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Title: Data capture of historical spinal cord injuries into the New Zealand Spinal Cord Injury Registry

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Introduction: The New Zealand Spinal Cord Injury Registry (NZSCIR) is a recently developed national registry collecting information on patients admitted to the Burwood Spinal Unit (BSU) or the Auckland Spinal Rehabilitation Unit (ASRU) with a new spinal cord or cauda equina injury, resulting in a motor or sensory deficit. It covers all traumatic and non-traumatic spinal cord injuries (SCIs). Data collected includes demographics, hospital admissions, injury aetiology, severity and clinical outcome measures. This registry was established in conjunction with the Rick Hansen SCI Registry in Canada, however NZ is the only country in the world that includes non-traumatic SCI data. The NZSCIR will be used to identify SCI trends, including at risk populations and high risk activities.

Aim: To enrol and enter minimal data set information on all persons with a new SCI admitted to the BSU in the decade prior to the establishment of the NZSCIR (between the 1st January 2007 and 1st August 2016).

Method: Information was gathered using patient medical records at the BSU, and the CDHB Health Connect South (HCS) database. A two-stage process occurred.

1. Each new BSU patient admitted during the last decade was enrolled into the registry using name, gender, date of birth, NHI number, type and date of injury.

2. A further minimal data set was collected for enrolled patients, using medical records and databases. The data set included all hospital admission and discharge dates surrounding the SCI, as well as the injury aetiology i.e. the manner in which the injury occurred. Traumatic injuries were broken down into subgroups: Sports, Assault, Transport, Fall, Other traumatic cause (e.g. surgery related), Non-traumatic, or Unknown.

Non-traumatic spinal cord dysfunctions were further defined under multiple acquired conditions including cancer, viral infection, and vascular infarcts.

Results: Throughout this project I enrolled 775 patients and completed 202 minimal datasets on traumatic SCI admission from 2011-2016.

Results from enrolments (total 775)

Gender	Male: 558 (72%)	Female: 217 (28%)
Type of Injury	Traumatic: 565 (73%)	Non-traumatic: 209 (27%)

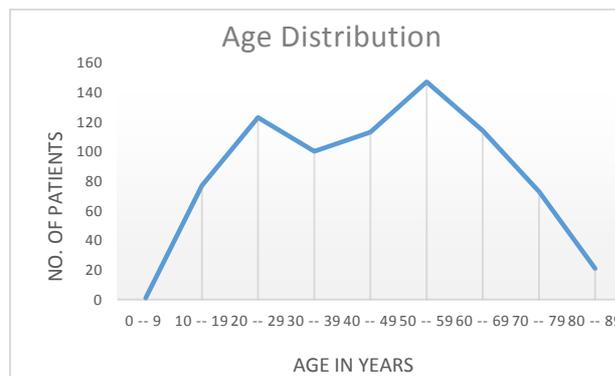


Fig. 1. Age distribution of BSU enrolments

SCIs were most commonly sustained between the ages of 20-29 (123 admissions) and 50-59 (147 admissions). A bimodal age distribution is observed (see Fig 1), and also seen internationally. Those in their 20s sustained more transport related injuries, whilst those in their 50s sustained more injuries from falls.

Results from minimal data sets (total 202)

	2011	2012	2013	2014	2015	2016
<i>Sports</i>	9	4	10	8	12	5
<i>Transport</i>	14	14	12	13	22	9
<i>Fall</i>	3	10	5	7	4	13
<i>Other</i>	3	4	6	5	5	4
Total admissions	29	32	34	33	43	31

Fig 2 shows transport is the most common cause of traumatic SCI between 2011-2015, but in 2016, falls became the most common. Sporting-related injuries fluctuate between second and third most common. The most prevalent types of sporting injuries are diving and equestrian. Each cause of injury was broken down further to provide a more accurate description of the injury. Fig 3 shows light transport vehicles (i.e. cars, trucks and vans) account for 60% of all transport injuries. Motor biking is the second most common cause of transport SCI (18%).

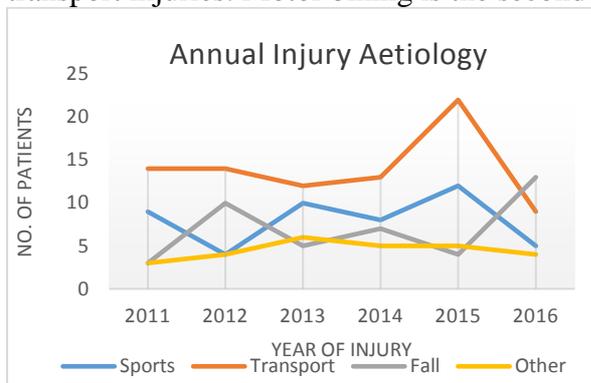


Fig 2. Annual Injury Aetiology 2011-2016

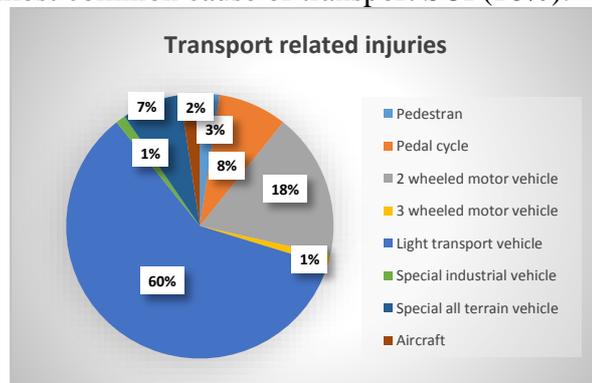


Fig 3. Breakdown of types of transport which cause SCI

Discussion: Some results obtained reflect the current international trends. Globally, men sustain more SCI's, and age has a bimodal pattern (20 and 50 year peaks) which is well documented. Transport is seen internationally as a leading cause for SCIs. We are seeing an increase in the number of fall-related SCIs, and this could be a result of the aging population. This new NZSCIR information will allow NZ researchers to investigate the SCI trends from the last decade.

There were many difficulties associated with obtaining this data. Inconsistencies were observed in hospital admission/discharge dates, date and cause of injury in the majority of files. Any treatment that occurred outside of HCS catchment area was not available, making accurate recording of all inpatient stays difficult. Identifying the first presentation of symptoms for non-traumatic patients was difficult as some had a history of neurology long before hospitalisation, some had inconsistent motor and sensory deficits, and many went through multiple admissions/discharges before being referred to the BSU. My recommendation would be to use first BSU/ASRU admission date for non-traumatic SCI in the NZSCIR, going forward for ease and consistency. I was unable to complete all minimal datasets, including neurology assessments, for all enrolled patients within the timeframe. The magnitude of work required for retrospective data entry is large. Each dataset took approx. 15-20min to complete, but those with complicated histories could take 40min. I have learnt the importance and impact of accurate note taking.

In conclusion, this historical data will be used to compare with current prospectively collected NZSCIR data. The registry will guide future research objectives to help those with SCIs, and inform quality improvement across NZ's SCI services.