The Rick Hansen Spinal Cord Injury Registry (RHSCIR) is a national SCI Registry that enters SCI patients from acute-care centers across Canada.

For networks that are establishing SCI registries, the experiences and lessons learned in the development of RHSCIR may provide useful insights and guidance [1)].

The Rick Hansen SCI Registry (RHSCIR) is a pan-Canadian prospective observational registry of individuals sustaining a traumatic spinal cord injury.

There are 31 sites – major Canadian acute care and rehabilitation hospitals – that collect patient data for the Registry. In addition, international collaborations are underway in China, New Zealand, Israel and others.

This registry links clinicians, researchers, and health care administrators with the goal of improving both research and clinical practice for individuals with SCI. The registry helps to facilitate the translation of research into clinical practice and to promote evidence-based practices.

There are over 5,000 individuals with traumatic SCI participating in the Registry.

The Registry is located in 15 major cities across Canada.

How many people sustain a traumatic SCI each year? What was the cause of their injury and how severe was it? What treatments result in better outcomes? What piece of equipment will have the greatest impact on a patient's recovery?

Ideally, every researcher, clinician and healthcare administrator would have access to this type of information. Questions like these are the reason that the Rick Hansen SCI Registry was established.

By collecting a person's demographic information (age, date of injury, sex, location, etc.) and clinical data (level and type of injury, admission and discharge dates, complications etc.), it enables researchers and healthcare providers to answer critical questions about care including evaluating how their patients are being treated and helping identify how to improve SCI care at their facility.

With a condition that varies as much as SCI does from person to person, data platforms and registries are one of the only ways to study the many variations and complications and outcomes of such an infrequent, high-cost medical condition across a dispersed population like Canada's. Without such research, there is no way to know how to improve care or bring new therapies into practice.

To predict the feasibility of conducting clinical trials of acute SCI within Canada, Thibault-Halman et al., have applied the inclusion/exclusion criteria of six previously conducted SCI trials to the RHSCIR dataset and generated estimates of how many Canadian individuals would theoretically have been eligible for enrollment in these studies. Data for SCI cases were prospectively collected for RHSCIR at 18 acute and 13 rehabilitation sites across Canada. RHSCIR cases enrolled between 2009-2013 who met the following key criteria were included: non-penetrating traumatic SCI; received acute care at a RHSCIR site; age >18- <75 years, and had complete admission single neurological level of injury data. Inclusion and exclusion criteria for the Minocycline in Acute Spinal Cord injury (Minocycline), Riluzole,

Surgical Timing in Acute Spinal Cord Injury Study (STASCIS), Cethrin, Nogo antibody study (NOGO) and Sygen studies were applied retrospectively to this dataset. The numbers of patients eligible for each clinical trial were determined. 2166 of the initial 2714 cases (79.8%) met the key criteria and were included in the dataset. Projected annual numbers of eligible patients for each trial was: Minocycline 117 cases; Riluzole 62 cases; STASCIS 109 cases; Cethrin 101 cases; NOGO 82 cases; and Sygen 70 cases. An additional 8.0% of the sample had a major head injury (GCS≤ 12) and would have been excluded from the trials. RHSCIR provides a comprehensive national dataset which may serve as a useful tool in the planning of multicentre clinical SCI trials [2].

1)

Noonan VK, Kwon BK, Soril L, Fehlings MG, Hurlbert RJ, Townson A, Johnson M, Dvorak MF; RHSCIR Network. The Rick Hansen Spinal Cord Injury Registry (RHSCIR): a national patient-registry. Spinal Cord. 2012 Jan;50(1):22-7. doi: 10.1038/sc.2011.109. Epub 2011 Nov 1. PubMed PMID: 22042297.

2)

Thibault-Halman G, Rivers CS, Bailey C, Tsai E, Drew B, Noonan V, Fehlings M, Dvorak MF, Kuerban D, Kwon BK, Christie S. Predicting recruitment feasibility for acute spinal cord injury clinical trials in Canada using national registry data. J Neurotrauma. 2016 Sep 14. [Epub ahead of print] PubMed PMID: 27627704.