



Rick Hansen Institute
Institut Rick Hansen

RHSCIR

Rick Hansen Spinal Cord Injury Registry

A look at traumatic spinal cord injury in Canada in 2016



VERSION 2.0 SEPTEMBER 2018

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 6,000 individuals with traumatic spinal cord injury 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 2016**, is a detailed look at some of the clinical and demographic data collected from **660 RHSCIR participants in 2016**.

In this report, you will find information about the type of injury, patient demographics, care pathway, length of hospital stay, secondary complications and social and economic 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 15.

¹Noonan VK, Fingas M, Farry A, Baxter D, Singh A, Fehlings MG, Dvorak MF. Incidence and Prevalence of Spinal Cord Injury in Canada: A National Perspective. *Neuroepidemiology*. 2012;38:219–226.

Krueger H, Noonan VK, Trenaman LM, Joshi P, Rivers CS. The economic burden of traumatic spinal cord injury in Canada. *Chronic Diseases and Injuries Canada*. 2013;33(3):113-112.



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 accidents or falls, have an estimated average lifetime cost of \$2 million per individual and for the 1,389 people who sustain a traumatic SCI each year, the annual cost is estimated to be \$2.7 billion (in 2015 Canadian dollars).¹ This includes direct costs such as hospital stay and indirect costs such as lost productivity due to premature mortality.

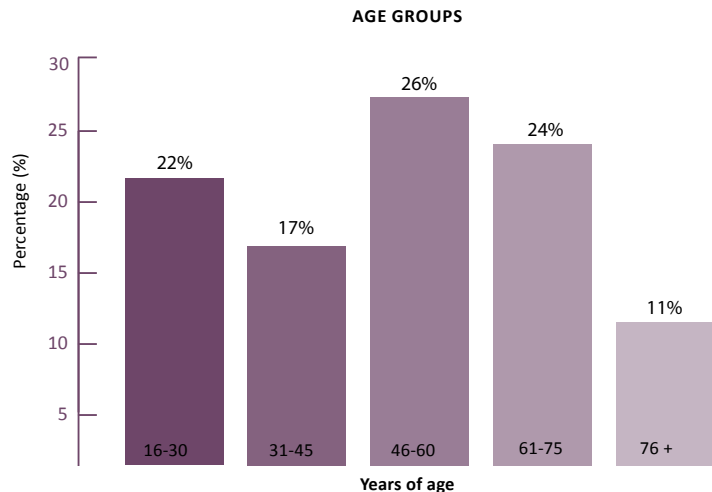
In order to better understand the complex needs of individuals who sustain a traumatic SCI, the Rick Hansen Spinal Cord Injury Registry (RHSCIR) was created from the vision of two men: Canadian icon and Paralympian Rick Hansen and renowned spine surgeon and researcher, Dr. Marcel Dvorak. With 31 participating facilities in every major Canadian city, RHSCIR includes more than 6,000 participants making it the largest database that tracks the experiences of individuals living with traumatic SCI in Canada.

RHSCIR is a **prospective observational study** that collects clinical and demographic data from Canadian acute and rehabilitation hospitals specializing in SCI care and treatment. In recent years, RHSCIR has expanded to China, New Zealand and Israel, making it a truly global study that connects the international SCI research and clinical care communities.

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.

WHAT DOES THE POPULATION LOOK LIKE?

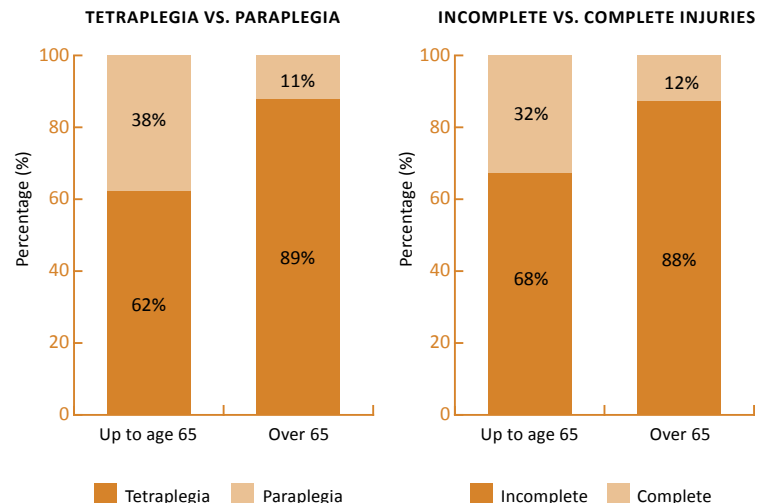
The average age of RHSCIR participants was 53.0 years old in 2016, an increase from previous years (in 2013, the average age of RHSCIR participants was 49.6 years old). As the average age in Canada continues to increase, the trend is expected to continue.²



²On July 1, 2015, preliminary estimates from Statistics Canada show that nearly one in six Canadians (16.1%)—a record 5,780,900 Canadians—was at least 65 years old. According to the most recent population projections, the proportion of persons aged 65 years and older will continue to increase and should account for 20.1% of the population on July 1, 2024. <http://www.statcan.gc.ca/daily-quotidien/150929/dq150929b-eng.htm>

WHAT IS THE SEVERITY AND LEVEL OF INJURY?

Tetraplegia or quadriplegia, which is complete or partial loss of sensation and/or movement in the arms, trunks and legs, 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 in part or the entire trunk.



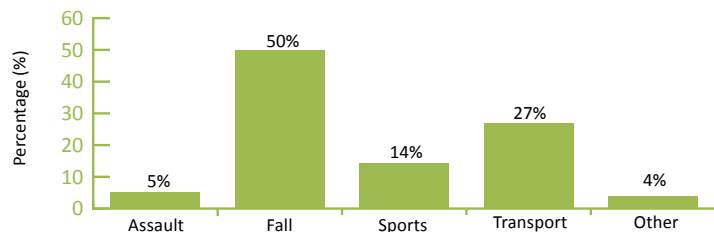
In addition, injuries where some motor or sensory function is retained below the level of injury (**incomplete injuries**), were more common than **complete injuries** which have a complete lack of sensory and motor function below the level of injury. In comparing the two graphs above, **incomplete tetraplegia** 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).

HOW DOES THE INJURY OCCUR?



The mechanism of injury provides a snapshot of how participants were injured. Falls were the most common type of injury that occurred among RHSCIR participants. A traumatic SCI as a result of a fall can be caused by a slip on the sidewalk to something more severe such as a fall from a three-story apartment balcony. Falls were 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 33 years old and the average age of people who experienced a fall was 61 years old.

MECHANISM OF INJURY



The average age for people who experienced an assault was
33 YEARS OLD



The average age for people who experienced a fall was
61 YEARS OLD

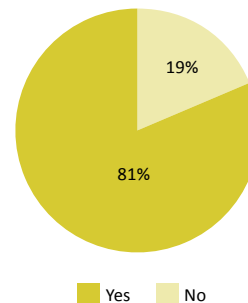
WHERE DO PEOPLE GO AFTER INJURY TO RECEIVE TREATMENT?



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, 2016 RHSCIR data showed that the vast 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.³

ADMISSION TO RHSCIR ACUTE HOSPITAL WITHIN 24 HOURS (%)



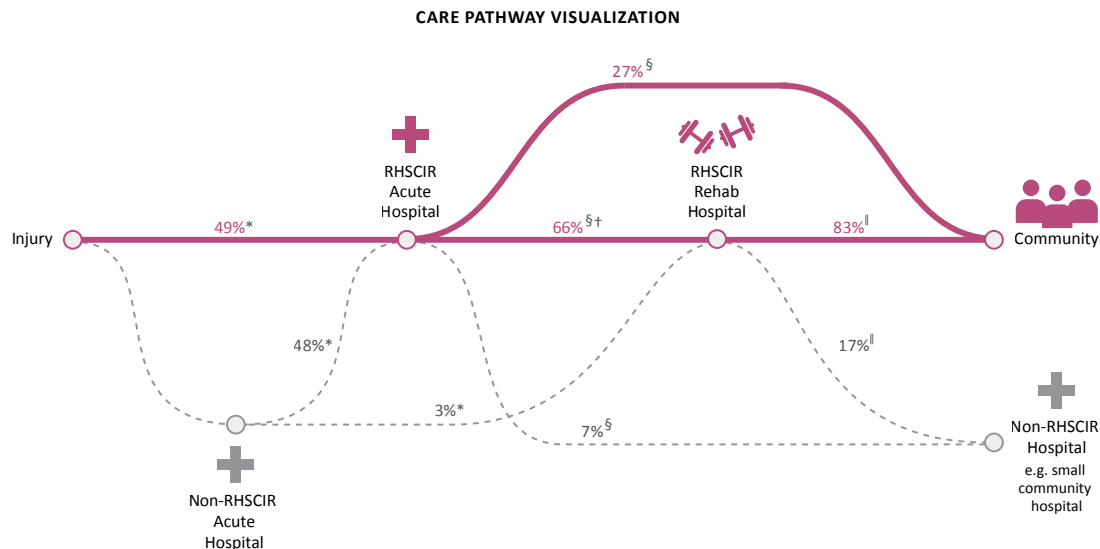
³ Parent S, Barchi S, LeBreton M, Casha S, Fehlings MG. The Impact of Specialized Centers of Care for Spinal Cord Injury on Length of Stay, Complications, and Mortality: A Systematic Review of the Literature. Journal of Neurotrauma. 2011;28(8):1363-1370.

WHAT IS A PERSON'S CARE PATHWAY?

The care pathway is 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 2016 RHSCIR data, half of individuals were admitted to a **RHSCIR Acute Hospital** immediately once the injury was sustained.

The majority (62%) 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 circuitous route through the health care system.

Mortality during the initial **RHSCIR Acute Hospital** stay was 8%. Only individuals who survived their injury and acute hospital stay are included in the care pathways below.



* All patients

§ All patients that went to a RHSCIR Acute Hospital

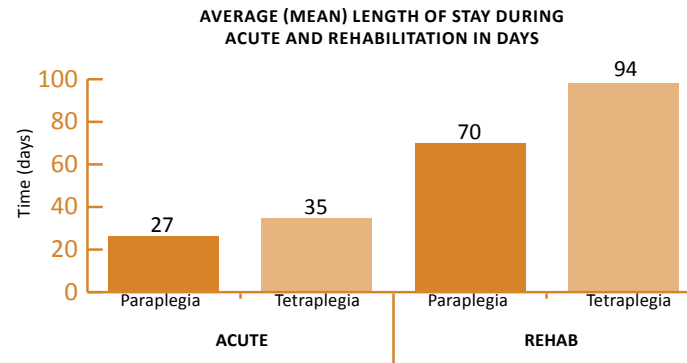
|| All patients that went to a RHSCIR Rehab Hospital

† Of the patients who went from a RHSCIR Acute Hospital to a RHSCIR Rehab Hospital, 10% went to the community or to another hospital to wait for RHSCIR rehab

WHAT IS THE DURATION OF THE HOSPITAL STAY?

RHSCIR captures length of stay during the acute and rehabilitation admission. For 2016, the average number of days spent in acute care following a traumatic SCI was 24 days for individuals with paraplegia and 34 days for individuals with tetraplegia.

The average length of stay for those who were admitted to a ***RHSCIR Rehab hospital*** was 72 days for paraplegia and 83 days for tetraplegia.



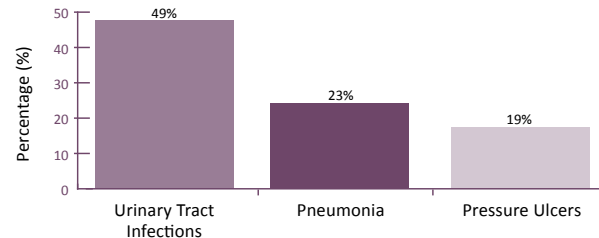
HOW OFTEN DO SECONDARY COMPLICATIONS OCCUR IN ACUTE AND/OR REHABILITATION CARE?



Secondary complications refer to the range of conditions that occur after sustaining the initial injury. People with spinal cord injury can expect to experience multiple complications that arise after their injury. Some of the most common secondary complications people with traumatic SCI experience in the hospital are **pneumonia**, **pressure ulcers** and **urinary tract infections** (UTIs). These complications can diminish quality of life, negatively impact living in the community and if left untreated, can lead to re-hospitalization for urgent care or result in death.

According to 2016 RHSCIR data, UTIs were the most common secondary complication in hospital, followed by pneumonia, then pressure ulcers (Stages⁴ II, III, IV or **Suspected Deep Tissue Injury** as defined by the US National Pressure Ulcer Advisory Panel). In 2016 RHSCIR data, 58% of participants reported the occurrence of at least one of these secondary complications during acute and/or rehab stays. Approximately 20% of individuals with traumatic SCI report multiple secondary complications.

SECONDARY COMPLICATIONS DURING ACUTE AND/OR REHABILITATION CARE



⁴ Stage 1 not included in this analysis because the pressure ulcer is not considered severe enough to affect outcomes.



IN 2016

45%

OF RHSCIR PARTICIPANTS
EXPERIENCED A UTI,
PNEUMONIA, AND/OR PRESSURE
ULCER DURING THEIR ACUTE
HOSPITAL STAY

FOR 499 RHSCIR PARTICIPANTS IN 2016, THE **THREE MOST COMMON SECONDARY COMPLICATIONS COST** RHSCIR ACUTE HOSPITALS⁵

~\$1 MILLION UTIs

~\$3.4 MILLION PNEUMONIA

~\$3 MILLION PRESSURE ULCERS



All numbers based on 2015 Canadian dollars and calculated on a sample size of 499 participants for whom we have complete acute complications data available.

⁵ Chan, B, Ieraci L, Mitsakakis, N, Pham B, Krahn M. Net costs of hospital-acquired and pre-admission PUs among older people hospitalised in Ontario. Journal of Wound Care. 2013;22(7):341-2, 344-6.

Hellsten EK, Hanbidge MA, Manos AN, Lewis SJ, Massicotte EM, Fehlings MG, Coyte PC, Rampersaud YR. An economic evaluation of perioperative adverse events associated with spinal surgery. Spine Journal. 2013;13(1):44-53.

Wardle G, Wodchis WP, Laporte A, Anderson GM, Ross Baker G. The sensitivity of adverse event cost estimates to diagnostic coding error. Health Services Research. 2012;47(3 Pt 1):984-1007.

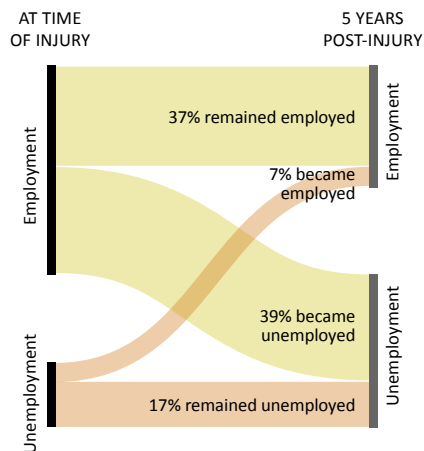
WHAT ARE THE SOCIAL IMPACTS POST-INJURY?



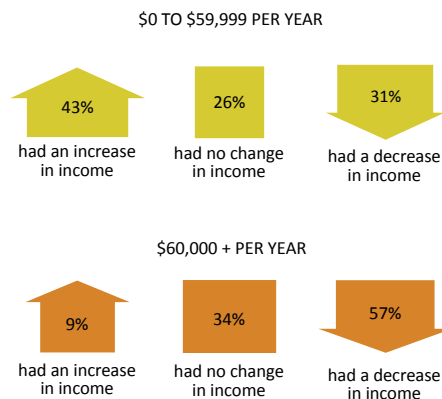
An individual sustaining a traumatic SCI can expect a number of significant life changes including changes in employment status, household income and relationships. The following information provides participant responses recorded at five year follow-up interviews. The most significant changes occurred in employment status and household income: just under half

of individuals who were employed at the time of injury were unemployed after five years and just over one third of participants 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.

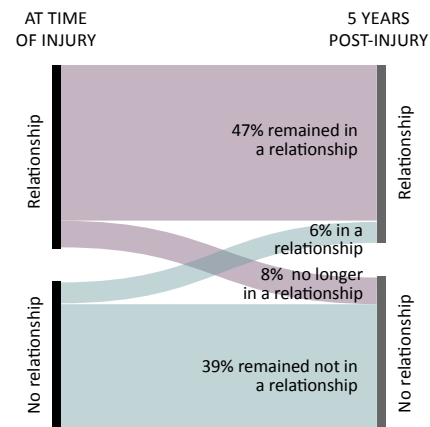
CHANGE IN EMPLOYMENT STATUS FIVE YEARS POST-INJURY



CHANGE IN HOUSEHOLD INCOME FIVE YEARS POST-INJURY



CHANGE IN RELATIONSHIP STATUS FIVE YEARS POST-INJURY





1. PEOPLE WITH TRAUMATIC SPINAL CORD INJURIES ARE GETTING OLDER

Canada's population is aging at an increased rate and so too is the average age of people who sustain a traumatic spinal cord injury. As a result of the aging population, falls are the most common type of injury. Although older individuals are more likely to sustain less severe injuries, when they do sustain a more severe injury, their health care needs are more complex.

2. SECONDARY COMPLICATIONS PRESENT A SIGNIFICANT BURDEN

Reducing the incidence and severity of secondary complications can eliminate excess health care costs and improve quality of life. Currently, more than half of RHSCIR participants are experiencing secondary complications during their hospital stay.

3. TRAUMATIC SPINAL CORD INJURIES RESULT IN SIGNIFICANT LIFE CHANGES

People with traumatic SCI who participated in RHSCIR are faced with a number of social impacts such as changes in employment status, income levels and relationships. Most significantly, employment and household income levels declined for participants five years after injury. However, RHSCIR data also shows that the vast majority of relationship statuses remained unchanged after the same time frame.

RHSCIR DATA PROVIDES INSIGHTS TO IMPROVE CARE



In conclusion, RHSCIR will continue to connect clinicians, researchers, health care administrators, and people living with SCI in order to facilitate the translation of research into clinical practice, and promote evidence-based practices to improve outcomes for those living with SCI.

As we move forward, RHSCIR will keep evolving to ensure it facilitates world class research, promotes excellence in care and meets the needs of people living with SCI.



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 April 24, 2017.

Data collected (number of participants injured) in 2016

660 (357 expanded data set, 54%)

Number of participants represented in each data summary:

Age: 658

Gender: 658

Paraplegia vs Tetraplegia: 402

Complete vs Incomplete: 469

Mechanism of Injury: 520

Mechanism of Injury by Age: 520

Time to RHSCIR Admission within 24 Hours: 492

Care Pathway: 569

Length of Stay in Acute: 341

Length of Stay in Rehab: 267

Secondary Complications – Pneumonia, UTI, Pressure Ulcers: 570

Number of five year post-injury community follow-up interviews completed between 2013 and 2016:

Employment: 235

Income: 178

Relationship Status: 271

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 in part or the entire trunk. It is caused by an injury to the spinal cord in the thoracic (trunk) or below.

Pneumonia

An infection in the lungs.

Pressure ulcer

Tissue is injured by pressure and/or shear.

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 10 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.

Suspected Deep Tissue Injury (SDTI)

An area of discoloured skin that appears to have tissue underneath that may have been damaged by pressure and/or shear.

Tetraplegia or Quadriplegia

Complete or partial loss of sensation and/or movement in the arms, trunks 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.

Urinary Tract Infection (UTI)

A bacterial infection of the urinary tract.

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