Guidelines to be followed by centres, services and units in order to be designated as Reference Centres, Services and Units of the National Health System, as agreed by the Interterritorial Board

45. CARE OF THE PATIENT WITH COMPLEX SPINAL CORD INJURY

The Reference Centre, Service or Unit will be able to care for patients, children and adults, with different types of spinal cord injuries and at every stage (from C1 to cauda equina).

Comprehensive rehabilitation of the patient with spinal cord injury is a complex care process with the purpose of restoring functionality, decreasing and/or compensating, in as much as possible, the functional differences happening in the person affected by this severe pathology.

The goals of the rehabilitation process should be:
- Establishing the most adequate measures to prevent possible complications and decrease their effects when occurring.
- Achieving the highest level of functional autonomy possible (physical, emotional and social).
- Restoring self-esteem and favouring a constructive state of mind, being able to empower the retained abilities.
- Favouring the best possible social reintegration (active, independent and satisfactory).
- Informing and advising the family in understanding and managing the new situation.

The Reference Centre, Service or Unit will include all diagnostic and therapeutic procedures, listed below, required by these patients; in addition, it will be a support unit for diagnostic assessment, definition of therapeutic and monitoring strategies, and a consultant for clinical units which usually care for these patients, regardless the time of development.

Diagnostic, therapeutic and rehabilitation procedures that the Reference Centre, Service or Unit should offer:

- Comprehensive assessment of the patient with spinal cord injury.
- Comprehensive rehabilitation treatment of the patient with spinal cord injury.
- Counselling and training of the patient and caretaker in terms of activities of daily living.
- Respiratory disease rehabilitation for patients with severe spinal cord injury depending on a respirator (Removing respirator, adapting portable respirator to electric wheelchair, other techniques of ventilation support).
- Treatment and rehabilitation of neurogenic bladder and other urologic problems associated.

- Treatment and rehabilitation of neurogenic bowel dysfunction and other digestive problems associated.
- Special techniques for gait and seating assessment and rehabilitation (Gait kinetic and kinematic analysis, analysis of pressure distribution between the patient and the pressure relief surface, physical and functional intensive treatment by using robotic electromechanical systems with partial bodyweight suspension).
- Comprehensive diagnosis and treatment of spasticity (medical and surgical).
- Neuropathic pain care, including rehabilitation and pharmacological treatment as well as use of invasive techniques for cases of severe neuropathic pain.
- Special care of pressure ulcers (Prevention, risk assessment, assessment and conservative treatment or reconstructive plastic surgery when indicated).
- Assessment and treatment of voice and deglutition changes.
- Orthopaedic surgery in the spinal cord injury.
- Tetraplegic hand surgery.
- Care of psychiatric and psychological problems (Prevention and treatment of post-traumatic stress disorders, relaxation techniques to control anxiety, individual and/or family interventions, treatment of other adaptation or psychopathologic disorders affecting well-being and life quality) and behavioural problems.
- Sexuality care for patients with spinal cord injury, counselling and rehabilitation of sexual dysfunctions related to the disability of neurological origin (Erectile dysfunction, sexual desire disorders, orgasmic dysfunction, etc.). Including, when needed, couple counselling and therapy.
- Fertility diagnosis and treatment in patients with spinal cord injury.
- Social reintegration and adaptive sports programme.

A. Rationale for the proposal

► Epidemiological data on spinal cord injury (incidence and prevalence).	- Incidence: 2.5 new cases of patients with spinal cord injury / 100,000 population/year. 1,000 new cases per year are estimated. - Prevalence: Around 500 people with spinal cord injuries / 1,000,000 population.

B. Guidelines to be followed by Centres, Services and Units in order to be designated as Reference Centres, Services and Units treating patients with spinal cord injury

► Experience of the Reference Centres, Services and Units: - Activity: • Number of patients that should be assisted or procedures that should be performed in a year to ensure an adequate care of the patient with spinal cord injury.	- Active programme of comprehensive treatment (medical, surgical and rehabilitation) of the patient with spinal cord injury for, at least, 10 years. - An average of 100 new patients with spinal cord injury admitted during the year in the last 3 years; of these, at least: ▪ An average of 30 tetraplegic patients, 10 requiring prolonged mechanical ventilation support (for more than 60 days after the injury happened) in the last 3 years. ▪ An average of 5 patients under 18 years old in the last 3 years. - Diagnostic, therapeutic and rehabilitation procedures in patients with spinal cord injury and/or problems arising from the condition: ▪ Counselling and training of the patient and caretaker in terms of activities of daily living: •An average in the last 3 years of 40 new patients included in the re-education programme on activities of daily living during the year. • An average in the last 3 years of 40 new patients included in the home adaptation programme during the year. ▪ Respiratory disease: • An average in the last 3 years of 5 patients who had a portable respirator adapted to their electric wheelchair during the year. • An average in the last 3 years of 5 patients with prolonged mechanical ventilation support (for more than 60 days after the injury happened) whose respirator has been removed during the year. • Diaphragmatic pacemaker implantation programme available for patients with spinal cord injuries.

	▪ Neurogenic bladder and other urologic problems associated: • An average in the last 3 years of 100 urodynamics analysis in patients with spinal cord injury. • An average in the last 3 years of 30 surgical procedures in patients with spinal cord injury with neurogenic bladder complications during the year (Infiltrations of botulinum toxin into sphincter and detrusor, external sphincterotomy, cervicotomy, vesicoureteral reflux treatment, vesicoureteral and kidney lithotripsy, neuromodulation and neurostimulation techniques…) ▪ Gait and seating assessment and rehabilitation: • 40 patients treated in robotic assisted gait systems with partial bodyweight suspension during the year. • 15 gait kinetic and/or kinematic analysis during the year. • 35 analysis of pressure distribution between the patient and the resting surface during the year. ▪ Spasticity and pain treatment: • An average in the last 3 years of 20 new patients with spinal cord injury assisted in the pain treatment programme during the year. • Active programme of implantation of devices for continuous intrathecal perfusion of drugs, with at least an average in the last 3 years of 4 devices implanted during the year. ▪ Treatment of pressure ulcers: • An average in the last 3 years of 20 surgical procedures for treating pressure ulcers, in patients with spinal cord injuries during the year (Surgical debridement of pressure ulcers, surgical resection, pedicled musculocutaneous flaps and grafts). ▪ Treatment of voice and deglutition changes: • An average in the last 3 years of 20 new patients with spinal cord injury assisted for: voice training for patients with mechanical ventilation, voice re-education for patients suffering problems during endotracheal intubation, dysphagia clinical assessment and additional examinations. ▪ Orthopaedic surgery:

	• An average in the last 3 years of 20 surgical procedures in a year of orthopaedic surgery in patients with spinal cord injury. ▪ Tetraplegic hand surgery: • Active programme of tetraplegic hand surgery available. ▪ Care of psychiatric, psychological and behavioural problems: • An annual average of 100 patients with spinal cord injury with psychological and/or psychiatric monitoring in the last 3 years. ▪ Sexuality care: • An average of 20 patients assisted in psycho-sexual rehabilitation programmes in the last 3 years. ▪ Care of sexual dysfunction caused by organic disorders: • An average of 20 spinal cord injured patients cared for erectile dysfunction, ejaculatory dysfunction or seminal assessment in the last 3 years.
- Other data: research on the subject, postgraduate teaching, continuing training, publications, etc.	- Accredited postgraduate teaching: Unit participation in the internship and residency programme of the Centre. - Participation in research projects and publications in the field. - Continuing training programme standardized and authorized by the centre's board of directors. - Clinical multidisciplinary sessions, at least once a month, in order to make clinical decisions and coordinate treatments. - Social reintegration and adaptive sports programme for the patient with spinal cord injury authorized by the centre's board of directors.
► Specific resources of the Reference Centres, Services and Units:	The centre must observe Act 51/2003, December 2nd, on equal opportunities, non-discrimination and universal accessibility for disabled people.
- Human resources required for the adequate care of the patient with spinal cord injury.	The multidisciplinary team in charge of the patient with spinal cord injury must provide, at all times, the best medical, surgical and rehabilitation care in a comprehensive, continuous and personalized way and with the highest human, scientific and technical level.

	- Continuity of medical and nursing care guaranteed, 24 hours a day 365 days a year. - 5 specialists in physical medicine and rehabilitation. - 1 internist and/or pulmonologist. - 1 neurologist. - 1 urologist, with full-time dedication to patients with spinal cord injury, or 2 part-time. - 1 psychiatrist. - 1 clinical psychologist. - 1 plastic surgeon with part-time dedication to patients with spinal cord injury. - 1 general and digestive surgeon with part-time dedication to patients with spinal cord injury. - 1 surgeon specialized in orthopaedics and trauma with part-time dedication to patients with spinal cord injury. - 5 occupational therapists with, at least, 50% of their time dedicated to patients with spinal cord injury; of them, at least 2 therapists are in charge of the re-education on activities of daily living and the assessment of home adaptation, together with their other care activities. - 1 speech therapist supporting the treatments of patients with spinal cord injury. - Nursing staff. - 10 physiotherapists with, at least, 50% of their time dedicated to treatment of patients with spinal cord injury. - At least, 1 professional dedicated to the physical activity adaptation programme.
Experience of the team members.	- At least 3 of the specialists in physical medicine and rehabilitation with 3 years experience in treating patients with spinal cord injury. -Internist and/or pulmonologist with, at least, 3 years experience in patients with spinal cord injury and assisted ventilation. - Neurologist with, at least, 3 year experience in treating patients with spinal cord injury. - Urologist with, at least, 3 year experience in treating patients with spinal cord injury and in related urologic problems. - Psychiatrist with, at least, 3 year experience in treating patients with spinal cord injury. - Clinical psychologist with, at least, 3 year experience in treating patients with spinal cord injury.

	- Plastic surgeon with, at least, 3 year experience in treating patients with spinal cord injury and related problems. - General and digestive surgeon with, at least, 3 year experience in treating patients with spinal cord injury and related problems. - Surgeon specialized in orthopaedics and trauma with, at least, 3 year experience in treating patients with spinal cord injury and related problems. - At least one of the team specialists with training in phoniatrics and experience in treating patients with spinal cord injury. - At least one of the team specialists with experience in andrology and in treating patients with spinal cord injury. - At least 3 of the occupational therapists with experience in treating patients with spinal cord injury. - Speech therapist with experience in treating patients with spinal cord injury. - At least 10 nurses with experience in treating patients with spinal cord injury. - At least 5 physiotherapists with 3 year experience in treating patients with spinal cord injury.
- Specific equipment required for the adequate care of the patient with spinal cord injury.	- Hospitalization area for patients with spinal cord injury, adapted to their disability: ▪ Rooms and surrounding areas without architectonic barriers. ▪ Disabled bathrooms. ▪ Mechanical and electric systems to facilitate position changes. ▪ An area of supervised monitoring must be included. - Care area for patients with spinal cord injury adapted to their disability, without architectonic barriers, which must have: ▪ Hydraulic stretcher. ▪ Mechanical/electric equipment to facilitate patient moving. - Physiotherapy area with: ▪ Hydraulic stretchers. ▪ Inclined planes. ▪ Specific area for electrostimulation. ▪ Hydrotherapy with therapy pool. - Area for training of the patient and caretaker on activities of daily living, with at least:

	▪ 2 beds. ▪ 1 toilet. ▪ 1 sink. ▪ 1 bath for moving training. ▪ Training course for wheelchair use. - Operating theatre available with the equipment required for general, urology, orthopaedics and trauma and plastic surgery. - For treatment of the respiratory disease, there must be, at least: ▪ 5 mechanical ventilation support systems (respirators). ▪ 1 equipment for pulmonary function testing including flow-volume curve. ▪ 1 fibrobronchoscope ▪ Continuous cutaneous oximetry. ▪ Non-invasive ventilation systems (BIPAP, CPAP…). - For treatment of neurogenic bladder and other urologic problems associated there must be, at least: ▪ Video urodynamics equipment. ▪ Ultrasound scanner. - For gait and seating assessment and rehabilitation there must be, at least: ▪ 1 robotic assisted gait systems with bodyweight suspension control. ▪ 1 system to measure support pressure in the contact area between skin and cushion. ▪ 1 kinetic equipment and/or 1 kinematic equipment for movement analysis. - For treatment of pressure ulcers there must be equipment for vacuum assisted closure. - For treatment of voice and deglutition changes there must be: ▪ 1 laryngostroboscope ▪ Respiratory incentive spirometer and secretion aspirator. ▪ Laryngeal mirrors for deglutition stimulation. - For treatment of organic sexual dysfunctions there must be, at least: ▪ Vibro stimulator. ▪ Rectal stimulator.
► Resources from other units and	- Social workers services/unit with experience in treating patients with spinal cord injury.

services besides those belonging to the Reference Centres, Services and Units required for the adequate care of the patient with spinal cord injury.	- Anaesthesia services/unit with experience in treating patients with spinal cord injury. - Intensive care and/or resuscitation services/unit with experience in treating patients with spinal cord injury. - Neurophysiology services/unit, performing a minimum of 100 neurophysiological studies per year (EMG, motor and sensory evoked potentials, reflex studies, sleep studies) to patients with spinal cord injury. It must be able to provide: EMG, motor and sensory evoked potentials, reflex studies, sleep studies. - Diagnostic imaging services/unit, with MRI and neuroradiology and experience in treating patients with spinal cord injury. - Obstetrics and gynaecology services/unit with experience in obstetrics and gynaecologic care of patients with spinal cord injury and with the ability to perform artificial insemination and in-vitro fertilization.
► Procedure and clinical results indicators of the Reference Centres, Services and Units [c]:	**The indicators will be agreed with the Units that will be designated.**
► Existence of an adequate IT system (Type of data that the IT system must include to allow identification of the activity and evaluation of the quality of the services provided)	- Filling up the complete MBDS of hospital discharge. - The unit must have a *registry of patients with spinal cord injury* which at least must include: Medical record number. - Date of birth. - Sex. - Patient's habitual region of residence. - Admission date and discharge date. - Type of admission (Emergency, planned, other). - Type of discharge (Home, hospital transfer, voluntary, death, transfer to a healthcare centre, other.) - Service in charge of patient's discharge. - Main diagnosis (ICD-9-CM). • Type of spinal cord injury, cause of the injury, level of injury, ASIA classification, assessment of functional state.

	- Other diagnosis (ICD-9-CM). - Diagnostic procedures provided to the patient (ICD-9-CM): Type of procedure and date when it was provided. - Therapeutic procedures provided to the patient (ICD-9-CM): Type of procedure and date when it was provided. - Rehabilitation procedures performed to the patient. - Complications (ICD-9-CM). - Patient's monitoring. The unit must have the required data which should be sent to the Spanish National Health Service Reference Centres, Services and Units Appointment Commission Secretariat for yearly reference unit monitoring.

[a] *Criteria to be assessed by the Appointment Commission.*
[b] *Experience will be accredited by certification from the hospital manager.*
[c] *Clinical results standards, agreed to by the experts group, will be assessed, initially by the Appointment Commission, while in the qualification process, as more information from the Reference Centres, Services and Units is being obtained. Once qualified by the Appointment Commission, the Quality Agency will authorize its compliance, as for the rest of guidelines.*

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