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Spinal Cord Institute
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Rick Hansen Spinal Cord Injury Registry

A look at spinal cord injury in Canada in 2021

About:

The Rick Hansen Spinal Cord Injury Registry (RHSCIR): A look at SCI in Canada in 2021 provides a snapshot of information on people who sustained a ***traumatic spinal cord injury*** (***tSCI***) or ***non-traumatic spinal cord injury*** (***ntSCI***) in Canada. In this fact sheet, 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 fact sheet is to serve as a descriptive account with no endorsement of, or recommendations about, policies or programs.

RHSCIR is a ***prospective observational study*** that collects demographic and clinical data from Canadian acute and rehabilitation (rehab) hospitals specializing in SCI care and treatment. Information from individuals with SCI is collected during their hospital stay and throughout their lifetime after integrating back into the community. With 30 participating facilities from across Canada, RHSCIR includes over 10,000 participants, making it the largest registry that tracks the experiences of individuals living with SCI in Canada. For previous reports and more details, visit **https://praxisinstitute.org/research-care/key-initiatives/national-sci-registry/**.

Thank you for your generous contribution:

Thank you to the 10,881 individuals with spinal cord injuries who have generously contributed their time and experiences to 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.

30 participating facilities over 10,000 participants

Spinal Cord Injury and the Registry

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. tSCI refers to injuries to the spinal cord or cauda equina that are sustained as a result of trauma such as serious vehicle crashes or falls. ntSCI refers to any impairment of the spinal cord or cauda equina function that is not the direct result of an external force or trauma, but is instead the result of a degenerative disorder, or birth defect. 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. Amyotrophic Lateral Sclerosis (ALS) and Multiple Sclerosis (MS) are not included in the RHSCIR non-traumatic data set.

In 2021, there were 682 tSCI and 466 ntSCI new RHSCIR participants. RHSCIR captures 60-70% of all acute tSCI in Canada when compared to other national data sources (Canadian Institute for Health Information)[1].

In Canada, of the 86,000 individuals living with SCI, it was estimated that approximately 30,000 people live with tSCI[2,3]. Although SCI affects fewer individuals when compared to other chronic conditions, the economic burden is substantial. For people with tSCI, it was estimated that approximately 1,100 people were discharged from hospital with a tSCI each year and the estimated average lifetime cost is $2 million per individual[3,4]. This includes direct costs like hospital stay and indirect costs such as lost productivity due to premature mortality.

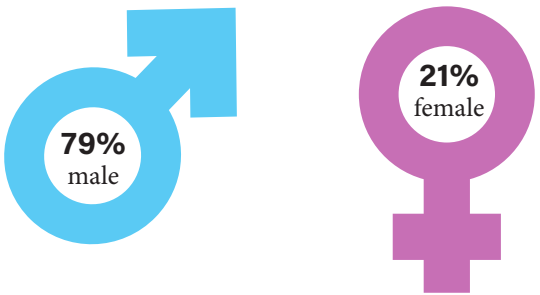
[1] Noonan VK, Chan E, Santos A, Soril L, Lewis R, Singh A, Cheng CL, O'Connell C, Truchon C, Paquet J, Christie S, Ethans K, Tsai E, Ford MH, Drew B, Linassi AG, Bailey CS, Fehlings MG; RHSCIR Network. Traumatic Spinal Cord Injury Care in Canada: A Survey of Canadian Centers. J Neurotrauma. 2017;34(20):2848-2855.

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

[3] Thorogood NP, Noonan VK, Chen X, Fallah N, Humphreys S, Dea N, Kwon BK, Dvorak MF. Incidence and prevalence of traumatic spinal cord injury in Canada using health administrative data. Frontiers in Neurology. 2023;14:1201025.

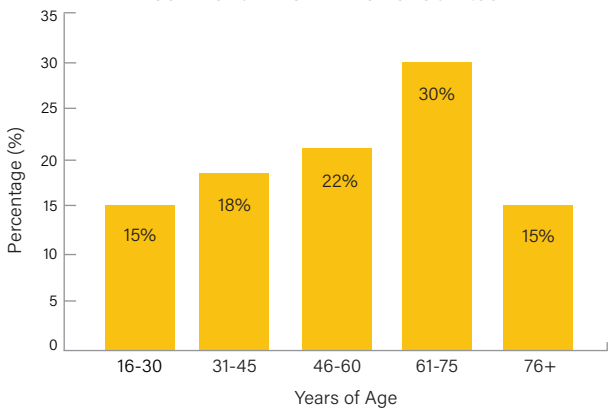
[4] Krueger H, Noonan VK, Trenaman LM, Joshi P, Rivers CS. The economic burden of traumatic spinal cord injury in Canada. Chronic Diseases and Injuries Canada. 2013;33(3):113-112.

RHSCIR POPULATION BY SEX: tSCI



The average age at injury was 55 years old for participants with tSCI and 60 years old for participants with ntSCI. 79% of participants with tSCI and 58% of participants with ntSCI were male.

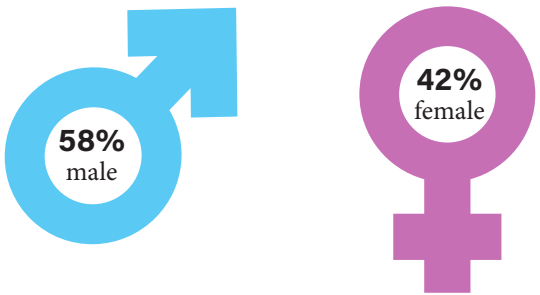
RHSCIR POPULATION BY AGE GROUP: tSCI



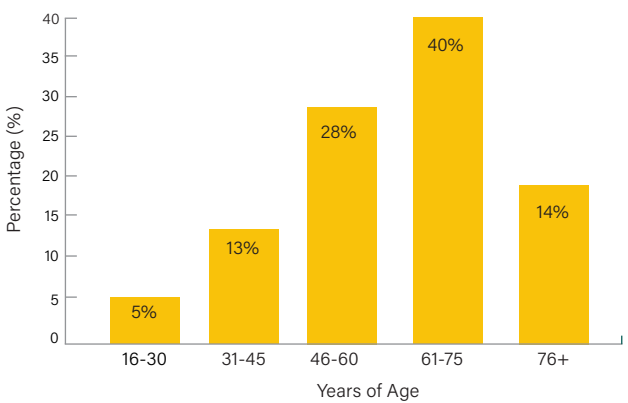
THE AVERAGE AGE AT INJURY

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

RHSCIR POPULATION BY SEX: ntSCI*



RHSCIR POPULATION BY AGE GROUP: ntSCI*



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

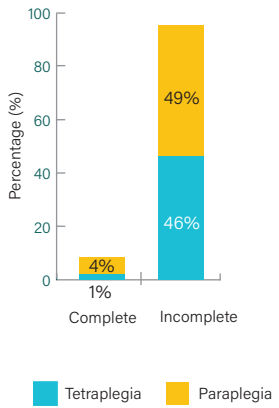
Tetraplegia or quadriplegia is complete or partial loss of sensation and/or movement in the arms, and typically in the torso and legs.

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.

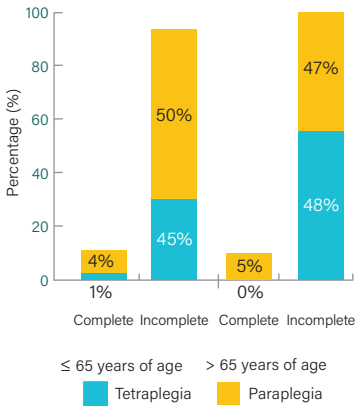
Tetraplegia was more common than paraplegia among participants with tSCI. Meanwhile, paraplegia was slightly more common among participants with ntSCI.

Incomplete injuries were more common than ***complete injuries*** in both participants with tSCI and ntSCI across all age groups.

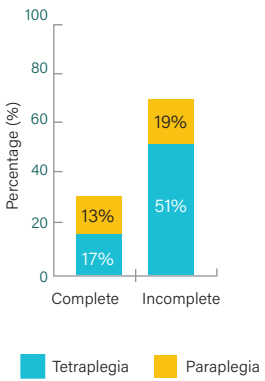
SEVERITY AND LEVEL OF INJURY: ntSCI*



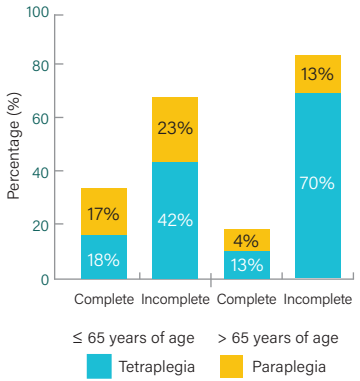
SEVERITY AND LEVEL OF INJURY BY AGE GROUP: ntSCI*



SEVERITY AND LEVEL OF INJURY: tSCI



SEVERITY AND LEVEL OF INJURY BY AGE GROUP: tSCI



INCOMPLETE INJURIES ARE MORE COMMON

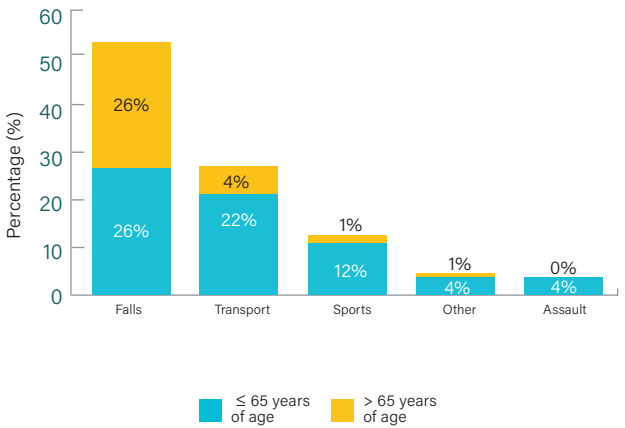
*This is a limited data set. See denominators on page 17.

The mechanism of injury provides a snapshot of how participants were injured.

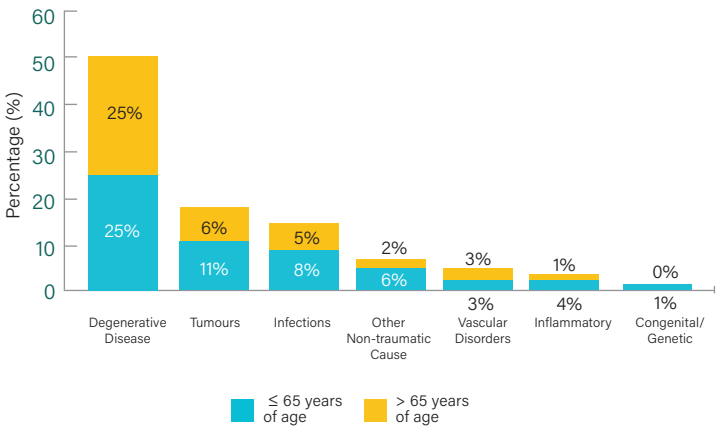
The most common type of traumatic injury was falls, followed by transportation, sports, other causes of injury (e.g. work-related injuries), and assault. The average age for people who experienced a fall was 63 years old and for those who experienced a transportation injury it was 47 years old.

The most common non-traumatic cause was degenerative disease, followed by tumour, infection, other non-traumatic cause (e.g. ***spinal hematomas***), ***vascular disorders, inflammation***, and ***congenital/genetic disorders***. The average age for people who experienced a degenerative disease was 63 years old and for those who experienced a tumour it was 59 years old.

MECHANISM OF INJURY BY AGE GROUP: tSCI



ETIOLOGY OF INJURY BY AGE GROUP: ntSCI*



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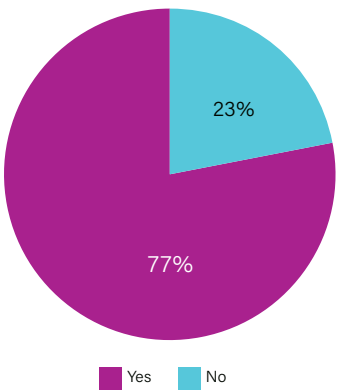
WHERE DO PEOPLE GO AFTER INJURY TO RECEIVE TREATMENT?

77% of participants with tSCI were admitted to a SCI-specialized acute hospital within 24 hours from injury regardless of whether they first went to a non-specialized hospital.

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



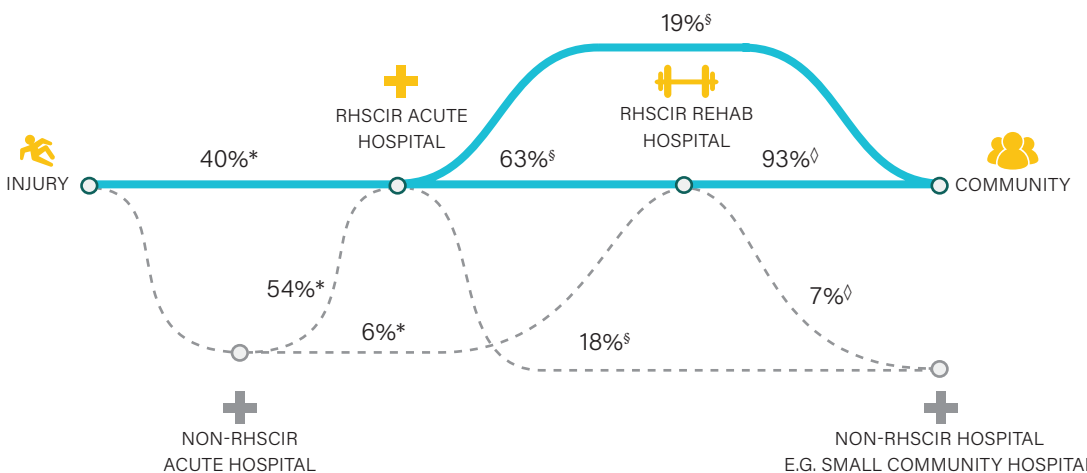
The care pathway is the journey an individual takes from the moment the injury is sustained until that individual returns to the community or to a hospital closer to home. The ideal care pathway for a person who sustains a tSCI is to be admitted as soon as possible to a ***RHSCIR acute hospital*** and then, if necessary, admitted to a ***RHSCIR rehab hospital*** to receive specialized rehab care.

Most individuals with tSCI were admitted to a RHSCIR acute hospital either directly (40%), or indirectly (54%) 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, 87% of individuals received surgery. For individuals with tSCI admitted to a RHSCIR acute hospital, 63% went on to a RHSCIR rehab hospital before returning to the community.

Mortality during the initial SCI-specialized acute hospital stay was 5% for tSCI participants.

CARE PATHWAY VISUALIZATION

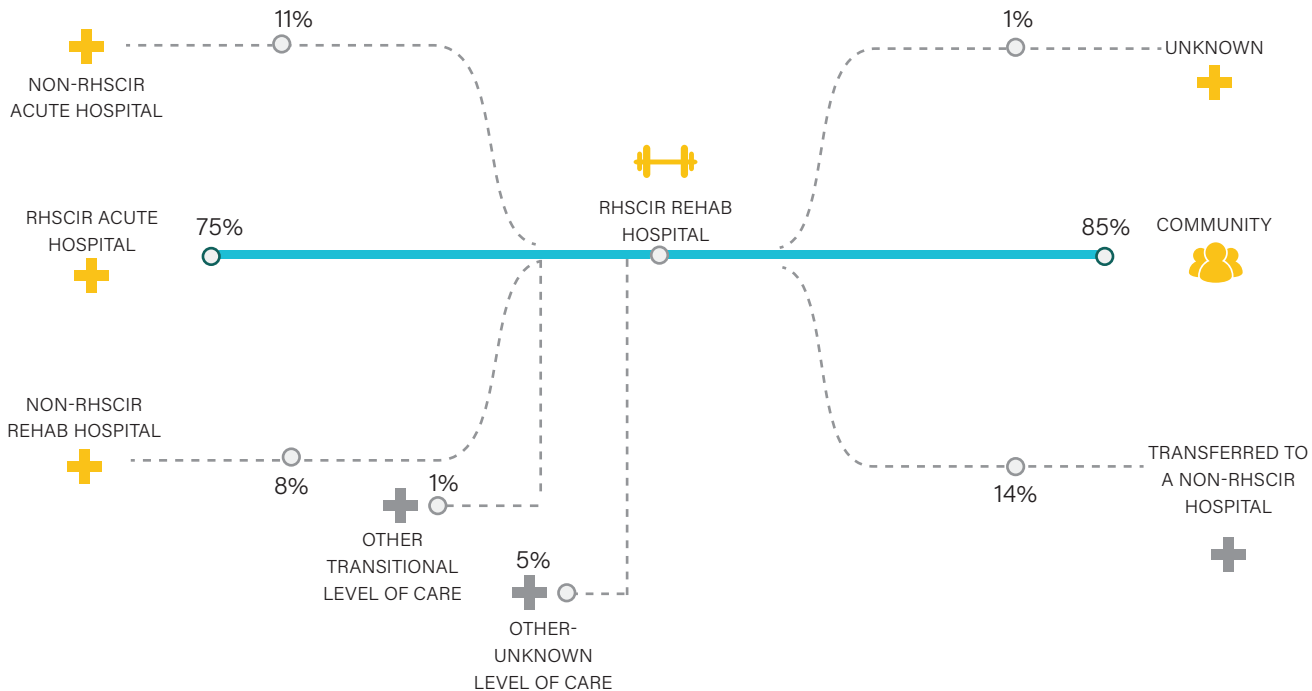


* All participants
§ All participants that went to a RHSCIR acute hospital
◊ All participants that went to a RHSCIR rehab hospital

Note: Only individuals who survived their injury and acute hospital stay are included in the care pathways.

For individuals with ntSCI who arrived at a RHSCIR rehab hospital, 75% arrived from a RHSCIR acute hospital and 11% arrived from a non-RHSCIR acute hospital. The remainder arrived from a non-RHSCIR rehab hospital (8%) or from other locations (6%) such as the community.

85% of individuals with ntSCI were discharged to the community (e.g. home, assisted living, long term care) after their inpatient stay at a RHSCIR rehab hospital.



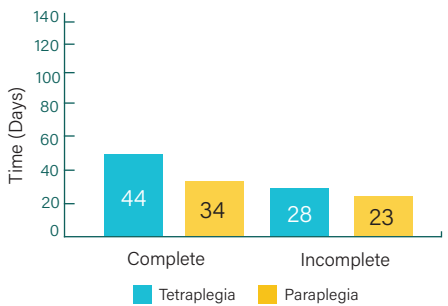
RHSCIR captures length of stay during acute and rehab admissions for those with tSCI, and length of stay during rehab admissions for those with ntSCI.

The average acute length of stay was 44 days for individuals with tSCI with complete tetraplegia, 28 days for those with incomplete tetraplegia, 34 days for those with complete paraplegia and 23 days for those with incomplete paraplegia.

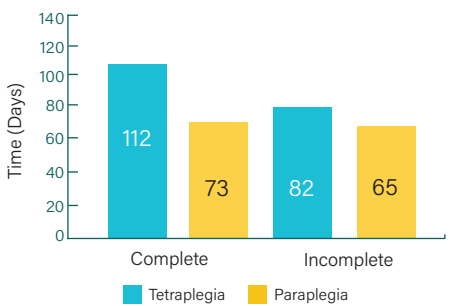
For individuals with tSCI who were admitted to a RHSCIR rehab hospital, the average length of stay was 112 days for those with complete tetraplegia, 82 days for those with incomplete tetraplegia, 73 days for those with complete paraplegia and 65 days for those with incomplete paraplegia.

For individuals with ntSCI who were admitted to a RHSCIR rehab hospital, the average length of stay was 95 days for those with complete tetraplegia, 67 days for those with incomplete tetraplegia, 70 days for those with complete paraplegia and 55 days for those with incomplete paraplegia.

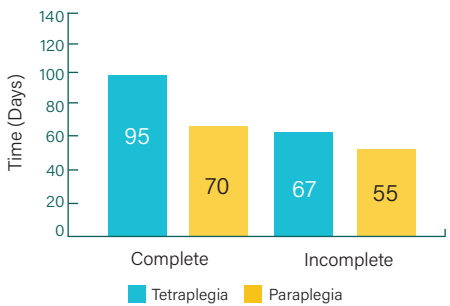
AVERAGE (MEAN) LENGTH OF STAY DURING ACUTE CARE IN DAYS: tSCI



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



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

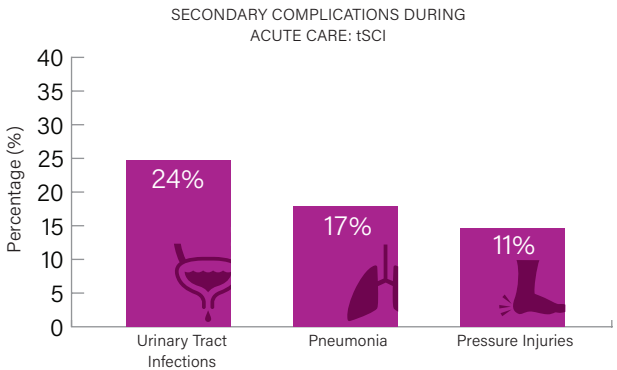


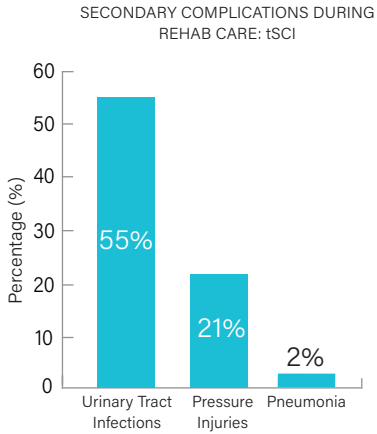
*This is a limited data set. See denominators on page 17.

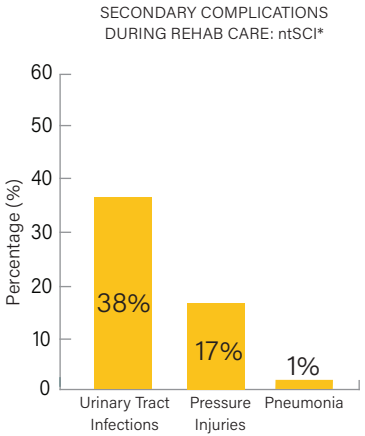
Secondary complications refer to the range of conditions that can occur after sustaining the initial spinal cord injury.

Urinary tract infections (***UTIs***) were the most common secondary complication in individuals with tSCI during their acute and/or rehab stays. For individuals with tSCI in acute care, ***pneumonia*** was the next common, followed by pressure injuries. For individuals with tSCI in rehab, ***pressure injuries*** were the second most common, followed by pneumonia. 56% of individuals with tSCI reported the occurrence of at least one of the secondary complications and 20% reported multiple secondary complications during acute and/or rehab stays.

UTIs were the most common secondary complication in ntSCI individuals during rehab stays, pressure injuries were the second most common, followed by pneumonia. 47% of ntSCI individuals reported having at least one of the secondary complications and 8% had multiple secondary complications during their stay.







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

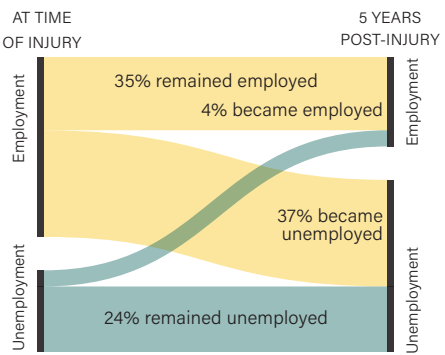
An individual sustaining a tSCI may experience a number of significant life changes, most notably in employment status, household income, and relationships. The following information comprises participant responses recorded at five years post-injury via follow-up interviews completed with individuals with tSCI between 2018 and 2021.

At five years post-injury, 37% of individuals who were employed at the time of their injury became unemployed. Of those who were unemployed at the time of their injury, only 4% had become employed at five years post-injury.

Of the participants who earned less than CAD $,60,000 per year, 52% saw a decrease in income at five years post-injury. Of the participants who earned more than CAD $60,000 per year, 62% saw a decrease in income at five years post-injury.

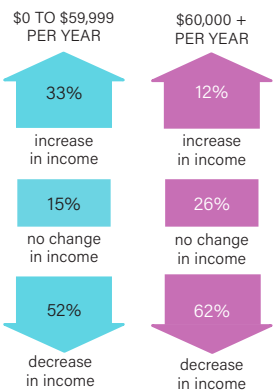
Relationship status did not appear to be significantly impacted five years after the injury. For individuals who were in a relationship at the time of injury, 53% remained in a relationship at five years post-injury and 7% were no longer in a relationship. For individuals who were not in a relationship at the time of injury, 7% were found to be in a relationship at five years post-injury, and 33% remained not in a relationship.

CHANGE IN EMPLOYMENT STATUS



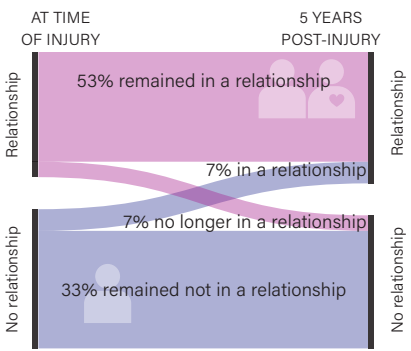
CHANGE IN HOUSEHOLD INCOME

5 YEARS POST-INJURY



CHANGE IN RELATIONSHIP STATUS

5 YEARS POST-INJURY



For more information on interpreting a Sankey Diagram, visit https://www.data-to-viz.com/graph/sankey.html

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 (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 03, 2022.

Data collected	tSCI	ntSCI
Number of new injuries in 2021	682	466
Number of consented participants	290 (42.5%)	N/A
Age	682	466
Sex	682	466
Severity and level of injury	575	420
Severity and level of injury by age	575	420
Mechanism of injury	568	390
Mechanism of injury by age	568	390
Time to RHSCIR admission within 24 hours	515	N/A
Where do people go after injury	515	392
Discharge destination	535	442

Data collected	tSCI	ntSCI
Care pathway	523	466
Length of stay in acute	379	N/A
Length of stay in rehab	286	381
Secondary complications - pneumonia, UTI, pressure injuries (acute or rehab)	621	N/A
Secondary complications - pneumonia, UTI, pressure injuries (acute)	549	N/A
Secondary complications - pneumonia, UTI, pressure injuries (rehab)	388	430
Surgery	573	N/A
Employment	279	N/A
Income	183	N/A
Relationship status	277	N/A

Percentages shown in each of the summaries have been calculated using the denominators above, individuals with either incomplete (i.e. data not available at time of the report) or 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.

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.

Congenital/genetic disorder
A disease or physical abnormality present from birth that causes damage to the spinal cord (e.g. skeletal malformations or tethered cord syndrome).

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).

Inflammation
Inflammation of the spinal cord from non-infectious causes (e.g. autoimmune conditions such as transverse myelitis).

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.

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 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 rehabilitation 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.

Spinal hematoma
Accumulation of blood which mechanically compresses the spinal cord.

Tetraplegia
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.

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

Vascular disorder
Any condition which disrupts the usual blood supply to the spinal cord. This can include hemorrhage, clot/infarcts and vascular malformations.

How to cite this document?

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The Praxis Spinal Cord Institute is a Canadian-based not-for-profit organization with the goal of creating a world without paralysis after spinal cord injury. It works towards this goal by accelerating research and translating clinical findings into practical solutions to develop new treatments, improve health care outcomes, reduce long-term costs and improve the quality of life for those living with spinal cord injury, **www.praxisinstitute.org**.

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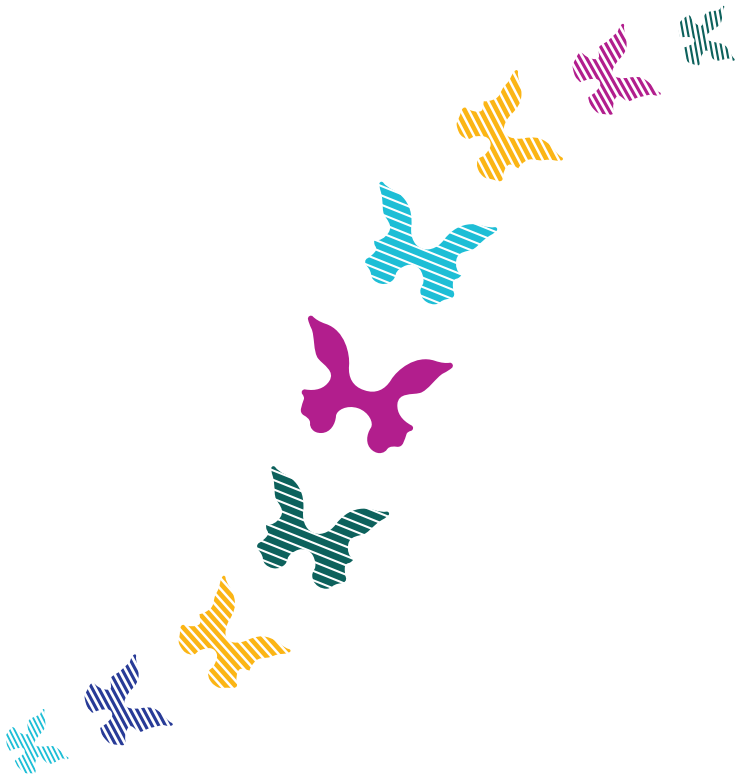

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