INTERNATIONAL SPINAL CORD INJURY DATA SETS

UPPER EXTREMITY BASIC DATA SET (Version 1.1) – COMMENTS

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The purpose of the International Spinal Cord Injury (SCI) Upper Extremity Basic Data Set is to standardize the collection and reporting of a minimal amount of information about upper extremity status in accordance with the purpose and vision of the International Spinal Cord Injury Data Sets (Biering-Sørensen et al. 2006). Standardisation of data collection and reporting is central to valid comparisons across sites and published papers.

It is intended that the International SCI Upper Extremity Basic Data Set be used in connection with the International SCI Core Data Set (DeVivo et al. 2006), the International SCI Musculoskeletal Basic Data Set (Biering-Sørensen et al. 2012) and the International SCI Pain Basic Data Set (Widerström-Noga et al. 2008). The International SCI Core Data Set includes information on dates of birth and injury, gender, etiology of spinal cord lesion and neurologic status. In addition, the International SCI Core Data Set captures information on the presence of vertebral injury, surgical management, associated injuries, discharge destination and the need for mechanical ventilation. In addition, it is assumed that the individuals with SCI being assessed with the International SCI Upper Extremity Basic Data Set will also have been assessed with the International Standards for the Neurological Classification of SCI (ISNCSCI) (Kirshblum et al. 2011) as well with the Spinal Cord Independence Measure (SCIM III) (Catz et al. 2007; Anderson et al. 2011).

A spinal cord lesion refers to any injury to the spinal cord, conus medullaris or cauda equina due to traumatic or non-traumatic insults.

Each variable and each response category within each variable has specifically been defined in the best way possible to ensure consistency in the collection and reporting of data, and to ensure the data are collected in a standard format.

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Version changes of the International SCI Upper Extremity Basic Data Set.

Version 1.0 to Version 1.1:

Two adjustments have been made:

In relation to the variable **Basic hand-upper extremity function** the following sentence has been added to the Description of the variable: *", or functional gain after upper extremity reconstructive surgery or during or after the use of a neuroprosthesis"* – this will enable the same scoring to be used following these interventions.

In relation to the variable **Shoulder function classification**, the option *"D. Full range of movement (ROM) of shoulder and independent reaching forward and upward"* was changed to "*D. Ability to reach in all directions including lifting hand above the head reflecting at least grade 3 strength in the shoulder flexors and abductors and elbow extensors*." The modification was made since the current options A to C are descriptions of abilities, while option D more was specific implying strength of at least 3 for shoulder abduction and flexion, but without specifying it. In addition, it has been decided to distinguish between active and passive movement. By reaching we intend to explain that the elbow extension function has strength of at least 3. With the new wording we use a descriptive option D like for the options A to C, but on the same time include a little quantification like in option C.

VARIABLE NAME: Date performed.

DESCRIPTION: This variable documents the date of data collection.

CODES: YYYY/MM/DD

COMMENTS: As the collection of data on upper extremity status may be carried out at any time following the spinal cord lesion, the date of data collection is imperative for computing time since the initial spinal cord lesion and to relate the information to other data collected on the same individual at various time points.

VARIABLE NAME: Basic hand-upper extremity function

DESCRIPTION: This variable consists of two items, one for the right upper extremity and one for the left upper extremity. Each item describes the hand-arm function as it relates to motor innervation, or functional gain after upper extremity reconstructive surgery or during or after the use of a neuroprosthesis.

CODES: Description of upper extremity function related to motor innervations. The check box (one only for each site – right/left - separately) should be marked if any of these are relevant:

Specify the level of hand-upper extremity function as being:

1. **No upper extremity function at or below the elbow**
No voluntary control of elbow, wrist, or hand muscles; no grasping function; severely limited active placing or reaching of the arm.

2. **Passive tenodesis hand**
Passive hand functions with neither voluntary control of extrinsic and intrinsic hand muscles nor ability to actively extend the wrist. Opening and closing of the hand is only possible by supination or pronation of the forearm (passive tenodesis effect) with no active grasping movements of the hand. Bimanual grasping by stabilizing objects between two hands or passive tenodesis grasp is effective only in a limited workspace.

3. **Active tenodesis hand**
No voluntary control of extrinsic and intrinsic hand muscles but active wrist extension allowing for passive movements of fingers dependent on a tenodesis effect. Limited single-handed grasping function in a restricted workspace.

4. **Active extrinsic hand**
Voluntary control of wrist and some extrinsic finger muscles allowing for weak grasping by means of some active opening and closing of the hand with or without tenodesis but reduced dexterity.

5. **Active extrinsic-intrinsic hand**

Voluntary control of extrinsic and intrinsic hand muscles and the ability to perform different grasp forms (e.g. power grip (holding a hammer), precision grip (holding an egg), lateral power pinch (key-grip), precision-pinch (holding a needle)) but with limitations of muscle strength and dexterity.

COMMENTS: The description of hand-upper extremity function based on pattern of complex muscle innervation focused on hand movements provides complementary information to measures of activities of daily living (ADL) (Kalsi-Ryan et al. 2012b). While the latter are sensitive to reveal the impairment of specific functions they are not disclosing the underlying innervation and principal kind of grasping (Kalsi-Ryan S et al. 2012b; Cacho et al. 2011). Also retrieving the muscle strength of ISNCSCI upper extremity key muscle function does not reveal how the individual is able to use the hand – forearm – proximal arm in complex movements (Kirshblum et al. 2011b; Rudhe & van Hedel 2009). The 5 levels of hand function described integrate the innervation of upper extremity muscles required to perform hand movements (like grasping and holding objects in the hand, manipulation (pro/supination) and placement) and depend on a sufficient voluntary innervation. Therefore, the ability to perform the described hand functions is not only dependent on the innervation per se but also the ability to release movements against potential antagonistic muscles or changes within the fibro-elastic tissues (like increased muscle tone and contractions) counteracting movements (Steeves et al. 2012). The combination of these hand function assessments with ADL measures is able to elucidate if the individual is experiencing either an improvement or deterioration of the voluntary control of hand function (like changes in the neurological level or within myotomes) or if changes in his ADL are rather dependent on changes in his/her skill levels (like effects of training or non-use) (Zariffa et al. 2011). Therefore, follow up assessments of these 5 levels of hand function will help to disclose relevant changes in the innervation pattern of individuals with cervical SCI.

VARIABLE NAME: Shoulder function classification

DESCRIPTION: Shoulder function classification based on observed function of the shoulder and upper extremity.

CODES: Each side is scored separately according to the following 4-point scale:

A. No active placing or reaching of the arm.
B. Severely limited but able to position hand on a desk, without assistance, but not able to reach to the mouth/head (gravity compromises the movements).
C. Limited but able to reach mouth/head with difficulty or altered movements, e.g. weak or absent pronation-supination or wrist flexion-extension.
D. Ability to reach in all directions including lifting hand above the head reflecting at least grade 3 strength in the shoulder flexors and abductors and elbow extensors.

COMMENTS: Scores from the hand-upper extremity function (numerical values from 1 to 5) are coupled with scores from this item (letter values from A to D). For example, a person with central cord syndrome or with a high tetraplegia could be scored as 3A or 3B, and a person with less affected shoulder function could be scored as 3C or 3D. The combination of a numerical value (1-5) and a letter (A-D) defines the whole upper extremity rather than just hand function.

VARIABLE NAME: Use of assistive devices

DESCRIPTION: Assistive devices include all equipment used to augment or provide upper extremity/hand function to perform activities. This includes equipment such as universal cuffs, hand splints and orthoses, including spring-loaded types, adaptive devices (built-up utensils, writing, splint, cup holders, etc.), surface *functional* electrical stimulation (FES), and robotic feeders.

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Not included:
Equipment used for positioning the hand\arm to prevent tightness or contractures such as static resting hand splints, elbow extension splints, etc;
Equipment used for therapeutic interventions to train, strengthen or exercise the hand\arm such as surface *therapeutic* electrical stimulation, passive range of motion machine, etc;
Environmental control units
Implanted technology
Free standing robotic arms

CODES: Never or less than monthly
Not weekly, but one or more times monthly
Not daily, but one or more times weekly
Used daily

COMMENTS: Splints can be used to improve functioning (for instance writing splints, typing splints, etc.). Clinical practice supports the use of splints but little evidence about their effectiveness is available in the literature (Connolly et al. 2012). Flexor hinge splints (Nichols et al. 1978) are infrequently used. Suspension and arm support devices are used in individuals with C4-C5 tetraplegia and found to be beneficial; however, evidence about their efficacy is unavailable (Atkins et al. 2008). Standardisation of splinting protocols was found to be difficult (Curtin 1994) but recommendations about usage of different types of splints are published in textbooks (Kirshblum et al. 2011; Mulcahey 2008). A number of adaptations of writing material, cutlery, ADL equipment (quite often individually made) can be used to enhance usage of impaired upper extremity function (Kirshblum 2011). With surface FES systems, paralysed muscles are stimulated to contraction, which is the function needed, for instance, to provide grasp. The use of FES was reviewed (Ragnarsson 2008). It should be noted that various

surface FES systems have very different capabilities and fidelity of the grasp produced.
Robotic assistive devices like robotic feeders are used increasingly to improve the independence and quality of life of persons with disabilities (Brose et al. 2010).

VARIABLE NAME: SCI-related complications to upper extremity function like pain, spasms, contractures, oedema.

DESCRIPTION: This variable describes any complications to upper extremity function like pain, spasms, contractures, oedema.

CODES: Minimal – no complications or complications have minimal impact on function
Moderate – complications have moderate impact on function
Extensive – complications have extensive impact on function

COMMENTS: It will include all:
Pain (nociceptive, neuropathic, general, focal)
Spasms (helpful, harmful, general, focal)
Contractures (minor, major)
Oedema (minor, major)

This will not include:
- Concomitant injuries to the extremity at the time of injury such as brachial plexus injury, amputation, fracture, etc
- Self-inflicted injuries to the extremity

For more detailed pain description it is advised to use the International SCI Pain Basic Data Set (Widerstöm-Noga et al. 2008)

VARIABLE NAME: Upper Extremity/Hand Reconstructive Surgery

DESCRIPTION: This variable documents if reconstructive surgery has been performed specifically for the improvement of arm and/or hand function.

CODES: Yes:
Includes any surgical procedures to the arms and/or hands to restore function, i.e. soft tissue reconstruction such as tendon transfers, lengthenings and releases; de-rotational osteotomies; implantation of a functional electrical stimulation system.

No:
Excluded are:
Surgical procedures to the arms or hands during initial management of the SCI for repair of concomitant brachial plexus injury or for treatment of concomitant upper extremity fractures, burns or other injuries.

Surgical procedures that may have an effect on the upper extremity but are not performed specifically to the upper extremity to improve function, e.g. surgical implant of baclofen pump; and dorsal rhizotomy.

Surgical procedures to the upper extremity for purposes other than to improve function, e.g. surgery for cosmesis; hygiene; positioning; skin grafts for pressure sores, burns, etc; management of fractures or other injuries.

Unknown

COMMENTS: Reconstructive arm and hand surgery, including surgically implanted functional electrical stimulation systems and nerve transfers (Peckham et al 2001: Keith 2001; Mackinnon et al 2012; Fridén & Gohritz 2013), is sometimes performed after discharge from initial rehabilitation and when neurological stability has been documented. While these surgeries can include tendon and muscle lengthenings and releases and de-rotational osteotomies, the primary surgical procedure to restore upper extremity function after SCI involve tendon transfers (Keith & Peljovich 2012; Fridén et al 2011; Kozin et al 2010; Leclerq et al 2008; Mulcahey 2008; Mulcahey et al 2003). In cases of SCI, tendon transfers are performed when two or more muscles that provide the same function have been preserved; one of the tendons can be transferred to restore distal function without compromise to the original function. As an example, in an individual with a C5 level SCI with preserved function of the brachialis, biceps and brachioradialis muscles, the brachioradialis can be transferred distally to restore wrist extension without compromising voluntary elbow flexion. The number of distal movements that can be restored with tendon transfers relies entirely on the number of muscles/tendons available for tendon transfer (McDowell CL, et al 1986; Hentz VR et al. 2010).

VARIABLE NAME: Performed Upper Extremity/Hand Reconstructive Surgery

DESCRIPTION: This variable documents the kind of reconstructive surgery has been performed.

CODES: Check all that apply

	Type of surgery	Yes / No / Unknown	Date of surgery (yyyy/mm/dd)
Soft Tissue Reconstruction	Tendon transfer for elbow extension (right)	□ Yes □ No □ Unknown	
	Tendon transfer for elbow extension (left)	□ Yes □ No □ Unknown	
	Tendon transfer for wrist extension (right)	□ Yes □ No □ Unknown	
	Tendon transfer for wrist extension (left)	□ Yes □ No □ Unknown	
	Restoration of pinch and or grasp (right)	□ Yes □ No □ Unknown	
	Restoration of pinch and or grasp (left)	□ Yes □ No □ Unknown	
	Tendon/muscle releases or lengthenings (right)	□ Yes □ No □ Unknown	
	Tendon/muscle releases or lengthenings (left)	□ Yes □ No □ Unknown	
	Other, specify:_____	□ Yes □ No □ Unknown	
Osteotomy with or without rotation and or Arthrodesis	Humerus (right)	□ Yes □ No □ Unknown	
	Humerus (left)	□ Yes □ No □ Unknown	
	Radius (right)	□ Yes □ No □ Unknown	
	Radius (left)	□ Yes □ No □ Unknown	
	Ulnar (right)	□ Yes □ No □ Unknown	
	Ulnar (left)	□ Yes □ No □ Unknown	
	Wrist (right)	□ Yes □ No □ Unknown	
	Wrist (left)	□ Yes □ No □ Unknown	
	Fingers/Thumb (right)	□ Yes □ No □ Unknown	
	Fingers/Thumb (left)	□ Yes □ No □ Unknown	
Implantable FES	specify:_____	□ Yes □ No □ Unknown	
Other	specify:_____	□ Yes □ No □ Unknown	

COMMENTS: **Nothing should be checked if "NO" was documented for variable "**Upper Extremity/Hand Reconstructive Surgery"

Tendon transfer for elbow extension: Tendon transfer for elbow extension has been performed to restore/augment active elbow extension. The most common procedures to restore elbow extension in SCI are the deltoid-to-triceps transfer and biceps-to-triceps transfer (Kozin 2010; Leclerq 2008; Mulcahey 2003)

Tendon transfer for wrist extension: Tendon transfer for wrist extension has been performed to restore/augment active wrist extension. The primary procedure for restoration of wrist extension in SCI is transfer of the brachioradialis to radial wrist extensors (Fridén 2005)

Tendon transfer of pinch and grasp: Tendon transfer for pinch and\or grasp has been performed to restore/augment active hand function. The procedures used to restore hand function vary (Keith 2012; Fridén 2011; Zancolli 2002; House 1985; Waters 1985).

Tendon and muscle releases and/or lengthenings:

Other: Other surgical soft tissue reconstruction to improve arm/hand function such as tenodesis procedures (Treanor 1992; Waters 1985).

Osteotomy with or without rotation and/or arthrodesis : Osteotomy has been performed to position the extremity for function. In cases of internal rotation contracture of the shoulder and/or forearm supination contracture, a de-rotational osteotomy is performed to position the arm and forearm for function, respectively (Coulet et al 2010); these are usually done as a precursor to or in combination with tendon transfers. Fusion has been performed to stabilize a joint to improve function. The most common joints that are fused are in the thumb (House, et al 1992; Waters 1985).

Implantable FES: An FES system has been implanted in the upper extremity to restore stimulated arm and/or hand movement (Kilgore et al 2008; Peckham et al 2001; Mulcahey et al 1997).

Other: May include nerve transfer or other surgeries meant to restore arm and/or hand function.

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INTERNATIONAL SPINAL CORD INJURY UPPER EXTREMITY BASIC DATA SET FORM (Version 1.1)

Date performed: YYYY/MM/DD

Evaluation of the RIGHT and LEFT upper extremity separately:

Ability to reach and grasp (part of the GRASSP test):	**Shoulder function classification:**
1. No upper extremity function at or below the elbow No voluntary control of elbow, wrist, or hand muscles; no grasping function; severely limited active placing or reaching of the arm. **2. Passive tenodesis hand** Passive hand functions with neither voluntary control of extrinsic and intrinsic hand muscles nor ability to actively extend the wrist. Opening and closing of the hand is only possible by supination or pronation of the forearm (passive tenodesis effect) with no active grasping movements of hand. Bimanual grasping by stabilizing objects between two hands or passive tenodesis grasp is effective only in a limited workspace. **3. Active tenodesis hand** No voluntary control of extrinsic and intrinsic hand muscles but active wrist extension allowing for passive movements of fingers dependent on a tenodesis effect. Limited single-handed grasping function in a restricted workspace. **4. Active extrinsic hand** Voluntary control of wrist and some extrinsic hand muscles allowing for grasping with or without tenodesis enabling some active opening and closing of the hand but reduced dexterity and reduction of workspace. **5. Active extrinsic-intrinsic hand** Voluntary control of extrinsic and intrinsic hand muscles with full workspace and the ability to perform different grasp forms (e.g. power grip, precision grip, lateral power pinch, precision pinch) but potential limitations of muscle strength and dexterity.	**A.** No active placing or reaching of the arm. **B.** Severely limited but able to position hand on a desk, without assistance, but not able to reach to the mouth/head (gravity compromises the movements). **C.** Limited but able to reach mouth/head, with difficulty or altered movements, e.g. weak or absent pronation-supination or wrist flexion-extension. **D.** Ability to reach in all directions including lifting hand above the head reflecting at least grade 3 strength in the shoulder flexors and abductors and elbow extensors.

Basic right hand - upper extremity function: __ __ (select one number (1-5) and one letter (A-D) from above corresponding to the best description of the hand and upper extremity function)

Basic left hand - upper extremity function: __ __ (select one number (1-5) and one letter (A-D) from above corresponding to the best description of the hand and upper extremity function)

Use of assistive devices (all equipment like splints, adaptive equipment, surface functional electrical stimulation (FES), etc.) used to enhance upper extremity function:

□ Never or less than monthly
□ Not weekly, but one or more times monthly

□ Not daily, but one or more times weekly
□ Used daily

Complications to upper extremity function like pain, spasms, contractures, oedema, etc.:
□ Minimal – no complications or complications have minimal impact on function
□ Moderate – complications have moderate impact on function
□ Extensive – complications have extensive impact on function

Upper Extremity/Hand Reconstructive Surgery
□ Yes □ No □ Unknown
If Yes, fill in below

Performed Upper Extremity/Hand Reconstructive Surgery
Check all that apply

	Type of surgery	Yes / No / Unknown	Date of surgery (yyyy/mm/dd)
Soft Tissue Reconstruction	Tendon transfer for elbow extension (right)	□ Yes □ No □ Unknown	
	Tendon transfer for elbow extension (left)	□ Yes □ No □ Unknown	
	Tendon transfer for wrist extension (right)	□ Yes □ No □ Unknown	
	Tendon transfer for wrist extension (left)	□ Yes □ No □ Unknown	
	Restoration of pinch and or grasp (right)	□ Yes □ No □ Unknown	
	Restoration of pinch and or grasp (left)	□ Yes □ No □ Unknown	
	Tendon/muscle releases or lengthenings (right)	□ Yes □ No □ Unknown	
	Tendon/muscle releases or lengthenings (left)	□ Yes □ No □ Unknown	
	Other, specify:_____	□ Yes □ No □ Unknown	
Osteotomy with or without rotation and or Arthrodesis	Humerus (right)	□ Yes □ No □ Unknown	
	Humerus (left)	□ Yes □ No □ Unknown	
	Radius (right)	□ Yes □ No □ Unknown	
	Radius (left)	□ Yes □ No □ Unknown	
	Ulnar (right)	□ Yes □ No □ Unknown	
	Ulnar (left)	□ Yes □ No □ Unknown	
	Wrist (right)	□ Yes □ No □ Unknown	
	Wrist (left)	□ Yes □ No □ Unknown	
	Fingers/Thumb (right)	□ Yes □ No □ Unknown	
	Fingers/Thumb (left)	□ Yes □ No □ Unknown	
Implantable FES	specify:_____	□ Yes □ No □ Unknown	
Other	specify:_____	□ Yes □ No □ Unknown	