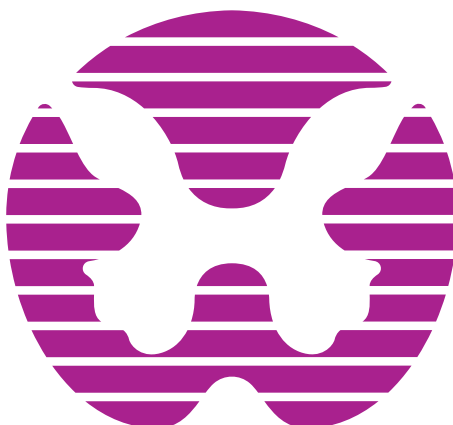


An Overview of Pediatric Spinal Cord Injury in Canada



Nancy Thorogood, PhD
Jennifer Lee, MPH
Vanessa Noonan, PT MSc, PhD
Penny Clarke-Richardson, BA, MBA

Published March 2020



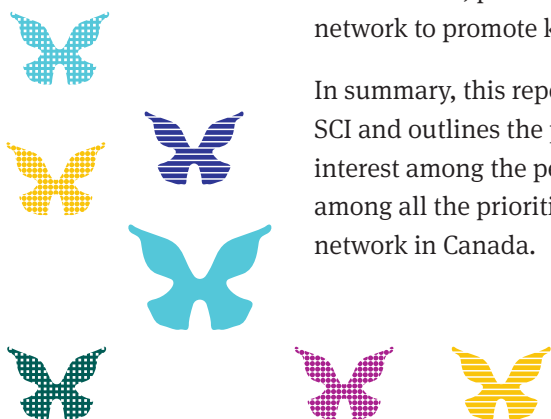
Executive Summary

The incidence of pediatric spinal cord injury (SCI) is relatively low; however, the consequences are devastating with substantial impact on young people living with the condition, their families, the health care system and society. To date, most of the research evidence available has focused on spinal cord injury in adults. An environmental scan was undertaken by the Praxis Spinal Cord Institute (formerly Rick Hansen Institute) to examine the landscape of pediatric SCI research in Canada through a literature review, key informant interviews and questionnaires. As part of the interviews the topic of care emerged and was explored. This report provides an overview of aspects of pediatric SCI in Canada and serves as a starting point for future planning in both research and care.

Research in this report is defined as filling gaps in evidence. In Canada, pediatric SCI research is limited due to challenges such as lack of funding and difficulty identifying and recruiting participants. Most pediatric SCI research has been made possible by either including additional neurological conditions or combining pediatric and adult participants into a single study. The research priorities identified in this report include: understanding pediatric SCI epidemiology; advancing pediatric SCI data collection; and filling gaps in evidence related to care, health and wellness.

To enhance the quality of care in pediatric SCI there is a need to implement existing evidence into practice. In Canada, treatment for children with SCI occurs at pediatric hospitals and general hospitals with pediatric units along with other neurological conditions. While pediatric care at these facilities have positive aspects, there are opportunities for improvement. The priorities in care relate to three overall themes including: advancing health and wellness; providing support (e.g., training, resources, equipment); and developing a network to promote knowledge sharing.

In summary, this report describes the results of a Canadian environmental scan in pediatric SCI and outlines the priorities in research and care. Findings from this scan indicate a strong interest among the pediatric SCI stakeholders to collaborate and it is recommended that among all the priorities identified, the first step should be the creation of a pediatric SCI network in Canada.



Acknowledgments

We would like to thank all of the individuals who took the time to share their valuable perspectives. This work would not have been possible without the openness, honesty and willingness of the pediatric SCI community in Canada. The underlying theme for all the stories and experiences are shared by parents, researchers, health care providers, community organizations and operational leaders was the need for change.

Funding for this initiative was made possible through support from the Rick Hansen Foundation and the Government of Canada through Western Economic Diversification Canada.



Table of Contents

Introduction	5
Methods.....	6
Data Collection	6
Data Analysis	6
Results	7
Key Informants.....	7
Responses and Demographics	7
Generating Evidence: Pediatric SCI Research in Canada	8
Better Care: Pediatric SCI Care in Canada	12
Limitations and Next Steps	15
Conclusions	16
References	17
Appendix A: Literature Search for Canadian Pediatric SCI Research	18
Appendix B: Questionnaire for Clinicians, Researchers and Administrators	20
Appendix C: Informants.....	21
Appendix D: Locations of Pediatric Hospitals and Hospitals with Pediatric Units.	22



Introduction

Spinal cord injury (SCI) is a costly and life-altering health condition that has substantial impact on the lives of those injured and their families. While SCI can be acquired at any age, the incidence and prevalence of SCI are higher in adults compared to children.¹⁻⁶ Given the rarity of pediatric SCI, most research has focused on the adult population. Due to a marked difference in certain features of SCI between children and adults, there is a need for specialized research and care in pediatric populations.^{5,7}

Praxis Spinal Cord Institute is a Canadian-based not-for-profit organization that leads global collaboration in spinal cord injury research, innovation and care. Praxis actively engages people with SCI and other world-class experts to work together to find solutions to improve care, reduce adverse events and explore therapies for this chronic condition. As much of the published evidence, ongoing research and networks focus on SCI in adults, Praxis has primarily been involved with SCI in adults.

There is now a growing interest to include pediatric SCI. Praxis has recognized this and recently supported the validation of International SCI Data Sets for pediatric populations.⁸ To further understand the landscape of pediatric SCI in Canada, an environmental scan was conducted. This report describes results from interviews and questionnaires with key informants across Canada and provides a starting point for discussions in future planning and prioritization.



Methods

Data Collection

Key informants were recruited through a snowball sampling method, beginning with an initial sample of key informants who suggested additional informants with experience in pediatric SCI.⁹ The initial sample of key informants included members of the Praxis Network and select Canadian researchers with published research paper(s) relevant to pediatric SCI (see *Appendix A: Literature Search for Canadian Pediatric SCI Research*). These initial contacts were emailed and recommendations were obtained for additional contacts.

In an attempt to seek input from a wider audience, Praxis tweeted a brief description of the project and a request for involvement on Twitter. Individuals were invited to participate in a 30-minute semi-structured telephone interview or complete a questionnaire, to share their role and/or experiences with pediatric SCI. Interviews took place between July and September 2018. There were at least two team members present during each telephone interview to ask questions and take notes. The team notes were aggregated for the analysis.

Key informants included pediatric SCI family members/caregivers, community organization representatives, clinicians, researchers and administrators. The questions covered areas such as their role, areas and experiences with pediatric SCI research and care and suggested priorities. A copy of the questionnaire is included in *Appendix B: Questionnaire for Clinicians, Researchers and Administrators*.

Data Analysis

The interview notes and questionnaire results were examined using a thematic analysis approach. An inductive methodology was used where the analysis began with the large pool of key informants' responses and was reduced in subsequent rounds of review by grouping similar observations to identify themes. Specifically, the de-identified and aggregated responses were reviewed and key points were coded. The codes were then grouped into categories and the categories were reviewed to identify topics. The topics were subsequently grouped into sub-themes and themes, based on repeating patterns within the responses.

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction held during the International Spinal Cord Society Annual Scientific Meeting between September 13-15, 2018 in Sydney, Australia, provided an opportunity to share initial study findings with attendees and seek input from international experts which helped to refine the analysis.



Results

KEY INFORMANTS

Responses and Demographics

One hundred and fourteen individuals were contacted and 61 responded of which 21 reported that they did not work in pediatric SCI and were excluded. The participation rate (85%; $n=34/40$) was high with 23 interviews and 11 questionnaires completed. Responses were obtained from individuals in eight provinces and interviews and/or questionnaires were conducted in five provinces (Figure 1). The individual key informants who wished to be identified are listed in *Appendix C: Key Informants*.

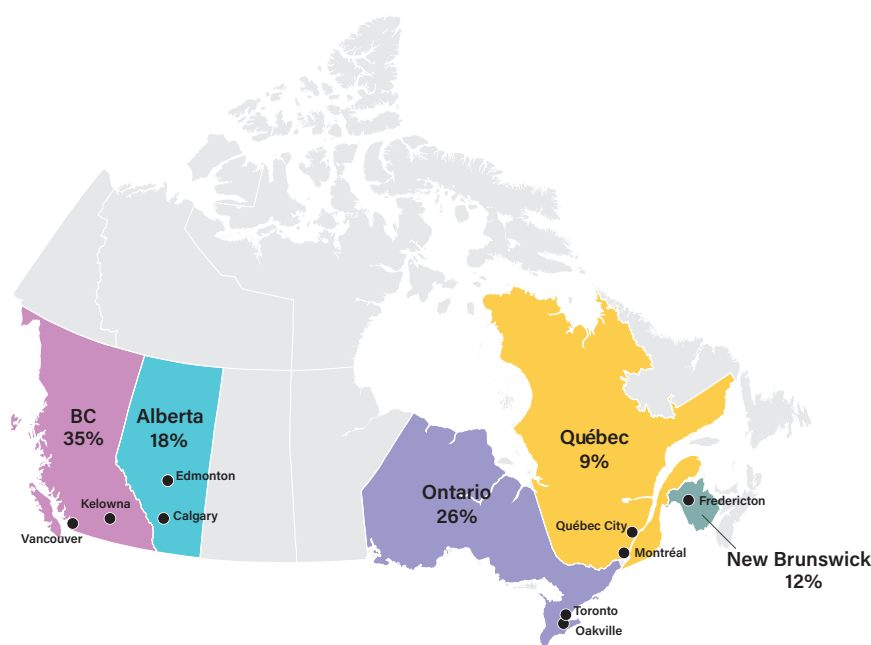


Figure 1. Key Informant Map

Please note: None of the individuals contacted in Newfoundland and Labrador, Nova Scotia, Manitoba and Saskatchewan participated as key informants ($n=34$).



Key Informants had varied backgrounds and roles in pediatric SCI (Figure 2). The largest proportion (41%) of key informants identified as clinicians. These clinical roles were broadly represented by developmental pediatricians, pediatric neurosurgeons, pediatric nurse practitioners, pediatric surgeons, pediatric urologists, occupational therapists, physiatrists, physiotherapists and social workers.

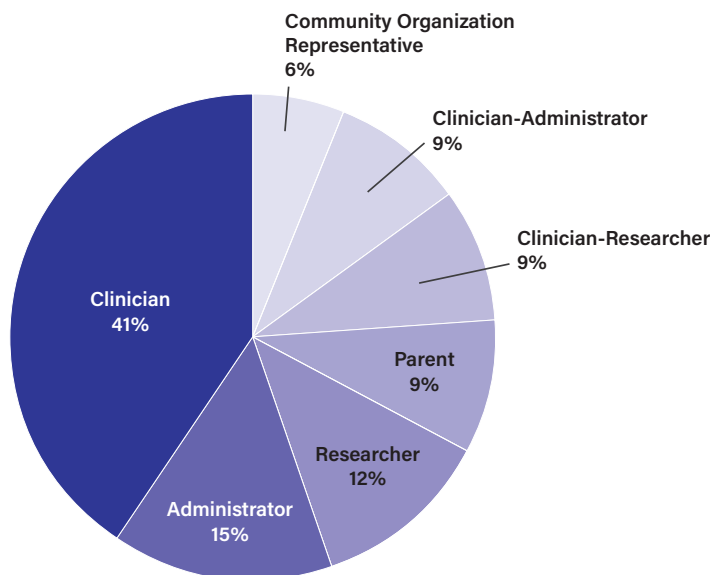


Figure 2. Roles of Key Informants

Generating Evidence: Pediatric SCI Research in Canada

DEFINING PEDIATRIC SPINAL CORD INJURY

The majority of informants defined the age of pediatric SCI as up to 18 years of age, though this upper limit ranged from 16 to 21 years of age across all informants' responses. While most provinces had a definitive age at which an individual with pediatric SCI transitions into adult care, it was not as straightforward from the clinical perspective. In clinical practice, whether adolescents receive pediatric or adult care depended on the individual situation and local facilities (*see Care Pathway section, page 12*).

All respondents included SCI from both traumatic and non-traumatic causes when defining pediatric SCI. Spina bifida was often defined as separate from SCI, though in clinical practice children with SCI and spina bifida are often grouped together. Spina bifida is a congenital cause of non-traumatic SCI.¹⁰ SCI is only one aspect of spina bifida and there is distinct care (e.g., spina bifida clinics, prenatal management), research (e.g., risk factors), surveillance, prevention, funding and associations dedicated to spina bifida and neural tube defects.

ONGOING AND COMPLETED RESEARCH

The interviews and literature review (*Appendix A: Literature Search for Canadian Pediatric SCI Research*) revealed a lack of pediatric SCI research in Canada. While the majority of informants did not know of any pediatric SCI research currently taking place in Canada, a few informants spoke of past and present pediatric SCI research areas; these are summarized in Table 1.

Of the research projects mentioned, many were not specific to children with SCI and often included children with other neurological conditions or physical disabilities.



Table 1. Areas of Pediatric SCI Past and Present Research in Canada

RESEARCH TOPIC
Adaptive equipment
Ambulation and mobility
Bladder and bowel
Functional electrical stimulation rowing/arm/leg
Mental health
Outcomes of pediatric vs. adult sustained SCI
Pediatric to adult transition
Physical activity
Spinal stability
Stress and resiliency
Upper extremity guidelines
Urology
Wheelchair skills

RESOURCES FOR CLINICIANS

The majority of clinicians were unaware of specific guidelines or resources for pediatric SCI. Most clinicians who used guidelines, referred to adult guidelines for SCI care (e.g., The Clinical Practice Guidelines from the Consortium for Spinal Cord Medicine, Paralyzed Veterans of America).¹¹ Clinicians working in pediatrics often consulted with clinicians who provide care for adults with SCI. Some clinicians educated themselves about pediatric SCI through internet resources, informal networks, international literature¹² and conferences.

Informants were generally unaware of any formal network or community of practice for pediatric SCI in Canada. Several spoke of this as a priority. Many informants desired a better understanding of what others involved in pediatric SCI are doing and wished to have a forum for collaboration, sharing ideas and asking questions.

A few Canadian resources for pediatric SCI were identified by informants and through a literature search. These resources included a national pediatric C-spine clearance guidelines, clinical practice guidelines for cervical spine injuries¹³ and a pathway developed by a pediatric intensive care unit for the management of SCI in children and young adults. Furthermore, a clinical pathway for rehabilitation is currently under development at a rehabilitation hospital in Canada.



CANADIAN PEDIATRIC SCI REGISTRIES

Informants were not aware of any Canadian pediatric SCI registries. While some organizations and facilities collect data at the local level that may be used for research, there are barriers to using the data. Challenges included variations in the definition of pediatric SCI and the inclusion of pediatric SCI with other pediatric conditions.

RESEARCH CHALLENGES

There are many barriers to pediatric SCI research (see Table 2). Given the low incidence and prevalence, there is limited funding available for pediatric SCI research. For clinicians, some find conducting research difficult given the lack of time, administrative support and compensation, and they may have other competing priorities. For researchers, many have difficulty finding others to collaborate with due to the lack of pediatric SCI research in Canada. No multi-centre studies were specifically mentioned by informants. Recruitment and participation in studies are difficult given travel and family constraints, limited time, lack of knowledge about study opportunities or lack of perceived benefit in participation. While having champions for research and care is important to raising awareness, it is often challenging to find such champions in pediatric SCI.

Table 2. Research Challenges in Pediatric SCI

RESEARCH CHALLENGES
Data availability
Finding collaborators
Funding
Lack of champions in pediatric SCI
Recruitment
Resources
Time availability for clinicians and families



RESEARCH PRIORITIES

There are several areas in pediatric SCI that require more research. In this project, we define research as work needed to fill gaps in evidence. Informants identified a number of research priority topics which were grouped into three general themes with specific sub-themes and topics (see Table 3. Research Priorities for Pediatric SCI).

Table 3. Research Priorities for Pediatric SCI

THEME	SUBTHEMES	TOPICS
Epidemiology	Differences between populations	<ul style="list-style-type: none"> - Children with SCI vs. spina bifida - Children with SCI vs. adults with SCI—developmental neuroplasticity in recovery
	Pediatric-specific	<ul style="list-style-type: none"> - Considerations for growth/development - Long-term comorbidities/mortality
Data	Measurement	<ul style="list-style-type: none"> - Pediatric-specific outcomes - Measurement of physical activity - Injury classification in young children
	Tracking	<ul style="list-style-type: none"> - Tracking outcomes into adulthood, trajectory - Vocational outcomes
Care, health and wellness	Acute care	<ul style="list-style-type: none"> - Tissue engineering - Cord functional recovery - Timing of surgical intervention
	Rehabilitation	<ul style="list-style-type: none"> - Locomotor training - Balance training - Amount and intensity of rehabilitation - Augmented robotics
	Developing and evaluating programs & interventions	<ul style="list-style-type: none"> - Transition into adulthood programs - Behavioural interventions—physical activity - Evaluation of existing programs—community, peer support, funding, clinics - Optimal length of stay - Implementing constraint-induced movement therapy - Interventions at different developmental stages
	Psychosocial issues	<ul style="list-style-type: none"> - Mental health - Social integration - Quality of life - Education—integration into school - Community experience
	Secondary health complications	<ul style="list-style-type: none"> - Neuropathic pain - Cardiovascular risk, blood pressure management - Osteoporosis
	Canada-specific	<ul style="list-style-type: none"> - Canadian guidelines or pathways for pediatric SCI care—bowel, bladder, infection prevention/treatment - National standards for rehabilitation - Collaborative national database for outcome research - Adapting programs developed in other countries



Better Care: Pediatric SCI Care in Canada

STRUCTURE OF PEDIATRIC SCI CARE

In contrast to research which aims to fill the gaps in evidence, the goal of providing better care requires implementing existing evidence into practice.

Hospitals and clinics across Canada provide care for children with SCI, with pediatric care structured according to the presenting condition (e.g., spina bifida, oncology, muscular dystrophy). Specialized centres or programs may focus on SCI and spina bifida, or include broader populations, such as any spinal cord conditions or neurological impairments. Pediatric centres do not have the specialized spine units that established adult facilities often have primarily due to the low incidence of SCI in the pediatric population. Some children in their adolescent years are treated in adult facilities to receive more SCI-specific care (*see Care Pathway section below*).

CARE PATHWAY

Informants frequently spoke about care pathways in pediatric SCI. In facilities where informants were located, children optimally receive acute care at a pediatric trauma centre (directly after acquiring a SCI or transferred from another ward). Following acute care, children may receive inpatient rehabilitation care at the same hospital or be transferred to a rehabilitation facility. Some adolescents are treated at pediatric facilities while others are treated at adult facilities. This is dependent on physical maturity and their individual needs, and occasionally the preference of the family. Some adult facilities also have youth/adolescent programs to accommodate older children approaching adulthood.

Upon discharge from inpatient rehabilitation, children may receive outpatient rehabilitation at the same facility, may be sent elsewhere for outpatient rehabilitation or may be sent home. Once in the community, access to rehabilitation varies from province-to-province. Not all provinces have community rehabilitation and not all rehabilitation facilities allow for readmission. Some facilities readmit clients specifically for new rehabilitation goals or medical reasons.

Pediatric rehabilitation programs usually follow up with children, where some have outpatient clinics. Children can be seen on a regular basis as an outpatient up until they reach adulthood. After this time, there may or may not be an adult program into which they can transition to. In some areas adults and children are treated within the same facility and pediatric clients may transition into the adult care and remain at the same facility.

One of the main differences across provinces was the transition between pediatric and adult care. Unfortunately, many adolescents fall between the cracks during the transition process or do not have anywhere to transition into. While transition of care was recognized as a gap in many places across Canada, there were some facilities that put programs in place to ensure a smooth transition. For example, there are adolescent transition clinics to facilitate the transfer to adult care. These clinics can be very effective, though could be stronger with



more resources and time. While other facilities ease transition by housing pediatric and adult services within the same building (allowing for staff sharing).


PRIORITIES IN CARE

While the initial focus of this report was research, informants highlighted many priorities in care. These priorities were grouped into three general themes with specific sub-themes and topics that are listed in Table 4. Priorities in Care for Pediatric SCI. There is overlap between current priorities in care and the research priorities identified by informants (Table 3. Research Priorities for Pediatric SCI).

Rehabilitation equipment and clinician training in pediatric SCI were consistently identified as areas that could be improved across Canada. Families and SCI organizations were dissatisfied with the amount of rehabilitation care, interruption in care and lack of appropriate equipment. Families often travelled great distances, and at their own expense, to specialized facilities in the United States to receive rehabilitation with state-of-the-art equipment.

Additionally, family and community organizations consistently mentioned access to information and resources, navigation of care and peer and family support as areas for focus. Peer and family support existed in some areas but were not available in others. In one province there was a project underway to extend family support within pediatric SCI.

Table 4. Priorities in Care for Pediatric SCI

THEME	SUBTHEMES	TOPICS
	Care, health and wellness	<ul style="list-style-type: none"> - Consistent treatment - Holistic approach to care - Access to level of expertise found at adult facilities while retaining psychosocial benefits of pediatric facilities - Sensory assessment of children with varying verbal abilities - Airway considerations for tracheostomy
	Transition to adult care	<ul style="list-style-type: none"> - Considerations for growth/development - Long-term comorbidities/mortality
	Rehabilitation phase of care	<ul style="list-style-type: none"> - Care—time/length/intensity of rehabilitation care, access to rehabilitation care - Equipment—more and better equipment - People—more needed, specialized training and clinician capacity - Specific areas—orthopedic needs, nutrition and weight management, skin prevention, bone health, mental health, tone
	Rehabilitation in the community phase	<ul style="list-style-type: none"> - Standard follow-up procedures (discharge plan) - Ongoing rehabilitation in the community - Options for returning to intensive rehabilitation - Community support for rural areas - More clinicians - More intense blocks of rehabilitation
	Growth/development	<ul style="list-style-type: none"> - Ongoing education as children get older - Support changing rehabilitation goals with development - Service during major developmental changes - Vocational supports

THEME	SUBTHEMES	TOPICS
Support	Education & training for clinicians	<ul style="list-style-type: none"> - Specialized pediatric SCI training - Knowledge of resources - Maintenance of competency
	Resources/support for consumers	<ul style="list-style-type: none"> - Ease with navigating care—having a care navigator - Community organizations that cover pediatrics - Peer and family support - Caregiver needs
	Communication	<ul style="list-style-type: none"> - Between community organizations and hospitals - Between hospitals and family
	Financial	<ul style="list-style-type: none"> - Personal equipment/assistive devices - Equipment for facilities - Rehabilitation services - Transportation
Network development	Community of practice	<ul style="list-style-type: none"> - Sharing ideas, knowledge and resources - Ability to ask questions of experts
	Knowing the community	<ul style="list-style-type: none"> - Knowing who to connect and collaborate with - Knowledge of what others in pediatric SCI are doing



Limitations and Next Steps

A limitation of this work was the geographical clustering of the participants resulting from snowball sampling. This may have resulted in a less representative view of the Canadian pediatric community. Since informants were initially recruited through the Praxis Network, contacts recommended by these informants could have been more knowledgeable about pediatric SCI and better connected to the pediatric SCI community than most.

While the initial focus of the report was pediatric SCI research, informants had limited knowledge about research. Informants wanted to speak more about care which may reflect the state of pediatric SCI in Canada. Data was collected via interviews or questionnaires. The interviews were not recorded or transcribed verbatim; notes were compiled from the interviews to conduct a thematic analysis. Contacts found early in the data collection period were asked to complete an interview, while contacts identified later were asked to complete a questionnaire due to time constraints. This mixed approach to data collection may affect the robustness of the results.

To our knowledge this is the first scan in pediatric SCI research and care and can inform future planning. The theme of 'Care, Health and Wellness' was identified in both research and care (refer to Table 3. Research Priorities for Pediatric SCI and Table 4. Priorities for Care in Pediatric SCI). Other areas of importance in research included the epidemiology of pediatric SCI and the need for data. In the area of pediatric SCI care, the need for providing more supports and the development of a network were highlighted.

To advance this work it is recommended that a forum for collaboration, sharing ideas and asking questions among researchers and clinicians is a priority. Suggested next steps to advance pediatric SCI research and care include agreeing to collect common data elements to promote comparisons among centres and collaborations in research as well as creating an opportunity to network. As part of the Steel Assembly (<https://steelassembly.org/>), there is an opportunity for stakeholders working in the areas of pediatric SCI to connect. This is a very practical first step which can begin connecting colleagues working in pediatric SCI both in Canada and internationally.



Conclusions

This report describes the findings from a Canadian environmental scan in pediatric SCI; a diverse group of key informants contributed a comprehensive perspective of priorities in pediatric SCI research and care. Despite the impact of pediatric SCI on individuals, families and the health care system, little research has been conducted with respect to pediatric SCI in Canada. To advance pediatric SCI research and care it is recommended that among all the important priorities identified, creating a network is an essential first step. This will bring together all the Canadian pediatric SCI stakeholders and provide a mechanism for knowledge sharing and collaboration on the priorities in research and care which will ultimately improve the health and well-being of children living with SCI.



References

1. Chen Y, Devivo MJ. Chapter 2: Epidemiology. In: Vogel LC, Zebracki K, Betz RR, Mulcahey M, eds. *Spinal Cord Injury in the Child and Young Adult*. Mac Keith Press; 2014:15-27.
2. Dryden D, Saunders L, Rowe B, et al. *The Epidemiology of Traumatic Spinal Cord Injury in Alberta, Canada*. Can J Neurol Sci. 2003;30:113-121.
3. Pickett W, Simpson K, Walker J, et al. *Traumatic Spinal Cord Injury in Ontario, Canada*. J Trauma Inj Infect Crit Care. 2003;55(6):1070-1076.
4. Pickett GE, Campos-Benitez M, Keller JL, Duggal N. *Epidemiology of Traumatic Spinal Cord Injury in Canada*. Spine (Phila Pa 1976). 2006;31(7):799-805.
5. Reilly CW. *Pediatric Spine Trauma*. J Bone Jt Surgery, Inc. 2007;89-A(Supplement 1):98-107.
6. Noonan VK, Fingas M, Farry A, et al. *Incidence and Prevalence of Spinal Cord Injury in Canada: A National Perspective*. Neuroepidemiology. 2012;38(4):219-226.
7. Parent S, Dimar J, Dekutoski M, Roy-Beaudry M. *Unique Features of Pediatric Spinal Cord Injury*. Spine (Phila Pa 1976). 2010;35(21S):S202-8.
8. Carroll A, Vogel LC, Zebracki K, Noonan VK, Biering-Sorensen F, Mulcahey MJ. *Relevance of the International Spinal Cord Injury Basic Data Sets to Youth: an Inter-Professional Review with Recommendations*. Spinal Cord. 2017;55(9):875-881.
9. Given LM. Snowball Sampling. In: *The SAGE Encyclopedia of Qualitative Research Methods*. SAGE; 2008:816.
10. New PW, Marshall R. *International Spinal Cord Injury Data Sets for Non-Traumatic Spinal Cord Injury*. Spinal Cord. 2014;52(2):123-132.
11. Paralyzed Veterans of America. Publications: *Clinical Practice Guidelines*. <https://www.pva.org/publications/clinical-practice-guidelines>. Accessed February 8, 2019.
12. Vogel LC, Zebracki K, Betz RR, Mulcahey M, eds. *Spinal Cord Injury in the Child and Young Adult*. 1st ed. London: Mac Keith Press; 2014.
13. Chung S, Mikrogianakis A, Wales PW, et al. *Trauma Association of Canada Pediatric Subcommittee National Pediatric Cervical Spine Evaluation Pathway: Consensus Guidelines*. J Trauma. 2011;70(4):873-884.



Appendix A:

LITERATURE SEARCH FOR CANADIAN PEDIATRIC SCI RESEARCH

A search was performed through PubMed with the search terms:

((spinal cord injur*) AND (pediatric or child or children or adolescent or infant) AND (Canada OR Canadian)).

The search was limited to English language, humans and publication date between 1998/01/01 – 2018/12/31. The search yielded 266 results. The following were identified as potentially relevant to pediatric SCI:

Table A1: Canadian Literature Search Results

TITLE	AUTHORS	DETAILS	THEME
Relevance of the international spinal cord injury basic data sets to youth: an Inter-Professional review with recommendations.	Carroll A, Vogel LC, Zebracki K, Noonan VK, Biering-S��rensen F, Mulcahey MJ.	Spinal Cord. 2017 Sep;55(9):875-881. doi: 10.1038/sc.2017.14. Epub 2017 Feb 28. Review.	Data
Training to improve walking after pediatric spinal cord injury: a systematic review of parameters and walking outcomes.	Gandhi P, Chan K, Verrier MC, Pakosh M, Muselman KE.	J Neurotrauma. 2017 May 1;34(9):1713-1725. doi: 10.1089/neu.2016.4501. Epub 2017 Jan 13. Review.	Outcome measures
Diagnostic accuracy of neuromonitoring for identification of new neurologic deficits in pediatric spinal fusion surgery.	Neira VM, Ghaffari K, Bulusu S, Moroz PJ, Jarvis JG, Barrowman N, Splinter W.	Anesth Analg. 2016 Dec;123(6):1556-1566.	Acute management - surgical treatment
Spinal cord injury in pediatric age in Spain. Reality of a national reference center.	Perez-de la Cruz S, Cimolin V, Gil-Agudo A.	Childs Nerv Syst. 2015 Jun;31(6):917-21. doi: 10.1007/s00381-015-2681-y. Epub 2015 Apr 3.	Epidemiology; characteristics
Relationships between wheeling parameters and wheelchair skills in adults and children with SCI.	Sawatzky B, Hers N, MacGillivray MK.	Spinal Cord. 2015 Jul;53(7):561-4. doi: 10.1038/sc.2015.29. Epub 2015 Feb 17.	Outcome measures - SmartWheel Clinical Protocol, wheelchair skills test 4.1, push effectiveness
Cervical spine injuries and collar complications in severely injured paediatric trauma patients.	Chan M, Al-Buali W, Charyk Stewart T, Singh RN, Kornecki A, Seabrook JA, Fraser DD.	Spinal Cord. 2013 May;51(5):360-4. doi: 10.1038/sc.2013.6. Epub 2013 Mar 5.	Acute management/ treatment
Wheelchair skills training programme for children: a pilot study.	Sawatzky B, Rushton PW, Denison I, McDonald R.	Aust Occup Ther J. 2012 Feb;59(1):2-9. doi: 10.1111/j.1440-1630.2011.00964.x. Epub 2011 Dec 5.	Rehabilitation

TITLE	AUTHORS	DETAILS	THEME
Spinal cord injury in the pediatric population: a systematic review of the literature.	Parent S, Mac-Thiong JM, Roy-Beaudry M, Sosa JF, Labelle H.	J Neurotrauma. 2011 Aug;28(8):1515-24. doi: 10.1089/neu.2009.1153. Epub 2011 Jun 9. Review.	Epidemiology; characteristics; neuroprotective approaches
Spinal cord injuries without radiographic abnormality at two pediatric trauma centers in Ontario.	Trigylidas T, Yuh SJ, Vassilyadi M, Matzinger MA, Mikrogianakis A.	Pediatr Neurosurg. 2010;46(4):283-9. doi: 10.1159/000320134. Epub 2010 Dec 15.	SCIWORA
Unique features of pediatric spinal cord injury.	Parent S, Dimar J, Dekutoski M, Roy-Beaudry M.	Spine (Phila Pa 1976). 2010 Oct 1;35(21 Suppl):S202-8. doi: 10.1097/BRS.0b013e3181f35acb. Review.	Characteristics
Spinal cord transection in a child after non-penetrating trauma.	Zeiler FA, McDonald PJ.	Can J Neurol Sci. 2010 May;37(3):400-1. No abstract available.	Acute management/ treatment - surgical treatment
Canadian C-spine Rule and the National Emergency X-Radiography Utilization Low-Risk Criteria for C-spine radiography in young trauma patients.	Ehrlich PF, Wee C, Drongowski R, Rana AR.	J Pediatr Surg. 2009 May;44(5):987-91. doi: 10.1016/j.jpedsurg.2009.01.044.	Acute management/ treatment
Anterior penetrating sacral injury in a child. Case illustration.	Serletis D, Khoshyomn S, Gerstle JT, Rutka JT.	J Neurosurg. 2005 Nov;103(5 Suppl):471. No abstract available.	Characteristics
The ankle clonus test is not a clinically useful measure of spinal cord integrity in children.	Ewen A, Cox RG, Davies SA, Luntley JB, Rubin Y, Fick GH, Bart BB.	Can J Anaesth. 2005 May;52(5):524-9.	Outcome measure - ankle clonus test
Outcome of functional electrical stimulation in the rehabilitation of a child with C-5 tetraplegia.	Davis SE, Mulcahey MJ, Smith BT, Betz RR.	J Spinal Cord Med. 1999 Summer;22(2):107-13.	Rehabilitation - e stim
Environmentally responsive temperature instability in pediatric spinal cord injury.	McLean DE, Kearney J, Cawley MF.	Spinal Cord. 1999 Oct;37(10):705-9.	Characteristics

Canadian authors for whom email contact information was either given through the paper or available on the first page of Google were emailed, requesting participation through the questionnaire. This method was also used for authors of papers identified through papers referenced by the aforementioned papers, as well as others found by the authors of the report through informal searches on Google Scholar or PubMed.

Appendix B:

QUESTIONNAIRE FOR CLINICIANS, RESEARCHERS AND ADMINISTRATORS

1. Would you like your name to appear in a list of key informants in the final report?
2. Do you work in pediatric SCI?
3. Do you identify as a clinician, researcher, both, or something else?
4. Where do you work? (Organization/institution, city)
5. What is your role?
6. How do you define pediatric SCI? (Age range, case definition)
7. How many years have you been involved with pediatric SCI?
8. What conditions do you focus on?
9. If you are a clinician, where do you see pediatric SCI clients?
10. What aspects of pediatric SCI are currently being researched in Canada, and where? (Institutions/organizations, cities)
11. What aspects of pediatric SCI are you currently involved in?
12. Do you know of other individuals or organizations involved in pediatric SCI care/research in Canada? Please list.
13. Do you know of any resources available for pediatric SCI research in Canada? Please list.
14. Do you know of any funders for pediatric SCI research in Canada? Please list.
15. If you are involved in research, what has your experience been with recruitment for pediatric SCI studies?
16. A) If you are a clinician, do you know of any specific guidelines or resources for decision-making for clinicians with respect to pediatric SCI research or care? Please list.

B) If you answered yes to the above, are they routinely used in your organization?
17. Do you feel there are gaps in knowledge regarding pediatric SCI? If so, what are they?
18. Which areas of pediatric SCI research do you feel should be prioritized?
19. Do you collaborate with anyone else in pediatric SCI care or research in Canada? If so, in what capacity?
20. Do you know of anyone else we could get in touch with who might be able to inform this scan? Please provide contact information if possible.
21. Do you have any additional comments?

Appendix C:

KEY INFORMANTS

Praxis would like to express our extreme gratitude to all key informants of this report for sharing their time and expertise. The following key informants have allowed their names to be published:

Kelly Arbour	Chester Ho	Jasmin Ma	Jacqueline Purtzki
Conny Betuzzi	Stuart Howe	Shane McCullum	Jennifer Raabe
Doug Cochrane	Bev Irwin	Patrick McDonald	Andrea Rabel
Guy Coulombe	Dilshad Kassam-Lallani	Vivek Mehta	Louise Rudden
Tina Del Duca	Carol King	Peter Metcalfe	Bonnie Sawatzky
Krista Fraser	Nancy Lanphear	Golda Milo-Manson	Diane Schoenhoff
Vithya Gnanakumar	Sarah Lavoie	Ivona Novak	Zoe Schwartz
Melissa Grassmick	Trischa Lowe	Colleen O'Connell	Catherine Truchon

Table C1. Affiliations of Key Informants

AFFILIATION	CITY	PROVINCE
Alberta Children's Hospital	Calgary	AB
Anne Johnston Health Station	Toronto	ON
BC Children's Hospital	Vancouver	BC
Centre Hospitalier Universitaire Sainte-Justine	Montreal	QC
Glenrose Rehabilitation Hospital	Edmonton	AB
Holland Bloorview Kids Rehabilitation Hospital	Toronto	ON
The Hospital for Sick Children (SickKids)	Toronto	ON
Institut National d'Excellence et Sante et en Services Sociaux (INESSS)	Quebec	QC
International Collaboration on Repair Discoveries (ICORD)	Vancouver	BC
Spinal Cord Injury Alberta	Edmonton	AB
Spinal Cord Injury Ontario	Toronto	ON
Stan Cassidy Centre for Rehabilitation	Fredericton	NB
Stollery Children's Hospital	Edmonton	AB
Sunny Hill Health Centre for Children	Vancouver	BC
University of British Columbia (Okanagan)	Kelowna	BC
University of Calgary	Calgary	AB
University of Toronto	Toronto	ON



Blusson Spinal Cord Centre
6400 - 818 West 10th Avenue
Vancouver BC, V5Z 1M9 CANADA

Phone: 604.827.2421
Email: info@praxisinstitute.org
Website: praxisinstitute.org



Proudly
accredited by
Imagine Canada