SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No:	170119S
Service	Spinal Cord Injury Services (Adults and Children)
Commissioner Lead	*For local completion*
Provider Lead	*For local completion*

1. Scope

1.1 Prescribed Specialised Service

This service specification covers the provision of spinal cord injury services for adults and children.

1.2 Description

Spinal cord injury (SCI) is an insult to the spinal cord at any level resulting in a change, either temporary or permanent in the normal motor, sensory or autonomic function of the cord. Spinal cord injury services refer to the services provided by the eight spinal cord injury centres (SCIC) in England for adults, young people and children who have sustained a non-progressive injury to the spinal cord or cauda equina. Injuries which result from physical trauma are referred to as 'traumatic' and injuries which result from disease or infection are referred to as 'non-traumatic'.

The Service will provide the following:

- Acute outreach to newly injured patients with SCI in other settings for clinical assessment and patient and staff support.
- Acute inpatient care following injury and during the period of recovery, including non-surgical or surgical management of the injury as required, and ventilatory support if needed.
- Restorative rehabilitation and re-enablement, and reintegration into the community.
- Life-long follow-up of people living with spinal cord injury to prevent and manage SCI related complications.
- Further admission if necessary for medical or surgical management for SCI related conditions or complications.
- Support for patients to maximise their potential for independent living, and for return to employment, education, hobbies and activities of everyday living.
- Education concerning SCI related issues for patients and those caring for them in the community to promote good health, and avoid complications and hospital admissions.

- Outreach services to patients with SCI in other healthcare and community settings.
- Channels for effective communication between the SCIC and patients, families, service providers, and local commissioners.
- Capacity and resources to meet the requirement for data entry concerning referral, admission, management pathway, discharge, clinical outcomes, and outpatient visits on the National Spinal Cord Injury Database.

1.3 How the Service is Differentiated from Services Falling within the Responsibilities of Other Commissioners

NHS England commissions the following activity for spinal cord injury patients provided by the SCI Centre (SCIC) host provider, including;

- Any part of the initial admission to the SCIC's host trust provider following injury, wherever in the provider the patient is situated where a SCI consultant is responsible for the patient's care, either solely or as part of a formally agreed joint consultant care arrangement, even if the patient is treated for another related or non-related condition during that spell (e.g. hand injury, epilepsy). Occasionally the initial admission may be interrupted by a temporary transfer to another setting.
- Any further admission or attendance for SCI-related care, wherever the treatment is located in the SCICs host provider (e.g. cystoscopy, tendon transfer), where a SCI consultant is responsible for the patient's care, either solely or as part of a formally agreed joint consultant care arrangement.

CCGs commission:

- Services for patients treated in or by SCICs who do not have a spinal cord injury as defined above, except where this service is defined elsewhere as a service commissioned by NHS England.
- Patients admitted to SCICs with injury to the spinal column but intact neurology.
- Patients with progressive disease, except where this is covered by a service defined elsewhere as a service that is commissioned by NHS England. However, if spinal cord dysfunction has arisen from the effects of a benign tumour that has been primarily managed by an appropriate specialty, the patient may transfer to the SCIC for rehabilitation and lifelong SCI related follow up. At this point, NHS England commissions the patient's care.
- A&E attendance and initial admission following spinal cord injury up until transfer to a SCIC.
- Assisted conception services and sperm storage, with the exception of electro-ejaculation, which is part of the specialist SCI service.
- Maternity care, delivery (obstetrics) and care of the new-born.
- Any further admission or attendance of a person with SCI for non-SCI-related care when the patient is treated by a clinician who is not an SCI clinician, except where the service is defined elsewhere as a service commissioned by NHS England.
- People with SCI treated in centres (specialist or non-specialist) that are not recognised SCICs.
- Patients who remain in a SCIC after they are clinically fit for discharge are a CCG commissioning / funding responsibility unless other agreed arrangements are already in place.
- Care in the community, including the provision, maintenance and replacement of equipment required to support the patient in the community, except where this is defined as a service commissioned by NHS England.
- The provision of disability equipment, except where this is defined as a service commissioned by NHS England.

The service is low volume, high cost. SCICs provide lifelong, coordinated and integrated specialist care, not provided in any other service. Whilst patients with acute cases of

SCI may be seen in major trauma centres (MTC), SCI is one of the highly specialist conditions that MTCs should refer on early.

2. Care Pathway and Clinical Dependencies

2.1 Care Pathway

The service is described in the National Care Pathways for Spinal Cord Injury: www.nscisb.nhs.uk

A **traumatic spinal cord injury** has an injury severity score (ISS) of 16 and according to MTC protocols should normally be transferred by ambulance or helicopter to the MTC, by-passing the trauma units. All major trauma centres are linked to specific SCICs and function in a network with trauma units. National protocols determine the referral process from the MTC and from the trauma units to the linked SCIC. These protocols concerning medical, nursing and therapy management will be modified and agreed locally by the SCIC in collaboration with the linked acute centres. Referral is made through the National Spinal Cord Injury Database (NSCID) within 12 hours of injury. If agreed protocols do not exist the SCIC should also be telephoned within 4 hours.

The SCIC will undertake outreach by specialist practitioners to patients who may meet the criteria for SCIC admission within five calendar days following referral and maintain regular specialist support until admission. Patients are transferred from the MTC to the SCIC as soon as they are fit for transfer and when a bed is available. It may be required to transfer patients back from the SCIC back to a Trauma Centre or Unit or other hospital following rehabilitation.

Non-traumatic spinal cord injury referral also follows established protocols, is made via the NSCID and outreach visits are undertaken as for traumatic injuries. Some non-traumatic spinal cord injury patients are referred from trauma units or general hospitals, but many which are secondary to compressive pathology such as inflammatory diseases, haematoma or epidural abscess will first be referred from the presenting unit to the neurology or the spinal surgery service (which is often co-located with the MTC). Referral to the SCIC will then be made from the that service. Late referral SCI or cauda equina injury may be made by primary care.

On admission to the SCIC, all patients undergo acute management and initial rehabilitation for the consequences of the SCI including bowel, bladder, skin, and ventilation requirements. The presenting aetiology may also need to be managed. There is a rehabilitation focus from the outset with treatment by a co-ordinated multidisciplinary team.

Once fit for mobilisation patients are managed using goal orientated pathways. These national care pathways provide a coherent management plan together with identified points at which measurement can be taken for audit and governance purposes.

There will be regular (weekly) MDT meetings to make management decisions concerning the inpatients with a SCIC rehabilitation consultant, a senior nurse from the SCI ward, a SCI physiotherapist, a SCI occupational therapist, a discharge coordinator and a clinical psychologist or a person responsible for psychological wellbeing.

This programme of care will include the following specifications:

- that each patient should have a statement of rehabilitation aims and component elements to achieve those aims;

- that documented goal-planning meetings should be held between the MDT staff and the patient. Family and significant others should be encouraged to participate and contribute to goals set. Following acute injury, the first meeting should take place within 3 weeks of mobilisation and subsequent meetings no less often than 4 weekly thereafter;
- discharge must be considered from admission and planning takes place with MDT staff, the patient, family and significant others where appropriate, and community personnel at or before mobilisation.

Particular focus is placed on the management of skin, bladder, bowel, psychological wellbeing and functional outcomes. There is an emphasis on patient education and self-management and the need to prevent avoidable complications.

The rehabilitation programme requires highly specialised nursing, therapy and psychology inputs and access to appropriate equipment; in particular, seating.

The first admission is supported by a number of specialisms, in particular urology. Input may also be required from plastic surgery, orthopaedic surgery, spinal surgery, neurosurgery and other specialties for the management of comorbidities.

In those SCICs admitting children and young people there must be a full MDT with training and experience in the care of SCI in this age group. (see appendix 1)

The SCIC will assess and prescribe the wheelchair and seating, where required and liaise with the wheelchair service who will provide the wheelchair and seating requirements for discharge.

Discharge planning starts from or before mobilisation and is highly specialised, requiring assessment leading to provision of a combination of, adaption of accommodation, care packages and equipment. The discharge process is complex, involving multiple agencies. A comprehensive discharge MDT discharge summary and patient information with contact numbers will be provided.

Outcome measures are taken at defined intervals including the ISNCSCI (ASIA) (impairment), SCIM III (disability / activity) and subsequently the CHART (social participation) scales. All these are recorded on the National Spinal Cord Injury Database.

Following discharge, patients are reviewed by outreach practitioners and in outpatient clinics. Care for the consequences of SCI is life-long with regular clinic or telephone review appointments (6 weeks, 6 months, and 1, 2 and 3 years then at least every 3 years or more often depending on the clinical indications).

Further admissions occur electively, commonly for further rehabilitation, urological, orthopaedic and plastic surgical procedures, pain management and spasticity management. Emergency further admissions are most frequently related to respiratory, skin and urinary diagnoses.

2.2 Interdependence with other Services

Co-located services - on the same site as the SCIC:

- Accredited Specialised Spinal Surgery Service (orthopaedic or neurosurgical)
- Accredited Critical Care Service. (ITU and HDU)
- Imaging including MRI

- Microbiology
- Urology
- Plastic Surgery
- Liaison Mental Health / Psychiatry Service
- Specialist Pain Management
- Care of the Elderly
- Dietetics
- Speech and Language Therapy
- For those SCICs delivering a service to children and young persons with SCI, an accredited provider of specialised paediatrics, appropriate facilities, and members of the MDT with training and experience in the care of SCI in this age group (see appendix 1)

Desirable:

- A Major Trauma Centre
- Accredited Specialised Neurosurgery Service

Interdependent services include:

- Gynaecology and Maternity
- Hand and upper limb surgery
- Ear, nose and throat surgery
- Neurorehabilitation services
- Specialised complex disability equipment services
- Orthotics
- Peer support
- Fertility services
- General Practice and Community Health Services including District Nursing,
- Community Mental Health Services, Occupational Therapy, Physiotherapy,
- Wheelchair Services
- Social Services Departments and Housing Departments
- Care agencies
- Education and further education, Driving Ability Assessment Centres, Disability
- Employment Advisory Services
- Financial and legal advice services
- Advocacy Services
- Charities, self-help groups and voluntary agencies.

Effective delivery of the SCI service specification and national care pathways is dependent on close collaboration between the SCIC teams and the numerous health and social care agencies responsible for identification and referral to the service and for provision of discharge packages and community support. Interagency communication, education and information exchange to promote an understanding of the individual needs of people sustaining and living with SCI are essential requirements for all involved in any aspect of the seven national care pathways, including services required for discharge to the community.

The centres each have defined catchment areas which are based on the Major Trauma Networks, i.e. a Major Trauma Centre and its surrounding Trauma Units. Thus, every hospital with an emergency department in England has a specific linked one to one relationship with a named SCIC.

SCICs should take a full part in the Major Trauma Network(s) to which they are linked.

3. Population Covered and Population Needs

3.1 Population Covered By This Specification

Adults and children with spinal cord injury accessing services provided by recognised Specialised Spinal Cord Injury Centres in any location and adults and children with cauda equina syndrome.

Services outside the scope of the Specialised SCI Service:

Some SCI Centres currently treat in their beds or clinics a range of patients who do not fall under the scope of the Specialised SCI Service. Examples include (not an exhaustive list):

- people with Functional SCI
- people with congenital long-term conditions such as spina bifida
- people without SCI having treatment for pressure ulcers
- people with multiple sclerosis or other progressive disorders
- people with spinal column injury without spinal cord injury
- people with SCI who have completed their rehabilitation or treatment and who are awaiting community services, accommodation, equipment, or with other issues preventing discharge.

3.2 Population Needs

In 2017/18 864 patients with acute SCI were admitted to the eight SCICs of whom 67% were male and 33% were female. Of those recorded, 49% were admitted as a consequence of a traumatic accident such as a road traffic accident, fall or sporting injury and 51% had suffered a non-traumatic aetiology. An increasing workload is the proportion of non-traumatic injury for example associated with major disc prolapse, complications of spinal or vascular surgery, or transverse myelitis. It is estimated that more than 150 patients per year with acute SCI appropriate for SCIC management (excluding cauda equina injury) are not referred to, or do not gain access to a SCIC.

In addition, approximately 600 patients with possible acute SCI or cauda equina syndrome are managed in outpatients or supported by outreach services.

Approximately 5% of patients are aged 80 and older. These patients are more likely to present with increased co-morbidities, resulting in additional challenges for management and discharge.

Approximately 2.5% of patients are aged 14 years and below, and 2.5% are aged 15 to 18 years. For children and young people (CYP) spinal cord injury beds and service provision are very limited and there is significant geographical imbalance. (see appendix 1)

There are one to four times as many further admissions to SCICs for ongoing management of, or with complications of, SCI as there are new acute injuries. The length of admission is variable but overall this represents a considerable workload and use of beds and resource. Nationally 15% of beds are designated as readmission beds but 22% of bed day capacity is used for further admissions.

Ventilation beds are under particular pressure. 22% of ventilation bed capacity is used for emergency or planned readmission rather than acute injury. The additional needs of ventilated patients may present additional difficulties in arranging discharge.

Infection control bed management requires about 9% of bed day capacity to be used for patients admitted with infections or for screening. There is a small additional usage for those acquiring infections in the centres. Infection control management will impact on the rehabilitation programme and access to facilities.

3.3 Expected Significant Future Demographic Changes

In recent years the service demands have changed substantially.

- There has been a steady increase in age at injury with concomitant increases in comorbidities and duration of rehabilitation. In 2009 the modal age range was 30-40 years, increasing to 65-69 years in 2017/18.
- There has been a steady increase in the proportion of cervical spinal injuries which have more complex rehabilitation needs and require extended lengths of stay. In 2017/18 this had risen to 51%
- There has been a significant increase in the proportion of non-traumatic spinal cord injury with concomitant increasing comorbidities and increased length of stay. In 2008, 21% of new injuries were non-traumatic; in 2017/18 this had more than doubled to 51%.
- There has been an increasing trend in the number of incomplete injuries who may require a significantly increased average length of stay to achieve functional goals.
- Delayed discharge is increasingly common, with consequent pressure on beds. 17% of discharges were delayed in 17/18 by more than 2 weeks.
- There has been a decrease in funded spinal cord injury beds from 425 in 2008 to 395 in 2017/18.
- Since 2001 the population of England has increased by 12% and is predicted to continue rising by about 1% per year
- There is a significant unmet need. In 2008, 10% of 829 members of the Spinal Injuries Association reported they had never been under the care of a SCIC. It is estimated that more than 150 new patients per year (excluding cauda equina injury) are not referred to, or do not gain access, to SCIC care.
- There is an increasing awareness of the consequences of cauda equina syndrome and demand for SCIC management.
- With increased life expectancy there is an increasing need to prevent or manage complications that can develop over many years particularly in the ageing patient cohort. Further admissions for planned interventions and unplanned emergencies often require support from the SCI Centres

There are about 1200 new spinal cord injury cases per year in England appropriate for admission to a SCIC (excluding cauda equina injury). The growth in the population of England is the biggest factor affecting demand growth. By mid-2024 the population will have increased by 4.1 million (7.5%). The South-Eastern quadrant of England will experience population growth above the average. London is projected to have an increase of 13.7%, East of England 8.9% and South-East England 8.1%.

3.4 Evidence Base

The Standards for Adults requiring Spinal Cord Injury Care revised and approved (by the Spinal Cord Injury CRG) 19th November 2013.

Standards for Children and Young People (<19 years) requiring Spinal Cord Injury Care approved by the SCI CRG 9th December 2014.

Standards for People with Mental Health Problems requiring Spinal Cord Injury care (adults) approved by the SCI CRG 11th August 2015.

Spinal Cord Injury Pathways approved by the SCI CRG December 2012

The Initial Management of Adults with Spinal Cord Injuries. Advice for Major Trauma Networks. Approved by the CRG in Spinal Cord Injuries. March 2016

Developing Lead Responsibilities for English Spinal Cord Injuries Centres. Report of the CRG in Spinal Cord Injury. May 2013

A Paralysed System – The All Party Parliamentary Group on SCI

NHSE Spinal Cord Injury Service Review 2017 (not published)

National Peer Review Report: Spinal Cord Injury Centres 2016/17 (publication pending)

Specialised Spinal Cord Injury Services. Annual Statement. 2017/18 (publication pending)

BOAST 8 – British Orthopaedic Association Standards for Trauma – The Management of Traumatic Spinal Cord Injury.

These documents may be accessed via: www.nscisb.nhs.uk

4. Outcomes and Applicable Quality Standards

4.1 Quality Statement – Aim of Service

The aim of the service is to optimise autonomy and health in people with SCI by:

- providing acute management and rehabilitation of people with SCI
- providing ongoing management of people with SCI
- promoting optimal outcomes, leading to reduced mortality and morbidity
- supporting patients to maximise their potential for independent living and for return to employment, education, hobbies and activities of daily living.

To achieve this aim, SCI patients should receive excellence in patient-centred, multi-disciplinary care in the most appropriate environment.

1. SCI patients will be admitted to and managed in dedicated SCI beds and wards with facilities consistent with the management of paralysed and neurologically compromised people.
2. The medical consultants will be accredited in rehabilitation medicine with specific training in SCI management and rehabilitation. Other members of the medical team will have access to SCI education.
3. Specialist nursing staff will provide advice and care in specialist fields such as respiratory and ventilation support, pressure area care, bladder and bowel management including promoting and managing continence, personal hygiene, nutritional and emotional support. They have a substantial educational role and also provide home outreach after discharge.

4. SCI specialist physiotherapy staff will provide a wide range of rehabilitation modalities to maximise restoration of function including respiratory and ventilation support.
5. SCI specialist occupational therapists will provide a wide range of therapy to facilitate independence such as working with hand function and promotion of participation.
6. Clinical psychology staff will have SCI expertise and experience to support patients and other staff.
7. Outreach staff, pre- and post admission, will have the experience necessary to assist with the range of SCI assessments and problems presented.
8. Discharge coordinators will have experience in the particular needs of SCI patients and community liaison.
9. There will be other SCI specialist teams, for example speech and language therapists, dietitians, and pain management teams who have training and experience to meet the particular needs of this population.
10. In those SCICs admitting children and young people there must be a full MDT with training and experience in the care of SCI in this age group. (see appendix 1)

NHS Outcomes Framework Domains

Domain 1	**Preventing people from dying prematurely**	✓
Domain 2	**Enhancing quality of life for people with long-term conditions**	✓
Domain 3	**Helping people to recover from episodes of ill-health or following injury**	✓
Domain 4	**Ensuring people have a positive experience of care**	✓
Domain 5	**Treating and caring for people in safe environment and protecting them from avoidable harm**	✓

4.2 Indicators Include:

The SCI Centres will submit to the National SCI database the data items required to monitor quality and outcomes as agreed by, and at intervals specified by the SCI Working Group of the Spinal Services CRG. This will include, but not be restricted to, the collection of data on:

1. The Spinal Cord Injury Dashboard data set
2. ISNCSCI (ASIA) at admission, 28 days post injury, at discharge, at 6 and 12 months and then 24 months post injury (excluding cauda equina)
3. SCIM at mobilisation, completion of rehabilitation, 6, 12 and 24 months post-injury (excluding cauda equina)
4. CHART at 2 and 5 years post-injury
5. Psychometric assessment at mobilisation and discharge

6. Patient Reported Outcome Measure – Friends and Family Test
7. Patient referral and injury details
8. Outreach and referral-to-admission data
9. First admission data
10. Discharge planning data
11. Further admissions data
12. Outpatient data
13. Non-admitted care data

No.	Indicator	Data Source	Outcome Framework Domain	CQC Key question
Clinical Outcomes				
101	Mean time (in days) from Injury to referral (newly injured patients) to spinal cord injury centre (SCIC)	SSQD via Spinal Registry	2, 3, 4	Effective, caring
102	Proportion of newly injured patients with traumatic and non-traumatic spinal cord injury will receive a face to face outreach visit from the SCIC acute outreach team within 5 days of the referral of the patient to the SCIC, to support the patient and the treating team	SSQD via Spinal Registry	2, 3, 4	Effective, caring
103	Proportion of newly injured spinal cord injury patients admitted to SCIC who had Grade 3 or 4 pressure ulcer on admission	SSQD via Spinal Registry	2, 3, 4	Effective, caring
104	Mean time from fit for admission to admission into a SCIC under the care of a spinal cord injury consultant	SSQD via Spinal Registry	2, 3, 4	Effective, caring
105	Mean time from injury to mobilisation for neurological levels C1 to C4	SSQD via Spinal Registry	2, 3, 4	Effective, caring
106	Mean time from injury to mobilisation for neurological levels C5 to C8	SSQD via Spinal Registry	2, 3, 4	Effective, caring
107	Mean time from injury to mobilisation for neurological levels T1 to T12	SSQD via Spinal Registry	2, 3, 4	Effective, caring
108	Mean time from injury to mobilisation for neurological level L1 and below	SSQD via Spinal Registry	2, 3, 4	Effective, caring
109	Mean time from fit to discharge to discharge	SSQD via Spinal Registry	2, 3, 4	Effective, caring
110	Proportion of patients whose first goal planning meeting takes place within 3 weeks of mobilisation	SSQD via Spinal Registry	2, 3, 4	Effective, caring

111	Proportion of unplanned further admissions to SCIC within 8 weeks of discharge	SSQD via Spinal Registry	2, 3, 4	Effective, caring
112	Proportion of patients with ASIA score prior on admission	SSQD via Spinal Registry	2, 3, 4	Effective, caring
113	Proportion of patients with discharge ASIA score at discharge	SSQD via Spinal Registry	2, 3, 4	Effective, caring
114	Proportion of patients with 2-year ASIA score recorded	SSQD via Spinal Registry	2, 3, 4	Effective, caring
115	Mean Spinal Cord Independence Measure (SCIM) uplift mobilisation to discharge	SSQD via Spinal Registry	2, 3, 4	Effective, caring
116	Proportion of patients with 2-year CHART recorded	SSQD via Spinal Registry	2, 3, 4	Effective, caring
117	Proportion of newly injured patients waiting more than 30 days from injury to admission	SSQD via Spinal Registry	2, 3, 4	Effective, caring
118	Proportion of spinal cord injury bed days occupied by delayed discharge patients.	SSQD via Spinal Registry	2, 3, 4	Effective, caring
119	Proportion of bed days occupied by non spinal cord injury outliers.	SSQD via Spinal Registry	2, 3, 4	Effective, caring
120	Proportion of newly injured patients with core NSCID data completed.	SSQD via Spinal Registry	2, 3, 4	Effective, caring
Patient Experience				
201	There is a key worker policy.	Self declaration	2, 4	Caring, responsive
202	There is an agreed policy for a 24/7 service for telephone advice on SCI issues, to patients and carers.	Self declaration	2, 4	Effective, caring, responsive
203	The SCIC has a policy on a goal-orientated programme of care.	Self declaration	2, 3, 4	Effective, caring, responsive
204	There is patient information available.	Self declaration	4	Caring, responsive
205	The SCIC has undertaken an exercise during the previous two years prior to review to obtain feedback on patients' experience of the services offered.	Self declaration	4	Effective, caring, responsive
Structure and Process				
301	The SCIC under review is party to an agreement between the relevant commissioners, the SCIC and referring MTCs, and trauma units.	Self declaration	4, 5	Effective, responsive, well-led
302	There should be a weekly meeting to make decisions on the management of SCI inpatients.	Self declaration	2, 3, 4, 5	Safe, effective, caring, responsive
303	There are named lead(s) at the SCIC for the management of service provision and governance.	Self declaration	2, 4	Effective, Well-led

304	There is a 24/7 rota of named, SCI consultants for the SCIC.	Self declaration	1, 2, 3, 4, 5	Safe, effective, caring, responsive
305	There is a 24/7 rota of physiotherapists for the SCIC.	Self declaration	2, 3, 4, 5	Safe, effective, caring, responsive
306	The SCIC should have at least 20 beds on a ward dedicated exclusively for the treatment and rehabilitation of spinal cord injured patients.	Self declaration	1, 2, 3, 4, 5	Effective, caring, responsive
307	There are co-located services as per the service specification.	Self declaration	1, 2, 3, 4, 5	Safe, effective, responsive
308	The SCIC has a training strategy in place.	Self declaration	4, 5	Effective, responsive, well-led
309	The SCIC should agree with the network governance group, network patient pathways for the referral and transfer of patients with SCI from MTCs, trauma units and other sources of referral.	Self declaration	1, 2, 3, 4, 5	Safe, effective, caring, responsive
310	There are agreed guidelines as per the service specification	Self declaration	1, 2, 3, 4	Safe, effective, caring, responsive
311	The SCIC has carried out at least one audit of clinical practice in the year prior to the review.	Self declaration	1, 2, 3, 4	Safe, effective, well-led

5. Applicable Service Standards

5.1 Applicable Obligatory National Standards

National Service Framework: children, young people and maternity services. 2004

5.2 Other Applicable National Standards to be met by Commissioned Providers

The provider should meet the following standards:

a. The Standards for Adults requiring Spinal Cord Injury Care revised and approved (by the Spinal Cord Injury CRG) 19th November 2013.

b. Standards for Children and Young People (<19 years) requiring Spinal Cord Injury Care approved by the SCI CRG 9th December 2014.

c. Standards for people with Mental Health Problems requiring Spinal Cord Injury care (adults) approved by the SCI CRG 11th August 2015.

5.3 Other Applicable Local Standards

Not applicable

6. Designated Providers (if applicable)

Spinal cord injury services are provided by the following SCICs in England:

- Duke of Cornwall Spinal Treatment Centre, Salisbury

- North-West Regional Spinal Injuries Centre, Southport
- London Spinal Cord Injuries Centre, Stanmore
- Midland Centre for Spinal Injuries, Oswestry
- National Spinal Injuries Centre, Stoke Mandeville
- Golden Jubilee Spinal Cord Injuries Centre, Middlesbrough
- Princess Royal Spinal Injuries Centre, Sheffield
- Yorkshire Regional Spinal Injuries Centre, Wakefield

The National Spinal Injuries Centre (Stoke Mandeville) and the London Spinal Cord Injury Centre (Stanmore) are the only centres with paediatric beds within the SCIC.

Other trusts can admit children to separate paediatric departments. Subsequently, during the daytime, the patient is taken to the centre within the trust to access spinal cord injury services.

7. Abbreviation and Acronyms Explained

The following abbreviations and acronyms have been used in this document:

A & E	Accident and Emergency
ASIA	American Spinal Injuries Association
BOAST	British Orthopaedic Association Standards for Trauma
C1-C4	Cervical neurological levels – 1 to 4
C5-C8	Cervical neurological levels – 5 to 8
CCG	Clinical Commissioning Group
CHART	Craig Handicap Assessment and Reporting Technique
CRG	Clinical Reference Group
CYP	Children and Young People
FIM	Functional Independence Measure
HADS	Hospital Anxiety and Depression Scale
HDU	High Dependency Unit
ISS	Injury Severity Score
ISNCSCI	International Standards for Neurological Classification of Spinal Cord Injuries
ITU	Intensive Therapy Unit
L1	Lumbar neurological level – number 1
MDT	Multi-Disciplinary Team
MRI	Magnetic Resonance Imaging
MTC	Major Trauma Centre
NSCID	National Spinal Cord Injury Database
SCI	Spinal Cord Injury
SCIC	Spinal Cord Injury Centre
SCIM	Spinal Cord Independence Measure
T1-T12	Thoracic neurological levels – 1 to 12

Grade 3 pressure ulcer - full thickness skin loss extending down to but not through underlying fascia.
Grade 4 pressure ulcer - extensive destruction of deep tissues.

Appendix 1
Services for Children and Young People

Spinal cord injury services for children and young people are for those with non-progressive spinal cord injury as a result of trauma or disease, prior to the age of 19 years. The management of children and young people with spinal cord injury should be co-located, or have close links with a SCIC, facilitating integrated and coordinated care provision from specifically trained health care professionals in an environment that provides for their particular and individual needs. It allows for ongoing review of development and monitoring of skeletal growth, and facilitates transition into adult services. The child / young person and their family are placed at the centre of the care process.

This specification adheres to the principles of the service to adults, but takes account of the particular circumstances and requirements of this age group. The particular considerations are:

1. Care will be delivered by recognised spinal cord injury specialists, in conjunction with paediatric specialists, supported by appropriate staff, facilities and interventions in a recognised paediatric environment according to agreed National Guidelines and within a robust framework of clinical governance and audit.
2. Children, young people and their families will receive developmentally appropriate care, focussing on prevention of complications and optimising activity, participation, growth and development.
3. During acute management at a MTC or other hospital, children / young people with SCI must be referred to a SCIC, with paediatric spinal cord injury facilities and expertise, for ongoing and future rehabilitation and care needs.
4. The nominated SCIC should have a policy concerning the extent of acute care provision and elective/review services provided for children / young people with SCI it can provide. If this SCIC does not have such facilities the referral must be passed on to another SCIC.
5. The child / young person and family are best served by an experienced established service with established pathways of care. This provides peer support for the child / young person and family as well as maintaining continuous competence and developing specialised experience of MDT personnel.
6. Children / young people under the age of 16 years should not be treated on adult SCI wards. Adolescent facilities should be provided for young people aged 16 years and over.
7. After acute care the family should be fully informed of the options of rehabilitation facilities provided elsewhere and involved in the decision making of where best will meet the needs of the child / young person and their family at that time.

The Services:

The SCI service for children / young people will have appropriate planned pathways to access as required:

- Paediatric acute and critical care
- Paediatric anaesthesia
- Subspecialty support e.g. orthopaedics, spinal surgery, urology, plastic surgery. These specialists must have experience in managing the consequences of SCI.

The clinical lead will be provided by a consultant in spinal cord injuries who:

- Has at least two continuous years' experience in childhood onset spinal cord injury rehabilitation and adolescent healthcare.

- Participates in active and continuous clinical practice that relates to the population served.
- Demonstrates active learning and involvement in the professional community.
- The clinical lead should work in collaboration with a named paediatrician

Acute outreach teams reviewing the child / young person with SCI should have at least 2 years' experience of childhood onset SCI management.

The MDT personnel who deliver care to children / young people with SCI should be able to demonstrate an ability and knowledge in the following areas (to include but not limited to):

- Bio psychosocial effects of childhood onset SCI
- Impact of SCI on normal growth and development
- Family centred care
- Behaviour management
- Sexuality and sexual function
- Safeguarding
- Therapeutic play
- Transition to adult services
- Potentials & limitations of SCI at any given age range
- Discharge planning
- Education of children and families to promote mastery of skills and independence according to functional ability
- Social development and community resources
- Ageing effects of SCI

Qualified nursing staff delivering care to the child / young person with SCI should be a registered children's nurse with a current and working knowledge of caring for children / young people with SCI.

Allied healthcare professionals should have participated in active and continuous clinical practice within the areas of all relevant specialities (child, adolescent and adult healthcare and SCI rehabilitation) and hold current appropriate qualifications relevant to their field of practice. Service provision must include psychological care/specialist mental health professional for children/young people with SCI.

The child / young person with SCI must receive rehabilitation in a suitably specialised SCIC that can accommodate their needs The Centre should have an established network of support from existing patients for families of newly injured children / young people.

Ongoing formal (school) education should be delivered throughout the child/young person's rehabilitation.

Outcome measures for the child / young person with SCI are comparable to adult SCI rehabilitation pathways but differ according to the development age and age appropriate abilities. Outcome measures should be comparable between all centres treating children / young people with SCI. To include:

- An assessment of need e.g. The Needs Assessment Checklist (child)
- Spinal cord independence measure (SCIM)
- Lengths of stay
- Functional Independence Measure (FIM)
- ASIA impairment scale (in accurate under 5 years)
- Paediatric inventory of emotional distress (8-16yrs) / HADS (for older adolescents)
- Perceived manageability Scale (16yrs+)

- Appraisals of Disability: Primary and Secondary Scale – Short Form (16yrs+)
- Paediatric Quality of Life Inventory Core Scale (adapted for SCI)
- Self-assessment questionnaire
- Educational attainment

Children / young people with new injuries being discharged should be reviewed again by the SCIC paediatric SCI team at 6 weeks post discharge and then no later than one year post discharge. A formal plan will be made for the child / young person to return to the SCIC for a minimum of an annual review for collective reassessment by the whole MDT team.
Some SCICs currently offer comprehensive outpatient review.

Thereafter children / young people with SCI should receive ongoing care and rehabilitation by the SCIC children / young people's SCI team until transition to adult SCI services.

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