

Ontario SCI Alliance Meeting Minutes –September 7, 2018

Chair: Peter Athanasopoulos – Executive Director of SCI Alliance

Recorder: Mariam Razi – Public Policy Analyst

Presenters: Stuart Howe – CEO, SCIO; Peter Athanasopoulos – Executive Director, SCI Alliance; Kent Bassett-Spiers – CEO, ONF; Dr. Heather Gainforth - Assistant Professor, UBC; Dr. Jamie Milligan, Centre for Family Medicine; Tory Bowman - Senior Manager, Knowledge Exchange, SCIO; Pamela Houghton – Professor, School of Physical Therapy, Western University; Sophia Yeu Li, University Health Network; Jessica Bassett-Spiers, ONF.

Agenda Items	Key Highlights	Outcomes
<p>Introductions [Peter Athanasopoulos]</p>	<p><u>Ontario SCI Alliance Background + Opening Remarks:</u></p> <ul style="list-style-type: none"> • Peter Athanasopoulos introduced the meeting agenda. Stuart (CEO, SCIO) and Kent (CEO, ONF) provided opening remarks. • The SCI Alliance meeting which took place on September 7 was a product of intense collaborative effort by the Ontario SCI Alliance and SCI community to provide strategic direction that the Alliance must adopt for the next 3 years. • To date, the Alliance has hosted several meetings / retreats with its partners using the integrated knowledge translation philosophies. These philosophies ensure service providers, researchers, policy makers and people with SCI collectively working together on common goals. 	<ul style="list-style-type: none"> • A key outcome of the Alliance meeting on September 7, 2018 has been the development of a unique community plan that leverages perspectives and feedback from 70 organizations, 250 members and a readership of 9000 community leaders and activists across Ontario.
<p>Presenting the Community Plan [Peter Athanasopoulos]</p> <ul style="list-style-type: none"> • SCI Community Three-Year Plan • Independent Review of 	<p><u>The SCI Community 3 Year Plan:</u></p> <ul style="list-style-type: none"> • The community plan will target three strategic directions: 1) enhancing capacity 2) building the coalition and 3) creating fair and equitable services across Ontario. 	<ul style="list-style-type: none"> • This “Community Plan” received unanimous endorsement at the Alliance table, including from the CEO of ONF and SCIO

<p>Mobility Devices</p> <ul style="list-style-type: none"> • Pathways of Care 	<ul style="list-style-type: none"> • Alliance members agreed that resourcing data collection is integral to ensure that we have baseline data to support the evidence and direction of the plan. • Members also highlighted the need to include social detriments of health as part of the accessible healthcare for the plan and indicated that we set the bar high to ensure quality care for all <ul style="list-style-type: none"> ○ There was a consensus to focus on care and access to services vs cost and that regardless of what consensus is provided to individual with SCI it shouldn't predicate the scope of service offered. <p><u>Independent Review of Mobility Devices:</u></p> <ul style="list-style-type: none"> • Alliance members strongly emphasized the need for front line support (regional support coordinators and peer support coordinators across all LHINS) and called for a multi-pronged approach in engaging people from SCI community across Ontario. • Unanimous support was offered for the direction and independent review of mobility devices and the need to leverage strength in numbers to achieve better outcomes and broader reach within the SCI community. • The members also supported the notion of monthly communications as standard practice for the SCI Alliance communication moving forward. 	<p>who are fully committed to resourcing this Plan guided by community needs.</p> <ul style="list-style-type: none"> • SCIO, ONF and RHI will be working with multiple funders to ensure sufficient resources are in place to achieve the goals outlined in the plan. • Peter and Mariam from SCIO will continue to provide both operational and Government Relations support to the Alliance members and will be actively working with the current government to bring attention to the community plan as we work collectively towards designing solutions to address the needs of the community.

Integrated Knowledge Translation Principals
 [Dr. Heather Gainforth]

- **Research Participation Platform**

Developing Research Participation Platform for Ontario

- Dr. Heather Gainforth presented strong supporting evidence explaining to members how the research community in the SCI space is currently “stuck on repeat” with a focus on publication without application.
- There is currently an estimated 17 – 20 year gap between discovery and implementation.
- In order to bridge this tremendous gap, there is an urgent need to include the community’s perspective and involve all stakeholders – especially people with SCI. The research must be conducted in partnership with SCI communities to facilitate an inclusive and comprehensive impact.
- As a result, it is critical that we make it easier for stakeholders such a people with SCI by providing them the necessary accommodation and supports when asking them to participate.
- The community must address the logistics of accommodation especially for people with SCI and budget this under best practice for research engagements.
- Community must also “build capacity” so that broader SCI research community can conduct research in partnership with SCI communities.

- Dr. Gainforth proposed “developing and implementing “ integrated knowledge translation guiding principles to conduct and disseminate research in partnership with the spinal cord injury community”
- These guiding principles can improve the quality of partnerships in SCI research, and close the gap between research and practice
- All members are encouraged to review the “knowledge-to-action-Framework” and SCIO’s knowledge to action model which introduces system and policy changes into the translation of research into practice.
- The Alliance put a motion forward to endorse the IKT model and SCIO’s process for supporting research partnerships and recruitment. This motion was approved.

<p>Primary Care Strategy - Mobility Clinics [Dr. Jamie Milligan]</p>	<p><u>Mobility Clinics and Physician Engagement Network</u></p> <ul style="list-style-type: none"> • The Mobility Health Clinic was first introduced as an interdisciplinary model in 2010 in partnership with SCIO and ONF • The goal of the clinic is to make primary care accessible for people with physical disabilities across Ontario • Currently the Clinic provides primary care to over 70 individuals with SCI and works to support implementation of research findings into practice • The overall objective is to replicate the mobility clinic across multiple regions in Ontario • The Mobility Clinic will work towards creating resources, supports, training programs for any family physician across Ontario interested in provided services to people with SCI 	<p>The Alliance members proposed six recommendations for the Primary Care Strategy:</p> <ul style="list-style-type: none"> • Utilize “SCI Hallways” as a tool for SCI specialties to engage family physician • Develop a one-pager outlining the strategy, the recommendations and the expectations from the Alliance members and the SCI community • Develop a recruitment strategy with SCI specialists and physiatrist to identify primary care physician champions who already work with people with spinal cord injury. • Develop new marketing materials for “take-this-card-to-your-doctor” • Version 2.0 will be piloted soon with all 5 dedicated SCI rehab centers • Utilize the expertise of regional service coordinators as well as peer support coordinators across all 14 LHINS to identify family physician champions interested in supporting people with spinal cord
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		<p>injuries</p> <ul style="list-style-type: none"> • SCIO should dedicate SCI health science centers and the mobility clinics to arrange a meeting to address the recommendations from Alliance members with a target goal of recruiting 50 family physicians by March 2019.
<p>Knowledge Exchange Products and Webcasts [Tory Bowman]</p>	<p>Knowledge Exchange Products and Webcasts</p> <ul style="list-style-type: none"> • The three major Knowledge Exchange initiatives presented to SCI Alliance members included the following: <ul style="list-style-type: none"> ○ An OTN led knowledge exchange series with education credits from OMA for physician on primary care, neuropathic pain management and bladder management. ○ The knowledge exchange series has adopted the knowledge integrated principles within the creation of its knowledge exchange products ○ Two on-line education curriculum will be created over the next two years on neuropathic pain and bladder management ○ For more information, check out our social media channels for the live products. 	<ul style="list-style-type: none"> • All participating members of the Alliance expressed unanimous support for the direction of knowledge mobilization tools and webcasts presented during the meeting and expressed appreciation for SCIO's commitment to redevelop and disseminate the prevention and treatment of pressure injury guide. • The Alliance members recommended using the SCIRE community as a knowledge portal to disseminate information - these products will be housed on SCIO's website moving forward and can be used by any other portal through SCIO's website.

<p>Prevention and Treatment of Pressure Injuries [Pamela Houghton and [Sophia Li]</p> <ul style="list-style-type: none"> • New Technologies for Pressure Injuries 	<p><u>Prevention and Treatment of Pressure Injuries</u></p> <ul style="list-style-type: none"> • The Alliance recognized early on that the SCI community action plan provided limited insight in supporting prevention and treatment of pressure injury initiatives. As a result, “Pressure Injuries” was presented as a last topic during the meeting to encourage a greater degree of priority for pressure injury initiative in Ontario. • The presentation focused on the importance of national collaboration and unity of key evidence based research outcomes and practices as well as the importance of introducing Electric Stimulation therapy for pressure injuries into OHIP. <p><u>New Technologies for Pressure Injuries</u></p> <ul style="list-style-type: none"> • Sophia lee from UHN was invited by the Alliance to present new technology using Electric Stimulation therapy for pressure injuries. <p><u>Questions for Discussion</u></p> <ul style="list-style-type: none"> • What are the right interventions to tackle pressure injuries? • What are we missing? Knowledge is not enough. (Collaborations with physicians, altering care provider attitudes, and limited research sample size etc.) • Is E-STIM the next frontier in new technologies for Pressure Injuries? • Do we have a practice-based model to test this type of technology? 	<ul style="list-style-type: none"> • Pamela’s network will be reaching out to the SCI Alliance regarding next steps in the future and her network will be engaging and seeking support for the Alliance. • Key Alliance members and Pamela’s network will be meeting over the next three months to identify collaboration opportunities moving forward. • Alliance members recommended synergy between Sophia’s work at UHN and the national E-STIM collaborative project led by Pamela Houghton. Pamela and Sophia will be working together to present new ideas in collaborative activities with Alliance members and the national electric STIM collaborative network.
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<p>North American SCI Consortium Update (NASCIC) [Jessica Bassett-Spiers]</p>	<p><i>North American SCI Consortium Update</i></p> <ul style="list-style-type: none"> • NASCIC was formed on October 12, 2017 to take action against the continual lack of engagement of the SCI community in research. • The purpose of the North American Spinal Cord Injury Consortium is to bring together the many organizations in North America that advocate, represent, or communicate with people living with spinal cord injury • NASCIC believes that people with lived experience need to be equitable partners along the continuum of research to ensure the end results are oriented toward consumer needs, are clinically relevant, and transparent to better enhance uptake. <p><i>Next Meeting</i></p> <ul style="list-style-type: none"> • TBD – Jan 2019 – Joint Meeting between Ontario SCI Alliance & Ontario Implementation Network 	<ul style="list-style-type: none"> • Alliance will be providing monthly updates on the progress of NASCIC and all interested members are encouraged to join NASCIC for more details • Social media strategy has been developed to promote the product and Alliance members are encouraged to participate.
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