

Collaborative networks to achieve innovations in care

Transforming SCI rehabilitation care through innovation

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Canadian Spinal Cord Injury – Rehabilitation Association

Preamble

There are many things that are distinctly Canadian including, but not limited to, maple syrup, a passion for Tim Horton's Coffee and Hockey, the Beaver, legal marijuana, universal health care, our propensity to repeatedly apologize by saying "sorry" and of course our love of "collaboration." This preamble provides a uniquely Canadian perspectives on how we as a community are working to innovate and advance care for individuals with spinal cord injury or disease.

We have a number of communities of practice that are working in concert to lead discovery research; summarize epidemiological data; synthesize evidence through the conduct of systematic, scoping, narrative reviews, and meta-analysis; develop living guidelines and generate related practice tools (decision trees, risk-stratification tools, operative definitions, etc.); use implementation science methods to define and incrementally work toward best practice implementation; evaluate our success through the collection of indicators and comparison of our performance relative to established benchmarks; create policy to uphold practice standards, and meaningfully engage with stakeholders to understand their perspectives on practice innovation and its impact (Figure 1).

Although we have a small number of geographically disparate centres in Canada ($n = 31$), people are able

to coalesce around common goals and work toward a common vision. The ongoing success and sustainability of our health system are contingent on our ability to share information across sectors of the health system over the individual's lifespan, with those who are attuned to the information provided and able to implement innovations in a timely, responsive, safe, equitable, and efficient manner. It is our interconnectedness and willingness to collaborate that sparks opportunity to abandon ineffective practice and embrace innovations in care. The following abstracts provide a succinct summary of existing collaborations.

Disclaimer statements

Contributors None.

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Conflicts of interest Dr Craven is the Chair of the Canadian Spinal Cord Injury Rehabilitation Association. This association supports and promotes excellence in all aspects of rehabilitation care for regulated health care professionals, family members and individuals with spinal cord injury across their lifespan.

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Figure 1. An overview of the ongoing research, clinical, policy and engagement processes to drive advancements in SCI rehabilitation care within and across Canadian networks.

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The Rick Hansen Spinal Cord Injury Registry

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PRAXIS Spinal Cord Institute for Canadian Spinal Cord Injury – Rehabilitation Association

The Rick Hansen Spinal Cord Injury Registry (RHSCIR) is a pan-Canadian prospective observational registry enrolling individuals sustaining a new spinal cord injury (SCI) at 30 acute care and rehabilitation facilities across nine provinces.^{1,2} RHSCIR was initiated in 2004 as a research study sponsored by the Praxis Spinal Cord Institute. The objectives of RHSCIR are to: (1) collect data on individuals with SCI to answer a priori research questions and support future studies; (2) facilitate implementation of best practices, and (3) link clinicians, researchers, health care administrators, and individuals with SCI as well as community groups.

A core dataset that includes demographics, information about the injury, and the hospital stay is collected for all participants. A more detailed expanded dataset with follow-up questionnaires performed at 18 months, 5-, and 10-years following injury is collected for those who provide informed consent. Data elements in RHSCIR align to the International SCI Data Sets³ where possible and are reviewed every few years. Initially RHSCIR only included participants with a new traumatic SCI, but to better understand the impact of SCI, in 2020 RHSCIR was expanded to enroll those with a non-traumatic cause of SCI who attended an RHSCIR rehabilitation, as a start due to the varied nature of the journey of care for this population.

With data on over 9000 participants to date, RHSCIR has supported more than 120 publications addressing topics such as the impact of injury (e.g. predicting rehabilitation length of stay⁴) and care (e.g. timing of surgery⁵) on patient outcomes. Descriptive summaries of the clinical and demographic data are publicly available in the annual national reports.⁶ Biannual site reports tailored to clinicians at participating sites with a focus on best practice implementation are also produced. Access to national RHSCIR data is facilitated by Praxis Spinal Cord Institute via the RHSCIR data use and disclosure policy and is available

to researchers with a request that aligns with the permitted purposes of the registry. Through engaging with its network, RHSCIR has also supported quality improvement initiatives, such as the Qmentum Accreditation Program, and best practice initiatives on implementation of the Spinal Cord Independence Measure,⁷ the Standing and Walking Assessment Tool,⁸ and the International Standards for the Neurological Classification of SCI (ISNCSCI)⁹ through training, as well as the development and use of the ISNCSCI algorithm.¹⁰

In Canada, a data strategy is being developed by engaging a broad range of stakeholders to enhance how SCI data, collected from RHSCIR and other data sources, can inform both research and care. This will involve further embedding SCI core data elements into standards of care to support quality improvement initiatives and aligning with the vision of a learning health system defined as a process where advances in science, informatics, and care generate new knowledge, which is refined and informs best practices as part of continuous health care improvement.¹¹ Given the heterogeneity of SCI, another focus will be to link clinical data and patient-reported outcomes to other SCI data types, including imaging and biological data (e.g. neurochemical biomarkers) to develop personalized treatment algorithms. A key part of the data strategy will involve engagement of patients, families, and community organizations to ensure the SCI data collected is meaningful and ultimately can support optimizing outcomes following SCI.

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Developing people-centered Accreditation Standards and an Assessment Program for spinal cord injury in Canada

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PRAXIS Spinal Cord Institute and the Health Standards Organization for Canadian Spinal Cord Injury – Rehabilitation Association

Accreditation is an assessment process that healthcare organizations such as hospitals and rehabilitation centers do voluntarily to evaluate their care delivery and ensure alignment with evidenced-based standards. In Canada, the Health Standards Organization (HSO)¹ works with individuals with lived experience and diverse experts (healthcare providers and administrators, policy makers, academics, and researchers) to develop the health standards and assessment programs, which are then independently evaluated and accredited by Accreditation Canada.²

In 2012, the first set of standards were developed for spinal cord injury (SCI) care in acute³ and in-patient rehabilitation⁴ settings. To date, 16 acute and rehabilitation centers participating in the Rick Hansen SCI Registry (over 50%) have been accredited using these standards through the Accreditation Canada Qmentum Program.^{5,6} In 2019, HSO and the Praxis Spinal Cord Institute embarked on a collaborative program to engage SCI stakeholders, in particular people with lived experience, to understand their needs prior to revising and updating the standards. The first phase consisted of conducting a needs assessment of people living with SCI as they transition out of an in-patient setting into the community to identify gaps and opportunities for enhancing the current rehabilitation standards.

Results found the current system is primarily healthcare provider focused; furthermore, people with SCI have difficulties navigating the system, especially between phases of care (acute to rehabilitation,

rehabilitation to community, re-admission from community). In 2021, the second phase commenced with the development of the HSO National Standard of Canada, *Integrated People-Centered Spinal Cord Injury Rehabilitation Program*, which will replace the existing SCI in-patient rehabilitation standard in 2023. This revised standard will serve as the basis for an SCI rehabilitation program that focuses on principles of people-centered care that is coordinated and integrated along the SCI continuum irrespective of where the care is being offered.

Disclaimer statements


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Canadian Spinal Cord Injury Best Practice (Can-SCIP) Guideline

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Within the field of SCI, existing clinical practice guidelines focus on a specific impairment or segment within the health continuum and often do not provide a comprehensive overview of all pertinent clinical questions. There are ongoing challenges in accruing an adequate sample size to conduct randomized controlled trials, often restricting the ability to general Level 1 evidence to inform best practice. Further, current clinical practice guidelines often do not adequately address community care due in part to the allocation of health system resources and existence of community sector administrative data sources. As SCI results in a complex constellation of impairments necessitating tertiary care, a clinical practice guideline that provides high-quality, interprofessional comprehensive care recommendations is required.

The Can-SCIP (Canadian Spinal Cord Injury Best Practice) Guideline is the first comprehensive living clinical practice guideline providing evidence-based recommendations for adults with a SCI in Canada, throughout an individual's care journey, from pre-hospital emergency care through acute and rehabilitation care, and on to community care. The Can-SCIP Guideline was developed using a systematic and rigorous evaluation of 41 previously published clinical practice guidelines and evidence by the Can-SCIP Expert Panel. The Expert Panel consisted of an interprofessional panel of experts including clinicians, individuals with lived experience, researchers, administrators, knowledge translation experts, educators, and policymakers.

The Can-SCIP Guideline includes 585 best-practice recommendations, adopted, or refined from existing clinical practice guideline recommendations or newly developed recommendations based on evidence from systematic reviews conducted by the Spinal Cord Injury Research Evidence (SCIRE) team. The Can-SCIP Guideline is organized in two sections: Components of the Ideal SCI Care System and Management of Secondary Health Conditions. The first section is directed towards health system leaders who make decisions about human resources, capital equipment, staff training, physical space, and specialized equipment needed for optimal care. Section two addresses specific secondary health conditions and is directed towards clinicians and individuals with SCI. Newly developed recommendations within section two highlight the research conducted by clinicians and scientists within Canada who are leading the development of innovations within several areas including, autonomic dysreflexia, bone health, early surgical spinal cord decompression, hemodynamic monitoring, respiratory care, sexual health, and upper limb rehabilitation.

The Can-SCIP Guideline will adopt a living guideline approach to provide with up-to-date and high-quality advice to target users to overcome the challenges faced by other clinical practice guideline development groups, where the latest evidence may not be incorporated within a guideline for several years.

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Spinal Cord Injury Implementation and Evaluation Quality Care Consortium

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Spinal Cord Injury Implementation and Evaluation Quality Care Consortium for Canadian Spinal Cord Injury – Rehabilitation Association

The Spinal Cord Injury Implementation and Evaluation Quality Care Consortium (SCI IEQCC) is a collaborative network focused on achieving optimal and equitable healthcare services for Canadians through the implementation of indicators¹ and best practices² within SCI rehabilitation, to ensure the functional recovery, health, and wellbeing for individuals living with Spinal Cord Injury or Disease (SCI/D) (www.sciconsortium.ca).

The activities of the SCI IEQCC have strong academic underpinnings stemming from prioritization of rehab domains³ based on gaps between knowledge generation and implementation,⁴ and the feasibility and urgency of domain implementation⁵ from an SCI stakeholder perspective. Launched in 2019, the initial activities of the SCI IEQCC were supported by a provincial network in Ontario, comprised of five tertiary SCI rehabilitation programs, community organizations, non-governmental organizations, stakeholders, and individuals with lived experience, who support the translation of knowledge into practice using quality improvement and implementation science methods.

Building off the work of the SCI-High Project¹ and the National SCI Knowledge Mobilization Network,² the SCI IEQCC was established to implement indicators of SCI rehabilitation excellence, with a focus on the following domains: emotional well-being,⁶ sexual health,⁷ walking mobility,⁸ wheeled mobility,⁹ tissue integrity,¹⁰ and urinary tract infections.¹¹ Further domains and indicators will be added as the Consortium work continues in 2021, including the implementation of the community participation domain.¹²

Participating tertiary academic rehabilitation centres in Ontario includes Hamilton Health Sciences, Providence Care Hospital, St. Joseph's Health Care London, The Ottawa Hospital Rehabilitation Centre,

Toronto Rehabilitation Institute – University Health Network. In addition, Ontario is an active member of the network with satellite services in each region where the aforementioned SCI programs are located.

Leadership, policy, finance, and legal support were provided through a central operations team, steering committee, and a leadership team comprised of health system leaders from participating organizations. The implementation of selected indicators and related best practices was championed by Implementation and Evaluation Specialists at each participating organization and supported through local Site Implementation Teams including managers, frontline staff, and individuals with lived experience.¹³

In a learning health system, appropriate collection, analysis, and reporting of indicator data allow for the identification of care gaps, performance evaluation, and comparative benchmarking. To achieve that, structure, process, and outcome indicators were collected across participating sites and de-identified data were transferred to the central site for analysis and provincial report card development. These report cards provide comparable and actionable information that organizations can use to track their progress over time.

The SCI IEQCC has been successful in fostering a high degree of organizational engagement and commitment to common goals and deliverables. Inter-professional integration of service delivery was established through the development of 15 local site implementation teams who worked to implement site-specific quality improvement strategies, best practice tools, and resources. Collaboration between network members was facilitated through network meetings, newsletters, and online platforms, which provided a forum to exchange ideas, information, and evidence. Practice variations and internal program needs were

Table 1 Tertiary academic rehabilitation sites and domains at which their implementation is focused.

Domains	Emotional well being	Sexual health	Walking	Wheeled mobility	Tissue integrity	Urinary tract infection	Community participation
Ontario sites (Phase I + II)							
Toronto Rehabilitation Institute	X	X	X	X	X	X	X
St. Joseph's Health Care London	X	X	X	X	X	X	X
The Ottawa Hospital	X	X	X	X	X	X	X
Hamilton Health Sciences	X	X	X	X	X	X	X
Providence Care Hospital	X	X	X	X	X	X	X
National sites (Phase II)							
Nova Scotia Rehabilitation Centre	X	X	X	X	X	X	
Stan Cassidy Centre for Rehabilitation	X	X	X				
Queen Elizabeth Hospital	X	X	X				
Foothills Medical Centre						X	
Glenrose Rehabilitation Hospital						X	

identified through the creation of practice profiles. Virtual education and training workshops were presented by national content experts to support the learning needs of network members and staff involved with the provision of care across the participating rehabilitation sites.

As we expand from a provincial to a national network, maintaining high engagement will be critical to our sustainability and success. Collaborating with other provincial networks including the Alberta Health Services Neurosciences, Rehabilitation & Vision Strategic Clinical Network (NRV SCN), and the Spinal Cord Injury Network of The Atlantic Provinces (SCINAPS), we have the opportunity to work with stakeholders from additional sites including Stan Cassidy Centre for Rehabilitation (Fredericton, NB), Nova Scotia Rehabilitation Centre (Halifax, NS), Queen Elizabeth Hospital (Charlottetown, PEI), Foothills Medical Centre (Calgary, AB), and Glenrose Rehabilitation Hospital (Edmonton, AB).

Ensuring world-class quality of care delivery to patients with SCI demands a secure and timely collection, transfer, and reporting of data to enable identification and subsequent achievement of benchmarks. The future success of the SCI IEQCC will be dependent on further enrichment of the current data strategy and timely provision of data to inform implementation activities to advance care (Table 1).

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Canadian Activity-Based Therapy Community of Practice

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Canadian Activity-Based Therapy Community of Practice for Canadian Spinal Cord Injury – Rehabilitation Association

Activity-based therapy (ABT) is defined as interventions that involve “repetitive neuromuscular activation below the level of spinal injury, typically achieved through intensive, task-specific movement practice”.¹ There is now emerging evidence on the potential for neuroplasticity below the level of spinal cord injury or disease (SCI/D) in response to certain types of stimuli. Rehabilitation has historically emphasized compensatory strategies to improve function and maximize independence; however, there is a shift towards maximizing neurorecovery given this is a priority for individuals living with SCI/D² and the potential for neuroplasticity. To ensure all Canadians living with SCI/D can benefit from ABT, there is a need to obtain consensus on the delivery (e.g. timing, method, dosage) and to develop standardized guidelines and measures to assess the delivery and impact of ABT.

In 2019 a Canadian ABT Summit brought together a diverse group of stakeholders to create a five-year Canadian ABT Strategy for SCI to advance the evidence and implementation of ABT.³ Individuals with lived experience, frontline clinicians, healthcare administrators, researchers, funders of SCI/D research, and health policy experts identified key strategic priority areas. Examples of priorities included: identifying current ABT activities across the continuum of care, creating a network to facilitate dialogue across the continuum of care, developing and implementing best practice recommendations for ABT, and studying optimal timing, methods, and dosage of ABT to promote desired outcomes.

Following the summit, a working group was convened to perform an environmental scan of technologies used to provide ABT and therapist perspectives from across the continuum of care (acute care, rehabilitation, and community clinics).⁴ Subsequently, an ABT Community of

Practice (CoP) was formed in the fall of 2020 with the goal of engaging a larger diverse group of stakeholders to work collaboratively to move the Canadian ABT strategy priorities forward. The group has provided a variety of educational opportunities around ABT, including a public virtual ABT Expo in September 2020,⁵ webinars, and a podcast (Spinal Moves). The CoP also conducted a Delphi Process to review and update the priorities and setting one-year goals for the eight priority areas identified as important and feasible. Five new working groups have been established to support collaborations toward achieving these identified goals. This work will hopefully expedite the advancement of the priorities leading to improved awareness of ABT for both individuals with SCI/D and clinicians and increased access to quality ABT in Canada.

Disclosure statement

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Collaborative networks to achieve innovations in care

Spinal Cord Injury Canada: A collaborative, federated network supporting people with spinal cord injuries and their families

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Spinal Cord Injury Canada (SCI Canada) represents a federated network of eight independent, provincial non-profit community service organizations on a common mission to help people with spinal cord injuries and their families adjust, adapt, and thrive as they deal with a new injury or overcome the ongoing challenges of living and aging with a physical disability. Established in 1945 by World War II veterans who sustained spinal cord injuries in the war, SCI Canada's founders took innovative measures, including helping create the Department of Veterans' Affairs, establishing the world's first rehabilitation center for people with SCI, and building a supportive network of people and organizations across the country.

Although the provincial organizations within the SCI Canada federation arose from a common ancestor, each has evolved differently to meet the challenges of changing needs, priorities, technologies, and fiscal realities within their provincial jurisdictions. What unites the network is a shared focus on assisting people living with SCI to achieve independence, self-reliance, and full community participation, particularly through the provision of peer support services.

SCI Canada itself has continued to evolve. Today, its purpose is to support collaboration amongst its network of provincial organizations and engagement in innovative projects and federal advocacy activities aimed at improving the lives of persons with SCI, and their families. This includes working with our research, clinical, private sector, and government partners to advance research, care, laws, and policies that support this aim. SCI Canada's operations are led by the

Executive Directors' Council, which comprises the chief staff person from each provincial organization within the federation. The Council hires the Executive Director for SCI Canada, who assumes lead responsibility for managing operations and projects and initiatives designated by the Council.

SCI Canada was built on the concept of members helping members to live successfully with SCI. In other words, it was built on the power and strength of peer support. Seventy-six years later, peer support remains a common element within the diverse suite of services provided by SCI Canada's network of organizations and is a priority area for ongoing development and expansion. To this end, SCI Canada has undertaken extensive partnerships with Canadian researchers who are helping to reveal the "magic" of peer support and co-develop outcome measures that will allow for improved training of peer mentors, program development, and demonstrate the efficacy of the services they provide.

The organizations comprising SCI Canada's federated network do a lot with a little, but they don't do it alone: partnerships with other organizations, researchers, clinicians, and policy makers are essential for achieving their collective missions. Canada is fortunate to have a wealth of research and health care talent and infrastructure focused on the priority issues faced by people with SCI. By working together and adhering to partnership principles, like the Integrated Knowledge Translation Guiding Principles for Conducting SCI Research in Partnership¹, we can support people with SCI and their families to thrive

as fully participating members in communities throughout our vast, diverse country.

Disclosure statement

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