

# Evidence and utilisation of spinal cord injury services in NSW

AUGUST 2020

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Produced by: NSW State Spinal Cord Injury Service

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Preferred citation: NSW Agency for Clinical Innovation. *Evidence and utilisation of spinal cord injury services in NSW: Evidence Series*. Sydney: ACI; 2020.

SHPN (ACI) 190018

ISBN 978-1-76081-068-9

Version: V0.1; ACI0180 [08/20]

Trim: ACI/D20/1183

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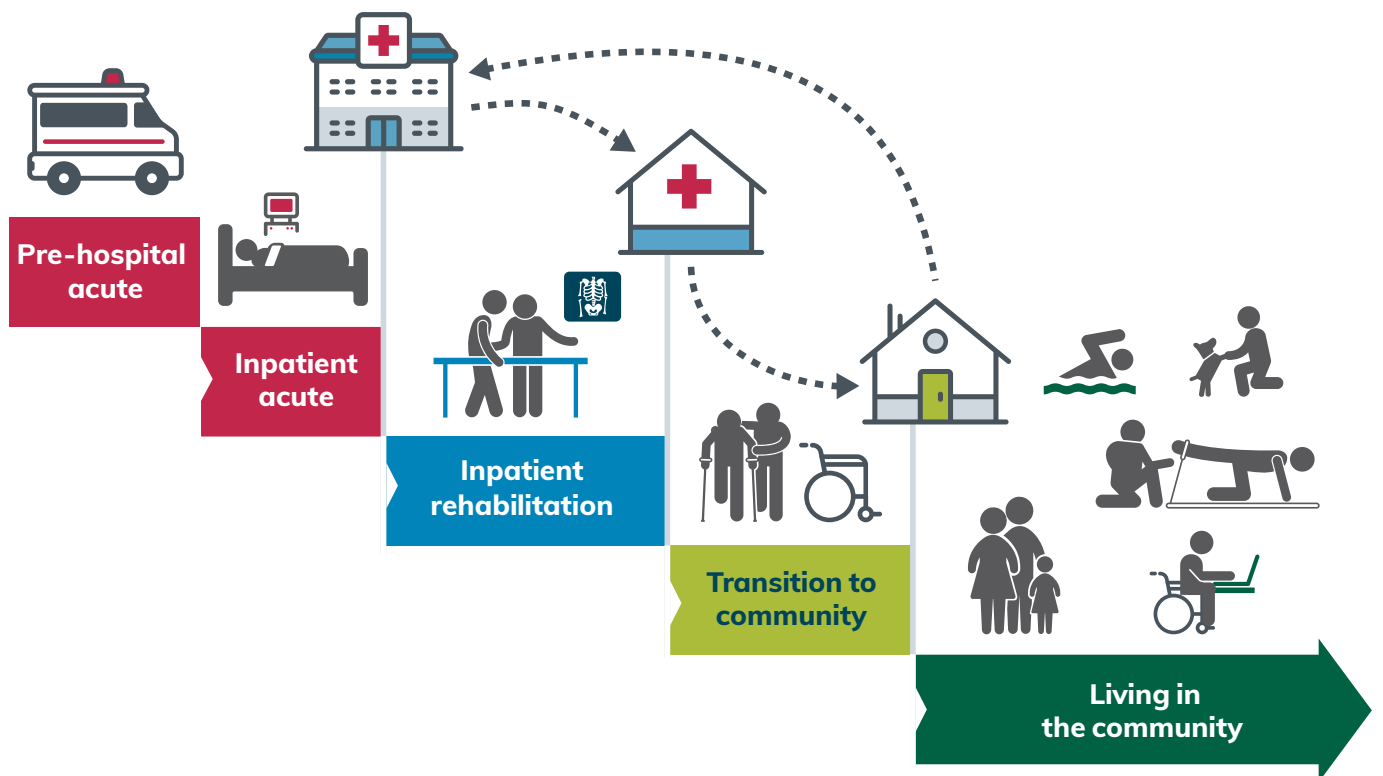
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# The continuum of care over the lifespan of a person with spinal cord injury

## At a glance

The profound, life-changing consequences associated with spinal cord injury can be addressed or compensated for with the right access to specialist support, services and equipment.

Comprehensive care across life stages requires ongoing access to highly specialised services, with an interdisciplinary approach to address medical, physical, functional, psychological, social, vocational and leisure issues.



# Foreword

Experiencing a spinal cord injury is a life-changing event that can impact every aspect of the injured person's life, and the lives of their family and friends. The injury, whether the result of trauma or disease, leads not only to impairment or loss of sensation and muscle movements, but also affects bladder, bowel, sexual function, as well as control over other vital organs. In addition to more obvious physical effects, the injury requires psychological adaptation and adjustment to cope with new life challenges; all of which can have profound effects on a person's health and wellbeing, functioning, ability to participate in everyday activities and quality of life.

A spinal cord injury also marks the start of an ongoing relationship between a patient and the healthcare system. In 2017-18, 344 people sustained a new serious spinal cord injury, and there were an estimated 5,500 people living with an existing spinal cord injury in NSW (690 per million population), based on hospital records from 2001-02 onwards.\*

Effectively addressing the often complex, lifelong needs of people with a spinal cord injury involves an integrated network of services spanning acute and subacute rehabilitation and community settings. Across this continuum, there is a particular imperative to provide safe care – as we know that people with spinal cord injury are at particular risk of infections and other preventable, serious complications. We also know that improved patient outcomes are associated with timely access to evidence-based urgent, intensive medical and surgical care in the acute phase; availability of specialist facilities with expertly trained staff in the rehabilitation phase; and ongoing care and support in the community.

Delivering the best spinal cord injury care in partnership with patients requires a system-wide effort. Key roles are played by supra local health district specialist services and by outreach and community-based services across the metropolitan and rural areas of the state. Integration across services, interagency collaboration, redesign methods and co-design will all play an important role in effective planning of services and delivery of care. Looking forward, improvements in clinical practice and patient outcomes will also rely on translational research and implementation science.

Many trials of new technologies and therapies targeting neuroprotection, repair and restoration of function are underway worldwide. However, at this point in time, improvements in patient outcomes are optimised through participation in targeted specialist rehabilitation.

It is clear that access to specialist rehabilitation is restricted by the total number of beds available, as well as inefficiencies in patient flow resulting from the National Disability Insurance Scheme and My Aged Care processes.

This report highlights the need to redesign the way we deliver care to people with spinal cord injury in NSW to address current gaps, challenges and ensure equitable access to specialist care or specialist guided care.

The potential to explore innovative models of care delivery, incorporating telehealth and specialist guided care, provides an opportunity to enhance system capacity.

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# Evidence and utilisation of spinal cord injury services in NSW

# Summary

Spinal cord injury refers to persistent damage to neural tissue and disruption of transmission along the nerves. A spinal cord injury can have a profound effect on a person's functional status, ability to participate in daily activities and quality of life. A spinal cord injury also marks the start of an ongoing relationship with the healthcare system.

In 2017-18, there were 344 people who experienced serious spinal cord injury. Overall, there is an estimated 5,500 people living with an existing spinal cord injury in NSW (690 per million population).\*

## Evidence on spinal cord injury in acute care

There is good evidence that timely and direct admission to specialised care in an acute interdisciplinary spinal cord injury unit, is associated with better neurological outcomes, lower complication rates and reduced length of hospital stay. Decompression surgery should be undertaken in the first 24 hours following injury, and for many types of surgery, there is a strong relationship between the number of times a hospital performs a specific surgical procedure and the outcomes for patients. Specialised care in the acute phase has been shown to be more cost effective.

## Evidence on spinal cord injury in rehabilitation care

Most people with spinal cord injury make significant functional gains during inpatient rehabilitation. Those initially cared for in interdisciplinary, specialist units achieve greater or faster functional gains during rehabilitation and specialised rehabilitation has been shown to be a significant and strong predictor of a patient returning home.

There is some evidence of a 'rehabilitation dose effect' with improvements in motor Functional Independence Measure (FIM) positively associated with total hours of therapy (up to a certain time point). However, other studies found that the total amount of treatment received during rehabilitation was not associated with differences in patient outcomes.

A 2011 Victorian study demonstrated improvements in FIM motor scores among patients with non-traumatic spinal cord injury were greater for those in specialist rehabilitation units than for those in non-specialist units<sup>1</sup>. More recent data from the Australasian Rehabilitation Outcomes Centre (AROC) show that for key subgroups in NSW, relative functional gains are greater among those cared for in specialist centres<sup>2</sup>.

There is expert consensus that psychosocial rehabilitation should begin as soon as possible after admission to support patients to cope and adjust to life following the injury.

## Evidence on spinal cord injury in community care

Education and support improve the confidence of rural clinicians in managing people with spinal cord injury.

Rural key workers have been shown to be an effective support for local clinicians and service providers, improving communication and service coordination between rural and metropolitan services.

Social participation of people with spinal cord injury is supported by adequate financial resources, accessible transportation and social support.

Telehealth applications have been shown to provide support for improved self-management of common comorbidities. Multiple telehealth programs have been associated with positive results in perceived health and patient satisfaction.

## Utilisation of services in NSW

### **There is increasing demand for healthcare services in NSW for people with spinal cord injury.**

The number of new serious spinal cord injury cases and all-cause hospitalisation of people with a history of serious spinal cord injury have increased in recent years. The number of specialist spinal cord injury centres and their capacity to provide inpatient care has, however, remained stable.

Spinal cord injuries vary in severity and in the need for admission to specialist care. In 2017-18, there were 344 people admitted with a serious spinal cord injury, which is defined as first ever acute hospitalisation with a principal or additional diagnosis code for spinal cord injury and an acute length of stay of >5 days, or a rehabilitation stay of >30 days (Appendix 1).

Among these 344 patients, 111 (32%) were admitted directly to one of the two specialist hospitals (97 with a diagnosis code for tetraplegia or paraplegia and 14 with cauda equina). A further 38 patients (11%) were initially admitted to a non-specialist hospital but were transferred to a specialist centre during their index hospitalisation (29 tetraplegia or paraplegia cases and 9 cauda equina cases).

This means that 195 patients (57%) with a serious spinal cord injury did not receive any care at a specialist hospital during their index hospitalisation. They were admitted across 34 non-specialist centres. At least 125 (64%) of these patients would likely have benefitted from specialist services – 44 patients with any type of tetraplegia, eight with complete paraplegia and 73 with cauda equina with bowel and/or bladder dysfunction.

Better outcomes are associated with treatment in a specialist unit. Hospital-acquired complications are more common in patients who are transferred to specialist care after two days of acquiring a spinal cord injury.

## Gaps in spinal cord injury care

### **Improved access to specialist care is required.**

Despite recent increases in outreach support for non-specialist units, there remains a need for more specialist and specialist-guided services.

**There are a lack of data and information about unwarranted clinical variation across different healthcare providers.** Care for people with spinal cord injury is delivered by a range of professionals, units and hospitals, spanning from highly specialised technical care to routine services. There are few validated metrics that are clinically relevant, scientifically robust and operationally feasible to assess variation in care.

**An evidence-informed review of admission criteria and referral pathways for people with spinal cord injury would guide improvement and help ensure early access to the most appropriate care.** Greater clarity around patient pathways and admission criteria support delivery of the right care, in the right place, at the right time. There are potential gains to be made through innovative approaches to the provision of care, such as telehealth, clinical decision support systems and the use of predictive analytics.

**The extent to which funding, based on the national weighted activity units, supports the range and complexity of care provided to people with SCI is worthy of review.** There is a need to better understand the application of activity-based funding to spinal episodes across the continuum of care, with a special focus on cost drivers for acute and subacute care.

\* This is an underestimate of the total number of people living with an existing spinal cord injury in NSW. It does not include people who had a spinal cord injury prior to 2001-02 and no subsequent hospital episode from 2001-02 onwards with the spinal cord injury noted in the hospital record. A study by New et al. estimates that the prevalence of traumatic spinal cord injury in Australia is between 490 and 886 per million population and including non-traumatic spinal cord injury would make it higher.<sup>34</sup>

# Introduction and background

The spinal cord extends from the foramen magnum, the opening at the base of the skull, to the conus medullaris, the most distal bulbous part of the cord at the level of the first and second lumbar vertebrae. The spinal cord transmits neural information between the brain and the rest of the body and integrates this information to enable voluntary initiation of body movement and regulation of autonomic functions, such as blood pressure and respiration.

Spinal cord injury refers to persistent damage to neural tissue and disruption of transmission along the nerves. About two-thirds of injuries are a result of trauma (e.g. motor vehicle accidents or falls) and the remaining one-third are non-traumatic (resulting from non-progressive disease processes, such as infection, haemorrhage, ischaemia, inflammation [myelitis] or spinal canal stenosis).

The injury causes loss of sensation and movement, as well as disruption to internal organ function, including bowel, bladder, and sexual impairments. It can have profound effects on patients' functional status, ability to participate in the activities of daily living and quality of life.

Spinal cord injuries are commonly categorised into complete tetraplegia, incomplete tetraplegia, complete paraplegia and incomplete paraplegia, and unspecified cauda equina (Appendix 1).

Four phases of care for spinal cord injury span:

1. **Pre-hospital** – stabilisation of vital functions and preservation of neurological function.
2. **Acute** – prioritising and treating injuries to minimise impairment, pain and psychological suffering.
3. **Sub-acute** – inpatient rehabilitation enhancing function, compensating for loss of function, preventing complications, assisting with emotional adjustment.
4. **Community reintegration and ongoing care** – promoting health and wellbeing, social inclusion and participation.

A spinal cord injury marks the start of an ongoing relationship between the healthcare system and the person with spinal cord injury, as they progress through acute, rehabilitation and community phases. Patient flows are complex and many people with spinal cord injury move in and out of services in a non-linear way.

## Data and methods

Data for this report were drawn from:

### 1. Literature search

A rapid review of PubMed was conducted in 2017, with an update in September 2018. Key search terms included: spinal cord injuries/organisation and administration [MeSH]; spinal cord injuries AND treatment outcome AND organisation and administration AND guidelines. Snowball searches were conducted from the reference lists of key articles.

### 2. Guideline and jurisdictional review

Guidelines and policies for spinal cord injury care are produced by many healthcare entities. Arrangements in New Zealand, Switzerland, the United States and the United Kingdom were reviewed. Within Australia, Queensland and South Australia have models of care for people with spinal cord injury and policy documents that informed this report.<sup>3</sup>

### 3. NSW Policy context review

Key policy documents that were reviewed include:

- Selected Specialty and Statewide Service Plan, Number 8: Spinal Cord Injury; 2010<sup>4</sup>
- NSW Critical Care Tertiary Referral Networks and Transfer of Care (Adults) [PD2018\_011]<sup>5</sup>
- Independent Hospital Pricing Authority (IHPA) pricing framework for Australian Public Hospital Services.<sup>6</sup>



#### 4. Health and healthcare databases and analysis

Quantitative data were drawn from:

- NSW Admitted Patient Data Collection; Emergency Department Data Collection; Registry of Births, Deaths and Marriages, accessed via Hospital Performance Data, NSW Ministry of Health Secure Analytics for Population Health Research and Intelligence.
- Australasian Rehabilitation Outcomes Centre reports.
- Spinal Cord Injury Database and State Spinal Cord Injury Service (SSCIS) reports – includes incident cases for traumatic and non-traumatic spinal cord injury in NSW for patients who are admitted to the specialist spinal units and readmissions by this cohort.
- Royal North Shore Plastics Service Report 2017.

A pseudo-registry was constructed to estimate the prevalence of spinal cord injury patients in NSW. Using a 17-year lookback, all hospital records were searched for a diagnosis code indicating a spinal cord injury (Appendix 1). Presence of a qualifying code triggered inclusion of the patient in the registry, regardless of where the code occurred in the record (i.e. principal diagnosis or additional diagnosis 1-50). Serious index cases were defined as first ever acute hospitalisation with a spinal cord injury diagnosis code and an acute length of stay over five days; or a rehabilitation stay over 30 days. Throughout this report, a hospitalisation refers to a contiguous set of hospital episodes, including transfers between hospitals and changes in care type.

#### 5. Patient surveys

In 2016-17, an online survey was distributed via the two key community groups, Spinal Cord Injuries Australia (SCIA) and ParaQuad NSW.

#### 6. Patient stories

A representative sample of people with spinal cord injury at specialist services were asked by spinal

cord injury clinicians to contribute stories about their experiences of care.

#### 7. Patient and clinician consultation

In 2017, Nexus Management Consultants on behalf of the State Spinal Cord Injury Service (SSCIS) conducted:

- 23 face-to-face interviews with people with spinal cord injury
- six site visits involving interviews with inpatients and clinicians
- meetings with community organisations, SCIA and ParaQuad NSW.

More than 100 clinicians were consulted about current delivery models and operational arrangements; approaches to continuous improvement, and involvement in benchmarking; the effectiveness of current approaches; groups of patients/consumers for whom specific strategies are required; and priorities for service development.

#### Aboriginal Impact Statement

In order to assess spinal cord injury from an Aboriginal perspective, the analyses included in this report were conducted with Aboriginal and non-Aboriginal groups. The proportion of both spinal cord injury index and total hospitalisation patients, who identified as Aboriginal, was about 3%. This is a similar proportion to that of the NSW population who identify as Aboriginal (2.8%). There have not been separately reported in this document, given the low numbers, to maintain confidentiality of those individuals.

The Aboriginal Impact Statement conducted in 2016 recognised that existing services are not well designed to accommodate the special cultural and community needs of Aboriginal people and may result in poor outcomes. Further work will need to be done in this area and is underway with other ACI networks.

# The research evidence

## ‘What works’ in spinal cord injury care

Systematic reviews and evidence-based guidance regarding spinal cord injuries are published by a range of international bodies, such as The Spinal Cord Injury Research Evidence initiative, and the Congress of Neurological Surgeons.<sup>7,8</sup>

Recent articles in the peer reviewed literature have addressed controversial areas of practice in the treatment of spinal cord injury, including the use of corticosteroids, such as methylprednisolone sodium succinate, the optimal timing of surgical intervention, the type and timing of anticoagulation prophylaxis, the role of magnetic resonance imaging, and the type and timing of rehabilitation.<sup>9</sup>

This report focuses primarily on healthcare delivery arrangements rather than therapeutic and clinical decisions.

The research evidence gathering process focused on four questions:

1. What works in acute care?
2. What works in rehabilitation?
3. What works in primary and community care?
4. What is cost effective care for people with spinal cord injury?

A summary of key consensus statements for high quality care for patients with spinal cord injury is shown below in Table 1.

**Table 1: Summary of recommendations for high quality spinal cord injury care**

### Key consensus statements defining high quality care for patients with spinal cord injury

All patients with spinal cord injury admitted to hospital should have a written care plan that outlines:

- management of autonomic dysreflexia for patients at risk (T5-6 or above)
- respiratory management to prevent or treat chest complications
- commencing thromboembolic prophylaxis if immobilised with bed rest or admitted for medical illness or surgery
- preventive measures to avoid pressure sores
- adequate nutrition
- bowel and bladder management program
- management of spasticity and avoidance of secondary musculoskeletal complications.<sup>10</sup>

Rehabilitation should:

- be offered to patients with acute spinal cord injury when they are medically stable and can tolerate required rehabilitation intensity<sup>11</sup>
- incorporate psychosocial support.<sup>12</sup>

All patients with spinal cord injury admitted to hospital should have appropriate discharge planning involving:

- the patient and his/her family and carers
- relevant members of the multidisciplinary team
- direct contact with the community care team.<sup>10</sup>

The following should be in place before discharge:

- arrangements for transport, care and equipment needs
- full reports from all professionals involved with their care
- appropriate transport arrangements made for future outpatient or review appointments.<sup>10</sup>

## What works in acute care?

There is increasing evidence to show that timely and direct admission to specialised care is associated with better neurological outcomes, lower complication rates, and reduced length of stay.<sup>13-17</sup> More specifically, the latest guidance suggests decompression surgery should be undertaken in the 24 hours following spinal cord injury.<sup>18</sup>

## What works in rehabilitation?

Most people with spinal cord injury make significant functional gains during inpatient rehabilitation. Those initially cared for in specialist units have been shown to achieve more or faster gains during rehabilitation.<sup>19</sup> Receiving specialised rehabilitation has been shown to be a significant and strong predictor of returning home.<sup>20</sup>

Some studies have found a 'rehabilitation dose effect' with improvements in motor Functional Independence Measure (FIM) positively associated with total hours of therapy (up to a certain time point).<sup>21</sup> However, other studies found that the total amount of treatment received during rehabilitation was not associated with differences in patient outcomes.<sup>22</sup>

A Victorian study found that for people with non-traumatic spinal cord injury, improvements in FIM motor scores in specialist spinal cord injury rehabilitation units were better than those in non-specialist units.<sup>23</sup>

Psychosocial rehabilitation is associated with better outcomes, particularly when it is initiated as soon as possible after admission, subject to the patient's medical condition and cognitive status.<sup>12</sup>

Qualitative studies of patient perspectives suggest that the skills and vision of rehabilitation staff are considered to be of crucial importance.<sup>24</sup>

## What works in community care?

Telehealth has been shown to improve self-management of common comorbidities. Multiple telehealth programs have been associated with positive results in perceived health and patient satisfaction (although there are no proven links to outcomes).<sup>25</sup>

Education and support improves the confidence of rural clinicians in managing people with spinal cord injury.<sup>26</sup>

Rural key workers have been shown to be effective support for local clinicians and service providers, improving communication and service coordination between rural and metropolitan spinal cord injury services.<sup>26</sup>

Adequate financial resources, accessible transportation and social support helps facilitate patient social participation. Physical accessibility issues, unsupportive social attitudes and mental health issues have been shown to be barriers to community participation.<sup>27</sup>

## What is cost-effective care?

Specialised care, particularly in the acute phase has been shown to be more cost effective.<sup>28</sup> Similarly, early surgical decompression is more cost effective than delayed surgery.<sup>29</sup>

For elderly patients, surgical management and rehabilitation of acute traumatic cervical spinal cord injury is more costly, but similarly effective when compared with younger adults with similar impairment.<sup>30</sup>

Despite a relatively high initial cost, specialist rehabilitation has been shown to be cost-efficient, producing savings in ongoing care, costs, and relieving pressure on acute care services.<sup>31</sup>

## Current delivery arrangements

### Specialist services for adults

Table 2 shows provision of care for adults with a spinal cord injury is centred at two specialist acute units at Prince of Wales and Royal North Shore hospitals and two specialist rehabilitation units at Prince of Wales Hospital and Royal Rehab. There are 28 specialist acute adult beds and 40 specialist adult rehabilitation beds. Specialist units have wheelchair accessible physical facilities and specialised ward equipment. They can draw on the services of the host facility – including intensive care, urology, plastic surgery, pain management, infectious diseases, respiratory and renal medicine services.

For admission to a specialist spinal cord injury service in NSW, a person must have a persistent spinal cord injury resulting from either a traumatic injury or a non-progressive disease. Priority is given to people with complex needs, based on criteria such as the level and extent of neurological injury to the spinal cord; the complexity of care; the presence of comorbid conditions and/or functional limitations; and the need for highly specialised treatment, services and expertise.

As well as inpatient care, specialist centres also provide highly specialised networked services such as adult outpatient and community outreach across the state. Networked services are funded by a service agreement between the local health district (LHD) and the service provider.

Table 2: Key services for people with spinal cord injury

Service type	Adult	Children and young people
<b>Acute spinal cord injury units</b>	Prince of Wales Hospital: 10 beds Royal North Shore Hospital: 18 beds	Sydney Children's Hospital (Randwick) The Children's Hospital (Westmead) John Hunter Children's Hospital
<b>Rehabilitation</b>	Prince of Wales Hospital: 20 beds Royal Rehab: 20 beds	Rehab2Kids (Randwick) Kids Rehab (Westmead)
<b>Outpatient</b>	Prince of Wales Hospital Royal North Shore Hospital Royal Rehab	Sydney Children's Hospital (Randwick) The Children's Hospital (Westmead) HNEkidsRehab Services
<b>Specialist outreach and community-based</b>	NSW Spinal Outreach Service Rural Spinal Cord Injury Service Hunter Spinal Cord Injury Service	Paediatric Spinal Outreach Service Northcott Disability Services
<b>Transition to adult services</b>	n/a	Trapeze (Sydney Children's Hospitals Network) Agency for Clinical Information Transition Care
<b>Primary care</b>	General practice and other primary care providers	
<b>Other key agencies and service providers</b>	EnableNSW icare lifetime care (formerly the Lifetime Care and Support Authority of NSW) icare workers care My Aged Care National Disability Insurance Agency/Scheme	Community-based health professionals Housing NSW ParaQuad NSW (the Paraplegic and Quadriplegic Association of NSW) Sargood Foundation Spinal Cord Injuries Australia

## Outpatient and community services for non-admitted patients

Prince of Wales Hospital provides a specialist multidisciplinary spinal outpatient clinic. Royal North Shore Hospital and Royal Rehab offer medical outpatient appointments, with variable access to specialised staff from other disciplines (Table 3).

## Community-based services

The Spinal Outreach Service (SOS) provides specialist multidisciplinary support, education and clinical interventions to patients following their discharge from hospital. Services aim to maintain health and promote community integration. There are separate metropolitan and rural SOS programs. Hunter New England LHD hosts the Hunter Spinal Cord Injury Service (HSCIS), a community-based service for people in the Hunter and Lower Mid North Coast Region. HSCIS provide multidisciplinary therapy after discharge from specialist or non-specialist units and life-long health services. Outpatient clinics are delivered in collaboration with John Hunter Hospital Rehabilitation Medicine services.

## Rural spinal outreach service

The Rural Spinal Cord Injury Service links rural areas with the spinal cord injury units, providing specialist multidisciplinary care to people living outside metropolitan Sydney. It also provides education sessions to rural clinicians. It is funded through the Rural Outreach Fund.

The rural service is based on a 'hub and spoke' model. Rural coordinators are supported locally by the Brain Injury Rehabilitation Program, conveyed through service level agreements, with spinal cord injury-specific support and linkages provided by the SOS in Sydney.

Each year, nine specialist medical and multidisciplinary 2-3 day clinics are held in different regional centres for people with spinal cord injury (Appendix 2).

Table 3: Specialty clinics for spinal cord injury, by hospital

<b>Royal North Shore</b>
<ul style="list-style-type: none"> <li>• Spinal Cord Medical Clinic</li> <li>• Fertility Clinic</li> <li>• Sexual Function Clinic</li> <li>• Urodynamic Clinic</li> <li>• Spinal Plastics Service</li> <li>• Spasticity Clinic</li> <li>• Tetraplegic Hand Clinic</li> </ul>
<b>Prince of Wales</b>
<ul style="list-style-type: none"> <li>• Multidisciplinary Intervention</li> <li>• Assistive Fertility and Sexual Dysfunction Treatment Service</li> <li>• Urology and Urodynamic Services</li> <li>• Spinal Pressure Care Clinic</li> <li>• Spasticity Clinic</li> <li>• Orthotic Clinic</li> <li>• Spinal Cord Rehabilitation Medical Clinic</li> <li>• Seating Service</li> </ul>
<b>Royal Rehabilitation Centre Sydney</b>
<ul style="list-style-type: none"> <li>• Spinal Cord Rehabilitation Medical Clinic</li> <li>• Seating Service</li> </ul>

## Specialist services for children

Sydney Children's Hospital and The Children's Hospital Westmead provide services for acute, subacute and ambulatory care. Upon discharge, children are referred to the Paediatric Spinal Outreach Service, managed by Northcott Disability Services. Nursing, occupational therapy, physiotherapy and social work services are provided in the community, and staff liaise with local providers. Outpatient services are also available through the Sydney Children's Hospital Network and Hunter New England HNEkidsRehab Services. Transition of adolescents to adult services occurs between the ages of 16-18. The transition to the adult SOS is facilitated by the ACI Transition Care Network and Trapeze, the chronic care and transition service of the Sydney Children's Hospital Network.

**An overview of services and related clinical pathways is provided in Appendix 3.**

# Index hospitalisations in NSW

In 2017-18, there were 344 patients with an index hospitalisation for a serious spinal cord injury, an increase from 274 patients in 2001-02. The number of patients admitted to a specialist unit was fairly stable over the time period, ranging from 77 to 118 each year, while the number admitted to a non-specialist unit ranged from 148 to 233 each year (Figure 1).

There are four pathways that patients follow during their index hospitalisation. In 2017-18:

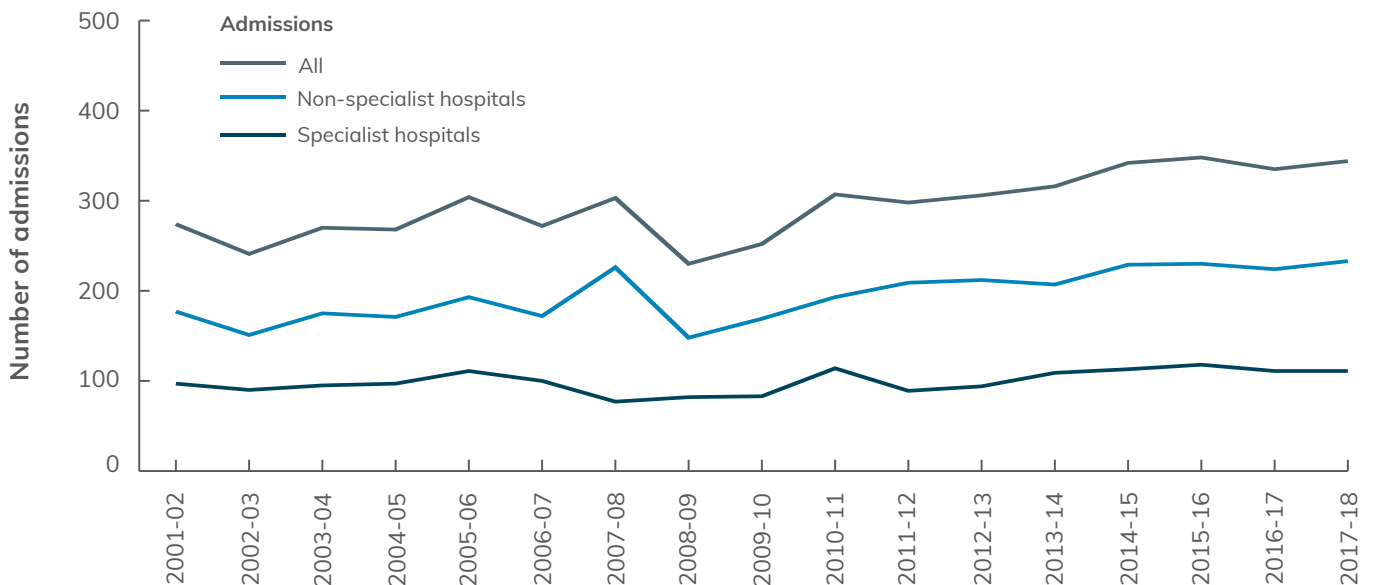
- 111 (32%) were admitted directly to a specialist hospital
- 8 (2%) were admitted to a non-specialist hospital and transferred to a specialist hospital in less than two days
- 30 (9%) were admitted to non-specialist and transferred to specialist after two or more days
- 195 (57%) were admitted to and remained at a non-specialist hospital (Figure 2).

Patients who have one of the following injuries should be prioritised (due to complexity) for admission to a spinal cord injuries unit, or if there is insufficient bed capacity, provided access to specialist care due to complexity:

- tetraplegia (complete, incomplete, or unspecified)
- paraplegia complete
- cauda equina with bowel and/or bladder problems.

For patients who were admitted to, and remained in, non-specialist care, 125 (64%) should have received some input from specialist care based on their injury and its complexity (Figure 2). This is likely to underestimate the need, given that the groups containing patients with incomplete or unspecified paraplegia will include complex cases that should also be prioritised for specialist care. Those patients whose transfer to specialist care was delayed for more than two days, had a longer length of stay (median 142 days) compared to all other pathways (median 62 days or less).

Figure 1: Index hospitalisations for serious spinal cord injury by admission to specialist and non-specialist (public and private) hospitals, NSW 2001-02 to 2017-18



\*Based on only six patients.

In 2017-18, 124 patients (36%) had at least one of the following hospital-acquired complications during their index hospitalisation - infection, respiratory complication, pressure injury and/or fall with harm. Complications were most common in patients transferred to specialist units after two or more days compared with patients on other pathways (Figure 3).

In 2017-18, 183 patients (53%) had a spinal decompression or fusion procedure during their index hospitalisation. The date of the procedure was available for 136 patients. Of these patients, the percentage that had their procedure on the same day or one day after admission was 81% in specialist care, 17%\* transferred to specialist care in less than two days, 67% transferred to specialist care after two or more days, and 60% remained in non-specialist care.

Figure 2: Index hospitalisations for serious spinal cord injury by care pathway, trauma status, and diagnosis group, NSW 2017-18

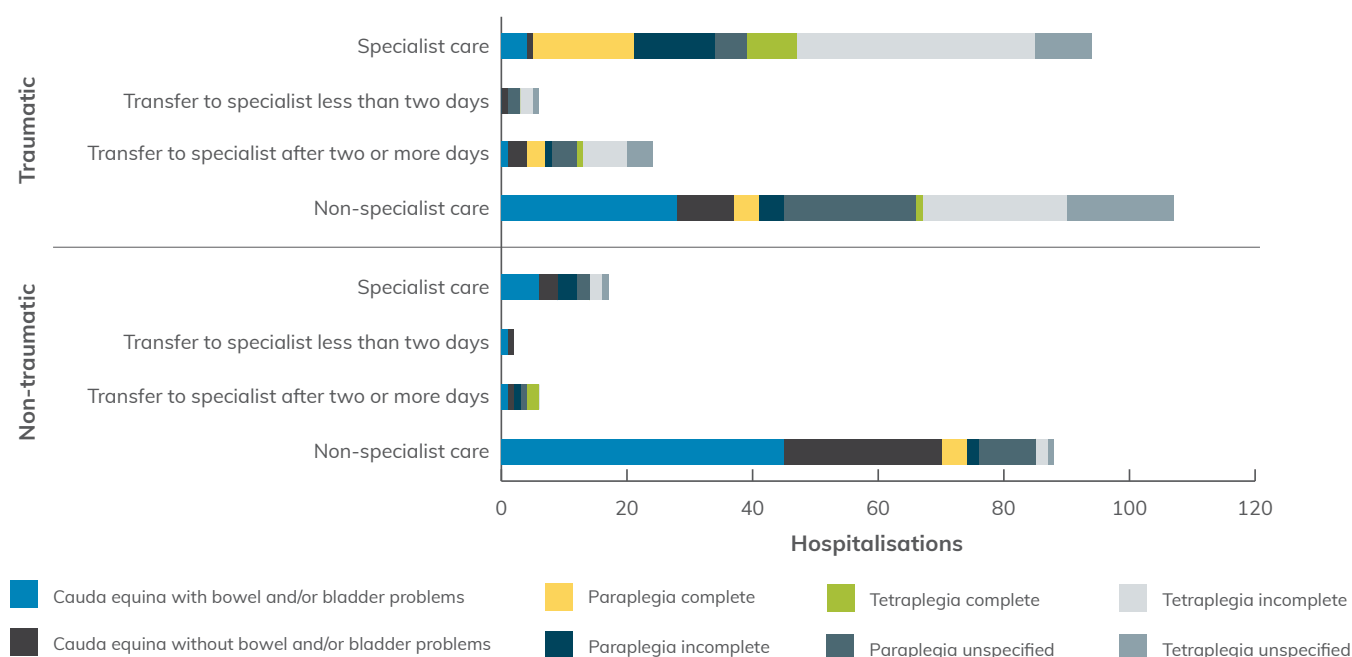
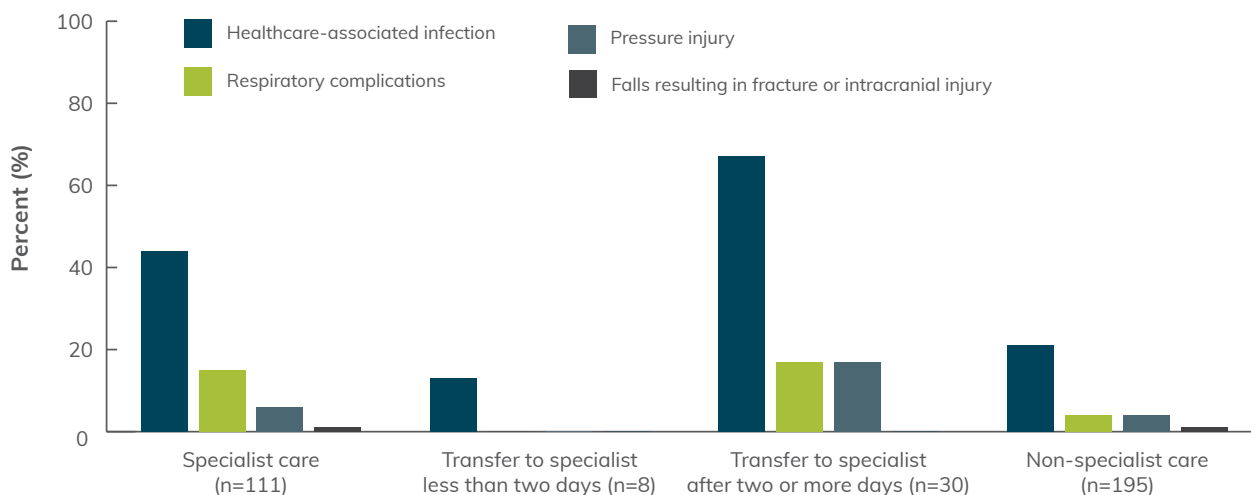


Figure 3: Hospital-acquired complications during the index hospitalisation for serious spinal cord injury by care pathway, NSW 2017-18



Note: Transfers to specialist care are recommended within 24 hours. However, as we cannot precisely measure the time to transfer in hours, we have identified transfers that occurred the same-day or one day after admission and those that occurred two or more days after admission.

# Prevalence and subsequent hospitalisations

Between 2001-02 and 2017-18, a total of 8,246 people had a diagnosis of a spinal cord injury noted in their hospital records. Of these, 2,748 are known to have died. Therefore, in 2017-18, there were an estimated 5,498 people living with a spinal cord injury in NSW (690 per million population).<sup>\*</sup> Among these people, 3,172 are known to have had a serious spinal cord injury.

In 2017-18, 1,252 people with a history of a serious spinal cord injury were admitted at least once to a hospital in NSW; 925 (74%) at least once for acute overnight care.

The number of people with a history of serious spinal cord injury hospitalised each year increased by a factor of two, from 590 in 2008-09 to 1,252 in 2017-18 (Figure 4).

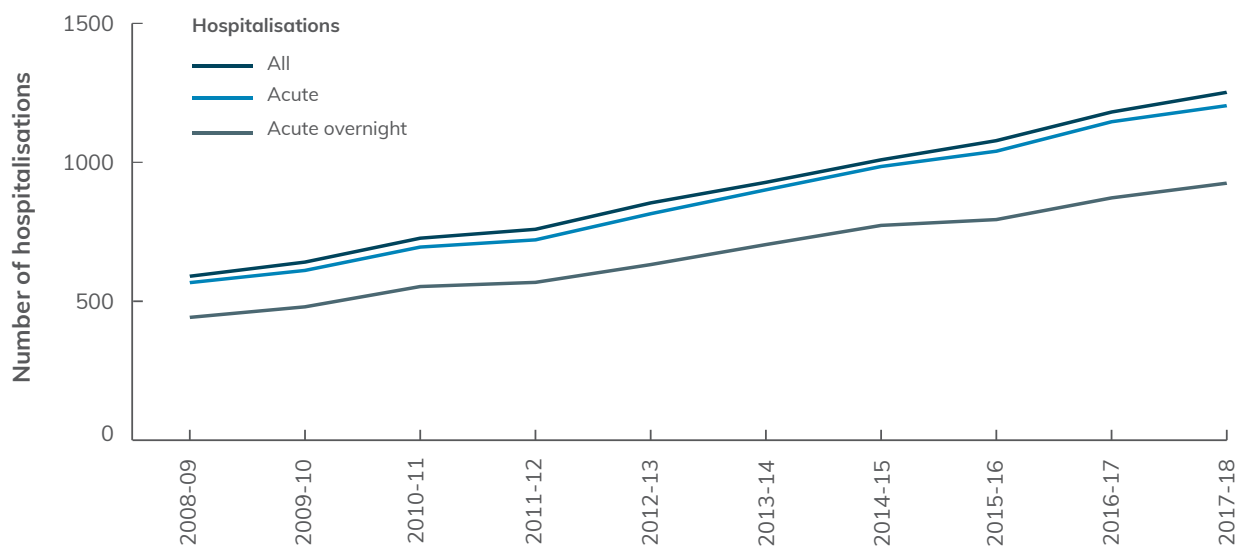
Patients often have multiple hospitalisations in a year. In 2017-18, there were 3,888 hospitalisations for people with a history of

serious spinal cord injury, of which, 1,658 (43%) were acute overnight hospitalisations.

The total number of hospitalisations among people with a history of serious spinal cord injury increased from 2,217 in 2008-09 to 3,888 in 2017-18 (Figure 5).

Among the 1,658 acute overnight admissions in 2017-18, 252 (15%) were admitted directly to a specialist hospital, 4 (<1%) were admitted to a non-specialist hospital and transferred to a specialist hospital in less than two days, 16 (1%) were admitted to non-specialist care and transferred to specialist care after two or more days, and 1,386 (84%) were admitted to and remained at a non-specialist hospital. Most of the hospitalisations at the specialist hospital were by people with paraplegia or tetraplegia, 210 (83%). For non-specialist hospitalisations, 847 (61%) were by people with paraplegia or tetraplegia (Figure 6).

Figure 4: Number of people with a history of serious spinal cord injury who were hospitalised, all and acute overnight, NSW 2008-09 to 2017-18



<sup>\*</sup>This is an underestimate of the total number of people living with a spinal cord injury in NSW. It does not include people who had a spinal cord injury prior to 2001-02 and no subsequent hospital episode from 2001-02 onwards with the spinal cord injury noted in the hospital record. A study by New et al. estimates that the prevalence of traumatic spinal cord injury in Australia is between 490 and 886 per million population and including non-traumatic spinal cord injury would make it higher.<sup>34</sup>



In 2017-18, the most common principal diagnosis for the acute overnight hospitalisations was septicaemia (80, 5%), followed by urinary system disorder (75, 5%), cellulitis (47, 3%), autonomic

nervous system disorder (39, 2%), and pressure injury (37, 2%). The percentage of these patients that went to non-specialist care only was 85%, 81%, 85%, 28% and 54% respectively.

Figure 5: Number of hospitalisations for people with a history of serious spinal cord injury, all and acute overnight, NSW 2008-09 to 2017-18

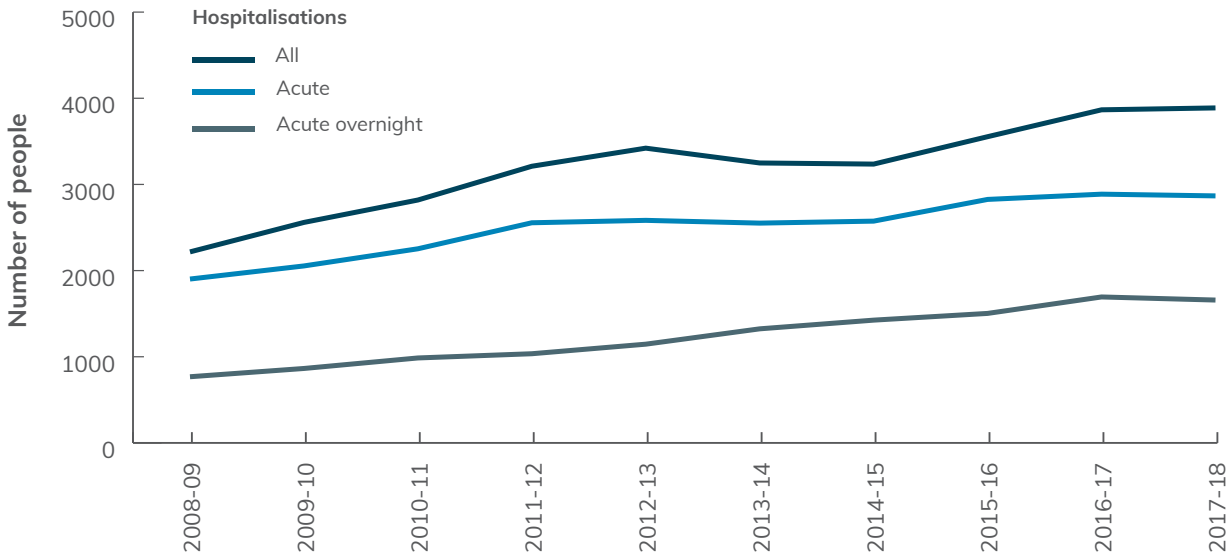
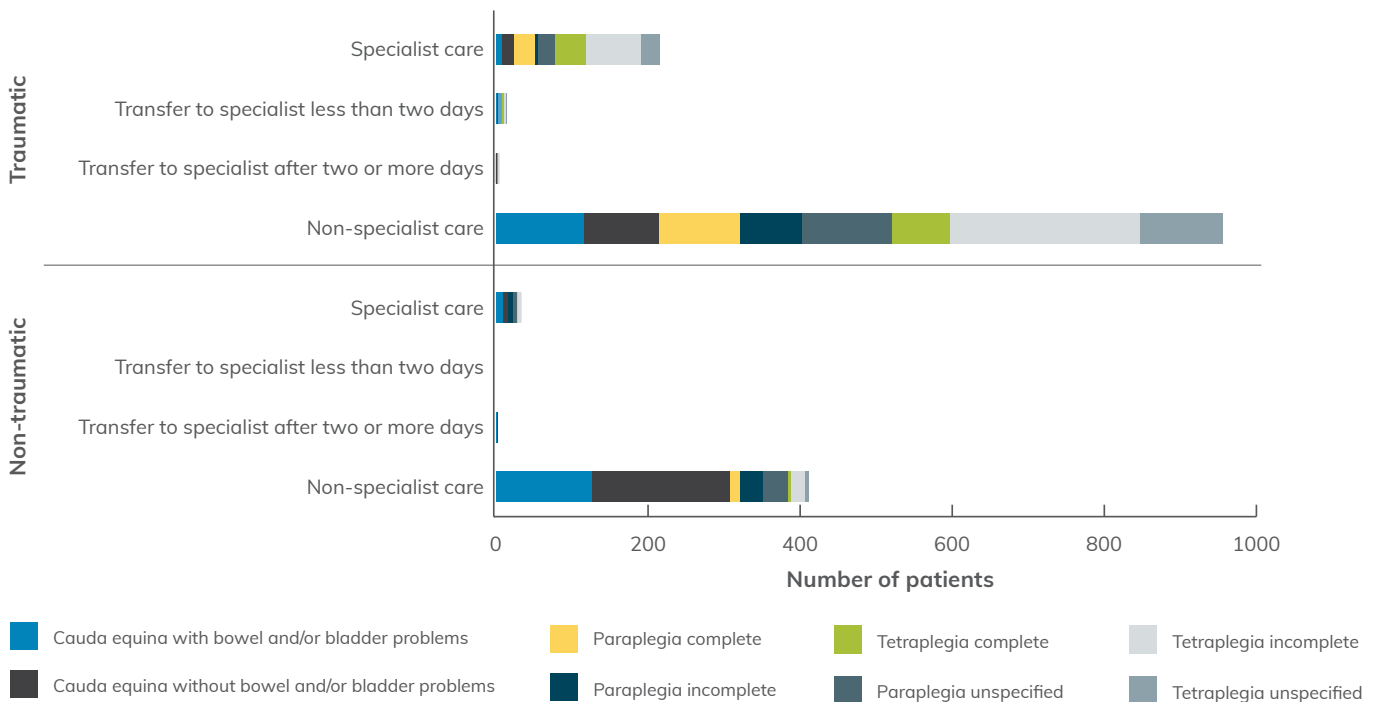


Figure 6: Acute overnight hospitalisations for people with a history of serious spinal cord injury by care pathway, trauma status and diagnosis group, NSW 2017-18



# Hospitals providing care

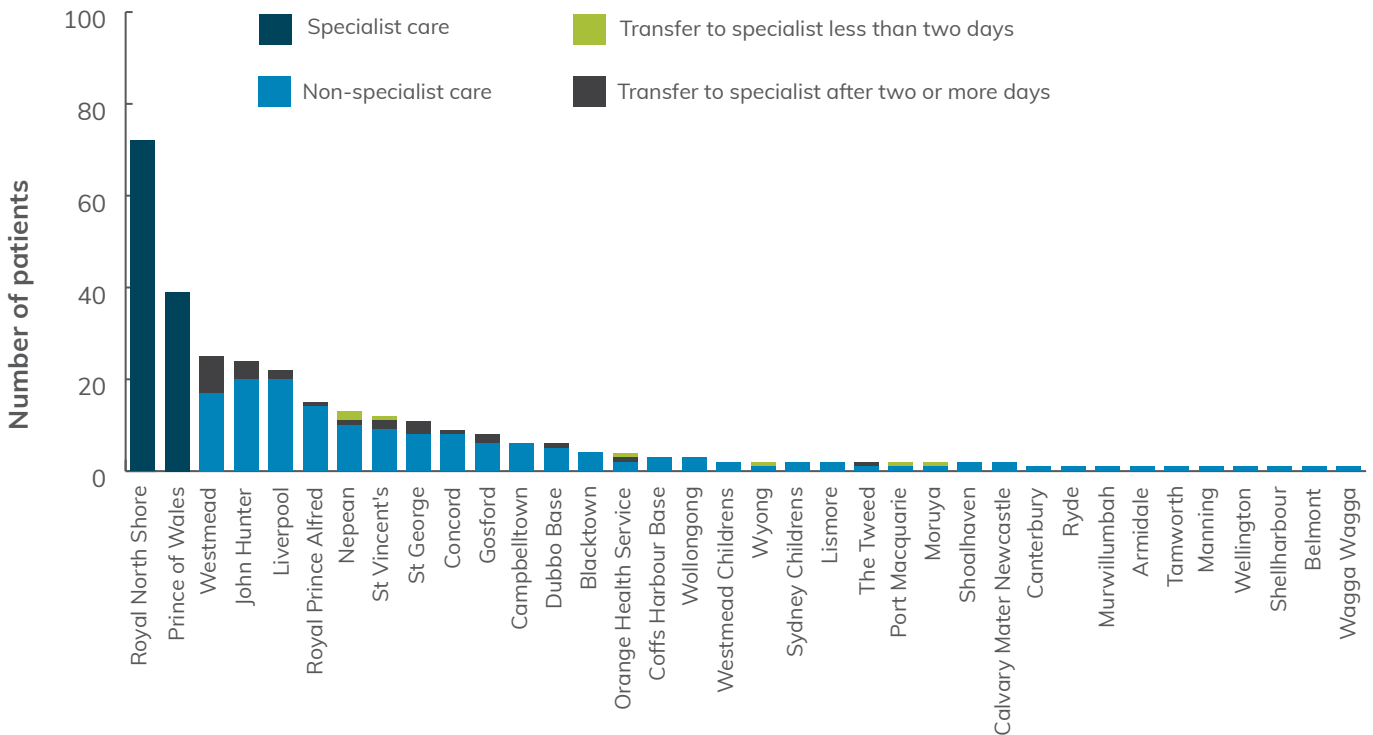
Many public hospitals in NSW provide care to people with serious spinal cord injury, both at the index hospitalisation and subsequent hospitalisations.

In 2017-18, 34 non-specialist public hospitals admitted patients for their index serious spinal cord injury hospitalisation. The two specialist public hospitals admitted the highest number of patients, while 23 non-specialist public hospitals admitted fewer than five patients. For the 23 non-specialist public hospitals that admitted fewer than five patients, 36 out of 42 (86%) patients at these hospitals received care only in a non-specialist hospital (Figure 7).

In 2017-18, 99 non-specialist public hospitals admitted patients with a history of a serious spinal cord injury for acute overnight care. The two specialist public hospitals had the most admissions, while 68 non-specialist public hospitals had fewer than 10 admissions.

For the 68 non-specialist public hospitals that had fewer than 10 admissions, 187 out of 193 (97%) patients at these hospitals received care in a non-specialist hospital only. Of the 31 non-specialist hospitals with at least 10 admissions, volumes ranged from 12 to 65 (Figure 8).

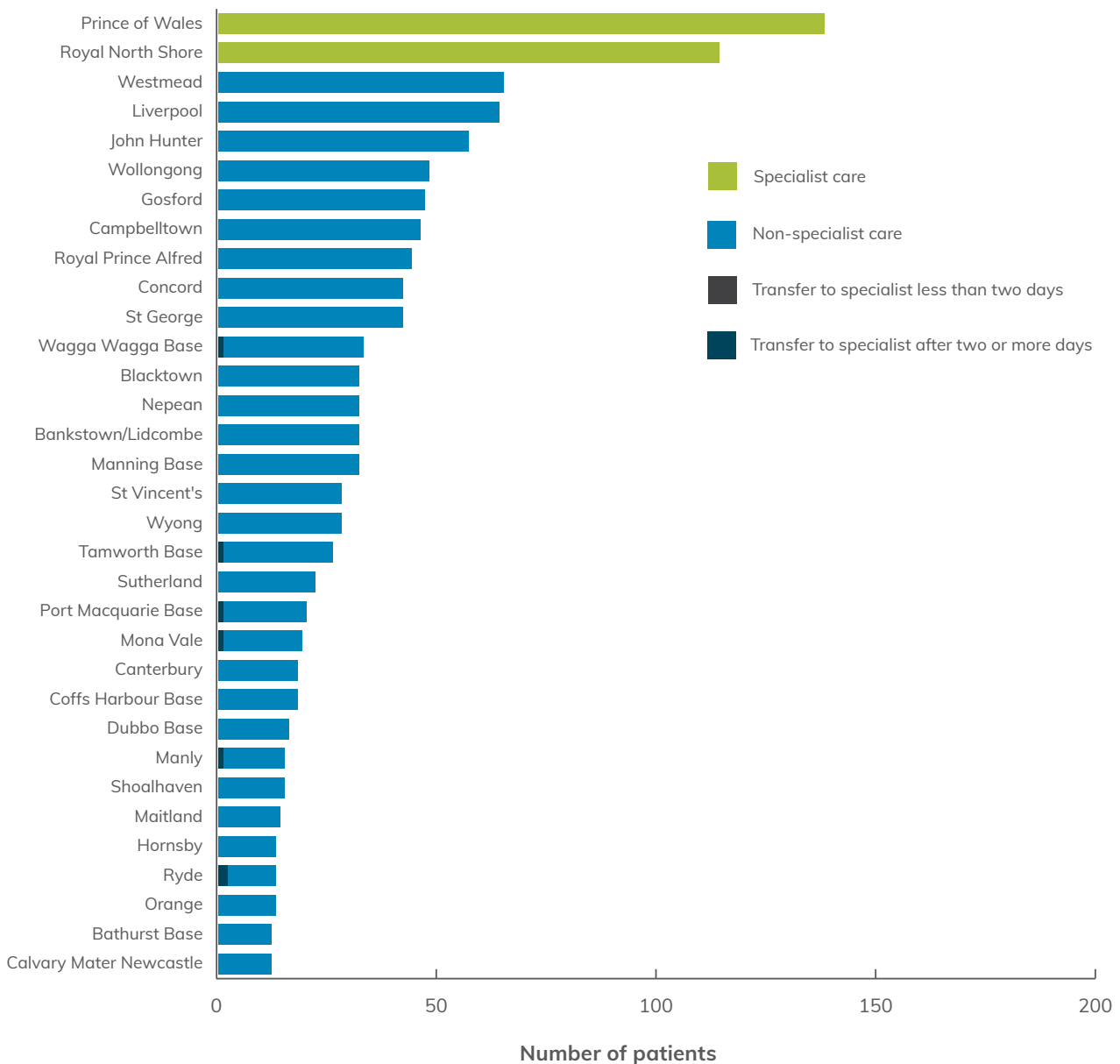
Figure 7: Index hospitalisations for serious spinal cord injury by admitting public hospital and care pathway, NSW 2017-18



These data highlight the geographical extent of hospital care provided for people with spinal cord injury – both in the acute phase and for ongoing care. It also raises questions about associations between quality and volume. It is well established that, for many types of surgery, there is a strong relationship between the number of times a

hospital (or a team, or a surgeon) performs a specific surgical procedure and the outcomes for patients.<sup>36</sup> While minimum volumes are not well delineated for spinal cord surgery or for hyper-acute care, such highly specialised services generally benefit from a minimum volume of cases.

**Figure 8: Number of acute overnight hospitalisations for people with a history of serious spinal cord injury by admitting public hospital and care pathway, NSW 2017-18 (public hospitals with at least 10 admissions)**



## Patient flows and specialist beds

Caring for spinal cord injury patients requires a range of specialist services varying in breadth and intensity. Internationally, spinal cord injury services deliver those services using an organisational model that centres on dedicated beds.<sup>23</sup>

Although dedicated beds allow for the delivery of complex care, they are often a scarce resource. Any delays in discharging patients from a bed can have a knock-on effect, preventing other patients from accessing the most appropriate care.

A 'snapshot' approach to gauge the extent of delays in spinal cord injury services showed that on 10 December 2019, among the 68 specialist beds available across the state, 33 had patients who were ready for discharge and 25 waiting to be admitted (Figure 11).

For the patients ready for discharge, the median wait was 25 days at Prince of Wales, 14 days at Royal North Shore, and 62 days at Royal Rehab. The reasons for waiting included delays in availability of accommodation and National Disability Insurance Scheme (NDIS) approvals (Figure 11).

# Rehabilitation

Rehabilitation services for people with spinal cord injury span a range of specialist and non-specialist, public and private facilities.

Patients can have substantial delays in specialist acute care beds waiting to transition to rehabilitation care. In 2017-18, the median wait for patients accessing specialist units was 20 days (range one to 195 days).<sup>37</sup>

In 2017, there were 295 rehabilitation episodes for spinal cord injury patients. Of these, 112 (38%) occurred in specialist rehabilitation units, 143 (48%) in non-specialist public rehabilitation units, and 40 (14%) in private units.

Between 2008 and 2017, the number of rehabilitation episodes in public units (both specialist and non-specialist) increased from 214 to 255 (Figure 9).

For patients with spinal cord injury, change in functional status is an important outcome measure. For most spinal cord injuries, patients achieve higher functional gains in specialist rehabilitation units compared with non-specialist units (Figure 10).

At the end of the rehabilitation phase, some patients experience substantial delays for non-health related reasons such as funding for accommodation, care and equipment needs.<sup>41</sup>

On 20 June 2019, there were four patients ready for discharge at Prince of Wales Hospital and 11 patients at Royal Rehab (with median waits up to that date of 18.5 and 95.5 days respectively).

On 10 December 2019, this increased to 12 patients (median wait 25 days) and 8 patients (median wait 62 days) at Prince of Wales and Royal Rehab respectively.<sup>41</sup>

Figure 9: Number of spinal cord injury rehabilitation episodes by hospital type, 2008-2017

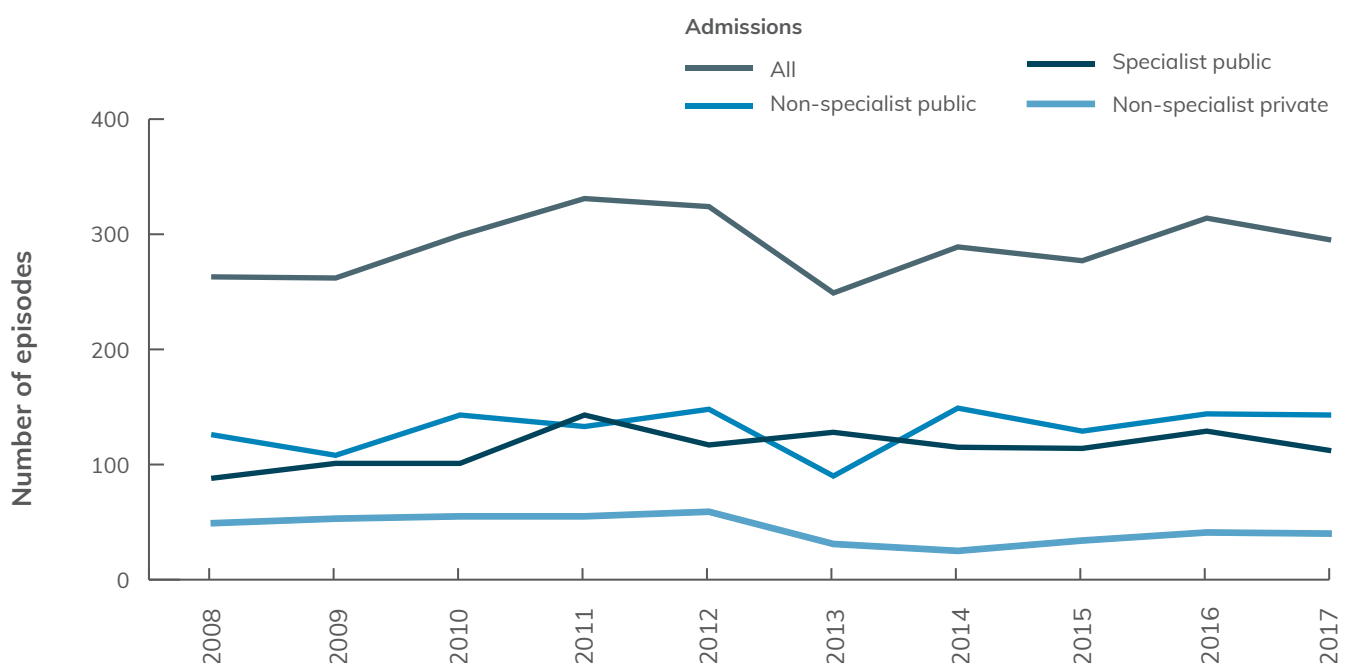
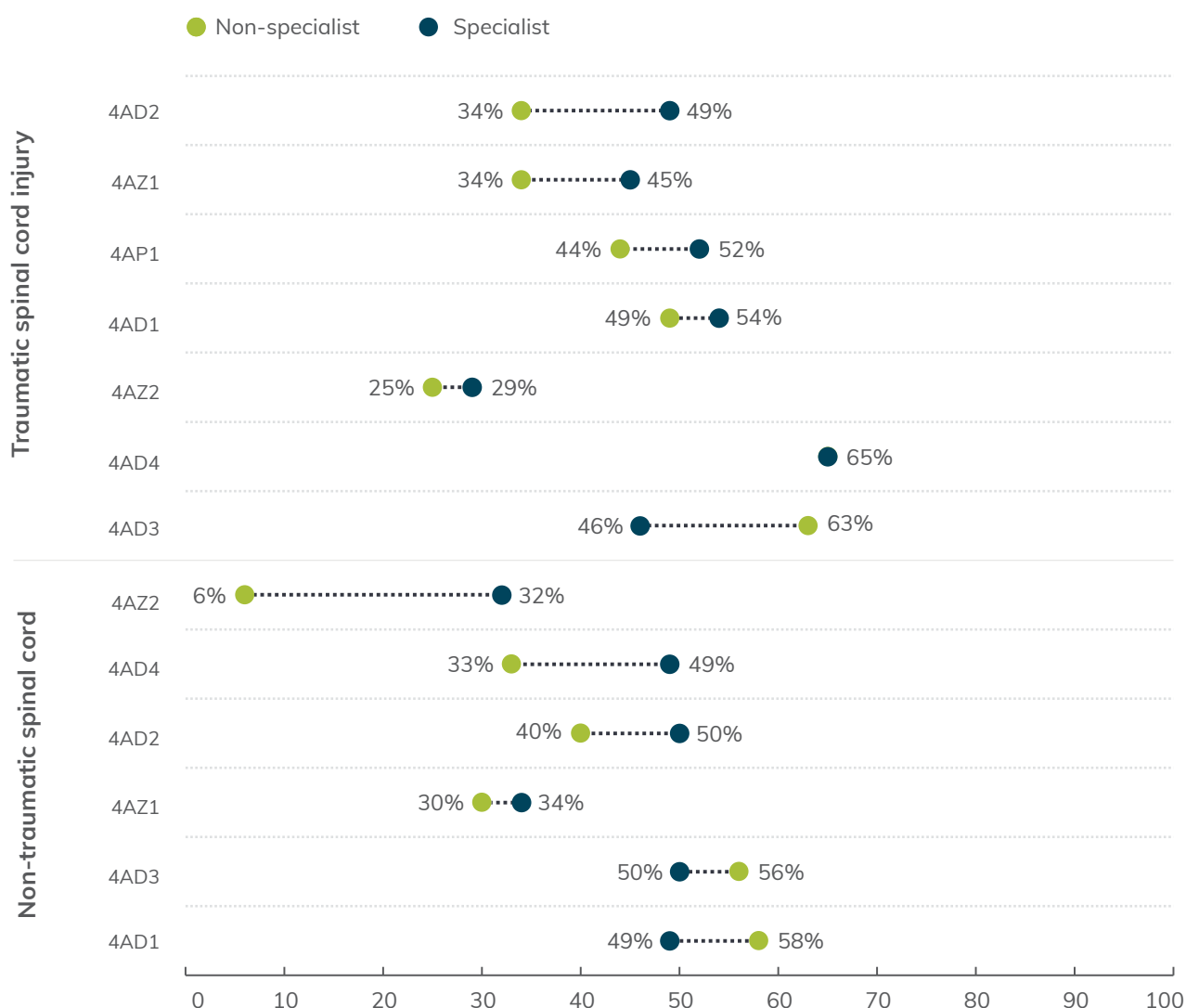


Figure 10: Patients with spinal cord injury, percentage relative functional gain, specialist and non-specialist rehabilitation units, by Australian National Subacute and Non-Acute Patient classes, 2013-2017



Levels of functioning for spinal cord injury are categorised by the following Australian National Sub-acute and Non-Acute Patient Version 4 classes:

4AD1	Spinal cord dysfunction, Age ≥50, weighted FIM motor 42-91
4AD2	Spinal cord dysfunction, Age ≥50, weighted FIM motor 19-41
4AD3	Spinal cord dysfunction, Age ≤49, weighted FIM motor 34-91
4AD4	Spinal cord dysfunction, Age ≤49, weighted FIM motor 19-33
4AP1	Major Multiple Trauma, weighted FIM motor 19-91
4AZ1	Weighted FIM motor score 13-18, Brain, Spine, MMT, Age ≥49
4AZ2	Weighted FIM motor score 13-18, Brain, Spine, MMT, Age ≤48

Source: Australasian Rehabilitation Outcomes Centre.<sup>38</sup>

# A patient flow snapshot of NSW Spinal Injuries Units



On **Tuesday 10 December 2019** there were:

**10 acute and 20 rehabilitation beds**

 available at **Prince of Wales**

**How many patients were in a bed waiting to be discharged?**

**12 patients**



**How long had they been waiting?**

**13–123 days**

(Median = 25 days)

**Why had they been waiting?**

- Housing
- Home modifications
- NDIS approval

**How many were waiting to be admitted to a bed?**

From other wards in this hospital

**3 patients**

From other hospitals

**3 patients**

**18 acute beds**

 available at **Royal North Shore**

**How many patients were in a bed waiting to be discharged?**

**13 patients**



**How long had they been waiting?**

**1–133 days**

(Median = 14 days)

**Why had they been waiting?**

- 11 patients waiting for RR bed
- 2 patients waiting for National Disability Insurance Scheme (NDIS) plan approvals to go home directly

**How many were waiting to be admitted to a bed?**

From other wards in this hospital

**6 patients**

From other hospitals

**1 patient**

**20 rehabilitation beds**

 available at **Royal Rehab**

**How many patients were in a bed waiting to be discharged?**

**8 patients**



**How long had they been waiting?**

**30–252 days**

(Median = 62 days)

**Why had they been waiting?**

- 7 patients waiting for NDIS plan approvals to go home directly
- 1 non resident awaiting accommodation

**How many were waiting to be admitted to a bed?**

From other wards in this hospital

**1 patient**

From other hospitals

**11 patients**

Source: Access and exit block data SCIU.<sup>41</sup>

## Community and primary care

In 2017, the Spinal Outreach Service provided services to 157 people with spinal cord injury living in the community after hospital discharge. Each client received an average 37.5 hours of input from the multidisciplinary team of occupational therapy (30% of contact time), nursing (21.5%), social work (28%), physiotherapy (15%) and medical and other (6.5%).<sup>39</sup>

In 2017, the Rural Spinal Cord Injury Service had about 700 patients on its database across six rural and regional LHDs in NSW (Table 4).

Between 2007 and 2017, the service conducted an average of 10 rural visits and 120 comprehensive health and wellbeing assessments per year. In the first nine months of 2018, demand for services exceeded capacity and almost 37% of referred

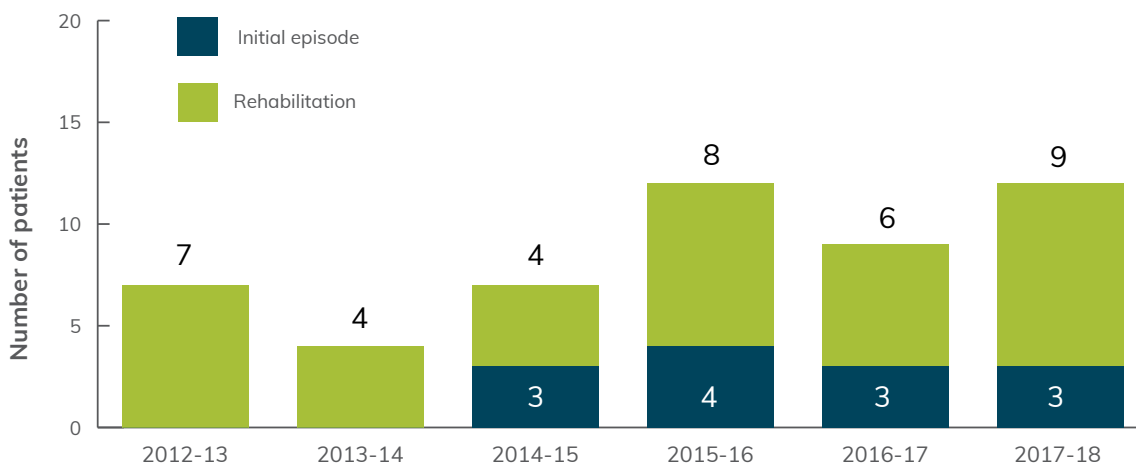
patients were unable to access care. The service also conducted 94 education workshops across all rural and regional LHDs to around 2,500 attendees – an average of 250 clinicians attended each year.

In 2017 Hunter Spinal Cord injury Service provided services to 190 people with spinal cord injury including people post-discharge from their index admission, post-discharge from subsequent hospitalisations and referrals directly from the community; each person received an average 19 hours of input from the multidisciplinary team. In the same year 49 outpatient spinal cord injury clinic appointments were conducted in collaboration with John Hunter Hospital Rehabilitation Medicine.<sup>32</sup>

Table 4: Number of patients registered and managed by the Rural Spinal Outreach Service <sup>32,40</sup>

Hunter New England	Mid North Coast	Murrumbidgee	Northern NSW	Southern NSW	Western NSW	Total
113	117	101	149	92	123	695

Figure 12: Number of patients with spinal cord injury discharged from specialist care to nursing home, 2012-13 to 2017-18



Source: Australasian Rehabilitation Outcomes Centre.<sup>38</sup>



Data on discharge destinations provide some insight into the extent to which patients are supported to go home, and the proportion of patients who are discharged to nursing homes – which are not well suited to meet the needs of people with spinal cord injury. Between 2012-13 and 2017-18, the number of patients discharged from a specialist unit to a nursing home increased from 7 to 12, from 0% to 2% of patients discharged after initial care and from 7% to 8% of discharged rehabilitation patients (Figure 12).

People with spinal cord injury are at risk of a range of complications, including pneumonia, autonomic dysreflexia, blood clots, pressure injuries, urinary and bowel problems, and depression.

*"Every time I try to make it all work for myself I get another pressure injury and end up back in hospital. I can't do anything whilst I am in hospital. It affects my work and I just got the promotion I wanted. I've been working towards*

*this promotion for years and now I have to tell my employer that I need a minimum two months off work. This is awkward for me as a new manager and makes me look bad."*

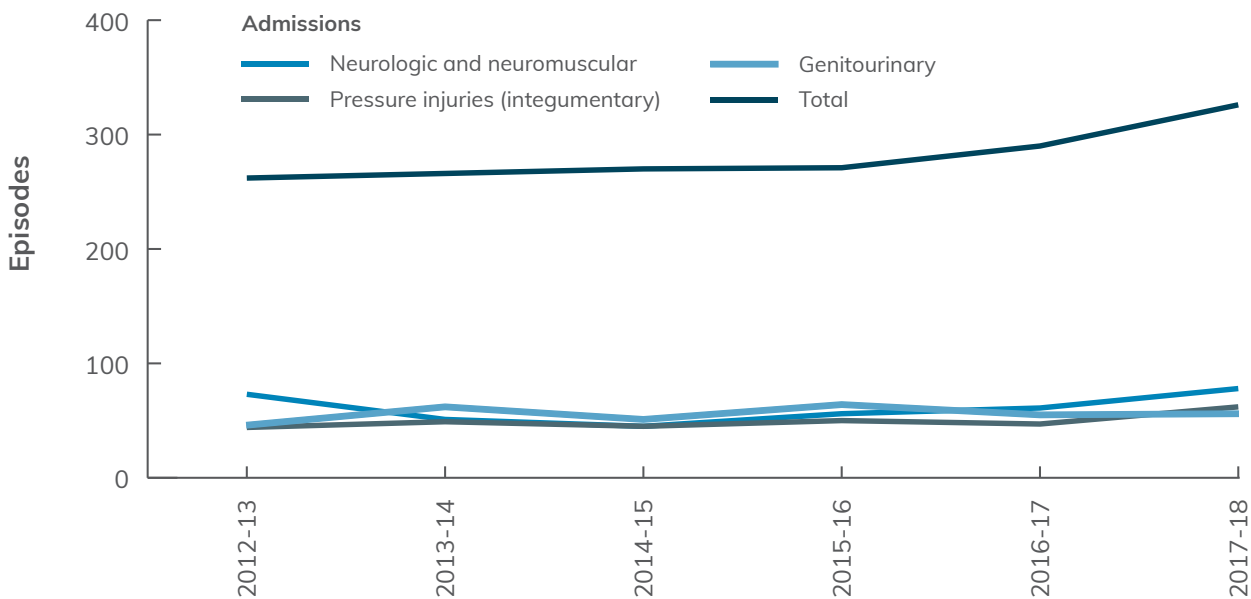
– Person with spinal cord injury.

While some hospitalisations for these complications are unavoidable, many are potentially preventable with effective community and primary care.

In 2017-18, there were 326 re-hospitalisations for complications to specialist units among people with established spinal cord injury, an increase from 262 in 2012-13 (Figure 13). In 2017-18, the median length of stay for hospitalisation was eight days (range 1-310 days).<sup>37</sup>

The three main types of complications were neurological and neuromuscular (24% of total and average length of stay (ALOS) of 14 days); pressure injuries (19%; ALOS 57 days); and genitourinary (17%, ALOS 9 days).<sup>33,35</sup>

Figure 13: Re-hospitalisations by people with established spinal cord injury to specialist spinal cord injury units, total and selected principal diagnoses, 2012-13 to 2017-18



# Patient and carer perspectives

Patient and carer perspectives on spinal cord injury care are essential to understand what is working well in current delivery arrangements and where there may be gaps in meeting their physical, mental, emotional and social needs.

In 2016-17, an online survey was completed by 47 people living with spinal cord injury. They provided feedback on many aspects of care and support in various settings (Figure 14).

For most respondents, care and treatment while in hospital was led by a health professional (62%) and was well coordinated (54%). However, 33% of respondents reported that care from different clinicians and parts of the hospital was not well coordinated. While in rehabilitation, 62% of respondents said they were involved in goal-setting and 54% said their rehabilitation goals were achieved or mostly achieved. Transition to living in the community was the aspect of care with the highest proportion of negative experiences.

In this aspect, 47% of respondents reported no nominated worker to lead and coordinate the transition to the community, 41% reported no follow-up post discharge, and 51% felt they were inadequately prepared for living in the community.

People with spinal cord injury were also asked to contribute stories about their experiences of care at Prince of Wales Spinal Unit, Royal North Shore Spinal Unit, Royal Rehab, and the Spinal Outreach Service.

Peter’s story highlights the importance of specialist rehabilitation, the Spinal Outreach Service and financial support to live well with a spinal cord injury at home and in the community. In contrast, some patients commented on a lack of financial support to live at home and the distress caused by having stay in hospital or at an aged care facility. Tom’s story reflects how the coordinated approach within the specialist units is often not available in generalist facilities.

Figure 14: Spinal cord injury patient survey, 2016-17

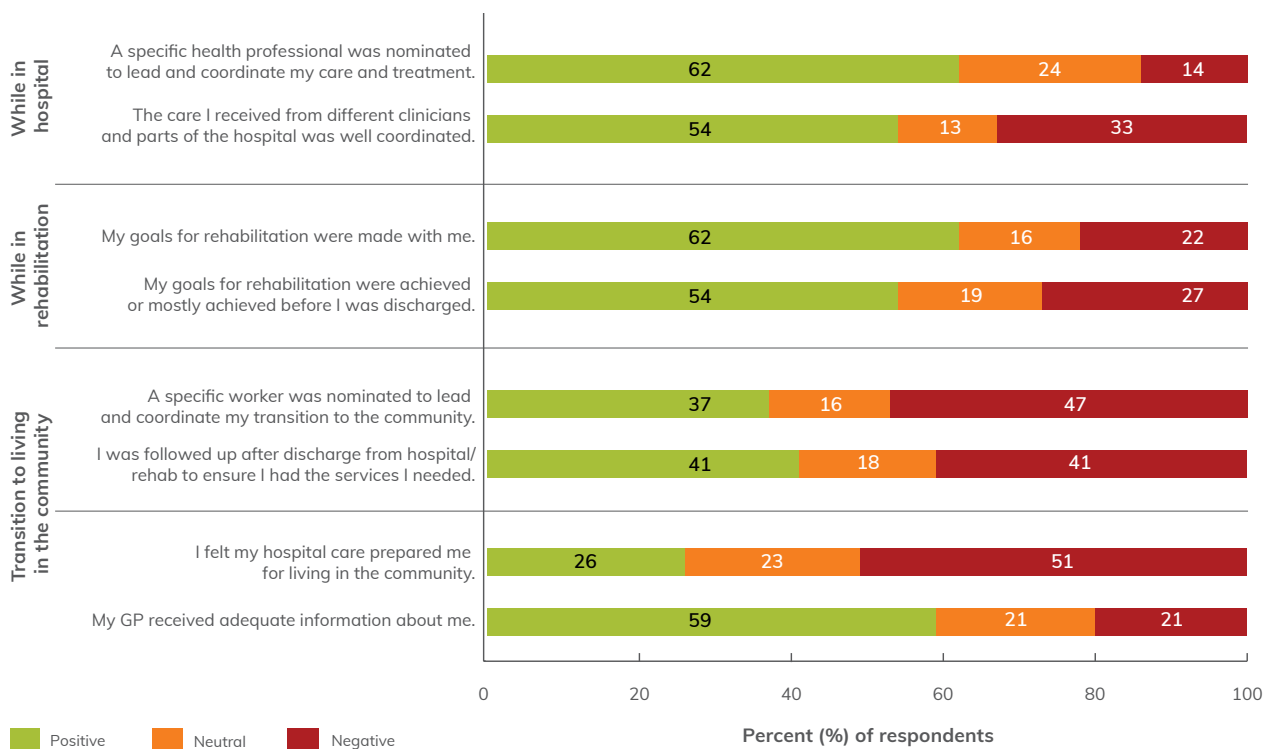


Figure 15: Spinal cord injury patient stories

### Peter's story

Peter is a 29-year-old man who sustained a complete C5 (tetraplegia) spinal cord injury after falling from a third-floor balcony. Peter was taken by ambulance to the spinal specialist trauma centre. After a comprehensive assessment by the trauma team, he was transferred to the operating theatre for early surgical decompression and stabilisation. This was followed by seven days of intensive care.

Peter was then transferred to the acute spinal cord injury unit where he spent five weeks. He initially struggled with his breathing and was unable to move his arms and legs. He often felt overwhelmed by his injury. Peter found it difficult to accept that he would not be able to walk again or return to his normal job as a builder, and would need to move back in with his parents to support his daily living.

When medically stable, Peter was transferred to the spinal cord injury rehabilitation unit where he spent 21 weeks. The focus was on achieving his goals to enable him to return to life in the community. Peter underwent daily rehabilitation to improve mobility and independence and attended group learning activities with other patients, family members and peer support workers and the vocational rehabilitation counsellors. He also made initial contact with the Spinal Outreach Service (SOS).

After approval of the NDIS package and other support arrangements, Peter was discharged to his parents' home. He received follow-up care from the SOS, referral to mainstream services, and calls from the vocational consultant and peer support worker.

Peter quickly adapted to life in the community with support and encouragement from his family, friends, specialist care team and his preferred GP and primary healthcare team. The construction firm he had worked for prior to injury supported his return to part-time work and provided funding for him to re-train in building project management.

### Tom's story

Tom had a fall resulting in a C6 incomplete spinal cord injury. He was taken to a nearby hospital and operated on. He was put on the waiting list to transfer to the Spinal Injuries Unit in Sydney for rehabilitation, but had to wait six weeks for a bed to become available. The staff in the neurosurgery ward were great, but they were not sure how best to care for Tom and had to contact the Spinal ward regularly for advice and guidance.

Once transferred to the spinal unit, Tom felt reassured because the staff knew how to look after him and had better equipment. He also got a lot of support from other patients, especially in the rehabilitation gym. It was difficult being far from home, and his wife and children could only visit on weekends, but he felt like he was getting the best care possible.

After finishing his spinal specific rehabilitation, Tom was transferred back to a local rehabilitation facility to be closer to his family. However, he felt abandoned there because they did not have a power wheelchair for him. Tom had to hire one from a local supplier and it took a week to arrive. He felt like he knew more about his needs than the staff did.

Once Tom's own equipment arrived, carers were organised and his home modified, he was discharged home. His wife helped him until all of his care became available. He did not receive any follow up care from the spinal unit and is not sure if he will be able to go back to work. He finds it helpful to talk to other patients from the Spinal Cord Injury Unit but wishes he could access the support they receive in Sydney.

# Clinician perspectives on best practice management

Through a series of interviews conducted by Nexus Management, clinicians were asked to describe what works best across the care continuum for people with spinal cord injury.

The clinicians described how the profound, life-changing consequences associated with spinal cord injury can be addressed or compensated for with the right access to specialist support, services and equipment.

Comprehensive care across life stages requires ongoing access to highly specialised services, with an interdisciplinary approach to addressing medical, physical, functional, psychological, social, vocational and leisure issues. The complex mix of interdependent services described below currently exist within the specialist services and are generally not available at the non-specialist services.

- Regular, periodic specialised medical assessment of complex comorbid multisystem problems related to the injury, including planned medical interventions, surgery and specialised investigations performed in hospital, such as overnight sleep studies.
- Hospital beds for planned and unplanned admissions.
- Subspecialty consultations, including cardiology, endocrine, gastroenterology, neurosurgery, orthopaedics, pain management, plastic surgery, psychiatry, respiratory medicine, upper limb reconstructive surgery and urology.
- Expert nursing staff and clinical nurse educators to:
  - assist the individual and family/carers to learn about their health condition
  - adapt to a new lifestyle and develop self-management skills for self-care activities of daily living and health maintenance in line with their changed abilities and limitations.
- Occupational therapy staff who:
  - review and prescribe appropriate and tailored adaptive equipment (e.g. activities of daily living devices, splints, wheelchair and cushion)
  - carry out home assessments and recommend modifications to enable the person to live independently
  - prescribe specialised assistive technologies, including environmental control systems, to support the person with impaired function to live in their own home.
- Physiotherapy staff who:
  - optimise the individual's physical performance and independence for mobility in everyday living and community access (including respiratory management and orthotic prescription)
  - provide education and therapy to reduce the long-term risk of overuse injuries, and optimise function as a person ages.

- Social workers and clinical psychologists to provide counseling, family therapy, individual psychotherapy, and training to develop self-management and coping skills to assist with dealing with life challenges, mood and adjustment disorders.
- A therapeutic recreation specialist to:
  - assist patients develop leisure skills
  - eliminate barriers to participation
  - use leisure activities as a way to promote health, functioning and quality of life in the community.
- A range of other specialist spinal cord injury service providers, such as dietitians, rehabilitation engineers, orthotists, vocational rehabilitation counselors and assistive technology specialists.
- Trained peers with spinal cord injury who can provide a unique form of support, encouragement, role modeling and mentoring, complementing the care from the treating health professional team.
- Appropriately trained carers with skills and knowledge in prevention and early intervention of complications and/or the ability to support the individual to initiate timely healthcare review.

*It's really important that all of the staff from surgical dressers and therapists, to the doctors and nurses, work well together and talk to each other to make sure that things don't go wrong.*

– Person with a spinal cord injury

# Current gaps in spinal cord injury care

## Acute care

The goals of acute care in spinal cord injury patients are to optimise survival rates, enhance functional recovery and reduce complications by providing evidence-based specialist care in a specialist unit and/or by providing multidisciplinary in-reach support where spinal cord injury unit beds are not available.

**Research evidence:** Specialist acute care is associated with better patient outcomes.

**Research evidence:** Early surgery (in the first 24 hours) is recommended and associated with better patient outcomes.

**Guidelines:** All patients with spinal cord injury admitted to hospital should have a written care plan that outlines (among other requirements) prophylaxis for thromboembolism, respiratory care, bladder and bowel programmes, diligent skin care to prevent pressure injury, and adequate nutrition.

The following data outline the current gaps in acute care:

- In 2017-18, 195 of the 344 people (57%) who had a serious spinal cord injury did not access specialist spinal cord injury care during their index hospitalisation.
- Of the 38 index cases transferred to a specialist spinal cord injury unit in 2017-18, the majority (30 patients, 79%) occurred outside of the recommended transfer guidelines.
- Currently there are 28 specialist acute beds in NSW. Additional patients may warrant admission to an acute specialist unit each year.
- Non-specialist hospitals lack the necessary range and scope of skills, staff and equipment to manage people who meet the criteria for admission to a specialist unit, but cannot be admitted due to lack of bed availability.

- In 2017-18, 183 of the 344 patients with a serious spinal cord injury had a spinal decompression or spinal fusion procedure during their index hospitalisation. The date of the procedure was available for 136 patients. Of these 136 patients, 93 (68%) had the procedure on the same day as admission or one day after admission. Patients were more likely to receive the procedure in a timely manner if admitted directly to a specialist hospital (51 out of 63, 81% [four with unknown procedure date]) compared with patients who received non-specialist care only (31 out of 52, 60% [15 with unknown procedure date]).
- Patients are often occupying specialist acute beds waiting to transition to rehabilitation. In 2017-18, the median delay was 20 days (range 1-195 days).
- In 2017-18, there were 1,658 acute overnight hospitalisations by people with a history of serious spinal cord injury. Most of these (84%) occurred in a non-specialist hospital. There were 68 non-specialist hospitals that admitted fewer than 10 patients for acute overnight care.

## Rehabilitation care

**Research evidence:** Most people with spinal cord injury make significant functional gains during inpatient rehabilitation. Those initially cared for in interdisciplinary, specialist units achieve more or faster functional gains during rehabilitation.

**Research evidence:** There is some evidence of a dose effect with rehabilitation – more rehabilitation is associated with better outcomes (based on FIM gains), up to a point/ceiling.

**Research evidence:** For patients with non-traumatic spinal cord injury, those admitted into specialist units had greater functional improvements during rehabilitation. This may also be true for patients with traumatic spinal cord injury.

**Guidelines:** Rehabilitation should be offered to patients with acute spinal cord injury when they are medically stable and can tolerate the required rehabilitation intensity.

**Guidelines:** All hospitalised patients with spinal cord injury should have appropriate discharge planning involving:

- the patient and his or her family and carers
- relevant members of the multidisciplinary team
- direct contact with the community care team.

**Guidelines:** The following should be in place before discharge:

- care plans for psychosocial care
- arrangements for transport, care and equipment needs
- full reports from all professionals involved with patients' care
- appropriate arrangements made for future outpatient or review appointments.

The following data point to current gaps in rehabilitation:

- In 2017, 183 of 295 rehabilitation episodes (62%) occurred in non-specialist rehabilitation units. For most classes of traumatic and non-traumatic spinal cord injury, patients achieve higher functional gains in specialist rehabilitation units compared with non-specialist units.
- For many patients who are clinically ready to transition to living in the community, there are substantial delays waiting for suitable accommodation and modifications. For example, on the 10 December 2019, for patients ready for discharge from rehabilitation at Prince of Wales and Royal Rehab, the median wait was 25 days and 62 days respectively.

- Nursing homes are not well suited to meet the needs of people with spinal cord injury. Between 2012-13 and 2017-18, the number of patients discharged from a specialist unit to a nursing home increased from 7 to 12 (from 0% to 2% of patients discharged after initial care and from 7% to 8% of discharged rehabilitation patients).

## Community care

**Research evidence:** Rural clinician confidence is improved by training.

**Research evidence:** Telehealth is an effective way to provide support to people with spinal cord injury living in the community.

**Research evidence:** Internationally, there is evidence of unmet health needs among individuals living with spinal cord injury in the community.

**Research evidence:** Routine, comprehensive, specialist follow-up services can result in improved health.

The following data point to current gaps in community care:

- In 2017-18, there were 326 re-hospitalisations to specialist units for complications among people with established spinal cord injury. While not all complications are avoidable, some are potentially preventable with appropriate community and primary care.
- People living in the Sydney metropolitan area and Illawarra Shoalhaven area, do not have access to similar level of lifelong multidisciplinary follow up for health promotion and early intervention offered by Rural Spinal Cord Injury Service.
- In the first nine months of 2018, demand for the Rural Spinal Cord Injury Service exceeded capacity and almost 37% of referred patients were unable to access care.

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## Appendix 1: Spinal cord diagnosis codes

Spinal cord diagnosis codes are provided in Table 5.

**Table 5: International Classification of Diseases - 10th revision - Australian Modification (ICD-10-AM) diagnosis codes for spinal cord injury**

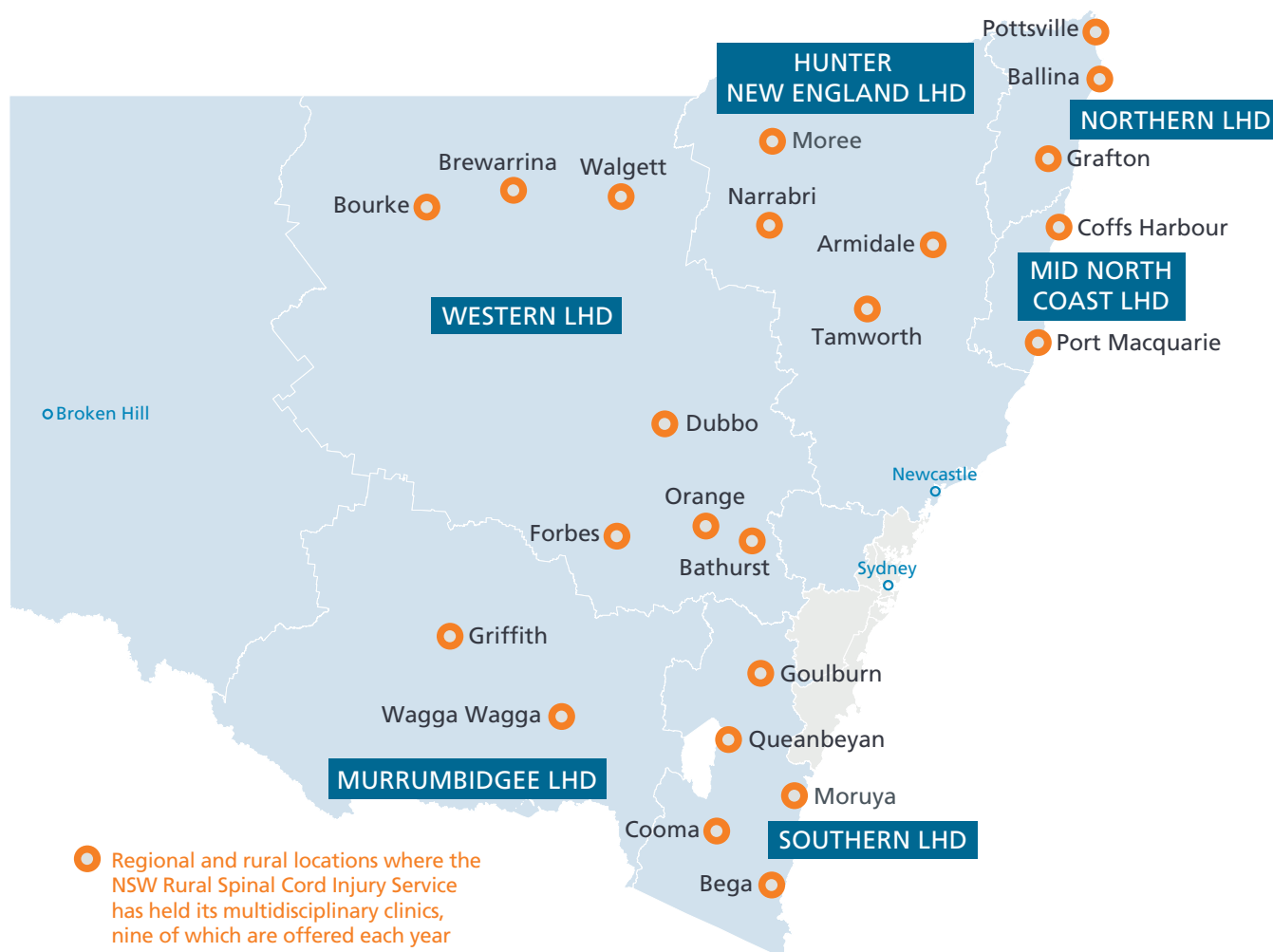
ICD-10-AM diagnosis code	Description
D33.4	Benign neoplasm of spinal cord
G82.01	Flaccid paraplegia, unspecified, acute
G82.03	Flaccid paraplegia, complete, acute
G82.05	Flaccid paraplegia, incomplete, acute
G82.11	Spastic paraplegia, unspecified, acute
G82.13	Spastic paraplegia, complete, acute
G82.15	Spastic paraplegia, incomplete, acute
G82.21	Paraplegia, unspecified, acute
G82.23	Paraplegia, unspecified, complete, acute
G82.25	Paraplegia, unspecified, incomplete, acute
G82.31	Flaccid tetraplegia, unspecified, acute
G82.33	Flaccid tetraplegia, complete, acute
G82.35	Flaccid tetraplegia, incomplete, acute
G82.41	Spastic tetraplegia, unspecified, acute
G82.43	Spastic tetraplegia, complete, acute
G82.45	Spastic tetraplegia, incomplete, acute
G82.51	Tetraplegia, unspecified, acute
G82.53	Tetraplegia, complete, acute
G82.55	Tetraplegia, incomplete, acute
G83.4	Cauda equina syndrome
S14.10	Injury of cervical spinal cord unspecified
S14.11	Complete lesion of cervical spinal cord
S14.12	Central cord syndrome [incomplete cord injury] of cervical spinal cord
S14.13	Other incomplete cord syndrome of cervical spinal cord
S14.7x	Functional level of cervical spinal cord injury
S24.10	Injury of thoracic spinal cord unspecified
S24.11	Complete lesion of thoracic spinal cord
S24.12	Incomplete cord syndrome of thoracic spinal cord
S24.7x	Functional level of thoracic spinal cord injury
S34.3	Injury of cauda equina
S34.7x	Functional level of lumbar spinal cord injury

Note: A serious spinal cord injury is defined as: First ever acute hospitalisation with a spinal cord diagnosis code as the principal diagnosis or any additional diagnosis and an acute length of stay of more than five days or rehabilitation length of stay of more than 30 days.

## Appendix 2: NSW Rural Spinal Cord Injury Service

The below map (Figure 16) shows the regional and rural locations where the NSW Rural Spinal Cord Injury Service has held its multidisciplinary clinics, nine of which are offered each year.

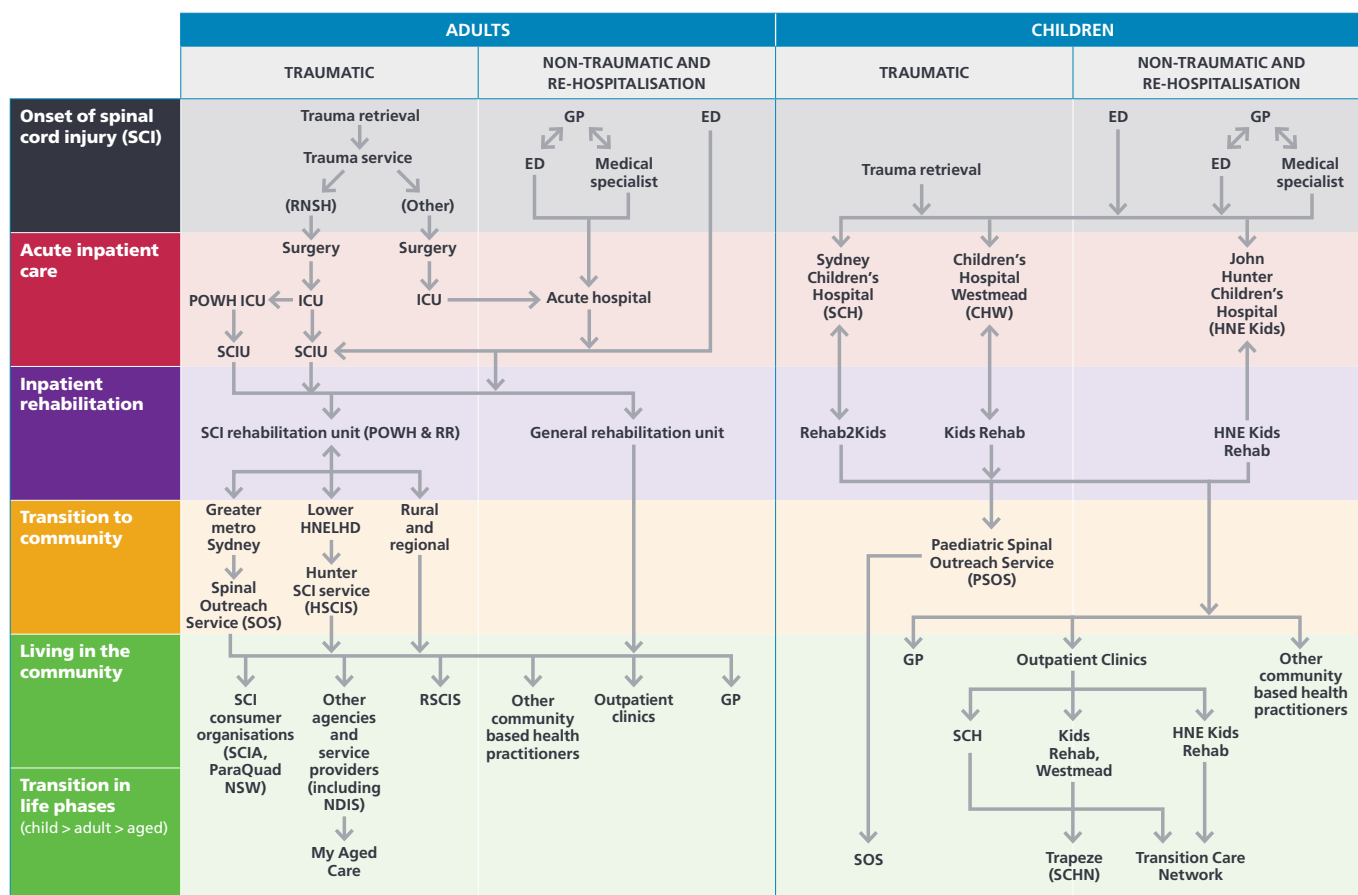
Table 16: NSW Rural Spinal Cord Injury Service multidisciplinary clinics



# Appendix 3: Spinal cord injury services in NSW

The below schematic (Figure 16) provides a schema of spinal cord injury services in NSW

Figure 17: Schematic of spinal cord injury services in NSW



## Abbreviations

CHW	Children's Hospital Westmead
ED	Emergency Department
GP	General Practitioner
HNE	Hunter New England
HNELHD	Hunter New England Local Health District
HSCIS	Hunter Spinal Cord Injury Service
ICU	Intensive care unit
NDIS	National Disability Insurance Scheme
NSW	New South Wales
POWH	Prince of Wales Hospital

PSOS	Paediatric Spinal Outreach Service, Northcott
RNSH	Royal North Shore Hospital
RR	Royal Rehab
RSCIS	Rural Spinal Cord Injury Service
SCH	Sydney Children's Hospital
SCHN	Sydney Children's Hospitals Network
SCIA	Spinal Cord Injuries Australia
SCIU	Spinal Cord Injury Unit
SCI	Spinal Cord Injury
SOS	Spinal Outreach Service

## Appendix 4: Trauma diagnosis codes

The following trauma diagnosis codes (Table 6) were used to classify serious spinal cord injuries as traumatic or non-traumatic.

Table 6: ICD-10-AM diagnosis codes for trauma

ICD-10-AM diagnosis codes	Description
V01-V99	Transport accidents
W00-X59	Other external causes of accidental injury
X60-X84	Intentional self-harm
X85-Y09	Assault
Y10-Y34	Event of undetermined intent
Y35-Y36	Legal intervention and operations of war
Y40-Y84	Complications of medical and surgical care
Y85-Y89	Sequelae of external causes of morbidity and mortality

## Appendix 5: Bowel and bladder problems diagnosis codes

The following bowel and bladder problem diagnosis codes (Table 7) were used to classify injuries of cauda equina with or without bowel and bladder dysfunction.

Table 7: ICD-10-AM diagnosis codes for bowel and bladder problems

ICD-10-AM diagnosis codes	Description
K59	Other functional intestinal disorders
N39	Other disorders of urinary system
R15	Faecal incontinence
R19.5	Other faecal abnormalities
R32	Unspecified urinary incontinence
R33	Retention of urine

## Appendix 6: Spinal decompression and spinal fusion procedure codes

The following spinal decompression and spinal fusion procedure codes (Table 8) were used to identify patients with serious spinal cord injury who had spinal decompression or spinal fusion procedure during their index hospitalisation.

Table 8: ACHI procedure codes for spinal decompression and spinal fusion

ACHI procedure code	Description
<b>Spinal decompression</b>	
90024-00	Decompression of lumbar spinal canal, 1 level
90024-01	Decompression of lumbar spinal canal, >=2 levels
40330-00	Spinal rhizolysis
40303-00	Discectomy for recurrent disc lesion, 1 level
40303-01	Discectomy for recurrent disc lesion, 2 levels
48636-00	Percutaneous lumbar discectomy
40300-00	Discectomy, 1 level
40300-01	Discectomy, >=2 levels
40331-00	Decompression of cervical spinal cord, 1 level
40332-00	Decompression of cervical spinal cord with anterior fusion, 1 level
40333-00	Cervical discectomy, 1 level
40333-01	Cervical discectomy, 2 or more levels
40334-00	Decompression of cervical spinal cord, 2 or more levels
40335-00	Decompression of cervical spinal cord with anterior fusion, 2 or more levels
40345-00	Decompression of thoracic spinal cord via costotransversectomy
40348-00	Decompression of thoracic spinal cord via thoracotomy
40351-00	Anterior decompression of thoracolumbar spinal cord
<b>Spinal fusion</b>	
40351-00	Anterior decompression of thoracolumbar spinal cord
48660-00	Anterior spinal fusion, 1 level
48669-00	Anterior spinal fusion, >=2 levels
48642-00	Posterior spinal fusion, 1 or 2 levels
48645-00	Posterior spinal fusion, >=3 levels
48648-00	Posterolateral spinal fusion, 1 or 2 levels
48651-00	Posterolateral spinal fusion, >=3 levels
48654-00	Posterior spinal fusion with laminectomy, 1 level
48657-00	Posterior spinal fusion with laminectomy, >=2 levels
48654-01	Posterolateral spinal fusion with laminectomy, 1 level
48657-01	Posterolateral spinal fusion with laminectomy, >=2 levels

## Appendix 7: Hospital-acquired complications

The specifications for hospital-acquired complications developed by the Australian Commission on Safety and Quality in Health Care were used to identify hospital-acquired complications in the spinal cord injury cohort. The specifications are available at: <https://safetyandquality.govcms.gov.au/publications-and-resources/resource-library/hospital-acquired-complications-hacs-list-specifications-version-30>. A summary of the complication codes are provided below (Table 9-12) but the Commission's website should be referred to for full indicator specifications.

### Healthcare-associated infection

Table 9: ICD-10-AM diagnosis codes for healthcare-associated infection

ICD-10-AM diagnosis codes	Description
90024-00	Decompression of lumbar spinal canal, 1 level
N39.0, N30.0, O86.2, T83.5	Urinary tract infection
T81.4, T87.4, O86.0	Surgical site infection
J10.0, J11.0, J12.0, J12.1, J12.2, J12.3, J12.8, J12.9, J13, J14, J15.0, J15.1, J15.2, J15.3, J15.4, J15.5, J15.6, J15.7, J15.8, J15.9, J16.0, J16.8, J17.0, J17.1, J17.2, J17.3, J17.8, J18.0, J18.1, J18.2, J18.8, J18.9, J22	Pneumonia
A40.0, A40.1, A40.2, A41.0, A41.51, A41.52, A41.58,	Discectomy for recurrent disc lesion, 2 levels
B37.7, P36.0, P36.2, P36.4, U90.0	Blood stream infection
T82.7	Discectomy, 1 level
Z06.50, Z06.51, Z06.52, Z06.53, Z06.58, Z06.60, Z06.61, Z06.62, Z06.63, Z06.67, Z06.69, Z06.70, Z06.71, Z06.72, Z06.73, Z06.7, Z06.77, Z06.78	Infections or inflammatory complications associated with peripheral/central venous catheters
Z06.50, Z06.51, Z06.52, Z06.53, Z06.58, Z06.60, Z06.61, Z06.62, Z06.63, Z06.67, Z06.69, Z06.70, Z06.71, Z06.72, Z06.73, Z06.74, Z06.77, Z06.78	Multi-resistant organism
T82.6, T82.7, T83.6, T84.5, T84.6, T84.7, T85.71, T85.72, T85.78	Infection associated with prosthetics/implantable devices
A02.0, A02.2, A02.8, A02.9, A04.0, A04.1, A04.2, A04.3, A04.4, A04.5, A04.6, A04.7, A04.8, A04.9, A05.0, A05.1, A05.2, A05.3, A05.4, A05.8, A05.9, A06.0, A06.2, A06.3, A06.9, A07.0, A07.1, A07.2, A07.3, A07.8, A07.9, A08.0, A08.1, A08.2, A08.3, A08.4, A08.5	Gastrointestinal infections
A41.1, A41.2, A41.3, A41.4, A41.50, A40.3, A40.8, A40.9, A41.8, A41.9, A48.0, A02.1, A32.7, A48.8, A49.00, A49.01, A49.1, A49.8, A49.9, R65.1, R57.2, O85, P36.1, P36.3, P36.5, P36.8, P36.9	Other high impact infections

The healthcare-associated infection diagnosis code must be accompanied by a condition onset flag of 'Condition with onset during the episode of admitted patient care' to be hospital-acquired.

## Respiratory complications

Table 10: ICD-10-AM diagnosis codes for respiratory complications

ICD-10-AM diagnosis codes	Description
J80,J96.00,J96.01,J96.09,J96.90,J96.91,J96.99	Respiratory failure including acute respiratory distress syndromes requiring ventilation*
J69.0,J69.8,J95.4,O74.0,J95.8	Aspiration pneumonia
J81	Pulmonary oedema

\* And procedure code 13882-00, 13882-01, 13882-02, 92209-01, 92209-02

The respiratory complication diagnosis code must be accompanied by a condition onset flag of 'Condition with onset during the episode of admitted patient care' to be hospital-acquired.

## Pressure injury

Table 11: ICD-10-AM diagnosis codes for pressure injury

ICD-10-AM diagnosis codes	Description
L89.20,L89.21,L89.22,L89.23,L89.24,L89.25,L89.26,L89.27, L89.28,L89.29	Stage III ulcer
L89.30,L89.31,L89.32,L89.33,L89.34,L89.35,L89.36,L89.37, L89.38,L89.39	Stage IV ulcer
L89.90,L89.91,L89.92,L89.93,L89.94,L89.95,L89.96,L89.97, L89.98,L89.99	Unspecified decubitus and pressure area
L89.40,L89.41,L89.42,L89.43,L89.44,L89.45,L89.46,L89.47, L89.48,L89.49	Unstageable pressure injury
L89.50,L89.51,L89.52,L89.53,L89.54,L89.55,L89.56,L89.57, L89.58,L89.59	Suspected deep tissue injury

The pressure injury diagnosis code must be accompanied by a condition onset flag of 'Condition with onset during the episode of admitted patient care' to be hospital-acquired.

## Falls resulting in fracture or intracranial injury

Table 12: ICD-10-AM diagnosis codes for fracture or intracranial injury

ICD-10-AM diagnosis codes	Description
S06.00, S06.01, S06.02, S06.03, S06.04, S06.05, S06.1, S06.20, S06.21, S06.22, S06.23, S06.28, S06.30, S06.31, S06.32, S06.33, S06.34, S06.38, S06.4, S06.5, S06.6, S06.8, S06.9	Intracranial injury
S72.00, S72.01, S72.02, S72.03, S72.04, S72.05, S72.08, S72.10, S72.11, S72.2	Fractured neck of femur
S02.0, S02.1, S02.2, S02.3, S02.4, S02.5, S02.60, S02.61, S02.62, S02.63, S02.64, S02.65, S02.66, S02.67, S02.68, S02.69, S02.7, S02.8, S02.9, S07.0, S07.1, S07.8, S07.9, S12.0, S12.1, S12.21, S12.22, S12.23, S12.24, S12.25, S12.7, S12.8, S12.9, S19.7, S22.00, S22.01, S22.02, S22.03, S22.04, S22.05, S22.06, S22.1, S22.2, S22.31, S22.32, S22.40, S22.41, S22.42, S22.43, S22.44, S22.5, S22.8, S22.9, S28.0, S29.7, S32.00, S32.01, S32.02, S32.03, S32.04, S32.05, S32.1, S32.2, S32.3, S32.4, S32.5, S32.7, S32.81, S32.82, S32.83, S32.89, S39.7, S42.00, S42.01, S42.02, S42.03, S42.09, S42.10, S42.11, S42.12, S42.13, S42.14, S42.19, S42.20, S42.21, S42.22, S42.23, S42.24, S42.29, S42.3, S42.40, S42.41, S42.42, S42.43, S42.44, S42.45, S42.49, S42.7, S42.8, S42.9, S49.7, S52.00, S52.01, S52.02, S52.09, S52.10, S52.11, S52.12, S52.19, S52.20, S52.21, S52.30, S52.31, S52.4, S52.50, S52.51, S52.52, S52.53, S52.59, S52.6, S52.7, S52.8, S52.9, S59.7, S62.0, S62.10, S62.11, S62.12, S62.13, S62.14, S62.15, S62.16, S62.17, S62.19, S62.20, S62.21, S62.22, S62.23, S62.24, S62.30, S62.31, S62.32, S62.33, S62.34, S62.4, S62.50, S62.51, S62.52, S62.60, S62.61, S62.62, S62.63, S62.7, S62.8, S69.7, S72.3, S72.40, S72.41, S72.42, S72.43, S72.44, S72.7, S72.8, S72.9, S79.7, S82.0, S82.11, S82.18, S82.21, S82.28, S82.31, S82.38, S82.40, S82.41, S82.42, S82.49, S82.5, S82.6, S82.7, S82.81, S82.82, S82.88, S82.9, S89.7, S92.0, S92.1, S92.20, S92.21, S92.22, S92.23, S92.28, S92.3, S92.4, S92.5, S92.7, S92.9, S99.7	Other fractures

The fracture or intracranial injury diagnosis code must be accompanied by an external cause code of fall and a condition onset flag of 'Condition with onset during the episode of admitted patient care' to be hospital-acquired.



# Acknowledgements

We would like to thank Spinal Cord Injury Clinical Development Committee and members of the network who provided feedback and advice.

The Agency for Clinical Innovation (ACI) is the lead agency for innovation in clinical care.

We bring consumers, clinicians and healthcare managers together to support the design, assessment and implementation of clinical innovations across the NSW public health system to change the way that care is delivered.

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