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 5,400 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 2015** is a detailed look at some of the clinical and demographic data collected from **681 new RHSCIR participants in 2015**.

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 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 13.

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

In order to better understand the complex needs of individuals who sustain a traumatic SCI, the Rick Hansen Spinal Cord Injury Registry (RHSCIR) was created from the vision of two men: Canadian icon and Paralympian Rick Hansen and renowned spine surgeon and researcher, Dr. Marcel Dvorak. With 31 participating facilities in major Canadian cities, RHSCIR includes more than 5,400 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.

The **most vital and fundamental component of RHSCIR is its contributors – people with traumatic SCI.** Their continued participation determines the value and success of RHSCIR.
The average age of RHSCIR participants was 50.8 years old in 2015. 76% of participants were male and 24% were female.

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

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 total lack of sensory and motor function below the level of injury. In comparing the two graphs above, **incomplete tetraplegia** was more prevalent in individuals over 65 years old. This may be due to the nature of the injury (such as a fall from a short distance).
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 59 years old.

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

About half the time, participants enrolled in RHSCIR were initially admitted to a non-RHSCIR Hospital. However, 2015 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.\(^1\)

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 2015 RHSCIR data, just under half of individuals were admitted to a RHSCIR Acute Hospital immediately once the injury was sustained.

The majority (71%) 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 3%. Only individuals who survived their injury and acute hospital stay are included in the care pathways below.
RHSCIR captures length of stay during the acute and rehabilitation admission. For 2015, the average number of days spent in acute care following a traumatic SCI was 27 days for individuals with paraplegia and 39 days for individuals with tetraplegia.

The average length of stay for those who were admitted to a RHSCIR Rehab Hospital was 67 days for paraplegia and 98 days for tetraplegia.
Secondary complications refer to the range of conditions that occur after sustaining the initial injury. People with a 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 2015 RHSCIR data, UTIs were the most common secondary complication in hospital, followed by pneumonia, and then pressure ulcers (Stages II, III, IV or Suspected deep tissue injury as defined by the US National Pressure Ulcer Advisory Panel). In 2015 RHSCIR data, 57% of participants reported the occurrence of at least one of these secondary complications during acute and/or rehab stays. Approximately 27% of individuals with traumatic SCI reported multiple secondary complications.

\[\text{Stage 1 pressure ulcers were not included in this analysis because the pressure ulcer is not considered severe enough to affect outcomes.}\]
An individual sustaining a traumatic SCI can expect a number of significant life changes including changes in employment status, household income and relationships. The following information provides participant responses recorded at five-year follow-up interviews. The most significant changes occurred in employment status and household income: just over half of individuals who were employed at the time of injury were unemployed after five years. Just over half of the participants who were making $60,000+ prior to injury saw a decline in income over the same time frame. On the other hand, at five years post-injury, relationship status does not appear to be significantly impacted by the injury.
Note: RHSCIR collects both a core data set (restricted data set for both consented and non-consented participants) and an expanded data set for consented participants only. The RHSCIR data used for this report was extracted on June 28, 2017.

<table>
<thead>
<tr>
<th>Data collected (number of new injuries) in 2015</th>
<th>Number of five-year post-injury community follow-up interviews completed between 2012 and 2015:</th>
</tr>
</thead>
<tbody>
<tr>
<td>681 (394 expanded data set, 58%)</td>
<td>Employment: 229</td>
</tr>
<tr>
<td></td>
<td>Income: 178</td>
</tr>
<tr>
<td></td>
<td>Relationship Status: 253</td>
</tr>
</tbody>
</table>

Number of participants represented in each data summary:

- Age: 679
- Gender: 679
- Paraplegia vs Tetraplegia: 483
- Complete vs Incomplete: 514
- Mechanism of Injury: 621
- Mechanism of Injury by Age: 621
- Time to RHSCIR Admission within 24 Hours: 567
- Care Pathway: 619
- Length of Stay in Acute: 431
- Length of Stay in Rehab: 347
- Secondary Complications – Pneumonia, UTI, Pressure Ulcers: 631
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
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 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
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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