RHSCIR

Rick Hansen Spinal Cord Injury Registry

A look at traumatic spinal cord injury in Canada in 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 7,594 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 2018 is a detailed look at clinical and demographic data collected from 625 new RHSCIR participants in 2018.

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@praxisinstitute.org.

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

Certain terms are bolded throughout the report. For definitions, please refer to the glossary on page 15.

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. 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 30 participating facilities in major Canadian cities, RHSCIR includes more than 7,594 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 and information from individuals with SCI throughout their lifetime after integrating back into the community. RHSCIR has international collaborations with hospitals in New Zealand, China and Israel, marking its turn as a truly global endeavor.

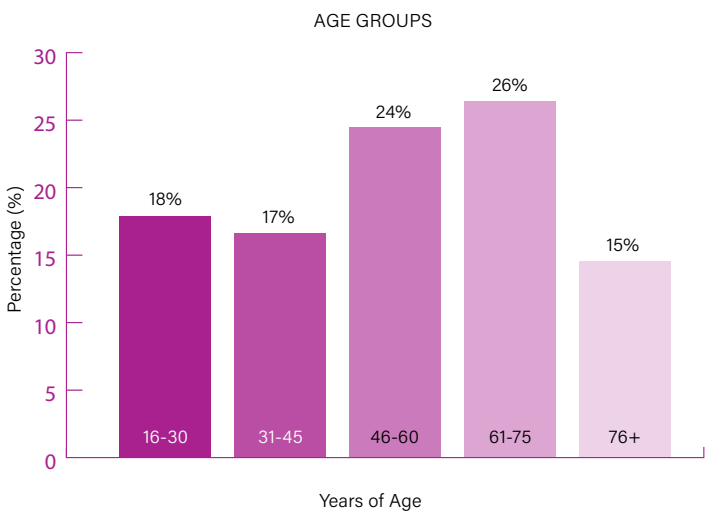
The most vital and fundamental component of RHSCIR is its contributors – people with traumatic SCI. Their continued participation determines the value and success of RHSCIR.

[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.

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.

WHAT DOES THE POPULATION LOOK LIKE?

The average age of RHSCIR participants was 53.4 years old in 2018. 77% of participants were male and 23% were female.



WHAT IS THE SEVERITY AND LEVEL OF INJURY?

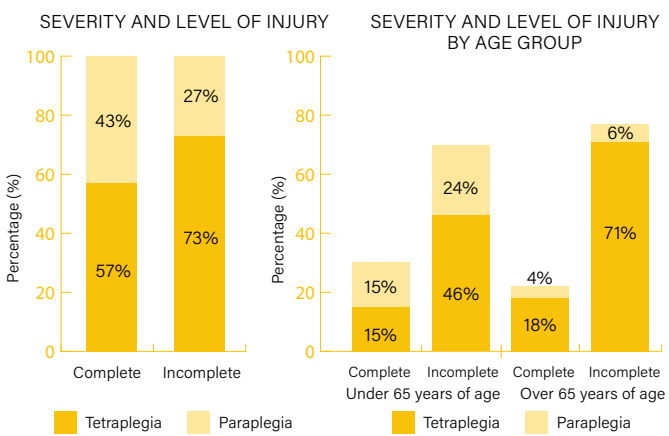
Tetraplegia or ***quadriplegia*** is complete or partial loss of sensation and/or movement in the arms, and typically in the trunk and legs.

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 trunk.

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 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.

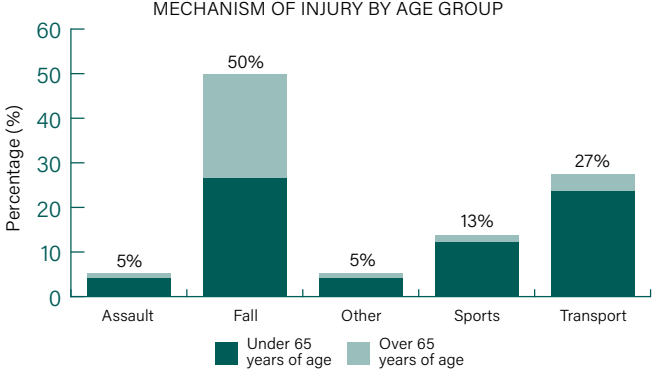
Incomplete tetraplegia was the most common type of traumatic SCI sustained among RHSCIR participants.



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 an 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 38 years old and the average age of people who experienced a fall was 63 years old, whereas for sports and transport related injuries the averages ages were 41 and 43 years old respectively.

MECHANISM OF INJURY BY AGE GROUP



The average age for people who experienced a transport-related injury was
43 YEARS OLD

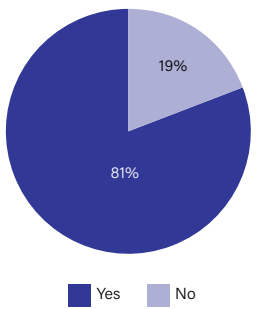
The average age for people who experienced a fall was
63 YEARS OLD

WHERE DO PEOPLE GO AFTER INJURY TO RECEIVE TREATMENT?

Hospitals that have specialized spinal cord injury programs and participate in RHSCIR are considered the leading 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 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.[2]

RHSCIR data showed that 81% 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***. As you'll see in the care pathway on the next page, just under half of the participants enrolled in RHSCIR were initially admitted to a ***non-RHSCIR Hospital***.

ADMISSION TO RHSCIR ACUTE HOSPITAL WITHIN 24 HOURS (%)



[2] 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.

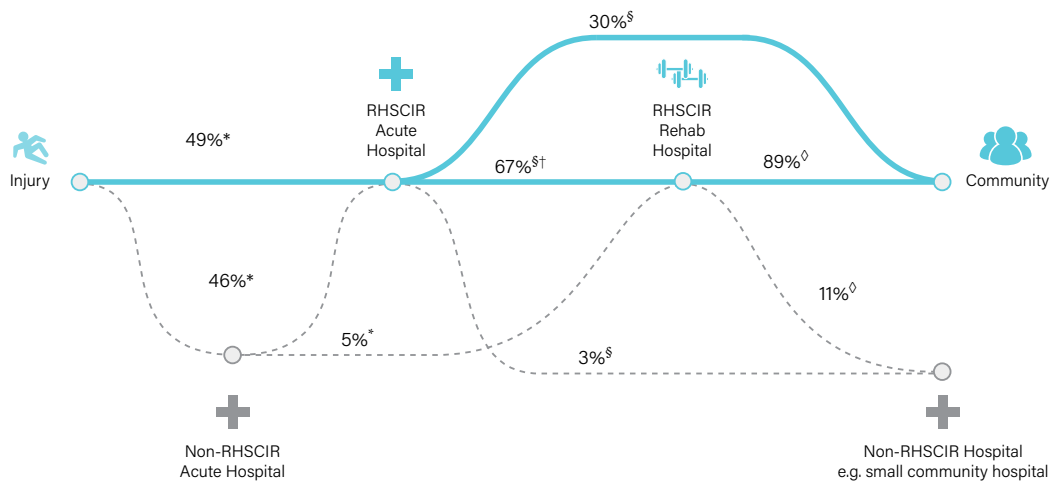
The care pathway is the journey an individual takes from the moment the injury is sustained until that individual returns to the community or is returned to a hospital closer to home. The ideal care pathway for a person who sustains a spinal cord injury is to be admitted as soon as possible to a ***RHSCIR Acute Hospital***, and then, if necessary, admitted to a ***RHSCIR Rehab Hospital*** in order to receive specialized care. In 2018 RHSCIR data, just under half of individuals were admitted to a ***RHSCIR Acute Hospital*** directly after the injury was sustained. Regardless of their care pathway, 82% of individuals received surgery.

For individuals admitted to a ***RHSCIR Acute Hospital***, 67% 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 just under 50% of individuals are walking independently with or without an aid.

Mortality during the initial ***RHSCIR Acute Hospital*** stay was 8.6%. Only individuals who survived their injury and acute hospital stay are included in the care pathways below.

CARE PATHWAY VISUALIZATION



* 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, 11% went to the community or to another hospital to wait for RHSCIR rehab

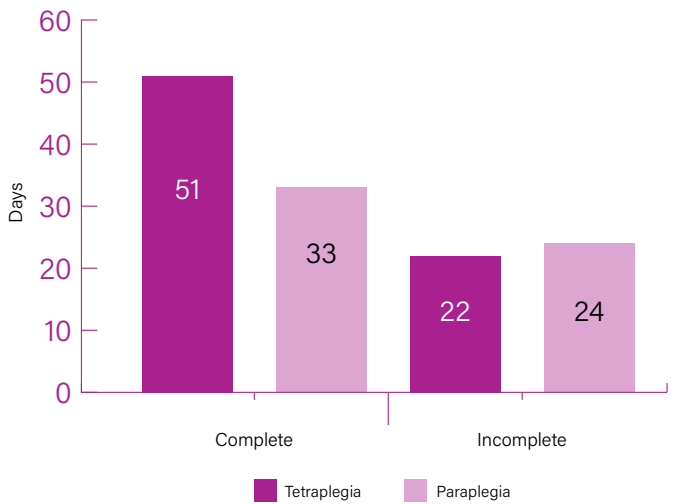
WHAT IS THE DURATION OF THE HOSPITAL STAY?

8

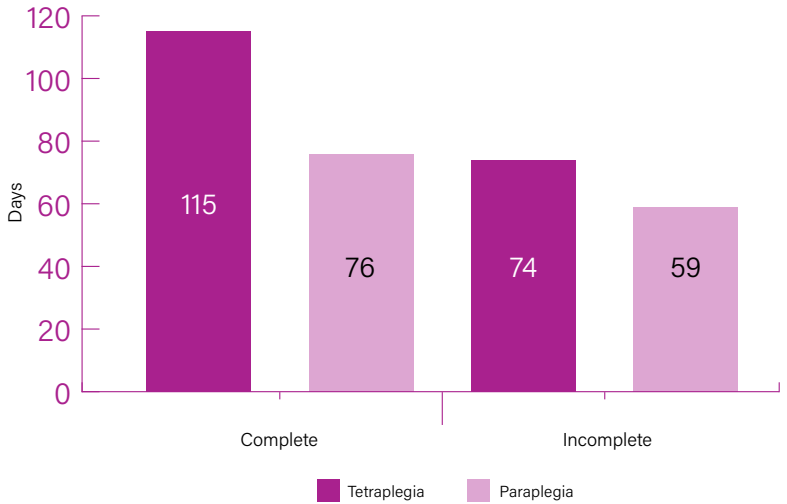
RHSCIR captures length of stay during the acute and rehabilitation admission. In 2018, the average number of days spent in acute care following a traumatic SCI was 24 days for individuals with incomplete paraplegia, 33 days for individuals with complete paraplegia, 22 days for individuals with incomplete tetraplegia and 51 days for individuals with complete tetraplegia.

The average length of stay for those who were admitted to a ***RHSCIR Rehab Hospital*** was 59 days for those with incomplete paraplegia, 76 days for those with complete paraplegia, 74 days for those with incomplete tetraplegia and 115 days for those with complete tetraplegia. The average length of stay for incomplete injuries in both acute and rehabilitation settings are lower for both paraplegia and tetraplegia.

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



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

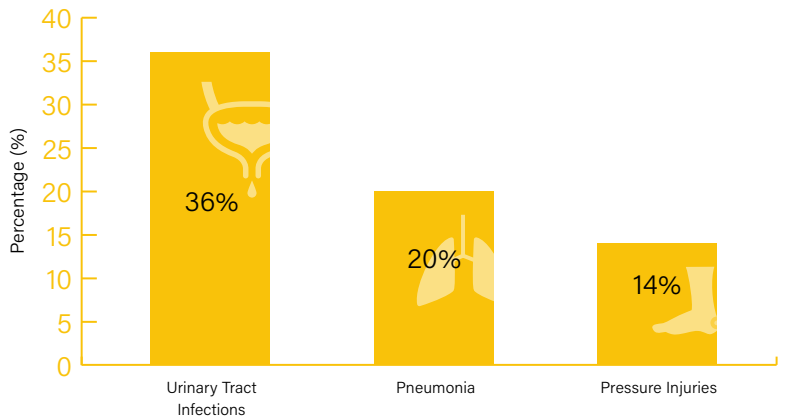


HOW OFTEN DO SECONDARY COMPLICATIONS OCCUR IN ACUTE AND/OR REHABILITATION CARE?

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 people with traumatic SCI experience in the hospital are ***pneumonia***, ***pressure injuries*** and ***urinary tract infections*** (UTIs). These complications can prolong hospitalization; they can also 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.[3]

According to 2018 RHSCIR data, UTIs were the most common secondary complication in hospital, followed by pneumonia, and then pressure injuries (Stages[4] II, III, IV or suspected deep tissue injury as defined by the US National Pressure Ulcer Advisory Panel). In 2018 RHSCIR data, 50% of participants reported the occurrence of at least one of these secondary complications during acute and/or rehab stays. Approximately 17% of individuals with traumatic SCI report multiple secondary complications.

SECONDARY COMPLICATIONS DURING ACUTE AND/OR REHABILITATION CARE



[3] 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.

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

In 2018,

39%

OF RHSCIR PARTICIPANTS

experienced a UTI, pneumonia, and/or pressure injury during their acute hospital stay.

Experiencing one or more of these secondary complications will add on average ~$14,333 to the cost of each acute SCI hospital admission.

Individually this will add

~ $1,841 for UTIs

~ $7,570 for pneumonia

~ $4,922 for pressure injuries

to the cost of each acute SCI RHSCIR hospital admission.[5]

All numbers based on 2015 Canadian dollars and calculated on a sample size of 375 participants for whom we have complete acute complications data available.

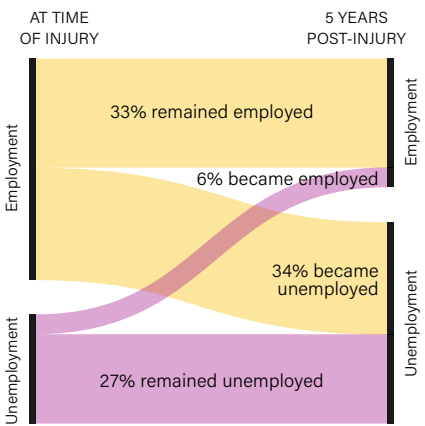
[5] Chan B, Ieraci L, Mitsakakis, N, Pham B, Krahn M. Net costs of hospital-acquired and pre-admission PUs among older people hospitalised in Ontario. Journal of Wound Care. 2013;22(7):341-2, 344-6.
Hellsten EK, Hanbidge MA, Manos AN, Lewis SJ, Massicotte EM, Fehlings MG, Coyte PC, Rampersaud YR. An 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?

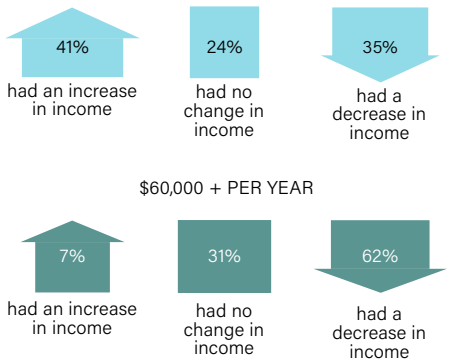
An individual sustaining a traumatic SCI can expect a number of significant life changes including changes in employment status, household income and relationships. The following information provides participant responses recorded at five year post-injury follow-up interviews. The most significant changes occurred in employment status and household income: 34% of individuals who were employed at the time of injury were unemployed after five years, and about half (49%) of participants saw a decline in household income. More than a third of participants with a household income under $60,000 a year saw a decline in income over the same time period whereas nearly two thirds of participants with incomes of $60,000 and above saw a decline in income.

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

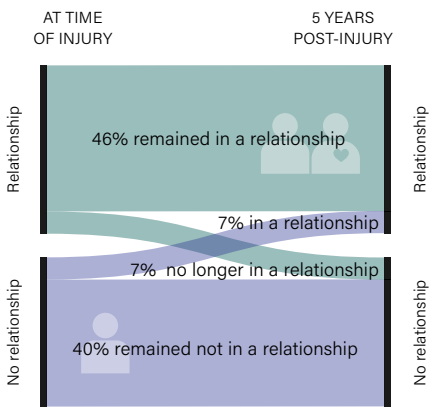
CHANGE IN EMPLOYMENT STATUS
FIVE YEARS POST-INJURY



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 spinal cord 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 half of RHSCIR participants are experiencing secondary complications during their hospital stay. The top three secondary complications in 2018 continue to be UTIs, pneumonia, and pressure injuries.

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. However, RHSCIR data also shows that for the vast majority of individuals, relationship status remains unchanged after the same time frame.

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.

DENOMINATORS FOR REPORT SUMMARIES

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 17, 2019.

Data collected (number of participants injured) in 2018

625 (**299** expanded data set, **48**%)

Number of participants represented in each data summary:

- Age: **625**
- Gender: **625**
- Severity and level of injury: **425**
- Severity and level of injury by age: **425**
- Mechanism of injury: **415**
- Mechanism of injury by age: **415**
- Time to RHSCIR admission within 24 hours: **357**
- Care pathway: **505**
- Surgery: **397**
- Independent walking: **228**
- Length of stay in acute: **258**
- Length of stay in rehab: **195**
- Secondary complications - pneumonia, UTI, pressure injuries: **461**

Number of five year post-injury community follow-up interviews completed between 2015 and 2018:

- Employment: **411**
- Income: **275**
- Relationship status: **407**

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.

Pneumonia
An infection in the lungs.

Pressure ulcer/injury
Damage to skin and underlying 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 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 has a specialized spinal cord injury services and participates in RHSCIR.

RHSCIR Rehabilitation Hospital
A rehabilitation hospital that has a specialized spinal cord injury services 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
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 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.

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

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