INTERNATIONAL SPINAL CORD INJURY DATA SETS

UPPER EXTREMITY BASIC DATA SET (Version 1.0) – COMMENTS

The working-group consists of:

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Jan Friden,
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Milos Popovic, member of ASIA.
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Anne Sinnott,
Govert Snoek, member of ISCoS.

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), and e.g. 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, cause 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 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.

This document was produced under the umbrella of ISCoS and ASIA.

Acknowledgements:
We are thankful for comments and suggestions received from Lawrence Vogel,........
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 limb function

DESCRIPTION: This variable consists of one item, documenting:
Description of hand-arm function related to motor innervation

CODES: Description of upper extremity function related to motor innervations. The check box (one only) should be marked if any of these are relevant:

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

1. **No hand function**
   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 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 - tenodesis 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 (pulp pinch) but potential limitations of muscle strength and dexterity.
The description of hand-upper limb 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 limb key muscle functions is not revealing how the patient is able to use the hand – forearm – proximal arm as needed in complex movements (Kirshblum et al. 2011b; Rudhe & van Hedel 2009). The described 5 levels of hand function integrate the innervation of upper limb 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) countering movements (Steeves et al. 2012). The combination of these hand function assessments with ADL measures is able to elucidate if the patient 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 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 patients with cervical SCI.

**VARIABLE NAME:** Shoulder function classification

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

**CODES:** Each level of hand function related to motor innervations described above should be coupled with a level of shoulder function by following 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, and overcome gravity, with difficulty or altered movements, e.g. weak or absent pronation-supination or wrist flexion-extension.
D. Full range of movement (ROM) of shoulder and independent reaching forward and upward.

**COMMENTS:** The above codes A-D related to the level of shoulder function is to be combined with the level of hand function related to motor innervations. An example: The function of central cord syndrome or a high...
tetraplegia could be scored as 3A or 3B, while those with less affected shoulder function would score 3C or 3D. The combination of a numerical value (1-5) and a letter (A-D) would define the whole upper limb rather than just the focal hand function.

VARIABLE NAME: Use of assistive devices

DESCRIPTION: Assistive devices include all equipment that is used to augment or provide upper extremity/hand function for the purpose to perform activities. This includes equipment such as universal cuff, hand splints and orthoses, adaptive equipment (built-up utensils, writing splint, cup holder, etc), surface functional electrical stimulation (FES), and robotic feeders.

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
- Implant 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 practise support the use of splints but little evidence about effectiveness is available in the literature (Conolly et al. 2012). Flexor hinge splints (Nichols et al. 1978) seem being less frequently used nowadays. Suspension and arm support devices are used in patients with C4-C5 tetraplegia and found to be beneficial however evidence about effect is not available (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. 2002; 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 2002). With surface FES systems, paralysed muscles are stimulated to contraction, which is the function needed for instance to provide grasp. The current status about FES has been reviewed by Ragnarsson (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
The field of robotic devices and surface FES systems is evolving rapidly.

**VARIABLE NAME:** Complications to upper extremity function like pain, spasms, contractures, oedema, etc.

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

**CODES:**
- None
- Mild
- Extensive

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

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**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:
  - Include 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 limb fractures, burns or other injuries.
    - Surgical procedures that may have an effect on the upper limb but are not performed specifically to the upper limb to improve function, e.g. surgical implant of baclofen pump; and dorsal rhizotomy.
    - Surgical procedures to the upper limb 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.

**COMMENTS:**
- Reconstructive arm and hand surgery, including surgically implanted functional electrical stimulation systems (Peckham et al 2001; Keith 2001), is typically 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 limb 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 (reference McDowell).

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

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<th>Date of Surgery</th>
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<td>Elbow extension</td>
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<td>Extension</td>
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<td>Restoration of Pinch</td>
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<td>and or Grasp</td>
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<td>Tendon/muscle</td>
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<td>Wrist</td>
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<td>Fingers/Thumb</td>
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<tr>
<td>Implantable FES</td>
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</tbody>
</table>

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.
Tendon Transfer for Wrist Extension: Tendon transfer for wrist extension has been performed to restore or 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 or 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 (Tranor 1992; Waters 1985).

Osteotomy with or without Rotation and/or Arthrodesis:
Osteotomy has been performed to position the limb 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 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 limb to restore stimulated arm and/or hand movement (Kilgore et al 2008; Peckham et al 2001; Mulcahey et al 1997).
References:


INTERNATIONAL SPINAL CORD INJURY UPPER EXTREMITY BASIC DATA SET FORM (Version 1.0)

Date performed: YYYY/MM/DD

### Ability to reach and grasp (part of the GRASSP test):

<table>
<thead>
<tr>
<th>No hand function</th>
<th>Shoulder function classification:</th>
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</thead>
<tbody>
<tr>
<td>No voluntary control of elbow, wrist, or hand muscles; no grasping function; severely limited active placing or reaching of the arm.</td>
<td>A. No active placing or reaching of the arm.</td>
</tr>
<tr>
<td>2. Passive tenodesis hand</td>
<td>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).</td>
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<td>3. Active tenodesis hand</td>
<td>D. Full range of movement (ROM) of shoulder and independent reaching forward and upward.</td>
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<td>Voluntary control of extrinsic and intrinsic hand muscles with full workspace and the ability to perform different grasp forms (pulp pinch) but potential limitations of muscle strength and dexterity.</td>
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</tbody>
</table>

### Basic hand-upper limb 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, 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.:

- None
- Mild
- Extensive

### Upper Extremity/Hand Reconstructive Surgery
If Yes, fill in below

**Performed Upper Extremity/Hand Reconstructive Surgery**
Check all that apply

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<thead>
<tr>
<th>Soft Tissue Reconstruction</th>
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<tr>
<td>Tendon transfer for Elbow extension</td>
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<td>Restoration of Wrist Extension</td>
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<td>Restoration of Pinch and or Grasp</td>
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<td>Tendon/muscle Releases or lengthenings</td>
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<td>Other</td>
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<tr>
<th>Osteotomy without rotation and or Arthrodesis</th>
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**Implantable FES**