RHSCIR | a Canadian SCI Registry

Rick Hansen Spinal Cord Injury Registry

A look at spinal cord injury in Canada in 2020

Thank you to the 9,216 individuals with spinal cord injuries who have generously contributed their time and experiences to the Rick Hansen Spinal Cord Injury Registry (RHSCIR). We also wish to thank the dedicated clinicians, researchers and coordinators who collect, analyze and input data into RHSCIR. The contributions of everyone involved are vital to improving the care for those with spinal cord injuries and maximizing the potential for these individuals and others to reach the fullest recovery possible.

2020 was a uniquely challenging year, as the effects of the COVID-19 pandemic were felt around the globe. We recognize that various impacts of COVID-19 may be reflected in the data presented in this report.

Generous support for this project provided by the Government of Canada through Pacific Economic Development Canada (PacifiCan), Health Canada, and the Governments of British Columbia, Alberta, Manitoba and Ontario.

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RHSCIR HOSPITALS ARE LOCATED IN 15 CITIES ACROSS CANADA

The Rick Hansen Spinal Cord Injury Registry: A look at SCI in Canada in 2020 is a detailed look at clinical and demographic data collected from 751 (611 tSCI; 140 ntSCI) new RHSCIR participants in 2020.

In this report, you will find information about the type of injury, patient demographics, care pathway, length of hospital stay, secondary complications and social impacts after ***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 purpose of this report is to serve as a descriptive account with no endorsement of, or recommendations about, policies or programs. In 2020, RHSCIR began collecting data on ***non-traumatic SCI*** (***ntSCI***) in response to an increasing need to track incidence and outcomes across multiple types of spinal cord injury. As a result, this report has been expanded to include information on the non-traumatic spinal cord injury population.*

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@praxisinstitute.org**.

For more information about RHSCIR, please visit **praxisinstitute.org/research-care/key-initiatives/national-sci-registry/**

*Disclaimer: the non-traumatic SCI cohort for 2020 is partial, as information has only been collected on this population for a portion of the year due to facilities implementing data collection at different times. Therefore, non-traumatic SCI summaries presented in this report may not be generalizable.

Spinal cord injury 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, approximately 44,000 with ***traumatic SCI*** (***tSCI***) and 42,000 with non-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. For the approximately 1,389 people in Canada 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. It is estimated that approximately 2,286 people were discharged from hospital with a ntSCI each year, yet, not much is known regarding the costs for ntSCI.[2] In order to better understand the complex needs of individuals who sustain an 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 30 participating facilities in major Canadian cities, RHSCIR includes more than 9,000 participants, making it the largest database that tracks the experiences of individuals living with SCI in Canada.

[1] Noonan 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.

[2] 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.s

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

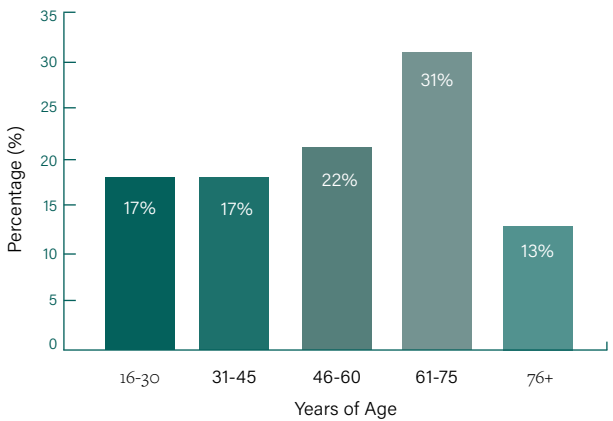
RHSCIR is a ***prospective observational study*** that collects clinical and demographic data from Canadian acute and rehabilitation (rehab) hospitals specializing in SCI care and treatment. Information from individuals with SCI is also collected during their hospital stay and throughout their lifetime after integrating back into the community.

THE 2020 RHSCIR REPORT HAS EXPANDED TO INCLUDE DATA FROM INDIVIDUALS WITH NON-TRAUMATIC SCI

A non-traumatic spinal cord injury is any impairment of the spinal cord or cauda equina function (i.e. motor or sensory deficit) that is not caused by an external trauma. Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS) are not included in the RHSCIR non-traumatic data set. Degenerative disorders and spinal tumours constitute the most common causes of ntSCI, whereas less common causes include vascular injury, infection, congenital deformities, and inflammatory conditions. There is a growing need to track the incidence and outcomes for both non-traumatic and traumatic SCIs, which is why RHSCIR expanded to begin collecting this data in 2020.

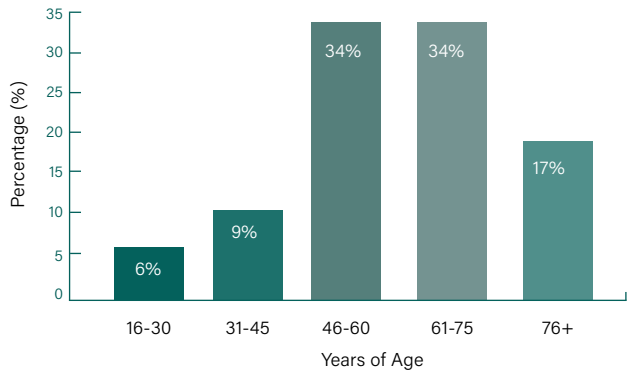
The average age of RHSCIR participants with tSCI was 54 years old in 2020. 76% of participants were male and 24% were female.

RHSCIR POPULATION BY AGE GROUP: tSCI



In the small cohort of individuals with ntSCI the average age of RHSCIR participants was 61 years old. Based on the 2020 data, 61% of RHSCIR ntSCI participants were male and 39% were female.

RHSCIR POPULATION BY AGE GROUP: ntSCI*



*This is a limited data set. See denominators on page 17.

WHAT IS THE SEVERITY AND LEVEL OF INJURY?

Tetraplegia or quadriplegia is complete or partial loss of sensation and/or movement in the arms, and typically in the torso and legs.

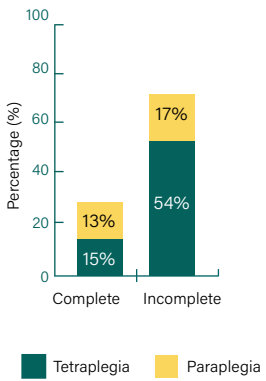
Paraplegia, on the other hand, is complete or partial loss of sensation and/or movement in the legs and often in part of, or the entire torso.

Within the tSCI population, ***incomplete injuries***, where some motor or sensory function is retained below the level of injury, were more common than ***complete injuries*** which usually have a total lack of sensory and motor function below the level of injury.

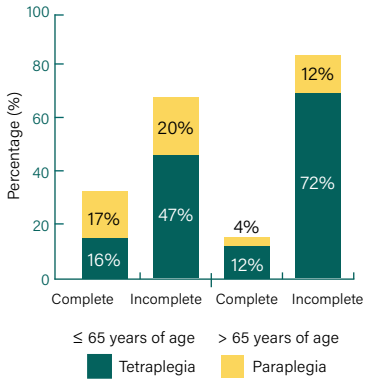
In addition, for those individuals with complete injuries there was a similar incidence of tetraplegia and paraplegia. Among those with incomplete injuries, a much larger percentage experienced tetraplegia.

Incomplete tetraplegia was the most common type of SCI sustained among RHSCIR participants for those with tSCI.

SEVERITY AND LEVEL OF INJURY: tSCI



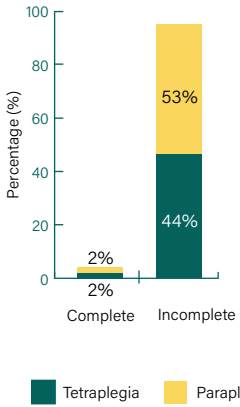
SEVERITY AND LEVEL OF INJURY BY AGE GROUP: tSCI



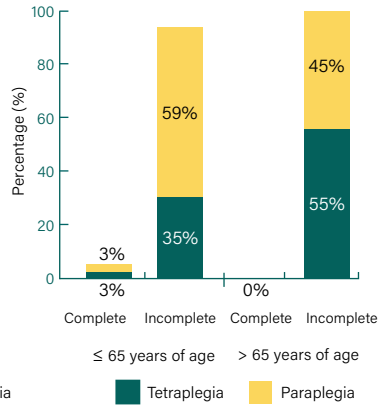
Within the ntSCI population, the 2020 data indicates that incomplete injuries were far more common than complete injuries. In addition, for those individuals with complete injuries, there was a similar incidence of tetraplegia and paraplegia. Among those with incomplete injuries, a larger percentage experienced paraplegia.

Incomplete paraplegia was the most common type of non-traumatic injury sustained among RHSCIR participants.

SEVERITY AND LEVEL OF INJURY: ntSCI*



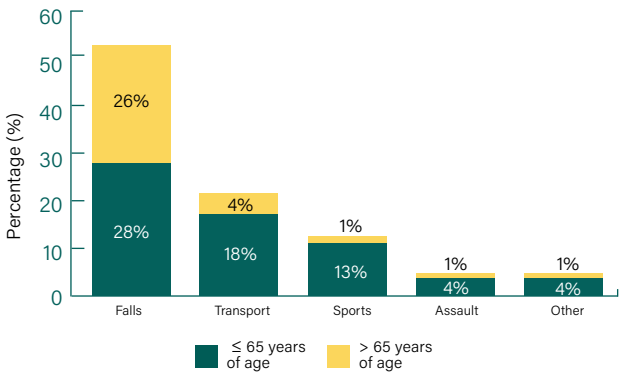
SEVERITY AND LEVEL OF INJURY BY AGE GROUP: ntSCI*



*This is a limited data set. See denominators on page 17.

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 with tSCI. A tSCI as a result of a fall can range from a slip on the sidewalk to something more severe such as a fall from an apartment balcony. Falls were followed by transportation and sports as the most common types of traumatic injuries, with assault and other reasons being less common. The mechanism of injury was also associated with age. For example, the average age of people who experienced a fall was 63 years old, whereas for sports and transport related injuries the averages ages were 42 and 46 years old, respectively.

MECHANISM OF INJURY BY AGE GROUP: tSCI



The average age for people who experienced a transport related injury was

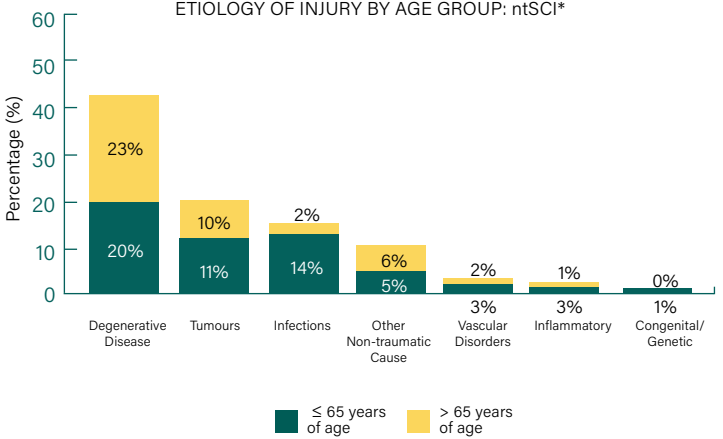
46 YEARS OLD

The average age for people who experienced a fall was

63 YEARS OLD

A ntSCI can result from a variety of etiologies, ranging from vascular disorders to degenerative and inflammatory diseases. In the non-traumatic population, degenerative disorders were the most common cause of spinal cord injury, followed by tumours, infections, and other non-traumatic causes such as spinal hematomas. The average age of people who experienced a degenerative injury was 65 years old. For people who experienced tumours or infections, the average ages were 64 and 52 years old, respectively.

ETIOLOGY OF INJURY BY AGE GROUP: ntSCI*

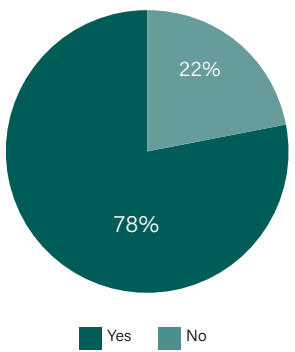


*This is a limited data set. See denominators on page 17.

WHERE DO PEOPLE GO AFTER INJURY TO RECEIVE TREATMENT?

Hospitals that deliver specialized SCI care and participate in RHSCIR are considered leading SCI centres in their geographic area. According to recent research, individuals who are admitted early to a hospital that specializes in SCI care, and are 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.[3]

PERCENTAGE OF INDIVIDUALS ADMITTED TO A RHSCIR ACUTE HOSPITAL WITHIN 24 HOURS (%): tSCI



RHSCIR data showed that 78% of RHSCIR participants with tSCI were admitted to a ***RHSCIR Acute Hospital*** within 24-hours from injury regardless of whether they first went to a non-RHSCIR Hospital. As you'll see in the care pathway on the next page, just under half the time, participants enrolled in RHSCIR were initially admitted to a non-RHSCIR Hospital.

[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?

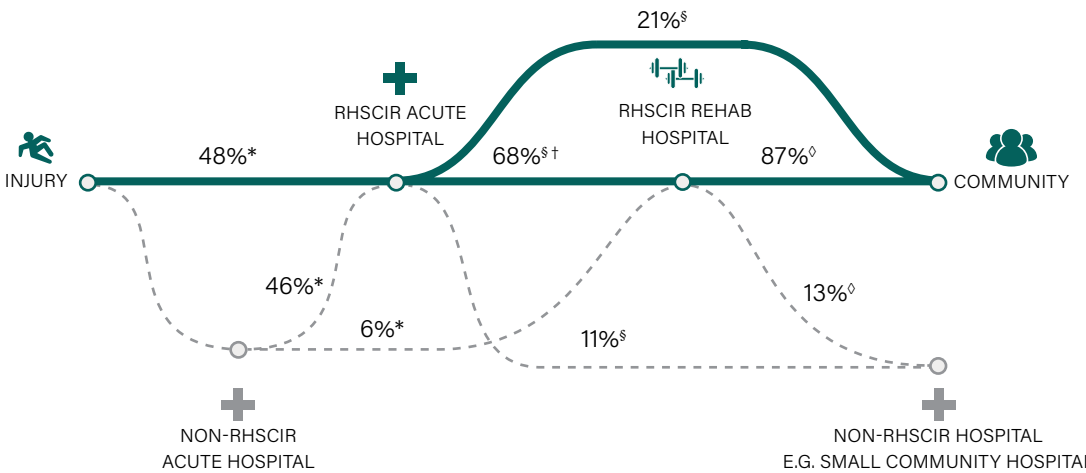
The care pathway is the journey an individual takes from the moment the injury is sustained until that individual returns to the community or is returned to a hospital closer to home. The ideal care pathway for a person who sustains a tSCI is to be admitted as soon as possible to a RHSCIR Acute Hospital, and then, if necessary, admitted to a ***RHSCIR Rehab Hospital*** in order to receive specialized rehab care. Based on 2020 RHSCIR data, almost all individuals with tSCI were admitted to a RHSCIR Acute Hospital either directly (48%), or indirectly (46%) via a non-RHSCIR acute hospital. The remaining 6% of participants were admitted to a non-RHSCIR acute hospital prior to being admitted to a RHSCIR Rehab Hospital. Regardless of their care pathway, 85% of individuals received surgery.

For individuals with tSCI admitted to a RHSCIR Acute Hospital, 68% 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.

At the point of final discharge from a RHSCIR hospital 42% of individuals with tSCI were walking independently with or without an aid.

Mortality during the initial RHSCIR Acute Hospital stay was 9%. Only individuals who survived their injury and acute hospital stay are included in the care pathways below.

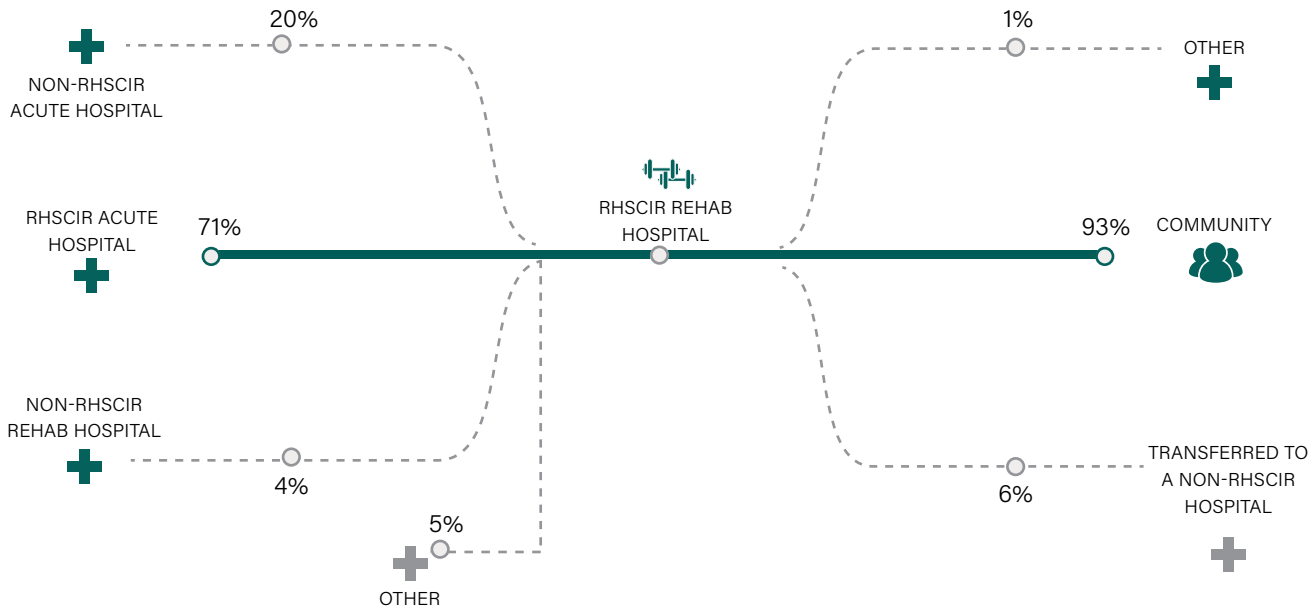
CARE PATHWAY VISUALIZATION



* All participants
§ All participants that went to a RHSCIR Acute Hospital
◊ All participants that went to a RHSCIR Rehab Hospital
† Of the participants who went from a RHSCIR Acute Hospital to a RHSCIR Rehab Hospital, 4% went to the community or to another hospital to wait for RHSCIR rehab.

For individuals with ntSCI who arrived at a RHSCIR Rehab Hospital, 71% arrived from a RHSCIR Acute Hospital and 20% arrived from a non-RHSCIR acute hospital. The remainder arrived from a non-RHSCIR rehab hospital (4%) or from other locations (5%) such as the community.

Most of those with ntSCI were discharged to the community (e.g. home, assisted living, long term care) from their inpatient stay at a RHSCIR Rehab Hospital.

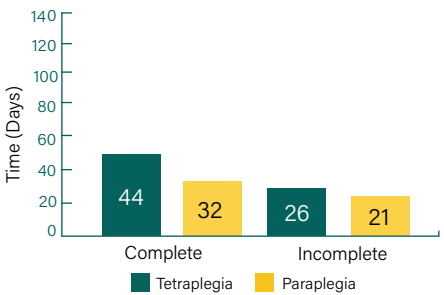


WHAT IS THE DURATION OF THE HOSPITAL STAY?

8

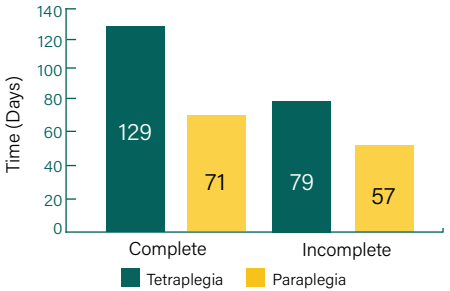
RHSCIR captures length of stay during acute and rehab admissions for those with tSCI. In 2020, the average number of days spent in acute care following a tSCI was 21 days for individuals with incomplete paraplegia, 32 days for individuals with complete paraplegia, 26 days for individuals with incomplete tetraplegia and 44 days for individuals with complete tetraplegia.

AVERAGE (MEAN) LENGTH OF STAY DURING ACUTE CARE IN DAYS: tSCI



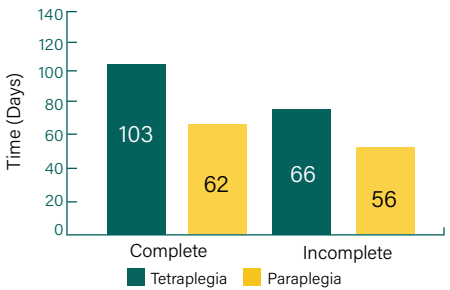
The average length of stay for those who were admitted to a RHSCIR Rehab Hospital was 57 days for those with incomplete paraplegia, 71 days for those with complete paraplegia, 79 days for those with incomplete tetraplegia and 129 days for those with complete tetraplegia.

AVERAGE (MEAN) LENGTH OF STAY DURING REHABILITATION CARE IN DAYS: tSCI



RHSCIR captures length of stay during rehab admissions for those with ntSCI as well. In 2020, the average number of days spent in rehab care following a ntSCI was 56 days for individuals with incomplete paraplegia, 62 days for individuals with complete paraplegia, 66 days for individuals with incomplete tetraplegia and 103 days for individuals with complete tetraplegia.

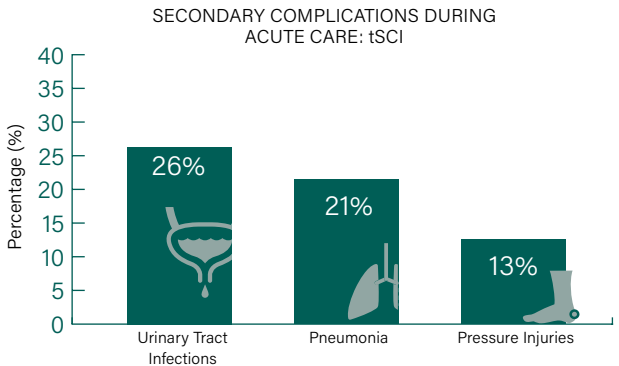
AVERAGE (MEAN) LENGTH OF STAY DURING REHABILITATION CARE IN DAYS: ntSCI*



*This is a limited data set. See denominators on page 17.

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

Secondary complications refer to the range of conditions that can occur after sustaining the initial spinal cord injury. Some of the most common secondary complications that people with SCI experience in the hospital are ***pneumonia***, ***pressure injuries*** and ***urinary tract infections*** (***UTIs***). These complications can prolong hospitalization and diminish quality of life in the community. Complications during the hospital stay have been associated with an increased risk of secondary complications in the community, and can lead to re-hospitalization or result in death.[4]

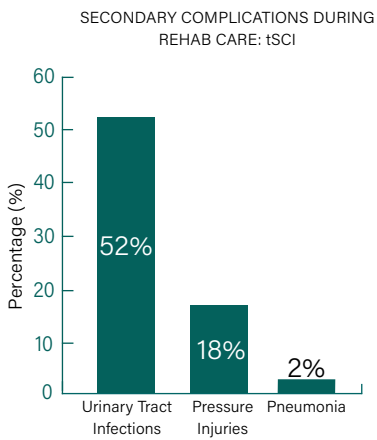


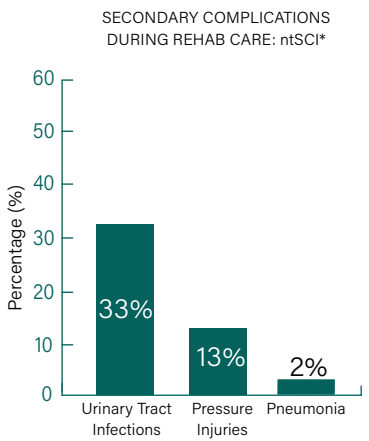
[4] Jaglal SB, Munce SE, Guilcher SJ, Couris CM, Fung K, Craven BC, Verrier M. Health system factors associated with rehospitalizations after traumatic spinal cord injury: a population-based study. Spinal Cord. 2009 Aug;47(8):6049. doi:10.1038/sc.2009.9. Epub 2009 Mar 10. PubMed PMID:19274059.

[5] Stage 1 pressure injuries were not included in this analysis because the pressure injury is not considered severe enough to affect outcomes.

According to 2020 RHSCIR data, UTIs were the most common secondary complication in hospital for those with tSCI, followed by pneumonia, and then pressure injuries (stages II, III, IV or ***deep tissue injury*** as defined by the US National Pressure Injury Advisory Panel).[5] Based on 2020 RHSCIR data, 57% of participants with tSCI reported at least one of these secondary complications during acute and/or rehab stays. Approximately 20% of individuals with tSCI reported multiple secondary complications.

Much like tSCI, the most common secondary complications in individuals with ntSCI are pneumonia, pressure injuries and urinary tract infections (UTIs), with UTIs being the most common. Based on 2020 RHSCIR data, 41% of participants with ntSCI reported at least one of these secondary complications during their rehab stay. Approximately 6% of individuals with ntSCI report multiple secondary complications.





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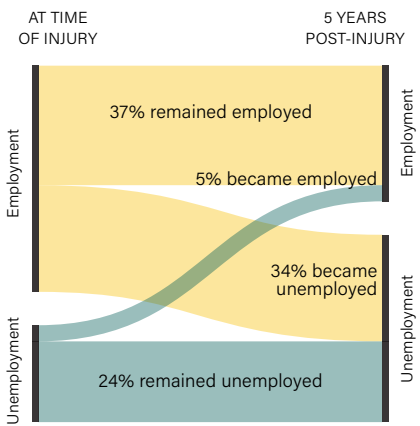
WHAT ARE THE SOCIAL IMPACTS POST-INJURY?

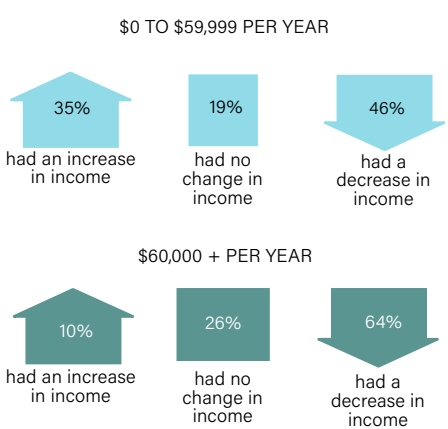
An individual sustaining a tSCI can expect a number of significant life changes including changes in employment status, household income and relationships. The following information comprises participant responses recorded at five years post-injury for follow-up interviews completed with individuals with tSCI between 2017 and 2020. The most significant changes occurred in employment status and household income: 34% of individuals who were employed at the time of injury were unemployed after five years, and 56% of participants saw a decline in household income. Nearly half of participants with an annual household income under $60,000 saw a decline in income over the same time period, and nearly two thirds of participants with annual incomes of $60,000 and above also saw a decline. It is important to note that the COVID-19 pandemic may have contributed to changes in employment throughout 2020, and therefore may be reflected in the results presented here.

On the other hand, at five years post-injury, relationship status does not appear to be significantly impacted by the injury.

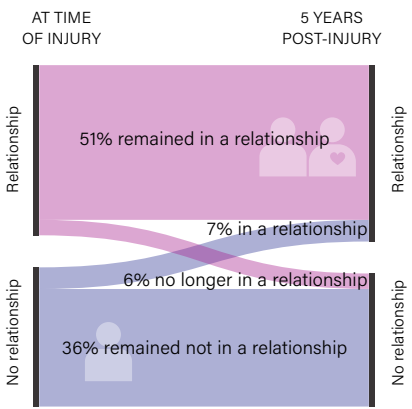
CHANGE IN EMPLOYMENT STATUS
FIVE YEARS POST-INJURY



CHANGE IN HOUSEHOLD INCOME
FIVE YEARS POST-INJURY



CHANGE IN RELATIONSHIP STATUS
FIVE YEARS POST-INJURY



1. AGING IS HAVING AN IMPACT ON THE CARE OF TRAUMATIC SPINAL CORD INJURY

As a result of the aging Canadian population, falls are the most common type of traumatic spinal cord injury. Although older individuals are more likely to sustain milder injuries, when they do sustain a more severe injury, their health care needs are more complex due to the increased likelihood of experiencing ***comorbidities*** alongside their spinal cord injury.

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, just over half of RHSCIR participants with traumatic SCI experienced secondary complications (UTIs, pressure injuries, pneumonia) during their hospital stay. During rehab care, the incidence of secondary complications is lower in the non-traumatic population, however, given the limited sample size from only a few hospitals, this may not be fully representative of the non-traumatic population across RHSCIR facilities.

3. TRAUMATIC SPINAL CORD INJURIES RESULT IN SIGNIFICANT LIFE CHANGES

For individuals sustaining a traumatic SCI, changes in employment status, income levels and relationships can occur. Two areas where there are significant life changes are employment and household income levels. Both declined for participants five years after injury, and for those with a lower income, the proportion of individuals experiencing a decrease in income after SCI is larger than three years ago. However, RHSCIR data also shows that the vast majority of relationship statuses remained unchanged after the same time frame.

4. NON-TRAUMATIC SPINAL CORD INJURIES

For individuals sustaining a non-traumatic SCI, trends within the limited data set suggest people are more likely to be paraplegic than tetraplegic, and much more likely to have an incomplete injury than a complete one. This differs to the traumatic SCI population where trends show individuals are more likely to be tetraplegic than paraplegic. Length of stays also differ, as those with non-traumatic injuries often have a shorter stay in rehab than those with traumatic injuries. By far the most common non-traumatic etiology was degenerative disease which is consistent with the non-traumatic population having an older average age.

RHSCIR DATA PROVIDES INSIGHTS TO IMPROVE CARE

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. In addition to this report, RHSCIR provides ongoing clinical reports to clinicians at participating RHSCIR facilities.

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. As traumatic SCI is only a portion of the SCI population, RHSCIR begun collecting non-traumatic SCI data in the registry in 2020 in order to capture a more complete picture of SCI incidence in Canada. This report is the first to reflect data collected in the non-traumatic SCI population, and Praxis looks forward to continue to share more information in future reports.

Note: RHSCIR collects both a core data set (minimal data set for both consented and non-consented participants) and an expanded data set for consented participants only.

Data for those with traumatic SCI is collected during acute and rehab care and at community follow-up. Data for those with non-traumatic SCI is collected during rehab care only.

The RHSCIR data used for this report was extracted on September 30th, 2021.

Data collected (number of new injuries) in 2020	**tSCI**	**ntSCI**
Age	611	140
Gender	611	140
Severity and level of injury	415	117
Severity and level of injury by age	413	117
Mechanism of injury	506	111
Mechanism of injury by age	506	111
Time to RHSCIR admission within 24 hours	468	N/A
Where do people go after injury	468	105
Care pathway (tSCI)	341	N/A

Data collected (number of new injuries) in 2020	**tSCI**	**ntSCI**
How do people arrive at a RHSCIR rehab facility (ntSCI)	N/A	105
Discharge destination	480	128
Length of stay in acute	362	N/A
Length of stay in rehab	219	114
Secondary complications - pneumonia, UTI, pressure injuries (acute or rehab)	550	N/A
Secondary complications - pneumonia, UTI, pressure injuries (acute)	486	N/A
Secondary complications - pneumonia, UTI, pressure injuries (rehab)	292	129
Surgery	511	N/A
Independent walking	192	N/A

DENOMINATORS FOR REPORT SUMMARIES

Number of five-year post-injury community follow-up interviews completed between 2017 and 2020:

Data collected	tSCI	ntSCI
Employment	304	N/A
Income	198	N/A
Relationship Status	303	N/A

Percentages shown in each of the summaries have been calculated using the denominators above, individuals with missing data have not been included. This may skew the results if the pattern of missing data is not random and summaries should be interpreted accordingly.

Comorbidity
More than one disease or condition is present in the same person at the same time.

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 torso. It is caused by an injury to the spinal cord in the thoracic region (torso) or below.

Pneumonia
An infection in the lungs.

Pressure ulcer/injury
Damage to skin and underlying tissue caused 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 18 months, 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. This information can be used to inform future decisions through research and clinical care.

RHSCIR Acute Hospital
A trauma hospital that delivers specialized SCI care and participates in RHSCIR.

RHSCIR Rehab Hospital
A rehabilitation hospital that delivers specialized SCI care 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.

Deep tissue injury
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, and typically in the torso and legs. It is caused by an injury to the spinal cord in the neck.

Traumatic spinal cord injury (tSCI)
A spinal cord injury that occurs as a result of trauma such as a vehicle crash or fall from a building.

Non-traumatic spinal cord injury (ntSCI)
A spinal cord injury that is not the direct result of an external force, but is instead a result of illness (e.g. cancer or infection), degenerative changes, or birth defect.

Urinary tract infection (UTI)
A bacterial infection of the urinary tract.

PRAXIS
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Praxis Spinal Cord Institute is located on the unceded traditional territory of the Coast Salish Peoples, specifically the shared traditional territories of the *Sḵwx̱wú7mesh* (Squamish), *xʷməθkʷəy̓əm* (Musqueam) and *səl̓ilw̓ətaɁɬ* (Tsleil-Waututh) First Nations.