Te Whatu Ora
Health New Zealand

NZ Spinal Cord Injury Registry
Te Rēhita Whara Aho Tuaiwi ā-Motu

An Insider's Guide to NZSCIR Data

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Outline

NZ Spinal Cord Injury Registry
Te Rēhita Whara Aho Tuaiwi ā-Motu

- NZSCIR background
- How does it work?
- Te Tiriti obligations
- What is collected?
- Data use
- Annual reporting and website
- Data Access Processes
- Dashboards

NZSCIR background

- ACC SCI Action Plan 2014 - 2019
- Pilot study 2014 - 2015
- Partnership with Canadian Rick Hansen Institute (RHSCIR), now Praxis Institute
- Commenced data collection on August 1st 2016
- Governance Group led
  - Consumers, clinicians, service leaders, ACC, researchers and Praxis

He Kaupare. He Manaaki. He Whakaora.
prevention. care. recovery.

PRAXIS
Spinal Cord Institute

So how does it work?

Admission to either supra-spinal service (MMH/ASRU or ChCh Hosp/BSU) with a SCI or CE

MINIMAL dataset collection

OR

Consent for FULL dataset collection

Data Collection

- Acute + Rehab phase by Coordinators + clinicians
- Community Follow-Up @ 18 months and 5yrs+

Other Collection points:

- Historical MDS 2007-2016
- Community opt in

Te Tiriti obligations

Aiming to improve consent rates and use of data to address important issues for Māori

- **Te Reo Māori patient information booklets**
- **Māori partnerships (TAMA)**
- **Creating Māori Advisory Committee**

Translated Patient Information Booklets

Māori

Samoan

Simple Chinese

What is collected?

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Fully consented acute and rehab data set includes:

- Dates/times of injury/emergency details
- Dates/times of admission/discharge at each facility
- Demographic & socioeconomic details
- Medical history
- Interventions (traction/tracheostomy)
- Surgical information
- SCIM scores

Based on International SCI Data Sets

- Neurology data (AIS & SNL)
- Complications (respiratory, UTI, pressure areas)
- Urology interventions/diagnosis
- Physio measures (respiratory & mobility)
- OT data (equipment, ADLs)
- Nursing data (pressure injuries, bladder/bowel)
- Interviews incl. Self-efficacy, pain, services used

Community Follow Up questionnaire at 18mths, 5 years, 10 years+

Data use

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- Six annual reports released
- 10 year historical data analysis and pain papers published
- 5 year (2017-2021) report underway
- Pressure injury and Canadian comparison papers underway
- Clinician and Service audits
- In-services/Conferences/Presentations

NZST Website

www.nzscir.nz

- NZ Spinal Trust agreement
- Host our webpages
- Contains publicly available annual reports
- Offers opt in registration
- Point of contact for any queries

Annual Reports

Available at: www.nzscir.nz

Publications

EDITORIAL

New Zealand Spinal Cord Registry: a new milestone

Christine Howard-Brown, Ian Civil

The Ministry of Health, in its Tertiary Services Review in 1995, identified a number of issues specific to spinal cord impairment (SCI) rehabilitation.[1]

These issues included variable acute care outcomes, an inability to compare data between the two spinal rehabilitation services, and a need for agreed quality measures, together with a method to collect and share them.

Now, more than 20 years later, acute care, and longer-term outcomes for people with SCI are still not systematically collected, and rehabilitation data collection is limited to inpatient data using the Australasian Rehabilitation Outcomes Centre (AROC) register.[2] This means little is known about the true incidence of SCI in New Zealand, or the acute clinical and longer-term outcomes for people with SCI.

The clinical challenges that stem from the absence of a structured SCI registry have been noted by many New Zealand researchers.[3-9] The benefits of clinical registries to systematically collect data has a growing evidence base, demonstrating their value as key instruments for improving patient care, achieving optimal social, economic and quality of life outcomes, supporting health care planning, and for developing clinical research priorities.[10]

As suggested in the paper by Smaill et al in this issue of the *New Zealand Medical Journal*, the benefits of a national SCI registry could also greatly inform planning and delivery of services through improving data access on an otherwise hidden population of people ageing with SCI.

The impetus for a SCI registry has grown and is recognised in the New Zealand Spinal Cord Impairment Action Plan 2014–2019.[11]

The Action Plan, which has eight objectives, includes establishing a national SCI registry as a key activity which will contribute to achieving the best possible health and wellbeing outcomes for people with SCI.

As part of the implementation of the Action Plan, the Burwood Spinal Unit and Burwood Academy of Independent Living completed a 12-month feasibility pilot of two international registries.12 The pilot recommended adoption of the Rick Hansen Spinal Cord Injury Registry (RHSCIR), a pan-Canadian prospective observational registry which is principally funded by the Federal Government of Canadian (Health Canada, Western Economic Diversification Fund). The Action Plan governance group endorsed the pilot's recommendation, which has resulted in sustainable funding from ACC, Counties Manukau and Canterbury District Health Boards for establishing and maintaining a New Zealand RHSCIR. Over the last few months, a registry governance group and two coordinator registry positions have been established, as well as a formal arrangement entered into with RHSCIR. RHSCIR is also working with the New Zealand registry governance group to enable inclusion of non-traumatic spinal cord impairment data and long-term follow-up data, as data collection currently covers each new acute hospital admission to discharge from rehabilitation services. With ethics approval, *a priori* questions and data points confirmed, data entry will commence on 1 August 2016.

This marks an important milestone in the management of SCI in New Zealand, as the NZRHSCIR will support evidence-based quality improvement, including international benchmarking and presents unparalleled research opportunities.

ARTICLE

Epidemiology of traumatic spinal cord injury in New Zealand (2007–2016)

John Mitchell, Joanne Nunnerley, Chris Frampton, Tracey Croot, Alpesh Patel, Rowan Schouten

ABSTRACT

AIM: To investigate the epidemiology of traumatic spinal cord injury (TSCI) in New Zealand over a 10-year period.

METHODS: Ambispective data of all new patients admitted to New Zealand's two spinal rehabilitation units between January 2007 and December 2016 (n=929) were collated. Variables assessed included age at injury, gender, ethnicity, date of injury, aetiology, length of hospital stay, injury level, neurological status on discharge and discharge destination.

RESULTS: The incidence of TSCI averaged 22 (95% CI 21–24) per million, increasing 6% a year. The average incidence for Māori (29 per million people (95% CI 25–34)) was 1.8 times higher than New Zealand European (16 per million people (95% CI 15–18)), and show an increase of 14% a year. The median age of TSCI increased from 43 to 48 years. Overall, falls (32%), transport (32%) and sports (22%) were the most common causes of TSCI. Cervical TSCI (54%) were most common, particularly in older adults (70% over 75 years) and Māori (61%) and Pacific Island (72%) patients. Surgical rates remained stable (77%) but length of stay in hospital decreased over the study period.

CONCLUSIONS: The demographic of TSCI is changing in New Zealand. The median age of patients is increasing, as is the incidence, particularly for women, older adults and Māori patients.

A traumatic spinal cord injury (TSCI) is a life-changing event for an individual and their family/whānau. Vast costs are also associated with the extensive treatment, rehabilitation and lost productivity incurred.[1] The incidence for TSCI varies worldwide.[2,3] Recent multinational studies also suggest demographics are changing over time, with an increasing median age of TSCI and higher incidence in older adults.[3,4]

Previously published data on the epidemiology of TSCI in New Zealand is limited but suggests it may have one of the highest rates of TSCI in the western world, particularly among Māori and Pacific Islanders.[5,6] Understanding the demographics of this specific cohort will support healthcare planning, shape clinical research priorities and assist patient care to achieve optimal quality of life, social and economic outcomes.

The aim of this study is to utilise the newly established New Zealand Spinal Cord Injury Registry (NZSCIR) to better understand the epidemiology and demographic trends of patients admitted for spinal rehabilitation following TSCI in New Zealand over a 10-year period, from January 2007 to December 2016.

Methods

Patient population and the NZSCIR

Currently two centres provide spinal injury rehabilitation care in New Zealand, the Auckland Spinal Rehabilitation Unit (ASRU) and the Burwood Spinal Unit (BSU, Christchurch). The units were established with the aim that each location will serve half of the total New Zealand population (currently 4.69 million, 2018 census); however, due to the skewed population distribution in New Zealand the geographical catchment areas of each centre varies. The ASRU covers injuries sustained in the upper North Island, while the Burwood Spinal Unit (BSU) covers the lower North Island and the whole of the South Island.

The impact of pain on function after spinal cord injury

Jae Hong Ryu, Hannah Joyce, Christin Coomarasamy, Jessica Ozumba, Victoriya Semikina, Suresh Subramanian

ABSTRACT:

AIM: Pain is a common complication of spinal cord injuries (SCI). Our objective was to quantify those who had pain on discharge from rehabilitation, and the level of interference it had on their functionality.

METHOD: This study used data collected prospectively from 2018 to 2019 via the New Zealand Spinal Cord Injury Registry (NZSCIR). Questionnaires completed by patients on discharge provided the necessary data. Primary outcomes were the number of patients reporting pain, and the level of interference with their activities of daily living (ADLs), mood and sleep. Level of interference was quantified via a score from zero to 10. Scores of seven and above were considered "severe" interference.

RESULTS: Seventy-six-point six percent of patients in this study group reported having pain on discharge. The median scores for interference with functionality were all three out of 10. Twenty-three-point eight percent of patients reported severe interference with sleep, 16.7% with ADLs and 16.2% with mood.

CONCLUSION: The number of patients being discharged with pain from SCI rehabilitation units in New Zealand is similar to figures from other literature. Although significant functional impairments were not found overall, focus remains to optimise management for patients who do report "severe" interference.

In New Zealand, the most recent figures for the mean annual incidence of traumatic spinal cord injuries (TSCI) over a 10-year period has been found to be 22 per million people.[1] This has decreased from the previously estimated rate of 49 per million from 1998; however, it is difficult to gauge where this new estimate lies in the global context, given the wide variability of figures.[2,3] From the New Zealand Spinal Cord Injury Registry (NZSCIR) Annual Report in 2020, it was reported that the incidence rate of TSCI and non-traumatic SCI (NTSCI) combined was 44 per million. Local studies have also shown disparities in the incidence of TSCI in New Zealand, with more people of Māori and Pacific Island ethnicities having higher rates of injuries compared to others.[3,4]

Among patients with spinal cord injuries (SCI), one of the most prevalent chronic complications is pain.[5-7] A systematic review and meta-analysis by Hunt et al. classified chronic pain post-SCI using the International Spinal Cord Injury Pain (ISCIP) classification, and reported neuropathic pain in 79% of patients, musculoskeletal pain in 58% and visceral pain in 3%.[8] Fifty four percent reported two or more types of pain. The pooled prevalence in this meta-analysis was 68%. Consequently, pain can hinder patients' rehabilitation and their transition into community as it affects quality of sleep, ability to return to paid employment, mood and anxiety levels and social connectedness.[9-12]

Our study's primary objective was to determine the proportion of patients who reported pain on discharge, with a particular focus on how pain impacted their activities of daily living (ADLs), mood and sleep. The secondary objectives were to assess their satisfaction with pain management, and the relationship between pain and patient demographics such as ethnicity, age, level of injury, severity of injury (The American Spinal Injury Association (ASIA) Impairment Scale) and type of SCI (TSCI vs NTSCI).

The outcomes of this study hope to guide future decisions in community programmes and rehabilitation systems that can be established to support patients with a SCI after discharge. It will also contribute to the way that pain is discussed prior to discharge so that patients and their whānau feel more equipped for the transition.

Method

This was a retrospective study that used data collected prospectively of patients who sustained either a TSCI or a NTSCI and were admitted to one of the two spinal rehabilitation units in New Zealand. The rehabilitation units in New Zealand are the Auckland Spinal Rehabilitation Unit (ASRU) and the Burwood Spinal Unit (BSU). The ASRU admits

Pressure injury and Canadian comparison papers underway

Data use opportunities

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- Improve patient outcomes by informing policy planning & clinical practice
- Opportunity for ASRU/BSU interactions
- Provide insight into quality improvement initiatives
- Ongoing research

Access to data

- **Multi-level**
  - Annual report or dashboard aggregate data available for service/presentation/conference use
  - Clinicians access to their own identifiable data for audit (single site)
  - Researchers request for project feasibility
  - Clinicians/researchers may apply for national identifiable data with ethics approval
- **HDEC changes for St John MOU (2020) & release of identifiable data (post July 2022)**
- **Different level of sign off dependent on type of data requested**

Data Access Processes

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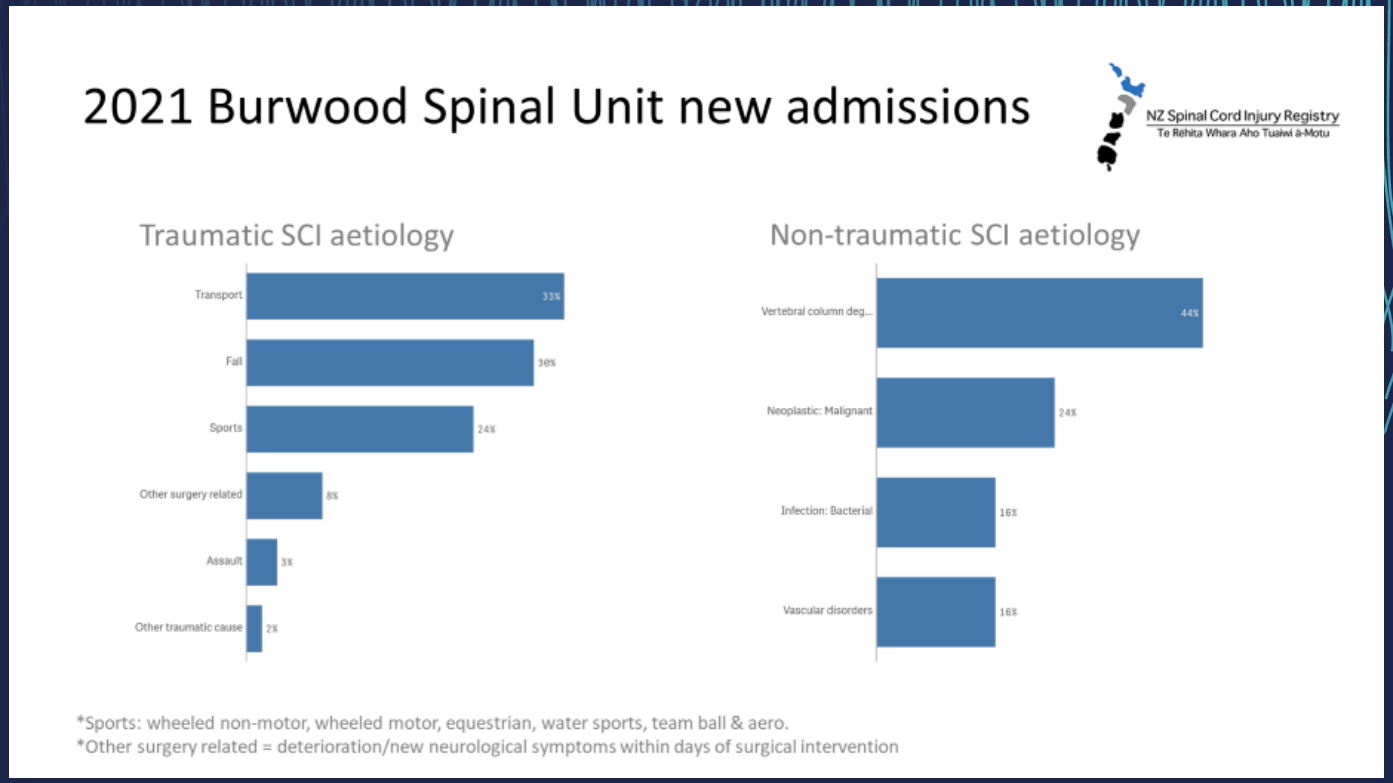
- **PowerPoint slides for presentations**



Data Access Processes

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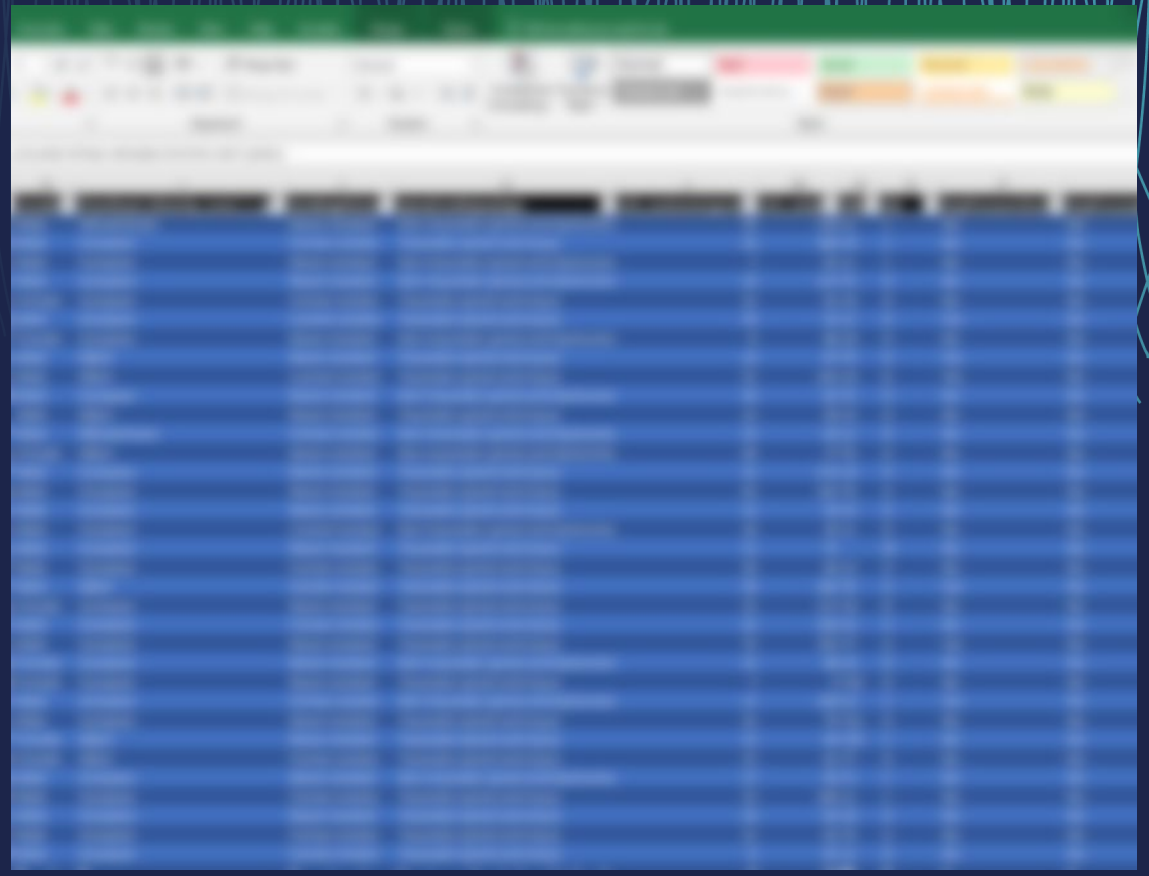
- Excel spreadsheets for audit purposes



Dashboards

NZ Spinal Cord Injury Registry
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- **Built by Praxis**
- **QlikSense platform**
- **Will be integrated into new Praxis Connect platform in 2024**
- **<u>Interactive</u> data updated monthly for:**
  - service updates
  - answering clinical/service questions
  - research feasibility queries
  - data cleaning

Qlik®

Dashboards

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- Demonstration of

Ngā mihi nui.
Any questions?

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Contact us

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