

Rick Hansen Spinal Cord Injury Registry

A look at traumatic spinal cord injury in Canada in 2014



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Thank you to the dedicated clinicians, researchers and coordinators who collect, analyze and input data into the Rick Hansen Spinal Cord Injury Registry (RHSCIR). We also wish to thank the 4,800 individuals with traumatic spinal cord injuries who have *generously contributed their time and experiences to RHSCIR*. The contributions of everyone involved are vital to improving the ability to provide care for those with spinal cord injuries and maximizing the potential for these individuals and others to reach his or her fullest recovery possible.

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RHSCIR HOSPITALS ARE LOCATED IN 15 CITIES ACROSS CANADA



The Rick Hansen Spinal Cord Injury Registry: A look at traumatic SCI in Canada in 2014 is a detailed look at some of the clinical and demographic data collected from 713 new RHSCIR participants in 2014.

In this report, you will find information about the type of injury, patient demographics, care pathway, length of hospital stay and social impacts after traumatic spinal cord injury (SCI). This is a small subset of the data that RHSCIR collects; other information includes details about surgery and other interventions, detailed diagnosis information, functional outcomes such as walking proficiency and independence and services provided to participants. The report's primary purpose is to serve as a descriptive account with no endorsement of, or recommendations about, policies or programs. However, the data can be informative to research and clinical practice as well as policy and program planning. Data from this report provides researchers, health care providers and decision makers with knowledge that may support strategies to improve SCI care services within their institutions.

We welcome feedback or questions on any aspect of this report. Please contact us at RHSCIR@rickhanseninstitute.org.

For more information about RHSCIR, please visit rickhanseninstitute.org.

Certain terms are bolded throughout the report. For definitions, please refer to the glossary on page 12.

Spinal cord injury (SCI) is a complex, debilitating and costly condition. No two injuries are the same and it can happen to anyone, at any time. For many, spinal cord injury also results in loss of independence, poverty and social isolation. In Canada, over 86,000 people live with SCI (43,974 with traumatic SCI). Although it affects fewer individuals when compared to other chronic conditions, the economic burden is near catastrophic. Injuries that are sustained as a result of trauma (also known as *traumatic spinal cord injury* or *traumatic SCI*) such as serious vehicle crashes or falls have an estimated average lifetime cost of \$2 million per individual.

In order to better understand the complex needs of individuals who sustain a traumatic SCI, the Rick Hansen Spinal Cord Injury Registry (RHSCIR) was created from the vision of two men: Canadian icon and Paralympian Rick Hansen and renowned spine surgeon and researcher, Dr. Marcel Dvorak.

RHSCIR is a *prospective observational study* that collects clinical and demographic data from Canadian acute and rehabilitation hospitals specializing in SCI care and treatment. It includes 31 participating facilities in major Canadian cities making it the largest database that tracks the experiences of individuals living with traumatic SCI in Canada. In 2014, it included 4,800 participants.

The most vital and fundamental component of RHSCIR is its contributors – people with traumatic SCI. Their continued participation determines the value and success of RHSCIR.

The average age of RHSCIR participants was 52.0 years old in 2014, an increase from 2013 (49.6 years old). 73% of participants were male and 27% were female.

Tetraplegia or **quadriplegia** is complete or partial loss of sensation and/or movement in the arms, and typically in the trunk and legs. It was the most common type of traumatic SCI sustained among RHSCIR participants for all age groups. Paraplegia, on the other hand, is complete or partial loss of sensation and/or movement in the legs and often in part of, or the entire trunk.

TETRAPLEGIA VS. PARAPLEGIA

INCOMPLETE VS. COMPLETE INJURIES



Injuries where some motor or sensory function is retained below the level of injury (*incomplete injuries*), were more common than *complete injuries* which have a total lack of sensory and motor function below the level of injury. In comparing the two graphs above, *incomplete tetraplegia* was more prevalent in individuals over 65 years old. This may be due to the nature of the injury (such as a fall from a short distance).



Falls, such as a slip on the sidewalk or fall from an apartment balcony, were the most common type of injury that occurred among RHSCIR participants. This was followed by transportation, sports and assault as the most common types of injuries. The type of injury was associated with age; for example, the average age for people who experienced an assault was 35 years old and the average age of people who experienced a fall was 60 years old.

MECHANISM OF INJURY

48% Percentage (%) 40 30% 13% 6% 3% Assault Fall Sports Transport Other The average age for people The average age for people who experienced an assault was who experienced a fall was **35 YEARS OLD 60 YEARS OLD**

Hospitals that have specialized spinal cord injury programs and participate in RHSCIR are considered the definitive spinal cord injury care centre in their geographic area. According to recent research, individuals who are admitted early to a hospital that specializes in SCI care and cared for by a specialized SCI team have better outcomes compared to individuals who are not admitted early (longer than 48 hours) to a SCI-specialized hospital and do not receive specialized care.

About half the time, participants enrolled in RHSCIR were initially admitted to a **non-RHSCIR Hospital**. However, 2014 RHSCIR data showed that the majority of RHSCIR participants were admitted to a **RHSCIR Acute Hospital** within 24-hours from injury regardless of whether they first went to a **non-RHSCIR Hospital**.¹

ADMISSION TO RHSCIR ACUTE HOSPITAL WITHIN 24 HOURS (%)

22% 78% Yes No

¹Parent S, Barchi S, LeBreton M, Casha S, Fehlings MG. The Impact of Specialized Centers of Care for Spinal Cord Injury on Length of Stay, Complications, and Mortality: A Systematic Review of the Literature. Journal of Neurotrauma. 2011;28(8):1363-1370.

The care pathway tracks the journey an individual takes from the moment the injury is sustained until that individual returns to the community or is returned to a hospital closer to home. The ideal care pathway for a person who sustains a spinal cord injury is to be admitted immediately to a *RHSCIR Acute Hospital*, and then, if necessary, admitted to a *RHSCIR Rehab Hospital* in order to receive specialized care. In 2014 RHSCIR data, just under half of individuals were admitted to a *RHSCIR Acute Hospital* immediately once the injury was sustained. 66% of individuals admitted to a **RHSCIR Acute Hospital** then went on to a **RHSCIR Rehab Hospital** before returning to the community. Individuals who do not directly enter a **RHSCIR Acute Hospital** often end up taking a more circuituous route through the health care system.

Mortality during the initial *RHSCIR Acute Hospital* stay was 7%. Only individuals who survived their injury and acute hospital stay are included in the care pathways below.



CARE PATHWAY FOLLOWING A TRAUMATIC SCI

- * All patients
- § All patients that went to a RHSCIR Acute Hospital
- All patients that went to a RHSCIR Rehab Hospital
- + Of the patients who went from a RHSCIR Acute Hospital to a RHSCIR Rehab Hospital, 6% went to the community or to another hospital to wait for RHSCIR rehab

In 2014, the average length of stay for those admitted to a RHSCIR Acute Hospital following a traumatic SCI was 27 days for individuals with paraplegia and 35 days for individuals with tetraplegia.

The average length of stay for those who were admitted to a **RHSCIR Rehab Hospital** was 70 days for paraplegia and 94 days for tetraplegia.



AVERAGE (MEAN) LENGTH OF STAY DURING

An individual sustaining a traumatic SCI can expect a number of significant life changes including changes in employment status, household income and relationships. The following information provides participant responses recorded at five-year follow-up interviews. The most significant changes occurred in employment status and household income: just over half of individuals who were employed at the time of injury were unemployed after five years. Over half of the participants who were making \$60,000+ prior to injury saw a decline in income over the same time frame. On the other hand, at five years post-injury, relationship status does not appear to be significantly impacted by the injury.



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Note: RHSCIR collects both a core data set (restricted data set for both consented and non-consented participants) and an expanded data set for consented participants only. The RHSCIR data used for this report was extracted on June 28, 2017.

Data collected (number of new injuries) in 2014 713 (375 expanded data set, 53%)	Number of five-year post-injury community follow-up interviews completed between 2011 and 2014: Employment: 186
Age: 712	Relationship Status: 203
Gender: 712	
Paraplegia vs Tetraplegia: 455	
Complete vs Incomplete: 508	
Mechanism of Injury: 640	
Mechanism of Injury by Age: 640	
Time to RHSCIR Admission within 24 Hours: 432	
Care Pathway: 634	
Length of Stay in Acute: 303	
Length of Stay in Rehab: 319	



Complete injury

An injury where there is no sensory and motor function (ability to feel, touch or move) preserved in the last nerves leaving the spinal cord (sacral 4th and 5th nerves). This usually results in a total lack of sensory and motor function below the level of the injury.

Incomplete injury

An injury where there is some sensory or motor function (ability to feel, touch or move) below the level of the injury. This must include the last nerves leaving the spinal cord (sacral 4th and 5th nerves).

Paraplegia

Complete or partial loss of sensation and/or movement in the legs and often in part of, or the entire trunk. It is caused by an injury to the spinal cord in the thoracic (trunk) or below.

Prospective observational study

A prospective study is designed to collect data on a going forward basis; in this instance, RHSCIR coordinators collect information from the time of injury through discharge from RHSCIR facilities and conduct follow-up interviews at one, two, five and ten year intervals to collect demographic and clinical data from participants. "Observational" indicates that there is no action or treatment included in the study but rather, an observation of the existing conditions reported by the participant and collected from medical records by the RHSCIR coordinator that can be used to inform future decisions through research and clinical care.

RHSCIR Acute Hospital

A trauma hospital that has a specialized spinal cord injury program and participates in RHSCIR.

RHSCIR Rehabilitation Hospital

A rehabilitation hospital that has a specialized spinal cord injury program and participates in RHSCIR.

Spinal cord injury (SCI)

The impairment of sensory and/or muscle function due to damage of the nerves in the spinal cord.

Tetraplegia or Quadriplegia

Complete or partial loss of sensation and/or movement in the arms, and typically in the trunk and legs. It is caused by an injury to the spinal cord in the neck.

Traumatic spinal cord injury (traumatic SCI)

A spinal cord injury that occurs as a result of trauma such as a vehicle crash or fall from a building as opposed to a non-traumatic injury which occurs as a result of illness (e.g. cancer) or birth defect.

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