB</i> |
| Ivan Florez <i>McMaster University, ON; Universidad de Antioquia</i> | Janet Curran <i>Dalhousie University, Maritimes SPOR SUPPORT Unit, NS</i> |
| Jenny Leese <i>University of British Columbia, BC</i> | Jullian MacLean <i>Northwest Territories SPOR SUPPORT Unit, NWT</i> |
| Kim Sears <i>Queen's University, ON</i> | Linda Li <i>University of British Columbia, British Columbia SPOR SUPPORT Unit, BC</i> |
| Priscille-Nice Sanon <i>Laval University, QC</i> | Rachel Rodin <i>WHO Collaborating Centre on Noncommunicable Disease Policy, Public Health Agency of Canada, ON</i> |
| Suzanne Morin <i>McGill University, QC</i> | Wai-Hin Chan <i>St. Michael's Hospital, Li Ka Shing Knowledge Institute, ON</i> |

Executive Committee (EC) presented the following:

- Ensure more patient partner representation on the committee – additional patient partners will be recruited to the committee as new members join the Alliance in 2019
- Discussions related to intellectual property and access:
 - Recommendations to have a formal policy in place for data ownership and data sharing
 - Promote publications of work being done and keep the science open access
 - Research products need to be appropriately branded as Alliance products with official templates and logo, and make them open access
- Communication and distribution strategy:
 - Begin sharing all presentations, reports and products on the Alliance website
- EC would like to see high-level budget allocation for all Alliance activities to help inform their funding decisions for various queries
- EC will begin providing quarterly reports to the Steering Committee starting 2019

| Knowledge Translation Committee | |
|--|---|
| <i>Mandate: Oversee and monitor knowledge translation activities for new knowledge and research products developed by the Alliance</i> | |
| Cheryl Koehn (co-chair) <i>Arthritis Consumer Experts, BC</i> | Heather Colquhoun (co-chair) <i>University of Toronto, ON</i> |
| Ahmed Abou-Setta <i>University of Manitoba, Manitoba SPOR SUPPORT Unit, MB</i> | Annette McKinnon <i>Arthritis Patients Advisory Board (APAB) of Arthritis Research Canada, ON</i> |
| Christopher Klinger <i>University of Toronto, ON</i> | Elliot PausJenssen <i>Saskatoon Council on Aging, SK</i> |
| Erna Snelgrove-Clarke <i>Dalhousie University, NS</i> | Graham Macdonald <i>Arthritis Research Canada, BC</i> |
| Ian Graham <i>Ottawa Hospital Research Institute</i> | Jennifer Watt <i>University of Toronto, St. Michael's Hospital, ON</i> |
| Jessie McGowan <i>University of Ottawa, ON</i> | Lynn Klein <i>Covenant Health, AB</i> |
| Pertice Moffitt <i>Aurora College, NWT</i> | Sandra Small <i>Memorial University of Newfoundland, NL</i> |
| Shamara Baidoobonso <i>Government of Prince Edward Island, PEI</i> | |

Knowledge Translation Committee (KTC) presented the following:

- KTC is working on scoping and refining their role and activities within the Alliance
 - Develop an infographic summarizing KTC core functions
- Conduct a needs assessment for KT across the Alliance
- Create a summary of the SPOR Support Units and their KT work to help us connect and collaborate with them
- Compile all available KT resources and create a repository of tools/resources to guide researchers
- Develop a KT strategy for the Alliance activities (i.e., Evaluate, Monitor, Support)
 - Analyze if the outputs of the queries meet the needs of the patients
 - Provide recommendations on how to make the Alliance activities more accessible by knowledge users
- Create resources to make research more accessible by patient partners and other knowledge users

| Partnerships Committee | |
|--|--|
| <i>Mandate: To oversee and monitor patient partner and stakeholder engagement activities of the Alliance</i> | |
| Peter Oxland (co-chair) <i>Alberta Health Services, Alberta SPOR SUPPORT Unit, AB</i> | Tanya Horsley (co-chair) <i>Royal College of Physicians and Surgeons, ON</i> |
| Ahmed Abou-Setta <i>University of Manitoba, Manitoba SPOR SUPPORT Unit, MB</i> | Charlene Soobiah <i>University of Toronto, ON</i> |
| Irfan Dhalla <i>Health Quality Ontario, St. Michael's Hospital, ON</i> | Janet Martin <i>Western University, ON</i> |
| Kelly Mrklas <i>Alberta Health Services, AB</i> | Kim Critchley <i>Government of Prince Edward Island, PEI</i> |
| Lyn-Miin Alikhan <i>Ministries of Health, Government of Ontario and Government of Alberta, AB/ON</i> | Martha Paynter <i>Dalhousie University, NS</i> |

Partnerships Committee (PC) presented the following:

- Decided to revise their terms of reference to operationalize the functions of the committee in order to gain more clarity on their role
- Intend to develop guidelines of how to work with other SPOR entities including SUPPORT Units
- Highlighted the need to build strategic partnerships with external organizations as well as with patients and end-users, while ensuring transparency of conflicts of interest
 - Important to build partnerships to help sustain the Alliance after 5 years
- Recommended that the Alliance engage with the Indigenous community and move forward with forming the Indigenous Peoples' Subcommittee

| Training Committee | |
|---|---|
| <i>Mandate: Oversee and monitor training and capacity-building initiatives of the Alliance</i> | |
| Kelly English (co-chair) <i>Arthritis Patients Advisory Board (APAB) of Arthritis Research Canada, BC</i> | Sophie Desroches (co-chair) <i>Laval University, QC</i> |
| Zahra Goodarzi (co-chair) <i>University of Calgary, AB</i> | |
| Amy Outschoorn <i>The College of Family Physicians of Canada, ON</i> | Chantelle Lachance <i>St. Michael's Hospital, Li Ka Shing Knowledge Institute, ON</i> |
| Cliff Lindeman <i>Alberta SPOR PIHCIN, AB</i> | Jennifer Donnan <i>Memorial University of Newfoundland, NL</i> |
| Leah Boulos <i>Maritime SPOR SUPPORT Unit, NS</i> | Lisa Keeping-Burke <i>University of New Brunswick, NB</i> |
| Lisa Strifler <i>University of Toronto, ON</i> | Marilyn MacDonald <i>Dalhousie University, NS</i> |
| Meghan Elliot <i>Alberta Health Services, AB</i> | Wanrudee Isaranuwachai <i>St. Michael's Hospital, University of Toronto, ON</i> |

Training Committee (TC) presented the following:

- The TC shared their plan and progress on the core competencies of the Alliance training program for the three education streams:
 - Stream 1 targets graduate-level research trainees and fellows to develop capacity in advancing the science and practice of KS, CPG, and KT
 - Stream 2 targets researchers and research staff to build on their diverse expertise and skills in health research and focus them on strengthening the capacity of KS, CPG, and KT
 - Stream 3 targets patients and decision makers (including clinicians, healthcare managers, and policy makers) interested in developing basic knowledge of the science of KS, CPG, and KT and how to apply the research evidence in practice
- They proposed approaches to evaluating participant competency development
 - Certification of completion
 - Tracking participation and core competency development through a checklist of activities as they relate to specific competencies
 - Certification by the type of science (e.g., knowledge synthesis, knowledge translation)
- Ensuring training activities offer adequate opportunities to develop all the core competencies
- Need to set up the mentorship program

Next Steps and Closing Remarks

- Each committee will finalize their action plan in the New Year based on the feedback received and discussions that took place
- SAVE THE DATE!
 - Next Annual General Meeting will be held in **Winnipeg, Manitoba on May 29th, 2019** alongside the [KT Canada Scientific Meeting 2019](#)



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**Drs Anita Kothari and
Ian Graham**

Dr. Ahmed Abou-Setta, University of Manitoba
Carolyn Shimmin, University of Manitoba
Dr. Charmayne Dubé, University of Manitoba
Dr. David Johnson, University of Calgary
Dr. Joyce Dogba, Laval University
Dr. Michelle Driedger, University of Manitoba

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Appendices