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The purpose of the International Spinal Cord Injury (SCI) Musculoskeletal Basic Data Set is to standardize the collection and reporting of a minimal amount of information about musculoskeletal 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 Musculoskeletal Basic Data Set be used in connection with the International SCI Core Data Set (DeVivo et al. 2006). 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.

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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**VARIABLE NAME:** Date performed.

**DESCRIPTION:** This variable documents the date of data collection.

**CODES:** YYYY/MM/DD

**COMMENTS:** As the collection of data on musculoskeletal 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.

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**VARIABLE NAME:** Neuro-Musculoskeletal history before spinal cord lesion.

**DESCRIPTION:** This variable consists of 3 parts, documenting:
- Pre-existing congenital deformities of the spine and spinal cord
- Pre-existing degenerative spine disorders
- Pre-existing systemic neuro-degenerative disorders

**CODES:**
- The check box should be marked if any of these are relevant:
  - Pre-existing congenital deformities of the spine and spinal cord
    - If yes specify:
      - Diagnosis
      - Location
      - If previous surgery due to this, description
      - Date of surgery YYYYMMDD
      - Unknown
  - Pre-existing degenerative spine disorders
    - If yes specify:
      - Diagnosis
      - Location
      - If previous surgery due to this, description
      - Date of surgery YYYYMMDD
      - Unknown
  - Pre-existing systemic neuro-degenerative disorders
    - If yes specify:
      - Diagnosis
      - Location
      - If previous surgery due to this, description
      - Date of surgery YYYYMMDD
      - Unknown

**COMMENTS:** Any neuro-musculoskeletal disorders preceding the onset of the spinal cord lesion are to be documented. This is important because relevant pre-existing neuromuscular disorders may influence management.

**Congenital disorders** include malformations or other pathology of **bones** (infantile idiopathic scoliosis (Dobbs et al. 2002; Pahys et al. 2009), congenital spinal canal stenosis (Kotil et al. 2007), achondroplasia (Laederich and Horton 2010; Benglis and Sandberg...
muskles (muscular dystrophy) or neural tissues (syringo-hydromyelia). These also include combined multi system/organ disorders such as myelomeningocele (MMC) (Guille et al. 2006; Rajpal et al. 2007), malformations of the craniocervical junction (i.e. Arnold Chiari type, congenital stenosis, Klippel-Feil anomalies etc.) (Fernandez et al. 2009; Nakamura et al. 2009; Pahys et al. 2009) or tethered cord (Kramer et al. 2009; Iskandar et al. 2001). Sometimes, these conditions are present in early childhood but only become symptomatic during adolescence or advancing age. This may be due to progression or unmasking of the condition.

Degenerative spine disorders present with aging. The most common disorders are lumbar (Abbas et al. 2010; Yasar et al. 2009) and cervical (Tracy & Bartleson 2010; Fehlings & Arvin 2009) spinal canal stenosis, spondylosis and degenerative systemic disorders (like diffuse idiopathic skeletal hyperostosis (DISH) and rheumatoid arthritis). These disorders typically develop slowly with the spinal cord often adapting to extensive morphological changes before notable impairment. The onset of impairments is usually slow and insidious and therefore not noticed by individuals for a considerable time. However, the degenerative changes can increase susceptibility to spinal cord lesions from relatively minor insults, e.g. minor falls with mild extension/flexion trauma inducing a central cord syndrome (Matz et al. 2009).

Systemic neuro-degenerative disorders comprise conditions like multiple sclerosis, amyotrophic lateral sclerosis and others. They typically occur in adults and are characterized by an acute or chronic progressive course, which can eventually present as tetra/paraplegia.

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**VARIABLE NAME:** Presence of spasticity / spasms.

**DESCRIPTION:** This variable documents the presence of spasticity / spasms

**CODES:**
- No
- Yes

**COMMENTS:** The presence of spasticity / spasms in the upper and lower extremities is captured using the modified Ashworth scale (MAS) (Bohannon & Smith 1987), i.e. > 1 on the MAS, or observation of spasms. A spinal cord lesion leaves the individual with involuntary spasms (muscle jerks), altered motor control, and/or spasticity in about half of all SCI individuals (Hsieh et al. 2008). This altered control can be expressed in a variety of ways (Priebe et al. 1996). The common definition of spasticity is based on the finding of increased resistance to passive stretch. Although MAS captures only a few aspects of a rather multidimensional and phenomenologically diverse
symptomatology, the clinically important key elements are measured (Pandyan et al. 2005). Abnormal motor control is manifested as negative signs (paresis or paralysis) or positive signs, often termed ‘spasticity’. This is a broader definition than focusing on exaggerated responses to passive movement, specifically velocity-dependent responses, which are present only about a third of the time in individuals with “spastic” SCI (Lance 1980). More commonly, the positive signs frequently and prominently include loss of coordination of voluntary movement and spasms, or involuntary movement. One way of characterizing the multidimensional nature of “spasticity” is with a battery of tests, but additional validation of these tests is required before advocating their widespread use (Sherwood & McKay 2006). (Modified) Ashworth (Ashworth 1964; Bohannon & Smith 1987), and Tardieu scales (1954) have proven useful to some extent, but rely on subjective evaluation of specific characteristics of spasticity and thus are limited in their applicability and are population dependent. They are commonly used for research purposes (Biering-Sørensen et al. 2006). It is noted that there may be mechanical changes in muscle fiber, collagen tissue, and tendon properties secondary to “spasticity” (Dietz & Sinkjaer, 2007), which may confound the assessment (Sherwood et al. 2000). However, contractures would not be expected to have an immediate response to therapies intended to ameliorate spasticity.

**VARIABLE NAME:** Treatment for spasticity within the last four weeks.

**DESCRIPTION:** This variable documents if the person with SCI has received any kind of treatment for spasticity within the last four weeks.

**CODES:**

- No
- Yes

**COMMENTS:** A “yes” is indicated if any kind of treatment has been used for spasticity over the last four weeks regardless of whether it was or was not prescribed. This may include physical, pharmacological, surgical or other. Four weeks has been chosen to give recent status.

**VARIABLE NAME:** Fracture(s) since the spinal cord lesion.

**DESCRIPTION:** This variable documents whether the person with SCI has had any type of fracture since the spinal cord lesion, the date the fracture occurred, and whether or not the fracture was a fragility fracture.

**CODES:**

- Location: Cervical spine, Shoulder/Humerus, Elbow, Forearm, Wrist, Hand, Thoracic spine, Lumbar spine, Pelvis (ilium, ischium, pubic symphysis, sacrum, coccyx), Hip/Femur, Knee, Tibia/fibula, Ankle, Foot – right and left when appropriate
- Date of Fracture (YYYY/MM/DD)
Fragility Fracture (check box)

**COMMENTS:**
The location of each fracture should be checked in the appropriate box. The date of the fracture should be recorded. If the precise date is unavailable, the month and/or year should be recorded and the date left blank. Only fractures not previously documented need to be recorded. Therefore if information for the dataset is being collected for the first time after SCI, all previous fractures since SCI should be recorded. Thereafter, only fractures which have occurred since the last recording of information for the dataset should be recorded.

It is important to distinguish between incident and fragility fractures. Fragility fractures result from low force injuries insufficient to fracture normal bone (Jiang SD et al. 2006; Craven et al. 2009). Common aetiologies of fragility fractures after SCI include leg torsion during transfers or rolling in bed, or falling to the floor from a wheelchair or commode on a flexed knee. Compression fractures of vertebral bodies should be considered fragility fractures, in the absence of reported trauma. In comparison, incident fractures are caused by injuries sufficient to fracture normal bone (i.e., motor vehicle accident). Fragility fractures should be noted by checking the corresponding box.

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**VARIABLE NAME:** Heterotopic Ossification (HO).

**DESCRIPTION:** This variable documents the diagnosis of HO. It is a diagnosis based on signs and symptoms and confirmed with positive imaging.

**CODES:**
- Presence or absence of HO for right shoulder, left shoulder, right elbow, left elbow, right wrist, left wrist, right hand, left hand, right hip, left hip, right knee, left knee, right ankle, left ankle, right foot, left foot.

Method used to document HO:
- X-ray
- CT-scan
- Triple phase bone scan
- Other method, specify________

**COMMENTS:**
HO refers to the abnormal formation of bone in soft tissues typically around joints such as the hips, knees, shoulders and elbows. The initial signs and symptoms are often related to inflammation with swelling, restricted range of motion, hyperemia, and, if perceived, pain. HO is associated with elevated serum alkaline phosphatase and confirmed with plain x-ray or CT indicating detectable calcified bone formation or triple phase bone scan. These are reliable and sensitive indicators of the formation process. HO can also be confirmed with MRI and ultrasound although these are less commonly used.

The incidence of HO varies in SCI populations from 10 to 53%. It commonly develops within the first 2–3 weeks after SCI and is most common at the hip (70–97%) and knee (van Kuijk et al. 2002; Banovac et al. 2001). Ultrasound can be used as a screening tool if there is a
high index of suspicion, but should then be confirmed by one of the tests listed (Citak et al 2011).

VARIABLE NAME: Contracture.

DESCRIPTION: This variable documents the presence of joint contractures.

CODES: Presence or absence of contracture(s) for right shoulder, left shoulder, right elbow, left elbow, right wrist, left wrist, right hand, left hand, right hip, left hip, right knee, left knee, right ankle, left ankle, right foot, left foot.

COMMENTS: Contractures are a common complication of SCI (Fergusson et al. 2006; Vogel et al. 2002; Eriks-Hoogland et al. 2008) and are characterized by a loss in passive joint range of motion (Farmer & James 2001; Lieber 2009). It is important to identify contractures in order to implement appropriate treatments and monitor change (Harvey & Herbert 2002). Passive joint range of motion can be measured quantitatively with a goniometer (van de Pol et al. 2010) however, for the purposes of this data set the committee recommends the use of visual and physical assessment to determine loss in joint range of motion. Only obvious loss in joint range of motion that can be readily seen or easily felt should be recorded as a contracture. More subtle loss in joint range of motion should only be recorded as a contracture if it warrants intervention or has clear and marked deleterious implications on function, hygiene, skin management or any other aspect of quality of life (Center NSCIS 1990). For example, subtle loss of passive elbow extension in a person with C6 tetraplegia would be recorded as a contracture if it clearly prevents the person from transferring. An equivalent subtle loss of passive elbow extension would not be recorded as a contracture in a person with C4 tetraplegia if it had no obvious and marked deleterious implications.

VARIABLE NAME: Degenerative Changes / Overuse.

DESCRIPTION: Degenerative neuromuscular and skeletal changes due to overuse after SCI.

CODES: Location: right/ left side of the Neck, Shoulder/Humerus, Elbow, Forearm, Wrist, Hand, Upper back, Lower back, Pelvis (ilium, ischium, pubic symphysis), Hip/Femur, Knee, Tibia/fibula, Ankle, Foot.

COMMENTS: This variable requires the assessor to distinguish musculoskeletal challenges induced by overuse from independently occurring neuropathic and visceral pain. Overuse injuries can result from repetitive movements causing joint (bone and cartilage) and muscular injuries. The most common symptom of overuse is pain or discomfort. Overuse injuries commonly occur at the musculotendinous junction but
can also occur at the cartilage, bone and bursa (Apple et al. 1996). Shoulder pain is present in approximately 30 to 70% of persons with SCI. Its severity and presence is determined by age, duration of injury, neurological level (more in people with tetraplegia), severity of injury, wheelchair use, sitting posture, flexibility, stability of the shoulder joint and overall body mass index. Shoulder pain is more common in people with SCI of older age, and for women (Dyson-Hudson & Kirshblum 2004, Lal, S, 1998, van Drongelen et al, 2006). Manual wheelchair users often experience pain that limits activities of daily living (ADL) such as transfers, propulsion and overhead reaching. Shoulder pain may be due to propelling a wheelchair over many years (Pentland 1994). It is however also seen in individuals heavily reliant on crutches or canes to ambulate (Jain et al. 2010). Overuse injuries of the elbow tend to result in muscle/tendon strains or nerve entrapments (Boninger et al, 2003). Wrist overuse injuries often lead to carpal tunnel syndrome. Lower extremities may also be affected in individuals with SCI. Knee problems have been described, due to e.g. trauma, and tears of ligaments (Mukand et al. 1998). In case the degenerative neuromuscular or skeletal changes due to overuse in the neck, upper or lower back is located in the midline without lateralization both right and left is to be marked.

VARIABLE NAME: Spinal cord injury related neuromuscular scoliosis.

DESCRIPTION: This variable documents any appreciable observable lateral deviation in the normally straight vertical line of the spine due to the sequelae of SCI.

CODES: No
Yes

COMMENTS: No: The head is aligned over the pelvis during unsupported sitting (not balanced with arms/hands; lateral supports; chest straps; etc) or while standing erect.

Yes: There is an observable deviation of the head over the trunk and pelvis during unsupported sitting or standing due to scoliosis as a co-morbidity of SCI.

Note: This variable does not include problems with the alignment of the spine due to problems other than SCI, such as Idiopathic Scoliosis; pre-injury neuromuscular scoliosis, as in Marfan’s Syndrome; Larson’s Syndrome; Downs Syndrome; Klippel Feil Syndrome, degenerative disk disease, osteoporosis in the aging spine, etc. There is a wide range of normal variation in sagittal profiles and it is possible that each individual has specific requirements for cervical/lumbar lordosis and thoracic kyphosis as a result of pelvic orientation. Scoliosis is defined as a 10 degree curvature of the spine (Scoliosis Research Society, 1976).
Scoliosis is a known musculoskeletal complication of SCI, particularly when SCI occurs at a younger age (Brown et al. 1984; Campbell & Bonnett 1975; Dearolf et al. 1990; Lancourt et al. 1981; Mayfield et al. 1981; Vogel et al. 2003; Lubicky & Betz 1996).

VARIABLE NAME: Method of assessment, when a scoliosis is present.

DESCRIPTION: This variable indicates the method(s) used to determine the presence of neuromuscular scoliosis.

CODES: Check all that apply
- Observation in sitting
- Observation in standing
- Plain Radiographs in sitting
- Plain radiographs in standing

COMMENTS: The clinical and physical examination is pivotal to the diagnosis of scoliosis and is evidenced by the observed lateral deviation of the head, trunk and pelvis over the spine and shoulder asymmetry. For the evaluation of neuromuscular scoliosis, it is important to temporarily remove any modification to a wheelchair or seating system that is providing external support to maintain head and spine alignment (for example, lateral supports, chest harness, etc) (Lubicky & Betz 1996; Lord et al. 1990; Mulcahey & Betz 2008). Likewise, any type of support to the trunk in the form of a brace or binder needs to be removed for assessment of the scoliosis.

A diagnosis of scoliosis requires a plain radiograph that shows a Cobb Angle of at least 10 degrees (O’Brien 2005; Terminology committee of the Scoliosis Research Society 1976). While the Cobb Angle of 10 degrees is used as the definitive diagnoses for idiopathic scoliosis, there is evidence that strong inter-rater reliability of the Cobb Angle in SCI also falls within 10 degrees and hence, has been adopted as the radiographic diagnosis of neuromuscular scoliosis (Gupta et al. 2007).

VARIABLE NAME: Surgical treatment of the scoliosis.

DESCRIPTION: This variable documents if the scoliosis has been surgical treated.

CODES: Check the box if Yes to surgical treatment
- Date to be given for the surgical treatment, if the date is not known
- Unknown to be checked

COMMENTS: Nearly all children injured with SCI prior to reaching skeletal maturity will develop scoliosis and 75% will require some type of surgical intervention to stop the progression of the curve (Brown et al. 1984; Campbell & Bonnett 1975). When the SCI occurs in adolescence, 78%
of children injured at 14 years, 57% of children injured at 15 year, and 50% of children injured at 16 years develop scoliosis that required either conservative treatment (modifications to wheelchair, bracing) or surgical intervention (spinal fusion) (Brown et al. 1984; Vogel et al. 2003).

VARIABLE NAME: Other musculoskeletal problems.

DESCRIPTION: This variable documents the presence of any other musculoskeletal problems not described above.

CODES: Other musculoskeletal problems; specify__________________

COMMENTS: This variable requires the assessor to specify any other type of musculoskeletal problem not captured in the other variables. This could among other issues include gibbus formation in relation to Pott’s paraplegia (Benzagmout et al. 2011; Moon et al. 2003).

VARIABLE NAME: Does any of the musculoskeletal challenges above interfere with your activities of daily living.

DESCRIPTION: This variable documents if any of the musculoskeletal challenges above interferes with daily activities, such as transfers, walking, dressing, showers, etc.

CODES: No – not at all
       Yes, a little
       Yes, a lot

COMMENTS: This variable requires the assessor to directly ask the individual with spinal cord lesion the following question “Does any of the musculoskeletal challenges above interfere with your activities of daily living (transfers, walking, dressing, showers, etc.)?” This variable captures the individual’s perceptions about any deleterious implications of any of the musculoskeletal challenges above on daily life. The perspective of the individual is important and this variable enables individuals to focus on activities relevant to them, whether it is due to spasticity (Lechner et al. 2006), heterotopic ossification, contracture(s), neuromuscular or skeletal overuse, scoliosis (Vogel et al. 2003; Lubicky & Betz 1996) or other musculoskeletal problems.
References:


van de Pol RJ, van Trijffel E and Lucas C. Inter-rater reliability for measurement of passive physiological range of motion of upper extremity joints is better if instruments are used: a systematic review. Australian Journal of Physiotherapy. 2010;56:7-17.


INTERNATIONAL SPINAL CORD INJURY MUSCULOSKELETAL BASIC DATA SET (Version 1.0)

Date performed: YYYY/MM/DD

Neuro-Musculoskeletal history before spinal cord lesion (collected once):

☑ Pre-existing congenital deformities of the spine and spinal cord
If yes, specify Diagnosis and Location__________________________________
If previous surgery due to this, description________________________________
Date of surgery YYYYMMDD       ☐ Unknown

☑ Pre-existing degenerative spine disorders
If yes, specify Diagnosis and Location__________________________________
If previous surgery due to this, description________________________________
Date of surgery YYYYMMDD       ☐ Unknown

☑ Pre-existing systemic neuro-degenerative disorders
If yes, specify Diagnosis and Location__________________________________
If previous surgery due to this, description________________________________
Date of surgery YYYYMMDD       ☐ Unknown

Presence of spasticity / spasms

☐ No ☐ Yes
Treatment for spasticity / spasms within the last four weeks?

☐ No ☐ Yes
Fractures, heterotopic ossifications, contractures, or degenerative changes/overuse:

<table>
<thead>
<tr>
<th>Fractures since spinal cord lesion (only those not documented previously)</th>
<th>Heterotopic ossification</th>
<th>Contracture</th>
<th>Degenerative changes / Overuse</th>
</tr>
</thead>
<tbody>
<tr>
<td>Right</td>
<td>Left</td>
<td>Date of fracture YYYY/MM/DD</td>
<td>Right</td>
</tr>
</tbody>
</table>

- Neck / Cervical spine
- Shoulder / Humerus
- Elbow
- Forearm
- Wrist
- Hand
- Upper back / Thoracic spine
- Lower back / Lumbar spine
- Pelvis
- Hip / Femur
- Knee
- Tibia / fibula
- Ankle
- Foot

Method used to document heterotopic ossification, if present:
- X-ray
- CT-scan
- Triple phase bone scan
- Other method, specify________

Scoliosis
- No
- Yes

If scoliosis is present, method of assessment (check all that apply)
- Observation in sitting
- Observation in standing
- Plain radiographs in sitting
- Plain radiographs in standing

If scoliosis is present, surgically treated? If Yes: Date of surgery YYYYMMDD
- Unknown

Other musculoskeletal problems; specify__________________________

Do any of the above musculoskeletal challenges interfere with your activities of daily living (transfers, walking, dressing, showers, etc.)?
- No – not at all
- Yes, a little
- Yes, a lot