Spinal Cord Injury Model of Care
Diagnostic Report - Draft

State Spinal Cord Injury Service (SSCIS)

The Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. It does this through:

- **service redesign and evaluation** – applying redesign methodology to assist healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services
- **specialist advice on healthcare innovation** – advising on the development, evaluation and adoption of healthcare innovations from optimal use through to disinvestment
- **initiatives including guidelines and models of care** – developing a range of evidence-based healthcare improvement initiatives to benefit the NSW health system
- **implementation support** – working with ACI Networks, consumers and healthcare providers to assist delivery of healthcare innovations into practice across metropolitan and rural NSW
- **knowledge sharing** – partnering with healthcare providers to support collaboration, learning capability and knowledge sharing on healthcare innovation and improvement
- **continuous capability building** – working with healthcare providers to build capability in redesign, project management and change management through the Centre for Healthcare Redesign.

ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to develop successful healthcare innovations.

A key priority for the ACI is identifying unwarranted variation in clinical practice. ACI teams work in partnership with healthcare providers to develop mechanisms aimed at reducing unwarranted variation and improving clinical practice and patient care.

# ACKNOWLEDGEMENTS

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### ABBREVIATIONS

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<tr>
<th>Abbreviation</th>
<th>Full Term</th>
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<tr>
<td>ABF</td>
<td>Activity Based Funding</td>
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<tr>
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<tr>
<td>ACT</td>
<td>Australian Capital Territory</td>
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<tr>
<td>AD</td>
<td>Autonomic dysreflexia</td>
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<td>ADHC</td>
<td>Ageing, Disability and Home Care</td>
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<td>ADL</td>
<td>Activities of daily living</td>
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<td>Allied Health Assistants</td>
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<td>AHS</td>
<td>Area Health Service</td>
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<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<td>ALOS</td>
<td>Average length of stay</td>
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<td>AMO</td>
<td>Attending Medical Officer</td>
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<tr>
<td>AT&amp;S</td>
<td>Assistive Technology &amp; Seating Service</td>
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<tr>
<td>BBQ</td>
<td>Barbecue</td>
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<tr>
<td>BIRP</td>
<td>Brain Injury Rehabilitation Program</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and linguistically diverse backgrounds</td>
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<td>CARPA</td>
<td>Community, Ambulatory, Rehabilitation, Population and Allied Health - A Directorate of the SCHN</td>
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<td>CATE</td>
<td>Critical Care, Acute Care, Trauma and Emergency Public Health Register</td>
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<td>Client-Centred Housing Offering Inspiring, Creating and Empowering Services</td>
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<td>CPDI</td>
<td>Clinical Program Design and Implementation (a Directorate in ACI)</td>
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<tr>
<td>DIC</td>
<td>Duration of initial care</td>
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<td>Disability management self-efficacy</td>
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<td>Day rehabilitation program</td>
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<td>Department of Veteran Affairs</td>
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<td>Full time equivalent</td>
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<td>Human Immunodeficiency Virus</td>
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<td>ISLHD</td>
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<td>ISNCSCI</td>
<td>International Standards for Neurological Classification of Spinal Cord Injury</td>
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<td>Abbreviation</td>
<td>Full Term</td>
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<td>John Hunter Children's Hospital</td>
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<td>Lifetime Care Support Scheme</td>
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<td>Multidisciplinary team</td>
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<td>Median length of stay</td>
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<td>Model of care</td>
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<td>Memorandum of understanding</td>
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<td>Non-government organisation</td>
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<td>New South Wales</td>
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<td>Northern Territory</td>
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<tr>
<td>NTSCI</td>
<td>Non-traumatic spinal cord injury</td>
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<td>Program of Appliances for Disabled People</td>
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<td>Return to work</td>
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<td>Sydney Children's Hospitals Network</td>
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<td>Spinal cord injury</td>
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<td>Specialty Health Network</td>
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<td>SIU</td>
<td>Spinal Injuries Unit</td>
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<td>Abbreviation</td>
<td>Full Term</td>
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<tr>
<td>SOS</td>
<td>NSW Spinal Outreach Service</td>
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<tr>
<td>SP</td>
<td>Speech Pathologist</td>
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<td>SPCC</td>
<td>Spinal Pressure Care Clinic</td>
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<td>SSCIS</td>
<td>NSW State Spinal Cord Injury Service</td>
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<td>Technical and Further Education</td>
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<td>TBI</td>
<td>Traumatic brain injury</td>
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<tr>
<td>TSCI</td>
<td>Traumatic spinal cord injury</td>
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<tr>
<td>VDT</td>
<td>Ventilator dependent tetraplegia</td>
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<tr>
<td>VMO</td>
<td>Visiting Medical Officer</td>
</tr>
<tr>
<td>WPITA</td>
<td>Westmead Post Traumatic Amnesia</td>
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EXECUTIVE SUMMARY

The State Spinal Cord Injury Service (SSCIS), a network of the NSW Agency for Clinical Innovation (ACI) is a series of statewide services responsible for the management of people who have sustained a spinal cord injury with evidence of damage to the neural tissues as a result of trauma, or from a non-progressive disease process. Traumatic SCI is caused by a direct or indirect external event (trauma), such as a motor vehicle accident, fall or sporting injury. Non-traumatic SCI (NTSCI) may be due to infection, haemorrhage, ischaemia, inflammation (myelitis) or benign tumours affecting the spinal cord, or spinal canal stenosis. Progressive conditions such as demyelinating and degenerative conditions of the spinal cord as well as compression by metastatic lesions are not the province of the spinal service.

The SSCIS has commenced the development of a new model of care for the management and support of children and adults with a spinal cord injury in NSW. In line with the ACI methodology, after a project initiation phase the first stage in the development of a model of care is a ‘diagnostic’ review which then leads to solution design and implementation of a more detailed improvement process. This report on the diagnostic phase aims to better understand spinal cord injury management systems and practices and to identify needs of consumers and evidence-practice gaps in service provision.

METHODS

The project methods have involved collating information from multiple sources, including:

- a selective review of the literature on best practice models of care, modes of service delivery for adults and children with spinal cord injury (see appendix 1 for the literature review)
- a series of visits to specialist spinal cord injury services and other health services across NSW (see appendix 2 for a list of the services visited)
- face-to-face and telephone consultations with over 25 people living with spinal cord injury, including parents of children with spinal cord injury (see section 4 for themes from consultations and appendix 2 for a list of those consulted)
- an online survey, distributed by the community-based organisations, ParaQuad NSW and Spinal Cord Injuries Australia, completed by 47 people living with spinal cord injury (see appendix 6 for full analysis of consumer survey)
- an extensive round of consultations with over 100 clinicians across NSW, including individual and group consultations (see section 5 for themes from consultations and appendix 2 for a list of those consulted)
- an online survey, distributed across the SSCIS network, completed by 43 clinicians (see section 5 – survey responses have been included in this section)
- a series of consultations with other key stakeholders, including government agencies, non-government organisations and consumer organisations (see appendix 2 for a list of those consulted)
- a workshop on 19 August 2016 with 45 key stakeholders to discuss some principles to underpin an ideal model of care and to identify key issues, service gaps and potential priorities for the solution design and implementation phases of the model of care (see appendix 4 for list of workshop participants).
SPINAL CORD INJURY: A SNAPSHOT

According to the Australian Institute of Health and Welfare (1), 362 new spinal cord injuries (SCI) were reported in Australia in 2007-08, the latest year for which data from the ASCIR1 is available. The majority (79%) of these were due to traumatic causes. In Australia non-traumatic SCI (NTSCI) is primarily due to degenerative conditions and tumours, compared to low income countries where NTSCI is predominantly due to infections (TB and HIV) (2).

Unlike adults, most SCI in children relates to non-traumatic causes including tumours and transverse myelitis. In fact, non-traumatic cases account for two thirds of children with spinal cord injury and the number of children with a newly acquired traumatic spinal cord injury each year is small.

Traumatic SCI (TSCI) was most frequent in the 15-24 year age group (30%), although trends show a significant increase in the average age at injury from 38 years in 1995-96 to 42 years in 2007-08. Males accounted for 84% of traumatic SCI. Transport-related injuries (46%) and falls (28%) were the main contributors to TSCI.

Available data provided the following overview of SCIs in NSW:

- the incidence estimates of New et al (3) would suggest a range of 291 to 361 to new SCI cases in NSW each year:
  - 130-200 traumatic
  - 161 non-traumatic
- the spinal units at Royal North Shore Hospital (RNSH) and Prince of Wales Hospital (POWH) have been treating approximately 130 new cases per year over the last seven years
- the majority of these cases have been traumatic although there has been considerable variation in the ratio of traumatic to non-traumatic cases over the last seven years
- the NSW health system can expect an increase in the proportion of older people with SCI.

The gap between the incidence estimates and actual numbers suggest that not all people with SCI in NSW are being seen in the two spinal injury units, especially those with NTSCI, or that the incidence estimates are an over-estimate.

SPINAL CORD INJURY SERVICES IN NSW

The SSCIS as a network of the Agency for Clinical Innovation (ACI) comprises approximately 300 clinician, management, consumer and researcher members across NSW and there are two key SSCIS governance bodies: the Steering Committee and the Clinical Development Committee, which are underpinned by a series of committees, sub-committees and special working groups, as shown in figure A.

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1 The Australian Spinal Cord Injury Register (ASCIR) is a national register of incident cases of spinal cord injury which occur in Australia and overseas to Australian residents. The ASCIR operates as a collective venture of the Directors of all six spinal units (SUs) in Australia and the National Injury Surveillance Unit (NISU), a Collaborating Unit of the Australian Institute of Health and Welfare (AIHW). The ASCIR is funded as part of the NISU program, which is managed and operated by the Flinders University Research Centre for Injury Studies (RCIS)
The network of services comprises (see appendix 5 for detail of services):

- **acute care**: two spinal cord injury units at POWH (10 acute beds) and RNSH (18-20 acute beds) admitting both acute / new SCIs and readmissions for complications and co-morbidities of SCI.
- **rehabilitation**: two units at POWH (20 beds, which are collocated with the acute unit) and Royal Rehab (20 beds).
- **outpatients** clinics: POWH, RNSH and Royal Rehab.
- **paediatric** services: the two hospitals in the Sydney Children’s Hospital Network and the John Hunter Children’s Hospital.
- **outreach** services: the NSW Spinal Outreach Service (SOS) for clients residing in the Sydney metropolitan area. The Rural Spinal Cord Injury Service (RSCIS) with RSCIS Coordinators located in, and funded by, rural LHDs work in a ‘hub and spoke’ model with the SOS, which conducts nine clinics per year at different towns across regional and rural NSW. The Paediatric Spinal Outreach Service located at the Northcott Disability Service for children across NSW.
- **community** care: services provided and/or funded by a number of agencies including Hunter Spinal Cord Injury Service, Spinal Cord Injuries Australia (SCIA), Paraplegic and Quadriplegic Association of NSW (ParaQuad NSW), Lifetime Care, Enable NSW and the Sargood Foundation, which will open in late 2017.

The development of the model of care is occurring in the context of transformational change with the implementation of the National Disability Insurance Scheme (NDIS) which will have profound, but still unresolved, implications for the relationship between the health and disability sectors. The role of the NSW government provider, Ageing Disability and Home Care (ADHC), in direct service provision is being wound down as the NDIS is progressively introduced across NSW.
Data included in this report was sourced from the NSW Spinal Cord Injury Database (SCID) managed by the SSCIS. It is important to note that the database only contains information on activity at the three adult inpatient units and does not contain data on:

• paediatric services
• the spinal outreach service and the rural spinal cord injury service
• outpatient clinics
• people with spinal cord injury who are admitted to other hospitals across NSW.

Data over the past seven years shows the following:

• The number of new spinal cord injury cases admitted each year to either RNSH or POWH ranged between 106 and 136.
• The majority were admitted to RNSH with the proportion fluctuating between 72% in 2014 to 59% in 2015
• Non-traumatic cases (NTSCI) accounted for approximately 23% of total new cases (24% at RNSH and 21% at POWH).
• The number of readmissions ranged between 181 and 291 per year. On average 67% of these patients were admitted to RNSH and 33% to POWH.
• Readmissions account for more than double the number of new spinal cord injury cases accounting for 42% of the bed days at RNSH and 58% of the bed days at POWH.
• Most (73%) readmissions were unplanned and 27% were planned. Unplanned readmissions represent 64% of the readmission bed days taking up approximately 11 beds in 2015.
• A total of 19 Aboriginal and Torres Strait Islander people with a SCI (2.2% of the total new cases) and 44 patients (5%) from a non-English speaking background were admitted.
• In relation to compensation covered by Lifetime Care Support Authority, on average 24.5% of patients at RNSH and 15.4% at POWH were eligible for compensation.

SCID collects a lot of information that is not analysed, such as where a patient lives when they have their accident. However, Middleton et al. (4) found that 30% of people who sustain a SCI return to live in rural and remote communities.

THE DIAGNOSTIC: WHAT WE’VE LEARNED

Broadly, people with spinal cord injury have four sets of interactions with the service system across their lifetime:

• at the onset of their spinal cord injury (e.g. trauma)
• at re-entry / re-admission to the service for management of complications or co-morbidities
• in assisting in their transition to living in the community
• while living in the community.

Figure B maps these three phases to the care setting and also shows how the mix of services and support from the health sectors and other sectors (e.g. disability services, community services, transport and accommodation) change over time. It should be noted, of course, that the journey is not as linear as depicted and varies from individual to individual.

Some of the key points to highlight in the figure below are:
- The health sector and, specifically, specialist spinal cord injury services have the major role to play in responding to a trauma or other cause of non-traumatic SCI.
- In the phase involving a transition back to community living, the health and other sectors are both heavily involved.
- For people living in the community independently, their interaction will be primarily with the non-health sectors and most health care will be with non-specialist staff (e.g. GPs, community nurses).

**FIGURE B - PEOPLE WITH SCI: A LIFETIME PERSPECTIVE**

Figure B provides a framework for considering six key system-wide findings of this diagnostic review that emerge from the literature review, online surveys and consultations.
Key Findings (see section 6.1 for full details)

1. The existing service system has a number of inherent strengths

2. The health services need to integrate with other sectors to better meet the lifetime needs of people with spinal cord injury.

3. Services and resources are concentrated at the ‘front-end’ (i.e. acute care)

4. There are inequities in access to services

A consistent theme across the consultation phase was the inequity of access to services for different groups:
- regional, rural and remote areas
- limited multidisciplinary clinics in metropolitan Sydney similar to the rural outreach clinics
- Illawarra/Shoalhaven have no access to the SOS & RSCIS services and have no local services equivalent to Hunter SCIS
- people aged 65 years and over are disadvantaged in accessing specialist and support services
- differential access to care for compensable and non-compensable clients
- many adults with non-traumatic spinal cord injury are not referred to the two spinal units
- relatively small numbers of Aboriginal people admitted to the spinal units raises the question as to whether they are missing out on specialist services

5. Services need to incorporate truly person-centred care that also addresses peoples’ psychological care and support needs

6. Comprehensive and timely data is required for robust service planning and development

Phases in the life of people with spinal cord injury (see section 7 for details):

The diagnostic review also presents detailed findings and issues for the three phases in the life of people with spinal cord injury:

1. At the onset of their spinal cord injury (e.g. trauma)

2. At re-entry / re-admission to the service for management of complications or co-morbidities.
   Issues identified for phases 1 and 2 include:
   - some people with SCI are not accessing the spinal specialist services
   - there are differences in the model of care and clinical practice across the two units
   - many patients remain in the inpatient units when they are functionally ready to be transferred to another setting for ongoing rehabilitation or community living
   - many patients admitted with potentially preventable complications.

3. In assisting in their transition to living in the community
   - long delays in people returning to community living due to extended delays in equipment, funding and home modifications
   - lack of suitable accommodation modified public housing

4. While living in the community
   - lack of community-based specialist skills, especially in regional, rural and remote areas
   - shortage of locally-based multidisciplinary outpatient clinics and home visiting specialised services
   - local hospital, support and primary care staff do not have the training, experience and confidence in managing people with SCI
peoples' general health issues not directly related to their spinal cord injury may not be well managed.
- lack of coordination among service providers
- lack of proactive, systematic multidisciplinary review of people living with spinal cord injury to promote well-being and prevention of complications.

THE DIAGNOSTIC: WHAT WE’VE LEARNED - PAEDIATRICS

Given the small numbers and the different models of care, it is proposed that paediatric spinal cord injury rehabilitation be considered in the overarching model of care for paediatric rehabilitation services that has been commissioned by the Sydney Children’s Hospital Network (SCHN) and the Kaleidoscope paediatric rehabilitation service in the Hunter New England LHD. Nevertheless, it is critical that there be a separate model of care for children with spinal cord injury that addresses the following identified needs:

- ongoing education and support of local health and support staff by SCHN and Paediatric Spinal Outreach Service (PSOS) staff
- dedicated paediatric rehabilitation beds at the Children’s Hospital Westmead (CHW)
- strengthened formal links with the adult spinal cord injury units
- inclusion of paediatric data in the spinal cord injury database
- streamlined transition to adult SCI services.

TOWARDS A NEW MODEL OF CARE

The purpose of this diagnostic report was to establish whether there is a case for change, that is, whether there is a need for a new model of care for people with spinal cord injury. In drawing on the literature and an extensive round of consultations with clinicians and consumers, as outlined in sections 6 to 8, the diagnostic finds that there is indeed a compelling case for change.

The diagnostic concludes that the health system needs to focus on better meeting the lifetime needs of people with spinal cord injury by:

- actively engaging with other sectors (e.g. disability, community services) in collectively improving the quality of life and well-being of people with spinal cord injury
- refocussing health services to facilitating peoples’ longer-term participation in community life away from the current emphasis on the acute care phase
- adopting truly person-centred practice that addresses the full range of peoples’ needs, including their emotional and psychological well-being, as well as their immediate medical needs.

The shift to a lifetime focus is consistent with the principles of the NDIS and the Lifetime Care and Support Scheme (LTSS) and, indeed, the implementation of the NDIS provides a unique opportunity to better embed the health system within a larger systemic approach.

Fundamental to this shift to a focus on lifetime support is the need to increase access to post-acute rehabilitation and transitional or ‘step-down care’ for clients and families and carers. The literature underlines the central importance of early, intensive post-acute rehabilitation in contributing to improvements in clients’ function, independence and quality of life. In this context, there is a pressing need for more increased transitional housing and accommodation options, preferably in community settings. Consideration should also be given to opportunities for sport recreation and social networks as valuable contributors to long term rehabilitation, health promotion and wellness.
Also, central to a new model of care is the need for improved equity of access to services, including community-based rehabilitation and support services. People living in regional, rural and remote areas, in particular, have poorer access to specialist services and therapy close to where they live.

In planning for future service developments, consideration needs to be given in the model of care to addressing the population distribution and projected growth areas across NSW (eg in Western Sydney).

The growing numbers and proportion of people over 65 years old are especially disadvantaged – they are not eligible for NDIS and not well served by the aged care system. Similarly, the growing numbers of adults with non-traumatic spinal cord injury also appear to be missing out on specialist care.

The diagnostic review has also highlighted some service development issues in the acute care settings:

- the need to clarify pathways and transfer protocols, particularly as POWH is not a trauma hospital
- the need for clearer clinical pathways and protocols to streamline discharge planning and facilitate timely transfer to more suitable rehabilitation settings
- the need to address differences in the clinical practices across the two spinal cord injury units
- the need for consistent data definitions for ‘acute’, ‘sub-acute’ and ‘rehabilitation’ across the two spinal units to facilitate benchmarking and service planning.

In summary, this diagnostic review concludes that there is a case for a new model of care and this was strongly supported by the consumers, consumer organisations and clinicians we consulted and the report sets out:

- some draft principles to underpin the model of care
- some proposed service development priorities for the development of the model of care

**MODEL OF CARE PRINCIPLES**

The diagnostic project steering committee agreed that the new model of care should be underpinned by a set of principles that will guide further service development. The following set of draft principles incorporate feedback and discussion on draft principles discussed at the August 2016 stakeholder workshop and in the draft versions of this diagnostic report (see section 9.1 for details).

1. Care and support of people with spinal cord injury focuses on their lifetime care and support needs.
2. The service system is person-centred and actively engages people with spinal cord injury, and their family and support networks, in making informed choices in managing their care and lives.
3. People with spinal cord injury have access to services and support as close as possible to where they live.
4. Those people who require specialised, complex spinal care have timely access to the spinal cord injury services.
5. While in hospital, people with spinal cord injury receive timely, individualised comprehensive rehabilitation that develops their lifelong skills, and supports their psychological adjustment and wellbeing.

6. While in hospital, people with spinal cord injury are assigned a key worker, who helps them navigate their hospital stay and transition back to the community.

7. On leaving hospital, people with spinal cord injury have timely access to the equipment, care, housing, ongoing rehabilitation and specialised services to support their return to community living and participation.

8. Care and support for people with spinal cord injury is coordinated and easy to navigate across health, community and other related services.

9. While living in the community, people with spinal cord injury are actively supported by a range of services in maintaining health and psychological well-being over their lifetime.

SERVICE DEVELOPMENT PRIORITIES
These principles have significant implications for SSCIS and the development of statewide spinal cord injury services. The August 2016 stakeholder workshop aimed to translate the principles into service development priorities and the proposed priorities can be grouped into six broad groupings or ‘planks’, as depicted in the figure C below (Priority Planks) and in section 9.2).

The planks lay out a framework for guiding shorter-term and medium term action and for informing future investment decisions for spinal cord injury services across NSW.

To this end, table 7 (pg 67) summarises some potential priorities for each plank that emerged from the August 2016 workshop and from feedback on the draft versions of this diagnostic report. It needs to be reinforced that these are some initial and draft proposals only; they will be subject to review, refinement and ranking in the next stage of the development of a model of care and, of course, some would require additional funding. They are presented only to suggest some possible steps in translating the principles and planks into a new model of care and to begin the process of identifying priorities for future investments.
A NEW SCI MODEL OF CARE

Multi-sector integration
- Engaging other sectors to deliver lifelong, person-centred support

Specialist services access & integration
- Improving integration of spinal network services, including increased access to post-acute rehabilitation and support close to where people live

Local capacity building
- Building the capacity of local health, disability and NGO services to support people to live independently in the community

Independence through self-management
- Orienting services to build people’s independence and self-management skills

Person-centered services
- Building the capacity of specialist services to promote person-centred care

Informed decision making
- Developing integrated data systems to better plan, evaluate and improve services
Introduction

The NSW Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. The State Spinal Cord Injury Service (SSCIS), a network of the ACI, is committed to ensuring that people with spinal cord injury (SCI) residing in NSW receive the highest quality services, coordinated in collaboration with other stakeholders to facilitate individual independence and achievement of personal goals.

The current Selected Specialty and Statewide Service Plan (Number 8): Spinal Cord Injury released by the (then) Department of Health in December 2010 expires in 2016. Under the NSW Health governance arrangements, the Ministry of Health will no longer be publishing statewide ‘plans’ as in the past, however, statewide planning for particular services will be undertaken to help inform purchasing decisions. To this end, the SSCIS has commenced the development of a high level model of care for the management and support of children and adults with a spinal cord injury in NSW.

In line with the ACI methodology, as depicted in figure 1, after a project initiation phase, the first stage in the development of a model of care is a ‘diagnostic’ review which then leads to solution design and implementation of a more detailed improvement process. This report on the diagnostic phase aims to better understand spinal cord injury management systems and practices and to identify needs of consumers and evidence-practice gaps in service provision.

FIGURE 1: ACI PROCESS FOR DEVELOPING THE MODEL OF CARE: THE DIAGNOSTIC STAGE

Methods

The diagnostic review and the overall development of the model of care are being led by an SSCIS Project Executive Planning Committee which reports to the SSCIS Clinical Development Committee which, in turn, reports to the SSCIS Steering Committee (see appendix 3 for membership of the Project Executive Planning Committee and project team). The SSCIS Project Executive Planning Committee endorsed the project methods which have involved collating information from multiple sources, including:

- a selective review of the literature on best practice models of care, modes of service delivery and associated resourcing with evidence for their efficacy and cost effectiveness in relation to the care, management and support of people (adults and children) with spinal cord injury (see appendix 1 for the literature review)
- a series of visits to specialist spinal cord injury services and other health services across NSW (see appendix 2 for a list of the services visited)
- face-to-face and telephone consultations with over 25 people living with spinal cord injury, including parents of children with spinal cord injury (see section 4 for themes from consultations and appendix 2 for a list of those consulted)
- an online survey, distributed by the community-based organisations, ParaQuad NSW and Spinal Cord Injuries Australia (SCIA), completed by 47 people living with spinal cord injury (see appendix 6 for full analysis of consumer survey)
- an extensive round of consultations with over 100 clinicians across NSW, including individual and group consultations (see section 5 for themes from consultations and appendix 2 for a list of those consulted)
- an online survey, distributed across the SSCIS network, completed by 43 clinicians (see section 5 – survey responses have been included in this section)
- a series of consultations with other key stakeholders, including government agencies, non-government organisations and consumer organisations (see appendix 2 for a list of those consulted).

A workshop was held on 19 August 2016 with 45 key stakeholders (see appendix 4 for a list of the workshop participants) to:
- obtain feedback and confirm the project’s findings to that point
- discuss some principles to underpin an ideal model of care
- identify key issues, service gaps and potential priorities for the solution design and implementation phases of the model of care.

Following that workshop, a draft report on the diagnostic project was distributed to members of the SSCIS Project Executive Planning Committee for online feedback and for discussion at a meeting with the committee on 21 September 2016. A revised draft of the diagnostic report that incorporated feedback on the initial draft was sent for broader consultation to the participants of the August 2016 workshop as well as members of the Project Executive Planning Committee, SSCIS Steering Committee, SSCIS Clinical Development Committee and key stakeholders.

Structure of this Report

This final report on the diagnostic review consolidates feedback on the two earlier draft reports and is structured as follows:
- section 1 provides a snapshot of spinal cord injury
- section 2 describes existing spinal cord injury services across NSW and presents data on those services
- section 3 summarises the key themes emerging from the literature review
- section 4 provides a summary of the consultations with people with spinal cord injury, including the online survey results
- section 5 provides a summary of the consultations with clinicians, including the online survey results
- section 6 identifies the key, high-level learnings from the diagnostic review
- section 7 provides more detailed findings for each of three adult care ‘phases’: acute care, transition, living in the community
- section 8 presents some key issues in rehabilitation of children with spinal cord injury
- section 9 proposes some next steps in the development of the model of care, including some underlying principles, potential service development priorities and a draft implementation strategy.
1. Spinal Cord Injury: A Snapshot

The State Spinal Cord Injury Service (SSCIS) is a series of statewide services responsible for the management of people who have sustained a spinal cord injury with evidence of damage to the neural tissues as a result of trauma, or from a non-progressive disease process. Traumatic SCI is caused by a direct or indirect external event (trauma), such as a motor vehicle accident, fall or sporting injury. Non-traumatic SCI (NTSCI) may be due to infection, haemorrhage, ischaemia, inflammation (myelitis), or benign tumours affecting the spinal cord, or spinal canal stenosis. Progressive conditions such as demyelinating and degenerative conditions of the spinal cord as well as compression by metastatic lesions are not the province of the spinal service.

According to the Australian Institute of Health and Welfare (1) 362 new spinal cord injuries (SCI) were reported in Australia in 2007-08, the latest year for which data from the ASCIR\(^1\) is available. The majority (79%) of these were due to traumatic causes. In Australia non-traumatic SCI is primarily due to degenerative conditions and tumours, compared to low income countries where NTSCI is predominantly due to infections (tuberculosis (TB) and human immunodeficiency virus (HIV))(2).

Unlike adults, most SCI in children relates to non-traumatic causes including tumours and transverse myelitis. In fact, non-traumatic cases account for two thirds of children with spinal cord injury and the number of children with a newly acquired traumatic spinal cord injury each year is small.

Traumatic SCI (TSCI) was most frequent in the 15-24 year age group (30%), although trends show a significant increase in the average age at injury from 38 years in 1995-96 to 42 years in 2007-08. Males accounted for 84% of traumatic SCI. Transport-related injuries (46%) and falls (28%) were the main contributors to TSCI.

In the absence of other population-based data on the incidence and prevalence of SCI, service utilisation data can provide some insight into whether there are changes in the underlying profile of the condition. The following data shows the numbers of newly injured adults (it does not include children or readmissions) who were admitted to the spinal injury unit (SIU) at either Royal North Shore or Prince of Wales hospitals for their acute care and initial post-injury rehabilitation between 2009 and 2015. While the figure shows that the numbers of new admissions have been quite stable, ranging from 121 to 136 over that time, this does not mean that the actual rate of new injuries is stable because:
- the figures do not include other new patients with SCI who are admitted to other hospitals in NSW
- the hospitals have been running at high levels of bed occupancy and may not have been able to accommodate additional cases.

Figure 2 shows variation in the proportion of traumatic and non-traumatic SCI over the seven year period, varying from 2:1 in 2014 to 5:1 in 2012.
FIGURE 2: NUMBER OF NEW TRAUMATIC AND NON TRAUMATIC SPINAL CORD INJURY CASES, 2009 - 2015

Nature of injury

The most common injury is incomplete tetraplegia, followed by incomplete paraplegia, as shown in figure 3.

FIGURE 3: NATURE OF INJURY, 2009 -2015

Gender and age of patients

New spinal cord injuries are more prevalent among males than females. In 2015, there were over two males with a spinal cord injury to every female and this ratio was even greater in earlier years.

As shown in figure 4, the age of cases has also changed. For example, in 2009 more people aged 16 to 45 years than people older than 45 years had acquired spinal cord injury, while in 2015 there were more, older people (97) than younger people (36) with new spinal cord injuries.
Cause of injury

There has been an increase in the number of people who acquired their spinal cord injury from falls (35 in 2009 to 50 in 2015). Spinal cord injuries resulting from motor vehicle accidents and motor bike accidents have remained roughly the same or have been falling over the last six years.

Surgery

Most people with spinal cord injuries have surgery: 85% of new cases in 2015. Most of this initial spinal surgery (72% in 2015) was conducted in SSCIS hospitals (RNSH or POWH hospitals) and patients were transferred to SSCIS hospitals within 24 hours of injury in 40%-50% of the time.

1.1 Future Demand

New et al. (3) estimated the incidence and prevalence of TSCI in Australia as of June 30, 2011. Their lower estimate of incidence was 21.0 per million population per year, and the upper estimate was 32.3 per million population per year. This is higher than the oft quoted incidence of 15 cases per million (5).

The derived prevalence rates of New et al. (3) for TSCI ranged from 490 per million population up to 886 per million population.

For NTSCI in Australia the incidence rate is in the order of 26 cases per million (2). New et al (6) have also estimated the NTSCI rate for Australia (extrapolated from the state of Victoria) which translated to a population prevalence rate of 364 persons per million. With the population ageing NTSCI is expected to increase substantially in the coming decades.
TABLE 1: INCIDENCE AND PREVALENCE RATES FOR SPINAL CORD INJURY

<table>
<thead>
<tr>
<th></th>
<th>Rate per million adults</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Incidence</strong></td>
<td></td>
</tr>
<tr>
<td>TSCI</td>
<td>15 – 32 cases</td>
</tr>
<tr>
<td>NTSCI</td>
<td>26 cases</td>
</tr>
<tr>
<td><strong>Prevalence</strong></td>
<td></td>
</tr>
<tr>
<td>TSCI</td>
<td>490 – 886 cases</td>
</tr>
<tr>
<td>NTSCI</td>
<td>364 cases</td>
</tr>
</tbody>
</table>

1.2 Summary

The key messages from this snapshot of spinal cord injury are that:
- the incidence estimates of New et al would suggest a range of 291 to 361 to new SCI cases in NSW each year:
  - 130-200 traumatic
  - 161 non-traumatic
- the spinal units at RNSH and POWH have been treating approximately 130 new cases per year over the last seven years
- the majority of these cases have been traumatic although there has been considerable variation in the ratio of traumatic to non-traumatic cases over the last seven years
- the NSW health system can expect an increase in the proportion of older people with SCI.

The gap between the incidence estimates and actual numbers suggest that not all people with SCI in NSW are being seen in the two spinal injury units, especially those with NTSCI, or that the incidence estimates are an over-estimate.
2. **Spinal Cord Injury Services in NSW**

The State Spinal Cord Injury Service (SSCIS) was established following the recommendations of a report of the Greater Metropolitan Services Implementation Group in 2001. Some of the milestones in the SSCIS history are:

**2003**
- appointment of an interim director
- appointment of an implementation coordinator, later to become the SSCIS Network Manager
- establishment of the metropolitan based Spinal Outreach Service

**2006**
- appointment of the SSCIS Clinical Director

**2007**
- establishment of the *SSCIS Clinical Development Committee* as the lead committee for the Network
- appointment of a non-medical co-chair of SSCIS
- establishment of the *SSCIS Psychosocial Strategy*

**2008**
- establishment of the *Rural Spinal Cord Injury Service* with the appointment of four Rural Coordinators

**2007/2008**
- integration of the *Rural Spinal Cord Injury Service* with the metropolitan-based *Spinal Outreach Service 2007* - with the development and establishment of four (now five) rural coordinator positions across rural NSW in 2007/2008 in a hub and spoke model

**2008/9**
- development of the *Spinal Seating Professional Development Program* of on-line learning modules and experiential workshops (reviewed and updated in 2016)

**2009**
- launch of a series of resources developed by the *SSCIS Psychosocial Steering Committee*

**2010**
- transfer of the SSCIS to the Agency for Clinical Innovation

**2013**
- Establishment of the NSW Paediatric Spinal Outreach Service

**2014**
- official launch of the Model of Care for Prevention and Integrated Management of Pressure Injuries in People with a Spinal Cord Injury and Spina Bifida

**2015**
- review of the network’s committee structure and establishment of the SSCIS Steering Committee as the lead strategic committee and SSCIS Clinical Development Committee as the lead clinician representative committee
- establishment of the statewide SCI Pressure Injury Clinical Champions Group
- development by the ACI Pain Management Network of the Spinal Cord Injury Pain on-line resource

**2015/16**
- development of the on-line SCI and Spina Bifida Pressure Injury Toolkit
2016
- launch of the Emotional Wellbeing Toolkit.
- Between 2006-07 and 2010, the (then) Statewide Services Branch of the (then) Department of Health, in collaboration with SSCIS, developed a statewide spinal cord injury services plan for NSW. The plan expires in 2016 and the SSCIS is now operating under fundamentally different governance arrangements than previously. The model of care will therefore need to take account of the changed arrangements, under which statewide spinal cord injury services are designated as a ‘Supra Local Health District (LHD) Service’.

The following sets out the roles and responsibilities of the key stakeholders in the provision of Supra LHD Services:
- the Ministry of Health's Health System Planning and Investment (HSPI) Branch is responsible for the planning and future demand projections of Supra LHD Services
- the purchase of agreed Supra LHD Services are managed by the System Purchasing and Performance Division of the Ministry of Health as part of the annual service agreement process, consistent with the NSW Health Purchasing Framework and the NSW Health Performance Framework, and in consideration of the annual NSW Health budget
- funding for Supra LHD services is managed by the Highly Specialised Services Steering Committee (comprising certain LHD/Specialty Health Network (SHN) Chief Executives, and managed by the System Purchasing and Performance Division)
- Supra LHD Services are assigned a Clinical Lead (in the case of SCI, the clinical lead is the ACI) responsible for providing expert clinical advice in support of annual Service Agreement processes, proactively identifying emerging issues and collaborating with HSPI and other key NSW Health stakeholders to address agreed priorities
- LHDs/SHNs are responsible for the delivery of Supra LHD Services and to provide advance advice to the Ministry of Health on planning issues for existing Supra LHD Services.

2.1 SSCIS Governance

The network comprises approximately 300 clinician, management, consumer and researcher members across NSW and figure 5 shows the governance arrangements for the network.

As depicted in the figure, there are two key SSCIS governance bodies: the Steering Committee and the Clinical Development Committee, which are underpinned by a series of committees, sub-committees and special working groups.

The SSCIS Steering Committee is co-chaired by two senior executives nominated by the Chief Executive of the LHDs that house the two specialist spinal units in NSW, Northern Sydney and South Eastern Sydney LHDs. The Clinical Director of SSCIS is a member of the SSCIS Steering Committee. Broadly, its terms of reference state that the role of the committee is to ‘provide leadership and advice on matters relating to the planning, enhancement, and delivery of statewide spinal cord injury (SCI) services in the NSW health care services’.

The SSCIS Clinical Development Committee is either chaired by the clinical director of the SSCIS or the co-chair and comprises a sample of clinical (medical and non-medical) and consumer representatives drawn from across the network. Broadly, the role of the Clinical Development Committee is to provide expert advice, recommendations and guidance to the SSCIS Steering Committee, ACI, other government agencies and non-government organisations regarding best practice spinal cord injury management.
2.2 Adult Care

The acute services of the SSCIS for adults are located at POWH and RNSH (more detail on services is provided in appendix 5). As summarised in table 2, the catchment for POWH is south of the harbour in Sydney and the southern part of NSW (including the ACT) and north of the harbour in Sydney or in the northern part of NSW for RNSH and Royal Rehab.
TABLE 2: REFERRAL NETWORK FOR ADULTS

<table>
<thead>
<tr>
<th>Referring LHD</th>
<th>Receiving SCI Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td>South Eastern Sydney</td>
<td>POWH</td>
</tr>
<tr>
<td>Illawarra / Shoalhaven</td>
<td></td>
</tr>
<tr>
<td>Sydney</td>
<td></td>
</tr>
<tr>
<td>South West Sydney</td>
<td></td>
</tr>
<tr>
<td>Murrumbidgee</td>
<td></td>
</tr>
<tr>
<td>Southern NSW</td>
<td>RNSH</td>
</tr>
<tr>
<td>St Vincent’s Heath</td>
<td></td>
</tr>
<tr>
<td>ACT</td>
<td></td>
</tr>
<tr>
<td>Northern Sydney</td>
<td></td>
</tr>
<tr>
<td>Central Coast</td>
<td></td>
</tr>
<tr>
<td>Nepean/Blue Mountains</td>
<td></td>
</tr>
<tr>
<td>Western Sydney</td>
<td></td>
</tr>
<tr>
<td>Far West</td>
<td></td>
</tr>
<tr>
<td>Hunter/New England</td>
<td></td>
</tr>
<tr>
<td>Mid North Coast</td>
<td></td>
</tr>
<tr>
<td>Northern NSW</td>
<td></td>
</tr>
<tr>
<td>Western NSW</td>
<td></td>
</tr>
</tbody>
</table>

On average over the last seven years, 63% of new spinal cord injury patients went to RNSH and 37% went to POWH and a slightly higher proportion (66%) of non-traumatic cases went to RNSH over this period.

RNSH sees more than their expected share of people with complete paraplegia and tetraplegia (66% in the case of complete paraplegia and 64% in the case of complete tetraplegia compared to the expected share of 63%). These patients tend to have a longer median length of stay (MLOS) than incomplete patients.

It is generally accepted that the younger patients (15 – 44 years) would have shorter lengths of stay than older patients (45+ years). The age of patients between the two hospitals has been fairly equally distributed in terms of their relative shares. However, as figure 4 in section 1 shows, there has been an increase in the number of older patients in recent years, especially in 2015.

POWH is not classified as a trauma hospital so patients with a high energy mechanism of injury with a spinal cord injury may be transferred to POWH after spending some time in a trauma hospital before transfer to POWH. However, those patients with low energy mechanism of injury and /or single system injury are taken directly to POWH by the ambulance service. RNSH, however, is a designated trauma hospital and patients will spend their entire stay there including time in the SIU. If it is clear that a multi-trauma patient has a spinal cord injury they may be taken directly to RNSH even if they live in the catchment for the SIU at POWH. At least some of these patients would receive part of their care at RNSH before transfer to the SIU at POWH, where they would be identified as a new patient.
Rehabilitation

Rehabilitation for a person with a spinal cord injury occurs either at POWH (rehabilitation is collocated with the acute unit) where there are 20 beds or at Royal Rehab (RR) where there are also 20 beds. As RR is a third schedule hospital and separate from RNSH, spinal cord injury patients do not automatically go there when they are ready for discharge from RNSH and RR accepts referrals (especially NTSCI patients) from other hospitals. There is therefore often a delay in discharge from RNSH while waiting for a bed at RR; the median delay over the past seven years for a RNSH patient awaiting rehabilitation was 31 days. Moreover, RR cannot accept patients with ventilator dependent tetraplegic (VDT), so these patients stay at RNSH and may be discharged to a general hospital near the patient’s home as a transitional option prior to discharge into the community.

The rehabilitation units have highly specialised rehabilitation staff, ward and therapy facilities for rehabilitation and appropriate equipment permitting specialised rehabilitation programs - to ensure each individual can reach their maximum potential functional independence. Active vocational and community access programs are offered. Close links have been developed with TAFE, ParaQuad NSW, Spinal Cord Injuries Australia (SCIA) and other organisations to facilitate vocational and community reintegration.

A psychosocial strategy was implemented in 2007-08 to improve the quality of life of people with spinal cord injury through better integration of physical health with psychological well-being, improved relationships with health professionals, increased capacity to return to work, improved self-management and more adaptive coping. (7)

Outpatients

The following table depicts the distribution of outpatient clinics across RNSH, POWH and RR.

<table>
<thead>
<tr>
<th>Outpatient clinics</th>
<th>RNSH</th>
<th>POWH</th>
<th>RR</th>
</tr>
</thead>
<tbody>
<tr>
<td>medical follow up</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>complex follow up with a multidisciplinary team</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>spinal consultation liaison psychiatry</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>spinal surgical</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>spinal plastics</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>tetraplegic hand clinic</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>spasticity</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>seating</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>assistive technology and seating</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>sexuality/fertility</td>
<td>●</td>
<td>●</td>
<td>●</td>
</tr>
<tr>
<td>spinal hydrotherapy</td>
<td></td>
<td></td>
<td>●</td>
</tr>
</tbody>
</table>

2 A statewide working party in 2010 with representatives from all acute and rehabilitation services defined the commencement of rehabilitation as the time:
• when the client is able to sit in a chair for a period of at least 60 minutes to participate in active rehabilitation and on 3 consecutive working days.
• the client has the ability to achieve active rehabilitation goals with the level of injury
• the client has no pressure area or wound that prevents sitting up in wheelchair for extended periods and/or participating actively in rehabilitation (e.g. on a prone trolley)
The NSW Spinal Outreach Service (SOS) is a multidisciplinary service that commenced in 2003/04 to provide support for clients discharged from the spinal injury units to maximise their community reintegration. It is for clients residing in the Sydney metropolitan area and does not cover the Hunter New England LHD (HNELHD) or the Illawarra Shoalhaven LHD (ISLHD). Clients are offered up to 12 months of support.

The Rural Spinal Cord Injury Service (RSCIS) initially commenced as a pilot project and is now fully amalgamated with the metro service to allow staffing efficiencies across both teams, hence creating the NSW Spinal Outreach Service.

The RSCIS is a hub and spoke model providing access for clients across NSW to a specialised multidisciplinary team via a visiting clinic. The local Rural Spinal Cord Injury Coordinators act as the spokes of the service providing on the ground, local, face-to-face support for clients. Initially, four (4) RSCIS Coordinator positions were established one in each rural Area Health Service (AHS), with each covering extensive geographical areas. The restructure of AHSs into Local Health Districts (LHD) has resulted in each RSCIS Coordinator covering two (2) LHDs, adding cross LHD border differences to the challenge of distance. The RSCIS conducts nine clinics per year at different towns across regional and rural NSW.

The NSW SOS plays a significant role across NSW as a consulting service to support local rural clinicians in managing clients with SCI. Nine rural educational days are conducted annually with in excess of 250 clinicians from regional and rural NSW attending. This consulting role is vital in building local service capacity but is not accounted for in the activity-based funding (ABF) environment. A similar educational/consulting role is not available for metropolitan clinicians.

**Community care**

**Hunter SCI Service (HSCIS)**

Funded and governed by HNELHD, the Hunter Spinal Cord Injury Service (HSCIS) is based in a Community Health Centre in Newcastle, is run by the HNELHD, and provides specialist (outpatient) clinics by a multidisciplinary team (Nurse, Physio, OT, SW, Psychologist, and Rehabilitation Physicians), and also sees patients in their home (in the Community). It follows up people with a spinal cord injury for life and has over 400 people on its books. It provides direct services to clients.

**Spinal Cord Injuries Australia (SCIA)**

SCIA is a non-government organisation with offices in NSW in Sydney, Wollongong, Alstonville on the North Coast, Tamworth and Mudgee. SCIA provides a range of services including accommodation, emergency care, employment assistance, exercise programs, information and resources, peer support, injury prevention in the workplace, policy and advocacy and grants and research.
Paraplegic and Quadriplegic Association of NSW (ParaQuad NSW)

ParaQuad NSW was established in 1961 to provide a support system to people with a spinal cord injury by developing services and care regimes with the aim to help them achieve their life choices after injury. It has offices in Sydney and Newcastle and its services include clinical programs (150-190 episodic therapy interventions inclusive of nursing, social work and occupational therapy are provided every two months), personal care programs (all carers employed through ParaQuad are given specific training in the care of spinal cord injury prior to commencement of their care services), accommodation (Ferguson Lodge at Lidcombe provides 24-bed full-care rooms, 10 two bedroom independent living villas and a separate gymnasium and function area), spinal app solutions, health care products, education and training for carers and health professionals and DVA services.

Lifetime Care

Lifetime Care (formerly the Lifetime Care and Support Authority of NSW) is a statutory authority established under the Motor Accidents (Lifetime Care and Support) Act 2006. The Authority is responsible for the administration of the Lifetime Care and Support Scheme, which provides lifelong treatment, rehabilitation and attendant care for people who have a spinal cord injury, a moderate to severe brain injury, multiple amputations, serious burns or blindness from motor accidents in NSW. The Lifetime Care and Support Scheme applies, regardless of whom was at fault, to children under 16 years of age who are injured in a motor accident from 1 October 2006 and adults who are injured in a motor accident from 1 October 2007. The scheme purchases a range of treatment, rehabilitation and care services for its clients.

Enable NSW

Enable NSW was established in 2007 to implement the major reforms based on recommendations made in a review of the Program of Appliances for Disabled People (PADP). It provides equipment and services to people in NSW with chronic health conditions or disability to assist them with mobility, communication and self-care.

Ageing, Disability and Home Care (ADHC)

Ageing, Disability and Home Care (ADHC) is part of the Department of Family and Community Services (FACS) and is responsible for providing services and support to older people, people with a disability, their families and carers. With the implementation of the National Disability Insurance Scheme (NDIS), the role of ADHC in direct service provision is being wound down.

Sargood Foundation

Sargood on Collaroy is a jointly funded initiative of the Sargood Foundation and Lifetime Care and will be operated by Royal Rehab when it opens in late 2017 to provide a range of innovative health and wellness, education and training, and lifestyle and recreational programs for people with a SCI living in the community to improve their resilience, independence, wellbeing and community participation.

2.3 Paediatric Services

Children with a spinal cord injury as a result of trauma or non-trauma receive inpatient care at one of the two Sydney children’s hospitals at Randwick or Westmead both of which are part of the Sydney Children’s Hospital Network (SCHN). While they receive their acute care, they may have joint care with the rehabilitation service - Rehab2Kids at Randwick and Kids Rehab at Westmead.
At Randwick, after their acute care they are transferred to designated rehabilitation beds. Westmead does not have designated rehabilitation beds.

On discharge the child is referred to the Paediatric Spinal Outreach Service (PSOS) which is provided by Northcott Disability Services on contract from NSW Health. PSOS is a statewide service for 0-18 year olds who live in NSW and have an acquired spinal cord injury sustained through trauma or disease. It provides nursing, occupational therapy, physiotherapy and social work services. The team travels to the community where the child lives and liaises with local therapists to provide services or provides services directly themselves. The service is intended to have ongoing involvement in the care/support/therapy provision of children throughout development up until discharge from paediatric services and transition to adult services.

The child is also referred to the outpatient service provided by the paediatric rehabilitation departments of the two Sydney children’s hospitals. Within Hunter New England Local Health District (HNELHD) a child with a traumatic spinal cord injury goes to Sydney and is treated as an inpatient at one of the Sydney children’s hospitals. HNELHD provides inpatient acute and rehabilitation for children with non-traumatic spinal cord injury at the John Hunter Children’s Hospital (JNCH). With the establishment in recent years of a specialist paediatric rehabilitation service (ie HNEkidsRehab) there is now potential to provide inpatient rehabilitation for children with a traumatic spinal cord injury if they are deemed appropriate for transfer from SCHN to JHCH for locally based inpatient care. HNELHD also provides specialised outpatient paediatric rehabilitation via HNEkidsRehab. Further developments in HNELHD include a paediatric intensive care unit due to open in 2017.

Transition of children with a spinal cord injury to an adult spinal cord injury service occurs at age 18 and has improved significantly in recent years with assistance from the ACI transition coordinator and Trapeze, the SCHNs transition service. Nevertheless, the transition process often remains difficult for families as they have often developed a long relationship with the paediatric services and the adult services do not provide the same ‘one stop shop’.

2.4 Service Utilisation

In this section the focus is on the utilisation of SSCIS services at the three hospitals – RNSH, POWH and RR - with data from the Spinal Cord Injury database (SCID). SCID does not provide information on paediatric services or non-inpatient episodes – outpatients, outreach and regional services. Nor does it provide data on spinal cord injury patients who are admitted to other hospitals.

Figure 6 shows that in the last seven years there were between 106 and 136 new spinal cord injury patients admitted per year to either RNSH or POWH. The majority of these patients go to RNSH and this has been the pattern for the last seven years with the proportion fluctuating from 72% in 2014 to 59% in 2015.

New cases of spinal cord injury also include non-traumatic cases (NTSCI). On average over the last seven years non traumatic cases were 23% of total new cases (24% at RNSH and 21% at POWH).
SCID collects a lot of information that is not analysed, such as where a patient lives when they have their accident. However, Middleton et al. (4) found that 30% of people who sustain a SCI return to live in rural and remote communities.

SCID information on Aboriginal status and culturally and linguistically diverse backgrounds (CALD) show the numbers are not large – over the last seven years there was a total of 19 Aboriginal and Torres Strait Islander people with a SCI (2.2% of the total new cases) and 44 patients (5%) from a non-English speaking background.

In relation to compensable status, on average over the last seven years 24.5% of patients at RNSH were covered by Lifetime Care while at POWH the comparable number was 15.4%. It is unclear what the reasons are for this difference in the client profile.

**Length of stay**

Figure 7 shows the average length of stay (ALOS) and figure 8 shows the median length of stay (MLOS) for the 10 acute beds at POWH and the 18-20 beds at RNSH. While the figures show that the average and median LOS for RNSH are much greater than for POWH, this result needs to be treated with caution. Firstly, the comparison between RNSH and POW is not like with like: the definition used at POWH to record when a patient is no longer acute differs from the practice at RNSH where, in SCID, the total stay is called acute (i.e. time spent in ICU and the SIU).
The Australian Institute of Health and Welfare (AIHW) describes the length of stay for new cases of spinal cord injury in terms of the duration of initial care (DIC), which is the period from the date of injury to the date of discharge from the spinal cord injury unit to another hospital, home, nursing home or other accommodation (8). However, it is not possible to make this comparison with the data that exists and the way in which it is grouped. Similarly, it is not possible to identify the total length of stay for individual spinal cord injury patients, especially if they are transferred from another hospital.

Readmissions\(^3\)

People with a spinal cord injury may be readmitted to the acute services. Over the past seven years there have been a combined (RNSH and POWH) total each year of between 181 and 291 readmissions. Figure 9 shows the distribution of these cases between the two acute hospitals. On average over the past seven years, 67% of these patients have gone to RNSH and 33% to POWH. Over the last seven years readmissions represent over double the number of new spinal cord injury patients at RNSH and almost double the number of new spinal cord injuries at POWH; they represent 42% of the bed days at RNSH and 58% of the bed days at POWH.

Most (73%) of these readmissions are unplanned and 27% were planned. The unplanned readmissions represent 64% of the readmission bed days which was the equivalent of 11 beds in 2015.

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\(^3\) These are commonly referred to as ‘readmissions’ even though they may occur months or years after a previous admission. Strictly speaking, they do not fulfil the ABF definition of a readmission which occurs within a limited time of discharge from, and is directly related to, a hospital admission.
The main reason for readmission includes pressure injuries, bowel and bladder issues, neurological and digestive issues. Pressure injuries represent 15% of readmissions at RNSH and 38% of bed days; at POWH they were 15% of readmissions and 46% of bed days.

The median length of stay (MLOS) for readmissions at RNSH can be seen in figure 11. They tend to be higher at POWH where the MLOS for the past seven years was 11 days compared to 9 days at RNSH.
FIGURE 11: MEDIAN LENGTH OF STAY FOR READMISSIONS BY HOSPITAL AND YEAR

Source: NSW SSCIS Spinal Cord Injury Database
3. **A Selective Literature Review: Key Themes**

The brief for this diagnostic phase stated that the project was to include a ‘rapid review of the literature’ to assist in identifying best practice models of care. This section discusses some of the key findings emerging from the full literature review, which is at appendix 1. The full review covers:

- a discussion of the definition of ‘model of care’
- an overview of spinal cord injury services in Australia and internationally
- identification of some key issues for spinal cord injury services.

This section captures some of the key themes from the literature review.

### 3.1 Outcomes of SCI Services

Expert consensus recommends the expeditious transfer, within 24 hours of injury, to a specialist spinal cord injury unit, where there is an interdisciplinary team equipped to provide comprehensive care for the many and complex issues associated with traumatic spinal cord injury. Early admission to a specialist spinal cord injuries unit is believed to significantly reduce the rate of medical complications in patients. Peer reviewed data analysis from RNSH and POWH shows this to be the case (9, 10).

There is consensus that early decompression of the cervical spinal cord after traumatic injury (within eight hours) might have a positive impact on the functional and neurological outcomes. There is some evidence for this effect in animal models and sporadic clinical reports in humans (11).

A meta-analysis of qualitative research by Whalley Hammel (12) found that the most important dimension of rehabilitation for people with SCI is the calibre and vision of the rehabilitation staff. The authors identified seven key dimensions that are crucial for a successful adjustment outcome:

- the importance of acceptable staff attitudes and behaviours
- the need to involve the person with a spinal cord injury in decision making
- the value of spinal cord injury peers in the adjustment process
- the relevance of rehabilitation program content
- the institutional nature of the inpatient rehabilitation environment, which has often been criticised for being overly structured, inflexible and standardised
- the importance of connecting the past to the future in the adjustment process
- making the rehabilitation relevant to the outside community and society.

In their review of the literature, Barclay et al. (13) found that adequate personal care assistance, appropriate social support, having adequate specialised equipment, and appropriate occupational therapy input were found to facilitate social and community participation, whereas problems with transport, inaccessibility of the natural and built environment, issues with healthcare services and rehabilitation providers, and pain were identified as barriers.

Roels et al. (14) reported on a randomised controlled trial that showed evidence that a vocational rehabilitation programme based on the principles of supported employment integrated in a multidisciplinary team enhances employment for SCI people.
3.2 Psychosocial Care & Person-Centred Care

While physical aspects of rehabilitation have been well studied and developed, psychosocial aspects of care have to a large extent been overlooked.

Adjustment following spinal cord injury, according to Middleton and Craig (4) is non-linear and possibly cyclical; it is also a product of the combination of biological, psychological and social modifying factors.

Some research by Papadimitriou and Carpenter (15) although limited, indicates that implementation of person-centred care (PCC) contributes to patients’ self-worth, sense of confidence, and self-esteem. The American Geriatric Society Expert Panel on Person-Centred Care (16) identified elements essential to realising PCC:

- an individualised, goal-oriented care plan based on the person’s preferences
- ongoing review of the person’s goals and care plan
- care supported by an inter-professional team in which the person is an integral team member
- one primary or lead point of contact on the healthcare team
- active coordination among all healthcare and supportive service providers
- continual information sharing and integrated communication
- education and training for providers and, when appropriate, the person and those important to the person
- performance measurement and quality improvement using feedback from the person and caregivers.

The appointment of a primary or lead contact is exemplified by the designation of a key-worker to each new person with a spinal cord injury admitted to an inpatient rehabilitation program. The key worker concept is an element of NSW guidelines to improve rehabilitation and outcomes for people with a spinal cord injury (17) and has been used with success with inpatients with spinal cord injury in the National SCI Centre, Stoke Mandeville Hospital in the United Kingdom (18).

In an effort to improve rehabilitation and outcomes for people with a spinal cord injury in NSW, Middleton et al. (17) describe psychosocial guidelines that have been developed to provide direction for enhanced service delivery, staff training and care processes. While these guidelines are specifically applied to the inpatient rehabilitation phase, it is important to state that psychosocial support and management should begin during the acute/admission phase of spinal cord injury management, and support should continue in the community, for instance, providing assistance with social re-integration, employment and injecting resources into family members and caregivers.

Cijsouw et al. (19) found that disability-management self-efficacy (DMSE) – the confidence that people with a chronic condition have in their ability to manage the consequences of their condition – is associated with higher levels of participation and life satisfaction after spinal cord injury. These findings are congruent with those of another recent study by Craig et al. (20) that found a similar correlation coefficient between DMSE and a measure of autonomy in participation.

3.3 Consumer Involvement

From the consumers’ perspective, a review of research by Furlan et al. (21) found the areas of greatest interest for people with SCI as reported in two large-scale surveys include motor function, bowel and bladder control, sexual function, and pain.
Similarly, Simpson et al (22) identified 24 studies (a combined sample of 5262 subjects) from electronic databases with the intention of increasing the understanding of the perceived importance of life domains and priorities that contribute to well-being for individuals with spinal cord injury. While the questionnaires varied across studies, a consistent set of priorities emerged. Functional recovery priorities were identified for the following areas: motor function (including arm/hand function for individuals with tetraplegia, and mobility for individuals with paraplegia), bowel, bladder, and sexual function. In addition, health, as well as relationships, emerged as important life domains.

Lo et al (23) attempted to determine functional areas perceived by consumers as most important. They found arm/hand function had the highest preference; that is, retaining and not trading off existing arm/hand function for other improved functions. There were no significant differences found in preferences between bladder/bowel function and walking or elimination of pain, although walking was preferred in earlier (≤ 10) post-injury years and pain amelioration became more important with a longer duration (>10 years) post-injury. Sexual function had the lowest preference when traded against the other four functions.

In an earlier study to improve the relevance of research in the spinal cord injury area, Anderson (24) developed a survey in which subjects in the USA were asked to rank seven functions in order of importance to their quality of life. A total of 681 responses were completed. Regaining arm and hand function was most important to persons with tetraplegia, while regaining sexual function was the highest priority for people with paraplegia. Improving bladder and bowel function was of shared importance to both injury groups. The majority of participants indicated that exercise was important to functional recovery, yet more than half either did not have access to exercise or did not have access to a trained therapist to oversee that exercise.

3.4 Hospital Readmissions

Middleton et al. (25) investigated the frequency, cause and duration of rehospitalisation in individuals with spinal cord injury living in the community in NSW. Over a ten-year period (1990-2000), 253 persons (58.6%) required one or more spinal-related readmissions, accounting for 977 re-hospitalisations and 15,127 bed-days (ALOS 15.5 days; median 5 days). The most frequent causes for rehospitalisation were genitourinary (24.1% of readmissions), gastrointestinal (11.0%), further rehabilitation (11.0%), skin-related (8.9%), musculoskeletal (8.6%) and psychiatric disorders (6.8%). Pressure injuries accounted for only 6.6% of all readmissions, however, contributed a disproportionate number of bed-days (27.9%), with an ALOS of 65.9 (median 49) days and over 50% of readmissions (33 out of 64) occurred in only nine individuals aged under 30 years. Overall rehospitalisation rates were high in the first four years after initial treatment episode, averaging 0.64 readmissions (12.6 bed-days) per person at risk in the first year and fluctuating between 0.52 and 0.61 readmissions (5.1-8.3 bed-days) per person at risk per year between the second to fourth years, before trending downwards to reach 0.35 readmissions (2.0 bed-days) as the tenth year approaches.

3.5 Discharge Barriers

New (26) reports that the most common reasons for a discharge barrier were: waiting for approval for long-term and supported care or services, residential care, home modifications, family deliberations regarding discharge planning and the provision of equipment necessary for discharge. The reasons accounting for the greatest number of additional hospital days were: home modifications, residential care, equipment necessary for discharge, waiting for approval for long-term and supported care or services and accommodation for people unable to return to their
previous residence without readily available alternatives. Over the study period 17.5% of all bed-days were occupied by patients deemed to be clinically ready for discharge from the spinal rehabilitation unit but who had a discharge barrier. New (26) concludes that barriers to discharge from rehabilitation for patients with spinal cord damage are common, substantial, and represent an important opportunity for health systems improvement.

3.6 Access to Services

In Queensland, Cox et al. (27) revealed a high need for a specialist, multidisciplinary spinal cord injury outreach service following primary rehabilitation.

The centrality of general practitioners to spinal cord injury is demonstrated in a study of peer-reviewed articles which revealed that approximately 90% of people with spinal cord injury identify family physicians (GPs) as their regular doctors and 63% have spinal cord injury specialists. The authors claim that regular follow up by specialised teams and annual comprehensive health examination, are supported by the evidence.

There are many articles on the potential of telehealth to improve access to services where telehealth is defined as the ‘delivery of health care at a distance, using information and communication technology’ (28). The major rationales for its introduction have been to decrease costs, improve efficiency and increase access in health care delivery. Cited advantages of telehealth apart from improved access include cost-effectiveness, enhanced educational opportunities, improved health outcomes, better quality of care, better quality of life, enhanced social support and time efficiency (28).

About one-third of the 2,073 patients referred to the Queensland Spinal Cord Injuries Service between 2008 and 2013 lived further than 200 km from Brisbane and van de Pol et al. (29) concluded that telehealth models of care, which promote better engagement with local health service providers (such as general practitioners, nurse practitioners and allied health professionals) could improve equity of access and reduce the need for extensive travel.

In the delivery of many health services in Australia, Aboriginal people and those from culturally and linguistically diverse backgrounds often have poorer access to health services and poorer health outcomes than the rest of the population. A literature review of studies by Gary et al. (30) specifically investigating racial and ethnic disparities in spinal cord injury care services and outcomes, indicated that after a SCI, racial and ethnic minority groups have shorter hospital lengths of stay, higher rehospitalisation rates, higher levels of depression, more days in poor health, greater degrees of unemployment, more difficulties with mobility, lower self-reported subjective well-being and quality of life and life satisfaction, and greater risk of marital breakup.
4. Themes from Consultations: People Living with Spinal Cord Injury

The project used a number of approaches to consultation with consumers and their representatives, including:

- meetings during site visits with inpatients and people with spinal cord injury and carers being supported in the community (23 interviews)
- meetings with the two major community organisations working with people with spinal cord injury, Spinal Cord Injuries (SCIA) and ParaQuad NSW
- an online survey distributed via the two key community groups, SCIA and ParaQuad NSW and the ACI newsletter.

The individual interviews with people with spinal cord injury were invaluable, especially for those now living in the community. Many inpatients declined to meet with the consultants during our site visit and this is understandable given the focus on recovery and self during these initial months post-injury. Further, they are not in a position to provide a broader, system-wide perspective. The meetings with the community organisations proved invaluable in providing a more strategic overview of unmet need and changes required and the survey provided a comprehensive way to gain feedback and document it.

4.1 Interview Themes

We interviewed 23 people with spinal cord injury (and three also had carers or partners in attendance). As shown in table 3 the vast majority were male (82%) and there was considerable variety across this group in terms of time since their injury ranging from recent injuries to over 40 years. Given the small numbers involved, it is not possible to draw definitive conclusions from these interviews, nevertheless, some common themes did emerge.

For those people living in regional and rural settings, the most common issue raised was the lack of support in the community upon discharge from the spinal cord injury units. This was particularly true of those whose injury occurred many years ago – indeed some of the people indicated that they had received no support or referrals upon leaving hospital. For some, the only ongoing contact they had with the service system were follow-up visits to Royal North Shore Hospital, which are a huge burden, both financially (transport and accommodation costs) and logistically.
TABLE 3: PROFILE OF 23 PEOPLE WITH SCI INTERVIEWED

<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>19</td>
<td>83%</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>17%</td>
</tr>
<tr>
<td>Time since injury</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>9</td>
<td>39%</td>
</tr>
<tr>
<td>1-5 years</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>6-10 years</td>
<td>2</td>
<td>9%</td>
</tr>
<tr>
<td>11-25 years</td>
<td>4</td>
<td>17%</td>
</tr>
<tr>
<td>25+ years</td>
<td>7</td>
<td>30%</td>
</tr>
<tr>
<td>Where residing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spinal unit</td>
<td>6</td>
<td>26%</td>
</tr>
<tr>
<td>Community</td>
<td>17*</td>
<td>74%</td>
</tr>
<tr>
<td>Institution</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Usual residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>6</td>
<td>26%</td>
</tr>
<tr>
<td>Regional</td>
<td>6</td>
<td>26%</td>
</tr>
<tr>
<td>Rural</td>
<td>9</td>
<td>39%</td>
</tr>
<tr>
<td>Unknown</td>
<td>2</td>
<td>9%</td>
</tr>
</tbody>
</table>

* Of these, one was interviewed as an outpatient at RNSH and one was attending a clinic at SCH

In this context, the Rural Spinal Cord Injury Service was seen as a major improvement for this group of people in providing access to specialist services closer to where they live. However, it was noted that the clinics are infrequent and only in a small number of locations and at least two people consulted commented that it was not easy to obtain an appointment.

Another common issue raised by people living in regional and rural areas was the lack of experience and knowledge among general health services in providing services to people with spinal cord injury. That is, when accessing local hospitals and services for issues unrelated to their spinal cord injury, they often experienced a lack of understanding and sensitivity to managing people with SCI. For example, one person had had a number of experiences with medical and other staff who were unaware of autonomic dysreflexia, a potentially life-threatening condition for individuals with spinal cord injury.

Another common theme for those people living in the community was the lack of wheelchair access to a range of services and facilities, including transport, parking shopping centres, toilets and sporting and other recreational facilities that are essential for their active participation in local community life.

The issues raised by those people with recent injuries who are still inpatients include:

- some concerns about the skills and commitment of some staff in the units, especially agency staff
- a perception of staff shortages
- a concern that there is no one person ‘keeping track of you’
- poor food choices, especially noticeable for the long stays experienced by people with spinal cord injury.

People in the inpatient units also commented on the importance of peer support and psychological support and a number interviewed also argued for transitional accommodation where newly injured
adults could go before home so as to adjust to new ways of doing things (e.g. cooking) while being exposed to peers who have been through the same process. SCIA provides an apartment – called CHOICES (which stands for Client-Centred Housing Offering Inspiring, Creative, and Empowering Services) - at Little Bay which is an essential extension of the peer support service provided in the spinal units. It is available to all people with a spinal cord injury during their time in hospital, who can choose to stay for multiple periods of up to 7 days with another injured person, or with their family or friends. While people are staying at CHOICES, they have access to a wide range on information and advice from many sources, including peers if desired.

One person we interviewed commented on the volume and complexity of information that is provided at discharge but noted that it does not include important financial information (e.g. about accessing funding; managing finances). She advocated for more user-friendly and online resources, including videos and tools using social media.

4.2 Community Organisation Consultations

The consultations with the two community organisations, SCIA and ParaQuad NSW, highlighted some fundamental concerns with the current service system.

The first issue relates to language. It was noted that the term ‘patient journey’ is problematic because it immediately implies that the focus is medically-driven and not about the person and their lifelong aspirations. For many people with spinal cord injury, including a number we interviewed, they live fulfilling, independent lives in the community and are only ‘patients’ and ‘consumers’ when they have sporadic interactions with the health system. The acute phase of treatment with traumatic spinal cord injury usually represents a fraction of their lifetime experience.

Accordingly, SCIA representatives argue that the starting point should be the goals and expectations of people with spinal cord injury and to work backwards from that in developing a system that meets their lifetime needs. They see the NDIS as a once in a lifetime opportunity to rethink the system, along the lines of the Swiss Paraplegic Center, where the person’s needs determines their transition between phases and effort is spent equally on housing, employment and skills development rather than being siloed, as in NSW and Australia. Necessarily, this involves greater interaction and coordination between the health, disability and other sectors.

Like SCIA, ParaQuad NSW representatives were concerned about the policy for the Spinal Outreach Service to exit patients after 12 months, although it was acknowledged that some clients continue to receive services beyond this ostensible cut-off date. Nevertheless, there was seen to be some benefit in having clients transition from the service, possibly after two years, as this can promote self-management and skills acquisition.

Service development priorities identified by ParaQuad NSW include:
- improved support for people who need to re-enter the health system
- better discharge planning for people with spinal cord injury from rural and local hospitals
- more transitional and respite care accommodation
- meeting the needs of the growing population of older people with spinal cord injury
- the establishment of metropolitan coordinators akin to the rural coordinators
- access to services in rural and regional communities
- services for teenagers who are often not well suited in either paediatric or adult settings.
4.3 Online Survey

This section provides a summary of the major findings of the online survey of people with spinal cord injury (see appendix 6 for the full analysis). A total of 47 people who had used spinal cord injury services participated in the online survey about aspects of the care and support they received in various settings, and their overall views and ideas for service improvements, including 14 who were carers or family members of people with spinal cord injury. Most consumers were currently receiving care from community-based services (30%) or through clinics, specialist visits or the outreach program (23%). There were no current inpatients of the specialist spinal cord injury units in the online survey.

Table 4 summarises the characteristics of the survey population. 60% of respondents are now aged between 40 and 65 years of age but at the time of injury the age range was more evenly distributed, with 32% under 19 years and 26% between 20 and 29 years. Respondents to the survey lived in metropolitan Sydney (39%), regional NSW (48%) or rural NSW (14%). They are mostly living at home with family and friends (72%).

**TABLE 4: PROFILE OF 47 PEOPLE WITH SCI WHO COMPLETED THE ONLINE SURVEY**

<table>
<thead>
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<th>%</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>25</td>
<td>53%</td>
</tr>
<tr>
<td>Female</td>
<td>22</td>
<td>47%</td>
</tr>
<tr>
<td><strong>Age at time of acquiring a spinal cord injury</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-9 years</td>
<td>4</td>
<td>9%</td>
</tr>
<tr>
<td>10-19 years</td>
<td>11</td>
<td>23%</td>
</tr>
<tr>
<td>20-29 years</td>
<td>12</td>
<td>26%</td>
</tr>
<tr>
<td>30-39 years</td>
<td>3</td>
<td>6%</td>
</tr>
<tr>
<td>40-65 years</td>
<td>17</td>
<td>36%</td>
</tr>
<tr>
<td>65+ years</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td><strong>Age now</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-9 years</td>
<td>0</td>
<td>0%</td>
</tr>
<tr>
<td>10-19 years</td>
<td>4</td>
<td>9%</td>
</tr>
<tr>
<td>20-29 years</td>
<td>7</td>
<td>16%</td>
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<tr>
<td>30-39 years</td>
<td>4</td>
<td>9%</td>
</tr>
<tr>
<td>40-65 years</td>
<td>26</td>
<td>60%</td>
</tr>
<tr>
<td>65+ years</td>
<td>2</td>
<td>5%</td>
</tr>
<tr>
<td><strong>Usual residence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metropolitan</td>
<td>17</td>
<td>39%</td>
</tr>
<tr>
<td>Regional</td>
<td>21</td>
<td>48%</td>
</tr>
<tr>
<td>Rural</td>
<td>6</td>
<td>14%</td>
</tr>
</tbody>
</table>

The survey used an approach adapted from the Picker Principles of Person-Centered Care (31), on the advice of the SSCIS Project Executive Planning Committee, covering six principles:
- coordination and integration of care
- involvement of family and friends
- respect for values, preferences and expressed needs
- information communication and education
- emotional support
• transition and continuity.

We also asked people about their best and worst experiences in care and their ideas for service improvements.

4.4 Support from the Service System and Others

The majority of respondents (57%) were not currently receiving support from the major insurance schemes and ADHC schemes. 20% were receiving assistance through the Lifetime Care and Support Scheme and only 4% through the NDIS. NDIS participation is expected to increase over the coming years.

Care by family and friends (unpaid) was provided to 45% of people, some people used a combination of both paid and unpaid care, however quite a high proportion (20%) reported no carer support.

FIGURE 12: SERVICE PROVIDERS THAT RESPONDENTS HAD USED

There was a substantial spread of contact and support from the identified spinal care injury services, many having contact with dedicated spinal outreach services and outpatient services (54.3%). Support from other community-based services was substantial (17.4% had contact with either public health or non-government community-based services). Three people were managed by interstate spinal acute services, two by district level hospitals.

4.5 Experiences Through the Major Phases and Aspects of Care and Support

We asked respondents about their experiences of care and support in the health system and services provided by the SSCIS. They were asked to consider 25 statements about various
aspects of the care they received and to rate them on a scale, ‘strongly disagree’ to ‘strongly agree’.

The statements were organised around the major phases of care - acute care, rehabilitation, transition to living in the community. They do not cover aspects of lifetime care and support in the community, but focus on people’s experiences with health services which form part of the SCI network.

The full range of responses to the seven areas of interest shows that for many statements there was a spread of positive and negative responses.

The highest favourable responses (agree, strongly agree) were for coordination of care while in hospital and the setting of goals while in rehabilitation. For most respondents the care and support while in hospital was well coordinated and led by a nominated clinician. Involvement of family and friends to the degree that the primary consumer wanted was also rated very favourably.

The highest proportion of unfavourable responses (disagree, strongly disagree) was for questions about transition to living in the community. 51% felt they were inadequately prepared for living in the community.

Respondents were asked questions about their experiences through the major phases of care and support following a spinal cord injury.
While in hospital
Care and support while in hospital was well coordinated and led by a nominated clinician for most people

Over 60% experienced a nominated clinician for coordinating care and over 50% felt care within the hospital was well coordinated. 33% considered that care from different clinicians and parts of the hospital was not well coordinated.

Information, communication and education
Processes that surround leaving hospital were highlighted for improvement

58% of respondents rated themselves as adequately informed about their condition and treatment while in care. 48% reported having received inadequate information about their future capacity for ADL, and 35% did not gain sufficient or expected information about the process of transition.

While in rehabilitation
Consumers were involved in goal-setting

62% of clients were involved in goal-setting, however the belief that goals were achieved dropped to 54% of respondents.

Involvement of family and friends
There was appropriate involvement of family and friends for most people

73% of respondents consider the level of involvement appropriate and 67% considered that clinicians and caregivers recognised the role of family and friends in support.

Transition to living in the community
Over half felt they were inadequately prepared for living in the community

47% of respondents reported no nominated worker to lead and coordinate the transition to the community.

Overall, almost one in three (32%) reported inadequate follow up post discharge. Of the 30 people who sustained their spinal cord injury in the last 10-15 years, 27% (8 people) reported inadequate follow up post discharge.

Respect for values, beliefs and expressed needs
Consumers had largely positive experiences being treated with respect and involved in decision-making

68% reported being involved in decisions about their own care and treatment and being treated with respect and dignity. 25% reported not being treated with respect and dignity.

Emotional support
Consumers did not consider their emotional needs were met

31% of people considered that clinicians and caregivers did not provide adequate emotional support and 35% in relation to family and carers. 33% reported health professionals involved not discussing any fears or anxieties had about their condition and treatment.

Two areas of care and support are highlighted as requiring development in the model of care:

- planned and supported transition for hospital to living in the community
- providing effective emotional support to the person and family/carers.

4.6 Overall Experiences and Suggestions for Improvement

The online survey provided for free form responses to a series of questions on people’s overall experiences of care and their priorities for service improvements.

Respondents were asked to identify the best experience when receiving care or support. By far the majority of responses identified individual clinicians or professional groups such as
physiotherapists and the support from the community-based organisations, SCIA and ParaQuad NSW.

Support, kindness, professionalism were cited as behaviours most admired. The opportunity to engage in sports during rehabilitation was welcome.

Less positive experiences focused on poor communication between staff and services and lack of involvement of person in small decisions which affected their well-being and immediate experiences.

Person-centred care as the driving philosophy was emphasised as very important.

Many of the identified negatives were repeated as suggestions for improvement:
- better understanding of needs
- improved communication and decisions around medication management
- better planning for discharge
- improvements in the physical environment and features that enforce respect and dignity as an adult.

Other service improvements related to a broad range of issues summarised in table A7 in appendix 6. The main messages relate to:
- improving support while living in the community post hospital care
- integration of hospital and community services and in particular sharing knowledge between staff
- meeting the needs of rural consumers
- training staff in person-centred care approaches
- creating a home-like environment in hospital focused on optimising independence.
5. Themes from Consultations: Clinicians

We met with over 100 clinicians in our consultation program and fieldwork visiting major services and some regions and used a guided structured interview format in covering the following topics:

- current delivery model - how it operates, the role of clinicians, the relationships between the components (trauma care, transfer to spinal acute unit, acute care, rehabilitation, transition planning, outpatient and community-based services)
- operational arrangements for patient pathway planning and implementation
- approach to continuous improvement, involvement in performance benchmarking
- the perceived strengths of the current service system - current initiatives in the service
- evidence locally (data, evaluations) on effectiveness of current approach
- groups of patients/consumers for whom specific strategies are required
- local protocols for managing a patient’s journey and transfer of care through the stages of care at your service
- perceived priorities for service development.

We also distributed an online survey to clinicians through the ACI newsletter receiving 43 responses from the groups shown in table 5:

<table>
<thead>
<tr>
<th>TABLE 5: ONLINE SURVEY RESPONDENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical</strong></td>
</tr>
<tr>
<td><strong>Nursing—hospital &amp; community</strong></td>
</tr>
<tr>
<td><strong>Allied health</strong></td>
</tr>
<tr>
<td>**Other ***</td>
</tr>
<tr>
<td><strong>Total</strong></td>
</tr>
</tbody>
</table>

* Rehabilitation Engineer (1) Rural coordinator (1)

The survey focussed on three specific questions:

- What are the strengths of the current delivery of spinal cord injury services across NSW?
- What are the weaknesses or gaps in the service system for people with spinal cord injury?
- What are the top three priorities for service improvement to spinal cord injury services?

The following analysis combines the themes emerging from face-to-face consultations with the survey results, where appropriate, on the three issues we asked clinicians about in both forms: survey and face-to-face interviews.

5.1 Strengths of the Current Delivery System

The strengths of the services were identified firstly and most consistently as high quality resourced specialist services with outreach models, working across the continuum of care from acute services to outreach in the community and the opportunity for return to hospital as needs change.

<table>
<thead>
<tr>
<th>Specialist statewide network</th>
<th>Highly specialised services have developed for patients with complex needs and this builds staff skills and capabilities in a specialised field. Many people cited passion and commitment as characteristics of staff working in SCI services.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural service through mobile clinics</td>
<td>The capacity to provide services to rural communities through mobile clinics, and the funding of rural coordinators was highly regarded.</td>
</tr>
</tbody>
</table>
The SOS is valued as an essential support for people transitioning to the community. Extension of the service to lifelong care in the community is being advocated for.

Communication between disciplines, between services and in the interests of patients, was seen as a positive feature of the existing service system.

- Timely access for patients through transfer policies to a specialised network.
- The roles of specialist services and staff in up-skilling generalists and community clinicians to build capacity and promote better outcomes clients in the community.
- For those eligible, the relatively generous Lifetime Care and Support Scheme.
- Relatively well resourced allied health teams in acute and rehab settings including clinical psychology services, and highly specialised supports such as the seating service and the plastics service.
- Reliance on evidence base for services, delivered as equitably as possible.
- Good mechanisms to share expertise in the very small paediatric spinal service.
- Vocational services.

5.2 Weaknesses of the Current Delivery System

Clinicians also identified the weaknesses or gaps in the service system with the following themes emerging.

Poor rural access, notwithstanding support for the current attempts at outreach, was the most frequently mentioned gap. Regional and rural clients have poorer access to specialist medical and even general allied health professionals. There was a repeated view that generalists or recent graduates working in regional or rural centres lacked the specialist knowledge and skills needed to assess and treat people with spinal cord injury. Overnight accommodation/travel options which are wheelchair accessible for rural clients in Sydney are limited. There is a lack of local peer support groups, spinal-appropriate leisure and sporting activities in rural areas.

This was highlighted many times. Service eligibility for those over 65 and therefore provision is very compromised.

Those without access to insurance schemes, and patients with non-traumatic SCI will experience poorer access and quality of services.

There is a need for improved understanding among clinicians across different service settings - acute, rehabilitation and community – about improving the respective services offered and links between services.

The statewide units are all within a 17km radius of each other and there are no multidisciplinary outreach clinics in metropolitan Sydney similar to the rural clinics. No spinal co-ordinator or specialist services in the Illawarra/Shoalhaven area. Ability to access public urological services and public respiratory services is limited and there are gaps in long term multidisciplinary care and assessment services.

Limited outpatient therapy and lack of home visits and follow up were cited as the cause of preventable inpatient admissions.

There needs to be timely access to pressure care equipment to prevent progression of pressure injury. At the moment, long-term follow-up for medical review, review of age related functional changes, and review of equipment is poorly structured.

There is no spinal specific dietetic outpatient services where patients can be referred once discharged.

No multidisciplinary clinics for outpatients at RNSH or Royal Rehab- crucial for spinal clients who are at risk of overuse syndrome, prevention of pressure injuries with review of equipment as well as physiotherapy to educate in preventing overuse issues.

Delayed access to specialised outpatient services at RNSH eg. Video-urodynamic tests, Spinal Plastics Clinics
Waiting times | Waits for funding of equipment, home modifications and care were viewed as unacceptably long. Likewise wait lists for local services/specialists were also considered unacceptable and led to increased morbidity and preventable inpatient admissions.

Transitional/discharge accommodation | There is a lack of adequate accommodation as people wait for modifications or for people requiring more assistance than can be provided at home. There is no Housing NSW strategy or point of contact.

Psychosocial support | Psychosocial support is an area of unmet need.

### 5.3 Priorities for Service Improvement

Clinicians in face-to-face interviews and through the online survey were asked to nominate their top three priorities for service improvement.

The table below summarises the main themes. They mirror in most aspects the gaps and weaknesses. Top priorities are:

- Increasing skills and support in rural areas
- Providing transitional care and accommodation, both for those needing extra support prior to returning home, and those awaiting home modifications and equipment in a home-like environment
- Services to support an ageing population and addressing the inequities for the over 65yr olds.

<table>
<thead>
<tr>
<th>SUGGESTIONS</th>
<th>SUMMARY</th>
</tr>
</thead>
</table>
| Increase skills and support in rural areas | • Expansion of the rural outreach service.  
• Establishment of additional Rural Spinal Cord Injury Coordinator positions to cover all rural LHDs  
• Increased use of telehealth.  
• More community engagement with people with a SCI in rural areas.  
• Up-skilling and / or retaining skilled rural clinicians who provide face-to-face local clinical services to SCI clients.  
• Improve wheelchair/seating services rurally. |
| Transitional care/ accommodation | • Accommodation or transitional care places for those waiting for modifications to housing or awaiting permanent housing to enable hospital beds to be vacated faster.  
• Provision of transitional accommodation for post-discharge prior to returning home as part of rehab process.  
• Access to respite beds. |
| Services for clients over 65 years of age | • Timely funding of home modifications and equipment and care for people with SCI regardless of age or insurance status, and as they age and needs change.  
• Alternative equipment access/ funding avenue for clients aged over 65 with Commonwealth aged care funding.  
• Alternatives to nursing homes for clients 65+. |
| Training for community staff and care providers in specialised SCI care | • Provide education and mentorship to NDIS providers in spinal specific care and interventions.  
• NDIS should identify providers who have relevant experiences / expertise in treating spinal clients.  
• Increase number of community nurses with specialist training/ experience in SCI treatment. |
<p>| Funding increase | • More community based resources to deal with clients and their issues, at home and to keep |</p>
<table>
<thead>
<tr>
<th>SUGGESTIONS</th>
<th>SUMMARY</th>
</tr>
</thead>
<tbody>
<tr>
<td>For specific SCI services, particularly in the community</td>
<td>them out of hospital.</td>
</tr>
<tr>
<td>• Ongoing funding for case management services - case managers to have clinical backgrounds.</td>
<td>• Spinal Outreach Service should be funded as lifetime support not time limited.</td>
</tr>
<tr>
<td>• A crisis intervention service with people and equipment that could offer advice and intervention for clients with pressure injuries, or significant, sudden changes in their ability e.g. fractured leg.</td>
<td>• Management of longer term medical and psychosocial needs in the community (including care supports).</td>
</tr>
<tr>
<td>Collaboration between acute care, rehabilitation &amp; community based services</td>
<td>Better in-reach from Royal Rehab to RNSH – reduce assessments and improve transition.</td>
</tr>
<tr>
<td>• Peer support for clients, including establishment of peer support groups in rural areas.</td>
<td>• Transitioning care for 14–16 year olds – need more flexibility for this group and psychosocial supports and vocational supports essential for this group. Model needs to address these young people.</td>
</tr>
<tr>
<td>Other</td>
<td>• Sport, leisure activities and transport services need to be improved in rural areas.</td>
</tr>
<tr>
<td>• Improvement of carer training by provider agencies - legally they should establish that the particular carer who is sent to a SCI patient has been trained and how or where</td>
<td>• Enhanced psychology resources for all inpatient and outpatient SCI services across the State.</td>
</tr>
<tr>
<td>• Enhanced psychology resources for all inpatient and outpatient SCI services across the State.</td>
<td>• NDIS/Health &quot;boundary issues&quot; to avoid the development of service gaps and poor equipment outcomes.</td>
</tr>
</tbody>
</table>
| • Differences between LHDs on the extent to which community health staff can engage with clients’ equipment issues. | 5.4 Consultations with Surgeons

A meeting with a group of neurosurgeons and orthopaedic surgeons from across NSW was held on 13 August 2016 to discuss their relationship with the spinal units and opportunities for service improvement (see appendix 2 for the participants in the meeting). The meeting agreed that, in general, communication from transferring hospitals and the spinal cord injury units was seen to be working well and the transfer of patients to SCI units has improved. However, some work on formalising the communication processes was recommended.

The group agreed on a set of broad characteristics of an ‘ideal model’:

- one acute spinal cord injury unit, located in a designated trauma hospital: two SCIUs were seen as ‘a structural inefficiency’ that leads to uncertainty and confusion in the system
- evidence is currently lacking for the ideal time-critical window to perform reduction or decompression of the spinal cord for neuro protection and to achieve the best neurological recovery possible
- however, surgeon opinion suggested that decompression, which may involve surgery or a reduction manoeuvre without surgery, needs to occur early as practically possible, ideally within the first 6-12 hours, including at a local site when this is appropriate in consultation with the spinal specialist unit, before transfer to a spinal unit (rather than the current minimum standard of 24 hours based on STASCIS (32) results, which have limitations and potential biases due to its non-randomised, observational design)
- the recommended practice to transfer patient with SCI to specialist unit within 24 hours of injury is based on evidence to prevent/reduce secondary medical complications (such as deep venous thrombosis and pressure injuries)
- transfer to a spinal cord injury unit should ideally occur immediately or immediately after surgery, depending on the clinical circumstances
while transfer to a spinal cord injury unit located in a designated trauma hospital (RNSH) is ideal for multi-trauma, the person with an isolated SCI and no other trauma, if they are in the POWH catchment area, should be transferred directly to POWH without having to go to a trauma centre and/or RNSH first

it may be appropriate for initial surgery and stabilisation to be done locally, so long as there are sufficient resources and clinical skills, followed by immediate post-operative transfer to the spinal cord injury unit

- co-location of acute and sub-acute rehabilitation services was seen as optimal.

Fundamental to the model is good communication between the local hospital and the spinal unit, the group recommended that formal communication with the spinal cord injury unit be mandatory in the model of care, and that the SSCIS draft transfer guidelines should stipulate that the initial communication that occurs between the referring trauma centre and the receiving spinal specialist hospital should be between the surgeon at the trauma centre and the surgeon/spinal specialist at the spinal hospital. This would help improve communication, facilitate specialist to specialist discussion about the most appropriate time and location of the surgery/initial management and speed up the transfer to the spinal hospital. The model would therefore set out a 'default' pathway, from which departure may be negotiated on a case by case basis between the local surgeon and spinal units. It was also felt that a formal policy of non-refusal of transfers for acute spinal cord injury to the spinal units was important in reducing the time to transfer and should be part of the default pathway.

The group also identified the need for the model of care to incorporate:

- improved data collection systems to monitor and improve model of care, including the establishment of a data registry
- clear eligibility criteria, especially for patients with non-traumatic SCI (noting that prognosis needs to be a major consideration)
- direct access to rehabilitation after surgery in the group with non-traumatic SCI, rather than transfer to an acute SCIU
- mandated standardised neurological assessment according to International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI)
- stronger links with regional centres for locally-based rehabilitation
- internal hospital protocols for patient pathways between, for example, ICUs and trauma units and the spinal units
- development of common standards of care for acute SCI at trauma centres.

Other specific issues noted by the group included:

- the growing group of elderly patients who have sustained central cord syndromes from trips, stumbles and low falls – they are often not transferred to the units, remain in hospital and often end up in nursing homes where they can languish
- the pathway to POWH for multi-trauma patients because POWH not a designated trauma hospital.
6. The Diagnostic: What We’ve Learned

Broadly, people with spinal cord injury have four sets of interactions with the service system across their lifetime:

- at the onset of their spinal cord injury (e.g. trauma)
- at re-entry / re-admission to the service for management of complications or co-morbidities
- in assisting in their transition to living in the community
- while living in the community.

Figure 13 maps these three phases to the care setting and also shows how the mix of services and support from the health sectors and other sectors (e.g. disability services, community services, transport and accommodation) change over time. It should be noted, of course, that the journey is not as linear as depicted and varies for individual to individual.

FIGURE 13: PEOPLE WITH SCI: A LIFETIME PERSPECTIVE

Some of the key points to highlight in figure 13 are:

- the health sector and, specifically, specialist spinal cord injury services have the major role to play in responding to a trauma or other cause of non-traumatic SCI
- in the phase involving a transition back to community living, the health and other sectors are both heavily involved
- for people living in the community independently, their interaction will be primarily with the non-health sectors and most health care will be with non-specialist staff (e.g. GPs, community nurses).

Figure 13 provides a framework for considering the key findings of this diagnostic review and this section sets out six key system-wide findings while section 7 provides more detailed findings for three phases above.
Both sections integrate the results of the literature review, service mapping and online surveys with the findings from the consultations with people with spinal cord injury, clinicians and other key stakeholders. The key themes are synthesised as a six high level learnings which will inform the next steps in the development of the model of care.

6.1 Key Findings

1. **The existing service system has a number of inherent strengths**

   The model of care needs to acknowledge and build upon the strengths of the existing system that were identified during the consultations and review of service systems elsewhere:
   - staff working across the spectrum of spinal cord injury services are, in general, very experienced and passionate about meeting the needs of people with spinal cord injury
   - the specialist inpatient units are acknowledged as providing highly complex care at a high quality
   - the work of the specialist units is truly multidisciplinary, bringing together medical, nursing and a diverse range of allied health professionals in addressing the complex interplay of physical and psychological factors for people with spinal cord injury
   - the process of transferring traumatic spinal cord injury patients to the two metropolitan spinal units has been streamlined and improved in recent years
   - the spinal outreach service and the establishment of the rural coordinators has improved access to the specialist services
   - the SSCIS is supported by research conducted in the John Walsh Centre for Rehabilitation Research which is part of the Kolling Institute at Royal North Shore Hospital.

2. **The health services need to integrate with other sectors to better meet the lifetime needs of people with spinal cord injury.**

   As depicted in figure 13, the health system, across the spectrum of services – from acute care to post-acute rehabilitation and ongoing support in the community – has a major role in enabling people with spinal cord injury to live independent, fulfilling lives. However, it cannot do it alone.

   A fundamental conclusion of this diagnostic review is that there needs to be greater engagement with the other sectors in designing a systemic response that collectively contributes to the well-being of people with a spinal cord injury: the disability sector, the aged care sector and community organisations, including transport and accommodation providers. The consumer organisations consulted during this review suggested such an arrangement needs to be much more than improved communication; they saw the need for structural reform that looks at the whole-of-life needs of people with spinal cord injury. Central to such an arrangement would be the involvement of the funding bodies, such as the National Disability Insurance Agency (NDIA) and Lifetime Care, in designing a client-focussed system.

   Indeed, while the implementation of National Disability Insurance Scheme (NDIS) provides considerable challenges, it provides a unique opportunity for the health sector to collaborate and work with other private providers to provide a true continuum of service delivery across a person’s lifespan.

3. **Services and resources are concentrated at the ‘front-end’ (i.e. acute care)**

   Not only does the health sector need to better embed itself within a larger system, there needs to be improved integration of services within the health system itself. Much of the resourcing is
currently focused on the acute end of the care journey and while for many people with spinal cord injury, the acute phase of their trauma or condition is critical, it is but a small part of their lifetime experience with a disability. As noted above, one of the strengths of the existing system is the quality of care in the acute setting, the major concern raised by people with traumatic spinal cord injury is that the health system had not well prepared them for living in the community or supported them sufficiently while they were there.

In turn, some consumers commented on the lack of connection between services; that is, the acute services were not seen as joined up or integrated in meeting peoples’ health needs over the course of their lifetime. This is also reflected in the lack of data capturing the lifetime experience of people with spinal cord injury; the data that were available pertained, at best, to individual services (see key finding 6 below).

There was commonly perceived to be a shortage of community-based services. The limited number of specialist non-inpatient services and outpatients clinics are unable to meet the demand for periodic specialist multidisciplinary review and community-based treatment to help keep people healthy and out of hospitals and avoid unnecessary return to hospital which, as suggested in section 2.4, constitute a sizeable proportion of total inpatient bed days.

4. There are inequities in access to services

A consistent theme across the diagnostic project was the inequity of access to services for different groups.

- **People in regional, rural and remote areas**, have limited access to specialist medical, nursing and allied health services, reflecting the shortage of specialist skills in these areas and the concentration of specialist services in the large population centres of Sydney and Newcastle. While the Rural Spinal Cord Injury Service has made a significant difference for people in regional areas, the clinics are only held sporadically in a small number of regional centres and many parts of the state have few or no services. Additionally, the difficulties and challenges faced by the current five (5) RSCIS Coordinators each covering extensive geographical areas across the seven (7) rural and regional NSW LHDs, greatly limits their ability to provide equitable access and support to clients in remote areas.

  Even in metropolitan areas, there are limited numbers of multidisciplinary clinics similar to the rural outreach clinics and the ones that do exist, especially those attached to the hospitals, are operating at capacity. There is also lack of access to non-inpatient rehabilitation re-conditioning both for metropolitan and non-metropolitan clients. Moreover, it was noted that many of the medical staff and health professionals working in general hospitals lack the experience, skills and confidence to care for people with spinal cord injury.

  It also should be noted that people with a spinal cord injury in Illawarra/Shoalhaven have **no access to the SOS** and there are **no rural clinics** provided in the LHD and there is no equivalent to the Hunter SCIS.

- **People aged 65 years and over** are disadvantaged in accessing specialist and support services. They are not eligible for NDIS and have to navigate the limitations of the aged care system and at risk of ending up in a nursing home.
• There is differential access to care for compensable (e.g. Lifetime Care clients) and non-compensable clients, who have to finance much of their own equipment and support needs or rely on services such as Enable NSW, with sometimes limited scope. While the introduction of the NDIS may reduce the gap between these two groups, it is likely that differences will remain in peoples’ access to funding and services.

• Our consultations suggest that many adults with non-traumatic spinal cord injury are not being referred to the two spinal units and are either being treated in general rehabilitation or languishing in nursing homes. This is of particular concern because, as noted in section 1, this group is a growing proportion of adults with spinal cord injury.

• The relatively small numbers of Aboriginal people admitted to the spinal units, 19 in the last seven years, raises the question as to whether they are missing out on specialist services. It was also noted that in our consultations that existing services are not well designed to accommodate the special cultural and community needs of Aboriginal people and are thus likely to result in poor outcomes, consistent with evidence in the literature (see section 3).

5. Services need to incorporate truly person-centred care that also addresses peoples’ psychological care and support needs

One of the positives emerging from our consultations with people with spinal cord injury was their high regard for the skills and commitment of the staff. Nevertheless, the consumer survey results do highlight some concerns:

• 25% of respondents reported that they were not treated with respect and dignity
• 31% considered that clinicians and caregivers did not provide adequate emotional support
• 33% reported that the health professionals involved did not discuss any fears and anxieties about their condition and treatment.

These concerns were reinforced in some of our interviews with people with spinal cord injury, many of whom cited specific instances of where they had not been heard or respected. Similarly, peer workers we interviewed noted that while many staff were committed to their work and clients, some failed to demonstrate the respect and compassion required of working with people with a spinal cord injury.

One of the key themes of the literature review was the need for services to adopt a truly person-centred approach to care that incorporates:

• collaborative interaction between health providers and clients
• client-driven goal setting
• a focus on people’s strengths, life experiences and preferences
• flexible, individualised therapy and services
• empowerment of clients to manage their care.

The literature review also testifies to the importance of meeting the psychological care and emotional support needs of people, rather than attending to purely physical or medical needs.

6. Comprehensive and timely data is required for robust service planning and development

Data included in this report was sourced from the Spinal Cord Injury Database (SCID) managed by SSCIS. While the SCID database is a valuable asset, it has a number of limitations:
- it does not contain paediatric data
- it does not contain data on people with a spinal cord injury who are admitted to hospitals outside the three hospitals of RNSH, POWH and RR
- it does not contain data on outpatients, outreach services or community services such as Hunter SCIS
- there is a concern that the definition of ‘acute’ and ‘rehabilitation’ varies by hospital
- it is not possible with this data to trace the full lifetime experience of someone with spinal cord injury and this impedes service coordination and monitoring.

Moreover, as experienced in this project, the analysis of data is limited and confined to aggregate data only (e.g. it is not broken down by hospital; there is no analysis of where patient lives).
7. **Detailed Findings: Care Phases for Adults**

This section presents detailed findings for the three phases in the life of people with spinal cord injury discussed in section 6:

- at the onset of their spinal cord injury (e.g. trauma)
- at re-entry / re-admission to the service for management of complications or co-morbidities
- in assisting in their transition to living in the community
- while living in the community.

7.1 **Acute Care**

**Specialist acute care** refers to the spinal cord injury units at Royal North Shore Hospital (RNSH) and Prince of Wales Hospital (POWH). As noted in the literature review (see section 3), expert consensus recommends transfer within 24 hours of injury to a specialist spinal cord injury unit, where there is an interdisciplinary team equipped to provide comprehensive care for the many and complex issues associated with traumatic spinal cord injury. In addition, some people with SCI are readmitted to the units when they require complex specialist medical care and rehabilitation that cannot be provided locally.

The diagnostic report has identified the following issues within the acute care phase:

1. **Some people with SCI who should be admitted to the spinal units are not accessing the units**

The literature review noted that the expert international consensus was that people with traumatic spinal cord injury should be transferred to specialist spinal units within 24 hours of the traumatic event. Our consultations with staff of the spinal units and a group of neurosurgeons and orthopaedic surgeons suggest that, in general, the existing model of care complies with this practice, although some clarification of pathways and transfer protocols is warranted, particularly in light of the fact that POWH is not a designated trauma hospital.

While this diagnostic project did not have access to data on admissions of people with traumatic SCI to other units, there was some anecdotal evidence that some people are falling through the gaps and bypassing the specialist units. For example, it was noted that the spinal outreach services occasionally have clients referred to them who were previously unknown to the system.

In addition, there are concerns about access for the growing group of patients with non-traumatic spinal cord injury (NTSCI). There are no data from RSCIS about number of NTSCI patients who make it to the rural clinics and while their numbers have been growing in the two spinal units, it appears that some people may not have been referred to the units. Accordingly, there is a perceived need for better protocols and communication regarding service eligibility and treatment pathways, especially in rural areas.

2. **There are differences in the model of care and clinical practice across the two units**

The second key issue is that it appears that there are in effect two different models of care operating in the two spinal units in NSW. These apparent differences in the model of care can be seen in the following ways.

Firstly, the fact that POWH is not a trauma hospital leads to differences in the patient experience compared with RNSH which is a designated trauma hospital, where the patients will spend their
entire acute stay there including time in the SIU. At POWH, however, traumatic patients with a spinal cord injury may be transferred there after spending some time in another trauma hospital where they may receive surgery.

Secondly, at POWH rehabilitation is collocated with the acute unit while RNSH patients receive a substantial proportion of their rehabilitation at Royal Rehab. However, as a third schedule hospital and quite separate from RNSH, spinal cord injury patients do not automatically go to RR when they are ready for discharge from RNSH and, as noted in section 3, there is in fact often a delay in discharge from RNSH while waiting for a bed at RR.

Thirdly, there are some variations in the client profiles at each hospital, in terms of patient severity and compensable status (see section 3).

In combination, these differences may be contributing to the apparent differences between the two hospitals although, as noted in section 2, the MLOS across the two sites is not strictly comparable because they do not both use the Australian Institute of Health and Welfare definition of length of stay for new cases of spinal cord injury in terms of the duration of initial care (DIC), which is the period from the date of injury to the date of discharge from the spinal cord injury unit to another hospital, home, nursing home or other accommodation.

3. Many patients are unable to be transferred to more suitable rehabilitation settings and remain in the units when they are functionally ready to be transferred to another setting for ongoing rehabilitation

One of the most prominent issues in the literature, and a commonly identified concern nominated by people with spinal cord injury as well as clinicians, concerned the barriers for timely discharge to transitional rehabilitation. Not only is remaining in hospital incompatible with the desire of many people to return to community living, the experience of some consumers is that they did not access comprehensive, functionally-based rehabilitation during their stay that contributes to fostering independence and building self-management skills.

The key barriers to timely discharge were a shortage of suitable accommodation options, including step-down rehabilitation facilities, delays in home modifications and delays in access to equipment or access to funding for equipment. It was noted that these delays have been exacerbated in trials and early roll-out of the NDIS because some NDIA planners do not have the experience or clinical knowledge to make informed decisions about individuals’ needs.

4. There appear to be large numbers of people with SCI who are admitted to the spinal units with potentially preventable complications

As noted in the literature review in section 3, it is not uncommon for people with spinal cord injury to return for inpatient stays in the spinal units. It is estimated that unplanned admissions represented the bed day equivalent of 11 beds in 2015 (see section 2.4). Across the two units over the last seven years, pressure injuries account for approximately 16% of the readmissions and 43% of the bed days. Over the last three years, pressure injuries represented 13% of the separations and 36% of the bed days (see table 6). Unplanned pressure injuries are about one

4 These are commonly referred to as ‘readmissions’ even though they may occur months or years after a previous admission. Strictly speaking, they do not fulfil the ABF definition of a readmission which occurs within a limited time of discharge from, and is directly related to, a hospital admission.
third of pressure injury admissions and 27% of pressure injury bed days at RNSH; at POWH they are nearly half of pressure injury admission and 39% of pressure injury bed days. While it is difficult to ascertain the proportion of these that are needs-based and entirely appropriate versus those that represent avoidable readmissions, in concert with the literature our consultations suggest that a significant number could have been avoided had there been more appropriate and timely prevention and early intervention at the local level.


<table>
<thead>
<tr>
<th>Hospital</th>
<th>Unplanned PI</th>
<th>Planned PI</th>
<th>Total PI</th>
<th>Total readmissions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>#</td>
<td>%</td>
<td>#</td>
<td>%</td>
</tr>
<tr>
<td>RNS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separations</td>
<td>26</td>
<td>4.7</td>
<td>47</td>
<td>8.4</td>
</tr>
<tr>
<td>Bed days</td>
<td>722</td>
<td>8.0</td>
<td>1949</td>
<td>21.5</td>
</tr>
<tr>
<td>POW</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separations</td>
<td>14</td>
<td>5.7</td>
<td>18</td>
<td>7.3</td>
</tr>
<tr>
<td>Bed days</td>
<td>1268</td>
<td>17.2</td>
<td>2001</td>
<td>27.2</td>
</tr>
<tr>
<td>Total (both hosps)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Separations</td>
<td>40</td>
<td>5.0</td>
<td>65</td>
<td>8.1</td>
</tr>
<tr>
<td>Bed days</td>
<td>1990</td>
<td>12.1</td>
<td>3950</td>
<td>24.1</td>
</tr>
</tbody>
</table>

Source: NSW SSCIS Spinal Cord Injury Database

Avoidable readmissions are not only at odds with the fundamental goal of people living independently in the community, and thus inimical to their quality of life, they are expensive for the health system.

### 7.2 Transition to Community

The transition to community phase occurs in:
- specialist inpatient setting (e.g. POWH, RNSH, Royal Rehab, SCHN)
- inpatient beds in general hospitals across the state
- transitional housing settings
- outpatient clinics
- home settings.

The diagnostic project has identified the following issues with the transition to community:

1. **There are equipment, funding and home modification delays that lead to long delays in people returning home to live, which is often their preferred destination**
2. **There is a lack of accommodation options for those people who do not need to be in a spinal unit but require further rehabilitation before returning home or require access to suitable modified public housing**

There is a lack of accessible and affordable housing for rent and purchase for many people and it is difficult to obtain access to public housing. SCIA provides some short and long term accommodation in a number of properties around Sydney and ParaQuad provides some accommodation at Ferguson Lodge (see section 2.2). SCIA provides some unique accommodation – CHOICES – which is focused on helping people with a spinal cord injury and their families ready themselves to return home, before they are discharged from hospital.
CHOICES is an apartment in Little Bay where someone with a spinal cord injury (and their friends and family) can stay for up to seven days – the patient usually takes leave from hospital.

In Queensland, transitional rehabilitation occurs in the person’s home if they live in Brisbane and there are three houses in the community that can be used by patients who do not reside in the capital. At the Burwood service in Christchurch, NZ there is a hostel that is adjacent to the hospital for patients undergoing transitional rehabilitation following spinal cord injury.

3. **There is a shortage of community-based rehabilitation and support statewide and especially in regional and remote areas.**

7.3 **Living in the Community**

Living in the community refers to living in non-institutional settings which, ideally, is at home with family and support networks.

A number of key issues identified in this setting in this diagnostic project are:

1. There is a lack of community-based specialist skills, especially in regional, rural and remote areas
2. There is a shortage of locally-based multidisciplinary outpatient clinics and home visiting specialised services
3. Many local hospital, support and primary care staff do not have the training, experience and confidence in managing people with SCI
4. As a result, peoples’ general health issues not directly related to their spinal cord injury may not be well managed.
5. There is a lack of coordination among service providers, including local health and other community-based services
6. There is a lack of proactive, systematic multidisciplinary review of people living with spinal cord injury to promote well-being and prevent development of pressure injuries and other health issues.
8. Paediatric Issues

As noted in section 2, acute rehabilitation services for children with spinal cord injury are embedded in the paediatric rehabilitation units at the two hospitals in Sydney Children’s Hospital Network and at John Hunter Children’s Hospital in Newcastle. As also noted in section 2, children with a spinal cord injury represent only a small proportion of children attending these rehabilitation units. Further, unlike the adult units, children with non-traumatic spinal cord injury constitute a larger proportion of patients.

Given the small numbers and the different models of care, it is proposed that paediatric spinal cord injury rehabilitation be considered in the overarching model of care for paediatric rehabilitation services that has been commissioned by the Sydney Children’s Hospital Network and the paediatric rehabilitation service in the John Hunter Children’s Hospital. Nevertheless, it is critical that there be a separate model of care for children with spinal cord injury.

The table below summarises the main themes and priorities emerging from our consultations on the paediatric services.

<table>
<thead>
<tr>
<th>PRIORITY</th>
<th>THEME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community-based services</td>
<td>Sustainability of the NSW Paediatric Spinal Outreach Service (PSOS) to ensure continuing ability to provide spinal specialist multidisciplinary services to children with a SCI until they transition to adult services at approximately 18yrs of age.</td>
</tr>
<tr>
<td>Capacity building of local health and support services</td>
<td>Provide ongoing education and support of local health and support staff by SCHN and PSOS staff.</td>
</tr>
<tr>
<td>Inpatient services</td>
<td>Provide dedicated paediatric rehabilitation beds at CHW.</td>
</tr>
<tr>
<td></td>
<td>Strengthen formal links with the adult spinal cord injury units.</td>
</tr>
<tr>
<td>Data collection and reporting</td>
<td>Include paediatric data in the spinal cord injury database (SCID).</td>
</tr>
<tr>
<td>Transition to adult services</td>
<td>Streamline transition to adult SCI services, including psychological preparation of the child and family to a very different model of care.</td>
</tr>
<tr>
<td></td>
<td>Facilitate the transition of children with spina bifida, who constitute a significant proportion of the paediatric rehabilitation client population, to adult spina bifida services.</td>
</tr>
</tbody>
</table>

In relation to the proposed priority of capacity building local health and support services staff, it should be noted that there are some systematic barriers to be overcome. Firstly, Northcott Disability Services are an NDIS provider for children and adults with many different disabilities. The services that the NSW Paediatric Spinal Outreach Service (PSOS) aim to deliver are specifically targeting the paediatric SCI population in a format of a multidisciplinary outreach model, addressing the children’s ongoing health and disability related needs.

Secondly, educational/consultative work is not recognised under the ABF model and is therefore not encouraged by the Sydney Children’s Hospital Network.
9. Towards a New Model of Care

The purpose of this diagnostic report was to establish whether there is a case for change; that is, whether there is a need for a new model of care for people with spinal cord injury. In drawing on the literature and an extensive round of consultations with clinicians and consumers, as outlined in sections 6 to 8, the diagnostic finds that there is indeed a compelling case for change.

The diagnostic concludes that the health system needs to focus on better meeting the lifetime needs of people with spinal cord injury by:

- actively engaging with other sectors (e.g. disability, community services) in collectively improving the quality of life and well-being of people with spinal cord injury
- refocussing health services to facilitating peoples’ longer-term participation in community life away from the current emphasis on the acute care phase
- adopting truly person-centred practice that addresses the full range of peoples’ needs, including their emotional and psychological well-being, as well as their immediate medical needs.

The shift to a lifetime focus is consistent with the principles of the NDIS and the Lifetime Care and Support Scheme and, indeed, the implementation of the NDIS provides a unique opportunity (a ‘once in a generation opportunity’ as noted by one consumer organisation) to better embed the health system within a larger systemic approach.

Fundamental to this shift to a focus on lifetime support is the need to increase access to post-acute rehabilitation and transitional or ‘step-down care’ for clients and families and carers. The literature underlines the central importance of early, intensive post-acute rehabilitation in contributing to improvements in clients’ function, independence and quality of life. In this context, there is a pressing need for more increased transitional housing and accommodation options, preferably in community settings. Consideration should also be given to opportunities for sport recreation and social networks as valuable contributors to long term rehabilitation, health promotion and wellness.

Also, central to a new model of care is the need for improved equity of access to services, including community-based rehabilitation and support services. People living in regional, rural and remote areas, in particular, have poorer access to specialist services and therapy close to where they live.

In planning for future service developments, consideration needs to be given in the model of care to addressing the population distribution and projected growth areas across NSW (e.g in Western Sydney).

The growing numbers and proportion of people over 65 years old are especially disadvantaged – they are not eligible for NDIS and not well served by the aged care system. Similarly, the growing numbers of adults with non-traumatic spinal cord injury also appear to be missing out on specialist care.

The diagnostic review has also highlighted some service development issues in the acute care settings:

- the need to clarify pathways and transfer protocols, particularly as POWH is not a trauma hospital
- the need for clearer clinical pathways and protocols to streamline discharge planning and facilitate timely transfer to more suitable rehabilitation settings
• the need to address differences in the clinical practices across the two spinal cord injury units
• the need for consistent data definitions for ‘acute’, ‘sub-acute’ and ‘rehabilitation’ across the two
spinal units to facilitate benchmarking and service planning.

In relation to rehabilitation services for children with spinal cord injury, the key issues identified for
the relatively small numbers involved are to:
• strengthen community-based rehabilitation services and options
• build the capacity of local health and support staff in caring for children in their local
communities
• streamlining the transition to adult services.

Underpinning the development of a new model of care is the need for a comprehensive set of data
on people with spinal cord injury and their interactions with the health system and other sectors. In
addition, comprehensive data that tracks individuals across the course of their disability providing a
whole-of-life and whole-of-system perspectives for people with spinal cord injury and facilitates
service planning and development.

In summary, this diagnostic review concludes that there is a case for a new model of care and this
was strongly supported by the consumers, consumer organisations and clinicians we consulted.
The remainder of this section sets out:
• some draft principles to underpin the model of care
• some provisional service development priorities for the development of the model of care

9.1 Model of Care Principles

The diagnostic project steering committee agreed that the new model of care should
be underpinned by a set of principles that will guide further service development. The following set of
draft principles incorporate feedback and discussion on draft ones discussed at the August 2016
stakeholder workshop and in the draft versions of this diagnostic report.

1. Care and support of people with spinal cord injury focuses on their lifetime care and support
   needs.

2. The service system is person-centred and actively engages people with spinal cord injury, and
   their family and support networks, in making informed choices in managing their care and lives.

3. People with spinal cord injury have access to services and support as close as possible to
   where they live.

4. Those people who require specialised, complex spinal care have timely access to the spinal
   cord injury services.

5. While in hospital, people with spinal cord injury receive timely, individualised comprehensive
   rehabilitation that develops their lifelong skills, and supports their psychological adjustment and
   wellbeing.

6. While in hospital, people with spinal cord injury are assigned a key worker, who helps them
   navigate their hospital stay and transition back to the community.
7. On leaving hospital, people with spinal cord injury have timely access to the equipment, care, ongoing rehabilitation and specialised services to support their return to community living and participation.

8. Care and support for people with spinal cord injury is coordinated and easy to navigate across health, community and other related services.

9. While living in the community, people with spinal cord injury are actively supported by a range of services in maintaining health and psychological well-being over their lifetime.

9.2 Proposed Service Development Priorities

These principles have significant implications for SSCIS and the development of statewide spinal cord injury services. The August 2016 stakeholder workshop aimed to translate the principles into service development priorities and the proposed priorities that resulted can be grouped into six broad groupings or ‘planks’, as depicted in figure 14.

FIGURE 14: PRIORITY PLANKS

- **Multi-sector integration**: Engaging other sectors to deliver lifelong, person-centred support
- **Specialist services access & integration**: Improving integration of spinal network services, including increased access to post-acute rehabilitation and support close to where people live
- **Local capacity building**: Building the capacity of local health, disability and NGO services to support people to live independently in the community
- **Independence through self-management**: Orienting services to build people’s independence and self-management skills
- **Person-centered services**: Building the capacity of specialist services to promote person-centred care
- **Informed decision making**: Developing integrated data systems to better plan, evaluate and improve services

The planks lay out a framework for guiding shorter-term and medium term action and for informing future investment decisions for spinal cord injury services across NSW.

To this end, summarises some potential priorities for each plank that emerged from the August 2016 workshop and from feedback on the draft versions of this diagnostic report. It needs to be reinforced that these are some initial and draft proposals only; they will be subject to review, refinement and ranking in the next stage of the development of a model of care and, of
course, some would require additional funding. *They are presented only to suggest some possible steps in translating the principles and planks into a new model of care* and to begin the process of identifying priorities for future investments.

Moreover, the development of the model of care will need to take account of two factors in the SSCIS operating environment:

- the ongoing implementation of the National Disability Insurance Scheme, which has profound implications for the interaction between the health and disability sectors
- the activity-based funding management system in place across NSW Health, which does not easily accommodate the proposed increased emphasis on outreach and capacity building.
### TABLE 7: PROPOSED SERVICE DEVELOPMENT PRIORITY ACTIONS: SHORT TO LONG-TERM (AS IDENTIFIED DURING THE CONSULTATIONS)

<table>
<thead>
<tr>
<th>PLANK</th>
<th>DESCRIPTION</th>
<th>SHORT-TERM (LOW COST/NO COST)</th>
<th>MEDIUM TO LONGER TERM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multi-sector integration</td>
<td>Engaging other sectors to deliver lifelong, person-centred support</td>
<td>• Establish inter-agency mechanism with FaCS (Housing NSW) to facilitate quicker placement of people with SCI</td>
<td>• Establish a high-level inter-agency body to coordinate care and services to meet the holistic needs of people with spinal cord injury</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Actively engage relevant funding organisations (NDIA, LCSA, My Aged Care) in service modeling and process mapping to devise shared targets/KPIs to facilitate the achievement of each individual’s life goals as quickly and efficiently as possible.</td>
<td>• Establish agreements with other sectors to facilitate continuity of care</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Establish a high-level inter-agency body to coordinate care and services to meet the holistic needs of people with spinal cord injury</td>
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<td>➥</td>
</tr>
<tr>
<td>Specialist services access &amp; integration</td>
<td>Improving integration of spinal network services, including increased access to post-acute rehabilitation and support close to where people live</td>
<td>• Review referral and admission criteria to specialist services</td>
<td>• Introduce a range of transitional accommodation and support options to facilitate timely discharge and return to community living</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Identify key contacts across sector for rapid response to system access issues</td>
<td>• Extend rural outreach clinics and make available for people for life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Redefine and develop role of key worker as transition coordinator</td>
<td>• Increase number of RSCIS Coordinator positions to provide at least one in each rural / remote LHD.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Develop processes to improve communication, information sharing and collaboration across specialised acute, rehabilitation and outreach SCI services</td>
<td>• Establish additional accommodation for families near the spinal units so they can participate in care and transition</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Finalise acute SCI transfer guidelines</td>
<td>• Consider merits of expanding/relocating acute traumatic SCI services to one designated trauma hospital</td>
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<tr>
<td></td>
<td></td>
<td>• Develop transition model of care</td>
<td>• Establish a statewide equipment loan pool</td>
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<td></td>
<td>• Focus service access on preventable hospital admissions strategies clinics</td>
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<td></td>
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<td></td>
<td>• Build a care coordination process across specialised acute, rehabilitation and outreach SCI services (eg. primary contact person to facilitate goal planning, ongoing review, discharge management and assist with ‘care systems’ navigation)</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>• Review clinical variation across units to develop more consistent policies, processes and practices</td>
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<td></td>
<td></td>
<td></td>
<td>• Standardise goal setting, discharge planning and follow-up and related processes</td>
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<td></td>
<td>• Redesign and implement the role of Spinal Key Worker /Transition Coordinator to facilitate people moving back to the community from inpatient acute/sub-acute stay</td>
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<tr>
<td>PLANK</td>
<td>DESCRIPTION</td>
<td>SHORT-TERM (LOW COST/NO COST)</td>
<td>MEDIUM TO LONGER TERM</td>
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<tr>
<td>-------</td>
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</tr>
</tbody>
</table>
| Local capacity building | Building the capacity of local health, disability and NGO services to support people to live independently in the community | • Continue to promote and develop educational resources and tools for clinicians and health professionals  
• Establish escalation protocols for referral to specialist spinal services  
• Clarify pathways for transfer to and from local health and support services | • Establish metropolitan in-reach service model for non-spinal specialist facilities to support effective discharge planning and appropriate community linkages  
• Establish ‘satellite’ models (e.g. multidisciplinary team (MDT) clinics for proactive follow up, smaller spinal teams spread throughout Sydney metropolitan area)  
• Facilitate professional development of local clinicians (GPs, therapists, support workers etc)  
• Formalise networks with LHDs (e.g. hub and spoke model)  
• Establish processes that support people with SCI 24 hours a day (e.g. a 24 hour triage number)  
• Develop a comprehensive telehealth strategy |
| Independence through self-management | Orienting services to build peoples’ independence and self-management skills | • Finalise and promote the online pressure injury toolkit  
• Finalise and promote the pain navigator | • Continue to develop and promote educational resources and self-management tools  
• Strengthen peer support and involvement in programs  
• Create a rehabilitation environment that promotes independence, problem-solving and self-management (with an emphasis on a wellness/health maintenance and prevention of complications approach) |
| Person-centered specialist services | Building the capacity of specialist services to provide person-centred care | • Develop and implement educational programs about person-centred care  
• Introduce flexible care models during inpatient rehabilitation and community reintegration phases | • Implement a major workforce development strategy around principles of person-centred care and shared decision-making  
• Use co-design methodology in all projects aimed at strengthening person-centred care  
• Promote and further strengthen psychosocial care as developed by the SSCIS Psychosocial Strategy |
| Informed decision making | Developing data systems to better plan, evaluate and improve services | • Obtain periodic analysis of linked data from the new public health register (CATE)  
• Improve the collection, extraction, analysis and reporting of SCI data  
• Establish core data elements essential for planning and evaluation of service | • Establish processes to collect and report on patient experience, patient reported outcome measures (PROMS), quality of care, efficiency and cost  
• Investigate the feasibility of establishing an SCI data registry to capture and share data on a broad range of outcomes (e.g. employment, quality of life)  
• Encourage the network’s participation in research projects |
<table>
<thead>
<tr>
<th>PLANK</th>
<th>DESCRIPTION</th>
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</table>
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• Establish additional accommodation for families near the spinal units so they can participate in care and transition  
• Consider merits of expanding/relocating acute traumatic SCI services to one designated trauma hospital  
• Establish a statewide equipment loan pool  
• Focus service access on preventable hospital admissions strategies clinics  
• Build a care coordination process across specialised acute, rehabilitation and outreach SCI services (eg. primary contact person to facilitate goal planning, ongoing review, discharge management and assist with ‘care systems’ navigation)  
• Review clinical variation across units to develop more consistent policies, processes and practices  
• Standardise goal setting, discharge planning and follow-up and related processes  
• Redesign and implement the role of Spinal Key Worker /Transition Coordinator to facilitate people moving back to the community from inpatient acute/sub-acute stay |
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• Introduce flexible care models during inpatient rehabilitation and community reintegration phases | • Implement a major workforce development strategy around principles of person-centred care and shared decision-making  
• Use co-design methodology in all projects aimed at strengthening person-centred care  
• Promote and further strengthen psychosocial care as developed by the SSCIS Psychosocial Strategy |
| Informed decision making     | Developing data systems to better plan, evaluate and improve services        | • Obtain periodic analysis of linked data from the new public health register (CATE)  
• Improve the collection, extraction, analysis and reporting of SCI data  
• Establish core data elements essential for planning and evaluation of service | • Establish processes to collect and report on patient experience, patient reported outcome measures (PROMS), quality of care, efficiency and cost  
• Investigate the feasibility of establishing an SCI data registry to capture and share data on a broad range of outcomes (e.g. employment, quality of life)  
• Encourage the network’s participation in research projects |
# Appendix 1: Literature Review

## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABI</td>
<td>Acquired Brain Injury</td>
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<tr>
<td>ACI</td>
<td>Agency for Clinical Innovation</td>
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<tr>
<td>AFRM</td>
<td>Australasian Faculty of Rehabilitation Medicine</td>
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<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>ATSI</td>
<td>Aboriginal and Torres Strait Islander</td>
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<td>BA</td>
<td>Benefactors’ Association</td>
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<tr>
<td>BSU</td>
<td>Burwood Spinal Unit</td>
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<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
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<td>CCMs</td>
<td>Clinical care managers</td>
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<td>CHCs</td>
<td>Chronic health conditions</td>
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<td>CVD</td>
<td>Cardiovascular disease</td>
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<tr>
<td>DMSE</td>
<td>Disability-management self-efficacy</td>
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<tr>
<td>ED</td>
<td>Emergency department</td>
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<tr>
<td>ER</td>
<td>Emergency room</td>
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<tr>
<td>HRC</td>
<td>Hampstead Rehabilitation Centre</td>
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<tr>
<td>ICU</td>
<td>Intensive care unit</td>
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<td>NHS</td>
<td>National Health Service</td>
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<td>NIDILRR</td>
<td>National Institute on Disability, Independent Living, and Rehabilitation Research</td>
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<td>NRN</td>
<td>NeuroRecovery Network</td>
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<td>NSIC</td>
<td>National Spinal Cord Injury Centre</td>
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<td>NTSCI</td>
<td>Non traumatic spinal cord injury</td>
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<tr>
<td>PCC</td>
<td>Person centred care</td>
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<td>QSCIS</td>
<td>Queensland Spinal Cord Injuries Service</td>
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<td>SASCIS</td>
<td>South Australian Spinal Cord Injury Service</td>
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<tr>
<td>SCI</td>
<td>Spinal cord injury</td>
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<td>SCIMS</td>
<td>SCI Model Systems</td>
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<td>SIG</td>
<td>Special Interest Group</td>
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<td>SIU</td>
<td>Spinal Injuries Unit</td>
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<td>SPC</td>
<td>Swiss Paraplegic Centre</td>
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<td>SPOT</td>
<td>Spinal Outreach Team</td>
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<tr>
<td>TRP</td>
<td>Transitional Rehabilitation Program</td>
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<tr>
<td>TSCI</td>
<td>Traumatic spinal cord injury</td>
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Introduction

According to the Request for Quotation, the diagnostic review will include:

‘a rapid review of literature including grey literature & websites, to identify best practice models of care, modes of service delivery and associated resourcing with evidence for their efficacy and cost effectiveness in relation to the care, management and support of people (adults and children) with spinal cord injury.’

Search Method

The following databases were interrogated:

- PubMed (which includes Medline) using their systematic review function which provides citations for systematic reviews, meta-analyses, reviews of clinical trials, evidence-based medicine, consensus development conferences, and guidelines.
- The Cochrane Database for Systematic Reviews.

Search terms included: model of care, spinal cord injury AND models of care, services, rehabilitation, person-centred care, integrated care, community re-integration, follow-up, innovation, best practice

Many of the reports and documents from State and international websites are classed as ‘grey’ literature.\textsuperscript{5}

The literature review findings will be compared with the existing model of care for spinal cord injury (yet to be articulated). Also there are gaps in some of the detail for other countries. This review should be seen as a work in progress that will be expanded/elaborated.

\textsuperscript{5} Grey literature has been defined as “That which is produced on all levels of government, academics, business and industry in print and electronic formats, but which is not controlled by commercial publishers.” GL’99 Conference Program. Fourth International Conference on Grey Literature: New Frontiers in Grey Literature. GreyNet, Grey Literature Network Service. Washington D.C. USA, 4-5 October 1999
Definition of Model of Care

According to Davidson et al. (2006)⁶ there is ambiguity in the literature about what is meant by a ‘model of care’, and Queensland Health (2000)⁷ acknowledges the lack of a consistent definition, however they conclude that a model of care is a multidimensional concept that defines the way in which health care services are delivered. Davidson et al. go on to say that a ‘model of care’ describes the delivery of health care within the broader context of the health system and that a specific model of care should be amenable to evaluation.

In their guide to developing a model of care, the Agency for Clinical Innovation (ACI) has a similar definition:

A ‘Model of Care’ broadly defines the way health services are delivered. It outlines best practice care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place.⁸

A model of care is usually based on principles which are some combination of: patient/carer/family centric; needs based; networked; evidence based; safe, effective, efficient; equitable access; multidisciplinary teams; care coordination; appropriate care setting; leadership; integrated care.

It may focus on the key elements of a patient journey: referral processes, assessment, planning and coordination, service delivery, transfer of care, follow up & re-entry.

It can also set standards in relation to governance and leadership; care planning, coordination and delivery; standardised protocols and procedures; patient safety and experience, quality outcomes and data; education, training and clinical supervision, workforce management and support services, equipment.

It may identify the key enablers that will ensure the development of the model of care including workforce and education, care co-ordination and linkages, data, technology, infrastructure.

Finally, the care settings may be described: inpatient, outpatient, outreach. (However, sometimes the nature of the service is defined by the setting).

No definition of a ‘model of care’ describes these components in detail and yet they are evident in many of the models of care that have been developed by the ACI⁹. Maybe they are the multi-dimensional aspect of the definition of the model of care: depending on the view of the model, the emphasis will be different. If seen primarily as service elements, the focus will be on a description of the services and maybe the processes. If seen through the prism of the patient the emphasis will be more on the processes that hold the services in place and the system of care as a whole such as referral processes, information, case management, communication, follow up etc.

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As can be seen from the websites of many of the spinal cord injury rehabilitation services, the focus is mainly on the service elements.

**Setting the Scene for Spinal Cord Injury**

According to the AIHW (Norton, 2010) a total of 362 new cases of spinal cord injury (SCI) were reported in Australia in 2007-08 — 285 cases were due to trauma while 77 were due to other causes. The age-adjusted rate of persisting SCI from traumatic causes was similar to previous years at an estimated 15.0 new cases per million population (aged 15 years and older).

Incidence rates of SCI were higher for males than females at all ages. The average age at injury was 45 years, although patients who acquired an SCI traumatically were substantially younger on average than those who acquired their SCI non-traumatically (42 years vs 56 years).

Spinal cord injuries were most frequent in the 15–24 year age group. Increases in SCI numbers were seen in the 15–24 and the 65–74 year age group compared with the previous year. However, in the 25–34 year age category there was a decrease.

Patients with SCI tend to have lengthy hospitalisations. Overall, SCI patients had a median length of stay in hospital of 133 days.

Transport-related injuries (46%) and falls (28%) accounted for nearly three-quarters of the 285 cases of traumatic SCI during 2007–08.

The life expectancy of patients is estimated to be 70 per cent of the normal life expectancy for people with complete tetraplegia, 84 per cent for people with complete paraplegia and at least 90 per cent for those with an incomplete lesion.

New et al. (2015) estimates of the incidence and prevalence of traumatic spinal cord injury (TSCI) in Australia as of June 30, 2011. Their lower estimate of incidence was 21.0 per million population per year, and the upper estimate was 32.3 per million population per year. The derived prevalence rates ranged from 490 per million population up to 886 per million population. The prevalence was highest in males, persons aged 46 to 60 years, and those with tetraplegia. These rates are substantially higher than Norton’s estimated rates provided above.

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Summary of State and International Services

Australia

Two States in Australia have developed or have proposed a model of care for people with spinal cord injury – Queensland and South Australia. The details of these models are given in Attachment 1. The focus here will be on the features of the model from each State that are considered to be key elements.

QUEENSLAND

In the case of Queensland it is a description of the current model of service delivery for the Queensland Spinal Cord Injuries Service (QSCIS). Their service is underpinned by 6 key principles:

- Patient centred practice
- Maximising function and independence
- Equitable access
- Evidence based practice
- Interdisciplinary care teams
- Leadership

In brief, the key features of the model are as follows:

- It is a Statewide service
- There are 3 phases of intervention
  - Spinal Injuries Unit (SIU): acute management and primary rehabilitation
  - Transitional Rehabilitation Program (TRP): community based rehabilitation and support in the transition from hospital rehabilitation to community living
  - Spinal Outreach Team (SPOT): allied health and nursing consultancy and early intervention services for people with spinal cord injuries, their families and other health professionals and service providers throughout Queensland
- All services operate from the same site – Princess Alexandra Hospital – an acute tertiary hospital in Queensland
- There is a strong emphasis on governance and staff support and education
- Every new admission is allocated a rehab facilitator who is the main conduit for communication
- There is a distinction between primary and transitional rehabilitation
- As well as CTP insurance and Workover, every person with a spinal cord injury has access to a funding option called Spinal Cord Injury Response which is a state funded collaborative program including Disability Services, Department of Housing, Medical Aids and Subsidy Scheme and Queensland Health
- Spina bifida patients are eligible for adult services

SOUTH AUSTRALIA

The South Australian model of care for the rehabilitation of spinal cord injury is intended to be used to support service change and best practice within the funds that have been allocated. The

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model is expected to challenge how any current funds for this area are spent ensuring that the allocated funds are reviewed and used to deliver this best practice model of care.

Guiding principles
- SA Health’s aim ‘providing the right care at the right time and in the right place first time’ as well as
  - Client centred care
  - Maximum function and independence
  - Access and equity
  - Service consistency
  - Seamless service
  - Partnerships
  - Standards of care and support
  - Value of staff

Services of an optimal model of care:
- Acute services
- Sub acute inpatient rehabilitation
- Ambulatory rehabilitation
- Inreach
- Outpatient
- Outreach.

Important characteristics of model
- Appropriate governance structure for a statewide service
- Clear referral and admission criteria
- Importance of community reintegration
- Promotion of self management
- Spinal cord injury is lifelong so provision of care should be for life
- Awareness of needs of ATSI and CALD clients
- Importance of partnerships/interagency agreements
- Staff education and training
- Research
- Proposed use of telehealth.

International Services
A number of international services were reviewed. This information was obtained from their websites and many countries describe the service elements only not the processes or the total system of care. The key components and important features are summarised here.

UNITED STATES
The US Model Systems are specially selected by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to serve as models of the best treatments for people with SCI. As a group, they are world-renowned model systems of care for persons with

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spinal cord injuries. There are currently 14 institutions designated as Model Systems, being funded by grants from NIDILRR for five years at a time and then having to re-compete for grant funding.

The NIDILRR asks all Model Systems to:
- Establish a multidisciplinary system for providing rehabilitation services specifically designed to meet the unique needs of individuals with SCI, including:
  - Acute care (inpatient rehabilitation)
  - Periodic inpatient and/or outpatient follow-up
  - Independent living and employment
- Contribute research data to the National Spinal Cord Injury Statistical Center, the world's largest spinal cord injury database. This database has been the source of information for many important studies conducted at University of Michigan and throughout the nation. Researchers use this data to learn more about many aspects of SCI, including:
  - Long-term consequences of SCI
  - Medical rehabilitation
  - Health and wellness
  - Service delivery
  - Short-term and long-term interventions
  - Systems research
- Disseminate information and research findings to patients, family members, health-care providers, educators, policymakers and the general public.
- Nurture close working relationships with governmental and voluntary institutions and organizations to unify and coordinate scientific efforts, encourage collective planning, and promote the interchange of data and reports among SCI researchers.

In 2010 the Special Interest Group (SIG) on SCI Model System Innovation\(^\text{15}\) recommended:
- The SCI model system concept should be extended to address the ongoing postrehabilitative health care needs of individuals with a spinal cord injury
- The SCI model systems program document more systematically the health care encounters (e.g., rehospitalisations, ER visits, physician office visits, therapy visits) and other health-related experiences after discharge from rehabilitation
- The SCI model systems program fund a multi-site study or demonstration project to test one or more approaches to address the ongoing health care needs of individuals with SCI

To enable post rehabilitative needs to be taken into account, there needs to be more:
- Patient education and health behaviour change including the availability of psychosocial care after inpatient rehabilitation (because evidence shows that it is not always the optimal time for absorbing or learning new health behaviours)
- Telephone counselling, telehealth, Web delivered services
- Self management
- Peer support, counselling, mentoring
- Patient navigators/patient advocates
- Development of a standardised transitions data set to identify key data that should be communicated as a patient with a spinal cord injury transfers from one care setting to the next

Two Model Systems Hospitals are Craig Hospital in Colorado and the Shepherd Centre in Georgia. Details of these services are given in Attachment 1. In addition to the hallmarks of a good service – patient and family centred, individualised, comprehensive, interdisciplinary the perceived success factors of these two providers of care are the following:

- Good data systems
- Research is integral
- Clinical care managers/case managers are allocated
- Innovative programs – such as walking programs (NRN, Shepherd Step), maximal therapy (Beyond Therapy - Shepherd), health and wellness (PEAK), Ventilator Services Program (Shepherd)
- Lifelong plan for health and wellness (Craig)
- Neurorehabilitation psych (Shepherd)

NEW ZEALAND

BURWOOD HOSPITAL, CHRISTCHURCH

Burwood Hospital in Christchurch provides comprehensive, interdisciplinary assessment, treatment and rehabilitation for individuals with SCI who live throughout the entire South Island and lower half of the North Island.

Some notable features of this service are:

- Information booklet ‘All You Need to Know’ for patients/families
- Maori health workers on treating team (if applicable)
- A Key Worker is assigned to all rehabilitation patients who is a point of contact and assists with coordinating and co-chairing meetings
- Non government organisations provide vocational rehabilitation and research
- System of reassessment that is ongoing
- Lifelong care
- Congenital abnormalities are included
- Transitional rehabilitation is provided in adjacent spinal hostel

UNITED KINGDOM

STOKE MANDEVILLE, BUCKINGHAMSHIRE

There are 11 units in the UK designated to receive and treat spinal cord injured patients. Each National Spinal Cord Injury Centre is linked to a number of Major Trauma Centres. Stoke Mandeville is one of these national centres.

Some of its key features are:

- Provision of lifelong care
- No difference in funding of patients
- Dedicated workstream for older adults
- Referral criteria set by NHS Board
- Accepts ventilator dependent patients
- Goal directed care
- Works with patient and family
- Case manager is allocated to every patient
- Embraces cultural diversity
- Non discrimination policy
- Individual education manual provided to each patient
- Consultations with specialists as needed
- Encourages self management
- Acknowledges need for psychologist after discharge
- Fosters peer support
- Strong research activity
- Increasing use of telehealth.

SWITZERLAND

SWISS PARAPLEGIC CENTRE

The Swiss Paraplegic Centre (SPC) Nottwil is a privately owned clinic, recognised nationwide, specialising in primary care and holistic rehabilitation of patients with spinal cord injuries.

Some of its notable features are:
- It provides lifelong care
- It is private, well funded, with contributions from Foundation
- It has an ED and ICU
- A range of medical specialties are available
- Research is a fundamental activity.
Themes from Literature Scan

A number of themes have been gleaned from the literature. The focus is on the total system of spinal cord injury rehabilitation and not on the clinical best practice in spinal cord injury care (which is the majority of the research). These themes can be listed as:

1. General outcomes of spinal cord injury rehabilitation
2. Early access to specialised care
3. Psychosocial care
4. Person centred care
5. Expectations of consumers from research
6. Re-hospitalisation after SCI
7. Barriers to discharge from SCI rehabilitation
8. Community participation
9. Employment
10. Rural services
11. Importance of follow up, prevention and primary care
12. Non traumatic spinal cord injury
13. Telehealth
14. ATSI and CALD considerations.

1. General outcomes of spinal cord injury rehabilitation

A meta-synthesis of qualitative research by Whalley Hammell (2007)\textsuperscript{16} of 64 papers and 4 books found that the most important dimension of rehabilitation for people with SCI is the calibre and vision of the rehabilitation staff.

Six inpatient SCI rehabilitation centers in the SCIRehab study\textsuperscript{17} enrolled 1376 patients (from 2007-2009) and Whiteneck et al. (2012)\textsuperscript{18} showed that patient characteristics (demographic characteristics including age, marital status, occupation, insurance coverage as well as injury characteristics) are strong predictors of rehabilitation outcome (explaining a large proportion of the variation in outcome) and that the total amount of treatment received during rehabilitation from each of seven disciplines explains little additional variance.


\textsuperscript{17} The SCIRehab Project is a 5-year research effort (2005-2010) funded by the National Institute on Disability and Rehabilitation Research (NIDRR), examining outcomes attained during initial rehabilitation and in the first year after injury. Participating institutions include: Craig Hospital, Denver, CO; Carolinas Rehabilitation, Charlotte, NC; The Mount Sinai Medical Center, New York, NY; MedStar National Rehabilitation Hospital, Washington, DC; Rehabilitation Institute of Chicago, Chicago, IL; Shepherd Center, Atlanta GA.

In Australia, of 2014 cases admitted to spinal cord injury units between 1955 and 2006, Middleton, Dayton and Walsh et al. (2012)\(^{19}\) concluded that survival is related strongly to the extent of neurological impairment. In other words, mortality rates after spinal cord injury remain elevated, with life expectancy most significantly reduced in those persons with higher level, more significant impairment.

2. Early access to specialised care

Early access to specialised care after acute traumatic spinal cord injury is associated with improved outcomes, according to Wilson, Voth, Singh et al. (2016)\(^{20}\). In their population based cohort study performed in Ontario they found that while most patients (88.4%) reached the site of definitive care within 6 hours, only 34.2% reached surgery within 12 hours of arrival. A retrospective study of 70 patients who were operated on after traumatic cervical spinal cord injury at the Trauma Center Murnau, Germany\(^{21}\) found that early decompression (defined as within the first 8 h after the insult) had a significantly higher SCIM (Spinal Cord Independence Measure) suggesting that early decompression after traumatic cervical spinal cord injury might have a positive impact on the functional and neurological outcome of affected individuals.

Expert consensus recommends the expeditious transfer (“<24 hours of injury”) to a specialist Spinal Cord Injury Unit, where there is an interdisciplinary team equipped to provide comprehensive care for the many and complex issues associated with traumatic spinal cord injury. Middleton, Sharwood, Cameron et al. (2014)\(^{22}\) are proposing to undertake an observational study in two Australian states (NSW and Victoria) to describe the nature and timing of events occurring before commencement of specialist care, and to quantify the association between these events and patient outcomes.

In 2013 the Guidelines for the Management of Acute Cervical Spine and Spinal Cord Injuries were updated in the US. In the first publication of those guidelines in 2002, transportation was not addressed. The 2013 update recommends the transport of patients with a spinal cord injury to specialised acute treatment centres.\(^{23}\)

3. Psychosocial care

While physical aspects of rehabilitation have been well studied and developed, psychosocial aspects of care have to a large extent been overlooked.


Adjustment following spinal cord injury, according to Middleton and Craig (2008)\textsuperscript{24} is non-linear and possibly cyclical; it is also a product of the combination of biological, psychological and social modifying factors. Appraisal and re-appraisal are crucially involved resulting in behavioural and mental actions.

Whalley Hammill (2007)\textsuperscript{25} identified seven key dimensions that are crucial for a successful adjustment outcome. They are:

- The importance of acceptable staff attitudes and behaviours
- The need to involve the person with a spinal cord injury in decision making
- The value of spinal cord injury peers in the adjustment process
- The relevance of rehabilitation programme content
- The institutional nature of the inpatient rehabilitation environment, which has often been criticised for being overly structured, inflexible and standardised
- The importance of connecting the past to the future in the adjustment process
- Making the rehabilitation relevant to the outside community and society.

In an effort to improve rehabilitation and outcomes for people with a spinal cord injury NSW, Middleton et al. (2014)\textsuperscript{26} describe psychosocial guidelines that have been developed to provide direction for enhanced service delivery, staff training and care processes. While these guidelines are specifically applied to the inpatient rehabilitation phase, it is important to state that psychosocial support and management should begin during the acute/admission phase of spinal cord injury management, and support should continue in the community, for instance, providing assistance with social re-integration, employment and injecting resources into family members and caregivers.

One of the important elements of these guidelines is the designation of a key-worker to each new person with a spinal cord injury admitted to the inpatient rehabilitation program. The key-worker could be any member of the spinal cord injury team such as a psychologist, social worker, occupational therapist, physiotherapist, or rehabilitation nurse. The key-worker’s role is to ensure that a psychosocial needs assessment has been conducted and that assessment outcomes are considered when implementing treatment. The key-worker role is only active while the person with spinal cord injury is resident in the SCI Unit. The key-worker concept has been used with success with inpatients with spinal cord injury in the National SCI Centre, Stoke Mandeville Hospital in the United Kingdom.\textsuperscript{27}

4. Person centred care

Person centred care (PCC) has become a priority for the health care system, though according to Shaller and Fund (2007)\textsuperscript{28} we may be far from achieving this goal because key factors such leadership engagement, a strategic vision, patient and family engagement at multiple levels, a


\textsuperscript{25} op cit.


supportive work environment, routine measurement and feedback and information technology that supports organisational initiatives are necessary to achieving this goal.

The value of PCC has become increasingly evident as research reveals benefits ranging from reduced morbidity and mortality to lower costs. Some research, by Papadimitriou and Carpenter (2013),\(^{29}\) although limited, indicates that implementation of PCC contributes to patients' self-worth, sense of confidence, and self-esteem.

According to the American Geriatric Society Expert Panel on Person-Centred Care (2016)\(^{30}\) PCC means that individuals' values and preferences are elicited and, once expressed, guide all aspects of their health care, supporting their realistic health and life goals. Person-centered care is achieved through a dynamic relationship among individuals, others who are important to them, and all relevant providers. The Panel identified elements essential to realising this definition. They are:

- An individualized, goal-oriented care plan based on the person's preferences
- Ongoing review of the person's goals and care plan
- Care supported by an inter-professional team in which the person is an integral team member
- One primary or lead point of contact on the healthcare team
- Active coordination among all healthcare and supportive service providers
- Continual information sharing and integrated communication
- Education and training for providers and, when appropriate, the person and those important to the person
- Performance measurement and quality improvement using feedback from the person and caregivers.

The Panel highlights barriers to implementing a person centred approach – inconsistent terminology, traditional approaches to clinical practice, physician workload, cost, identifying appropriate quality indicators, lack of continuity in health records.

Heinemann et al. (2016)\(^{31}\) compared the perceptions of PCC between patients who continue to receive services from one of the SCI Model Systems (SCIMS) Hospitals in the US and those people with a spinal cord injury who no longer receive care from a SCI Model Systems Hospital. They found that patients with continuing SCIMS contact reported a higher level of PCC primarily reflecting goal setting and tailoring, than patients not receiving services recently from the SCIMS facility.

In a sample of 389, LaVela et al. (2015)\(^{32}\) concluded that limited empathy, communication, and holistic care may arise when providers focus on disease/disease management, rather than on patients as individuals.

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5. Consumers

The priorities of consumers/clients to the spinal cord injury research agenda are increasingly being taken into account.

A study\(^{33}\) was undertaken by Furlan et al. (2006) to examine the characteristics of the top 100 most frequently cited articles (so-called "citation classics") on traumatic spinal cord injury that were published between 1986 and 2003, and compared this selected professional literature with the consumers' perspective on the key issues in SCI research. From a consumers' perspective, the areas of greatest interest for people with SCI as reported in two previous large-scale surveys include motor function, bowel and bladder control, sexual function, and pain. Most of the top 100 most frequently cited articles on traumatic SCI (63%) explicitly focused on at least one of the topics of greatest interest to individuals with SCI. Motor function was the leading topic in the matching list between professional literature and consumers' perspective.

Similarly, Simpson et al. (2012)\(^{34}\) identified 24 studies (a combined sample of 5262 subjects) from electronic databases (Medline, EMBASE, CINAHL, and PsycINFO) with the intention of increasing the understanding of the perceived importance of life domains and priorities that contribute to well-being for individuals with spinal cord injury. While the questionnaires varied across studies, a consistent set of priorities emerged. Functional recovery priorities were identified for the following areas: motor function (including arm/hand function for individuals with tetraplegia, and mobility for individuals with paraplegia), bowel, bladder, and sexual function. In addition, health, as well as relationships, emerged as important life domains.

Lo et al. (2016)\(^{35}\) attempted to determine functional areas perceived by consumers as most important. They found arm/hand function had the highest preference, that is, retaining and not trading off existing arm/hand function for other improved functions. There were no significant differences found in preferences between bladder/bowel function and walking or elimination of pain, although walking was preferred in earlier (≤10) post-injury years and pain amelioration became more important with a longer duration (>10 years) post-injury. Sexual function had the lowest preference when traded against the other four functions.

In an earlier study to improve the relevance of research in the spinal cord injury area, Anderson (2004)\(^{36}\) developed a survey in which subjects were asked to rank seven functions in order of importance to their quality of life. A total of 681 responses were completed. Regaining arm and hand function was most important to quadriplegics, while regaining sexual function was the highest priority for paraplegics. Improving bladder and bowel function was of shared importance to both injury groups. The majority of participants indicated that exercise was important to functional recovery, yet more than half either did not have access to exercise or did not have access to a trained therapist to oversee that exercise.


6. Re-hospitalisation

Re-hospitalisation is a common occurrence for people with a spinal cord injury. In their study of 8668 persons with SCI from 16 Model Spinal Cord Injury Systems centers entered in the National Spinal Cord Injury Statistical Center database between 1995 and 2002, Cardenas et al. (2004)\textsuperscript{37} show that rehospitalisation rates among these people remain high, with an increased incidence in conditions associated with the genitourinary system (including UTIs), respiratory complications (including pneumonia), and diseases of the skin (including pressure injuries). They recommend that acutely injured patients need close follow-up to reduce morbidity and re-hospitalisations.

In a sample of 1137 participants in Canada, 381 had a pressure ulcer over the last 12 months (Lala et al 2014)\textsuperscript{38}. Pressure ulcers reduced the ability of individuals with SCI to participate in 19 of 26 community and daily activities. Pressure ulcers were also associated with a significantly higher number of consultations with family doctors, nurses, occupational therapists, and wound care nurses/specialists. Interestingly Groah et al (2015)\textsuperscript{39} conclude that pressure ulcers are highly individualised, which demands flexible pressure ulcer prevention strategies and pressure relief manoeuvres. They claim that education is the most effective tool to address this problem.

Middleton et al. (2004)\textsuperscript{40} investigated the frequency, cause and duration of rehospitalisations in individuals with spinal cord injury living in the community in NSW. Over a 10-year period (1990-2000), 253 persons (58.6%) required one or more spinal-related readmissions, accounting for 977 rehospitalisations and 15,127 bed-days (average length of stay (ALOS) 15.5 days; median 5 days). The most frequent causes for rehospitalisation were genitourinary (24.1% of readmissions), gastrointestinal (11.0%), further rehabilitation (11.0%), skin-related (8.9%), musculoskeletal (8.6%) and psychiatric disorders (6.8%). Pressure sores accounted for only 6.6% of all readmissions, however, contributed a disproportionate number of bed-days (27.9%), with an ALOS of 65.9 (median 49) days and over 50% of readmissions (33 out of 64) occurred in only nine individuals aged under 30 years. Overall rehospitalisation rates were high in the first 4 years after initial treatment episode, averaging 0.64 readmissions (12.6 bed-days) per person at risk in the first year and fluctuating between 0.52 and 0.61 readmissions (5.1-8.3 bed-days) per person at risk per year between the second to fourth years, before trending downwards to reach 0.35 readmissions (2.0 bed-days) as 10th year approaches.

7. Barriers to admission and discharge to/from spinal rehabilitation units

Ten spinal rehabilitation units in Australia, Canada, India, Ireland, Italy, Netherlands, Pakistan, Switzerland, UK and USA that admit both traumatic and non-traumatic spinal cord injury patients were surveyed between December 2010 and February 2013 on perception of barriers for admission into and discharge from spinal rehabilitation units (New et al. 2013)\textsuperscript{41}. Results show there were perceived barriers in accessing spinal rehabilitation units which ranged from no access to very high levels of barriers.

problem to a severe access problem. All units reported perceived barriers to discharge from spinal rehabilitation units. Compared with admission barriers, a greater perception of barriers to discharge was reported. The authors concluded that projects to identify and minimise the occurrence and impact of admission and discharge barriers could increase access to rehabilitation and improve the rehabilitation outcomes for patients.

In another article, New (2015) reports that the most common reasons for a discharge barrier were: waiting for approval for long-term and supported care or services, residential care, home modifications, family deliberations regarding discharge planning and the provision of equipment necessary for discharge. The reasons accounting for the greatest number of additional hospital days were: home modifications, residential care, equipment necessary for discharge, waiting for approval for long-term and supported care or services and accommodation for people unable to return to their previous residence without readily available alternatives. Over the study period 17.5% of all bed-days were occupied by patients deemed to be clinically ready for discharge from the spinal rehabilitation unit but who had a discharge barrier. New (2015) concludes that barriers to discharge from rehabilitation for patients with spinal cord damage are common, substantial, and represent an important opportunity for health systems improvement.

8. Community participation

Cijsouw et al. (2016) found that disability-management self-efficacy (DMSE) – the confidence that people with a chronic condition have in their ability to manage the consequences of their condition – is associated with higher levels of participation and life satisfaction after spinal cord injury. These findings are congruent with those of another recent study by Craig et al. (2015) that found a similar correlation coefficient between DMSE and a measure of autonomy in participation.

Barclay et al. (2014) in their search of the literature found that the terms participation, social participation and community participation were used interchangeably without clarification of meaning. They also found that adequate personal care assistance, appropriate social support, having adequate specialised equipment, and appropriate occupational therapy input were found to facilitate social and community participation, whereas problems with transport, inaccessibility of the natural and built environment, issues with healthcare services and rehabilitation providers, and pain were identified as barriers.

Data from 16 Model SCI Systems in the US was used by Norweg et al. (2011) to investigate the patterns, predictors, and benefits associated with driving a modified vehicle for people with SCIs. Of the 3726 participants, the study found that 36.5% of the sample drove a modified vehicle after SCI. Significant predictors of driving a modified vehicle post-SCI included being married at the time of the injury, being at a younger age at injury, having an associate’s degree or higher before injury.

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43 A Cijsouw, J J E Adriaansen, M Tepper, C A Dijkstra, S van Linden, ALLRISC, S de Groot and M W M Post (2016) Associations between disability-management self-efficacy, participation and life satisfaction in people with long-standing spinal cord injury, Spinal Cord advance online publication 31 May 2016; doi: 10.1038/sc.2016.80
paraplegia, a longer time since the injury, non-Hispanic race, white race, male sex, and using a wheelchair for more than 40 hours a week after the injury. Higher activity of daily living independence (in total motor function) at hospital discharge also increased the odds of driving. Driving increased the odds of being employed at follow-up by almost 2 times compared with not driving post injury. Drivers tended to have higher community reintegration scores, especially for community mobility and total community reintegration. Driving was also associated with small health-related quality-of-life gains, including less depression and pain interference and better life satisfaction, general health status, and transportation availability scores – all compelling evidence of the need to facilitate driving after SCI.

Krause and Bozard (2012)\textsuperscript{47} undertook a 35-year longitudinal study of people with a spinal cord injury. They found that overall social participation decreased over time, although the sitting tolerance and hours spent in gainful employment increased. Non-routine physician visits increased. Satisfaction with employment improved over time, whereas satisfaction with social life, sex life and health declined. Self-reported adjustment improved, but the prediction of future adjustment in 5 years declined.

9. Employment

Employment rates are low after a spinal cord injury. Ottomanelli & Lind (2009)\textsuperscript{48} found 60 articles in a review of published manuscripts between 1978 and 2008 with a report of employment rates for individuals with SCI. Results indicated that, in studies that examined paid employment, the average rate of any employment after SCI was approximately 35%. Characteristics associated with employment after SCI include demographic variables, injury-related factors, employment history, psychosocial issues, and disability benefit status.

A systematic review of the literature for the period 2000 and 2006 was undertaken by Ingeborg et al. (2007)\textsuperscript{49}. Among individuals with SCI working at the time of injury, 21 – 67% returned to work after injury. Return to work was higher in persons injured at a younger age, had less severe injuries and higher functional independence. Employment rate improved with time after SCI. Persons with SCI employed ranged from 11.5% to 74%. Individuals who sustained SCI during childhood or adolescence had higher adult employment rates. Most common reported barriers to employment were problems with transportation, health and physical limitations, lack of work experience, education or training, physical or architectural barriers, discrimination by employers, and loss of benefits. Individuals with SCI discontinue working at younger age.

Roels et al. (2016)\textsuperscript{50} investigated the effect of interventions enhancing (re)employment following spinal cord injury. After an extensive review of electronic databases, only one random controlled trial, including 201 patients describing an intervention over 1 and 2 years, was of sufficient quality. In this study, the employment rate was 26% after 1 and 31% after 2 years for competitive work compared with 10% in the control group. This randomised control trial showed evidence that a


\textsuperscript{49} Ingeborg Beate Lidal, Tuan Khai Huynh & Fin Biering-Sørensen (2007) Return to work following spinal cord injury: a review, Disability and Rehabilitation, 29:17, 1341-1375, DOI: 10.1080/09638280701320839

\textsuperscript{50} EH Roels, B Aertgeerts, D Ramaekers and K Peers, (2016) Hospital- and community-based interventions enhancing (re)employment for people with spinal cord injury: a systematic review, Spinal Cord, 54, 2-7; doi:10.1038/sc.2015.133; published online 25 August 2015
vocational rehabilitation programme based on the principles of supported employment integrated in a multidisciplinary team enhances employment for SCI people.

10. Rural services

In NSW, approximately 30% of people who sustain a spinal cord injury return to live in rural and remote regions, where population densities vary widely. In Queensland Cox et al. (2001) revealed a high need for a specialist, multidisciplinary spinal cord injury outreach service following primary rehabilitation.

Middleton et al. (2008) demonstrate the advantages that an integrated “hub-and-spoke” model bring to the Australian rural setting where local health professionals are supported with specialist advice, education, training, and resources builds local capacity and responsiveness to meet community needs and allows suitable triaging and treatment planning. The general practitioner (family physician) is an integral part of the rural network requiring support, although providing specialized services within the context of a busy rural practice and limited medical workforce remains challenging.

11. Importance of follow up, prevention and primary care

In Queensland and South Australia and in some countries, the person of the spinal cord injury specialist service is followed up for life by the service. Primary care and prevention is also very important for adults with a spinal cord injury (Weaver and LaVela (2007)).

McColl et al. (2012) searched peer reviewed journals from 1980 to 2009 and identified 42 articles on primary care and spinal cord injury and their inclusion criteria narrowed the number of articles to 21. Their analysis of these articles revealed that approximately 90% of people with spinal cord injury identify family physicians as their regular doctors and 63% have spinal cord injury specialists. The authors claim that regular follow up by specialised teams and annual comprehensive health examination, are supported by the evidence.

A study by Stillman et al. (2014) of 108 adults who use a wheelchair found that all but one participant had visited a primary care provider in the past 12 months and 85% had made one or more visits to a specialty care provider. They encountered a number of barriers when they sought care including inaccessible examination tables, a lack of transfer aids. They also received fewer preventative care screenings than their nondisabled counterparts – 89% had not been weighed, 60% of women over 50 had not had a mammogram; 40% had not received a Pap smear in the previous 3 years and only 45% had ever received bone density testing.

A comprehensive review of the clinical management of cardiovascular disease (CVD) and risk factors for individuals with SCI was conducted by Cragg et al. (2012)\(^{57}\). Their findings indicate that CVD is a critical issue in individuals with chronic SCI. Almost all risk factors for CVD are amplified in individuals with SCI, including physical inactivity, dyslipidemia, blood pressure irregularities, abnormal glycaemic control, and chronic inflammation. They recommend that clinicians should re-examine their own CVD risk factor treatment strategies to better reflect contemporary practice in similar high-CVD-event-risk patients and populations.

Saunders et al. (2014)\(^{58}\) assessed the lifetime prevalence of 7 chronic health conditions (CHCs) among a cohort of adults with chronic traumatic spinal cord injury. Of the 1678 participants, 49.5% reported having at least 1 CHC, with 23.2% reporting ≥2 CHCs. The most frequently reported CHC was high cholesterol (29.3%) followed by hypertension (28.7%) and diabetes (11.8%). Although the prevalence of CHCs significantly increased with increasing age, only hypertension and cancer were significantly associated with years postinjury. Four CHCs (diabetes, coronary artery disease, hypertension, high cholesterol) were significantly related to mobility status as measured by injury level and ambulatory status. However, after controlling for age, years postinjury, sex, and race, mobility status became nonsignificant in relation to coronary artery disease, but it remained significantly associated with diabetes, hypertension, and high cholesterol. They concluded that clinicians should be aware of the risk of chronic health conditions in persons with SCI and should screen for these conditions and regular maintenance activities related to SCI.

12. Non traumatic spinal cord injury

There is a group of patients who have a spinal cord injury that is not due to trauma – non traumatic spinal cord injury (NTSCI). Data for this group is scarce. New et al (2013)\(^{59}\) reported an Australian estimate of NTSCI (extrapolated from the State of Victoria) which translated to a population prevalence rate of 364 persons per million. With the population ageing this is expected to increase substantially in the coming decades. This compares with the estimated prevalence rate of TSCI in Australia of 540 persons per million.

For NTSCI in Australia the incidence rate is in the order of 26 cases per million (New et al., 2011 and 2014)\(^{60}\) which is higher than the TSCI rate of 15 cases per million per year (Cripps et al., 2011)\(^{61}\). In Australia NTSCI is primarily due to degenerative conditions and tumours, compared to low income countries where NTSCI is predominantly due to infections (TB and HIV).

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A review of costs by Access Economics (2009)\(^62\) showed a lifetime costs of $AUD5m for paraplegics, and $AUD9.5m for tetraplegics. It was estimated that 40% of these costs were borne by the individual and their families. The costs of TSCI are much higher than NTSCI – influenced by the higher rates of intubation and use of ICUs (New and Jackson, 2010)\(^63\).

13. Telehealth

There are many articles on the advantages of telehealth for the patient – increased access to health services, cost-effectiveness, enhanced educational opportunities, improved health outcomes, better quality of care, better quality of life, enhanced social support, time efficiency. \(^64\) Wade (2010)\(^65\) defines telehealth as the ‘delivery of health care at a distance, using information and communication technology. The major rationales for its introduction have been to decrease costs, improve efficiency and increase access in health care delivery.’

About one-third of the 2073 patients referred to the Queensland Spinal Cord Injuries Service between 2008 and 2013 lived further than 200 km from Brisbane and van de Pol et al. (2016)\(^66\) concluded that telehealth models of care, which promote better engagement with local health service providers (such as general practitioners, nurse practitioners and allied health professionals) could improve equity of access and reduce the need for extensive travel.

Dorstyn et al. (2013)\(^67\) investigate the short- and medium-term efficacy of counselling services provided remotely by telephone, video or internet, in managing mental health outcomes following spinal cord injury. They do this by reviewing 7 studies (a total of 272 participants) and even though there was some evidence that tele-counselling can significantly improve an individual’s management of common comorbidities following spinal cord injury, including pain and sleep difficulties, medium-term treatment effects were difficult to evaluate because of lack of data. Participants reported gains in quality of life 12 months after treatment. The authors concluded that there is need for further evidence, particularly randomised controlled trials, to establish the benefits and clinical viability of tele-counselling.

14. Considerations of people from an Aboriginal and Torres Strait Islander (ATSI) background and a culturally and linguistically diverse (CALD) background

In the delivery of many health services in Australia, people who are from an ATSI or CALD background are at risk of access to health services and often they have poorer health outcomes than the rest of the population. Research in the US found racial/ethnic variation appears to exist in

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post injury hospitalisation for individuals with spinal cord injury, with Hispanics showing the lowest rates of hospitalization at 1 and 5 years post injury and African Americans having a significantly higher number of days hospitalized at 10 years post injury (Mahmoudi et al. 2014). Similarly, according to Fyffe et al. (2014) non-Hispanic white and Hispanic participants had comparatively more improvement in self-care and mobility during inpatient rehabilitation compared with non-Hispanic black participants.

A literature review of studies by Gary et al. (2011) specifically investigating racial and ethnic disparities in spinal cord injury care, services, and outcomes indicated that after an SCI, racial and ethnic minority groups have shorter hospital lengths of stay, higher rehospitalisation rates, higher levels of depression, more days in poor health, greater degrees of unemployment, more difficulties with mobility, lower self-reported subjective well-being and quality of life and life satisfaction, and greater risk of marital breakup.

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Attachment 1: State & International Services

STATE: QUEENSLAND

Population Overview
Population: 4.333m. (2011 Census)
Aboriginal and Torres Strait Islander population: 156,000
Geography/Size: 1,734,156 km2

Spinal Cord Injury Model of Care in Queensland

<table>
<thead>
<tr>
<th>Important features/considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>• All services co-located on one acute hospital site – acute, rehab (primary and transitional) outpatients and outreach</td>
</tr>
<tr>
<td>• Importance of governance</td>
</tr>
<tr>
<td>• To best facilitate a coordinated approach to patient care at the Spinal Injuries Unit, the Rehabilitation Facilitator is accountable for ensuring that the patient centred model of care is occurring and that all patients undertaking rehabilitation services with the Spinal Injuries Unit experience a personalised and coordinated approach to their rehabilitation.</td>
</tr>
<tr>
<td>• The Rehabilitation Facilitator is the primary contact person for the patient and their family. The Rehabilitation Facilitator keeps in regular contact with the patient and their family to ensure</td>
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</table>

The Queensland Spinal Cord Injuries Service Model of Care (Queensland Health 2013)1 defines the model of care as a framework that establishes how spinal cord injuries services at Queensland Spinal Cord Injury Service (QSCIS) are delivered. It has been developed in collaboration with a broad range of stakeholders and outlines in detail all aspects of service delivery. The new model aims to provide equitable, consistent, and a systematic approach to rehabilitation for people with spinal cord injury. The model provides increased flexibility in rehabilitation programs that are tailored to an individual’s specific needs. It brings together evidence based principles to create a comprehensive service for patients.

It is underpinned by 6 key principles:
• Patient centred practice
• Maximising function and independence
• Equitable access
• Evidence based practice
• Interdisciplinary care teams
• Leadership

Governance
There is a management team at State level – meets monthly and is responsible for leadership, strategy and priorities of QSCIS. An operations team at the Spinal Injuries Unit (SIU) – acute management and primary rehabilitation – meet monthly to discuss the

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**Spinal Cord Injury Model of Care in Queensland**

Operational aspects of service delivery specific to the unit. The Spinal Outreach Team (SPO) and the Transitional Rehabilitation Program (TRP) managers meet regularly to discuss their operations and client caseloads.

**Staff Support and Education**

There is a strong focus on providing ongoing education at both a discipline specific and service level. Staff from every discipline come together once a month to attend QSCIS education and in-service. In addition, the team is involved in a quarterly case reflection. The SIU has a dedicated role for nurse education and a full-time clinical facilitator to induct and train newly appointed nursing staff, upskill existing staff and provide mandatory training updates. Specialised training is offered to staff who take up the role of Rehabilitation Facilitator and there is clear procedure for identifying and training new rehabilitation facilitators.

**SIU**

SIU is a 40-bed unit servicing Queensland. It is the only Spinal Injuries Unit in Queensland and one of the few Spinal Injuries Units in Australia that provides acute care, primary rehabilitation, transitional rehabilitation, outpatient services and outreach services from the one service.

The core interdisciplinary team consists of rehabilitation physicians, trainee rehabilitation registrars, residents, rehabilitation nurses, physiotherapists, occupational therapists, leisure therapist, social workers, and psychologist. The majority of these staff provide a service five days per week with the exception of rehabilitation nurses who provide services twenty-four hours a day. The team is further enhanced by consultation when required with other health professionals including speech pathology, pharmacy, dietetics, stomal therapy and visiting medical specialists including urologist, psychiatrist, plastic surgeon, neurosurgeon, pain specialist, respiratory physician, infection control specialist and orthopaedic surgeons. Peer support mentors are regularly available on site, as a service provided by the Spinal Injuries Association. All staff within the unit are aligned to a consultant group and there are four rehabilitation teams within the SIU. The team works with the patient, family, and carers in establishing goals to maximise an individual's independence and function.

There are a number of meetings to ensure optimal communication within and between disciplines: Operations, Case Conference, Admissions, Patient Centred Rehab Meetings, ADL, Patient Scheduling, Interdisciplinary Team Handover.

Important elements of patient journey:
- Referral to SIU as an acute or rehabilitation patient – there is a 6-bed facility for patients who require intensive medical monitoring and review until deemed medically stable
- Patient Orientation by rehab team, rehab facilitator, and social worker and admitting nurse – takes place over 7 days. Patient given a ‘Patient Portfolio’

<table>
<thead>
<tr>
<th>Operational Aspects</th>
<th>Important Features/Considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff Support and Education</td>
<td>That any issues arising as part of the patient’s rehabilitation pathway are attended to. This may include referring them to another team member if you cannot assist them with their direct request.</td>
</tr>
<tr>
<td>Staff Support and Education</td>
<td>There are four key areas of responsibility for the Rehabilitation Facilitator:</td>
</tr>
<tr>
<td>SIU</td>
<td>- orientating and welcoming the patient to the SIU</td>
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<tr>
<td>SIU</td>
<td>- co-ordination of Patient Centred Rehabilitation Meetings</td>
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<tr>
<td>SIU</td>
<td>- co-ordination of weekend leave</td>
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<tr>
<td>SIU</td>
<td>- co-ordination of discharge summaries</td>
</tr>
<tr>
<td>Important Features/Considerations</td>
<td>The role is not a standalone role but is incorporated into the duties of an identified key rehabilitation team member from the patient’s core rehabilitation team. The team member fulfilling this role may be from any of the disciplines within the unit.</td>
</tr>
<tr>
<td>Important Features/Considerations</td>
<td>- Staff support and education</td>
</tr>
<tr>
<td>Important Features/Considerations</td>
<td>- Distinction between primary rehab and transitional rehab</td>
</tr>
<tr>
<td>Important Features/Considerations</td>
<td>- One funding option is the Spinal Cord Injury Response which is a State funded collaborative program including Disability Services, Department of Housing, Medical Aids and Subsidy Scheme and Queensland Health</td>
</tr>
<tr>
<td>Important Features/Considerations</td>
<td>- Includes spina bifida patients in adult</td>
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<tr>
<td>Important features/considerations</td>
<td>Spinal Cord Injury Model of Care in Queensland</td>
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<tr>
<td>Assessment</td>
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<td>Individualised Rehabilitation Programs</td>
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<tr>
<td>Patient Centred Rehabilitation Meetings – including goal planning meetings</td>
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</table>

Preparing for the community
- Discharge planning – discharge checklist, discharge summaries from each disciplines, personal care planning
- Outpatient Services – 6 week appointment made after discharge date. Range of general and specific clinics including Urology, Spasticity Management, Sex & Fertility, Upper Limb Clinic, Plastic Surgery, Adult Spina Bifida
- Funding Options for Equipment, Housing/Home Modifications, Care – CTP insurance, Workcover, Spinal Cord Injury Response (state funded collaborative program including Disability Services, Department of Housing, Medical Aids and Subsidy Scheme and Queensland Health).

TRP
The Transitional Rehabilitation Program (TRP) model delivers rehabilitation services to clients of the Spinal Injuries Unit either in their own homes or in a homelike setting outside of the hospital environment. For individuals within the Brisbane metropolitan area, the Transitional Rehabilitation Program services are provided in the client’s homes if practicable. Individuals who live outside the Brisbane area are able to complete their rehabilitation in one of three community houses provided by the Transitional Rehabilitation Program for the duration of the program. These are wheelchair accessible homes located in the suburban areas of Brisbane. Individuals are able to live in these houses with their own families or significant others whilst participating in the Transitional Rehabilitation Program. TRP is designed to relocate the final weeks of rehabilitation from hospital to the community, and should therefore shorten SIU length of stay. TRP is promoted as the next “normal” stage of rehabilitation, rather than an optional “add on”.

SPOT
The Spinal Outreach Team (SPOT) aims to primarily perform a monitoring / early intervention and a consultancy / advisory role. All people discharged from the SIU, if in agreement, will be followed-up by telephone, or face to face, if necessary, at set periods by SPOT for the first 12 months after discharge from TRP or the SIU. Building the capacity of local service networks in SCI management helps address the issue of limited local expertise in the management of SCI. The SPOT can be used by:
- People with spinal cord injury who have been formally accepted as clients of QSCIS.
- (This includes past patients of the SIU (initial admissions and readmissions at discharge), people with SCI who are past patients of other specialist SIUs and who have moved to Queensland from interstate and people who have been followed-up on an ongoing basis at SIU outpatient clinics.)
- Family and friends of people with spinal cord injury.
- Health professionals or service providers working with people with spinal cord injury.
STATE: SOUTH AUSTRALIA

Population Overview:
Population: 1.597m. (2011 Census)
Aboriginal and Torres Strait Islander population: 30,000
Geography/Size: 985,334 km²

<table>
<thead>
<tr>
<th>Spinal Cord Injury Model of Care in South Australia</th>
<th>Important features/considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guiding principles</td>
<td></td>
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<tr>
<td>• SA Health’s aim ‘providing the right care at the right time and in the right place first time’ as well as</td>
<td>• The governance structure that reflects the requirements for the management of statewide services including a dedicated manager</td>
</tr>
<tr>
<td>• Client centred care</td>
<td>• One centre as the hub</td>
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<tr>
<td>• Maximum function and independence</td>
<td>• Educate/support general hospitals and local community services</td>
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<tr>
<td>• Access and equity</td>
<td>• Outreach services that provide support in transitional/community reintegration phase and promote self-management, among other things</td>
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<tr>
<td>• Service consistency</td>
<td>• Whole of life care</td>
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<tr>
<td>• Seamless service</td>
<td>• Suggested strategies for ATSI and CALD clients</td>
</tr>
<tr>
<td>• Partnerships</td>
<td>• Partnerships/interagency agreements</td>
</tr>
<tr>
<td>• Standards of care and support</td>
<td>• Staff education and training</td>
</tr>
<tr>
<td>• Value of staff</td>
<td>• Research</td>
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<tr>
<td></td>
<td>• Proposed use of telehealth</td>
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</tbody>
</table>

Acute traumatic spinal cord injury care to be provided at Royal Adelaide Hospital (11 beds) and Flinders Medical Centre (6 beds)

Optimal rehabilitation service model of care

1. A governance structure for rehabilitation services which reflects the requirements for the management of statewide services. A dedicated manager of the SASCIS with clear reporting lines, ensuring clear leadership and direction to this service.

2. One centre (Hampstead Rehabilitation Centre) as the hub (currently 25 beds) responsible for the provision of integrated rehabilitation specialist services for South Australia across the continuum including acute, sub-acute inpatient and ambulatory rehabilitation, in-reach, outpatient and outreach services. It will also provide support, education and training to metropolitan and country general hospitals in the provision of SCI services.

3. General hospitals (both country and metropolitan) shall work within their scope to manage the care of people with less significant neurological loss, and may also continue the care of complex patients on transfer from HRC to continue management closer to the patient’s home, with collaborative inputs from specialist services.

4. Outreach Service with a dedicated multidisciplinary team of health professionals with knowledge, skills and expertise in spinal cord injury management for the metropolitan and country regions of South Australia providing:
Ongoing community support in transitional/community reintegration phase
In-reach support to non-specialist acute hospital and rehabilitation units involved in the management of non-traumatic and traumatic spinal cord injury patients acute readmissions
Whole-of-life health promotion/maintenance, encouraging self-management with increased incentives and capacities among people with a spinal cord injury to facilitate wellness and good health
Prevention, early intervention and efficient community management of complications following SCI including crisis management
Support for rural services
This service may be co-located with inpatient and centre-based services at HRC

5. Specialist outpatient clinics to address multidisciplinary functional assessment and review in areas such as seating, pain, spasticity, orthotics, sexual health and fertility, urodynamics.

6. Transition services to enable timely transition from hospital, including suitable transitional accommodation, attendant care and other services to support ongoing discharge planning and community reintegration.

7. Community therapy programs. Specialist community based spinal cord injury rehabilitation services shall be provided to people with a spinal cord injury who are able to safely live in the community setting, with the aim of optimising physical recovery, function and psychosocial wellbeing, and maximise independence, vocation and lifestyle opportunities. Health care organisations, local councils and non-government agencies work in collaboration to establish partnerships that provide services which provide supportive, contextualised programs within the community setting.

8. Patient and carer/family support – the provision of specific information available to enable carers, families and friends of an individual with a spinal cord injury to be informed about the condition, effects and available supports. Pathways need to be established to allow patients, their family or carers to re-access these supports at any time during their lifespan with a spinal cord injury.

9. Appropriate funding model for the hub and to ensure equity of access to spinal cord injury services across the State.

Key requirements for inpatient rehabilitation
Clear admission criteria, referral pathways and transfer guidelines
Multidisciplinary and interdisciplinary care
Capacity to support current and projected demands
Staffing levels of medical, nursing and allied health to accurately reflect unit capacity and workload, guided by the Australasian Faculty of Rehabilitation Medicine (AFRM) guidelines
Staffing levels that enable the provision of specialist in-reach services and care planning for patients with a new SCI awaiting transfer to HRC
Access to investigational (such as x-rays, point of care testing and specialist (including ENT, Plastics)) services/review and after
hours medical cover
• Provision of weekend allied health therapy services
• Physical environment needs to enable ease of access to self-care facilities, promote patient privacy and dignity and encourage independence in everyday activities. It also needs to provide indoor and outdoor spaces for families to spend time together, including child friendly spaces, all within a rehabilitation context. Short term, on site (or near HRC), transitional accommodation that supports the practical transition to community living within a homelike environment
• Access to required equipment to facilitate safety and independence
• Vocational rehabilitation to be a focus of both inpatient and ambulatory rehabilitation programs
• Early involvement of discharge services to ensure seamless transition to community living

Key requirements for ambulatory rehabilitation
• Clear admission criteria and referral pathways
• Provision of services by multidisciplinary team/s
• Multiple access points of entry to service so that if an individual deteriorates whilst living in the community, a burst of ambulatory rehabilitation (home or centre based) can be provided rather than a hospital admission
• Centred based services provided in all metropolitan regions for ease of access to medical, nursing and allied health
• Vocational rehab to be a focus
• Outreach service with a dedicated multidisciplinary team for servicing metro and country regions of SA providing:
  • Ongoing community support in transitional/community reintegration phase
  • In-reach support to non-specialist acute hospital and rehabilitation units involved in the management of non-traumatic and traumatic spinal cord injury patients acute readmissions
  • Whole-of-life health promotion/maintenance, encouraging self-management with increased incentives and capacities among people with a spinal cord injury to facilitate wellness and good health
  • Prevention, early intervention and efficient community management of complications following SCI including crisis management
  • Support for rural services
  • This service may be co-located with inpatient and centre-based services at HRC

Specialist outpatient clinics
• Development of comprehensive outpatient centre-based services to address multi-disciplinary functional assessment and review in areas such as the following: seating, pain, spasticity, orthotics, sexual health and fertility, specialist consultations such as is required for upper limb assessment and surgical intervention if appropriate to maximise function and access to urodynamics.
### Key requirements of transition services

- Interagency agreement and funding in partnership with other key agencies (such as Disability SA, Housing SA) and non-government organisations (including GPs) to enable timely transition from hospital, including transitional accommodation, attendant care and other services to support ongoing discharge planning and community reintegration.

### Key requirements of community therapy programs

- Pathways into community therapy programs in partnership with other agencies

### Patient and carer/family support

- The provision of support and information to ensure continuity between the acute and rehabilitation services, is important in alleviating feelings of loneliness and fear of the unknown. This support needs to be available on arrival at the rehabilitation unit and following discharge from inpatient services. Pathways need to be established to allow patients, their family or carers to re-access these supports at any time during their lifespan with a spinal cord injury.

### Components of a paediatric model of spinal cord injury care

- Acute management
- Clear referral pathways that ensure all children with a spinal cord disorder (whether traumatic or medically acquired, or congenital in nature) are referred to the rehabilitation service for an opinion regarding future care
- Adequate levels of medical, nursing and allied health staff to meet acute and rehabilitation needs
- Access to ambulatory rehabilitation programs (home based and centre based) with multiple access points.
- Timely access to equipment, including specialised equipment and technology.
- Children with a medically acquired spinal cord injury are referred to the specialist paediatric rehabilitation services that are available.
- Formalised links with adult spinal cord injury service in relation to staff training and education, in particular to develop and maintain specialist skills in spinal cord injury.
- Development of procedures and evidence based guidelines for management of children with a spinal cord injury
- Availability of a transition service for children to facilitate and support their transition from paediatric to adult services that includes tailoring services to an individual's needs, active case management and allocation of a primary care provider
- Develop pathways to ensure timely and efficient transition from post-acute rehabilitation to country centres.

### Considerations for people from an Aboriginal and Torres Strait Island (ATSI) background

- Aboriginal Liaison Officer at hub rehabilitation service
- Access to interpreters in the provision of rehabilitation services to Aboriginal and Torres Strait Islanders
**Spinal Cord Injury Model of Care in South Australia**

<table>
<thead>
<tr>
<th>Important features/considerations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provision of gender and culturally appropriate care to Aboriginal Australians.</td>
</tr>
<tr>
<td>Use of alternative strategies for communicating with Aboriginal Australians who do not have English as their first language or are illiterate (for example, pictorial educational material).</td>
</tr>
<tr>
<td>Facilitating education programs for health professionals on cultural issues.</td>
</tr>
</tbody>
</table>

**Considerations for people from a Culturally and Linguistically Diverse (CALD) background**

<table>
<thead>
<tr>
<th>Considerations for people from a Culturally and Linguistically Diverse (CALD) background</th>
</tr>
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<tbody>
<tr>
<td>Access to interpreters in the delivery of services across the continuum.</td>
</tr>
<tr>
<td>Culturally appropriate variations to spinal cord injury services across the continuum should be considered for implementation such as educational materials that are pictorial or in different languages and establishing partnerships with culturally specific organisations to facilitate service provision.</td>
</tr>
<tr>
<td>Establishment of partnerships with community organisations that provide services to individuals from specific culturally and linguistically diverse backgrounds.</td>
</tr>
<tr>
<td>Training to promote cultural competence in the workforce delivering care to these individuals from a range of diverse cultural backgrounds.</td>
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</table>

**Key enablers**

<table>
<thead>
<tr>
<th>Key enablers</th>
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<tbody>
<tr>
<td><strong>Workforce</strong> – the Australasian Faculty of Rehabilitation Medicine (AFRM) recommends staffing levels for spinal cord injury inpatient and ambulatory rehabilitation, and these should be used as a guide. Recommendations for inpatient and outpatient spinal cord injury rehabilitation are also provided by the Victorian Allied Health Guidelines. There are no guidelines or benchmarks for acute or community spinal cord injury services.</td>
</tr>
<tr>
<td><strong>Education and training</strong> – the Australasian Faculty of Rehabilitation Medicine guidelines recommend that a minimum of 3% of effective full-time hours is allocated for formal in-service training and development at no cost to staff, for medical, nursing and allied health staff. This recommendation should apply to all staff providing services to individuals involved in spinal cord injury rehabilitation across the continuum of care.</td>
</tr>
<tr>
<td><strong>Partnerships</strong> – particular importance is placed on strengthening inter-sectoral partnerships.</td>
</tr>
<tr>
<td><strong>Safety and quality</strong> – A quality improvement and integrated performance monitoring approach is essential. This needs to include national benchmarking, quality improvement activities and comparative public reporting. The focus should include outcomes not just processes of care.</td>
</tr>
<tr>
<td><strong>Research</strong> – Research is important from both an organisational and professional perspective. From an organisational perspective research is one of the essential building blocks of an efficient and effective service. From a professional perspective research improves patient care, drives excellence and avoids stagnation.</td>
</tr>
<tr>
<td>Infrastructure and information technology:</td>
</tr>
<tr>
<td>o Suitable environments for the provision of spinal cord injury care including therapy and rehabilitation is vital to an individual’s</td>
</tr>
</tbody>
</table>

State Spinal Cord Injury Service (SSCIS) Spinal Cord Injury Model of Care Diagnostic Report
Spinal Cord Injury Model of Care in South Australia

Important features/considerations

- Recovery and outcomes and the ability of the service to provide care that efficiently and effectively.
- Information technology is also important to support the delivery of timely, effective and efficient spinal cord injury services and in particular support health professionals and patients not living in metropolitan Adelaide through the use of strategies such as telemedicine and tele-rehabilitation. To facilitate the use of some of these technologies, health professionals will need to be supported to up-skill and engage in these innovations.
COUNTRY: UNITED STATES

CRAIG HOSPITAL, DENVER, COLORADO

Spinal Cord Injury Model of Care – Craig Hospital, Denver, Colorado, USA

Introduction

Craig Hospital became a specialty hospital for the rehabilitation of people with a spinal cord injury (SCI) and traumatic brain injury (TBI) in 1956. Specialty hospitals often have years of experience - 13 average years of experience of therapy staff and 14 average years of experience of attending medical staff at Craig Hospital. 31,000+ patients with an SCI or TBI have been treated at Craig Hospital.

- 300 people with spinal SCI are treated at Craig each year (50-55 people at any one time)
- 75% of patients are male
- 40 is the average age of spinal cord injury patients
- 50% of patients’ injuries are motor vehicle related
- 17% of patients were injured in falls
- 10% of patients were injured playing sports
- 28 average number of days from date of injury to admission
- 55% have ASIA “incomplete” injuries (motor and/or sensory sparing)
- 91% discharges (varied by para/tetra etc.) directly to home
- Days hospitalized in first year after rehabilitation varied by type of spinal cord injury – 5.8 days for complete para; 6.7 days for C1-C4 complete tetra; 7.8 days for complete C5-C8 tetraplegia.
- Days of attendamt care required one year after discharge - 3.5 hours for complete para, 10.3 hours for C1-C4 complete tetra. 4.3 hours for complete C5-C8 tetraplegia
- Return to work and school averages exceed the averages of other rehabilitation programs across the country - 47% for complete para, 19% for C1-C4 complete tetra, 36% for complete C5-C8 tetraplegia
- 95% of patients and and families are very satisfied with their experience at Craig

All statistics are from National SCI Model System database 2009-2013

Components of service

1. Inpatient services. The inpatient spinal cord injury rehabilitation program not only serves patients who are newly-injured, but may also serve those who are experiencing a late onset complication of spinal cord injury and require a period of inpatient hospitalization. Such complications may include skin surgery, neurosurgery or other medical/surgical procedures.

   The approach is individualized, comprehensive, and family-oriented. Care is interdisciplinary.

   Core teams are comprised of the patient, his or her family, the physician, and a nurse, nurse technician, physical therapist,
occupational therapist, therapeutic recreation therapist, clinical care manager, clinical psychologist, dietician, chaplain and pharmacist. When necessary, representatives from respiratory therapy, speech/language pathology, and other consultants and treatment professionals who specialize in SCI also are included on the team.

Family is a critical part of the rehabilitation process at Craig Hospital. Family members are encouraged to participate in therapies, educational sessions, regular patient-family conferences and therapeutic outings. Craig has state-of-the-art accessible family apartments on-campus. Craig is a very family-friendly environment, with multiple family relaxation and hospitality areas. 30 days of free housing is provided to families. There is free wi-fi so family members can stay connected and keep working if needed.

Services available include:

- Rehabilitative neurosurgery
- Occupational Therapy
- Physical Therapy
- Speech Pathology
- Respiratory Therapy
- Urology – consultation for inpatients and outpatients
- Clinical care management - Clinical care managers (CCM) are critical members of each interdisciplinary team. CCMs provide assistance in patient and family counselling, education, accessing benefits, team coordination, planning for home, and advocacy.
- Therapeutic recreation
- Assistive technology – there is a loan bank which includes voice recognition software, computers on wheels, adaptive mouse devices, microphones, keyboards, a variety of mounts, Bluetooth ear pieces and various ways of controlling the environment (such as turning on/off TV and lights)there is
- Driving and Adaptive Transportation Program
- Community reintegration program – in the areas of Self-care, Functional Communication, Mobility at home and in the community, Employment, School, Homemaking/Child care, Independence, Time Management, Structured day, Safety/Consistency, Self-Advocacy, Health and Fitness, Recreation and Socialization, Money Management, Transportation.
- Rehab Engineering
- Chaplaincy
- Pharmacy
- The PEAK Center - an adaptive health and wellness center serving individuals from across the country with neurologic disabilities in order to optimize their recovery and to create a lifelong plan for their health and wellness.
- Research
2. Outpatient services

- **Interdisciplinary Outpatient Evaluations** at Craig Hospital are managed by a nurse practitioner or physician with years of experience working with patients with spinal cord injury. Each interdisciplinary team is also made up of nurses, therapists and clinical care managers. The evaluation is comprehensive and begins several weeks ahead with calls from our nurses to the patient, and from our clinical care managers to insurance case managers to align expectations.

  The evaluation includes:
  - a review of pertinent records and history-taking as necessary
  - an onsite SCI physical examination by our specialized nurse practitioners
  - an onsite nursing evaluation in the areas of bowel, bladder, medications, nutrition, and skin condition
  - on-site urologic exam
  - on-site physical and occupational therapy evaluations for motor/sensory changes, posture, mobility, activities of daily living and functional tests, equipment evaluation and minor repairs or adjustments
  - on site psychosocial evaluation
  - on site consultations with other specialists as necessary (neurosurgical consults, skin, pulmonary, etc)
  - radiological studies, CT, MRI, etc as necessary
  - a wrap-up team conference with the patient, family, staff, and case manager with evaluation results, and recommendations for a plan of care.
  - other services as requested in advance, e.g. gait/bracing clinic, seated mobility evaluations, podiatry, adaptive transportation consults, etc.

  - written reports documenting the results and recommendations
  - on-site clinical care managers to provide assistance/resources regarding funding or caregiver needs

A typical re-evaluation at Craig is conducted in an intensive 3-4 day period.

- **Other Outpatient services** – treatment plans are individualized to each patient's needs.

- **NeuroRecovery Network (NRN)** is an outpatient intensive therapy program designed to improve functional mobility, independence and quality of life in individuals who have sustained catastrophic spinal cord injury through physical and occupational therapy. Craig Hospital joined the cooperative network of six cutting-edge rehabilitation centers across the nation, in 2012. NRN is designed to provide and develop therapies to promote functional recovery and improve health and quality of life of people living with paralysis. The NRN physical therapy program utilizes locomotor training as its primary intervention to stimulate the nervous system and drive motor recovery. (Locomotor training is an activity based therapy designed to activate spinal pathways below the level of injury through manually facilitated step retraining over a body weight supported treadmill. By manipulating variables such as speed and body weight support, the therapists can challenge the patient’s nervous system in efforts to improve trunk control, posture, strength, independence, and in some cases return of ability to walk.)
Shepherd Center, located in Atlanta, Georgia, founded in 1975, is a private, not-for-profit hospital specializing in medical treatment, research and rehabilitation for people with spinal cord injury, brain injury, multiple sclerosis, chronic pain and other neuromuscular problems. It provides a full continuum of services from acute care, to inpatient rehabilitation, to outpatient and lifelong wellness programs.

Shepherd Center is a 152-bed facility. Last year Shepherd had 965 admissions to its spine and brain inpatient programs and 571 to its day patient programs. In addition, Shepherd sees more than 6,600 people annually on an outpatient basis.

Statistics

- 92 percent of spinal cord injury inpatients would definitely recommend Shepherd Center to others in need of rehabilitation care.
- 97% of patients rate their overall experience as excellent.
- Average age of patients with Spinal Cord Injury is 39 years – younger than most other rehabilitation facilities.
- Shepherd Center treats more than 300 patients each year.
- A typical inpatient stay ranges from 4-6 weeks.
- 83% of patients return home on discharge from Shepherd.
- Each patient participates in 4-5 hours per day of therapy.
- Patients experience an average of 30.5 points in functional improvement (FIM) during their stay at Shepherd.

Components of the spinal cord injury service

Referral

More than 500 U.S. hospitals, including major trauma centers, refer their spinal cord injury patients to the Shepherd Center. Shepherd Center has a 10-bed ICU allowing patients to begin the rehabilitation process as soon as possible.

Inpatient services

Each inpatient rehabilitation team consists of:
- Lead Physician with SCI Expertise
- Physical Therapist
- Respiratory Therapist
Spinal Cord Injury Model of Care – Shepherd Center, Atlanta, Georgia

Important developments/considerations

- Exercise Specialist
- Occupational Therapist
- Case Manager
- Chaplain
- Recreation Therapist
- Speech-language Pathologist
- Dietician
- Psychologist and Counselor
- Nurses and Patient Care Technicians

Services include:
- **Shepherd Step** - an intensive walking program to assist participants with motor-incomplete spinal cord injury in regaining the highest possible functional level of walking.
- **Beyond Therapy** - goes beyond the borders of traditional therapy programs, where the focus is on adapting to a new set of capabilities. Traditional therapy programs are designed to help patients become as independent as possible using compensatory strategies and training on how to care for themselves after discharge from the hospital.
- **The Shepherd Spine and Pain Institute** which takes a multi-disciplinary approach to the practice of medicine and specialize in the evaluation, diagnosis and application of interventional treatment for the management of pain and related disorders.
- **Shepherd Center's Medical/Surgical Unit** is equipped to treat patients who require medical or surgical interventions due to secondary complications resulting from an injury or degenerative disease.
- Specialty services include the treatment of:
  - Pressure sores
  - Urological complications
  - Gastrointestinal complications
  - Respiratory disease (i.e., pneumonia)
  - Deep vein thrombosis
  - Tendon transfers
  - Spasticity management
- **Ventilator services program** – is led by an experienced and aggressive team of respiratory therapists, pulmonologists and an intensivist who work to wean patients off ventilators whenever possible. For patients who remain ventilator dependent, Shepherd focuses on educating the patient on how to live an active lifestyle.
- **The Neuro-rehabilitation Psychology Department** at Shepherd Center is a comprehensive department that is staffed by a variety of mental health professionals, who are located on all services at Shepherd Center, both inpatient and outpatient.
Spinal Cord Injury Model of Care – Shepherd Center, Atlanta, Georgia

<table>
<thead>
<tr>
<th>Important developments/considerations</th>
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</thead>
<tbody>
<tr>
<td>Interventions address emotional, cognitive, behavioral, and pain issues that can accompany catastrophic injuries/illnesses.</td>
</tr>
</tbody>
</table>

**Outpatient services** at the Shepherd Center provide medical treatment, therapies and care for people with disabilities for a wide range of needs on an outpatient basis. These programs provide individualized, integrative care and include family members when appropriate.
Spinal Cord Injury Model of Care – Burwood Hospital, Christchurch, New Zealand

Introduction
The Burwood Spinal Unit (BSU) provides services for people with Spinal Cord Impairment (SCI) resulting from accident, illness or congenital abnormalities. It is a recognised tertiary service providing comprehensive, interdisciplinary assessment, treatment and rehabilitation for individuals with SCI who live throughout the entire South Island and lower half of the North Island.

The BSU consists of a 26 bed ward and a 4 bed Transitional Rehabilitation Unit. It offers inpatient services from the acute stage including pre-operative or other early management, through to rehabilitation and discharge planning. A range of outpatient, assessment and arranged admissions for specialised services are also provided. There is limited accommodation onsite for families and outpatients. The BSU is the only centre in New Zealand which provides rehabilitation to individuals with SCI who require ventilation.

The BSU also works in close collaboration with the New Zealand Spinal Trust and the Burwood Academy of Independent Living.

Components of service

Inpatient services
An acute referral is made by the referring hospital consultant to the on call rehabilitation consultant at Burwood. This may be from any hospital in the catchment area. Arrangements are then made to transfer the patient to Christchurch Public Hospital, if appropriate. All acute patients are admitted to BSU via Christchurch Public Hospital ICU, Orthopaedic Trauma Unit or the Neurology ward. Patients are then transferred to BSU as soon as they are medically stable.

Information about early management, the rehabilitation process, and hospital facilities is available in the Burwood Spinal Unit ‘All You Need to Know’ handbook.

Rehabilitation following a spinal impairment is carried out by an inter-disciplinary team together with the patient and their family/whanau. The inter-disciplinary team includes doctors, nurses, physiotherapists, occupational therapists, social workers, psychologist, health care assistants, surgeons, dieticians, speech language therapist, Maori health workers and vocational rehabilitation consultants.

Rehabilitation programmes are designed around specific needs and personal goals. Programmes will include many hours of physical

Important developments/considerations
- Information booklet ‘All You Need to Know’ for patients/families
- Maori health workers on treating team (if applicable) - “The spinal unit recognises that your cultural needs are an integral part of your rehabilitation journey.”
- Concept of Key Worker - a Key Worker is assigned to all rehabilitation patients who will be a point of contact and assist with coordinating and co-chairing meetings with you. The key worker will most likely be a member of the clinical team assigned to the patient.
- Relationship to non-government organisations - NZ Spinal Trust for provision of vocational rehabilitation and to Burwood Academy of Independent Living for research
- Good systems of reassessment
- Lifelong care
- Congenital abnormalities are included
- Transitional rehab in adjacent spinal hostel
training, learning how to manage personal care needs, and education about the impact of SCI. This programme gives the tools needed to gain independence and support self-determination.

**Transitional Rehab**
Transitional Rehabilitation is a programme designed to bridge the gap between being in hospital and returning home. The focus is on independence and autonomy. Transitional Rehabilitation is part of the Burwood Spinal Unit but located in the adjacent spinal hostel.

**Re-Assessment**
The Burwood Spinal Unit provides reassessment for people with spinal cord impairment. There are three types of reassessment: Advanced, Basic and Remote

**Advanced Reassessment**
Many patients will be booked for an advanced reassessment. It usually takes place approximately 6 months following discharge and is undertaken over 3 days.

**Basic Reassessments**
Basic reassessments generally occur approximately 12 months following the initial advanced reassessment and again thereafter at approximately 3 yearly intervals unless issues identified indicate more frequent reassessment is required. Reassessment is undertaken either at the Burwood Spinal Unit or at one of 12 centres, depending on where the patient lives.

**Remote Reassessment**
A remote reassessment comprises of a health questionnaire that is sent approximately every 12-18 months. The questionnaire is designed to address broad health issues as well as more specific concerns that commonly affect people with an SCI.

**Other Services include:**
- Occupational therapy outpatients
- Urology – inpatient, reassessment, outpatient
- Vocational Rehabilitation – inpatient and outpatient
- Intimacy clinic – inpatient and outpatient
- Physiotherapy – inpatient and outpatient
- Spasticity clinic – outpatient
- Upper Limb Surgery – inpatient – optimal timing for surgery is when the individual is physically, mentally and socially ready to undergo surgery and the demanding post-operative rehabilitation. One year following SCI is normally the earliest it is undertaken and it can be successfully performed as long as 30 years after the spinal cord injury.
- Research - The Burwood Academy of Independent Living is a dynamic organisation committed to improving the life experience of people recovering from serious injury and illness. Based onsite at Burwood Hospital in Christchurch, the Academy is dedicated to building a vibrant culture of research and learning. It is working to establish strong links to consumer organisations, universities and rehabilitation professionals.

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**State Spinal Cord Injury Service (SSCIS)** Spinal Cord Injury Model of Care Diagnostic Report 109
COUNTRY: UNITED KINGDOM

STOKE MANDEVILLE, BUCKINGHAMSHIRE

<table>
<thead>
<tr>
<th>Spinal Cord Injury Model of Care – Stoke Mandeville, Buckinghamshire, United Kingdom</th>
<th>Key features</th>
</tr>
</thead>
<tbody>
<tr>
<td>• There are 11 units in the UK designated to receive and treat spinal cord injured patients</td>
<td>• Lifelong care</td>
</tr>
<tr>
<td>• Each National Spinal Cord Injury Centre is linked to a number of Major Trauma Centres</td>
<td>• No difference in funding of patients</td>
</tr>
<tr>
<td>• Stoke Mandeville is one of these national centres</td>
<td>• Dedicated work stream for older adults</td>
</tr>
<tr>
<td>• At Stoke Mandeville there are 114 beds of which 62 are for rehab; 9 are for young people with a spinal cord injury; the remainder are for acute admissions or for people who are medically unstable and secondary elective admissions. There is a dedicated workstream to address the specific needs of the older adult</td>
<td>• Referral criteria set by NHS Board</td>
</tr>
<tr>
<td>• NHS funded</td>
<td>• Accepts ventilator dependent patients</td>
</tr>
<tr>
<td>• Provides culturally sensitive, comprehensive, goal directed, individualised, specialised, interdisciplinary rehabilitation service across the lifespan</td>
<td>• Goal directed</td>
</tr>
<tr>
<td>• Works with charitable and statutory organisations to promote a continuum of rehabilitative care through the delivery of high quality spinal rehabilitation services, education, and integrative sports and arts programmes</td>
<td>• Works with patient and family</td>
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</table>

Referrals
• Referrals are largely from 6 Major Trauma Centres that Stoke Mandeville is linked to
• Referral criteria are developed by the NHS England Commissioning Board
• Patients can be referred with traumatic or non-traumatic SCI, and may have a dual diagnosis, e.g. acquired brain injury

Admissions
• An individual who is ventilator dependent can be considered for admission for rehabilitation and training
• There is a multidisciplinary outreach team who is a link between the referral and admission who can advise and offer support to the person, their family and treating staff
• Re-admissions for short stay programmes are available for those with identified goals where they cannot access services locally but are expected to benefit from further therapies such as intensive gait training or further management of their personal care
• Other admissions will be made to the service to address secondary complications such as tissue viability, urology or spasticity management
• Individuals of all cultures are admitted and the programme strives to meet individual cultural needs of all patients
• There is a policy of non-discrimination on the basis of race, gender, disability, age, maternity and pregnancy, religion or belief, gender identity, marriage and civil partnerships and sexual orientation
• All patients and their families are allocated a Case Manager upon admission to the programme
• A comprehensive, individualised patient and family education programme is initiated upon admission and modified as the individual progresses in his/her rehabilitation programme
• Patients are allocated a Case Manager upon admission to the programme
• A comprehensive, individualised patient and family education programme is initiated upon admission and modified as the individual progresses in his/her rehabilitation programme

Other admissions will be made to the service to address secondary complications such as tissue viability, urology or spasticity management.
Spinal Cord Injury Model of Care – Stoke Mandeville, Buckinghamshire, United Kingdom

Key features

- An individualised education manual is provided to the patient and family
- A goal planning process takes place throughout a patient’s stay

Programme

- The inpatient wards provide a rehabilitation environment 24 hours a day, seven days a week. Regular scheduled rehabilitation therapy sessions occur Monday through to Friday with weekends directed to the practice of rehabilitation skills
- Services offered in the Spinal Cord System of Care
  - Spinal Cord Injury Consultant
  - Rehabilitation Nurse
  - Occupational Therapy
  - Recreational and leisure activities – sports / arts
  - Physiotherapy, including aquatic therapy and adaptive sports programmes
  - Clinical Psychology
  - Case Management and transition planning
  - Patient liaison and advocacy
  - Patient Education Programme
  - Pharmacist
  - Play Specialist (young people)
  - School Teaching Service (young people)
  - Posture and Seating assessment
- Depending on the unique needs of each individual, the following services are also provided:
  - Nutrition Services
  - Speech Language Therapist – communication assistance
  - Psychosexual therapy
  - Chaplaincy
  - Family Counselling
  - Vocational services
  - Orthotics
  - Other medical or surgical consultations
  - Adaptive technology service etc.
  - Interpreting service
  - Liaison Psychiatry
  - Liaison with wheelchair services
- All medical issues that may be a factor for a person with spinal cord dysfunction can be managed with consultation from various other specialists, as requested by the spinal doctors and team. The NSIC provides specialist care for those with spinal cord injury and associated complications such as...
### Spinal Cord Injury Model of Care – Stoke Mandeville, Buckinghamshire, United Kingdom

<table>
<thead>
<tr>
<th>Key features</th>
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<tbody>
<tr>
<td>o Autonomic dysreflexia</td>
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<tr>
<td>o Bowel function</td>
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<td>o Bladder function</td>
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<tr>
<td>o Circulation</td>
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<tr>
<td>o Cardiac Function</td>
</tr>
<tr>
<td>o Cognition / Psychological difficulties – Mood disturbance, pre morbid mental health</td>
</tr>
<tr>
<td>o problems, adjustment issues, ABI, special needs, pain management.</td>
</tr>
<tr>
<td>o Dysphagia</td>
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<tr>
<td>o Fertility</td>
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<td>o Infectious disorders</td>
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<tr>
<td>o Medication</td>
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<tr>
<td>o Metabolic Function</td>
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<tr>
<td>o Musculoskeletal complications</td>
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<tr>
<td>o Neurological changes</td>
</tr>
<tr>
<td>o Nutrition</td>
</tr>
<tr>
<td>o Pain – acute and persistent pain</td>
</tr>
<tr>
<td>o Respiration</td>
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<tr>
<td>o Sexual function</td>
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<tr>
<td>o Skin integrity</td>
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<td>o Spasticity</td>
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</tbody>
</table>

- Staff works with the patient and family to address aspects related to an individual capability to function using the goal planning process within their intended living environment. Examples include:
  o Activities of daily living
  o Assistive technology
  o Community integration
  o Drivers potential assessment
  o Durable Medical Equipment
  o Emergency Preparedness
  o Environmental Modifications
  o Leisure and recreation
  o Medication
  o Mobility
  o Orthosis/Prosthetics
  o Personal care assistant training
### Key features
- Seating
- Vocational Services
- Educational needs

### Discharge
- The case manager will assist with identifying potential difficulties with discharge transition and support people in their decision process prior to moving on from the rehabilitation environment. Discharge conversations are initiated within 2 weeks of admission.
- A mutually agreed discharge date is set.
- A **clinical psychologist** is available on discharge to work with adults, children and their families.
- **Peer support** is available.
- Patients receive **lifelong** care from the centre once they have made a transition from the inpatient programme. The Spinal Cord Injury Consultant and the Interdisciplinary Team will assist individuals served with lifelong health issues, self-management and prevention of potential risks and complications.
- Appointments after discharge from the ward are arranged for a Spinal Outpatients visit to clinic if needed and the outreach team can visit at home if required.
- The spinal outpatients department is starting to use telehealth technology for some of the consultations.

### Research
- There is strong research activity within the NSIC.
COUNTRY: SWITZERLAND

SWISS PARAPLEGIC CENTRE (SPC)

The Swiss Paraplegic Centre (SPC) Nottwil is a privately owned clinic, recognised nationwide, specialising in primary care and holistic rehabilitation of patients with spinal cord injuries. In addition to medical and therapeutic services, it also includes advisory services, as well as research in the area of paraplegia, prevention.

As a private clinic, the SPC also cares for patients who have general insurance cover, thanks to the support of the Swiss Paraplegic Foundation. This type of insurance accounts for 75% of the patients. The Swiss Paraplegic Foundation (SPF) and its Benefactors’ Association (BA) is the second-largest member organisation and the best-known aid organisation for people with a disability in Switzerland.

Services provided at SPC include:

<table>
<thead>
<tr>
<th>Medicine</th>
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<tbody>
<tr>
<td>Anaesthesiology</td>
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<td>Biomedical analysis</td>
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<tr>
<td>Dermatology</td>
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<tr>
<td>Gastro-enterology</td>
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<td>Gynaecology</td>
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<tr>
<td>Hand surgery</td>
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<tr>
<td>Ear, nose and throat medicine</td>
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<tr>
<td>Internal medicine</td>
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<tr>
<td>Intensive care medicine</td>
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<tr>
<td>Cardiology</td>
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<tr>
<td>Clinical research</td>
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<tr>
<td>Neuro-surgery</td>
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<tr>
<td>Neurology</td>
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<tr>
<td>Orthopaedic surgery / Spinal surgery</td>
</tr>
<tr>
<td>Paraplegiology</td>
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<tr>
<td>Physical medicine and rehabilitation</td>
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<tr>
<td>Plastic and reconstructive surgery</td>
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<tr>
<td>Pneumology</td>
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<tr>
<td>Psychiatry</td>
</tr>
<tr>
<td>Radiology / Neuro-radiology (CT, MRI)</td>
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<table>
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<tr>
<th>Key features</th>
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<tbody>
<tr>
<td>Lifelong care</td>
</tr>
<tr>
<td>Private, well-funded, contributions from Foundation</td>
</tr>
<tr>
<td>ED</td>
</tr>
<tr>
<td>ICU</td>
</tr>
<tr>
<td>A range of medical specialties</td>
</tr>
<tr>
<td>Research</td>
</tr>
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</table>
Spinal Cord Injury Model of Care – Swiss Paraplegic Centre (SPC), Switzerland

Key features

- Sports medicine
- Pain medicine
- Urology / Neuro-urology
- Dentistry

Care
- Intensive care
- Specialist care for paraplegia and neuro-muscular patients
- Core competences in: bladder, bowel, skin, wound and respiration management, spasticity
- Patient education
- Kinaesthetics / Movement
- Diabetes advice
- Podology
- Colon hydro therapy

Therapy and complementary medicine
- Acupuncture
- Chiropractic service
- Craniosacral therapy
- Ergotherapy
- Feldenkrais therapy
- Design therapy / Studio for Design
- Equine therapy
- Homeopathic medicine
- Art therapy
- Speech therapy
- Painting therapy
- Music therapy
- Physical therapy
- Physiotherapy
- Sport therapy
- Therapeutic riding
- Hydrotherapy
Spinal Cord Injury Model of Care – Swiss Paraplegic Centre (SPC), Switzerland

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Advice</td>
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<tr>
<td>Vocational guidance / Work trials</td>
</tr>
<tr>
<td>Psychology</td>
</tr>
<tr>
<td>Pastoral care</td>
</tr>
<tr>
<td>Social advice</td>
</tr>
<tr>
<td>Legal advice</td>
</tr>
<tr>
<td>Nutritional advice</td>
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<tr>
<td>Patient Support Service</td>
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</table>

Knowledge and learning
- Library
- Courses for patients and their relatives

Other services
- Orthopaedics and rehabilitation technology
- Incontinence items
- Wheelchair mechanics
- Vehicle adaptation
- Centre for Obstacle-free Building
- Sirmed (Swiss Institute for Rescue Medicine)

Research
The primary objective of clinical research at the SPC is to enhance the treatment given to patients. Clinical research is carried out by various departments within the SPC, frequently on an inter-disciplinary basis and in direct contact with patients. The Clinical Trial Unit provides support in planning, carrying out and coordinating clinical research projects.
Appendix 2: Consultations

Consumers

A total of 23 people with spinal cord injury (and/or their family members and/or carers) were interviewed, as summarised in the following table.

<table>
<thead>
<tr>
<th>PROFILE OF 23 PEOPLE WITH SCI INTERVIEWED</th>
<th>#</th>
<th>%</th>
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<tbody>
<tr>
<td>Gender</td>
<td></td>
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</tr>
<tr>
<td>Male</td>
<td>19</td>
<td>83%</td>
</tr>
<tr>
<td>Female</td>
<td>4</td>
<td>17%</td>
</tr>
<tr>
<td>Time since injury</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1 year</td>
<td>9</td>
<td>39%</td>
</tr>
<tr>
<td>1-5 years</td>
<td>1</td>
<td>4%</td>
</tr>
<tr>
<td>6-10 years</td>
<td>2</td>
<td>9%</td>
</tr>
<tr>
<td>11-25 years</td>
<td>4</td>
<td>17%</td>
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<tr>
<td>25+ years</td>
<td>7</td>
<td>30%</td>
</tr>
<tr>
<td>Where residing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spinal unit</td>
<td>6</td>
<td>26%</td>
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<tr>
<td>Community</td>
<td>17</td>
<td>74%</td>
</tr>
<tr>
<td>Usual residence</td>
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<tr>
<td>Institution</td>
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<tr>
<td>Metropolitan</td>
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<tr>
<td>Regional</td>
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<td>26%</td>
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<tr>
<td>Rural</td>
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<td>39%</td>
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<tr>
<td>Unknown</td>
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<tr>
<td>Where interviewed</td>
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<tr>
<td>Community</td>
<td>16</td>
<td>70%</td>
</tr>
<tr>
<td>Phone</td>
<td>5</td>
<td>22%</td>
</tr>
<tr>
<td>Outpatient clinic</td>
<td>2</td>
<td>9%</td>
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</table>

In addition, two peer workers from ParaQuad NSW were interviewed.

Executive/management representatives

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>James Middleton</td>
<td>Clinical Director, Co-Chair, Co-Chair</td>
<td>SSCIS</td>
</tr>
<tr>
<td>Louise Kelly</td>
<td>Co-Chair, Director, Primary Care &amp; Chronic Services</td>
<td>SSCIS</td>
</tr>
<tr>
<td>Chris Shipway</td>
<td></td>
<td>ACI</td>
</tr>
<tr>
<td>Peter Daly</td>
<td>A/Manager</td>
<td>Brain Injury Services, North Coast LHD</td>
</tr>
<tr>
<td>Stephen Lowndes</td>
<td>CEO</td>
<td>Royal Rehab</td>
</tr>
<tr>
<td>Liz Drolz</td>
<td>Executive Director of Nursing</td>
<td>Royal Rehab</td>
</tr>
<tr>
<td>Clayton King</td>
<td>Director of Medical Services</td>
<td>Royal Rehab</td>
</tr>
<tr>
<td>Andrew Montague</td>
<td>Executive Director Operations</td>
<td>NSRH &amp; NSLHD</td>
</tr>
<tr>
<td>Patrick Bolton</td>
<td>Director, Clinical Operations</td>
<td>POWH</td>
</tr>
<tr>
<td>Michael Pollack</td>
<td>Director, Rehabilitation Medicine</td>
<td>HNELHD</td>
</tr>
</tbody>
</table>
### Name | Position | Organisation
--- | --- | ---
Jonathan Holt | Acting General Manager | Community & Aged Care Services - Greater Newcastle Sector, HNE LHD
James Stormon | Clinical Program Director, CARPA | SCHN

#### RNSH

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Louise Kelly</td>
<td>Clinical Nurse Consultant, Spinal Cord Injury Unit, RNSH and Co-Chair SSCIS</td>
</tr>
<tr>
<td>Yvette Mair</td>
<td>Clinical Nurse Consultant, Spinal Cord Injury Unit</td>
</tr>
<tr>
<td>Sonia Jones</td>
<td>CNC, Spinal Cord injury Unit</td>
</tr>
<tr>
<td>Zoe Howard</td>
<td>Clinical Nurse Educator, Spinal Cord injury Unit</td>
</tr>
<tr>
<td>Shonell Youngberry</td>
<td>Acting NUM</td>
</tr>
<tr>
<td>Lucija Lavrencic</td>
<td>Clinical Nurse Consultant, Spinal Plastics Service</td>
</tr>
<tr>
<td>Sarah Webb</td>
<td>ICU Nurse Practitioner</td>
</tr>
<tr>
<td>Lisa Benad</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>David Simpson</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>Lydia Chen</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>Jane Yeomans</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>Jasbeer Kaur</td>
<td>Head of Department, Spinal Cord Injuries Unit</td>
</tr>
<tr>
<td>Lianne Nier</td>
<td>Staff Specialist (spinal rehab physician)</td>
</tr>
<tr>
<td>David Bowers</td>
<td>VMO (spinal rehab physician)</td>
</tr>
<tr>
<td>Priyadarshini Chari</td>
<td>Staff specialist (spinal rehab physician)</td>
</tr>
<tr>
<td>John Vandervord</td>
<td>Clinical Director Division of Surgery and Anaesthesia</td>
</tr>
<tr>
<td>Ray Raper</td>
<td>ICU Director</td>
</tr>
<tr>
<td>Nathan Hartin</td>
<td>Head, Orthopaedics &amp; Trauma Surgery</td>
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#### Royal Rehab

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>James Middleton</td>
<td>Clinical Director and Co-Chair, SSCIS</td>
</tr>
<tr>
<td>Christine Rolfe</td>
<td>Clinical Operations Manager, Spinal Injury Unit</td>
</tr>
<tr>
<td>Gerard Weber</td>
<td>Medical Director, Spinal Injury Unit</td>
</tr>
<tr>
<td>Gillian Garrett</td>
<td>Clinical Nurse Consultant</td>
</tr>
<tr>
<td>Catherine Ephraums</td>
<td>Clinical Psychologist</td>
</tr>
<tr>
<td>Nicole Loizou</td>
<td>Social Worker</td>
</tr>
<tr>
<td>Stephanie Houston</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>Ann Thompson</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>Donna Rainey</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>Kel Smith</td>
<td>Recreation Therapist</td>
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</tbody>
</table>

#### POWH

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sachin Shetty</td>
<td>Medical Director, Spinal Injuries Unit</td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Raj Reddy</td>
<td>Neurosurgeon</td>
</tr>
<tr>
<td>Annalisa Dezarnaulds</td>
<td>Clinical Psychologist, NSW State SCI Psychosocial Strategy Coordinator</td>
</tr>
<tr>
<td>Glen Stolzenhein</td>
<td>Clinical Nurse Consultant</td>
</tr>
<tr>
<td>Megan Pontin</td>
<td>Social Worker</td>
</tr>
<tr>
<td>Helen Walter</td>
<td>Social Worker</td>
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<td>Megan Bell</td>
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<tr>
<td>Belinda Cario</td>
<td>Occupational Therapist</td>
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<tr>
<td>Tessa Irwin</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>Claire Chance</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>Margaret Samson</td>
<td>Clinical Nurse Consultant SPCC (Spinal Pressure Care Clinic)</td>
</tr>
<tr>
<td>Victoria Sim</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>Sophie Denis</td>
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<tr>
<td>Keira Tranter</td>
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</tr>
<tr>
<td>Beverley Berelowitz</td>
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</tr>
<tr>
<td>Paula Carroll</td>
<td>Clinical Dietitian</td>
</tr>
<tr>
<td>Morgan Hee</td>
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</tr>
<tr>
<td>Jenny Johnston</td>
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<tr>
<td>Sam Steele</td>
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</tr>
<tr>
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<tr>
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</tr>
<tr>
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<tr>
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<td>Rehab2Kids Service Manager</td>
</tr>
<tr>
<td>Gary Williams</td>
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<tr>
<td>Rick Dunstan</td>
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<tr>
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<tr>
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<tr>
<td>Suzanne Benson</td>
<td>Clinical Neuropsychologist</td>
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<tr>
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**SCH**

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<td>Adrienne Epps</td>
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**CHW**

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<tr>
<td>Jodie Thompson</td>
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<td>Julie Anne Macey</td>
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<td>Jessica Weise</td>
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<td>Johanna Newsom</td>
<td>Physiotherapist</td>
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<td>Stephanie Tuck</td>
<td>Social Worker</td>
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<td>Suzanne Benson</td>
<td>Clinical Neuropsychologist</td>
</tr>
<tr>
<td>Anne Marie Sarandrea</td>
<td>Clinical Psychologist</td>
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</tbody>
</table>
### State Spinal Cord Injury Service (SSCIS) Spinal Cord Injury Model of Care Diagnostic Report

#### Antoinette Botman
**Position:** Staff Specialist, Head of Spinal Cord Injury and Spina Bifida

#### Simon Paget
**Position:** Staff Specialist, Kids Rehab

#### Mary-Clare Waugh
**Position:** Staff Specialist, Head of Kids Rehab

### Spinal Outreach Service

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
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</thead>
<tbody>
<tr>
<td>Selina Rowe</td>
<td>Manager, Spinal Outreach Service</td>
</tr>
<tr>
<td>Melissa McCormick</td>
<td>Manager, Rural Spinal Cord Injury Service</td>
</tr>
<tr>
<td>Nicky Moshirian</td>
<td>Registrar (rehab)</td>
</tr>
<tr>
<td>Carla Lewis</td>
<td>Clinical Nurse Specialist</td>
</tr>
<tr>
<td>Anne Whilley</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>Alison DiSanto</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>Lyndall Katte</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>Marsha Ben</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>Angela Pang</td>
<td>Social Worker</td>
</tr>
<tr>
<td>Alex Ommanney</td>
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</tr>
<tr>
<td>Rachel Harper</td>
<td>Vocational Consultant</td>
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### Rural Coordinators

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<tr>
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<tbody>
<tr>
<td>Jenni Barker</td>
<td>Southern and Murrumbidgee LHD</td>
</tr>
<tr>
<td>Alyssa Rogan and Cath Brabrook</td>
<td>Hunter New England LHD</td>
</tr>
<tr>
<td>Suzanne Johnston and Nadia Vaile</td>
<td>Western NSW LHD and Far West LHD</td>
</tr>
<tr>
<td>Chris Dent</td>
<td>Northern LHD</td>
</tr>
<tr>
<td>Peter Daly (acting)</td>
<td>Mid North Coast LHD</td>
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### NSW Paediatric Outreach Service

<table>
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<tr>
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</thead>
<tbody>
<tr>
<td>Jaie Thompson</td>
<td>Practice Lead</td>
</tr>
<tr>
<td>Deb Woodford</td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>Isabel Chapman</td>
<td>Physiotherapist</td>
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</table>

### Newcastle

<table>
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<tbody>
<tr>
<td>Kylie Jones</td>
<td>Regional Clinical Services Supervisor</td>
<td>ParaQuad NSW</td>
</tr>
<tr>
<td>Erin Doyle</td>
<td>Occupational Therapist</td>
<td>ParaQuad NSW</td>
</tr>
<tr>
<td>Grant Roulstone</td>
<td>Service Supervisor/Co-ordinator of Supports</td>
<td>ParaQuad NSW</td>
</tr>
<tr>
<td>Cathy Bros</td>
<td>Nursing Unit Manager – Rehab Ward</td>
<td>John Hunter Hospital</td>
</tr>
<tr>
<td>Karen O'Donoghue</td>
<td>Case Manager</td>
<td>John Hunter Hospital</td>
</tr>
<tr>
<td>Name</td>
<td>Position</td>
<td>Organisation</td>
</tr>
<tr>
<td>--------------------</td>
<td>-------------------------------</td>
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</tr>
<tr>
<td>April Mosley</td>
<td>Occupational Therapist</td>
<td>John Hunter Hospital</td>
</tr>
<tr>
<td>David Shakespeare</td>
<td>Physiotherapist</td>
<td>Hunter SCIS</td>
</tr>
<tr>
<td>Sharon Baille</td>
<td>Clinical Nurse Consultant</td>
<td>Kaleidoscope (Paediatric Rehabilitation)</td>
</tr>
<tr>
<td>Angie Myles</td>
<td>Transition Care Coordinator</td>
<td>ACI</td>
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**Others**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peter Perry</td>
<td>CEO</td>
<td>SCIA</td>
</tr>
<tr>
<td>Chris Nicholls</td>
<td>GM Transitional Services</td>
<td>SCIA</td>
</tr>
<tr>
<td>Lee Clarke</td>
<td>Northern NSW</td>
<td>SCIA</td>
</tr>
<tr>
<td>Jacqueline Scott</td>
<td>Senior Project Officer- Vocational Programs, LTCS</td>
<td>iCare</td>
</tr>
<tr>
<td>Amy de Paula</td>
<td>Occupational therapist</td>
<td>ParaQuad NSW</td>
</tr>
<tr>
<td>Jackie Hiller</td>
<td>A/Manager Enable NSW</td>
<td>Healthshare NSW</td>
</tr>
<tr>
<td>Louise Mather-Mullard</td>
<td>A/Manager, Clinical Services, Enable NSW</td>
<td>Healthshare NSW</td>
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</table>

**Spinal Surgeons’ workshop**

<table>
<thead>
<tr>
<th>Name</th>
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<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jerry Day</td>
<td>Neurosurgeon</td>
<td>Wollongong</td>
</tr>
<tr>
<td>Mitchell Hansen</td>
<td>Neurosurgeon</td>
<td>Newcastle</td>
</tr>
</tbody>
</table>
| Jonathan Ball      | Neurosurgeon and Spinal Surgeon  
Royal North Shore and North Shore Private Hospitals | RNSH                                             |
| Ralph Stanford     | Orthopaedic surgeon                          | POWH                                              |
| Yanni Sergides     | Neurosurgean & Spine Surgeon                 | RNSH                                              |
| Andrew Kam         | Director of Spinal Trauma at Westmead Hospital | Westmead & Westmead and Northwest Private Hospitals |
| Nathan L Hartin    | Head | Department of Orthopaedics and Trauma Surgery | Royal North Shore Hospital  
Visiting Surgeon | Spine and Scoliosis Unit | The Children's Hospital Westmead | RNSH |
| Mark Davies        | Neurosurgeon                                  | St George Hospital                                |
| Mark Sheridan      | Neurosurgeon                                  | Liverpool Hospital                                 |
| Kevin Seex         | Neurosurgeon                                  | Macquarie Neurosurgery (phone interview)          |
## Appendix 3: Committee Members

### Project Executive Planning Committee

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antoinette Botman</td>
<td>Staff Specialist, Head of Spina Bifida Services, Head of Spinal Cord Service, Kids Rehab</td>
<td>Children's Hospital Westmead</td>
</tr>
<tr>
<td>Heidi Haydon</td>
<td>Consumer representative</td>
<td>Spinal Cord Injuries Australia</td>
</tr>
<tr>
<td>Kylie Jones</td>
<td>Regional Clinical Services Supervisor</td>
<td>ParaQuad, NSW</td>
</tr>
<tr>
<td>Louise Kelly</td>
<td>Co-chair, SSCIS Clinical Nurse Consultant, Spinal Cord Injury</td>
<td>Royal North Shore Hospital</td>
</tr>
<tr>
<td>James Middleton (Chair)</td>
<td>Director and Co-Chair, SSCIS</td>
<td>Royal Rehab and Agency for Clinical Innovation</td>
</tr>
<tr>
<td>Peter Perry</td>
<td>Chief Executive Officer</td>
<td>Spinal Cord Injuries Australia</td>
</tr>
<tr>
<td>Christine Rolfe</td>
<td>Clinical Operations Manager, Spinal Injury Unit</td>
<td>Royal Rehab</td>
</tr>
<tr>
<td>Sachin Shetty</td>
<td>Director – Spinal Injuries Unit</td>
<td>Prince of Wales Hospital</td>
</tr>
<tr>
<td>Melissa McCormick</td>
<td>Manager</td>
<td>Rural Spinal Cord Injury Service</td>
</tr>
<tr>
<td>Kylie Wicks</td>
<td>Clinical Services Manager</td>
<td>ParaQuad NSW and BrightSky Australia</td>
</tr>
<tr>
<td>Adrienne Epps</td>
<td>Senior Staff Specialist, Head of Department, Rehab2Kids</td>
<td>Sydney Children’s Hospital</td>
</tr>
<tr>
<td>Jessy Kaur</td>
<td>Head of Department &amp; Spinal Rehabilitation Specialist Spinal Cord Injury Service</td>
<td>Royal North Shore Hospital</td>
</tr>
<tr>
<td>Frances Monypenny</td>
<td>Network Manager, SSCIS</td>
<td>Agency for Clinical Innovation</td>
</tr>
<tr>
<td>Selina Rowe</td>
<td>Manager</td>
<td>Spinal Outreach Service</td>
</tr>
<tr>
<td>Sally Scarpinato</td>
<td>Acting Service Manager</td>
<td>Hunter Spinal Cord Injury Service</td>
</tr>
<tr>
<td>Jenny Parkin</td>
<td>Implementation Manager, CPDI</td>
<td>Agency for Clinical Innovation</td>
</tr>
</tbody>
</table>

### Project Team

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frances Monypenny</td>
<td>Network Manager, SSCIS</td>
<td>Agency for Clinical Innovation</td>
</tr>
<tr>
<td>Marina Davis</td>
<td>Project Officer</td>
<td>Agency for Clinical Innovation</td>
</tr>
<tr>
<td>Jennifer Parkin</td>
<td>Implementation Manager, CPDI</td>
<td>Agency for Clinical Innovation</td>
</tr>
<tr>
<td>Greg Masters</td>
<td>Director</td>
<td>Nexus Management Consulting</td>
</tr>
<tr>
<td>Jill Hardwick</td>
<td>Consultant</td>
<td>Nexus Management Consulting</td>
</tr>
<tr>
<td>Michelle Wheeler</td>
<td>Consultant</td>
<td>Nexus Management Consulting</td>
</tr>
</tbody>
</table>
Appendix 4: Workshop Participants

- Marsha Ben, Physiotherapist, Spinal Outreach Service, Royal Rehab
- Lisa Benad, Senior Occupational Therapist, Spinal Cord Injury Unit, Royal North Shore Hospital
- Beverley Berelowitz, Social Worker, Spinal Plastics Outpatient Clinic, Prince of Wales Hospital
- Antoinette Botman, Staff specialist. Head of Spinal Cord Injury and Spina Bifida services, Kids Rehab, The Children’s Hospital at Westmead
- Candice Care-Unger, Social Worker, Spinal Outreach Service, Royal Rehab
- Claire Chance, Spinal Cord Injury Unit, Prince of Wales Hospital
- Priya Chari, Staff Specialist, Spinal Cord Injury Unit, Royal North Shore Hospital
- Marina Davis, Project Officer, ACI
- Sophie Denis, Physiotherapist, Spinal Cord Injury Unit, Prince of Wales Hospital
- Annalisa Dezarnaulds, Senior Clinical Psychologist, Spinal Cord Injury Unit, Prince of Wales Hospital
- Bill Fisher, Senior Rehabilitation Engineer, Assistive Technology & Seating, NSLHD
- Sky Fosbrooke, Rehabilitation Physiotherapist, Brain Injury and Rehabilitation Program, Rehab2Kids, Sydney Children’s Hospital
- Gillian Garrett, Spinal Clinical Nurse Consultant, Spinal Cord Injury Unit, Royal Rehab
- Tracy Graham, Senior Coordinator, Lifetime Care Support Authority, iCare
- Jonathan Holt, A/Manager, Hunter Spinal Cord Injury Service
- Wendy Jannings, Spinal Injuries Clinical Nurse Consultant, Northern Sydney Home Nursing Service
- Kylie Jones, Regional Clinical Services Supervisor, ParaQuad NSW
- Jasbeer Kaur, A/ Department Head, Spinal Cord Injury Services, Royal North Shore Hospital
- Louise Kelly, Spinal Clinical Nurse Consultant, Royal North Shore Hospital, Deputy Chair, SSCIS
- Lucija Lavrencic, Spinal Plastics Clinical Nurse Consultant, Spinal Plastics Outpatient Clinic, Royal North Shore Hospital
- Stephen Lowndes, Chief Executive Officer, Royal Rehab
- Neil Mackinnon, Manager, Service Coordination, Lifetime Care Support Authority, iCare
- Melissa McCormick, Manager, Rural Spinal Cord Injury Service, Royal Rehab
- Frances Monypenny, Network Manager, State Spinal Cord Injury Service, ACI
- Lianne Nier, Staff Specialist, Spinal Cord Injury Unit, Royal North Shore Hospital
• Eva Pilowsky, Medical Advisor, Ministry of Health
• Michael Pollack, Senior Staff Specialist, Rehabilitation Medicine, Area Director, Rehabilitation Medicine, Hunter New England LHD
• Christine Rolfe, Clinical Operations Manager, Spinal Cord Injury Unit, Royal Rehab
• Selina Rowe, Manager, Spinal Outreach Service (SOS), Royal Rehab
• David Shakespeare, Physiotherapist, Hunter Spinal Cord Injury Service
• Sachin Shetty, Director Spinal Medicine, Prince of Wales Hospital
• Victoria Sim, Occupational Therapist, Spinal Cord Injury Unit, Prince of Wales Hospital
• Ann Thompson, Occupational Therapist, Royal Rehab
• Jodie Thompson, Clinical Nurse Consultant, Outpatient Rehabilitation, Spinal & Brain Injury, Kids Rehab, Westmead Children’s Hospital
• Gerard Weber, Director, SCI Rehab Unit, Royal Rehab
• Kylie Wicks, Clinical Services Manager, ParaQuad NSW
• Jayne Yeomans, Physiotherapist, Spinal Cord Injury Unit, Royal North Shore Hospital
• Rehab, Westmead Children’s Hospital
Appendix 5: Details of SCI Services

Prince of Wales Hospital (POWH)

The Spinal Injury Unit (SIU) at POWH is responsible for people with a spinal cord injury (traumatic or non-traumatic) who live in the southern area of Sydney (south of the harbour) and the southern part of NSW.

POWH SIU has 30 beds – 10 for acute patients and 20 for rehabilitation. Because POWH is not a trauma centre, accident cases are usually taken by ambulance to the nearest trauma centre (in SESLHD these are St Vincent’s Hospital and St George Hospital.) The patient usually receives surgery (including spinal surgery) at this hospital and then is transferred to the POWH SIU. According to the literature this transfer should occur within 24 hours of the injury occurring and surgery (reduction or decompression) should occur within 6 hours of the spinal cord injury. At POWH the patient may need to go to the ICU and is then moved to the acute ward of the SIU.

Once rehabilitation begins, the patient receives a range of services including:
- allied health: physiotherapy, occupational therapy, dietetics, psychology, social work
- nursing education
- multidisciplinary education
- hydrotherapy
- goal planning
- community programs including access visits, CHOICES apartment in Little Bay, NSW
- advanced wheelchair training
- vocational rehabilitation.

Staffing for the 30 beds can be seen in table A1.

<table>
<thead>
<tr>
<th>Staff Category</th>
<th>FTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td></td>
</tr>
<tr>
<td>• Director</td>
<td>0.7</td>
</tr>
<tr>
<td>• Staff specialist/VMO</td>
<td>2.5</td>
</tr>
<tr>
<td>• Registrar</td>
<td>2.5</td>
</tr>
<tr>
<td>• Residents/interns</td>
<td>1</td>
</tr>
<tr>
<td>Nursing (including management roles)</td>
<td>TBC</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>5 inpatient &amp; 2 outpatients</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>4</td>
</tr>
<tr>
<td>Social Workers</td>
<td>3</td>
</tr>
<tr>
<td>Psychologists</td>
<td>0.8</td>
</tr>
<tr>
<td>Speech Pathologists</td>
<td>-</td>
</tr>
<tr>
<td>Admin</td>
<td>TBC</td>
</tr>
<tr>
<td>Other please specify: Dietitian</td>
<td>1</td>
</tr>
</tbody>
</table>
Outpatient services provided by POWH can be seen in table A2 below:

### TABLE A2: OUTPATIENT SERVICES

<table>
<thead>
<tr>
<th>Name of clinic</th>
<th>Function of clinic (pressure injuries, bowel care, pain, seating service, general follow up, physiotherapy)</th>
<th>Frequency of clinic (weekly, fortnightly or monthly)</th>
<th>Number of SCI patients on average per clinic over the last year</th>
<th>Staffing of service/clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spinal Medical Clinic</td>
<td>General follow-up Pressure injury review</td>
<td>Weekly x 4 Fortnightly</td>
<td>4-5 / clinic 2-3 / clinic</td>
<td>Spinal Rehab Physician Multi-disciplinary medical, nursing, dietitian &amp; social worker</td>
</tr>
<tr>
<td>Spinal Plastic Care Clinic</td>
<td>Spasticity</td>
<td>Weekly</td>
<td>2-3 / week</td>
<td>Multi-disciplinary medical, occupational therapist, physiotherapist</td>
</tr>
<tr>
<td>Spasticity Clinic</td>
<td>Complex follow up</td>
<td>Fortnightly</td>
<td>2 / clinic</td>
<td>Medical, occupational therapist, physiotherapist</td>
</tr>
<tr>
<td>Multi-Disciplinary Clinic</td>
<td>Complex patient review</td>
<td>Fortnightly</td>
<td>2 / clinic</td>
<td>Medical</td>
</tr>
<tr>
<td>Spinal Liaison Psychiatry Clinic</td>
<td>Complex patient review</td>
<td>Fortnightly</td>
<td>2-3 / clinic</td>
<td>Medical</td>
</tr>
<tr>
<td>Spina Bifida Clinic</td>
<td>Complex patient review</td>
<td>Fortnightly</td>
<td>2-3 / clinic</td>
<td>Medical</td>
</tr>
<tr>
<td>Seating Clinic</td>
<td>Wheelchair review</td>
<td>Weekly</td>
<td></td>
<td>Occupational therapist</td>
</tr>
<tr>
<td>Spinal Hydrotherapy</td>
<td>Supportive therapy</td>
<td>Weekly</td>
<td></td>
<td>Physiotherapist</td>
</tr>
<tr>
<td>Spinal Physio</td>
<td>Outpatient Clinic</td>
<td>Twice weekly sessions x 10 week</td>
<td></td>
<td>Physiotherapist</td>
</tr>
</tbody>
</table>
Patients with spinal cord injury are referred to RNSH if they live north of the harbour or in the northern half of the State. People, who sustain their injury at a location north of the harbour but live in the south, may be sent to RNSH, as it is a trauma centre, and after surgery, they will be transferred to POWH.

There are 19 beds on the Spinal Cord Injury (SCI) unit at RNSH. A patient with a recently acquired spinal cord injury may go from the Emergency Department (ED) to surgery then the Intensive Care Unit (ICU), before transfer to the Spinal Cord Injury Unit. Sometimes a patient may go to the orthopaedic ward. Even though the staff from the Spinal Cord Injury unit – ward 7E – may in-reach to the ICU or another surgical ward, to provide initial advice and support to the treating team, they do not take over medical management of the patient until they are medically stable. While on the SCI ward they receive:

- Medical management, respiratory management including ventilatory support when required, minimization of secondary complications, pain management and psychosocial support and monitoring and management of spinal cord injury specific issues i.e. spasm, pain, autonomic dysreflexia (AD), genito-urinary system issues, gastro-intestinal system issues, pressure injuries, definitive assessment of neurological function
- Nursing care (personal hygiene, establishing bladder and bowel routine, education, monitoring of skin, sexuality counselling, monitoring of vital signs, carrying out medical treatment)
- Social Work - assisting patients with financial/funding information and applications (inc. Centrelink/ Enable NSW/ Housing NSW/ Lifetime Care Support/iCare/NDIS; providing psychosocial support and counselling to patient, family and friends; assisting with emergency accommodation/parking/meals; arranging and attending family conferences; emergency financial support; insurance/superannuation information and support; provision of medical certificate/letters for schools, courts, workplace, credit institutions etc.; legal information and support
- Psychological / neuropsychological assessment and support / counselling
- Occupational Therapy
- Physiotherapy
- Clinical Nursing Consultation to inpatients of other facilities – to provide education, support and advice for best practice spinal management.

The unit also accommodates readmissions who have complications associated with their spinal cord injury such as pressure injuries, gastro-intestinal problems, genito-urinary problems etc. including tetraplegic patients who have had a tendon transfer surgery to reconstruct hand and arm function.

Services include:
- early and ongoing rehabilitation for people with a new spinal injury - personal care retraining, including functional bed mobility and transfer training
- domestic activities of daily living retraining
- early access home visits and complex home modifications
- specialised spinal equipment prescription and applications through Enable NSW
- vocational assessment and retraining – In-Voc Occupational Therapy involvement
- upper limb therapy, splinting, spasticity management, contracture management
- provision of adaptive aids for personal care tasks and computer or phone access
- return to leisure interests
- day leave planning
- wheelchair skills training
- family meetings and goal planning
- cognitive assessment/screening, Westmead Post Traumatic Amnesia (WPTA) Scale (prognostic tool that predicts severity of concurrent brain injury)
- group therapy- morning tea group
- discharge planning for high functioning spinal cord injured patients (i.e. walking, no bladder/bowel involvement) to ventilator dependent tetraplegics that are completely dependent for all care.

In addition to these services it is important to note the following:
- The Spinal Cord Injury Services at RNSH are considered supra-LHD services, admitting people with a SCI who reside within and outside NSLHD.
- It is important to note that other clinical services that play an important role in the management of the co-morbidities present in people with a SCI, eg. Plastic surgery, colorectal, respiratory & urology, are not supra-LHD services, but may continue to support the individuals throughout their life, even though they may reside outside NSLHD.
- The Spinal Plastics Service is a supra-LHD specialised service managing severe pressure injuries in people with a SCI and Plastic Surgeons play an essential role in the surgical management of these complex pressure injuries.
- Plastic Surgeons also provide surgical management of complex pressure injury wounds in people with Spina Bifida (SB) as there are limited services for people with SB in NSW. However, these patients do not currently fulfil the admission criteria for spinal services at RNSH and are therefore admitted to the plastic surgery / burns ward when surgical management of their pressure injuries is required. They generally also require considerable input from the Spinal Plastics Service. The similar needs of people with SB and pressure injuries to those with SCI were highlighted in the development of the ACI SSCIS Model of Care for Prevention and Integrated Management of Pressure Injuries in People with SCI and SB launched on the 25 March 2014.

Staffing of the RNSH SCI unit can be seen in the following table A3
### TABLE A3 STAFFING OF SCI UNIT – WARD 7E AT RNSH

<table>
<thead>
<tr>
<th>Staff category</th>
<th>FTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td></td>
</tr>
<tr>
<td>• Director</td>
<td>0.5</td>
</tr>
<tr>
<td>• Staff specialists/VMOs</td>
<td>1.3 staff specialist &amp; 0.2 VMO</td>
</tr>
<tr>
<td>• Registrars</td>
<td>1</td>
</tr>
<tr>
<td>• Residents/Interns</td>
<td>1</td>
</tr>
<tr>
<td>Nursing (incl. management roles)</td>
<td>29.55</td>
</tr>
<tr>
<td>Occupational therapists</td>
<td>2.5</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>2.9</td>
</tr>
<tr>
<td>Social Workers</td>
<td>0.7</td>
</tr>
<tr>
<td>Psychologists</td>
<td>0.63</td>
</tr>
<tr>
<td>Speech Pathologists</td>
<td>-</td>
</tr>
<tr>
<td>Admin</td>
<td>1.5</td>
</tr>
<tr>
<td>Other please specify: Surgical Dressers</td>
<td>6.0</td>
</tr>
</tbody>
</table>

Outpatient services at RNSH for people with a spinal cord injury are given in table A4.
### TABLE A4 OUTPATIENT CLINICS AT RNSH FOR PEOPLE WITH A SPINAL CORD INJURY

<table>
<thead>
<tr>
<th>Name of clinic</th>
<th>Function of clinic (pressure injuries, bowel care, pain, seating service, general follow up, physiotherapy)</th>
<th>Frequency of clinic (weekly fortnightly or monthly)</th>
<th>Number of patients with a spinal cord injury on average per clinic per year</th>
<th>Staffing of service/clinic (in FTE)</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spinal Medical Clinic</td>
<td>General clinic for reviews from community referrals or post discharge reviews</td>
<td>4 clinics per week (Mon-Wed)</td>
<td>60</td>
<td>Within established medical FTE</td>
<td></td>
</tr>
<tr>
<td>Tetraplegic Hand Clinic</td>
<td>Assessment of hand / upper limb function</td>
<td>monthly</td>
<td>66</td>
<td>0.1 physio</td>
<td></td>
</tr>
<tr>
<td>Spinal Plastics</td>
<td>Multidisciplinary assessment and management of pressure injuries</td>
<td>weekly</td>
<td>91</td>
<td>Plastic Surgeon 1.0 CNC 0.3 Physician 0.5 OT 0.4 SW 0.2 Dietitian 0.2OT assistant 0.4 admin</td>
<td>Operating Theatre time</td>
</tr>
<tr>
<td>Spinal surgical clinic</td>
<td>Colorectal review</td>
<td>fortnightly</td>
<td>48</td>
<td>Within established surgical FTE</td>
<td>No OT time designated for spinal plastics at present</td>
</tr>
<tr>
<td>Sexuality / fertility clinic</td>
<td>Assessment and treatment of sexual and ejaculatory dysfunction</td>
<td>weekly</td>
<td>22</td>
<td>Within established CNC &amp; Medical FTE</td>
<td></td>
</tr>
<tr>
<td>Spinal CNC</td>
<td>Telephone based consultancy service for community clients with a hospital avoidance focus</td>
<td>Mon-Fri Ad-hoc</td>
<td>432</td>
<td>Within established CNC FTE</td>
<td></td>
</tr>
</tbody>
</table>
Royal Rehab (RR) Spinal Rehabilitation Unit

RR is a third schedule hospital independent from RNSH yet most of their patients go there for rehabilitation after their stay at RNSH. However, RR also accepts patients from elsewhere and sometimes there is a delay for patients who are ready for discharge at RNSH awaiting a bed at RR. Over the last seven years 82% of the patients at RR were from a SCI facility (predominantly from RNSH).

There are 20 rehab SIU beds at RR. While on the ward, patients receive the following services:
- Medical services: ongoing inpatient medical services provided by staff specialists and registrar.
  As Royal Rehab is a sub-acute healthcare facility after hours medical services are available on an on call basis
- Nursing services
- Physiotherapy
- Hydrotherapy is available as part of the physio program. Seating program attended by physiotherapy
- Occupational Therapy
- ASTRIS Lifecare- commode scripting clinic x2 month
- Social Work
- Support groups are inclusive of the social work program
- Clinical Psychology
- Recreation therapy: Community access programs with OT & recreation and leisure activities.
- dietician
- Compensable Case Coordinator: Liaison with LTCS and insurers where appropriate.
- In-Voc: Liaison with employers, vocational counselling, work experience, some return to work and or facilitation work experience and assistance to review employment options
- Pharmacy services: clinical pharmacy provided at Royal Rehab
- medical imaging: routine x-ray imaging can be done at Royal Rehab
- Pathology services: provided at Royal Rehab.
- Accessed from Royal North Shore Hospital: VUD, urology consults, spinal plastics consultation, fertility clinic, tetraplegic hand clinic, medical outpatient services, medical imaging
- Mental Health Liaison services are available and accessed as required
- Podiatry services are available & accessed as required- external service provider
- Dental services are available & accessed as required- external service provider
- Peer Support is available and provided by SCIA. Client education program is conducted in collaboration with SCIA
- Transport services are provided for external appointments.

Staffing of the RR SCI unit can be seen in the table A5.
<table>
<thead>
<tr>
<th>Staff category</th>
<th>FTE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical</strong></td>
<td></td>
</tr>
<tr>
<td>• Director</td>
<td>0.1 (admin)</td>
</tr>
<tr>
<td>• Staff specialists/VMOs</td>
<td>1.1 (clinical)</td>
</tr>
<tr>
<td>• Registrars</td>
<td>1.0</td>
</tr>
<tr>
<td>• Residents/Interns</td>
<td>0</td>
</tr>
<tr>
<td><strong>Nursing (including management roles)</strong></td>
<td></td>
</tr>
<tr>
<td>• COM-NUM</td>
<td>1.0</td>
</tr>
<tr>
<td>• CNC</td>
<td>1.0</td>
</tr>
<tr>
<td>• CNE</td>
<td>0.63</td>
</tr>
<tr>
<td>• Nurses</td>
<td>21.0</td>
</tr>
<tr>
<td><strong>Occupational Therapists</strong></td>
<td>4.0</td>
</tr>
<tr>
<td><strong>Physiotherapists who also seating compared with other facilities where this is undertaken by Occupational Therapists</strong></td>
<td>5.0</td>
</tr>
<tr>
<td><strong>Social Workers</strong></td>
<td>1.8</td>
</tr>
<tr>
<td><strong>Psychologists-Clinical</strong></td>
<td>1.5</td>
</tr>
<tr>
<td><strong>Speech Pathologists</strong></td>
<td>Sourced as required-is available</td>
</tr>
<tr>
<td><strong>Admin</strong></td>
<td>1.0</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Recreation Therapists</strong></td>
<td>1.5</td>
</tr>
<tr>
<td><strong>Dietician</strong></td>
<td>0.4</td>
</tr>
<tr>
<td><strong>Compensable Case Coordinator</strong></td>
<td>0.55</td>
</tr>
<tr>
<td><strong>In-Voc- Vocational Consultant (SOS)</strong></td>
<td>0.6</td>
</tr>
<tr>
<td><strong>Allied Health Assistants (Physio &amp; OT)</strong></td>
<td>2.0</td>
</tr>
<tr>
<td><strong>Neuropsychologist</strong></td>
<td>Sourced as required-is available</td>
</tr>
</tbody>
</table>
Outpatient services at RR for people with a spinal cord injury are provided in table A6.

**TABLE A6 OUTPATIENT CLINICS AT RR FOR PEOPLE WITH A SPINAL CORD INJURY**

<table>
<thead>
<tr>
<th>Name of clinic</th>
<th>Function of clinic (pressure injuries, bowel care, pain, seating service, general follow up, physiotherapy)</th>
<th>Frequency of clinic (weekly fortnightly or monthly)</th>
<th>Number of SCI patients on average per clinic over the last year</th>
<th>Staffing of service/clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatient Spinal Medical Clinic only</td>
<td>Medical review and ongoing staff specialist consultation</td>
<td>3-4 clinics held weekly</td>
<td>Average 10 appointments per week with up to 75% attendance of appointments 2015 - 325 appointments attended.</td>
<td>Clinics staffed by unit staff specialists-35% of time spent on outpatient work. No nursing or multidisciplinary clinics provided.</td>
</tr>
<tr>
<td>Sexuality Clinic Service can be accessed by Spinal clients</td>
<td>Assist clients with sexuality issues post injury.</td>
<td>1 day per month</td>
<td>TBC</td>
<td>Clinical Nurse Consultant</td>
</tr>
<tr>
<td>Return to Driving</td>
<td>Enables access to driving assessments, lessons and testing</td>
<td>Booking made for clients when relevant</td>
<td>TBC</td>
<td>TBC</td>
</tr>
</tbody>
</table>
The staffing of the SOS can be seen in table A7 and is for the combined services of SOS Metro and RSCIS as all clinicians are employed to work across both service streams. The Vocational Consultants are dedicated to the In-Voc program only, so are not available to rural clients.

### Table A7 Staffing of SOS and RSCIS

<table>
<thead>
<tr>
<th>Staff category</th>
<th>FTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical</td>
<td></td>
</tr>
<tr>
<td>• Staff specialist/VMO</td>
<td>0.6</td>
</tr>
<tr>
<td>• Registrar</td>
<td>1</td>
</tr>
<tr>
<td>Nursing (Clinical Nurse Specialists)</td>
<td>2.4</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>2.8</td>
</tr>
<tr>
<td>Physiotherapists</td>
<td>2.6</td>
</tr>
<tr>
<td>Social Workers</td>
<td>2.8</td>
</tr>
<tr>
<td>Psychologists</td>
<td>0 (but needed)</td>
</tr>
<tr>
<td>Speech Pathologists</td>
<td>0</td>
</tr>
<tr>
<td>Admin</td>
<td>1.4</td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>• Manager</td>
<td>1</td>
</tr>
<tr>
<td>• Rural Manager</td>
<td>1</td>
</tr>
<tr>
<td>• Dietitian</td>
<td>0 (but needed)</td>
</tr>
<tr>
<td>• Recreational Therapy</td>
<td>0 (needed)</td>
</tr>
<tr>
<td>In-Voc Consultant</td>
<td></td>
</tr>
<tr>
<td>Rural Spinal Cord Injury Coordinators – employed by local LHD’s</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>5*</td>
</tr>
</tbody>
</table>

### Referral Source

**Spinal Outreach Service (SOS) Metro:**

1. **SIUs** are the predominant referral source.

   SOS allocates a unit representative to cover and follow up on referrals from the SIUs. Each SIU will then contact that unit rep to discuss referrals and forward on necessary paper work. Some of the clients referred by the SIUs may not come directly to SOS, with some going via another non-spinal rehab facility or will received aged care based time limited therapy first. Whilst the inpatient spinal team may initially refer clients to SOS, it becomes the responsibility of SOS to monitor where these clients are up to in their stay at the other facility to ensure the final discharge is managed well and the client isn’t sent home without the appropriate supports.

2. **Non SIUs** – small in number – this referral source is not actively marketed too due to limited resources in SOS team to manage the referrals that may eventuate.

   The SOS Manager manages referrals from Non-SIUs to ensure appropriate linkages with spinal specialists have been made and the client meets the eligibility criteria.

3. **Paediatric transition**

   The paediatric hospitals (CHW and Sydney Children’s) liaise directly with the SOS Manager to flag which paediatric clients will be of transition age over the following 12 months. This case
load is small in number. These clients are discussed in terms of which service will be best for them to access based on existing supports, ongoing issues needing management and location of residence – the age of 18 is challenging to determine best service as adolescents are often at the usual point of life change at that age, considering work, study options which may also include a change in residence.

Rural Spinal Cord Injury Service (RSCIS):

1. Spinal Cord Injury Units (SIUs)
   Transitional clients are linked in similar format to the metropolitan model, however not all clients are directly referred to the rural coordinators for follow up when they return home. This is primarily related to the capacity of the coordinator to do so. Where issues are flagged for follow up, clients will be referred to the coordinator. If not, the client will be placed on the database and invited to the next clinic closest to them within their geographical area.

2. Locally based community referrals to rural coordinators
   These may come from community nurses, occupational therapists, physios, case managers, rehabilitation specialists, local hospitals or rehabilitation units or general practitioners.

3. Community referrals directly to Spinal Outreach
   These may come directly from community clinicians as previous entry. In these cases the clients are also linked to the rural spinal coordinators via Spinal Outreach.

4. Clinic clients
   Clients are invited via mail out to those whom have consented to be on centralized database- they are also flagged by local spinal coordinators, clinicians and rehab specialists. Clients are triaged according to need centrally- based on current health status and linkages and support to other clinicians.

In-Voc
Clients are referred to In-Voc via the inpatient teams usual internal referral processes. At present the service is trialling the Out-Voc service program whereby the vocational team receive referrals directly from the SOS metro clinicians for clients they are actively working with. We expect the referral sources to broaden once the service is officially setup and resourced in 2017.

DISCHARGE

Spinal Outreach Service (SOS) Metro
During the 12 months with SOS metro, the team will try to connect clients to local services (eg local physio for hydrotherapy) that can provide them with long term support. Often these services are already involved before SOS discharges clients. In addition to this, the team will provide clients with a list of key contacts that they may need in the longer term. This list usually includes ParaQuad as the contact for new issues. On occasions the team may actively refer clients to ParaQuad if a new issue emerges with clients at the time of SOS discharge that cannot be resolved within 4-6 weeks – examples of this would be a client deciding at the last minute they would like a specific piece of customized equipment which may take months to trial, script and be funded and delivered. However the waiting list for ParaQuad has increased significantly and their service prioritisation have changed in line with NDIS.
Nursing – would refer to community nursing services typically who are likely to be involved simultaneously with SOS.

OT – rare to refer on, and very occasionally refer to ParaQuad but they have reported a 6 month wait list so clients often stay with SOS to resolve issues, unless there is a community OT available. However they can have up to an 18 month wait list (dependant on area and clinical priority of client). If client has funds to access and can afford a Private OT then this option would be taken, but generally this is rare.

PT – always linked with ParaQuad and SCIA in terms of knowing how to contact them in the future for self-referral and support. Will link with Community PT, Private PT if funds allow, and local hospital outpatient department services, POWH Spinal Outpatients, POWH hydro and local exercise physiologists where available.

SW – rarely referred to ParaQuad due to long waiting list, but again let clients know they can self-refer in the future. They are usually set up with case managers/care services to provide ongoing support and advocacy. For clients under 65yrs they are referred to COPS; clients with mental health issues are referred to their GP for mental health plan and referral to psychology and some specific MH programs. Youth support services are utilised where appropriate, and clients that have transitioned from Paediatric services continue to be monitored by Trapeze until 24 years of age. Complex centre link matters get referred to Centrelink SW if available.

All of the above referral onwards pathways are changing significantly with changes we are experiencing with rollout of NDIS, so we are now navigating the options case-by-case.

RURAL CLIENTS

Rural clients are referred to local community clinicians and local specialists – where they are available. Where possible they are linked to their local rehabilitation specialists and referred to local pain clinics, urologists, neurologists etc. When needed they are referred back to Sydney for tertiary services, this can be logistically challenging for clients to attend.

Rural coordinators follow clinic clients up for up to 6 months post clinic, depending on the need of the client and the geographic accessibility. Community clients are followed up within a timeframe dependant on their clinical need.

In-Voc

In-Voc clients may be referred on to a variety of Disability Employment Services (DES) or private rehab providers, depending on their insurance/funding type. The In-Voc program and RR are not DES, and as such are limited in accessing government funding at certain points of a client’s return to work (RTW). For clients not RTW but instead pursuing retraining/study opportunities, they may be linked with tertiary/TAFE disability support officers to provide specific support.

For all NSW SOS service streams all of the above has been the historical practices however in the ever changing environment of the NDIS and compensable clients, how discharge and referral on is managed is now changing due to the funding changes occurring for clients. Referral pathways previously there are no longer available, with clients needing to have funds available in their NDIS plans to access other services.
Relationship of Spinal Outreach Service (SOS) to General Practitioner (GP)

SOS Metro:
The GP is notified via letter of introduction when SOS starts with a client known to them. They are supported as needed by the team, in particular by the SOS Registrar who can liaise between the GP and the Spinal Specialist. The GP’s are provided with a copy of the final SOS Discharge summary.

RSCIS:
RSCIC coordinators- would usually aim to introduce their service to the GP. They will send them a flyer related to their service and inform the GP that they are currently involved with their client. They will contact the GP throughout the episode as needed and will inform the GP when the client is being discharged.

RSCIS clinic clients: Clients are asked to see their GP and to obtain a referral (where they are able) to attend the RSCIS clinic. GPs are also contacted via letter to let them know that their client is being seen by the clinic (which provides them with an opportunity to flag any issues) - they are also often contacted by the SOS registrar prior to clinic. GPs receive a comprehensive medical/multidisciplinary letter following the RSCIS assessment of their client and are offered the opportunity to contact the service for further support if required. GPs will link back into the service for advice and support and often contact the service to assist them to access tertiary spinal services in Sydney for their clients.
Hunter Spinal Cord Injury Service (HSCIS)

HSCIS is a community based specialist service providing services and support for people with SCI living in the community within the Hunter New England Local Health District (HNELHD). HSCIS is a service for adults with a SCI and includes young people transitioning to adult services. Offices and clinic rooms are located in the Newcastle Community Health Centre 621 Hunter St Newcastle. HSCIS are funded and governed by the HNELHD.

HSCIS is a multidisciplinary team (see staffing profile below) which receives very generous support from the staff specialists within the Rehabilitation Medicine department of the John Hunter Hospital. Services include outpatient clinic appointments, home visits, outreach clinics, consultation services to local therapists, education to clinicians, care providers, clients and their families. In-reach services of a consultative nature are also provided to staff in hospitals within our LHD.

As service provision is not currently time limited, the scope of service ranges from assisting people to return to community following their initial care and rehab, maximising their potential and adjusting to loss, through to the experience of aging with a spinal cord injury … and all of those needs that arise in between.

A large portion of the service is utilised in the process of replacing and/or upgrading equipment as required.

### TABLE A8 STAFFING OF HSCIS

<table>
<thead>
<tr>
<th>Staff category</th>
<th>FTE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service Manager</td>
<td>0.6</td>
</tr>
<tr>
<td>Nursing</td>
<td>0.8</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>2.0</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>1.0</td>
</tr>
<tr>
<td>Social Workers</td>
<td>0.6</td>
</tr>
<tr>
<td>Psychologist</td>
<td>0.4</td>
</tr>
<tr>
<td>Rehabilitation Assistant</td>
<td>0.6</td>
</tr>
<tr>
<td>Compensable Case Manager</td>
<td>0.4</td>
</tr>
<tr>
<td>Admin</td>
<td>0.8</td>
</tr>
</tbody>
</table>

### TABLE A9 OUTPATIENT CLINICS AT HSCIS FOR PEOPLE WITH A SPINAL CORD INJURY

<table>
<thead>
<tr>
<th>Name of clinic</th>
<th>Function of clinic</th>
<th>Frequency of clinic</th>
<th>Number of patients with a SCI on average per clinic per year</th>
<th>Staff of service / clinic (in FTEs)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outpatient Spinal Medical Clinic located in HSCIS clinic rooms</td>
<td>Medical review with Staff Specialist from Rehabilitation Medicine John Hunter Hospital</td>
<td>2-3 clinics per month</td>
<td>Average 3 appointments per clinic, av. 85 clients per year</td>
<td>Rehab physician with registrar and Clinical Nurse Specialist</td>
</tr>
<tr>
<td>Pain Clinic</td>
<td>Multidisciplinary approach to helping</td>
<td>3 clinics per year</td>
<td>Average 3 appointments per</td>
<td>Rehab physician, Pain medical</td>
</tr>
<tr>
<td>Service Description</td>
<td>Clients &amp; Services</td>
<td>Frequency</td>
<td>Notes</td>
<td></td>
</tr>
<tr>
<td>---------------------</td>
<td>--------------------</td>
<td>-----------</td>
<td>-------</td>
<td></td>
</tr>
<tr>
<td>HSCIS Outreach Clinic</td>
<td>To offer Allied health and nursing review to clients in remote areas of HNELHD</td>
<td>3 clinics per year</td>
<td>Average 6-8 clients per clinic, 22 clients per year</td>
<td></td>
</tr>
<tr>
<td>Seating Clinic</td>
<td>Specialist Seating review to mitigate problems associated with pressure, posture and discomfort</td>
<td>2 clinics per year</td>
<td>Average 5 clients per clinic, 10 clients per year</td>
<td></td>
</tr>
</tbody>
</table>

Clients manage chronic pain associated with SCI.

Clinic, 9-10 clients per year

Specialist, HSCIS psychologist, HSCIS physiotherapist

HSCIS Clinical Nurse Specialist, Occupational therapist, Physiotherapist

AT&S specialist seating team, HSCIS Occupational Therapists, physiotherapist
Sydney Children’s Hospital (SCH)

TYPICAL PATIENT JOURNEY

**SCI trauma** – All patients are admitted through emergency department (ED), where they are stabilised and transferred to the Paediatric Intensive Care Unit (PICU). Consult to ward based therapists may occur prior to formal medical consult to Rehab Registrar & CNC (*red phase*). The need for stabilization surgery (usually neurosurgical) during this acute phase will determine when a rehabilitation referral is made but children are ‘flagged’ by the Trauma CNC to the Rehab CNC.

- Once a referral to Rehab has been received, patient is discussed at weekly huddle meeting (Monday morning) and weekly inpatient team meeting (Wednesday morning) re progress, patient goals and management plan decided (*orange phase*). Level of involvement by rehabilitation will vary in orange phase ie from advise about continence management, through to splinting and positioning options.
- Patient is type changed to sub-acute type once medically stable and identifiable rehabilitation goals are determined with the family (*green phase*).
- Patient generally transferred from PICU to Rehabilitation Ward (C2S). They may be an acute patient in a rehabilitation bed for a short period of time prior to sub-acute type change occurring. Rehab team continues to see patient at this stage with therapy intensity determined by patient status. Rehabilitation Enrolled Nurse (EN) supports the ward Registered Nurses (RN) in delivering daily cares and routines. Rehab Allied Health Assistants (AHA) assist with delivering rehabilitation & therapy program.
- Discharge planning. Set up at home / equipment / transport / care will determine timing of this, step down to day only rehabilitation is offered to the family.
- Outpatient Department (OPD) therapy by Rehab2Kids offered when child’s progress plateaus and transport is not an issue back and forth to Randwick, otherwise, work with PSOS to identify local services.
- May have an appointment to the Brain Injury Rehabilitation Program (BIRP) clinic with the discharging rehabilitation consultant prior to transferring to the Spinal Clinic. This is determined by appointments availability.
- Appointments are also made to the Neuro-Rehabilitation Physiotherapist, and Occupational Therapist in Spinal Clinic or Spina Bifida Clinic.
- Community liaison with the PSOS is key in identifying issues to be followed up with family in the medical clinic.
- Neuro-Rehabilitation CNC role covers Spinal Clinic.
- If patient is compensable liaison with Lifetime Care Support Scheme (LTCSS) or private case manager is organised.

**Non-traumatic SCI** eg. Transverse myelitis, spinal tumour (post-acute oncology treatment ie not generally while receiving regular chemotherapy)

- Follow similar pattern as trauma patients above but more likely to stay as “orange” patient for longer than the trauma patients under their primary team eg neurology or oncology. Rehabilitation therapists will generally stay involved through the ‘orange’ phase.
- Outpatient follow-up in BIRP or Spinal Clinics, depending on needs of the child.
SERVICES PROVIDED TO A CHILD WITH A SPINAL CORD INJURY

- Nursing (RN, CNC, EN)
- Physiotherapy
- Occupational Therapy
- Clinical Psychology
- Neuropsychology
- Speech Pathologist
- Social Work
- Child Life Therapy
- Allied Health Assistants
- Rehabilitation Physician
- Hospital School
- Orthotist
- Outreach clinic.

STAFFING

1 X Staff Specialist, 1 X CNC & 1 X Admin staff are in roles that specifically include SCI in the scope of their position. One of the current physiotherapists has an interest and experience in SCI so tends to coordinate therapy needs for children with SCI but the clinical load may be shared by other therapists. All therapy needs for children with SCI are provided as part of the Rehab2Kids neuro-rehabilitation staff-complement so a specific FTE is not known.

OUTPATIENTS

TABLE A8 OUTPATIENT CLINICS AT SCH FOR CHILDREN WITH A SPINAL CORD INJURY

<table>
<thead>
<tr>
<th>Name of service/clinic</th>
<th>Function of service/clinic</th>
<th>Frequency of service/clinic (weekly, fortnightly or monthly)</th>
<th>Number of SCI patients on average per clinic over the last year</th>
<th>Staffing of service/clinic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spinal Clinic</td>
<td>Multidisciplinary review</td>
<td>4 clinics / yr</td>
<td>4-6 patients</td>
<td>May Include the following team members, on a needs basis:</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Rehabilitation Physician</td>
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<tr>
<td></td>
<td></td>
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<td></td>
<td>• Rehabilitation Clinical Nurse Consultant</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>• Urologist</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>• Orthopaedic surgeon</td>
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<td></td>
<td></td>
<td></td>
<td>• Neurosurgeon</td>
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<td></td>
<td>• PSOS</td>
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<td></td>
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<td></td>
<td></td>
<td>• Rehab2Kids Physiotherapist</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>• Occupational Therapist</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>• Orthotist</td>
</tr>
</tbody>
</table>

RELATIONSHIP BETWEEN REHAB2KIDS AND GP

- Communication via clinic correspondence and letters
- GP follows up blood tests or scans/x-rays and manages complications / health issues that may arise
• Depending on complexity, a general Paediatrician may be involved to follow up issues in the community.
Children’s Hospital Westmead (CHW)

TYPICAL PATIENT JOURNEY

Traumatic SCI: Children are transferred to the CHW via the Neonatal Emergency Transport Service (NETS) or Careflight. They are assessed in the Emergency Department and then transferred to the paediatric intensive care unit (PICU) for stabilization with surgical or non-surgical interventions. Inpatient paediatric rehabilitation team consult within 72 hours following admission to hospital. The child at this time is usually still in the paediatric intensive care unit (PICU). The inpatient rehabilitation team collaborate with PICU ward staff regarding early management (“red phase”). If possible they will be present during first meeting with the family when diagnosis and prognosis are discussed. The inpatient team will become actively involved with the child with a traumatic spinal cord injury whilst they are still a patient in PICU, and uniquely will enter a shared care arrangement with the acute medical teams during this period (“orange phase”). This involvement can include interventions such as education to families; skin assessments; bladder and bowel assessment; regular physical assessment of joint ranges and muscle tone; casting/moulding of splints as required; some therapy including possible use of the tilt table or sitting out in wheelchair.

After discharge from PICU to the ward, there may be a continued period of shared care when the child remains under the primary care of the trauma team or other subspecialty surgical team. This shared care phase is usually needed if the child has been involved in a major trauma and there are multiple injuries still requiring some active medical intervention for example a repaired bowel perforation may require more general surgical team involvement and monitoring and directing re-feeding until this is stabilized. In other cases where there has not been major multi trauma, the Inpatient Rehabilitation Team will take over care within 24-48 hours of leaving PICU. Once the rehabilitation team has taken over care (“green phase”) the child is classified as a “sub-acute” admission type.

Acquired SCI (oncology/infectious/bleed etc.): the child will usually have been admitted via ED to a ward or PICU under the oncology/general paediatrics/neurology/neurosurgery team. The inpatient rehabilitation team will consult once diagnosis has been made and may be involved during a period of shared care, taking over care when the primary team is no longer driving the patient’s management (orange and green phases).

The child with spinal cord injury of either aetiology will remain in the ward most appropriate to their initial diagnosis e.g. neurology/orthopaedic/surgical ward. Currently, a specific rehabilitation inpatient ward is not available therefore are seen by the multidisciplinary inpatient rehab is a mobile team which will continue to treat all patients with a spinal cord injury wherever they are located in the hospital. The child will, in most circumstances, stay in the same ward for the duration of their admission, however there are times when it can be beneficial for the child to transfer to a ward with a different specialty focus such as an adolescent ward to allow increased peer socialization and encouragement of independence or alternatively Turner care by parent ward; which gives an opportunity for a parent and child to stay within the hospital and ‘step down’ in the daily nursing care provided. The parent and child are provided with a larger room to accommodate two full size beds, equipment required and an accessible en-suite. Nurses in this space are available during business hours to provide assistance as required, however the daily care burden
is largely shifted to the parent and they are able to trial what it may be like to care for their child with a spinal cord injury at home.

When a patient is “orange” multidisciplinary inpatient team get involved (rehab physician on call, inpatient CNC, PT, OT, SP, SW, clinical psychology, neuropsychology, child life therapist, school) as required. Daily ward rounds by CNC and rehabilitation fellow and resident.

The inpatient rehab team meets regularly each week. There are twice weekly inpatient multidisciplinary meetings. The first of these, termed ‘Monday Huddle’ with the aim of quickly reviewing each patient’s weekly goals and identifying any issues that may impede these being achieved. The second meeting is the weekly case conference. This second meeting is an in-depth review of each patient’s functional status, achieved goals and discharge planning.

Regular family meetings (x1/month) are also held to discuss progress, ongoing goals and to establish discharge goals. Families are encouraged to set the agenda for these meetings. Adolescents are encouraged to join the meeting and participate as they feel comfortable.

Referral to the Northcott Paediatric Spinal Outreach Service (PSOS) occurs during the admission. Timing of referral is dependent on the individual patient and the inpatient team makes an assessment regarding when is the appropriate time to introduce this team to the child and family.

Once referred the PSOS team can assist the inpatient team with different community interventions such as home and school visits. In the metropolitan area they would accompany the inpatient team therapist however as they are a statewide service, for rural patients they would conduct these visits on behalf of the inpatient team. They can also be a resource in early planning for later community participation for the child post discharge; assisting with sourcing interim equipment for discharge prior to patient’s own equipment being available. In the final weeks leading up to discharge joint sessions with the inpatient team therapist are organised with the goal of getting to know the child and family and assisting them with a smoother transition into the community.

Once a child’s inpatient goals have been achieved, the child is discharged home. Other frequent factors that will influence timing of discharge for a child from their inpatient stay are typically housing issues and social issues that may involve Family and Community Services. Both of these are the main factors which may cause a delay in discharge for a child for many months.

At the time of discharge, the rehabilitation physician that has discharged the patient will continue on as the child’s outpatient rehabilitation physician for the duration of the follow-up in the spinal cord injury and disease service.

The child will have a community therapy team who in collaboration with the PSOS team take over allied health roles (PT, OT, SW, nursing). Kids Rehab has a specialist outpatient CNC who coordinates outpatient follow-up with rehab and other surgical/medical specialties. This role is the key point of contact at the hospital for the child and family but also other agencies such as Lifetime Care and Support, private case-managers, ENABLE NSW, schools, community continence nurses, Trapeze and other adult spinal units.
PSOS therapists can either be hands on therapists (metro) or if child lives in a rural/remote area they support local therapist where needed but can do outreach including hands-on interventions i.e. school visits and assessments for home modifications or equipment.

The outpatient Spinal Cord Injury and Disease (SCID) Service remains involved until the child turns 18 or when the child leaves school at which point they’re transitioned to adult SCI service and the Spinal Outreach Service (SOS). If the child had involvement with many other surgical or medical specialists in hospital they also link in with Trapeze transition service for coordinated transition.

Children do not usually require readmission for rehabilitation after discharge from CHW. However, the SCID team will get involved on consultative basis when child is readmitted for spinal/orthopaedic/urologic/other surgery with input from ward PT/OT/SW as required.

**RANGE OF SERVICES**

- Paediatric rehab physician - medical consultancy and management include spasticity management i.e. Botulinum toxin injections
- Clinical Nurse Consultant – consultancy and support of ward nursing staff regarding bladder/bowel management, wound/skin management, coordination of overall cares and (family and ward) education, leadership of the multidisciplinary team
- Physiotherapist – mobility (bed, transfers, gait), lower limb function, equipment provision, land and water based
- Occupational Therapist – upper limb function including self-care and other activities of daily living, leisure, equipment provision, home modification, cognition screening
- Speech Pathologist – high C-spine or dual diagnosis with traumatic brain injury (TBI) (feeding and communication needs)
- Social Worker – family emotional and practical supports
- Clinical psychology – emotional wellbeing of child including behaviour management
- Neuropsychology – cognitive assessment and management in TBI
- Child life therapist – involved in resuming developmentally appropriate leisure; diversion and activities that support overcoming challenging interventions (scans/cannula)
- Allied health assistants – implementation of individual exercise programs, assisting the therapist in sessions, assisting patient practice function tasks on a daily basis.
- School liaison – hospital school attendance or school at bedside; further school liaison in regards to census school reintegration usually by case manager and CNC
- Orthotics – provision via hospital orthotics dept.
- Subspecialty reviews at CHW – urology, spinal orthopaedic, general orthopaedic, endocrine, pain service, respiratory/sleep service
- Subspecialty reviews outside CHW – access to adult specialist seating services at POW/AT&S (currently pilot program), consultations at RNSH tetraplegic hand clinic (nerve/tendon transfers), access to adult diaphragmatic pacing service POW.
### STAFFING

#### TABLE A9 STAFFING OF SCI UNIT AT CHW

<table>
<thead>
<tr>
<th>Staff category</th>
<th>FTE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Medical</strong></td>
<td>1 head of Spinal Cord Injury and Spina Bifida service</td>
</tr>
<tr>
<td>• Director</td>
<td>5 AMOs each 0.1 FTE (total 0.6 FTE staff specialist)</td>
</tr>
<tr>
<td>• Staff specialists/VMOs</td>
<td>2 rehab fellows/registrars (0.4 FTE)</td>
</tr>
<tr>
<td>• Registrars</td>
<td>1 shared resident with neurosurgery dept. (0.1 FTE)</td>
</tr>
<tr>
<td>• Residents/Interns</td>
<td></td>
</tr>
<tr>
<td><strong>Nursing (including management roles)</strong></td>
<td>1 inpatient CNC (SCI and TBI/other 1.0 FTE)</td>
</tr>
<tr>
<td></td>
<td>1 outpatient CNC (0.4 FTE)</td>
</tr>
<tr>
<td><strong>Occupational therapists</strong></td>
<td>Inpatient team (2 FTE)</td>
</tr>
<tr>
<td><strong>Physiotherapists</strong></td>
<td>Inpatient team (2.6 FTE)</td>
</tr>
<tr>
<td><strong>Social workers</strong></td>
<td>Inpatient team (1 FTE)</td>
</tr>
<tr>
<td><strong>Psychologists</strong></td>
<td>1 clinical psychology (all inpatients and some outpatients), access to neuropsychology</td>
</tr>
<tr>
<td><strong>Speech pathologists</strong></td>
<td>Inpatient team (1FTE)</td>
</tr>
<tr>
<td><strong>Admin</strong></td>
<td>Secretary (SB and SCID service, 0.8 FTE)</td>
</tr>
<tr>
<td><strong>Other</strong></td>
<td>AMOs/CNCs/Clinical Psychology and admin staff are employed directly under Kids Rehab.</td>
</tr>
</tbody>
</table>

The remaining staff the inpatient rehab team work in a matrix type management structure. Within the clinical inpatient team the CNC leads and coordinated the team however operationally there are multiple line management pathways for therapy staff. These staff also manage other caseloads outside of rehabilitation which makes it impossible to state FTEs for each category. In this flexible model, each child with a spinal cord injury does receive the level of therapy intensity care they require however during times of increased workflow this may have a wider impact on the other acute caseloads and other staff needing to backfill to ensure acute caseloads are covered.

### OUTPATIENTS

#### TABLE A10 OUTPATIENT CLINICS AT CHW FOR CHILDREN WITH A SPINAL CORD INJURY

<table>
<thead>
<tr>
<th>Name of service/clinic</th>
<th>Function of service/clinic</th>
<th>Frequency of clinic (daily, weekly, fortnightly or monthly)</th>
<th>Number of SCI patients on average per clinic over the last year</th>
<th>Staffing of service/clinic (in FTE)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kids Rehab “Day Rehab Program” (DRP – pilot program)</td>
<td>Step down program after intensive inpatient therapy; patient discharged from ward but resides at home if metro or in Turner ward (care by parents) if travel too far incl. metro; intensive outpatient therapy with option to rest and attend hospital school;</td>
<td>As required/ tolerated: Min 3 hours/day Min 2-3 days/week Min 3 allied health Weekly medical review</td>
<td>Currently in pilot phase, 1 SCI patient participated so far</td>
<td>Currently use of existing inpatient and outpatient resources (allied health/nursing) Remain under AMO as per inpatient phase Coordinated by DRP coordinator/neuro-rehab manager Nil dedicated space</td>
</tr>
<tr>
<td>Name of service/clinic</td>
<td>Function of service/clinic</td>
<td>Frequency of clinic (daily, weekly, fortnightly or monthly)</td>
<td>Number of SCI patients on average per clinic over the last year</td>
<td>Staffing of service/clinic (in FTE)</td>
</tr>
<tr>
<td>------------------------</td>
<td>-----------------------------</td>
<td>-------------------------------------------------------------</td>
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<td>---------------------------------</td>
</tr>
<tr>
<td>Kids Rehab outpatient service</td>
<td>Outpatient medical follow-up and nursing consultancy CNC coordinates care/first point of call for complications Limited access to Kids Rehab clinical or neuropsychology services Multidisciplinary review with surgical subspecialist (urology/spinal/ortho/pain) where needed</td>
<td>No max duration</td>
<td>4 AMO clinic spots every week available</td>
<td>1 Head of service (A Botman) full time but 0.2 FTE involved in SCID outpts 1 CNC (0.4 FTE) 5 AMOs (as above)</td>
</tr>
</tbody>
</table>
| Paediatric Spinal Outreach Service (PSOS) | Statewide mobile paediatric specialist SCI service Funded by Ministry of Health Located at Northcott Disability Services Supports inpatient team in final inpatient phase Supports community therapists in delivering specialist services Education (family/school/allied health) and statewide SCI specialist service and resource development Research The original MOC and function of the PSOS was:  
- work closely with treating doctor and acute care hospital team to facilitate smooth transition  
- assist with home / school mods and equipment recommendations  
- provision of education services by website technology to prevent complications  
- case management and long-term care  
- consultative services to health professionals (rural/regional)  
- liaison with insurance companies  
- school education re integration  
- assistance with transition to adult services  
- undertake research in area of paed/adolescent spinal cord injury and related clinical conditions  
- Their current MOC and the MOU between Ministry of Health, SCHN and Northcott is under review | 1 clinician attends SCID clinic review & represents/reports back to others in team | 1-2 | 1 team lead (? FTE, line management, nil hands-on duties) 2 part time PT (1.2 FTE) 2 part time OT (1.6 FTE) 1 part time SW (1.0 FTE) 1 part time CNC (0.6 FTE) |
RELATIONSHIP BETWEEN KIDS REHAB AND GP

GP is the primary practitioner after discharge from hospital. GP receives copies of all correspondence i.e. hospital discharge summary and clinic reports. Kids Rehab phone GPs where needed to personally educate them on management of complications when they arise; to educate them in the specialist management.

For children with complex additional health needs (ventilated tetras, additional pathology) Kids Rehab recommends they have a local general paediatrician. We would have an agreement that the SCI specialist needs including the bladder/bowel management (and changes to this or management of complications) be left to the rehab specialist or be done in collaboration. The paediatrician’s role would be monitoring of the child’s general wellbeing and development.
Appendix 6: Consumer Survey: Full Analysis

1. OVERVIEW

Forty seven consumers who had used spinal cord injury services told us about their experiences via an online survey. They provided feedback on many aspects of the care and support they received, in various settings, and gave us with their overall views and ideas for service improvements.

The survey used an approach adapted from the Picker Principles of Person-Centered Care, on the advice of the Project Steering Committee. We canvassed six of the eight principles:

- coordination and integration of care
- involvement of family and friends
- respect for values, preferences and expressed needs
- information communication and education
- emotional support
- transition and continuity.

There were many aspects of care that people with spinal cord injury felt positive about. Staff and their skills and commitment were viewed as a major strength of the services. Service gaps were identified by consumers as well as issues with the environments in which care is provided and the need for improvements in philosophy of services, staff training and communication. Access to services is inequitable with particular unmet needs for rural consumers.

The following provides reporting against the major components of the survey:

- a profile of respondents—age, sex, place of residence, living arrangements, service contacts
- support from the service system and others—paid care, insurance schemes
- experiences through the major phases and aspects of care and support
- consumers sum-up of the best and worst of care, suggestions for service improvements.

2. PROFILE OF THE RESPONDENTS

In total there were 47 responses of which 14 were carers or family members of people with spinal cord injury.

2.1 Nature of contact with SCI services

Most consumers were currently receiving care from community-based services (30%) or through clinics, specialist visits or the outreach program (23%). There were no current inpatients of specialist spinal cord injury units.

This reflects two things: first, the consumer networks leading engagement in the survey mostly work with people as they transition and after they are in the community; and second, people in the

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72 Picker Institute Principles of Person-Centered Care at http://pickerinstitute.org/about/picker-principles/
acute phases of their treatment are generally focused on their care and recovery while in hospital, and declined participation.

This pattern of respondents may therefore be reflecting on past practices in hospital, not current day experiences.

**FIGURE A1: CURRENT CONTACT WITH SPINAL CORD INJURY SERVICES**

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current inpatient in hospital</td>
<td>0.0%</td>
</tr>
<tr>
<td>Current patient in rehabilitation - inpatient or outpatient program</td>
<td>10.7%</td>
</tr>
<tr>
<td>Currently receiving care through clinics, specialist visits, outreach program</td>
<td>23.4%</td>
</tr>
<tr>
<td>Currently receiving care from community-based services</td>
<td>29.8%</td>
</tr>
<tr>
<td>Carer/Family member</td>
<td>29.8%</td>
</tr>
<tr>
<td>Other, including no current contact</td>
<td>6.4%</td>
</tr>
</tbody>
</table>

**2.2 Age and sex of respondents**

Nearly equal numbers of men (53%) and women (47%) responded to the survey. Their age distribution is older now than at time of injury, though there is a good representation of children and young people (15) at time of injury.

**FIGURE A2: AGE AT TIME OF SCI AND NOW**

- **At time of acquiring a spinal cord injury**
  - 0-9 years: 8.5%
  - 10-19 years: 23.4%
  - 20-29 years: 25.5%
  - 30-39 years: 16%
  - 40-65 years: 6.4%
  - 65+ years: 9%

- **Age now**
  - 0-9 years: 0%
  - 10-19 years: 9%
  - 20-29 years: 16%
  - 30-39 years: 9%
  - 40-65 years: 60%
  - 65+ years: 0.0%
  - 5%
2.3 Region of residence and living arrangements

Respondents to the survey reflected a good spread between metropolitan (39%), regional NSW (48%) and rural NSW (14%). They are mostly living at home with family and friends (72%).

FIGURE A3: LIVING ARRANGEMENTS OF PEOPLE WITH SCI

2.4 Other characteristics

Nearly all respondents had English as a first language (98%).

3. SUPPORT FROM THE SERVICE SYSTEM AND OTHERS

The majority of respondents (57%) was not currently receiving support from the major insurance schemes and ADHC schemes.

FIGURE A4: ACCESS TO INSURANCE SCHEMES AND SUPPORT PACKAGES

Care by family and friends (unpaid) was provided to 45% of people, some people used a combination of both paid and unpaid care, however quite a high proportion (20%) reported no carer support.
There was a substantial spread of contact and support from the identified Spinal Care Injury Services, many having contact with dedicated spinal outreach services and outpatient services (54.3%). Support from other community-based services was substantial (17.4%) had contact with either public health or non-government community-based services. 3 people were managed by interstate spinal acute services, 2 by district level hospitals.

FIGURE A6: SERVICES PERSONS HAS EVER HAD CONTACT WITH

<table>
<thead>
<tr>
<th>Service</th>
<th>N=125 responses for 46 unique responders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prince of Wales Hospital (former Prince Henry)</td>
<td>32.6%</td>
</tr>
<tr>
<td>Royal North Shore Hospital</td>
<td>54.3%</td>
</tr>
<tr>
<td>Children’s Hospital at Westmead</td>
<td>8.7%</td>
</tr>
<tr>
<td>Sydney Children’s Hospital</td>
<td>0.0%</td>
</tr>
<tr>
<td>Royal Rehab or Moorong Spinal Unit</td>
<td>37.0%</td>
</tr>
<tr>
<td>Hunter New England Spinal Cord Injury Service</td>
<td>8.7%</td>
</tr>
<tr>
<td>Rural Spinal Cord Injury Service (RSCIS)</td>
<td>6.5%</td>
</tr>
<tr>
<td>Spinal Outreach Service</td>
<td>30.4%</td>
</tr>
<tr>
<td>Paediatric outreach service</td>
<td>2.2%</td>
</tr>
<tr>
<td>Outpatient services attached to one of the specialist spinal units</td>
<td>15.2%</td>
</tr>
<tr>
<td>Other hospital</td>
<td>15.2%</td>
</tr>
<tr>
<td>Other health clinic</td>
<td>6.5%</td>
</tr>
<tr>
<td>Community-based service – public health</td>
<td>8.7%</td>
</tr>
<tr>
<td>Community-based service – non-government</td>
<td>8.7%</td>
</tr>
<tr>
<td>Other spinal services in other States/Territories</td>
<td>6.5%</td>
</tr>
</tbody>
</table>
4. EXPERIENCES THROUGH THE MAJOR PHASES AND ASPECTS OF CARE AND SUPPORT

We asked respondents about their experiences of care and support in the health system and services provided by the State Spinal Cord Injury Service. They were asked to consider 25 statements about various aspects of the care they received and to rate them on a scale, ‘strongly disagree’ to ‘strongly agree’.

The statements were organised around the major phases of care—acute care, rehabilitation, transition to living in the community. They do not cover aspects of lifetime care and support in the community, but focus on people’s experiences with health services which form part of the SCI network.

The domains of the Picker Principles of Person-Centered Care covered are:
- coordination and integration of care
- involvement of family and friends
- respect for values, preferences and expressed needs
- information communication and education
- emotional support
- transition and continuity.

Domains on access to care (first 24/48 hours of care) and physical environment were not canvassed, as considered to be out of project scope. However, the issues of physical facilities were often raised by consumers during face-to-face interviews. The issue of how people with acute SCI first access dedicated spinal injury units was also an issue raised by clinicians during consultations, but consumers considered this aspect was largely out of their hands and thinking at the time of injury.

The following provides a broad selection of results, featuring responses to most of the 25 statements in the seven aspects of care.

4.1 Overall experience

The full range of responses to the seven areas of interest—25 questions—shows that for many statements there was a spread of positive and negative responses.

The highest favourable responses (agree, strongly agree) were for coordination of care while in hospital and the setting of goals while in rehabilitation. For most respondents the care and support while in hospital was well coordinated and led by a nominated clinician. Involvement of family and friends to the degree that the primary consumer wanted was also rated very favourably.

The highest proportion of unfavourable responses (disagree, strongly disagree) was for questions about transition to living in the community. 51% felt they were inadequately prepared for living in the community.
There was high use of the ‘neither agree nor disagree’, indicating a lack of resonance with some of the concepts derived from the Picker Principles of Patient Care (between 11.7% and 27.5% responses across all questions).

### 4.2 Reporting on selected measures

Respondents were asked questions about their experiences through the major phases of care and support following a spinal cord injury. These phases are:
- while in hospital
- while in rehabilitation
- transition to living in the community.

**Phases of care: Consumer-led? Well coordinated? Worked for me?**

For most respondents the care and support while in hospital was well coordinated and led by a nominated clinician. Over 60% experienced a nominated clinician for coordinating care and over 50% felt care within the hospital was well coordinated, while 33% considered that care from different clinicians and parts of the hospital was **not** well coordinated.

While in rehabilitation, 62% of clients were involved in goal-setting, however the belief that goals were achieved dropped to 54% of respondents.

Transition to living in the community was the aspect of care with the highest proportions of negative experiences. 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.

<table>
<thead>
<tr>
<th>ASPECT OF CARE &amp; SUPPORT</th>
<th>QUESTION</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>While in hospital</strong></td>
<td>A specific health professional was nominated to lead and coordinate my care and treatment.</td>
<td>Positive: 62% Neutral: 24% Negative: 14%</td>
</tr>
<tr>
<td></td>
<td>The care I received from different clinicians and parts of the hospital was well coordinated.</td>
<td>Positive: 54% Neutral: 13% Negative: 33%</td>
</tr>
<tr>
<td><strong>While in rehabilitation</strong></td>
<td>My goals for rehabilitation were made with me.</td>
<td>Positive: 62% Neutral: 16% Negative: 22%</td>
</tr>
<tr>
<td></td>
<td>My goals for rehabilitation were achieved or mostly achieved before I was discharged.</td>
<td>Positive: 54% Neutral: 19% Negative: 27%</td>
</tr>
<tr>
<td><strong>Transition to living in the community</strong></td>
<td>A specific worker was nominated to lead and coordinate my transition to the community.</td>
<td>Positive: 37% Neutral: 19% Negative: 47%</td>
</tr>
<tr>
<td></td>
<td>I was followed-up after discharge from hospital/rehab to ensure I had the services I needed.</td>
<td>Positive: 41% Neutral: 18% Negative: 41%</td>
</tr>
<tr>
<td></td>
<td>I felt my hospital care prepared me for living in the community.</td>
<td>Positive: 26% Neutral: 23% Negative: 51%</td>
</tr>
</tbody>
</table>
**Communication with consumer and family – adequate? In different aspects?**

Effective communication and information throughout all phases of care is essential to safe high quality care. Involvement of family and friends is considered a cornerstone of successful transition to community living for most people who have experienced the serious and enduring effects of spinal cord injury.

Over half of respondents rated themselves as adequately informed about their condition and treatment while in care. Again it is the processes that surround leaving hospital that are highlighted for improvement—48% reported receiving inadequate information about their future capacity for ADL and 35% did not gain sufficient or expected information on what to expect about the process of transition.

Appropriate involvement of family and friends was rated very highly—73% of respondents consider the level of involvement appropriate.

<table>
<thead>
<tr>
<th>ASPECT OF CARE AND SUPPORT</th>
<th>QUESTION</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information communication and education</td>
<td>Overall, I was adequately informed about my condition, care and treatment.</td>
<td><img src="#" alt="Responses" /></td>
</tr>
<tr>
<td></td>
<td>I was told what to expect in the process of transition from hospital to home.</td>
<td><img src="#" alt="Responses" /></td>
</tr>
<tr>
<td></td>
<td>I was given adequate information about my future capacity for activities of daily living.</td>
<td><img src="#" alt="Responses" /></td>
</tr>
<tr>
<td>Involvement of family and friends</td>
<td>My family and friends were involved in my care and treatment, to the extent that I wanted.</td>
<td><img src="#" alt="Responses" /></td>
</tr>
<tr>
<td></td>
<td>Clinicians and caregivers recognised the role of my family and friends in supporting me.</td>
<td><img src="#" alt="Responses" /></td>
</tr>
</tbody>
</table>

**Respect and dignity – support for emotional needs**

Respondents reported largely positive experiences being treated with respect and being involved in decision-making. Emotional support is an area for improvement with high proportions (33-35%) reporting unfavourable responses for this aspect of care and support.

<table>
<thead>
<tr>
<th>ASPECT OF CARE AND SUPPORT</th>
<th>QUESTION</th>
<th>RESPONSES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect for values, beliefs and expressed needs</td>
<td>I was involved in decisions about my care and treatment.</td>
<td><img src="#" alt="Responses" /></td>
</tr>
</tbody>
</table>
I was treated with respect and dignity. | 68% 7% 25%
---|---
Clinicians and caregivers provided emotional support to me. | 41% 28% 31%
Clinicians and caregivers provided emotional support to my family/carer. | 35% 30% 35%
Health professionals involved in my care discussed with me any fears or anxieties I had about my condition and my treatment. | 39% 28% 33%

5. CONSUMERS SUM IT UP

The online survey provided for free form responses to a series of questions on people’s overall experiences of care and their priorities for service improvements.

5.1 Best and worst experiences in care

Respondents were asked to identify the best experience when receiving care or support. By far the majority of responses identified individual clinicians or professional groups such as physiotherapists and the support from community-based organisations SCIA and ParaQuad.

Support, kindness, professionalism were cited as behaviours most admired. The opportunity to engage in sports during rehabilitation was welcome.

Less positive experiences focused on poor communication between staff and services and lack of involvement of person in small decisions which affected their well being and immediate experiences.

A few small changes to hospital life could make a world of difference for patients, the simplest and most effective fix would be more ways to spend time with each other and have a laugh. e.g. A BBQ outside for Friday night BBQ’s (this was suggested many times).

Person-centered care as the driving philosophy was emphasised:

Due to the time of the injury and my age there were very little educational and/or vocational services that were accessible, so there was no plan or support for me to continue my education if I wanted to when I was discharged from hospital.

Many of the identified negatives were repeated as suggestions for improvement:
• better understanding of needs
• improved communication and decisions around medication management
• better planning for discharge
• improvements in the physical environment and features that enforce respect and dignity as an adult.
…privacy and dignity is critical in such a life changing event. So having to share a room with 3 other people when coming to terms with things like being hoisted with your bum hanging bare out the back of a sling is just mortifying. All should have individual rooms. Also should sit down with each on arrival in rehab and explain how entire process will work from beginning to discharge.

5.2 Suggestions for service improvements

Service improvements related to a broad range of issues summarised in table A7 below. The main messages relate to:
- improving support while living in the community post hospital care
- integration of hospital and community services and in particular sharing knowledge between staff
- meeting the needs of rural consumers
- training staff in person-centered care approaches
- creating a homelike environment in hospital focused on optimizing independence.

<table>
<thead>
<tr>
<th>TABLE A7: SUGGESTIONS FOR SERVICE IMPROVEMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>SUGGESTIONS</td>
</tr>
<tr>
<td>Improved support</td>
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<tr>
<td>living in the community</td>
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<tr>
<td>Integration of</td>
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<td>hospital and community</td>
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<td>services</td>
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<td></td>
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<tr>
<td>Better meet the</td>
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<tr>
<td>needs of rural</td>
</tr>
</tbody>
</table>

State Spinal Cord Injury Service (SSCIS) Spinal Cord Injury Model of Care Diagnostic Report 157
<table>
<thead>
<tr>
<th>SUGGESTIONS</th>
<th>SUMMARY</th>
<th>SUPPORTING DATA</th>
</tr>
</thead>
<tbody>
<tr>
<td>consumers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- outreach services</td>
<td>More help/support/advice to enable local health professionals be able to work with people with SCI where they live and not have to wait for the next specialist clinic in their area. I can’t travel to Sydney for help.</td>
<td></td>
</tr>
<tr>
<td>- increase knowledge of hospital units about service availability in the regions</td>
<td>Ability to access services in Brisbane, which is closer, without cross border funding brick walls.</td>
<td></td>
</tr>
<tr>
<td>- I had a few medical issues and me and my family were apart for 9 months as we had nowhere to live while receiving medical treatment.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Training for staff in person-centered care</td>
<td>Communication between staff in various wards about movements</td>
<td>Staff (need to) listen to patients’ carers as the carer knows only too well how the patient is faring when it comes to pressure spots, infections/fevers and basic needs.</td>
</tr>
<tr>
<td>- specific training in respect and dignity for adults</td>
<td>Reminding surgical dressers to dry patients properly after a shower and train them to check the patient’s skin. When patients are scheduled for blood tests, x-rays, imaging etc then the they should be informed about it and when they would be scheduled before the porter or the pathology nurse arrives.</td>
<td></td>
</tr>
<tr>
<td>- listening to carers as they have unique understandings of person</td>
<td>Telling me what I needed to do less than a couple of weeks after my accident was too much to take on board, I think they need to educate themselves more fully on what sort of career you have before coming out and handing the person a list of jobs that could be available.</td>
<td></td>
</tr>
<tr>
<td>- timing of interventions (psych and voc-ed) led by person</td>
<td>At P.O.W there were two wheelchair bound ambassadors for re-hab. They are amazing, because they understand where S.C.I’s are coming from and what is going through your mind the help of just a fall back person is great. They were there for my wife also and are still there to speak to her or myself about any troubles or worries we may have.</td>
<td></td>
</tr>
<tr>
<td>- more training for GPS in spinal care and issues</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- make good use of peer workers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Create a homelike environment in hospital</td>
<td>Improve food quality as person may need to stay up to 6 months</td>
<td>The food supplied in a long term rehab ward is terrible. It is ok for three days after having your tonsils out but not when the ward becomes your home.</td>
</tr>
<tr>
<td>- increase opportunities to socialise with others in same situation</td>
<td>Considering a minimum of six months spent there should be more like a home than a hospital environment. Single rooms. Less like a clinical environment more like an environment conducive to emotional and psychological healing and well being</td>
<td></td>
</tr>
</tbody>
</table>
REFERENCES


The Australian Spinal Cord Injury Register (ASCIR) is a national register of incident cases of spinal cord injury which occur in Australia and overseas to Australian residents. The ASCIR operates as a collective venture of the Directors of all six spinal units (SUs) in Australia and the National Injury Surveillance Unit (NiSU), a Collaborating Unit of the Australian Institute of Health and Welfare (AIHW). The ASCIR is funded as part of the NiSU program, which is managed and operated by the Flinders University Research Centre for Injury Studies (RCIS).

A statewide working party in 2010 with representatives from all acute and rehabilitation services defined the commencement of rehabilitation as the time:

- when the client is able to sit in a chair for a period of at least 60 minutes to participate in active rehabilitation and on 3 consecutive working days.
- the client has the ability to achieve active rehabilitation goals with the level of injury
- the client has no pressure area or wound that prevents sitting up in wheelchair for extended periods and/or participating actively in rehabilitation (e.g. on a prone trolley)