



ONTARIO SPINAL CORD INJURY
— SOLUTIONS ALLIANCE —
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KEY FINDINGS FROM ONTARIO SCI ALLIANCE RETREAT

APRIL, 2018



ABOUT ONTARIO SCI ALLIANCE

The Ontario SCI Solutions Alliance is a formidable coalition of organizations and individuals with spinal cord injuries, who aim to effectively remove barriers faced by people living with spinal cord injuries.

The Ontario SCI Solutions Alliance believes that a cross continuum, multi sector, collaborative approach to addressing system barriers, will ensure that people with spinal cord injuries will receive the right services at the right time and that we, as service providers, researchers, and decision makers with people with SCI will be more effective in our roles.

MISSION

The mission of the Ontario SCI Alliance is to build an effective coalition of organizations, including working directly with Ontarians with Spinal Cord Injuries (SCI) who can effectively resolve barriers faced by people living with SCI. This Ontario SCI Alliance is focused on:

- **Improving response to individual needs**
- **Fostering systemic improvements**
- **Facilitating enhanced accountability**
- **Applying best practice SCI research**

EXECUTIVE SUMMARY

On April 13, 2018, the Ontario SCI Alliance came together with its membership across the province to host its 2018 Ontario SCI Alliance Retreat. The primary goal of the event was to bring together a cross-section of researchers, service providers, policy makers and people living with SCI in an open dialogue to discuss best practice opportunities as well as to identify the most effective community engagement strategies to support people with SCI.

The retreat round table discussions explored the following key topics areas:

- **Neuropathic Pain** (Pain Management)
- **Urohealth** (Bladder Management)
- **Pressure Ulcers** (Pressure Injuries)
- **Primary Health Care**

The discussions around the key topic areas were pivotal in informing the findings of this report and in identifying the best strategies to engage and mobilize the SCI community.

Throughout the day, the participants of the Alliance engaged in multiple consensus sessions to start the process of building a community driven plan and identify knowledge mobilization and community engagement activities required to amplify our community's voice.

This report will highlight where to direct our energy as an SCI community, and how to effectively engage the community members and their supporters in building our next 3- 5 years. The Ontario SCI Alliance will use the findings from this community plan to inform the incumbent government of Ontario of our SCI Community's expectations.

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INTRODUCTION

The 2018 Ontario SCI Alliance Retreat was co-led by Spinal Cord Injury Ontario and the Ontario Neurotrauma Foundation, in partnership with the Rick Hansen Institute. It was designed to accomplish three important tasks:

1. Start the process for The Alliance to build a three-year plan that will involve the community.
2. Identify how the SCI Community can support the results of the Summit work (hyperlink summit reports) over the next three-year period as part of The Alliance agenda
3. Create a checklist for successful community engagement to support identified ideas and recommendations from the Summits.

The **morning session** provided an opportunity to help everyone understand three important pieces of information.

- The event is part of the three-year plan
- The event is focused on getting information on how to involve the community to help with ideas and information from the Summits
- Continuous involvement with the SCI Community in the implementation of the plan.
- By the end of the morning, everyone in the room was expected to have the following information
- Information on the words, community, community engagement and why this work is important
- A summary of the summits, results through the Delphi Process, and community perspectives from the comments section
- Comments and reflections by the Community
- Presentation materials from the April 2018 Retreat can be found at: www.sciontario.org/ontarioscialliance

The **afternoon session** provided an opportunity for people to work in small groups on specific topics. The topics are Neuropathic Pain, Urohealth, Pressure Injuries, and Primary Care.

ABOUT THE SCI COMMUNITY

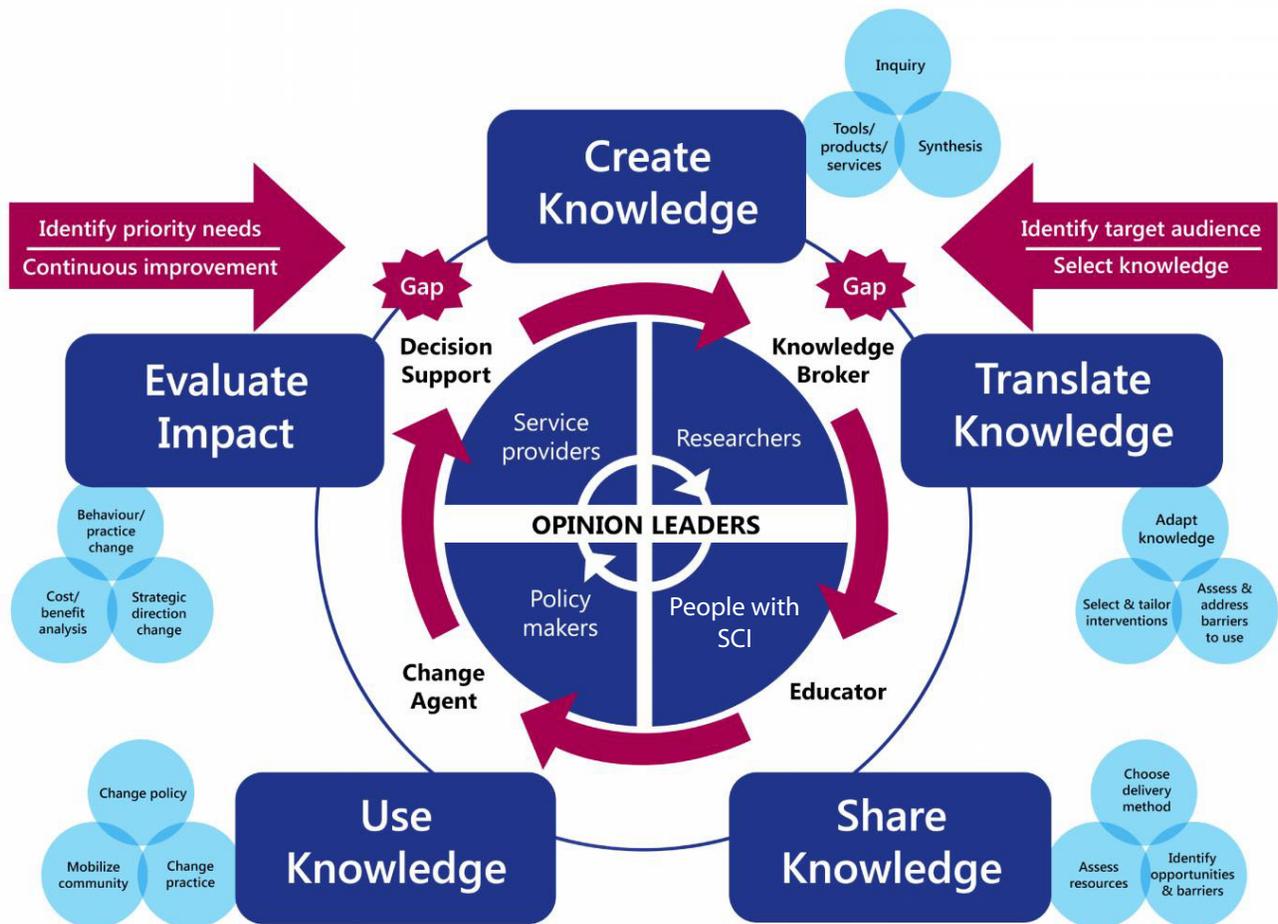
The SCI Community consists of the following groups.

- **PEOPLE WITH SCI** – Individual leaders from the SCI community and/or family members
- **POLICY MAKERS** – Individuals involved in health and social policy (e.g., individuals from the Ministry of Health and Long-Term Care)
- **SERVICE PROVIDERS** – Those involved in providing services in the community (e.g., Acute Care, Rehabilitation Centre Administrators, and Community Service Providers)
- **RESEARCHERS** – Those involved in SCI related research (e.g., Summit Leaders)

These four groups were referred to as the SCI Community in accordance with ALL activities of the Ontario SCI Alliance

KNOWLEDGE TO ACTION MODEL

Figure 1 is graphic from SCI Ontario Knowledge to Action Model. The four groups that make up the SCI Community are located at the centre of the diagram (opinion leaders). The major phases of knowledge translation are listed around the circle of the model. The phases include Create Knowledge, Translate Knowledge, Share Knowledge, Use Knowledge, and Evaluate Impact. The strength of the model is engaging the community in all phases of the knowledge-to-action process.



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Contact: Tory Bowman, tory.bowman@sciontario.org

STARTING POINT OF THE CONVERSATION

The Rick Hansen Institute (RHI), Ontario Neurotrauma Foundation (ONF), and Spinal Cord Injury Ontario (SCIO) supported four summits on the following topics.

- **Neuropathic Pain** (Pain Management)
- **Urohealth** (Bladder Management)
- **Pressure Ulcers** (Pressure Injuries)
- **Primary Care**

Each summit engaged a cross-section of researchers, service providers, clinicians, and people living with SCI to engage, discuss research, and clinical practice opportunities. At this time, the Summit Leaders were involved in various stages of implementation regarding ideas and recommendations identified during their Summit.

WHERE TO FOCUS OUR ENERGY AS A COMMUNITY

Looking across the four topic areas, the participants at the retreat identified a set of foci for the community over the next three to five years. The following is a summary of the areas of foci.

Craft a Coordinated Advocacy Effort

IDEAS INCLUDE:

- Advocate for research funding for pressure injury prevention and treatment and explore alternative treatment options
- Design a new funding criterion to address best care practices for pain management
- Work with the Provincial government to fund bladder management supplies
- Advocate for electric stimulation therapy as a government funded pressure injury treatment option
- Advocate for research funding, including data collection, change management and implementation
- Ensure family doctors are paid to have longer appointments with people with SCI and other disabilities

Focus on Services for Clients (the community)

IDEAS INCLUDE:

- Make seat assessments for wheelchairs equally available and affordable for all people with SCI.
- Work with health authorities to ensure that people with pressure injuries are treated equitably
- Ensure greater access to equitable treatment options, such as E-Stim ([i.e. Evidence Informed Treatment])
- Establish Payment and service delivery models from psychological/social perspective.
- Identify and implement person centered models [i.e. multi-model neuropathic pain clinics]
- Have a SCI-specific best practice clinic (mobility clinic) available to all family doctors serving people with SCI across Ontario
- Establish a mobility clinic in every LHIN
- 6 Incentivize referrals to a SCI-informed doctor

Strengthen Knowledge Transfer and Clinical Practices

IDEAS INCLUDE:

- Create expert networks of specialists on neuropathic pain and build a forum to share knowledge and information on pain management.
- Educate the Family and ER doctors on bladder management
- Provide more specialized training for urologists and neuro-urologists
- Provide SCI specific training manual for doctors to transfer necessary knowledge items

Support Research and Data management

IDEAS INCLUDE:

- Collect impact data to demonstrate cost-effectiveness and inform new simple and effective strategies
- Increase Research and Innovation funding in the practice area to build efficiencies and improve pain management
- Improve access to resources and information for people with SCI to accelerate pain management
- Develop a consolidated approach by bringing together services, resources and diverse perspectives from stakeholders such as existing strategists.

Create and Strengthen Education for Stakeholders

IDEAS INCLUDE:

- Have regular education sessions for patients (including adults with SCI), health care providers, caregivers, on treating and preventing pressure injuries
- Provide timely information to patients
- Have regular education sessions for health care providers
- Establish community of practice in every LHIN to meet the needs of people with SCI

KEYS FOR MEANINGFUL ENGAGEMENT

The following is a list of the important points to remember to support successful engagement of the community

- Make the Case for Getting Involved
- Staff the Effort
- Meaningful Data
- Educate Key Groups
- Unified Key Messages
- Participation that Makes a Difference
- Partner with Various Groups
- Learn from Other Strategies and Disability Groups

Actions or Activities that do not support Meaningful Engagement

The following is a list of actions that do not support successful engagement

- Calling SCI Leaders “Consumers” and “Patients” is entirely inappropriate and undermines the expertise and lived experience of a person with SCI
- Limited Stakeholder Inclusion in decision making
- Difficult to Understand Materials – Plain Language
- Limited Input & Information Sources
- Failure to Focus
- Burning Bridges
- Presenting Solutions of Limited Interest
- Failing to See Emerging Opportunities
- Focusing on More Money or Strictly Financial Incentives

FINDING BIG PICTURE SUCCESS

If we work on key areas of focus identified by this report and use meaningful engagement tools, we should be able to achieve the following results in three to five years:

Dynamic Partnerships

- Value based partnerships
- Attracting more companies and generating industry interest

Strong Community

- Creating urgency
- Creating a sense of community.
- Making sure that people feel heard and feel like they made a meaningful contribution
- A common national identity with provincial customized supports
- Capturing people’s emotions and their unique stories
- Changing behavioral patterns
- Inspiring people living with SCI to be proactive.
- Uniting behind a shared passion for advancing the Alliance agenda.

Strong Community Based Programs

- Establish regional seating clinics funded by the ministry, supported by vendors
- Have commitment from 7 rehab centres to address priority 1 (to move people through rehab continuum to community supports and services)
- Meaningful change and improved access to information on pain management
- Spread Self – management knowledge
- Changing health outcomes
- Ensuring that everyone has the supports and devices required to effectively manage care
- Provide quality and equitable services
- Secure funding for Medical Coverage and Supplies:
- Provide equitable access to optimal care (right care at the right time by the right provider)

Professional Development

- Shared development of a Model including collaborative decision making between Ministry of Health, auto insurance and health service providers)
- Adoption of new reimbursement criterion
- Investments and specialized training for urologists and neuro-urologists
- Specialized education and SCI training for Family and ER doctors
- Resources for Family Physicians
- Replace old forms of education and communication tools

Advocacy Work

- A unified voice and a strong sense of community
- Establish measurable engagement metrics across government sectors
- Funding for Medical Coverage and Supplies
- On the path to build a community of practice in every LHIN

Solid data and Information

- Central database for open access research
- Establish data strategy to reflect use
- Electronic accessible charts (both formal and permanent)

NEXT STEPS

The results from the consultation will be used to help a longer-term play for the Alliance

NEXT STEPS INCLUDE.

- Confirm the areas of focus as the starting point for building a strong three year to five-year strategic plan.
- Build a comprehensive engagement check list that will be used throughout the life of the strategy to support the community in the work
- Communicate and share the long-term vision to help people understand how the end goal for the work over for the next three year period