

### New Zealand Spinal Cord Injury Registry

# Calendar Year Report 2020



The New Zealand Spinal Cord Injury Registry (NZSCIR) would like to acknowledge the spinal service clinicians and coordinators for collecting and inputting data into the registry. Many thanks to statistician Asheel Ramanlal and Praxis Spinal Cord Institute for their support and expertise in developing this report. And finally, thank you to the participants who are enrolled in the NZSCIR – those with a spinal cord injury – for contributing their time and experiences to the registry.

How to cite this document:

New Zealand Spinal Cord Injury Registry (2021). New Zealand Spinal Cord Injury Registry Annual Summary Report 2020.



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### About this report

Adult acute care, rehabilitation and follow-up services for people with **spinal cord injury** (SCI) are provided in New Zealand (NZ) by two **supra-regional services**. Services are located at Christchurch Hospital and the Burwood Spinal Unit (BSU) in the Canterbury District Health Board (CDHB) and Middlemore Hospital and the Auckland Spinal Rehabilitation Unit (ASRU) within Counties Manukau Health (CM Health).

NZSCIR collects data on adults with **traumatic SCI** (tSCI) and **non-traumatic SCI** (NTSCI) in NZ. The NZSCIR Annual Report 2020 is an overview of the data collected from 214 NZSCIR participants who sustained either a new tSCI in 2020 or were admitted to either supra-regional spinal service 1 January - 31 December 2020 with a new NTSCI.

The data forming the 2020 calendar year covers a time where COVID-19 entered NZ. During the nationwide lockdown, participants were not approached for NZSCIR consent. As a result, more participants had the minimal data set collected compared to 2019.

This report includes information about participant demographics, type of SCI and its causes, length of hospital stay, functional outcomes and secondary complications after SCI. The report aims to serve as a descriptive account with no endorsement of, or recommendations about, policies or programmes. Data may, however, be informative for research and clinical practice, as well as policy and programme 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 facilities.

The NZSCIR governance group welcomes feedback or questions on this report. Please contact either NZSCIR Coordinator at <u>NZSCIR@cdhb.health.nz</u> or <u>NZSCIR@middlemore.co.nz</u>

More information about NZSCIR is available from <u>https://www.nzspinaltrust.</u> <u>org.nz/i-need-information/new-zealand-spinal-cord-injury-registry-nzscir/</u>

Certain terms are bolded throughout this report. Definitions can be found in the glossary on page 14.



### Spinal cord injury and the Registry

#### Spinal cord injury

The cause of the spinal cord damage determines if it is a traumatic injury or non-traumatic spinal cord dysfunction. An injury sustained from a physical impact, such as a fall or motor vehicle crash, is referred to as a traumatic SCI. An injury that occurs in other ways, such as from degeneration, infection or cancer, is referred to as non-traumatic spinal cord dysfunction.

#### About the Registry

The NZSCIR was established in August 2016 and is jointly funded by the Accident Compensation Corporation, CDHB and CM Health, in partnership with Praxis Spinal Cord Institute.

Data collected from the NZSCIR supports service improvements, research and improvements in clinical practice. Together these three activities help enable the best outcomes to be achieved for people with SCI.

A governance group which has representation from consumers, researchers, clinicians, funders and managers ensures the efficient and effective operation of the NZSCIR. Two Registry Coordinators, one employed at each DHB, provide the day to day management of the NZSCIR. The NZ Spinal Trust also provides some back office functions for the NZSCIR.

The NZSCIR has Health and Disability Ethics Committee approval enabling collection of a non-consented minimal data set. Data collected beyond this, including follow-up data, is subject to consent.

#### Contributors

The most vital and fundamental component of NZSCIR is its contributors people with a SCI. Thank you to those who have contributed their time and experiences to the Registry. Their continued participation determines the value and success of NZSCIR.

### What are the causes of spinal cord injuries?

Prior to the establishment of NZSCIR, the NZ incidence of SCI was estimated at 30 per million, with approximately half related to a traumatic injury. The World Health Organization estimates the incidence of SCI is between 40 to 80 cases per million<sup>1</sup>. Based on 2020 NZSCIR data, incidence in NZ is currently 44 per million, a reduction from 46 per million in 2019.

NZSCIR data across 2017-2020 calendar years found 66-68% of spinal cord injuries are traumatic injuries.

#### NZSCIR participants by SCI type 2020 (n=214)



Falls were the most common cause of traumatic injury in 2020. This remains the leading cause since Registry data collection began in 2016. An injury related to a fall can be caused by anything such as a slip to a fall from a height. In the age group 0-30 years, 27% of traumatic injuries were due to falls. This increases dramatically to 92% in the >76 years category. Falls remain the leading cause of tSCI for people aged 46 years and over.

Transport is the leading cause of SCI in those under the age of 45 years which is consistent with 2019 data. 37% of sporting injuries were water-related, such as diving into pools or rivers (down from 50% last year), and 37% from wheeled non-motorsports (mountain biking/cycling), up from 25% last year. There is an increasing trend of wheeled non-motor sports injuries: 19% in 2018, 25% in 2019, and 37% in 2020. 16% of sporting injuries in 2020 were from motor sports. The "Other" category relates to assault, deterioration of function post-surgery, or other non-classified causes.

#### Traumatic spinal cord injury causes (n=145)



The leading cause of non-traumatic dysfunction were **malignant neoplasms** (25%). This has increased from 19% in 2019. Disorders relating to degeneration of the spine were the second most common causes of non-traumatic dysfunction (22%, down from 29% in 2019). The spinal cord is protected by the spinal column. Deterioration of the spinal column, either in the discs, ligaments, joints or bones can lead to spinal cord damage.

Vascular causes (such as haemorrhage or lack of blood flow) account for 17% of NTSCI whilst infection is the cause of SCI in 14% of participants with a NTSCI. These findings are consistent with 2019 data. "Other" causes may include inflammatory, auto-immune diseases or syringomyelia.

Non-traumatic spinal cord dysfunction causes (n=69)

	Vortebral column		000		
Malignant neoplasm	degenerative disorders	Vascular disorders	Bacterial infection	Benign neoplasm	Other
25%	23%	17%	14%	9%	12%
(n=17)	(n=16)	(n=12)	(n=10)	(n=6)	(n=8)

### What does the population look like?

In 2020, males account for 72% of the entire SCI population. This is up from 66% in 2019.

There is an increase in the proportion of males who have non-traumatic SCI dysfunction, 67% compared to 52% in 2019. The proportion of males remains higher in traumatic injury groups, which is consistent every year since the Registry began in 2016.



#### Prioritised ethnicity by SCI type

Using Ministry of Health prioritised ethnicity reporting<sup>2</sup>, most participants (for both tSCI & NTSCI) were of European descent (48%). Māori were more likely to present with tSCI whilst Pacific peoples were more likely to have a NTSCI.

Pacific Peoples include Samoan, Tongan, and Cook Island Māori. Other includes Asian, Middle Eastern, Latin American and African ethnicities. People may choose more than one ethnicity and these are then prioritised for reporting as per Ministry of Health guidelines.



The average age of NZSCIR participants was 55 years old (up from 51 years last year). Of those with tSCI, the international trend of bimodal age distribution is seen, with the first peak being young adults (15 and 29 years), and the second peak occurring among older adults (61-75 years).

The number of people with NTSCI tends to steadily increase with age, peaking at 61-75 years. This trend has been consistent over the past five years.



#### Age group by SCI type

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### What is the severity and level of injury?

The spinal cord has four regions: **cervical**, **thoracic**, **lumbar and sacral**. The level of injury identifies the lowest level of the spinal cord (from the head) that has normal movement and sensation. In the graphs shown, people are grouped into tetraplegia and paraplegia based on their level of injury. Someone with **tetraplegia** has their arms, breathing muscles, trunk and legs affected as a result of a neck injury. Someone with **paraplegia** has their trunk and/or legs affected from an injury to their spinal cord below the neck region (thoracic, lumbar or sacral). All those people with an SCI may have bowel, bladder and sexual function affected. People with **incomplete** injuries at any level may be able to stand or walk, depending on how their spinal cord was affected (see grades below).

Those with a tSCI being more likely to be tetraplegic (67%), whilst 64% of persons with NTSCI are paraplegic. This trend has been consistent since NZSCIR records began in 2016.

Participants' severity and level of injury are routinely assessed throughout their recovery using a standardised assessment form at one of the two supraregional spinal services. The severity is graded in the categories below.

The extent of a participant's SCI is defined by the American Spinal Injury Association (ASIA) Impairment Scale (AIS).

**Grade A:** Impairment is **complete**; no motor or sensory function below injury level. **Grade B:** Impairment is incomplete; sensory function, but not motor function, is preserved below the neurologic level (the first normal level above the level of injury) and some sensation is preserved in the sacral segments S4 and S5.

**Grade C:** Impairment is incomplete; motor function is preserved below the neurologic level, but more than half of the key muscles below the neurologic level have a muscle grade less than 3 (i.e. Insufficient strength to move against gravity).

**Grade D:** Impairment is incomplete; motor function is preserved below the neurologic level, and at least half of the key muscles below the neurologic level have a muscle grade of 3 or more (i.e. the joints can be moved against gravity).

Grade E: Participant's functions are normal; all motor and sensory functions are unhindered.

AIS D remains the most common SCI classification in NZ and has the highest predictability for independent mobility one year post-SCI<sup>3</sup>. In the severity graph shown, data from 2% of all participants were excluded because a full assessment could not be completed.

#### Level of injury on rehab discharge



Severity on rehab discharge (traumatic & non-traumatic)



### What are the length of hospital stays?

NZSCIR captures length of stay (LOS) in acute and rehabilitation settings. The median length of stay across both sites (not shown on graphs) was 16 days in acute care (same as 2019) and 61 days in the rehabilitation service (up from 55 in 2019). As for 2019, those with tetraplegia spent longer in the acute and rehabilitation service (median 76 days compared to 72 days in 2019) than those with paraplegia (55 days compared to 59 days in 2019). In 2020, the median length of stay in rehabilitation for people with tetraplegia was 68 days, up from 61 days in 2019.

Medians are one way to show the middle point of data, but it is important to look at the whole range to understand the full picture. The box and whisker graphs to the right show these ranges.

2020 acute LOS data show greater differences across both sites compared to 2019. For the acute LOS, those with paraplegia had a similar distribution at both sites, compared to the distribution of those with tetraplegia.

The general spread of data show participants in Auckland stayed for longer in the acute phase compared with those in Christchurch. However, for rehabilitation, the graphs show the spread is greater for BSU participants compared to ASRU. This indicates those with paraplegia and tetraplegia stay for longer at BSU, as was also seen last year.



ASRU Acute: 2020 LOS (days) distributions



BSU Acute: 2020 LOS (days) distributions



#### ASRU Rehab: 2020 LOS (days) distributions



#### BSU Rehab: 2020 LOS (days) distributions



### Where do people go after discharge from hospital?

#### Discharge destinations (tSCI & NTSCI)

A private residence in the community was the most common location for discharged participants. "Hospital" indicates ongoing rehabilitation and discharge planning post-supra regional spinal service admission. Discharge destinations remain similar to 2019, with the largest increase showing in those discharging to their local hospital (16% in 2020 compared to 13% in the previous year), as opposed to private residence (65% in 2020 compared to 70% in 2019).



### How many people have surgery and how many walk 100m on discharge?

Rates of surgery are higher in those with tSCI (83% vs 70%) compared to those with NTSCI. Rates of surgery are very similar between the ASRU catchment (80%) compared to the BSU catchment (78%). On discharge from inpatient rehabilitation, 39% of all participants were **independently walking** in the community (classified as someone who is able to walk 100m outdoors unsupervised, with or without a mobility aid). Those with NTSCI were more likely to be walkers in the community (NTSCI 48% vs TSCI 35%), based on complete records of 130 participants.



### How often do secondary complications occur in acute and/or rehabilitation care?

**Pain** on discharge to the community was a commonly reported secondary complication. 66% of participants reported experiencing pain on discharge from rehab. This is the first year the registry is reporting pain in this way. In 2019, the pain data reported was for those who were receiving treatment for pain, which made up 72% of all those with SCI. This year that increased to 80%, based on the records of 123 participants with complete pain data.

**Urinary tract infections** (UTI) had a 17% incidence rate occurring during acute stay and a 35% incidence rate occurring during rehabilitation. Information is based on the records of 138 acute and 131 rehab participants with complete UTI data.

**Respiratory complications** occurred in 21% of participants during the acute phase (tSCI 26%; NTSCI 13%), and 22% during rehabilitation (tSCI 29%; NTSCI 9%). Those with tSCI were much more likely to have respiratory complications compared to those with NTSCI (based on records of 138 [acute care] and 131 [rehabilitation] participants). Of these acute respiratory complications in tSCI, almost three quarters (74%) were pneumonia. 39% of the respiratory complications reported in rehab for tSCI participants were obstructive sleep apnea, whilst pneumonia rates dropped to 48%.

**Pressure injuries** occurred during acute care in 10% of cases based on the records of 128 participants. Pressure injuries occurred during rehabilitation in 20% of cases, also based on the records of 128 participants.

**Pre-injury co-morbidities** reported were similar between the traumatic and non-traumatic SCI participants. The most common co-morbidities were hypertension, followed by diabetes, osteoarthritis, previous malignancy and depression. However, a significant difference is found between tSCI and NTSCI in respect to those with a documented medical history of heavy alcohol use. Of this group, tSCI was 10 times more likely than NTSCI.



### **NZSCIR** provides important information

NZSCIR helps 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. This report represents the fourth complete calendar year of data from the NZSCIR.

With four calendar years available, comparisons can start being made. This includes international trends. Together this data will inform improvements in how SCI is managed in NZ.

NZSCIR will keep evolving to ensure it facilitates world class research, promotes excellence in care and meets the needs of people living with SCI.

Refinements will continue to be made to the data sets and collection methods to gather more complete data moving forward. Dashboards (as shown below) are constantly being improved to ensure data can be visualised, cleaned and analysed to gain insights into NZ's SCI population. Community follow-up data collection is underway, as well as plans to enable more people with SCI to participate in the registry.



### **Denominators for report summaries**

NZSCIR collects an expanded full data set for participants who consented (n=139, 65%) and a minimal data set for those who were not consented (n=75, 35%).

Consents were down from 2019 (77%) due to COVID restrictions. During lockdown, participants were not approached for consent for the full data set. Participants were approached if still an inpatient once the lockdown lifted. Participants were deemed to have complete data if key expected admission and discharge data had been entered into the database. The NZSCIR data used for this report were extracted on 17 November 2021.

### References

- 1. World Health Organisation, 19 November 2013, Spinal cord injury, <u>https://www.who.int/news-room/fact-sheets/detail/spinal-cord-injury</u>. Retrieved November 2021.
- 2. Ministry of Health HISO 10001:2017 Ethnicity Data Protocols. September 2017. Ministry of Health. https://www.health.govt.nz/publication/hiso-100012017-ethnicity-data-protocols. Retrieved May 2021.
- Roberts, T. T., Leonard, G. R., & Cepela, D. J. (2017). Classifications In Brief: American Spinal Injury Association (ASIA) Impairment Scale. Clinical orthopaedics and related research, 475(5), 1499–1504. <u>https://doi.org/10.1007/s11999-016-5133-4</u>



Data collected from 214 persons with new injuries between 1 January 2020 and 31 December 2020 (or those with a first NTSCI rehab admission between these dates).

Number of participants represented in each data summary:

Traumatic SCI vs non-traumatic SCI: 214

Mechanism and cause of Injury: 214

Gender/ Ethnicity/ Age: 214

Pre-existing conditions: 139

Severity and level of injury: AIS 211 and level of injury 213

Surgical intervention rates: 214 (ASRU n=125; BSU n=89)

Walking in the community: 130

Length of stay: 213

Discharge destination: 213

Complications during acute care:

UTI: 138 Respiratory: 138 Pressure injuries: 128

Complications during rehabilitation:

Pain: 122 UTI: 131 Respiratory: 131 Pressure injuries: 128

### Glossary

Cervical spine - The upper seven vertebrae, located in the neck (C1 - C7). The nerves in this area control head and neck movement, the diaphragm, deltoids, biceps, and muscles controlling the wrist and hands.

Complete injury - An injury where there is no sensory and motor function (inability to feel 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).

Independently walking in the community – Classified by physiotherapists as someone who is able to walk 100m outdoors unsupervised, with or without mobility aids.

Lumbar spine - The five vertebrae in the lower back (L1 - L5). Injury to this area damages the very lowermost tip of the spinal cord (known as the conus medullaris) or the cauda equina which results in decreased control of hips and legs, as well as bladder, bowel and sexual function.

Malignant neoplasms - A cancerous tumour. An uncontrolled, abnormal growth of tissue that can spread to other parts of the body.

Non-traumatic spinal cord dysfunction/injury (NTSCI) - A spinal cord injury that occurs as a result of a medical cause such as degeneration, infection or cancer.

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) region or below, including cauda equina. May have bowel, bladder and sexual function affected.

Pressure injuries -Tissue injured by pressure and/or shear forces.

Respiratory complications – Includes pneumonia, venothromboembolic events (including pulmonary embolus and deep vein thrombosis), obstructive sleep apnea and other respiratory conditions.

Sacral spine -The five fused vertebrae located in the pelvic area (S1 - S5). As with lumbar injuries, damage to the sacral nerves can result in decreased control of hips, legs, bladder, bowel and sexual function.

Supra-regional spinal service/facility - NZ has two supra-regional spinal services and four facilities. Canterbury District Health Board: Christchurch Hospital (acute) and Burwood Spinal Unit (acute/rehabilitation). Counties Manukau Health: Middlemore Hospital (acute) and Auckland Spinal Rehabilitation Unit (rehabilitation).

Spinal cord injury (SCI) - Damage to the spinal cord resulting in impairment of muscle function, sensation and/or autonomic function (bowel, bladder and sexual function).

Tetraplegia or Quadriplegia - Complete or partial loss of sensation and/or movement in the arms, and typically in the trunk and legs. May have bowel, bladder and sexual function affected. It is caused by an injury to the spinal cord in the neck.

Thoracic spine - The twelve vertebrae that extend through the chest area (T1 - T12). The nerves in this area control chest and abdominal muscles.

Traumatic spinal cord injury (tSCI) - A spinal cord injury that occurs as a result of trauma such as a fall, a motor vehicle crash or sporting injury.

Urinary Tract Infection (UTI) - A bacterial infection of the urinary tract, treated with antibiotics.



NZSCIR is sponsored by the Accident Compensation Corporation, Canterbury DHB and Counties Manukau Health

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