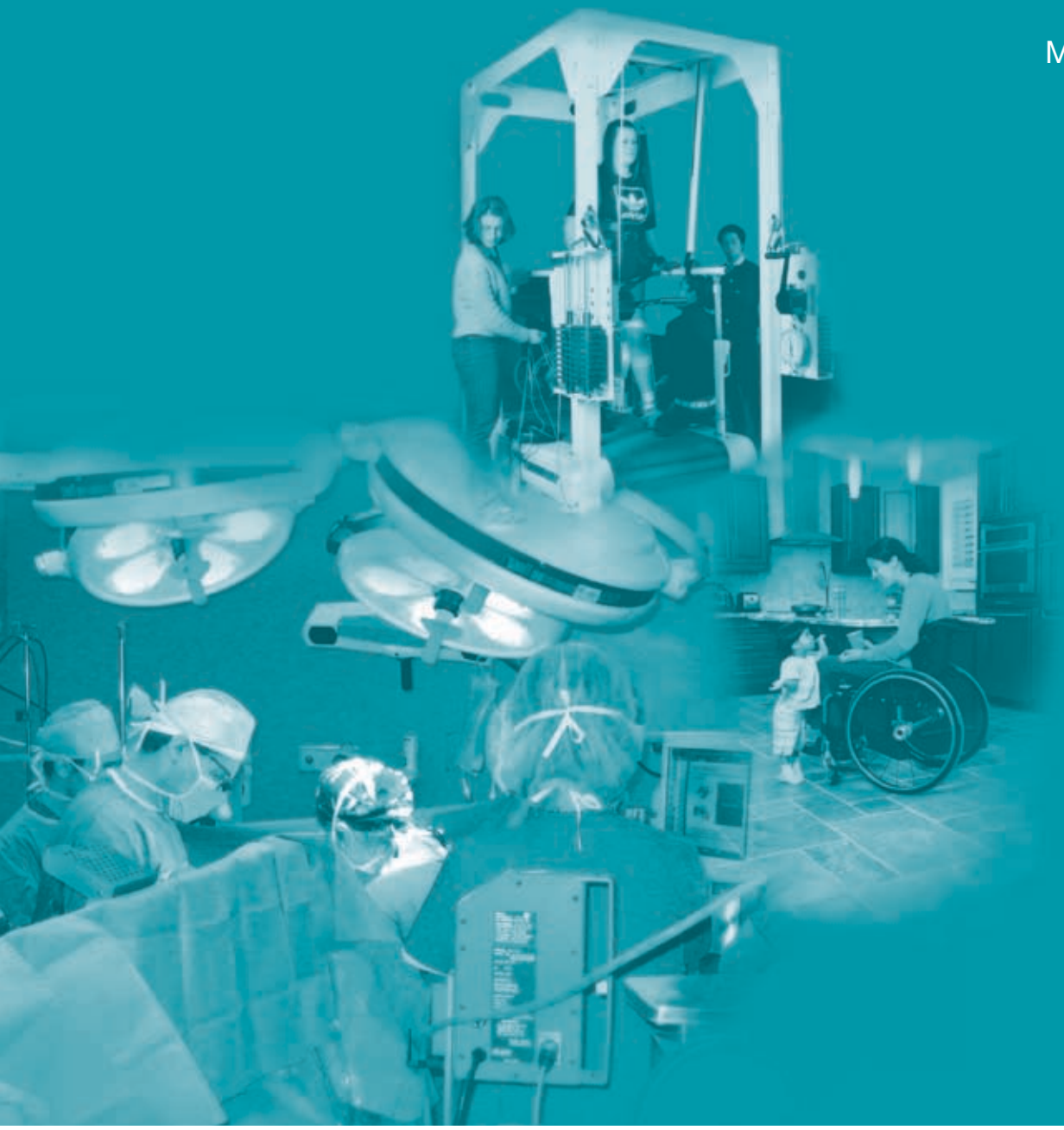
Ontario Spinal Cord Injury Informatics

Informing Practice Research and Innovations

November 2009

Molly Verrier, Lead
Henry Ahn
Cathy Craven
Brian Drew
Michael Fehlings
Michael Ford
Susan Jaglal
Daria Parsons



Ontario Neurotrauma Foundation
Fondation ontarienne de neurotraumatologie

The Ontario Spinal Cord Injury Registry (OSCIR) Pilot Project was a research initiative of the Ontario Neurotrauma Foundation. The model was based on the Rick Hansen Spinal Cord Injury Registry. This project was funded by the Ontario Neurotrauma Foundation and the Ontario Ministry of Health and Long-term Care.

Research Committee

Molly Verrier Dip P&OT MHSc Principal Investigator/Project Lead
Associate Professor, Depts of Physical Therapy and Rehabilitation Science, Faculty of Medicine, University of Toronto, Senior Scientist, Toronto Rehabilitation Institute

Henry Ahn MD FRCSC Adult Spinal Disorder and Orthopaedic Surgery, St. Michael's Hospital, University of Toronto Spine Program

Catharine Craven BA, MD, MSc, FRCPC, Assistant Professor, University of Toronto, Department of Medicine, Toronto Rehabilitation Institute

Brian Drew MD, FRCSC, Assistant Clinical Professor, McMaster University, Orthopaedic Surgeon, Hamilton General Hospital, Medical Director, Hamilton General Hospital Spine Unit

Michael Fehlings MD, PhD Professor and Director Neuroscience Program, University of Toronto, Director, Krembil Neuroscience Program, University Health Network

Michael Ford MD, FRCSC, Assistant Professor, Department of Surgery, University of Toronto, Active Staff Member, Sunnybrook Health Sciences Centre, Surgery Division of Orthopaedics

Susan Jaglal PhD, Toronto Rehabilitation Institute, Chair at the University of Toronto, Vice-Chair Research Department of Physical Therapy, Scientist, Institute of Clinical and Evaluative Sciences

Daria Parsons BSc, MSc Research Associate for SCI Informatics, Ontario Neurotrauma Foundation

Research Coordinators

Aimee Gallant B.Sc. (Eng)	Sunnybrook Health Sciences Centre
Karen Lepper BA (Hons), CCRA	Toronto Rehabilitation Institute, Lyndhurst Centre
Yangmei Li PhD	St. Michael's Hospital
Deborah Tsui MSc (PT)	Hamilton Health Sciences
Kayee Tung RN, BScN	University Health Network, Toronto Western Hospital

Other Acknowledgements

The Ontario SCI Registry Lead would like to thank:

Andrew White	OSCIR Database Developer/Architect and Programmer
Louise MacRae and Barb Ansley	part of Hamilton Health Sciences team
Michael Jurkiewicz	Data Analysis
Ariel Estulin (Comet art + design)	Graphic Design

Table of Contents

List of Figures

List of Maps

List of Tables

EXECUTIVE SUMMARY

Despite the low incidence but extremely high cost for life time health care, there is a lack of current, complete, reliable, and timely data on spinal cord injury (SCI) across the continuum of care in Ontario. This highlights the need for centralized analysis of SCI data to produce better data to support evidence-based best practices, measures of health system performance, and quality improvement in the services delivered to persons following SCI.

The Ontario Spinal Cord Injury Registry (OSCIR) was based on the model of the National Rick Hansen Spinal Cord Injury Registry (RHSCIR). OSCIR was implemented as a Pilot Project over a two year period in Toronto and Hamilton to determine if a health informatics resource could provide data sufficient to improve the clinical understanding of SCI and foster collaboration among care providers, health researchers and decision makers as a means to advance SCI care and manage costs. The goal of OSCIR was to determine the feasibility of using Registry data to gain an understanding of the clinical care continuum for individuals with SCI in Ontario to inform best practice.

There were 124 acute care cases included in the Pilot Project and 90 cases of traumatic SCI in rehabilitation compared to 27 non-traumatic cases. Eighty one percent of acute care cases consented to participate in the pilot compared to 97% of rehabilitation cases. Descriptive analysis on the OSCIR dataset showed that 82% of cases were admitted direct to service and 92% were considered urgent/emergent admissions. Falls (46%) accounted for the largest percentage of admissions followed by transport (34%). Twenty two percentage of the SCI cases sustained a mechanism of injury related to sports and recreation.The average age of SCI patients was 44 years for acute care compared to 42 years for traumatic rehabilitation cases and 59 years for non-traumatic rehabilitation cases. The mean length of stay (LOS) was 28 days in acute compared to 96 days for traumatic cases in rehabilitation (84 days for non-traumatic cases).

The primary barrier to timely transfer to acute care facilities was lack of a ventilator (73%). Patients with AIS-A that underwent early surgery had significantly greater improvement in their neurological outcome as compared with the late or no surgery group. CritiCall data facilitated analysis of referral patterns for SCI patients in Ontario. SCI patients are transferred to the United States because appropriate care is not available in Ontario. Maps were presented to show the referrals patterns at the LHIN level. The total inhospital cost including direct and overhead expenses for 124 acute cases and 90 rehabilitation cases was at $12,944,488 during the Pilot Project. These costs reflect inhospital costs only but more detailed costing of spinal cord injury is critical for future resource planning.

Non-traumatic SCI participants experienced a longer wait time for rehabilitation admission (onset days), had a shorter course of rehabilitation (LOS) and experienced a lower Spinal Cord

Independence Measure (SCIM) change scores between rehabilitation admission and discharge (SCIM change). Only 20% of the patients with incomplete traumatic SCI walked at admission to rehabilitation while 50% were walking at rehabilitation discharge. Requirements to walk in the community safely at discharge from rehabilitation were achieved in 45% to 61% of patients depending on the measure used to assess this capacity (speed, distance, postural control).

LESSONS LEARNED

It was possible to collect timely data to inform the SCI research questions and approaches to service delivery e.g. walking outcomes. It was possible to collect appropriate assessment data e.g. AIS in the emergency department at participating sites. At present, there are no specific protocols or consistent referral patterns in Ontario to ensure timely access to appropriate acute care spine specialty services or surgical intervention for SCI patients.

Leadership by hospital Executive and management levels, Site Investigators, the Principal Investigator/Lead and Research Associate was important to ensure successful implementation of the Ontario Spinal Cord Injury Registry. The Pilot Project demonstrated that it is possible to collect AIS scores with appropriate training and ongoing follow up. It was important to standardize time points for outcome measures to enhance interpretation. Training was required for certain critical data elements for spinal cord injury e.g. AIS, walking battery; AIS was added to the trauma data forms used in emergency departments. The data collection cost per case for OSCIR was high and the burden of data abstraction and data quality required significant Research Coordinator time. The number of data elements collected for OSCIR was only feasible for a Pilot Project.

In rehabilitation, information was collected on non-traumatic SCI patients in order to assess the difference between trauma and non-trauma patients in terms of sociodemographics characteristics, impairment (AIS, motor scores), rehabilitation onset and LOS, and Functional Independence Measure (FIM), SCIM change and efficiency. SCIM was more appropriate for spinal cord injury patients than FIM which is the standard in the National Rehabilitation Reporting System (NRS). Type and severity of pain and its impact on SCI inpatients was successfully implemented in rehabilitation data collection using a multidisciplinary assessment tool integrated into team practice. LiSAT-11 was successfully collected at six months post discharge from rehabilitation in Toronto via telephone interview. LiSAT-11 was feasible and well accepted and should be included in a future minimum data set to measure life satisfaction.

Technology is critical to the success of a Registry; web based data entry which would facilitate regular data analysis improving the quality of the data and timeliness of reporting to facilitate making patient care decisions in real time was not feasible for a Pilot Project.

FUTURE DIRECTIVES

DATA COLLECTION AND ACCESS

- All new SCI cases in Ontario should be identified through existing, state of the art approaches to optimize success in terms of timely, high quality data available for spinal cord injury e.g. Emergency Department Reporting System.
- Primary data collection for SCI patients should include electronic data collection in real time to facilitate data quality and analysis and use for clinical management.
- Limited, well defined data sets should be established across the continuum of care to enhance performance measurement and longitudinally to address Ontario research priorities. A Minimum Data Set should be defined by a consensus process taking OSCIR modifications into consideration to facilitate the development of a single SCI data source at the provincial level.
- Consideration should be given to including non-traumatic spinal cord injury cases in an SCI informatics system.
- Approaches for an SCI data collection system should have ties to the Office of the Information and Privacy Commission of Ontario to adhere to PHIPA requirements for data collection, use and disclosure to ensure alignment with an ever changing legislative environment related to registries.
- A strategy should be developed that will align with the national RHSCIR to ensure that Ontario capitalizes on the initial investment of OSCIR.
- A formalized Data Access Request should be established with RHSCIR to receive data on spinal cord injury patients in Ontario on a regular basis to facilitate data analysis to address Ontario's research questions including economic analysis of resource utilization.
- The definition for the Ontario Trauma Registry should be expanded to include isolated spine injuries rather than limited to cases with an Injury Severity Score > 12. AIS data collection for SCI patients should also be implemented through the Ontario Trauma Registry.

DATA QUALITY

- Primary SCI data collection should be routinely linked to administrative databases (e.g. National Ambulatory Care Reporting System, Discharge Abstract Database and the National Rehabilitation Reporting System) for data quality assessments e.g. chart abstraction and provincial level analysis based on assessment of referral patterns across the continuum of care.

PARTNERSHIPS

- The Ontario SCI Informatics Strategy Working Group should report data biannually to the Ontario Ministry of Health and Long-Term Care to enhance awareness of spinal cord injury as a priority population.
- The Ontario SCI Informatics Strategy Working Group should expand its membership to reflect Ontario stakeholders and update and implement the Ontario Data Strategy Framework.

STANDARDS AND PROTOCOLS

- AIS should be a provincial standard for SCI patients in Ontario.
- Standardized protocols should be established for the transport and treatment of spinal cord injury patients;
  - Protocols for access to acute spinal programs and trauma centres should be established.
  - Performance measures for positive health outcomes should be established for SCI patients.
  - Alternate level of care (ALC) data should be analyzed for SCI patients to develop appropriate outpatient and community services to facilitate timely discharge based on community service requirements to enhance quality of life during transition of SCI patients to the community.
- A seamless and shared process for consent and SCI data collection across acute and rehabilitation and longitudinal follow up should be established for the province.
- Specificity of rehabilitation data elements to better reflect important rehabilitation outcomes for SCI e.g. function - (SCIM), pain, mobility – (walking outcomes) should be included in an SCI Informatics strategy.
- Future data collection for community follow up should be based on recommendations from the national initiative on community integration.

CONCLUSIONS

The OSCIR Pilot Project was successful in achieving its objectives. The project determined the feasibility of implementing a Registry in Ontario to promote quality clinical care and management, inform research priorities, establish partnerships and began to develop an SCI Informatics strategy.

The goal of the Ontario SCI Registry Pilot Project was to lay the foundation for the development of a sustainable, provincial SCI Registry, customized to Ontario's health information management strategy. Without standards for data requirements in health records for SCI (e.g. standardized AIS classifications at specified time points), it appears that using research staff to abstract SCI data can provide the information required to meet a provincial research agenda.

Strategies such as web based entry and electronic health records with real time data entry need to be in place to ensure an adequate level of data completeness and data quality for the SCI population. Given that the technology is available, data collection will need to be redesigned to capture the full capacity of health informatics to optimize health outcomes across the continuum of care.

It is important to have a provincial SCI Informatics to inform practice, research and innovations.

INTRODUCTION

Despite the low incidence but extremely high cost for life time health care, there is a lack of current, complete, reliable, and timely data on spinal cord injury at the clinical level. All current provincial data to date has been captured at the population level[1,2,3,4]. More importantly, there has not been an analysis of SCI informatics across the continuum of care in Ontario. This highlights the need for centralized analysis of SCI data to produce better SCI informatics to support evidence-based best practices, measures of health system performance, and quality improvement in the services delivered to persons following SCI.

The Ontario Spinal Cord Injury Registry (OSCIR) was based on the model of the national Rick Hansen Spinal Cord Injury Registry (RHSCIR). OSCIR was implemented as a Pilot Project over a two year period in Toronto and Hamilton to determine if a health informatics resource could provide data sufficient to improve the clinical understanding of SCI and to foster collaboration among care providers, health researchers and decision makers as a means to advance SCI care and monitor costs. The goal of OSCIR was to determine the feasibility of using Registry data to gain an understanding of the clinical care continuum for individuals with SCI in Ontario to inform best practice.

STATE OF SCI KNOWLEDGE

Before the OSCIR Pilot Project, there was no single comprehensive source of SCI data, particularly clinical data. SCI data were limited and existed in silos with different data definitions in the different health sectors. Existing administrative data in the National Ambulatory Care Reporting System, Discharge Abstract Database, Ontario Trauma Registry and National Rehabilitation Reporting System are neither sufficiently specific nor comprehensive to gain an understanding of the care continuum for SCI. Specifically, there was a lack of:

- Linked records across databases to track the continuum of care for SCI patients,
- Detailed clinical information to track SCI treatment effectiveness,
- Lifetime follow-up on SCI patients to understand the obstacles to health care that SCI patients endure,
- Information to aid in the development and evaluation of prevention programs and policy, to make informed clinical care management decisions and to advance research,
- Opportunity for inter-disciplinary research to address the diverse issues facing individuals with SCI from onset of injury to community integration, and
- Knowledge exchange and data sharing about key priorities and initiatives for SCI.

---

[1] Couris CM, Guilcher SJT, Munce SEP, Fung K, Craven BC, Verrier MC, Jaglal SB (2009) Characteristics of Adults with Incident Traumatic Spinal Cord Injury in Ontario. *Spinal Cord* 23 June 2009; doi:10.1038/sc.2009.77.

[2] Jaglal SB, Munce SEP, Guilcher SJT, Couris CM, Fung K, Craven BC, Verrier MC (2009). Health System Factors Associated with Rehospitalization after Traumatic Spinal Cord Injury: A Population-Based Study. *Spinal Cord* 47(8):604-609

[3] Guilcher SJT, Munce S, Couris CM, Fung K, Craven BC, Verrier MC, Jaglal SB (2009) Healthcare Utilization in Non-Traumatic and Traumatic Spinal Cord Injury: A Population based Study. *Spinal Cord* advance online publication, 23 June 2009; doi:10.1038/sc.2009.78

[4] Munce SEP, Guilcher SJT, Couris CM, Fung K, Craven BC, Verrier MC, Jaglal SB (2009). Physician Utilization among Adults with Traumatic Spinal Cord Injury in Ontario: A Population-Based Study. *Spinal Cord* 47(6):470-476.

WHY ARE SCI DATA IMPORTANT IN ONTARIO?

The development of an SCI health informatics resource enables a much improved understanding of spinal cord injury by providing a source of integrated knowledge that facilitates collaboration between stakeholders to improve SCI care and, therefore, the quality of life for individuals that suffer this catastrophic injury and sustain significant co-morbidities across their lifespan. Centralization of spinal cord injury informatics is important because, if used strategically, it could:

- Establish Ontario as the leader in SCI clinical care, prevention programs and research built on quality information,
- Develop, promote and encourage the use of an efficient, timely and effective Ontario longitudinal SCI data retrieval and management reporting system,
- Facilitate the understanding of health service utilization across the continuum of care to improve service delivery for SCI patients,
- Enable evidence-based decision making to improve SCI patient care and health outcomes,
- Decrease health care costs through more efficient and effective service delivery for SCI,
- Provide comprehensive and integrated data for research to enable the development of effective prevention strategies,
- Assist in elevating SCI service delivery to the Ontario standards for stroke, cardiac and joint replacement care,
- Provide a single source for current, easily accessible, high quality, evidence-based information relevant to all stakeholders in the SCI community,
- Provide the potential for development and evaluation of protocols for clinical decision making,
- Enable funding for SCI related research initiated through key stakeholders in the forms of contract research, private sector partnerships, international collaborative activity and special research grants directed to spinal cord injury,
- Facilitate SCI related research and the attraction and retention of world class SCI researchers to Ontario, and
- Facilitate the translation of SCI research to the international community.

GOALS OF THE ONTARIO SCI REGISTRY PILOT PROJECT

The Ontario SCI Registry Pilot Project team developed five goals aimed at optimizing the vision of making Ontario a leader in spinal cord injury.

1. **CLINICAL SUPPORT AND MANAGEMENT**

   To promote, encourage and develop an efficient and effective SCI data retrieval and management reporting system by creating a Registry of SCI events.

2. **RESEARCH SUPPORT**

   To create a clinical and epidemiological based information source in order to promote collaboration between scientists and clinicians, and support true translational research through provincial, national and international data exchange and collaboration.

3. **QUALITY DATA AND INFORMATION**

   To ensure quality of the Registry data to enhance the authoritative nature of the data source.

4. **PARTNERSHIPS AND QUALITY IMPROVEMENT**

   To demonstrate flexibility and adaptability in helping partners achieve their SCI information goals.

5. **REMAIN CURRENT WITH CHANGING TRENDS AND ISSUES IN HEALTH CARE MANAGEMENT**

   To demonstrate how health information can feed into and shape innovation in health care management of spinal cord injury.

COMPONENTS OF THE ONTARIO SCI REGISTRY

The stakeholders for the Ontario SCI Registry are outlined in Appendix A. The foundational principles of OSCIR are outlined in Appendix B. The deliverables for the Registry are outlined in Appendix C. The Ontario Spinal Cord Injury Registry had five major components:

1 Development of the database and determination of relevant data elements

OSCIR DATABASE

As an interim measure to facilitate data analysis, the OSCIR Database was a customized application prepared in Microsoft Access®. It consisted of a front-end interface containing electronic versions of the Case Report Forms (CRFs), menus, queries, reports and program logic, and a back-end database containing the data. The database was intended to:

- Facilitate entry of Case Report Form data from participating OSCIR sites,
- Provide a security layer to protect and restrict access to the data,
- Manage data from participating OSCIR sites (combining data into a series of master files), and
- Create analysis files for use in standard statistical applications software.

The OSCIR database architecture involved the integration of CRFs, queries, reports, menus and logic in a relational database environment. The database at each site was encrypted and password-protected. Its customized security layer required a user account and password for controlled logon.

At each OSCIR site, the back-end database (the data) resided on the institution's network server while the front-end application (containing logic but no data) was installed on each Research Coordinator's computer at participating sites.

DATA ELEMENTS

RHSCIR data elements were adapted to align with acute care practices in Ontario. Data elements for rehabilitation practices were developed to complete the inhospital care continuum; a follow up data set was selected to determine life satisfaction at six months post discharge from rehabilitation. Salient research questions were developed by the OSCIR Research Committee to address specific practice issues. New data elements including diagnostic imaging, neuropathic pain, discharge disposition, functional outcomes (e.g. walking status, SCIM) and resource requirements on discharge were some of the data elements that were added to the national RHSCIR database to address Ontario's research questions and meet international data standards for SCI. One of the most important enhancements for OSCIR was the addition of specific time points for AIS data collection to align with important transitions in neurological recovery and service delivery based on provincial and international standards.

Decisions about the inclusion of data elements in OSCIR were made using the following criteria:

- Importance of data to the participating institution,
- Feasibility to collect,
- Reliability and validity of the data element,
- Utility of the data to define best practices, and
- International data standards for SCI.

2 Patient consent and data collection at the local hospital site

CONSENT

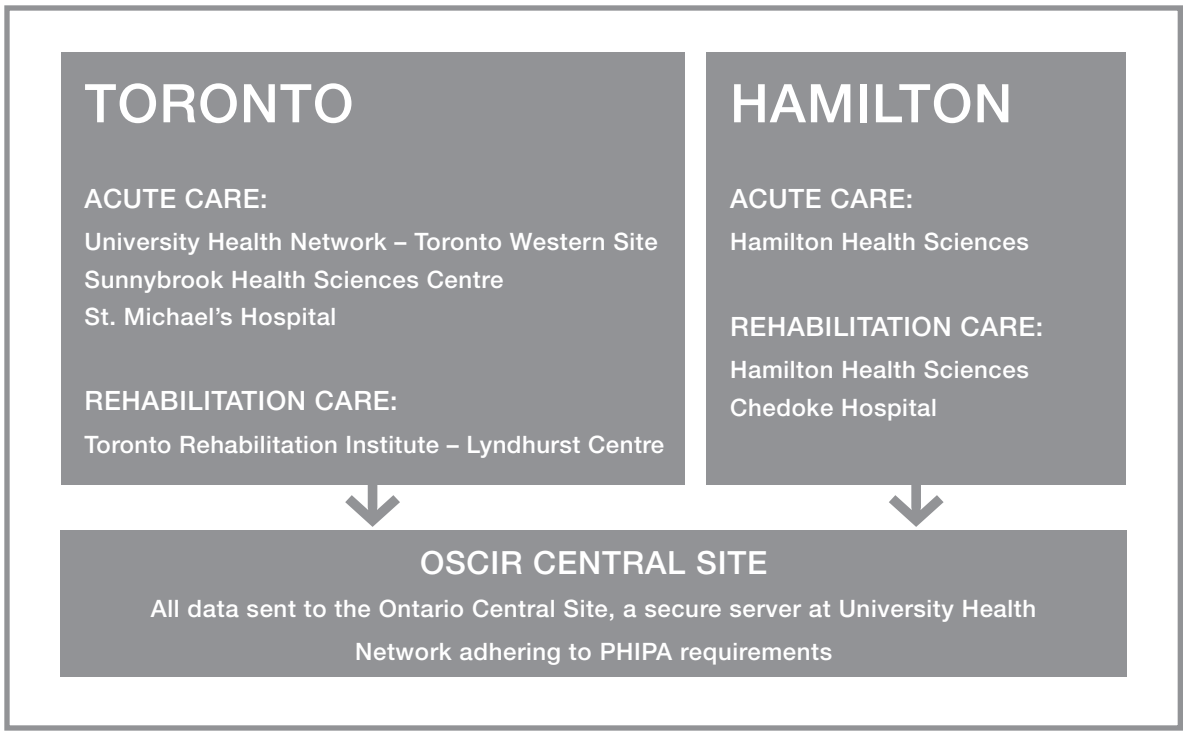
The patients' circle of care provider obtained consent from patients to be approached for participation in the OSCIR Pilot Project. Research Coordinators obtained written informed consent from patients with spinal cord injury to participate in the pilot.

SCI data collection adhered to PHIPA as patients provided written consent to:

- Participate in the Ontario Spinal Cord Injury Registry,
- Linkage of health data to other administrative data, and
- Contact after discharge to determine willingness to participate in future studies.

DATA COLLECTION

Research Coordinators were hired for each of the sites, trained in interviewing, data collection, abstraction and undertook the manage-



ment of data collection in each site under the guidance of an overall Research Associate. An ongoing communication plan for the Research Coordinators was established to ensure data collection processes were optimized in each site and aligned across sites. Data were collected in paper format and entered into a customized computer program designed for Ontario SCI data. Data were abstracted from the health records of patients consenting to participate in the study and patient interviews.

Participating sites were selected to ensure the greatest number of cases during the pilot time period. Sunnybrook Health Sciences Centre, St. Michael's Hospital, University Health Network and Hamilton Health Sciences agreed to participate in the acute care data collection and Toronto Rehabilitation Institute -Lyndhurst Centre and Chedoke Hospital as part of Hamilton Health Sciences agreed to participate in the rehabilitation data collection. Each of these sites had a spinal cord injury champion interested in establishing the research agenda in Ontario in addition to a willingness to collaborate across departments e.g. emergency department and/or research department within their participating site.

Data collection was intended to begin in July 2006 for a period of eighteen months. Because of delays in Research Ethics Board approval and signoff of Data Sharing Agreements, the actual data collection start states are:

Data Collection Start Dates by Participating Site

Hamilton Health Sciences	June 2, 2007
St. Michael's Hospital	August 16, 2007
Sunnybrook Health Sciences Centre	Oct 30, 2006
Toronto Rehabilitation Institute	April 11, 2007
University Health Network	July 17, 2007

Data collection for the OSCIR Pilot Project finished on March 31st, 2009.

3 Data transfer at the central repository

Data were electronically transmitted to a secure central server at University Health Network (UHN) which served as the central repository for OSCIR data as per a data sharing agreement.

4 Data storage by the Ontario central repository and integration of the data

Site data were combined into a master dataset using the OSCIR Access® database application. Data were stored on a secure server at UHN not connected to any third party network according to PHIPA requirements. The central repository provided technical linkages to local sites, technical support, ensured privacy and security of data, and provided data access to designated statisticians responsible for OSCIR data analysis.

5 Data quality and analysis

Each participating site proposed research questions pertinent to the delivery of health care across the continuum for persons with SCI in Ontario which were refined and approved by the Research Committee led by Molly Verrier (Appendix D). Knowledge translation activities from OSCIR can be found in Appendix E. Policies developed by the Research Committee can be found in Appendix F. Policies include:

- Use of OSCIR Data Policy
- New Data Element Addition Policy
- Publication Tracking Form

One of the first priorities of the data analysis plan was to develop strategies to assess data quality. The Database Manager wrote a program so each site could check data completeness and the quality of data e.g. to ensure priority data fields had the appropriate type of information within pre-set ranges before each hospital transmitted data to UHN for analysis.

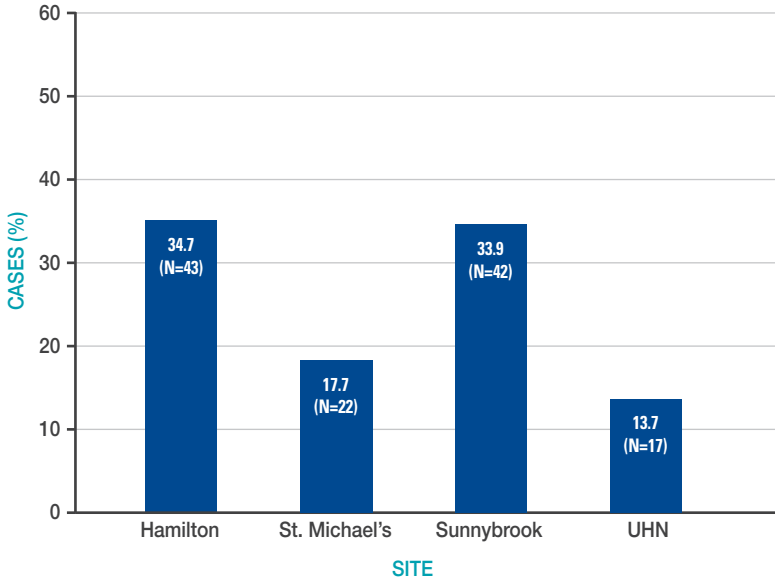
Demographics (age & sex), continuum of care variables (LOS & ALC days), neurological status (AIS classification) and functional outcomes (FIM & SCIM) were the minimum data set for assessing data completeness and quality by the investigators. Both manual and computer generated reminders were produced for missing data. There was inconsistent data completeness across the acute records for neurological status (AIS Scores); however, better data completeness was attained in the rehabilitation records. With the small sample size of 124 records for acute SCI, 90 traumatic and 27 non-traumatic records for rehabilitation, the cell sizes were not large enough to meet the standard cell size requirements (n>6) for reporting by SCI classifications (AIS A,B,C,D,E).

Monthly status reports were submitted by Research Coordinators to the Research Associate to track the status of data collection.

Data analyses (descriptive and statistical) were performed by exporting the data into SAS which was installed and executed on the central repository server.

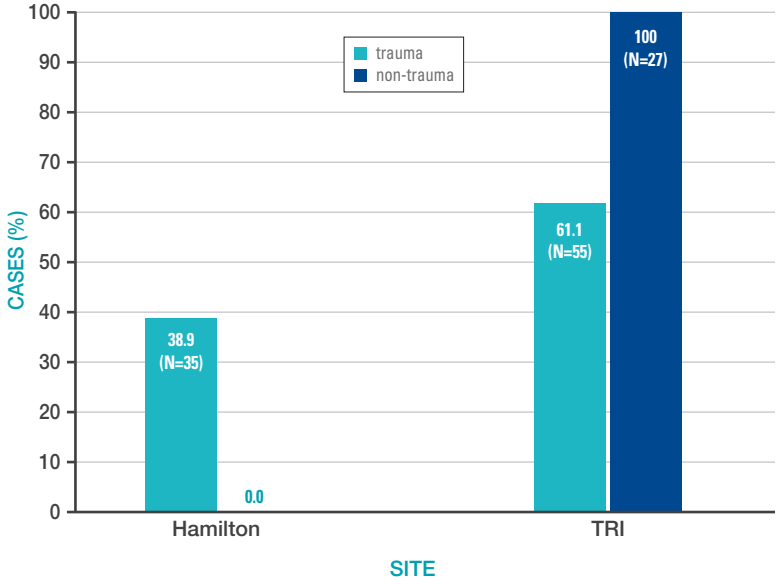
SCI PILOT PROJECT DESCRIPTIVE ANALYSIS

FIGURE 1
DISTRIBUTION OF ACUTE CASES



The largest percentages of acute care cases in the OSCIR pilot were from Hamilton Health Sciences (35%) and Sunnybrook Health Sciences Centre (34%). Eighteen percent were from St. Michael's Hospital and 14% were from the Western Division at the University Health Network. Of the total number of potential cases, 124 patients consented to participate in the Ontario Spinal Cord Injury Registry Pilot Project.

FIGURE 2
DISTRIBUTION OF REHABILITATION CASES



Sixty one percent of traumatic spinal cord injury rehabilitation cases were from Toronto Rehabilitation Institute compared to 39% from Hamilton's Chedoke site. All the non-traumatic cases were from Toronto Rehabilitation (n=27). One hundred and seventeen cases were included from rehabilitation sites (90 traumatic and 27 non-traumatic).

The largest number of traumatic cases referred to rehabilitation were from Hamilton (43%) and Sunnybrook (36%) for the Pilot Project.

TABLE 1: NUMBER OF TRAUMATIC CASES TRANSFERRED TO REHABILITATION BY ACUTE SITE

Site	N	%
Hamilton Health Sciences	39	43
St. Michael's Hospital	11	12
Sunnybrook Health Sciences Centre	32	36
University Health Network	7	8
Missing	1	1
Total Rehabilitation	**90**	**100**

Sixty percent of OSCIR patients were transferred to participating pilot sites by land ambulance. Twenty six percent were transported by air ambulance.

TABLE 2: METHOD OF TRANSPORT TO PARTICIPATING SITES

	N	%
Air ambulance	32	26
Land ambulance	75	60
Private vehicle	2	2
Air and land ambulance	8	6
Other	2	2
Missing	5	4
Total	**124**	**100**

Eighty two percent of cases included in the pilot study were transferred directly to orthopedics or neurosurgery compared to 18% that were admitted through the emergency department.

TABLE 3: DIRECT SERVICE ADMISSIONS

	N	%
Direct to service	102	82
Through emergency department	22	18
Total	**124**	**100**

Ninety two percent of spinal cord injury cases were admitted to hospital as urgent or emergent compared to 8% that were elective.

TABLE 4: TYPE OF ADMISSION TO ACUTE CARE

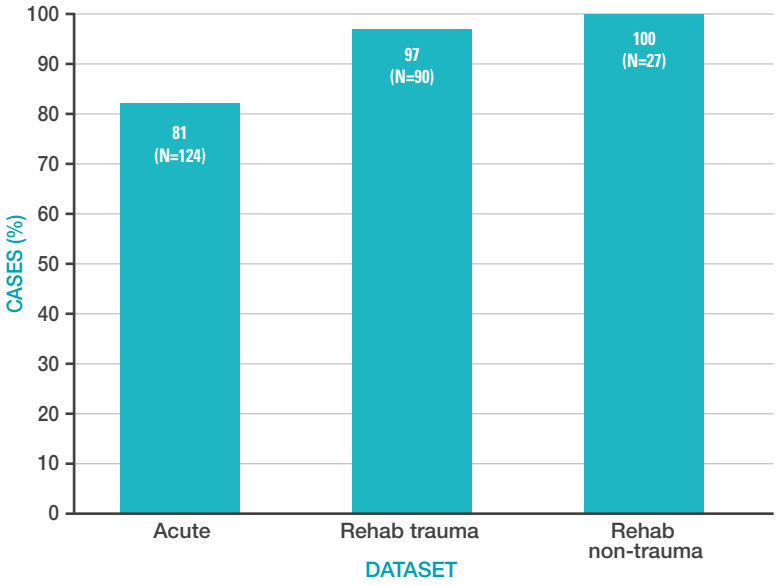
	N	%
Elective	10	8
Urgent/Emergent	114	92
Total	**124**	**100**

Falls (46%) accounted for the largest percentage of cases when analyzing mechanism of injury followed by transport related injuries (34%) e.g. motor vehicle crashes.

TABLE 5: MECHANISM OF INJURY

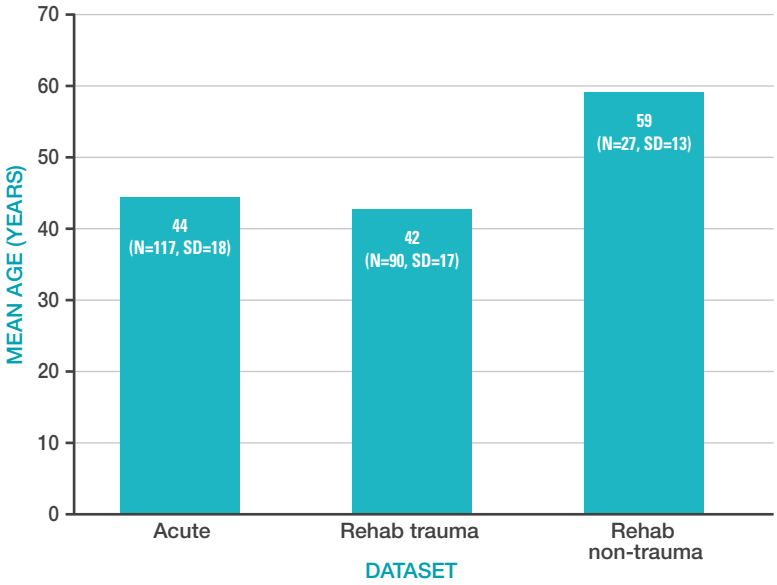
	N	%
Transport	42	34
Fall	57	46
Assault – Blunt	3	2
Assault - Penetrating	2	2
Other Traumatic Cause	20	16
Missing	0	0
Total	**124**	**100**

FIGURE 3
PERCENTAGE OF CASES THAT CONSENTED TO PARTICIPATE



Eighty one percent of spinal cord injury patients consented to participate in OSCIR in acute care participating sites compared to ninety seven percent of traumatic cases that consented in rehabilitation. All the non-traumatic cases at Toronto Rehabilitation agreed to participate in OSCIR.

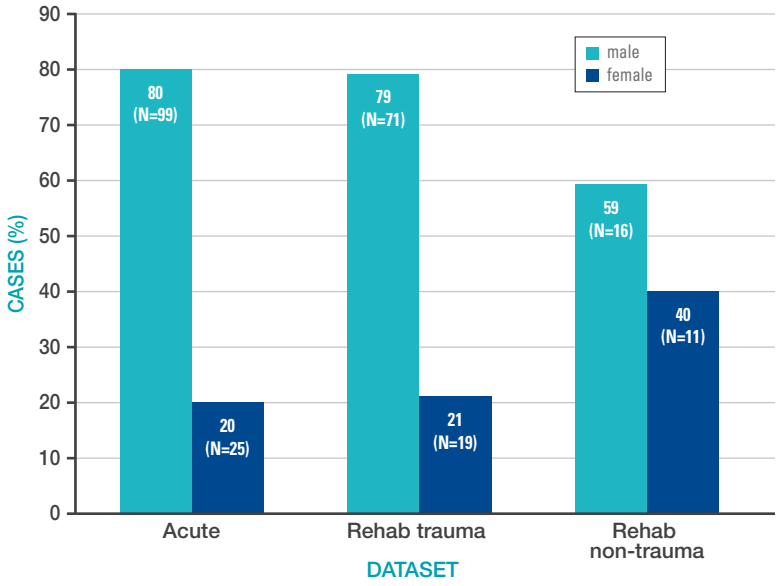
FIGURE 4
MEAN AGE



The mean age for acute care cases in the Pilot Project was 44 years compared to 42 for traumatic spinal cord injury cases in rehabilitation and 59 years for non-traumatic cases at TRI.

Eighty percent of acute care cases were male. Seventy nine percent of traumatic cases were male compared to 59% of non-traumatic in rehabilitation.

FIGURE 5
SEX DISTRIBUTION



Patients with spinal cord injury are classified according to completeness of injury using the American Spinal Injury Association (ASIA) Impairment Scale (AIS). The classifications of A, B, C, D, and E are listed below:

A = Complete, No sensory or motor function at S4/5

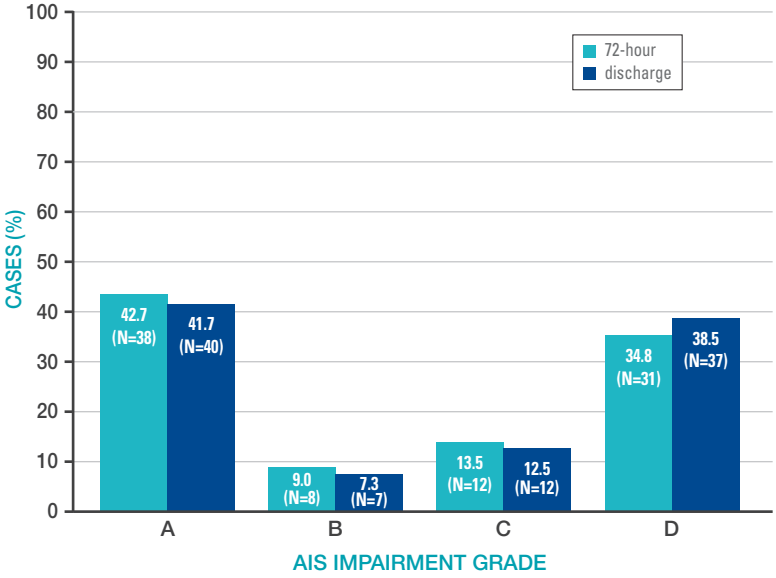
B = Sensory Incomplete, Sensory but no motor function at S4/5

C = Motor Incomplete, More than half of key muscles below a single neurological level have a grade less than 3

D = Motor Incomplete, Half or more of the key muscles below the single neurological level have a grade greater than or equal to 3

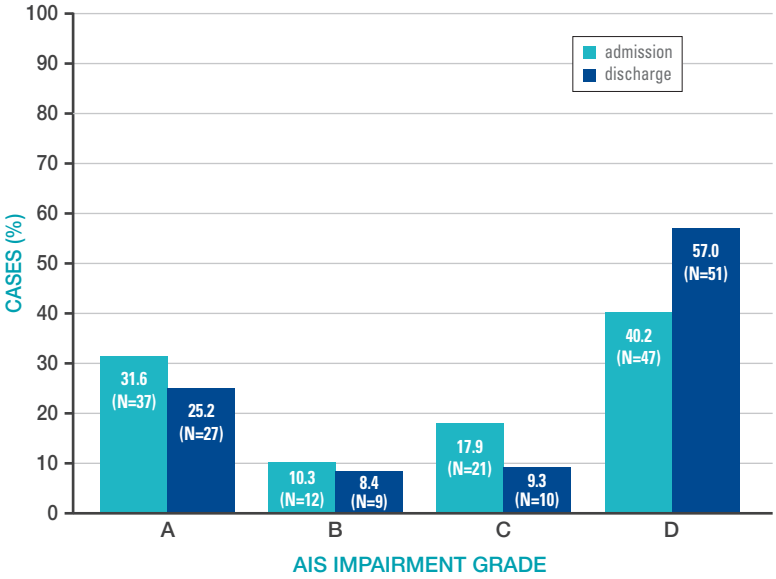
E = Normal sensory and motor function, All components of the International Standards Exam are normal

FIGURE 6
ACUTE AIS



AIS A was the most prevalent impairment grade within 72 hours from acute care admission (43%) and acute care discharge (42%).

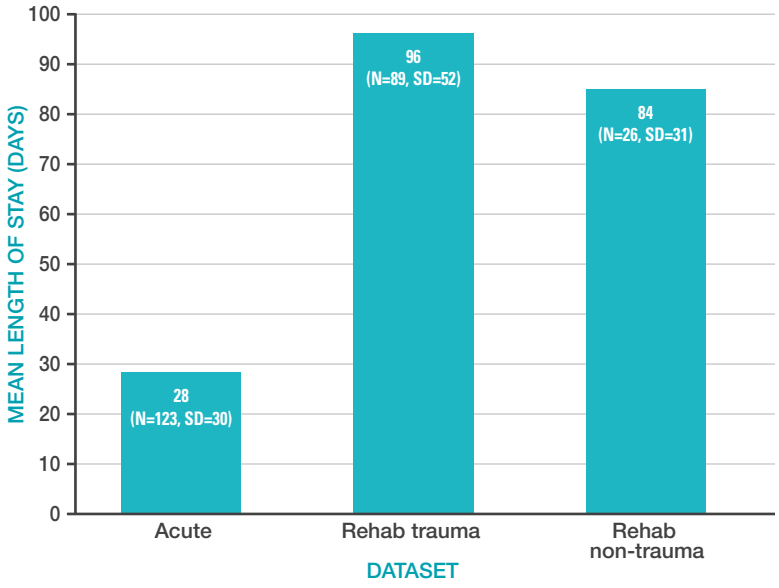
FIGURE 7
REHABILITATION AIS



The largest percentage of rehabilitation cases (traumatic and non-traumatic) was impairment grade D (40%) on admission compared to 57% on discharge. The improvement of neurological function was the combination of the effects of natural recovery and rehabilitation.

The mean length of stay was 28 days for acute care during the Pilot Project. The mean length of stay in rehabilitation was 96 days for traumatic cases compared to 84 days for non-traumatic cases.

FIGURE 8
MEAN LENGTH OF STAY FOR ACUTE AND REHABILITATION CASES



Twenty two percent of acute care cases in the Ontario Spinal Cord Injury Registry involved a sports and recreation injury.

FIGURE 9
MECHANISM OF SPINAL CORD INJURY RELATED TO SPORTS OR RECREATION

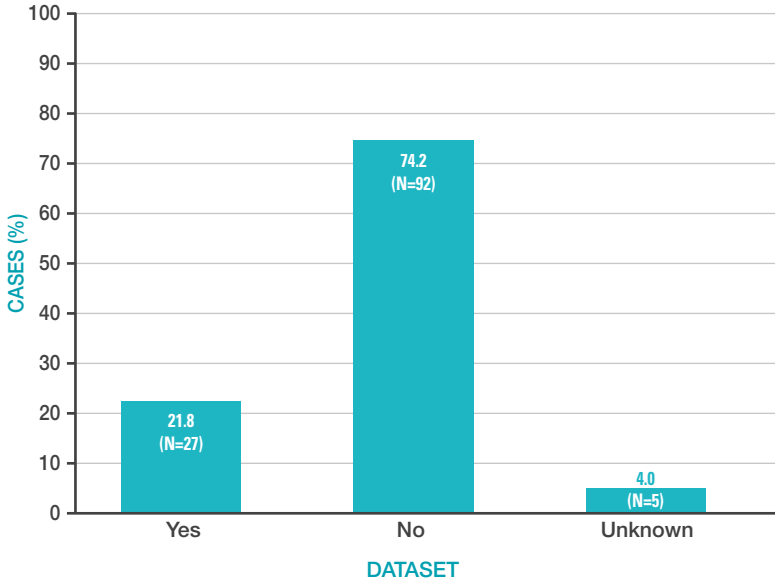
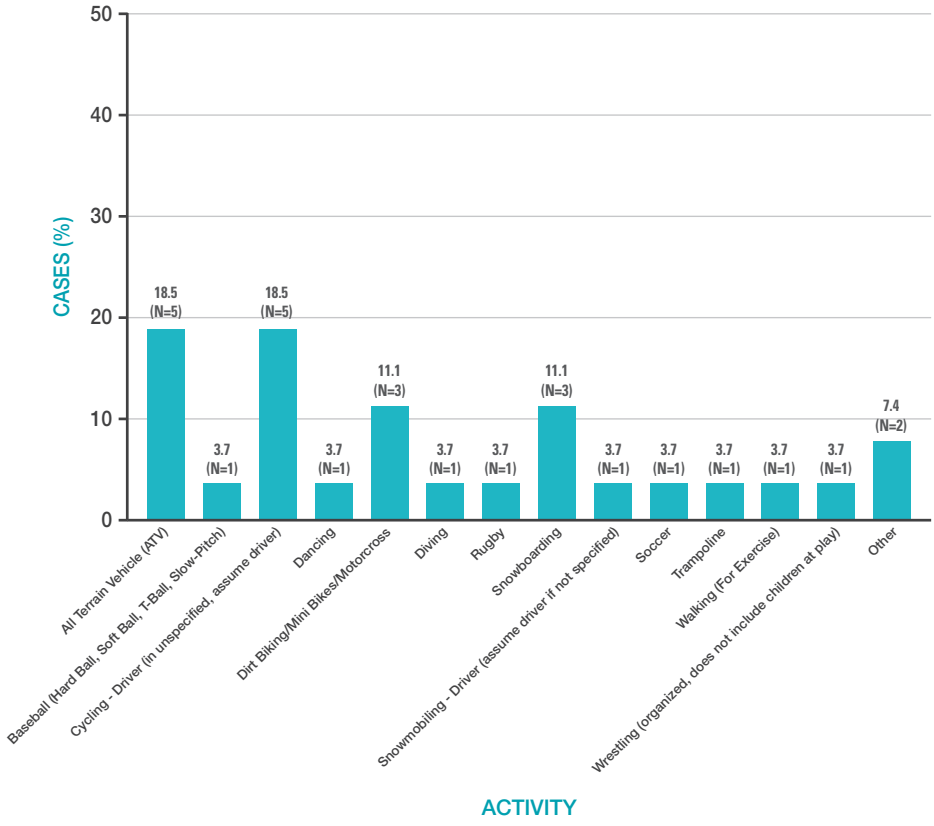


FIGURE 10
SPORTS OR RECREATION: SPECIFIC ACTIVITY (N=27)



Of sports and recreation injuries, the largest percentage of cases involved all terrain vehicles (19%) and cycling (19%).

TABLE 6: ACUTE CARE CASES WITH DOCUMENTED COMORBIDITIES	N	%
1 comorbidity	23	19
2 comorbidities	16	13
3 comorbidities	6	5
4 comorbidities	6	5
5 comorbidities	4	3
6 comorbidities	3	2
>6 comorbidities	2	2
Missing	64	52
Total	**124**	**100**

Forty nine percent of spinal cord injury cases in the Pilot Project had at least one comorbidity; 30% had two or more comorbidities. There were extensive missing data for this variable which could lead to under-reporting of comorbidities.

An MRI was not done 38% of the time for SCI cases in the pilot. For the cases in which an MRI was done, the MRI showed compression of neural elements in 68% of cases.

TABLE 7: FINDINGS FROM MAGNETIC RESONANCE IMAGING (MRI)

	N	%
MRI showed compression of neural elements		
Yes	52	68
No	11	14
Missing	14	18
Total	**77**	**100**

The mean time to surgical decompression ranged from 11.7 hours to 20.9 hours at participating sites. Time to decompression is a variable being investigated as early surgical decompression for SCI patients is demonstrating better recovery.

TABLE 8: TIME TO SURGICAL DECOMPRESSION BY SITE

	Mean (hours)
Mean Time to Decompression by Site	
Hamilton Health Sciences	13.5
St. Michael's Hospital	14.0
Sunnybrook Health Sciences Centre	20.9
University Health Network	11.7
	Median (hours)
Median Time to Decompression by Site	
Hamilton Health Sciences	13.8
St. Michael's Hospital	16.3
Sunnybrook Health Sciences Centre	22.0
University Health Network	11.0

Data showed that for 73% of SCI cases, availability of a ventilator was a barrier to timely transfer to an acute care facility.

TABLE 9: BARRIERS TO TIMELY TRANSFER TO ACUTE CARE FACILITY

	N	%
No barriers to transfer	9	9
Ventilator not available	75	73
ICU bed not available	2	2
Spine physician not available	8	8
Trauma bed not available	2	2
Other	2	2
Missing	5	5
Total	**103**	**100**

TABLE 10: ACUTE CARE DISCHARGE DISPOSITION (ALL SITES)	N	%
Private residence	8	6
Acute care hospital	6	5
Complex continuing care	1	1
Correctional institute	1	1
Rehabilitation	97	78
Other	1	1
Missing	10	8
Total	**124**	**100**

Seventy eight percent of acute care spinal cord injury cases were discharged to rehabilitation.

TABLE 11: SERVICE UTILIZATION AT DISCHARGE FROM REHABILITATION (TRAUMA AND NON-TRAUMA)	N	%
Assistive Technology	6	7
Attendant Services	15	18
Direct Funding	2	2
Supportive Housing	3	4
Long-Term Care Facility	2	2
Attendant Outreach Program	3	4
Case Management	4	5
Drivers Assessment and Training	11	13
Housing Services	1	1
Information Services	1	1
Peer Support Program	17	20
SCIPilot	14	17
Vocation Rehabilitation and Employment Services	3	4
Other Services	1	1
Total	**83**	**100**

Twenty percent of spinal cord injury patients received peer support services upon discharge from rehabilitation followed by attendant services (18%) and SCIPilot (17%). Thirty four cases had missing data for service utilization at discharge from rehabilitation.

TABLE 12: INDIVIDUALS CONTACTED BY THE CANADIAN PARAPLEGIC ASSOCIATION, ONTARIO (ALL ACUTE SITES)	N	%
No	31	25
Yes	17	14
Unknown	60	48
Not applicable	16	13
Total	**124**	**100**

The Canadian Paraplegic Association attempts to contact patients while they are still in the hospital to assist with organizing services early post injury. Fourteen percent of SCI patients were contacted by the Canadian Paraplegic Association (Ontario) compared to twenty five percent who were not contacted. This data element was missing 48% of the time indicating that a better early contact rate is in order.

HIGHLIGHTS OF RESULTS FROM OSCIR RESEARCH QUESTIONS

Acute Research Questions

All Acute Sites

1. How many calls must be made by a referring hospital to find an acute care bed using CritiCall data?

The provincial average for the number of physicians contacted to transfer spine patients was 3. The range, by LHIN, was 1 to 19 calls.

N=751	Total # MDs Contacted
AVERAGE	3.03
MEDIAN	2
MIN	1
MAX	19

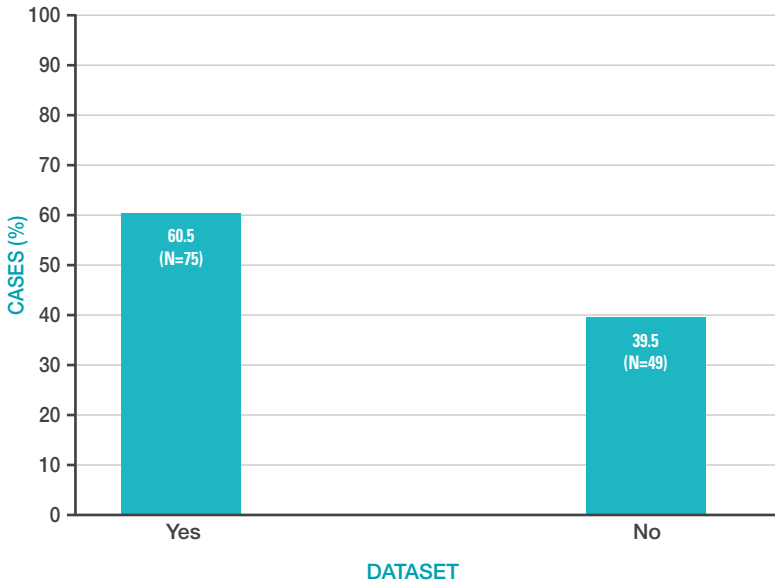
TABLE 13 CRITICALL ANALYSIS OF NUMBER OF CALLS TO FIND A BED FOR SPINE PATIENTS

	Total # of MDs Contacted			
Referring LHIN	Mean	Median	Min	Max
1 Erie St. Clair	5.08	4.50	1.00	10.00
2 South West	4.07	3.00	1.00	12.00
3 Waterloo Wellington	2.64	1.50	1.00	11.00
4 Hamilton Niagara Haldimand Brant	2.51	1.00	1.00	15.00
5 Central West	3.29	2.00	1.00	12.00
6 Mississauga Halton	3.41	3.00	1.00	17.00
7 Toronto Central	3.17	3.00	1.00	13.00
8 Central	3.31	2.00	1.00	13.00
9 Central East	2.90	2.00	1.00	13.00
10 South East	3.60	3.00	1.00	8.00
11 Champlain	1.67	1.00	1.00	4.00
12 North Simcoe Muskoka	3.47	2.50	1.00	19.00
13 North East	3.26	3.00	1.00	12.00
14 North West	3.75	3.00	1.00	8.00

2. What percentage of cases were involved in SCI research?

Sixty one percent of spinal cord injury patients included in the Ontario Spinal Cord Injury Registry were involved in other SCI research projects including clinical trials in acute care participating sites. This demonstrates that recruitment fatigue and cross study contamination could easily happen without tracking this variable to inform best research practices.

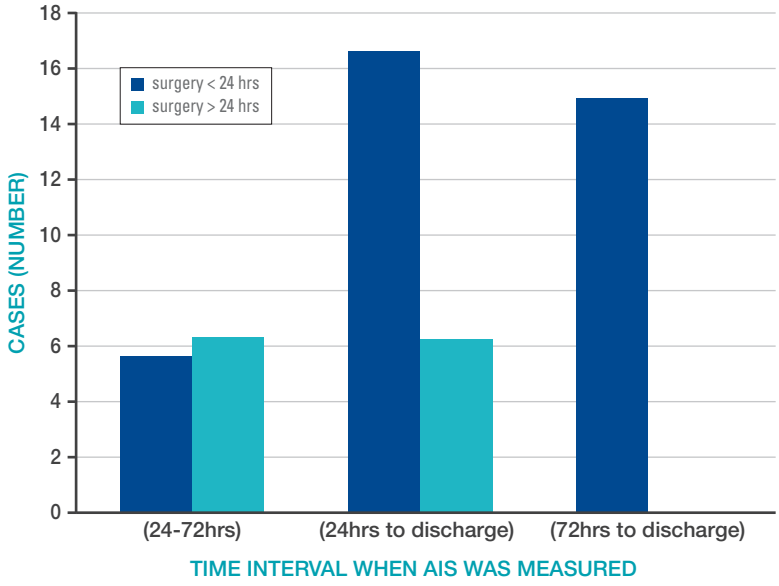
FIGURE 11
CASES INVOLVED IN OTHER SCI RESEARCH



University Health Network

3. Is there better improvement in AIS with early decompression?

FIGURE 12
TOTAL PERCENTAGE OF PATIENTS WITH COMPLETE MYELOPATHY WHO HAD AIS SCORE IMPROVEMENTS



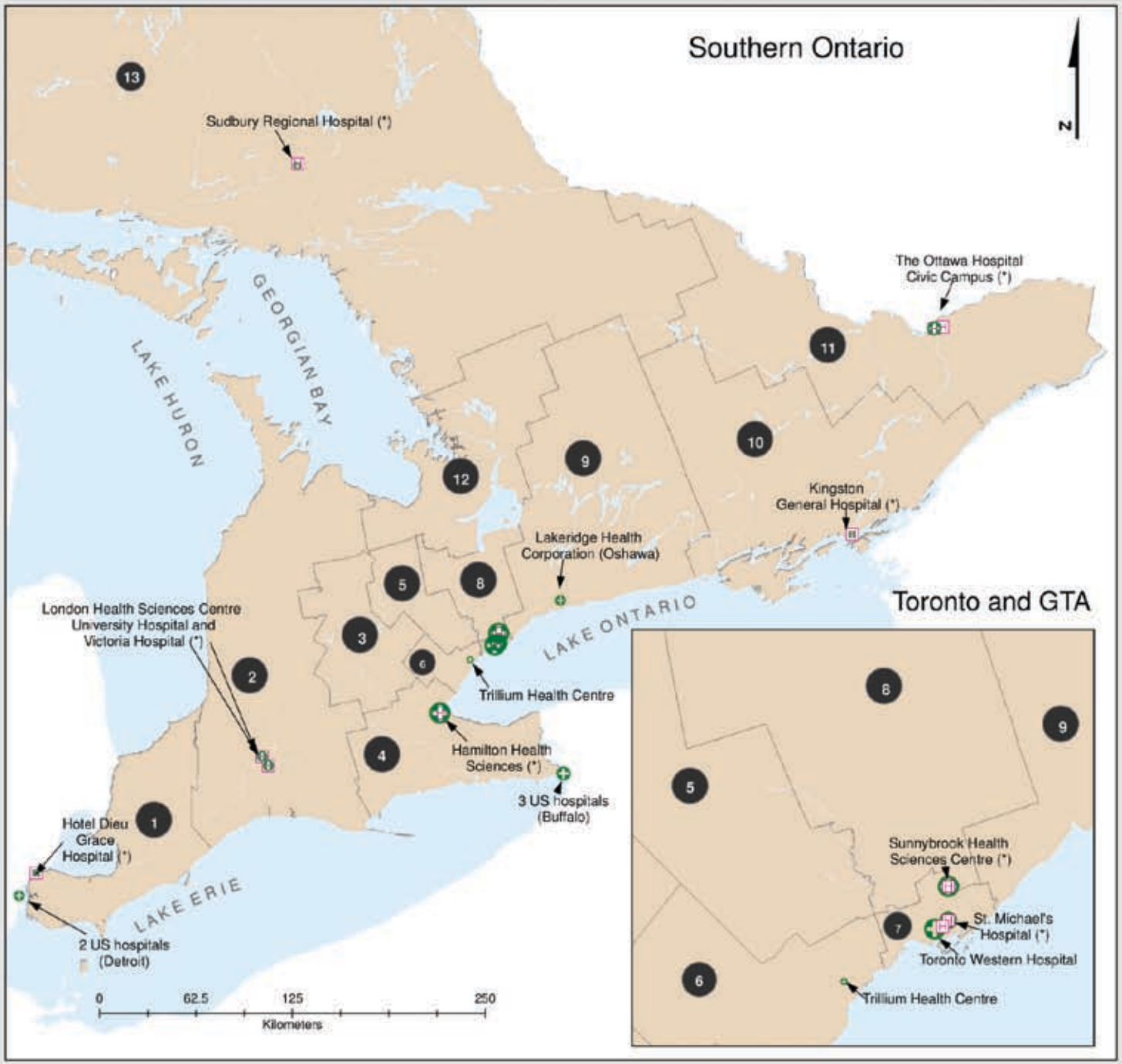
The graph shows that patients with AIS-A who underwent early surgery had significantly greater improvement in their neurological outcome as compared with late or no surgery group. Of the 117 patients used in the analysis, the results revealed that fourteen patients did not undergo surgery. A total of 43 patients received surgical intervention ≤24 hours while 60 patients were ≥24 hours. In patients with complete myelopathy, there is 12.43% ($p < 0.05$) increase in the chance of having at least one scale AIS improvement with early surgery compared with only 4.15% ($p<0.05$) with late surgery. This leads one to conclude that SCI patients should be transferred to a specialized spine centre immediately after the trauma so surgical decompression can be undertaken quickly to provide better functional outcomes.

Sunnybrook Health Sciences Centre

4. Do lack of acute spine care resources lead to delay in treatment for SCI patients?

MAP 1 demonstrates that spine cases are transferred to U.S. hospitals. Of the 751 patients with spine injuries transferred in 2006-2008, 2.2 - 4.3% were transferred to Buffalo and .08 - 2.1% to Detroit hospitals demonstrating the lack of capacity in centres in Ontario. Capacity and protocols need to be reviewed to improve access to care for SCI patients.

MAP 2 demonstrates the percentage of spine patients transferred outside their LHIN for care. Champlain, Hamilton, South West and Toronto Central keep some portion of spine patients within their LHINs. Waterloo Wellington, Central West, South East and Missisauga Halton LHINs transferred SCI patients to adjacent LHINs. North Simcoe Muskoka, North East and North West LHINs transferred patients to nonadjacent LHINs. Given the catastrophic nature of spinal cord injury, further investigation of the CritiCall data is required to increase the number of spinal cord injury patients that are treated close to home and family.



Receiving Hospitals

% of all transfers (751)	# of hospitals within each category
<0.8%	(3)
0.8% - 2.1%	(3)
2.2% - 4.3%	(1)
4.4% - 12.4%	(3)
>12.4%	(3)

Trauma Centres (14)

LHIN Boundaries

Labels correspond to receiving hospitals (* Trauma Centre)

Local Health Integration Networks

1. Erie St. Clair
2. South West
3. Waterloo Wellington
4. Hamilton Niagara Haldimand Brant
5. Central West
6. Mississauga Halton
7. Toronto Central
8. Central
9. Central East
10. South East
11. Champlain
12. North Simcoe Muskoka
13. North East
14. North West

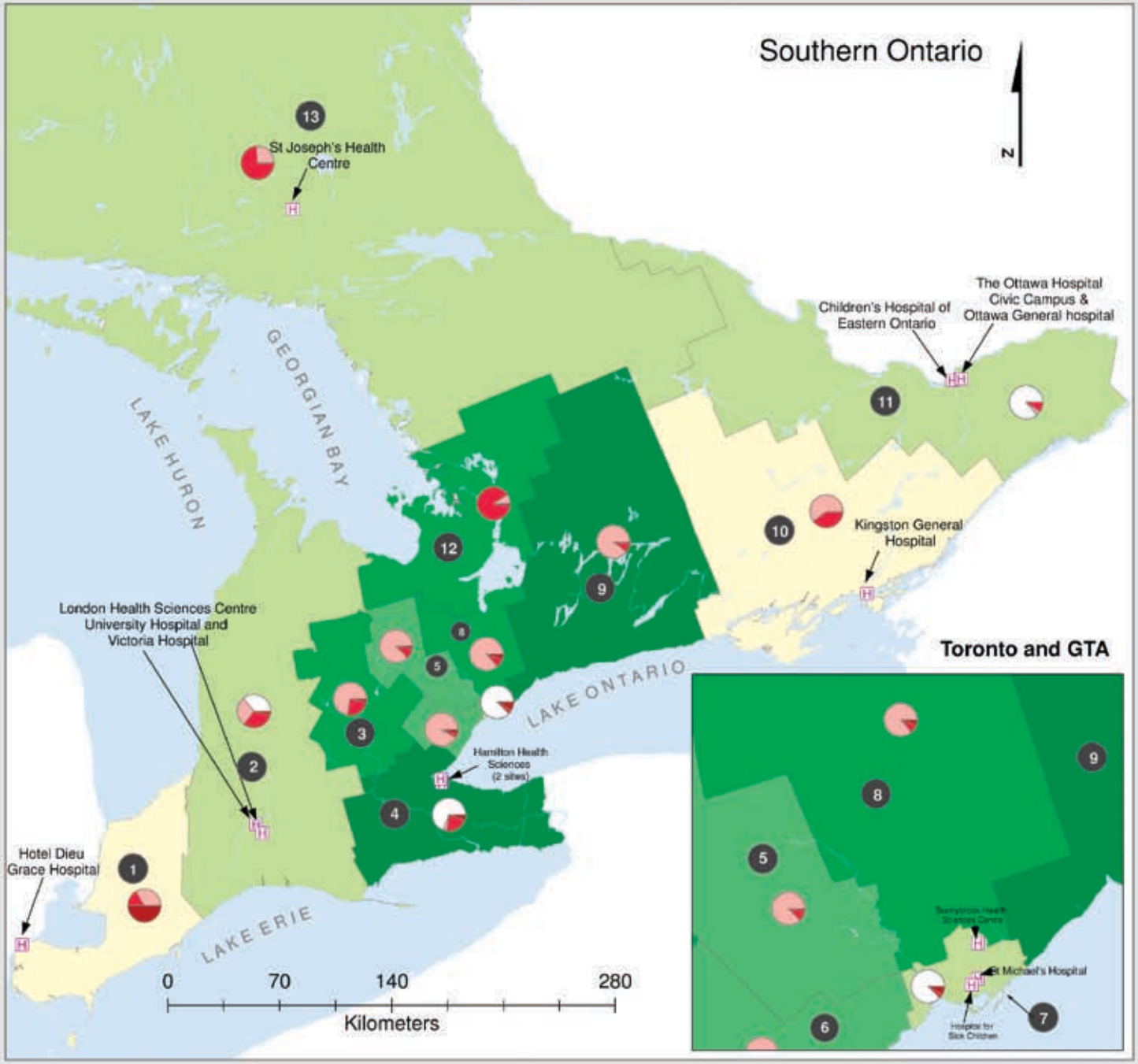
Source:

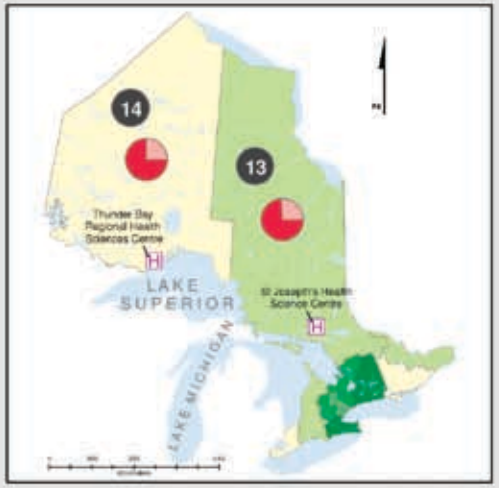
Ontario Spinal Cord Injury Registry. CritiCall Data.

Fiscal Years: 2006 - 2008

Projection: NAD 1983 Datum, UTM Zone 17 N

MAP 2: PROPORTION OF ALL TRANSFERS FOR SPINE SPECIALTIES BY LOCAL HEALTH INTEGRATION NETWORKS, ONTARIO: FY 2006 - 2008





% of transfers (n = 751)	Transfers destination
<1.7	Within LHIN
1.7 - 3.7	To adjacent LHIN
3.8 - 6.5	To non-adjacent LHIN
6.6 - 12.5	To USA
>12.5	

H Trauma Centres

Residential LHIN of patients transferred for spine specialties

Local Health Integration Networks

1. Erie St. Clair
2. South West
3. Waterloo Wellington
4. Hamilton Niagara Haldimand Brant
5. Central West
6. Mississauga Halton
7. Toronto Central
8. Central
9. Central East
10. South East
11. Champlain
12. North Simcoe Muskoka
13. North East
14. North West

Source:

Ontario Spinal Cord Injury Registry. CritiCall Data.

Fiscal Years: 2006 - 2008

Projection: NAD 1983 Datum, UTM Zone 17 N

St. Michael's Hospital

5. *What is the impact of spinal cord injury on the mortality rates and resource requirements on polytrauma patients with Injury Severity Scores (ISS) greater than 16 compared to patients with isolated spinal cord injuries?*

Fortunately there was only one death during the pilot study period so mortality analysis was not conducted. Data elements from the Ontario Trauma Registry were not included in the OSCIR pilot so the comparison could not be made between cases based on Injury Severity Score. In order to assess resource requirements, the total cost per diem data from the MOHLTC was applied to the number of acute and rehabllitation cases of spinal cord injury to estimate the overall hospital cost for the number of patients enrolled during the pilot time frame.

TABLE 14: INHOSPITAL ACUTE CARE COSTS

Acute	N	ACUTE INPATIENT Cost Per Diem ($) including direct and overhead costs 2006/07	Estimated Acute Hospital cost for SCI Patients in Pilot Project
Hamilton Health Sciences	43	1,418	60,974
St. Michael's Hospital	22	1,647	36,234
Sunnybrook Health Sciences Centre	42	1,460	61,320
University Health Network	17	1,777	30,209
Total	**124**		**188,737**
Estimated cost assuming mean length of stay is 28 days			**5,284,636**

TABLE 15: INHOSPITAL REHABILITATION CARE COSTS

Rehabilitation	N	REHAB Cost Per Diem ($) Including direct and overhead costs 2006/07$	Estimated Rehab Hospital cost for SCI Patients in Pilot Project
Hamilton Health Sciences	35	687	24,045
Toronto Rehabilitation (Traumatic)	55	709	38,995
Toronto Rehabilitation (Non-Traumatic)	27	709	19,143
Total	**117**		**82,183**
Estimated cost assuming mean LOS is 96 days for traumatic and 84 days for non-traumatic cases			**7,659,852**

The total inhospital costs including direct and overhead expenses for 124 acute cases and 90 rehabilitation cases was estimated at $12,944,488 for the Pilot Project. These costs reflect inhospital costs only so more detailed costing of spinal cord injury is critical for future resource planning.

*Source document: 2004/05, 2005/06, and 2006/07 Ontario Cost Distribution Methodology. www.mohltcfim.com

Hamilton Health Sciences

6. *Does the amount of time between injury and spine decompression or stabilization surgery relate to acute LOS?*

Cases included in the analysis 1) were admitted to Hamilton General Hospital; 2) had a known injury date and time; and 3) had a known surgery date and time (N=28).

FIGURE 13
RELATIONSHIP BETWEEN INJURY-TO-SURGERY TIME AND ACUTE CARE LENGTH OF STAY

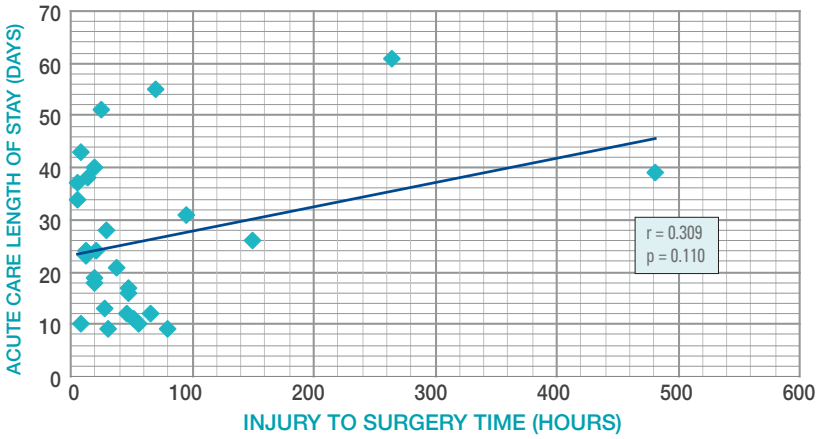


TABLE 16: MEAN INJURY-TO-SURGERY TIME AND ACUTE CARE LENGTH OF STAY

	Mean	Standard Deviation	N
Injury to Surgery Time (Hours)	62.7	97.6	28
Hamilton General Hospital Acute Care Length of Stay (Days)	26.1	14.8	28

Twenty-eight participants of the Ontario Spinal Cord Injury Registry – Hamilton Site were included in the data analysis for this research question. The mean acute care length of stay for these participants was 26.1 days. The mean time from spinal cord injury to spine decompression or stabilization surgery was 62.7 hours. The correlation between injury-to-surgery time and acute care length of stay (r = 0.309) was not statistically significant indicating that the injury-to-surgery time was not related to acute care length of stay.

7. Is Hamilton General Hospital Rehabilitation LOS related to Chedoke LOS?

SCI Cases who were admitted to Hamilton General Hospital and then Chedoke Hospital with LOS less than 300 days were used for analysis (N=35).

TABLE 17: HAMILTON GENERAL HOSPITAL REHABILITATION PRIOR TO CHEDOKE HOSPITAL REHABILITATION AND REHABILITATION LENGTH OF STAY

Admission to Hamilton General Hospital Rehabilitation	N	Chedoke Site Rehabilitation Mean Length of Stay (days)	SD	t	p-value
No	26	85.5	30.9	-1.540	0.133
Yes	9	66.6	34.2		

Thirty-seven participants of the Ontario Spinal Cord Injury Registry – Hamilton Site were admitted to Hamilton General Hospital and Chedoke Hospital. Of these, ten (27%) were admitted to Hamilton General Hospital Spine Unit's rehabilitation beds before admission to Chedoke Hospital's Spinal Cord Injury Rehabilitation Program. After removal of outliers, data from thirty-five participants were included in data analysis. The mean rehabilitation length of stay at Chedoke Hospital for participants who were not admitted to Hamilton General Hospital rehabilitation was 85.5 days. Although this was longer than the mean rehabilitation length of stay of 66.6 days for participants who were admitted to Hamilton General Hospital rehabilitation, the difference was not statistically significant.

Rehabilitation Research Questions

Hamilton Health Sciences – Chedoke Site

8. *What is the incidence of rehabilitation interruption by readmission to acute care?*

TABLE 18: RE-ADMISSION TO HAMILTON HEALTH SCIENCES ACUTE CARE FROM CHEDOKE HOSPITAL REHABILITATION

	N (%)	HHS Acute Care Re-Admission Mean Length of Stay (Days)
Participants Re-Admitted from Rehabilitation at Chedoke Hospital to Acute Care at Hamilton Health Sciences (HHS)	6 (15.4)	5 (Range: 1-13)

Thirty-nine participants of the Ontario Spinal Cord Injury Registry – Hamilton Site were admitted to Chedoke Hospital. Of these, six participants (15%) were re-admitted to a Hamilton Health Sciences for acute care. The mean length of stay of re-admission was 5 days.

9. *What is the LOS for acute care readmissions from rehabilitation and is readmission to acute care related to overall rehabilitation LOS?*

TABLE 19: REHABILITATION TO ACUTE CARE RE-ADMISSION AND CHEDOKE HOSPITAL REHABILITATION LENGTH OF STAY

Rehabilitation to Acute Care Re-Admission	N	Chedoke Site Rehabilitation Mean Length of Stay (days)	SD	t	p-value
No	33	82.0	33.6	-1.359	0.231
Yes	6	158.5	137.1		

The mean rehabilitation length of stay at Chedoke Hospital for participants whose rehabilitation was not interrupted by re-admission to acute care was 82.0 days. Comparatively, participants whose rehabilitation was interrupted by re-admission to acute care had a mean rehabilitation length of stay of 158.5 days. Although participants who were re-admitted to acute care had a longer length of stay at Chedoke Hospital's Spinal Cord Injury Rehabilitation Program than participants whose rehabilitation was not interrupted, this difference was not statistically significant. With 15% of cases requiring readmission, further consideration of medical status may be required before transfer to rehabilitation.

Toronto Rehabilitation Institute, Lyndhurst Site

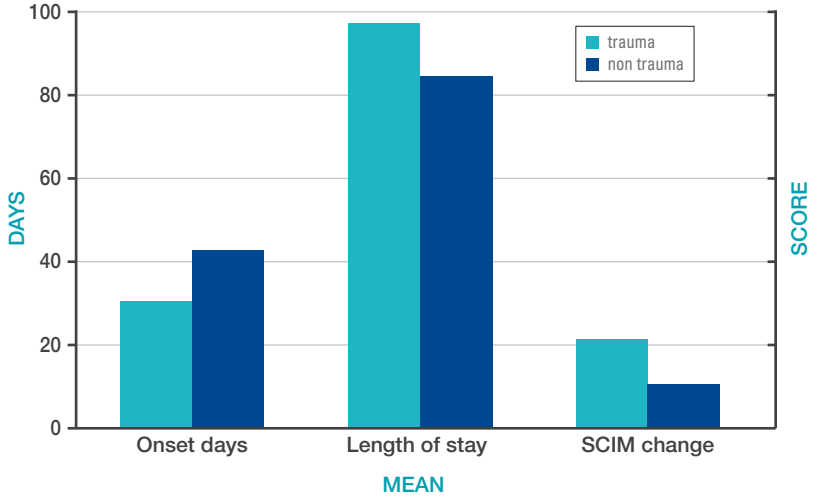
At Toronto Rehabilitation Institute, patients were eligible for study participation if they had a spinal cord injury resulting from an injury or certain illnesses. A traumatic SCI was defined as an injury resulting from a transfer of energy including a motor vehicle collision, fall or diving injury. There are many different illnesses which can result in spinal cord injury. Spinal stenosis, transverse myelitis and spinal tumours are a few of the many possible causes of a non-traumatic SCI. Other non-traumatic causes of SCI that were included in OSCIR at Toronto Rehabilitation are outlined in Appendix G.

10. *Are there important demographic differences between the trauma and non-trauma SCI population admitted for inpatient rehabilitation?*

    Demographic characteristics of patients with SCI of non-traumatic and traumatic etiology were assessed for differences. A number of variables were examined (marital status, weight, employment status, income), however, the predominant differences between the groups related to the age and sex of participants. Sixty one percent of trauma participants were male compared with 13% percent of non-trauma participants. The mean age of trauma participants was 42 years (14-74) while the mean age of non-trauma participants was 59 (28-82). A greater portion of participants with non-traumatic SCI were elderly women and trauma participants were young men which has significant implications for planning and implementing patient education sessions and discharge planning based on available social supports for these two diverse groups.

11. *Are there differences in Rehabilitation Onset Days (ROD), length of stay (LOS) and Spinal Cord Independence Measure (SCIM) change for trauma versus non-trauma participants?*

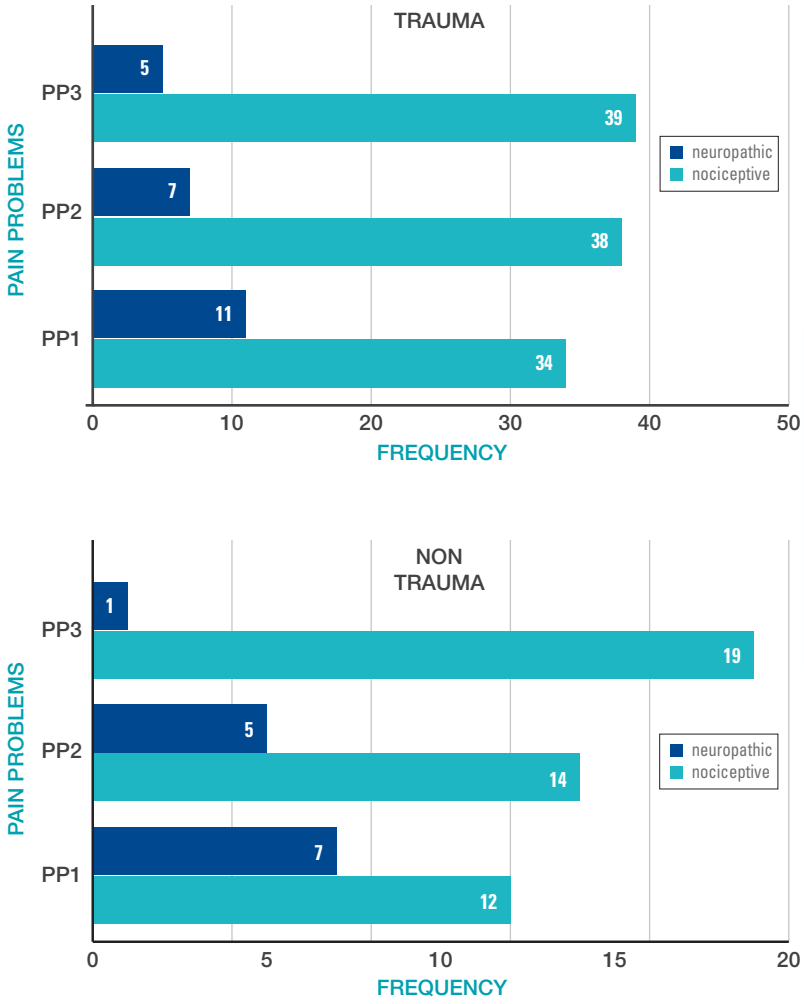
FIGURE 14
COMPARISON OF TRAUMA VS NON TRAUMA AT TORONTO REHABILITATION INSTITUTE



Non-traumatic SCI participants experienced a longer wait time for rehabilitation admission (onset days), had a shorter course of rehabilitation (LOS) and experienced lower Spinal Cord Independence Measure change scores between rehabilitation admission and discharge (SCIM change). This pattern of lower onset days among traumatic SCI patients may be in part to the recent wait time strategies implemented by the MOHLTC for patients with SCI of traumatic etiology. Given the increasing incidence of non-traumatic SCI, these findings are essential to guide resource planning for the SCI population. Further study of the reasons for the discrepancies in rehabilitation outcome among trauma and non-trauma patients is required as the differences in LOS alone are insufficient to explain the differences.

12. Are there differences in the type and severity of pain among SCI patients of traumatic versus non-traumatic etiology at rehabilitation discharge?

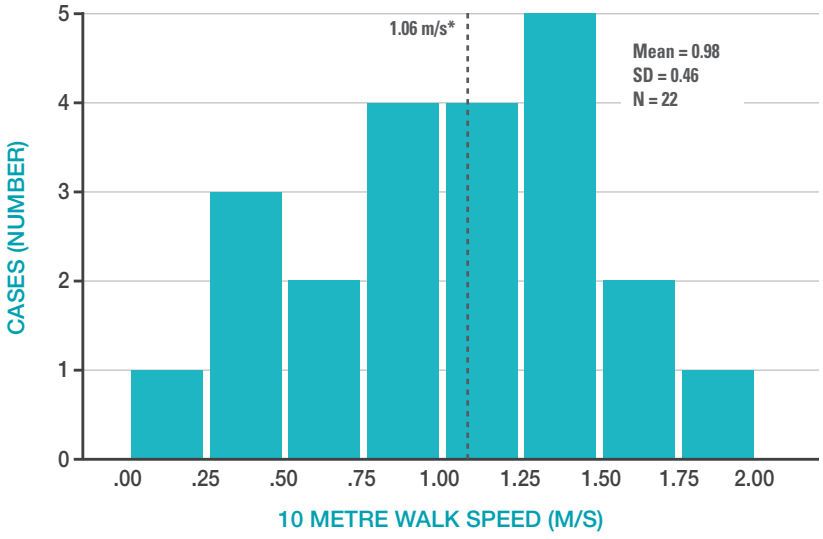
FIGURE 15
DIFFERENCE IN PAIN PROBLEMS (PP) BETWEEN TRAUMATIC AND NON-TRAUMATIC PATIENTS



There were no significant differences in the frequency of neuropathic versus nociceptive pain for traumatic and non-traumatic groups. The overall symptom severity was similar between the groups with exceptions for pain attacks for Pain Problem (PP) PP1 $p<0.05$. Within the groups, there was a higher frequency of neuropathic pain in the trauma group for PP1, PP2 and PP3, $p>0.01$.

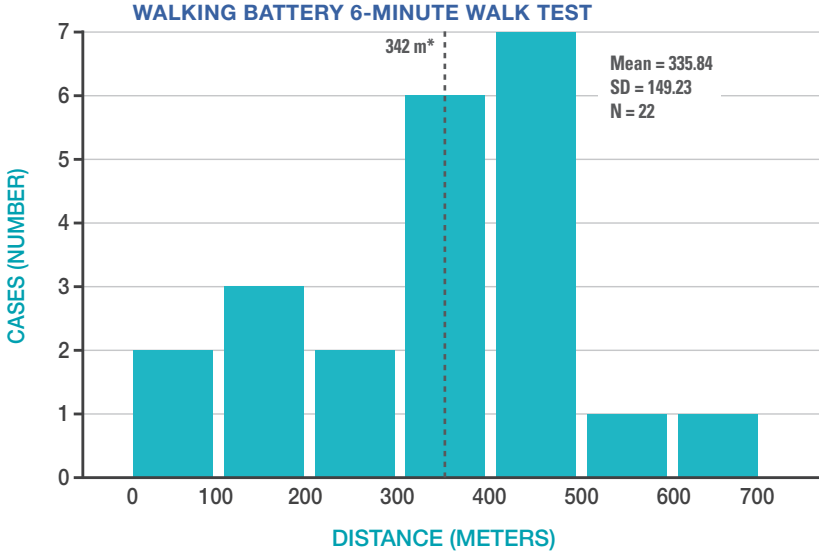
13. How do discharge battery scores relate to community ambulation?

FIGURE 16
WALKING BATTERY 10-METRE WALK TEST



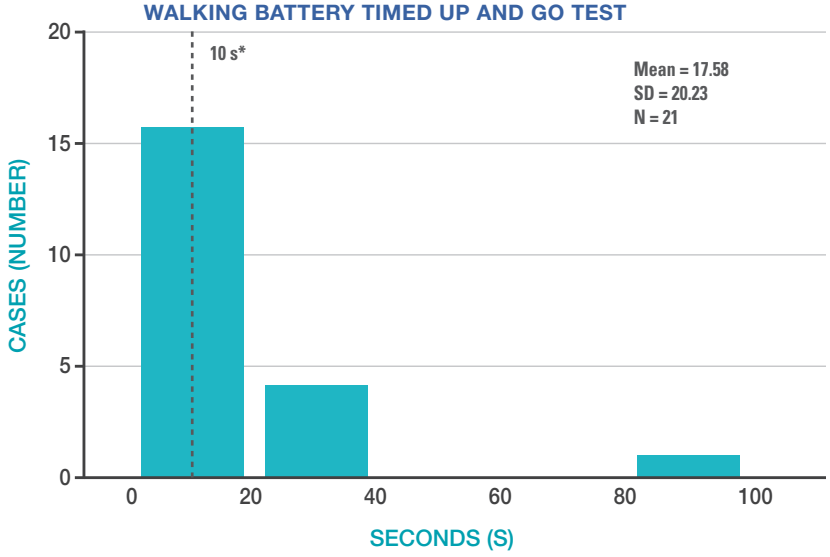
* Speed (in m/s) considered to classify an individual as a community ambulator (Lerner-Frankiel MB, Vargas S, Brown MB, Krusell L, Schoneberger W. Functional Community Ambulation: What are your criteria? Clin Management 1986; 6:12-15).

FIGURE 17
WALKING BATTERY 6-MINUTE WALK TEST



* Distance (in meters) considered to classify an individual as a community ambulator (Lerner-Frankiel MB, Vargas S, Brown MB, Krusell L, Schoneberger W. Functional Community Ambulation: What are your criteria? Clin Management 1986; 6:12-15).

FIGURE 18
WALKING BATTERY TIMED UP AND GO TEST



* Score (in seconds) considered to classify an individual as a non-faller community ambulator (Podsiadlo D, Richardson S. The Timed Up and Go - a Test of Basic Functional Mobility for Frail Elderly Persons. J. Am. Geriatric Soc 39(2):142-8, 1991).

As expected, there was a significant improvement in motor strength and functional status following rehabilitation based on Figures 16-18. The Spinal Cord Independence Measure (SCIM) was the best categorical outcome measure to demonstrate ambulation outcome. However, assessing whether patients are ready and safe for community ambulation requires more detailed assessment by the physiotherapist. Only 20% of the patients with incomplete traumatic SCI walked at admission to rehabilitation while 50% were walking at rehabilitation discharge. Requirements to walk in the community safely at discharge from rehabilitation were achieved in 45% to 61% of patients depending on the measure used to assess this capacity (speed, distance, postural control). A single outcome measure (categorical or timed) was not sufficient to accurately predict or characterize walking capacity for patients with incomplete SCI indicating that for best practice, multiple measures may need to be evaluated. Benchmarks for different aspects of ambulation to determine rehabilitation LOS as well as efficacy and effectiveness of different therapeutic approaches to training need to be established.

LESSONS LEARNED FROM THE OSCIR PILOT PROJECT

SCI POPULATION

- There were fewer SCI cases than expected over the course of the Pilot Project; it takes time to capture a sufficient number of cases during a pilot to conduct data analysis that will adhere to cell size recommendations for publication.

LEADERSHIP

- Buy-in was required from senior management at the CEO level at participating sites.
- A multi-disciplinary Advisory Committee was able to facilitate implementation of OSCIR in participating sites (Appendix H).
- Overall leadership was required to keep all aspects of the project on track and coordinate the multi-site team.
- Strong leadership was required from each participating site champion (Site Investigator).
- A collaborative working relationship was required between the Research Coordinator and Site Investigator at each participating site.

PARTICIPATING SITES

- The creation of a team consisting of a physician Site Investigator, a Research Coordinator, a nurse specialist, physiotherapist, and an operations manager at each participating site at the start of the pilot greatly facilitated the implementation of the SCI Registry.
- For the first time, collaboration was required between acute and rehabilitation sites, orthopedics and neurosurgery within acute care sites, and across participating sites creating a health system for SCI service delivery.
- The OSCIR Pilot Project conducted multi-discipline education of residents, physiotherapists and nurses to develop a systemic approach for spinal cord injury. At least fifty individuals were trained on the appropriate assessment of spine patients through the use of the AIS tool. A train-the-trainer approach was used for AIS training to ensure that residents received appropriate information at the start of their rotation. Pocket cards were distributed to residents to facilitate AIS documentation for SCI patients. Training was also required for the walking battery assessment.
- Practitioners learned and implemented new international standards of assessment (AIS, SCIM, pain, respiratory, muscle tone) for persons with SCI.
- Implementation of new forms including AIS data elements was required in emergency departments of participating acute care hospitals. In trauma centres, the Trauma Assessment Form was modified to include AIS.
- Participating sites established infrastructure that can be utilized to implement future research projects.

- Participating sites increased communication between emergency departments, intensive care units, and wards within sites to identify appropriate individuals for inclusion in the Ontario SCI Registry. This went beyond just recruitment in the Registry as it involved facilitating a comprehensive care plan at each site.
- There was an alignment of processes and practices across participating sites for spinal cord injury which is important when implementing best practices and standards of care.

DATA ELEMENTS

- Data elements for inclusion in OSCIR were developed by consensus to answer the Ontario research questions and aligned across the continuum of care according to standards set in the literature. Achieving consensus on SCI data elements for acute, rehabilitation and community follow up beyond the Pilot Project will require continued consultation, collaboration and consensus to ensure the data elements address the needs of Ontario stakeholders.
- It was possible to collect AIS scores with appropriate training and ongoing follow up. AIS data collection is fundamental to SCI data analysis.
- Standardizing time points for outcome measures e.g. AIS was important to enhance data analysis and interpretation for SCI patients (Appendix I). It is important that future spinal cord injury data collection include optional fields to align with the provincial research agenda.

CONSENT

- There was an urgency for patients with spinal cord injury to consent to participate in OSCIR so Research Coordinators could ensure that AIS was collected within 72 hours. It was difficult to get early consent from SCI patients because of the complexity of their condition e.g. they may be intubated.
- Re-consenting cases at Toronto Rehabilitation Institute, an REB requirement, was time consuming and resulted in significant delays in consenting patients.

DATA COLLECTION

- The data collection cost per case for OSCIR was high and the burden of data abstraction, data quality and completeness required significant Research Coordinator time. The number of data elements collected for OSCIR is only feasible for a Pilot Project.
- Complete and accurate data collection required well trained, multidisciplinary input from Research Coordinators, physicians and physiotherapists.

- Initially, OSCIR data were collected by one Research Coordinator in Toronto but this was changed to data collected by participating site personnel. The advantage of having one Research Coordinator was it was easier to influence the timing of the data collection. The advantage of having a Research Coordinator at each site was that they had existing relationships with health care providers making it easier to follow up on missing data.
- SCI data collection was useful for strategic planning within participating sites, in addition to addressing research questions.

COMMUNICATION

- An OSCIR newsletter was successful in providing updates to the Advisory Committee, Research Committee and participating sites between meetings.
- Regular weekly meetings between Research Coordinators and the Research Associate were useful to address questions regarding data definitions, collection, management and transmission of Registry data to improve consistency of data collection across participating sites.
- Regular monthly Research Committee meetings were chaired by the Project Lead to ensure the project deliverables were on track.
- Communication among staff across the transition from acute care to rehabilitation sites was critical to ensure continuity of patients participating in the pilot study.

TECHNOLOGY

- Technology is critical to the success of a SCI Registry; web based data entry would facilitate timely data analysis improving the quality of the data and timeliness of reporting to facilitate patient care decisions in real time. The cost of real time, web based data collection was prohibitive for a pilot.
- Sustainability of a longitudinal data system requires significant investment in technology and human resources.

PRIVACY

- Linkage of primary SCI data requires collection of personal health information to link to administrative data which is critical to the success of a Registry. The Ontario Trauma Registry, National Ambulatory Care Reporting System, Discharge Abstract Database and the National Rehabilitation Reporting System databases are important to expand the scope of research questions that can be answered. Although it is a limitation that these data are not timely, it is a cost efficient way to answer system level research questions at appropriate time intervals by linking with primary SCI data collection.

- Without being a designated prescribed Registry or entity, REB approval, consent and data sharing agreements were required for collection of SCI data making the process complex and cumbersome because of customization for each site's REB requirements.

ACCESS TO SCI CARE

- Analysis of CritiCall data demonstrated that there were no specific protocols or consistent referral patterns in Ontario to ensure timely access to appropriate acute care spine specialties services or surgical intervention for spine patients. Analysis of CritiCall data can facilitate access to appropriate spine care improving health outcomes for SCI patients.

OTHER

- It was possible to collect appropriate assessment data in the emergency department of trauma centres.
- It was possible to mix research and clinical staff in a common enterprise.
- Site Investigators required clinical research training, REB and privacy expertise.
- Timely, ongoing data analysis informed the SCI research agenda and approaches to service delivery e.g. walking battery.
- SCI data from the Pilot Project could be used to implement standard protocols e.g. type and timing of diagnostic imaging.
- The OSCIR Pilot Project had a selection bias to those patients who provided consent (81% in acute and 97% in rehabilitation).

LESSONS LEARNED FROM REHABILITATION DATA COLLECTION

- One of the achievements of the Ontario Spinal Cord Injury Registry was the development of a rehabilitation database for SCI. This included the following categories:
  - Sociodemographics
  - Impairment (AIS, motor scores, Δ scores)
  - Outcomes (FIM, SCIM, Onset, LOS)
  - Secondary Complications (bone mineral density, pain, spasticity)
  - Health Services Utilization (bounce backs, equipment, discharge resources)
  - Quality of Life post discharge (LiSAT-11)

  It was important for rehabilitation data collection that a minimum high quality data set was established for spinal cord injury that was value added and did not duplicate the National Rehabilitation Reporting System (NRS).
- A second innovation of OSCIR was to collect information on non-traumatic SCI patients in order to assess the difference between trauma and non-trauma patients in terms of sociodemographics characteristics, impairment (AIS, motor scores), rehabilitation onset and LOS, FIM, and SCIM change and efficiency.

- It is important to have a seemless and shared process for consent and data collection across acute, rehabilitation and follow up for spinal cord injury.
- SCIM was more appropriate for spinal cord injury patients than FIM which is the standard outcome measure in NRS mandated by the Ministry of Health and Long-Term Care.
- Pain (type & severity) and its impact on SCI inpatients was successfully implemented in rehabilitation data collection using a multi-disciplinary assessment tool integrated into team practice.
- It was important to identify community resource utilization to link with stakeholder organizations, services and therapies required for spinal cord injury patients. It is not sufficient to treat spinal cord injury patients in acute care and rehabilitation without appropriate transitions to community services to maximize health outcomes and quality of life.
- LiSAT-11 was successfully conducted at six months post discharge from rehabilitation in Toronto via telephone interview. LiSAT-11 was feasible and well accepted and should be included in a future minimum data set to measure life satisfaction.
- The OSCIR rehabilitation data collection highlighted gaps in service provision and charting practices and provided the ability to inform quality assurance and safety initiatives that will inform and facilitate future planning for SCI data collection.
- Issues such as bounce backs and service interruptions abound in the rehabilitation of spinal cord injury patients and affect data quality and rehabilitation service provision. The Registry can facilitate tracking bounce backs and service interruptions.
- For Registry data, recruitment procedures were streamlined and could be included in the admission process in future data collection.
- FIM data are mandated to be collected in the NRS so a system was established to ensure the FIM data were available for the SCI Registry.

FUTURE DIRECTIVES

DATA COLLECTION AND ACCESS

- All new SCI cases in Ontario should be identified through existing, state of the art approaches to optimize success in terms of timely, high quality data available for spinal cord injury e.g. Emergency Department Reporting System.
- Primary data collection for SCI patients should include electronic data collection in real time to facilitate data quality and analysis and use for clinical management.
- Limited, well defined data sets should be established across the continuum of care to enhance performance measurement and longitudinally to address Ontario research priorities. A Minimum Data Set should be defined by a consensus process taking OSCIR modifications into consideration to facilitate the development of a single SCI data source at the provincial level.
- Consideration should be given to including non-traumatic spinal cord injury cases in an SCI informatics system.
- Approaches for an SCI data collection system should have ties to the Office of the Information and Privacy Commission of Ontario to adhere to PHIPA requirements for data collection, use and disclosure to ensure alignment with an ever changing legislative environment related to registries.
- A strategy should be developed that will align with the national RHSCIR to ensure that Ontario capitalizes on the initial investment of OSCIR.
- A formalized Data Access Request should be established with RHSCIR to receive data on spinal cord injury patients in Ontario on a regular basis to facilitate data analysis to address Ontario's research questions including economic analysis of resource utilization.
- The definition for the Ontario Trauma Registry should be expanded to include isolated spine injuries rather than limited to cases with an Injury Severity Score > 12. AIS data collection for SCI patients should also be implemented through the Ontario Trauma Registry.

DATA QUALITY

- Primary SCI data collection should be routinely linked to administrative databases (e.g. National Ambulatory Care Reporting System, Discharge Abstract Database and the National Rehabilitation Reporting System) for data quality assessments e.g. chart abstraction and provincial level analysis based on assessment of referral patterns across the continuum of care.

PARTNERSHIPS

- The Ontario SCI Informatics Strategy Working Group should report data biannually to the Ontario Ministry of Health and Long-Term Care to enhance awareness of spinal cord injury as a priority population.
- The Ontario SCI Informatics Strategy Working Group should expand its membership to reflect Ontario stakeholders and update and implement the Ontario Data Strategy Framework.

STANDARDS AND PROTOCOLS

- AIS should be a provincial standard for SCI patients in Ontario.
- Standardized protocols should be established for the transport and treatment of spinal cord injury patients;
  - Protocols for access to acute spinal programs and trauma centres should be established.
  - Performance measures for positive health outcomes should be established for SCI patients.
  - Alternate level of care (ALC) data should be analyzed for SCI patients to develop appropriate outpatient and community services to facilitate timely discharge based on community service requirements to enhance quality of life during transition of SCI patients to the community.
- A seamless and shared process for consent and SCI data collection across acute and rehabilitation and longitudinal follow up should be established for the province.
- Specificity of rehabilitation data elements to better reflect important rehabilitation outcomes for SCI e.g. function - (SCIM), pain, mobility – (walking outcomes) should be included in an SCI Informatics strategy.
- Future data collection for community follow up should be based on recommendations from the national initiative on community integration.

CONCLUSIONS

The OSCIR Pilot Project was successful in achieving its objectives. The project determined the feasibility of implementing a Registry in Ontario to promote quality clinical care and management, inform research priorities, establish partnerships and began to develop an SCI Informatics strategy.

The goal of the Ontario SCI Registry Pilot Project was to lay the foundation for the development of a sustainable, provincial SCI Registry, customized to Ontario's health information management strategy. Without standards for data requirements in health records for SCI (e.g. standardized AIS classifications at specified time points), it appears that using research staff to abstract SCI data can provide the information required to meet a provincial research agenda.

Strategies such as web based entry and electronic health records with real time data entry need to be in place to ensure an adequate level of data completeness and data quality for the SCI population. Given that the technology is available, data collection will need to be redesigned to capture the full capacity of health informatics to optimize health outcomes across the continuum of care.

It is important to have a provincial SCI Informatics strategy to inform practice, research and innovations.

Appendices

APPENDIX A
STAKEHOLDERS

The key stakeholders for the Ontario SCI Registry are health care providers, researchers, managers and decision makers, and consumers.

Health care providers will maintain and access their patients' data within the Registry, and consult the Registry as a tool to gauge effectiveness of clinical intervention in the acute, rehabilitation, and community settings.

Researchers will use the Registry to identify and validate research opportunities to aid their pursuit of funding and industry partnerships, and ultimately to support leading edge research that facilitates the development and validation of effective interventions and therapies.

Managers and decision makers will consult the Registry for data on system performance, service planning and developing effective health policy.

Consumers will benefit from the Registry because it will house better information about their status and needs, and provide them with opportunities to influence and participate in research and service planning.

APPENDIX B
FOUNDATIONAL PRINCIPLES

Accessible

SCI data will be available to stakeholders for research and analysis at the local and provincial level.

Advisory Committee

An Advisory Committee will be established with medical champions from participating sites.

Authoritative Dataset

Developing the SCI Registry in the context of the HRT Information Management Strategy will enable the creation of an authoritative dataset for SCI.

Central Site

A central site will be established in Ontario. The central site will maintain the expertise for data collection, storage, analysis, transmission, provincial reporting and research.

Data Sources

SCI specific data elements that are not currently available will be collected and linked to existing databases e.g. CIHI.

Ethical Principles

A submission for the SCI Registry will be made for approval by Research Ethics Boards.

Limited Data Elements

Data elements will be limited to those required to address the goals of the Registry.

Longitudinal

The SCI Registry will be longitudinal from acute care through community follow up over the life-time of SCI patients.

Partnership

The SCI Registry will partner with the Ontario Neurotrauma Foundation, Health Results Team and RHSCIR to develop the Ontario SCI Registry.

Privacy

SCI data collection will adhere to PHIPA because patients will provide explicit informed consent to:

- Participate in the Spinal Cord Injury Registry
- Link CIHI data to the SCI Registry data
- Participate in regular follow up
- Participate in clinical trials.

Real Time Data Collection

The Toronto Pilot Project data collection should be real time.

SCI Data Elements

Complete and accurate AIS and FIM data collection is fundamental to the Registry and the data collection for the Registry will ensure that AIS and FIM scores are calculated and documented on patient charts.

Sustainability

The intent is that the SCI Registry will be sustainable over time through long term funding.

APPENDIX C
OSCIR DELIVERABLES

Phase 1 (2004-2006)

Investigation of the feasibility of utilizing CIHI to collect data for the Ontario Spinal Cord Injury Registry was undertaken. This approach was expected to increase the likelihood of sustainability of the Registry in Ontario. Discussions with CIHI to house the Registry were unsuccessful because of the large number of data elements in RHSCIR and the small number of spinal cord injury patients in Ontario. Once the decision was made to proceed with a Pilot Project in Toronto, the process for establishing the pilot sites and implementing data collection for an eighteen month feasibility study for the Ontario Pilot Project was developed. An implementation strategy dealing with all aspects (privacy, ethics, costing etc. of the local environments) of the Pilot Project was also developed.

ONTARIO NEUROTRAUMA FOUNDATION SCI PILOT PROJECT

- ONF agreed to participate in the national Rick Hansen Spinal Cord Injury Registry.
- An agreement was finalized between ONF and Toronto Rehabilitation Institute to contract for preliminary project work.
- Molly Verrier was retained as Principal Investigator/Lead.
- A Research Associate (Daria Parsons) was hired to assess site requirements (technical, personnel etc.) and to oversee the implementation of the Registry in each of the sites.
- CEOs of Sunnybrook Health Sciences Centre, St. Michael's Hospital, Western Division of University Health Network, and Lyndhurst Centre at Toronto Rehabilitation agreed to participate in the Toronto Pilot Project of the Ontario SCI Registry.
- An Advisory Committee was established. CEOs recommended an appropriate person from each institution as a member of the Advisory Committee.
- A medical champion was identified at each participating centre.
- A work plan was established for the project with approval of the Advisory Committee.
- Hamilton Health Sciences was included in OSCIR.

DEVELOP HUMAN RESOURCE PLAN

- A Human Resource Plan was drafted to determine skills required for Research Coordinators at participating sites.

IDENTIFY RISK AND MITIGATION STRATEGIES

- A Pilot Project risk and mitigation strategies document was drafted.

ENVIRONMENTAL SCAN

- A participating site survey was conducted to establish the number of SCI cases and data collection practices.
- Extensive consultations and site visits at participating centres facilitated the implementation of the SCI Registry in each of the sites.
- The number of spinal cord injury admissions was confirmed by participating sites.

APPENDIX C CONTINUED

PARTICIPATING SITE MEETINGS

- Data flow diagrams were drafted by site.
- Discussions occurred with privacy contacts at participating sites.
- The Principal Investigator/Lead attended a meeting with University of Toronto regarding the Toronto Spine Registry.

CONSULTATIONS

- A funding request was submitted the Health Results Team at the MOHLTC. The Ministry of Health and Long-Term Care funded the submission for the Ontario SCI Registry Pilot Project.
- The SCI Registry was mapped to Health Results Team Guiding Principles.
- RHSCIR data elements were reviewed by a Working Group and modifications were made to address Ontario research questions.
- Consultation occurred with the Canadian Paraplegic Association to delineate fields to capture services and resources required for SCI cases upon discharge from hospital to community.
- Consultation with Ontario stakeholders regarding Community Follow-up delineated a recommendation for assessing life satisfaction using the LiSAT-11 tool. A consensus report was drafted from a Community Follow-up meeting.
- Extensive consultation occurred with the MOHLTC to ensure that OSCIR data capture aligned with ministry standards. The Principal Investigator/Lead and the Research Associate sat on an ad hoc MOHLTC Registry group. Discussions with the MOHLTC occurred over a twelve month period to align the data with the HRT IM strategy to enhance the likelihood that there could be long-term sustainability.

MEETINGS

- Advisory Committee Meetings were held on April 8, March 8, June 3, and October 2005.
- A Working Group Meeting was held on December 9, 2005.
- Spinal cord injury data elements already collected at participating sites were reviewed including all databases and studies.
- Molly Verrier and Daria Parsons met with staff at the Information and Privacy Commissioner's Office (IPC) on May 3, 2006. For purposes of the Pilot Project, express consent was required from each spinal cord injury patient. IPC supported the Registry utilizing web-based data collection and offered to consult with the Research Ethics Boards of participating sites, if necessary.
- Consideration was given to applying for prescribed Registry status for spinal cord injury. This would eliminate the requirement for patient consent and REB approval would not be required. The disadvantage of this is that the patients could not be interviewed or followed up.

APPENDIX C CONTINUED

ESTABLISHMENT OF RESEARCH COMMITTEE

- Regular consultation occurred across the five institutions through monthly Research Committee meetings. This provided valuable input as to what data elements needed to be collected and at what time points to inform and align best practices.
- Each Site Investigator identified research questions that would be of particular interest to them that could be addressed from the Ontario Spinal Cord Injury Registry.

Phase 2 Implementation of OSCIR in Participating Sites (2006-2008)

CENTRAL REPOSITORY

- Criteria were developed for selection of the central repository.
- UHN was selected as the short term central repository for OSCIR because of their extensive information management experience across the continuum of care.
- Extensive discussions occurred with ICES regarding establishment of ICES as the long-term central site for SCI data in Ontario. The central site needed expertise for data collection, storage, analysis, provincial reporting and research. This would require close collaboration with an ICES Scientist which is the only way to have data analyzed at ICES.

IMPLEMENTATION AT SITES

- Research Coordinators were hired and trained in five (four acute and two rehabilitation sites) pilot sites in Toronto and Hamilton.
- REB approvals were sought from each participating site.
- Data Sharing Agreements were signed.
- Each spinal cord site's team consisting of a physician Site Investigator, a Research Coordinator, a nurse specialist, physiotherapist, and operations manager met to facilitate collection of data.
- Software was installed at each site.
- Pilot was launched.
- Data transmission to Ontario Central Site was tested.
- The Registry office was moved to ONF to reduce overhead costs of operations of the Registry during the data collection phase.
- Preliminary discussions occurred with the Ontario Health Information Standards Committee (OHISC) to implement AIS as a standard of care data element.

Phase 3 Data Analysis (2008-2009)

- Data completeness/data quality was assessed.
- Data analysis was conducted to address research questions.
- The Final OSCIR Report entitled *SCI Informatics Informing Practice Research and Innovation* was developed including descriptive data analysis, analysis of research questions, lessons learned and future directives.

APPENDIX D
OSCIR RESEARCH QUESTIONS

ACUTE RESEARCH QUESTIONS

Toronto Participating Sites (Research Committee)
1. How many calls must be made by a referring hospital to find an acute care bed using CritiCall data?
2. Was the patient part of the emergency IV saline study? (Did the patient receive any IV bolus pre-hospital?)
3. What is the mean arterial pressure (to determine hypotensive status)?
4. What is the time of injury to time of surgery (to determine if there are better outcomes if surgery is delayed until trauma patient is stable)?
5. How many patients are eligible for existing clinical trials?
6. How many patients are enrolled in clinical trials?
7. What are the barriers to timely admission of patients?
8. How do the injury AIS scores and sociodemographics of SCI patients on admission to the three acute teaching hospitals compare?
9. What is the patient severity (AIS scores) across participating sites?
10. How comparable is the LOS in the three acute hospitals?
11. What is the discharge disposition of the patients from the acute hospital? (e.g. by facility type: rehabilitation, LTC, home)
12. What are the changes in AIS scores from admission to discharge from acute hospitals?
13. What is the discharge FIM score?
14. What is the wait time to transfer to the rehabilitation facility? (Percentage of eligible for transfer)
15. What are the barriers to timely transfer of patients to rehabilitation at Lyndhurst e.g. halo vest, ventilation?
16. Is there adequate capacity (e.g. overall occupancy, sex-specific beds, isolation beds) in the rehabilitation facility to transfer all SCI requests?

Hamilton Health Sciences (Brian Drew)
1. Are there relationships between neurological level of injury and LOS, severity of injury (i.e. AIS) and LOS? If so, how are these correlated?
2. Is age related to specific causes of injury - e.g. are registrants > 50 years old more likely to be injured by falling?
3. Does the number or nature of co-morbid conditions relate to acute LOS?
4. Is acute LOS related to respiratory function as measured by peak cough flow and pulmonary function tests?
5. Does respiratory function relate to execution of and compliance with respiratory management by volume augmentation techniques?
6. Does the presence of neuropathic pain (as measured by DN4) relate to acute LOS?
7. Does the extent of pain interference measured at discharge from acute care relate to acute LOS?
8. Does the amount of time between injury and spine decompression or stabilization surgery relate to acute LOS or pain profile at discharge from acute care?
9. What is the incidence of HGH-Rehabilitation admission for RHSCIR candidates?
10. What is the LOS for HGH-Rehabilitation?
11. Is HGH-Rehabilitation LOS related to Chedoke LOS?
12. What is the data quality for AIS assessments within 24 and 72 hours of admission – i.e. incidence of assessment conducted, incidence of incomplete assessment, type of information missing from assessment, incidence of standard assessment form usage?

APPENDIX D CONTINUED

REHABILITATION RESEARCH QUESTIONS

Toronto Participating Sites (Research Committee)
1. How many acute trauma patients are eligible for enrollment in acute rehabilitation interventional research studies?
2. How do newly admitted traumatic SCI patients differ from the non-traumatic SCI patients at the inpatient rehabilitation facility e.g. demographic differences?
3. What is the LOS for each ASIA impairment group in the rehabilitation centre?
4. How do ASIA change scores (admission to discharge) relate to LOS?
5. How do SCIM change scores at admission and discharge relate to LOS?
6. Do discharge FIM scores reflect discharge disposition?
7. How do AIS change scores, discharge FIM scores, LiSAT-11 and sociodemographics relate to the discharge disposition of SCI patients?
8. What is the wait time to transfer to an appropriate community setting?
9. What are the barriers to transferring patients to the community e.g. PICC line, g tube, VAC therapy, central line, ventilator, oxygen, psychiatric, medical complexities, dual diagnosis (e.g. head injury/SCI), risk assessment (outcomes/disposition), legal issues (medical liability, financial, criminal)?
10. Are patients eligible for the Toronto Rehabilitation Institute community follow-up study?

Hamilton Health Sciences (Brian Drew)
1. What is the incidence of rehabilitation interruption by readmission to acute care?
2. What are the reasons for readmission to acute care from rehabilitation (i.e. diagnosis)?
3. What is the LOS for acute care readmissions from rehabilitation?
4. Is readmission to acute care related to overall rehabilitation LOS?
5. Are neurological level of injury and AIS at admission to rehabilitation related to occurrence of readmission to acute care from rehabilitation?
6. Is rehabilitation LOS related to respiratory function as measured by peak cough flow and pulmonary function tests?
7. Does the presence, intensity, duration, or prevalence of pain measured at discharge from rehabilitation relate to discharge FIM, SCIM, LiSAT-11, or rehabilitation LOS?
8. How are neurological level of injury and AIS related to total LOS and discharge disposition?

COMMUNITY FOLLOW UP

Toronto Rehabilitation Institute (Cathy Craven)
1. How do ASIA, SCIM, LiSAT-11 differ between rehabilitation discharge and 12 months post injury?

INDIVIDUAL INVESTIGATOR QUESTIONS

Sunnybrook Health Sciences Centre Acute (Michael Ford)
1. Does lack of spine care resources lead to delay in treatment for SCI patients (using CritiCall data)?

St. Michael's Hospital (Henry Ahn)
1. What is the impact of spinal cord injuries on the mortality rates and resource requirements on polytrauma patients with ISS greater than 16 compared to patients with isolated spinal cord injuries?

APPENDIX D CONTINUED

University Health Network (Michael Fehlings)
1. What proportion of SCI cases is undergoing surgery?
2. What is the time from injury to arrival in the SCI acute center?
3. What is the timing of surgery from injury to OR?
4. What percentage of SCI patients undergoes MRI?
5. What is the relationship between timing of surgery and neurological outcomes?
6. Is there a relationship between age and gender and neurological outcome after SCI?
7. What percentage of SCI patients receives methylprednisolone?

Toronto Rehabilitation Institute (Cathy Craven)
1. Are there important socio-demographic (age, sex, marital status, etc.) differences between the trauma and non-trauma SC population admitted for inpatient rehabilitation?
2. Are there differences in medical complexity, wait times for rehabilitation admission, onset days, LOS in rehabilitation, ALC days and discharge destination of SC patients of traumatic versus non-traumatic etiology?
3. Are there differences in FIM, SCIM and AIS Motor scores between patients with SCI of traumatic and non-traumatic etiology at rehabilitation admission?
4. Are there differences in the changes in AIS Motor scores, FIM change, FIM efficiency, SCIM scores and prevalence of neuropathic pain from rehabilitation admission to rehabilitation discharge in SC patients of traumatic versus non-traumatic etiology?
5. Are there differences in the type and severity of pain among SC patients of traumatic versus non-traumatic etiology at rehabilitation discharge?
6. Is a multidisciplinary assessment of pain feasible? Can rehabilitation team members determine the type of pain - neuropathic versus nocioceptive reliably with the assistance of the Pain DETECT tool?
7. Are there differences in the LiSAT-11 scores and sub scores for SC patients of traumatic versus non-traumatic etiology?
8. Are there associations between high SCIM scores and high LiSAT-11 scores?
9. What percentage of SCI patients has a DXA measure of BMD within 100 days and 1 year of injury?
10. Of those who have had a BMD what percentage included a measure of knee region BMD?
11. What spectrum of rehabilitation services are used in the first 3 months and one year after rehabilitation discharge- do they differ for those with traumatic versus non-traumatic SCI?

ICES (Susan Jaglal)
1. What is the comparison between ICD-10 codes and AIS scores for the SCI sample in OSCIR to validate the ICD-10 coding for linkage of data?

Principal Investigator (Molly Verrier)
1. What is the change in walking competency as measured by the walking battery between baseline and discharge from rehabilitation?
2. How does the discharge walking battery score relate to discharge AIS, SCIM, FIM and LiSAT-11?

APPENDIX E
SUMMARY OF KNOWLEDGE TRANSLATION; REPORT, POSTERS AND PRESENTATION

REPORT

Knowledge Translation Activities	For Whom	Principal Author	Coauthors
Ontario SCI Informatics Informing Practice, Research and Innovations November 2009 • Injury Prevention: Sports and Recreation Figure 9 (page 14) and 10 (page 15) in Report • Service Utilization at Discharge from Rehabilitation Table 11 (page 17) in Report	OMOHLTC ONF Other relevant stakeholders ONF Prevention Committee Canadian Paraplegic Association (Ontario)	Molly Verrier, Sr. Scientist, TRI	Ahn H Craven C Drew B Fehlings M Ford M Jaglal S Parsons D

POSTERS

	Poster Title	To Whom	Principal Author	Coauthors	Additional Authors
1.	Development of a Clinical Tool for use in the Rehabilitation Setting to Characterize and Classify Post-SCI Pain	3rd National Spinal Cord Injury Conference, November 7-8, 2009	Cathy Craven	**RESEARCH COMMITTEE** Henry Ahn Cathy Craven Brian Drew Michael Fehlings Michael Ford Susan Jaglal Molly Verrier	Hunter J Lepper K Flett H SCRP Pain Best Practice Team1
2.	The Inter Rater Reliability of the Pain*DETECT* for Assessment of Pain Type Among Patients With Acute Spinal Cord Injury	3rd National Spinal Cord Injury Conference, November 7-8, 2009	Cathy Craven	**RESEARCH COMMITTEE** Henry Ahn Cathy Craven Brian Drew Michael Fehlings Michael Ford Susan Jaglal Molly Verrier	Lepper K Hunter J Flett H SCRP Pain Best Practice Team1
3.	Ontario Spinal Cord Injury Registry (OSCIR) Pilot Project: A Feasibility Study for Implementing a Spinal Cord Injury Registry in Ontario	Presented to Health Results Team Innovations in Health Care Expo April 19/20.	Molly Verrier	**RESEARCH COMMITTEE** Henry Ahn Cathy Craven Brian Drew Michael Fehlings Michael Ford Susan Jaglal Molly Verrier	Parsons D
4.	Phase 1 Feasibility Evaluation of the Ontario Spinal Cord Injury Registry	CREMS April 2008	Molly Verrier	**RESEARCH COMMITTEE** Henry Ahn Cathy Craven Brian Drew Michael Fehlings Michael Ford Susan Jaglal Molly Verrier	Jurkiewicz M

APPENDIX E CONTINUED

POSTERS

	Poster Title	To Whom	Principal Author	Coauthors	Additional Authors
5.	Health Sciences Pilot Project of the Rick Hansen Spinal Cord Injury Registry.	15th Interurban Spinal Cord Injury Conference; October 25-26, 2007.	Deborah Tsui	RESEARCH COMMITTEE Henry Ahn Cathy Craven Brian Drew Michael Fehlings Michael Ford Susan Jaglal Molly Verrier	MacRae L Bugaresti J Drew B
6.	Ontario Spinal Cord Injury Registry & Rick Hansen Spinal Cord Injury Registry: Hamilton Health Sciences Pilot Project.	3rd National Spinal Cord Injury Conference & 16th Interurban Spinal Cord Injury Conference November 7-8, 2008	Deborah Tsui	RESEARCH COMMITTEE Henry Ahn Cathy Craven Brian Drew Michael Fehlings Michael Ford Susan Jaglal Molly Verrier	MacRae L Drew B
7.	How Walking Measures Inform Rehabilitation Practices	TRI Research Day November 2, 2009	Molly Verrier	RESEARCH COMMITTEE Henry Ahn Cathy Craven Brian Drew Michael Fehlings Michael Ford Susan Jaglal	Marinho A Flett H Lepper K Craven C

PRESENTATION

Title	For Whom	Principal Author
Walking Outcomes in Spinal Cord Injury: How do they Inform Rehabilitation Practice?	8th Annual Charles H. Tator Barbara Turnbull Lectureship Series in Spinal Cord Injury October 2, 2009	Verrier M

PUBLICATIONS

Scientific publications have been prepared for international peer reviewed journals by Site Investigators.

APPENDIX F
POLICIES

POLICY 1: USE OF OSCIR DATA POLICY

All proposals for research projects using OSCIR* should be submitted to the OSCIR Principal Investigator (PI) via fax or email. The Research Committee will review research project proposals every three months. This corresponds to submission deadlines of January 1, April 1 and October 1 of each calendar year. A response will be issued within one month. Priority will be given to projects that are scientifically novel, high-impact, answerable, and led by an investigator with a demonstrated track record in publications. The responses will be categorized as follows: the project is approved as submitted, approval conditional upon meeting specifications of the Research Committee, recommended for revision and re-submission, or rejected with reasons for rejection. Each proposal for a project should consist of a two page research outline that addresses the following issues:

- Title of the project.
- Questions to be answered by the study.
- Principal Investigator(s) and institutions, and contact information for the PI.
- Sponsoring Site Investigator (if a non-participating investigator is principal author).
- Background: in one or more paragraphs, the rationale for the study along with a summary of previous studies in this area. Appropriate references should be included.
- Methods: in general terms, the statistical methods that will be used for the study. A list of required data fields and time frame of the requested data should also be included.
- A two page "biosketch" for first time investigators with relevant publications in the past three years.
- An appendix with draft tables and figures that will be requested from the programmer. These draft tables should specify the programming and analysis requirements in as much detail as possible in order to use programmer time efficiently. The PI may wish to speak directly with the programmer prior to submitting the project.

Each PI may have a maximum of two approved projects in progress at any given time. Once papers using the OSCIR data have been submitted for publication, additional projects may be requested.

Once a project is approved, the investigators will be informed of the approximate time line upon which the programmer will be available to conduct analyses. The programmer and PI will work together directly once the analysis is underway. Each project will receive a maximum of 80 hours of programmer time from the OSCIR programmer. In the event that the project cannot be completed within the 80 hour time limit, the PI will need to fund any additional programming support.

No more than nine months shall elapse between approval of the project and submission of a manuscript for publication. All papers written using OSCIR data must be submitted to the Research Committee prior to submission and should acknowledge OSCIR and Research

APPENDIX F CONTINUED

Committee membership. A copy of all abstracts, publications, and presentations completed using OSCIR data must be submitted to the OSCIR PI prior to publication.

PIs may be required to sign a confidentiality agreement to ensure reciprocal confidentiality between the Research Committee and the study PI. OSCIR may post a list of approved projects on relevant website(s) e.g. ONF.

Because of privacy and confidentiality issues, data security issues, and to maintain consistency in the integrity of the OSCIR data, all of the individual level data must remain at participating sites and the central site at UHN.

All patients must have signed the consent or limited consent form to have data included in the analysis of a project. In addition, all patients must agree to have data linked to other databases on the CRF form completed prior to the abstracting of any data for the project. This agreement commits the Investigator to maintaining complete patient and hospital confidentiality with regard to all OSCIR data. Additionally, the UHN Central Site and/or ICES (in the case of linked data through ICES) may conduct a privacy impact assessment on each project using a standardized template, which includes information required by the Regulation to PHIPA, 2004. This policy will be reviewed as required.

POLICY 2: NEW DATA ELEMENT ADDITION POLICY

As of January 2008 all data fields are finalized for the Pilot Project. All requests for adding new data fields to OSCIR* in the future should be submitted to the OSCIR Principal Investigator (PI) via fax or email. The Research Committee will review the requests every six months. This corresponds to submission deadlines of January 1 and October 1 of the calendar year.

A response will be issued within one month. Priority will be given to data elements that relate to research questions that are scientifically novel, high-impact, answerable, and led by an investigator with a demonstrated track record in the area of the new field. Availability of funding will also be considered. The responses will be categorized as follows: the request is approved as submitted, approval conditional upon meeting specifications of the Research Committee, recommended for revision and re-submission, or rejected with reasons for rejection.

Each request for a new data field should consist of an outline that addresses the following issues:

- Title of the data field.
- Research questions to be answered by the field.
- PIs and institutions, and contact information for the PI.
- Sponsoring Site Investigator (if a non-participating investigator is principal author).

* OSCIR Data refers to all data captured on the Clinical Report Forms (CRFs) and is not restricted to data elements developed in Ontario. Version 8.0 for Acute Data Version: 7.2 for Rehabilitation Data (Trauma and Non -Trauma).

APPENDIX F CONTINUED

- Background: in one or more paragraphs, the rationale for the new field along with a summary of use in previous studies. Appropriate references should be included.
- Reliability and validity of the field should be outlined from the literature. A list of any associated data fields and time frame of the requested data field should also be included for the purposes of determining analysis procedures.
- The programming and analysis requirements (i.e. use of the associated data fields) in as much detail as possible.

PIs may be required to sign a confidentiality agreement to ensure reciprocal confidentiality between the Research Committee and the study regarding the research questions that the new data field will address. OSCIR may post a list of approved data fields on relevant website(s) e.g. ONF.

Because of privacy and confidentiality issues, data security issues, and to maintain consistency in the integrity of the OSCIR data, all of new data fields/elements must be resubmitted to the REB for approval. The same regulations for new data fields will apply as those the patient has agreed to in the existing consent. All patients must have signed the consent or limited consent form to have the data field included in the analysis of a project.

* OSCIR Data refers to all data captured on the Clinical Report Forms (CRFs) and is not restricted to data elements developed in Ontario. Version 8.0 for Acute Data Version: 7.2 for Rehabilitation (Trauma and Non-Trauma).

APPENDIX F CONTINUED
POLICY 3: PUBLICATION TRACKING FORM

Ontario Spinal Cord Injury Registry (OSCIR)
January 29, 2008

PUBLICATION TRACKING FORM
To be completed for local and central site requests

DATE

SUBMITTED BY (Name / Phone number)

SITE

- ☐ **OSCIR**
  - ☐ PI
  - ☐ RC ICES Scientist
- ☐ **Hamilton Health Sciences**
  - ☐ HHS Acute
  - ☐ HHS Chedoke
- ☐ **Toronto Rehabilitation Institute**
- ☐ **University Health Network**
- ☐ **St. Michael's Hospital**
- ☐ **Sunnybrook Health Sciences Centre**

TYPE OF SUBMISSION
(Please attach copy of submission):

- ☐ Abstract
- ☐ Poster
- ☐ Conference Presentation
- ☐ Peer Reviewed Journal
- ☐ Technical Report
- ☐ Manuscript
- ☐ Thesis ☐ Master's ☐ PhD
- ☐ Independent Study (please specify)

  _____
- ☐ Other (please specify)

  _____

Submitted to: _____

☐ Under Review ☐ Under Revision ☐ Accepted

Title: _____

Lead Author: _____

Contributing Authors: _____

REB Approval: ☐ Yes ☐ No

REB Approval Date: _____

REB Review Site: _____

REB Approval Number: _____

APPENDIX G
NON-TRAUMA ETIOLOGY INCLUSION TABLE FOR THE REHABILITATION DATA SET AT TRI

Cases with an SCI that met the non-trauma inclusion etiology outlined below had data collected at rehabilitation admission and discharge regardless of the referral site, if the rehabilitation admission was within one year of SCI onset.

Excluded	Included	Descriptor of Etiology
✖		ALS or Lou Gehrig's disease
	✖	Ankylosing Spondylitis
	✖	Arachnoiditis
	✖	B12 Deficiency/Myelopathy
	✖	Birth Trauma (causing SCI)
	✖	Cauda Equina (Non-traumatic)
✖		Cerebral Palsy
	✖	Cervical Stenosis
	✖	Cord Compression (unspecified)
	✖	Devic's disease
	✖	Disc (Subacute cervical disc lesion)
✖		Discitis
	✖	Drug induced Myelopathy
✖		Duchenne Muscular Dystrophy
	✖	Extradural Cord Compression
✖		Guillan Barre Syndrome
	✖	Infection (non specified)
✖		Multiple Sclerosis
	✖	Myelodysplasia
	✖	Myelopathy
	✖	Neurofibromatosis
✖	✖	Other Specify :
	✖	Paraplegia Sacrum and coccyx
	✖	Paraplegia Sacrum and coccyx
✖		Polyneuropathy
	✖	Radiation induced Myelopathy
	✖	Rheumatoid Myelopathy
✖		Spina Bifida Hydrocephalus
	✖	Spina Bifida Paraplegia
	✖	Spina Bifida Tethered cord
	✖	Spinal Cord Neoplasm intra or extradural
	✖	Syringomyelia (primary or secondary)
	✖	Tethered Cord
	✖	Transverse Myelitis
	✖	Tuberculosis
	✖	Vascular (embolic or nonembolic infarction or arterial thrombosis)

APPENDIX H
ADVISORY COMMITTEE MEMBERSHIP

Nana Adjei
Researcher, Sunnybrook Health Sciences Centre

Henry Ahn
Orthopedic Surgeon, St. Michael's Hospital

Kathy Boschen
Research Scientist,
Toronto Rehabilitation Institute

Deb Carew
Operations Director, Trauma and Critical Care,
Sunnybrook Health Sciences Centre

Cathy Craven
Physiatrist, Lyndhurst Site,
Toronto Rehabilitation Institute

Michael Fehlings
Neurosurgeon, Western Division,
University Health Network

Michael Ford
Orthopedic Surgeon, Sunnybrook
Health Sciences Centre

Howard Ginsberg
Neurosurgeon, St. Michael's Hospital

Colleen McGillvray
Physiatrist, Lyndhurst Site,
Toronto Rehabilitation Institute

Mary Ann Neary
Program Director, Western Division,
University Health Network

Daria Parsons
Research Associate,
Ontario Neurotrauma Foundation

Farhad Pirouzmand
Neurosurgeon, Sunnybrook
Health Sciences Centre

Yuriy Petrenko
Clinical Research Coordinator,
Western Division, University Health Network

Jane Topolovec-Vranic
Research Coordinator, Trauma and
Neurosurgery Program, St. Michael's Hospital

Molly Verrier (Chair)
Senior Scientist,
Toronto Rehabilitation Institute

Albert Yee
Orthopedic Surgeon, Sunnybrook
Health Sciences Centre

APPENDIX I
TIME POINTS FOR OUTCOME MEASURES

Time points	OSCIR OUTCOME MEASURE
<24 hours or Pre operatively For spine surgery	AIS
Post operatively for spine surgery or 72 hours	AIS
Acute care at 2 weeks	DN4 Neuropathic Pain Assessment Spasticity/Muscle Tone
Acute discharge or 1 month (post injury)	AIS FIM If d/c to community from acute: LiSAT-11 Pain Questionnaire
Rehabilitation admission	AIS FIM SCIM Pain
Rehabilitation discharge	AIS FIM SCIM Pain Spasticity
3 months (post injury)	AIS **UHN only**
6 months (post injury)	AIS **UHN only**
6 months (post discharge from rehabilitation)	AIS motor assessment only SCIM LiSAT-11

Ontario Neurotrauma Foundation

Fondation ontarienne de neurotraumatologie