INTERNATIONAL SPINAL CORD INJURY DATA SETS

MUSCULOSKELETAL BASIC DATA SET (Version 1.0) – COMMENTS

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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.

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

2007)), **muscles** (muscular dystrophy) or **neural tissues** (syringo-hydromyelia). These also include combined multi system/organ disorders such as myelomenigocele (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.

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. $\geq$ 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.

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:

Abbas J, Hamoud K, Masharawi YM, May H, Hay O, Medlej B, Peled N, Hershkovitz I. Ligamentum flavus thickness in normal and stenotic lumbar spines. Spine (Phila Pa 1976). 2010 May 20;35(12):1225-30.

Apple, D, Cody, R, Allen, A. Overuse Syndrome of the Upper Limb in People With Spinal Cord Injury. In: Apple, DF, Editor, Physical Fitness: A guide for individuals with spinal cord injury. Journal of Rehabilitation Research and Development, Chapter 5, 1996 (Clinical Supplement) : 97-108

Ashworth, B. Preliminary trial of carisoprodol in multiple sclerosis. Practitioner 1964; 192:540–542.

Banovac K, Williams JM, Patrick LD, Haniff YM. Prevention of heterotopic ossification after spinal cord injury with indomethacin. Spinal Cord 2001; 39: 370–374.

Benglis DM, Sandberg DI. Acute neurological deficit after minor trauma in an infant with achondroplasia and cervicomedullary compression. Case report andreview of the literature. J Neurosurg. 2007 Aug; 107(Suppl):152-5 Review.

Benzagmout M, Boujraf S, Chakour K, Chaoui Mel F. Pott's disease in children. Surg Neurol Int. 2011 Jan 11;2:1.

Biering-Sorensen F, Charlifue S, DeVivo M, Noonan V, Post M, Stripling T,Wing P. International Spinal Cord Injury Data Sets. Spinal Cord 2006;44:530-534.

Biering-Sørensen F, Nielsen JB, Klinge K. Spasticity-assessment: a review. Spinal Cord. 2006;44:708-22.

Bohannon RW, Smith MB. Interrater reliability of a Modified Ashworth Scale of muscle spasticity. Physical Therapy. 1987:67:206-7.

Boninger, M, Cooper, R, Fay, B, Musculoskeletal Pain and Overuse Injuries. In Lin V, Cardinas, DD, (Eds) Koontz, A, Spinal Cord Medicine: Principles and Practice, 2003:527-534.

Brown JC, Swank SM, Matta J, Barras DM. Late spinal deformity in quadriplegic children. J Pediatric Orthopedics, 1984;4:456-461.

Campbell J, Bonnett C. Spinal cord injury in children. Clinical Orthopedics 1975;112;114-123.

Center NSCIS. The Model Spinal Cord Injury Systems' Data Collection Syllabus for the National Spinal Cord Injury Database. Birmingham, AL: University of Alabama at Birmingham. 1990:110 - 230.

Citak M, Backhaus M, Kälicke T, Ucher I, Aach M, Meindl R, Muhr G, Frangen TM. Treatment of heterotopic ossification after spinal cord injury – clinical outcome after single dose radiation therapy. Z Orthop Unfall. 2011 Jan;149(1):90-3. Epub 2011 Feb 16. German.

Cook KF, Teal CR, Engebretson JC, Hart KA, Mahoney JS, Robinson-Whelen S, Sherwood AM. Development and validation of Patient Reported Impact of Spasticity Measure (PRISM). J Rehab Res Devel, 2007; 44 (3), 363-372.

Craven BC, Robertson LA, McGillivray CF, Adachi JD. Detection and Treatment of Sublesional Osteoporosis Among Patients with Chronic Spinal Cord Injury: Proposed Paradigms. Topics in Spinal Cord Rehabilitation 2009; 14(4):1-22.

Dearolf WW, Betz RR, Vogel LC, et al. Scoliosis is pediatric spinal-cord injured patients. J Pediatric Orthopedics 1990;10:214-8.

DeVivo M, Biering-Sørensen F, Charlifue S, Noonan V, Post M, Stripling T, Wing P. International Spinal Cord Injury Core Data Set. Spinal Cord 2006 Sep;44(9):535-40.

Dietz V, Sinkjaer T, Spastic movement disorder: impaired reflex function and altered muscle mechanics, Lancet Neurol 2007; 6: 725–33.

Dobbs MB, Lenke LG, Szymanski DA, Morcuende JA, Weinstein SL, Bridwell KH, Sponseller PD. Prevalence of neural axis abnormalities in patients with infantile idiopathic scoliosis. J Bone Joint Surgery Am. 2002 Dec; 84-A(12):2230-4.

Dyson-Hudson, T & Kirshblum, S. Shoulder Pain in Chronic Spinal Cord Injury, Part I: Epidemiology, Etiology and Pathomechanics. Journal of Spinal Cord Injury Medicine 2004;27:4-17.

Eriks-Hoogland I, de Groot S, Post M, van der Woude L. Passive shoulder range of motion in people with spinal cord injury during and one year after rehabilitation. In: Proceedings on the International Spinal Cord Society Annual Scientific Meeting. 2008. Durbin:58.

Farmer SE, James M. Contractures in orthopaedic and neurological conditions: a review of causes and treatment. Disability and Rehabilitation. 2001;23:549-58.

Fehlings MG, Arvin B. Surgical management of cervical degenerative disease: the evidence related to indications, impact and outcome. J Neurosurg Spine. 2009 Aug;11(2):97-100.

Fergusson D, Hutton B and Drodge A. The epidemiology of major joint contractures: A systematic review of the literature. Clinical Orthopaedics and Related Research. 2006;14:22-29.

Gupta MC, Wijesekera S, Sossan A, Martin L, Vogel LC, Boakes JL, Lerman JA, McDonald CM, Betz RR: Reliability of radiographic parameters in neuromuscular scoliosis. Spine 2007 32(6):691-5.

Guille JT, Sarwark JF, Sherk HH, Kumar SJ. Congenital and developmental deformities of the spine in children with myelomeningocele. J Am Acad Orthop Surg. 2006 May; 14(5): 294-302.

Harvey LA, Herbert RD. Muscle stretching for treatment and prevention of contracture in people with spinal cord injury. Spinal Cord. 2002;40:1-9.

Hsieh JTC, Wolfe DL, Miller WC, Curt A and the SCIRE Research Team "Spasticity outcome measures in spinal cord injury: psychometric properties and clinical utility" Spinal Cord 2008; 46, 86–95;

Iskandar BJ, Fulmer BB, Hadely MN, Oakes WJ. Congenital tethered spinal cord syndrome in adults. Neurosurg Focus 2001 Jan 15;10(1):e7.

Jain NB, Higgins LD, Katz JN, Garshick E. Association of shoulder pain with the use of mobiity devices in persons with chronic spinal cord injury. PM R. 2010 Oct;2(10):896-900.

Jiang SD, Dai LY, Jiang LS. Osteoporosis after spinal cord injury. Osteoporos Int 2006; 17: 180-192.

Kotil K, Kalayci M, Bilge T. Management of cercicomedullary compression in patients with congenital and acquired osseous-ligamentous pathologies. J Clin Neurosci 2007. Jun; 14(6):540-9.

Kramer JL, Dvorak M, Curt A. Thoracic disc herniation in a patient with tethered cord and lumbar syringomyelia and diastematomyelia: magnetic resonance imaging and neurophysiological findings. Spine (Phila Pa 1976). 2009 Jun 15;34(14):E484-7.

Lance JW, Symposium synopsis. In: R. G. Feldman, R. R. Young, and W. P. Koella, eds., Spasticity: Disordered Motor Control. Chicago, IL: Yearbook Medical, 1980, pp. 17–24.

Lal S. Premature degenerative shoulder changes in spinal cord injury patients. Spinal Cord. 1998 Mar;36(3):186-9.

Lancourt JE, Dickson JH, Carter RE. Paralytic spinal deformity following traumatic spinal cord injury in children and adolescents. J Bone Joint Surgery 1981;63(A):47-53.

Lechner HE, Frotzler A, Eser P. Relationship between self- and clinically rated spasticity in spinal cord injury. Arch Phys Med Rehabil. 2006 Jan;87(1):15-9.

Lieber R. Skeletal Muscle Structure, Function, And Plasticity: Lippincott Williams & Wilk 2009.

Lord J, Behrman B, Varzos N, Cooper D, Lieberman JS, Fowler WM. Scoliosis associated with Duchenne muscular dystrophy. Arch Phys Med Rehab 1990;71(1):13-7.

Lubicky J, Betz R. Spinal deformity in children and adolescents with spinal cord injury. In: Betz RR & Mulcahey MJ: (Eds) The Child with Spinal Cord injury. American Academy of Orthopedic Surgeons: Rosemont, IL, Chapter 32, pp363-370, 1996.

Mahoney JS, Engebretson JC, Hart KA, Robinson-Whelen S, Sherwood AM, Spasticity Experience Domains in Persons with Spinal Cord Injury, Arch Phys Med Rehabil 2007;88:287-94

Matz PG, Anderson PA, Holly LT, Groff MW, Heary RF, Kaiser MG, Mummaneni PV, Ryken TC, Choudhri TF, Vresiolovic EJ, Resnick DK; Joint Section on Disorders of the Spine and Peripheral Nerves of the American Association of Neurological Surgeons and Congress of Neurological Surgeons. The natural history of cercical spondylotic myelopathy. J Neurosurg Spine. 2009 Aug;11(2):104-11.

Mayfield JK, Erkkila JC, Winter RB. Spine deformity subsequent to acquired childhood spinal cord injury. J Bone Joint Surgery 1981;63A(9):1401-11.

Moon MS, Moon JL, Moon YW, Kim SS, Kim SS, Sun DH, Choi WT. Pott's paraplegia in patients with severely deformed dorsal or dorsolumbar spines: treatment and prognosis. Spinal Cord. 2003 Mar;41(3):164-71.

Mukand J, Sniger W, Kaufman J, Biener-Bergman S. Common causes of knee efusions in spinal cord injury. A random study. Am J Phys Med Rehabil 1998;77:113-117.

Mulcahey MJ, Betz RR. Pediatric Spinal Cord Injury Rehabilitation, Ch 66. In: The Pediatric Spine. (3rd Edition). New York: Thieme, 2008.

Nakamura M, Ishii K, Watanabe K, Tsuji T, Matsumoto M, Toyama Y, Chiba K. Clinical significance and prognosis of idiopathic syringomyelia. J Spinal Disord Tech. 2009 Jul;22(5):372-5.

O'Brien MF. (2005). Spinal Deformity Study Group Radiographic Measurement Manual Medtronic Sofamor Danek USA, Inc.

Pahys JM, Samdani AF, Betz RR. Intraspinal anomalies in infantile idiopathic scoliosis: prevalence and role of magnetic resonance imaging. Spine (Phila Pa 1976) 2009 May 20; 34(12): E434-8.

Pandyan AD, Gregoric M, Barnes MP, Wood D, van Wijck F, Burridge J et al. Spasticity: clinical perceptions, neurological realities and meaningful measurement. Disabil Rehabil 2005; 27: 2–6.

Pentland WE, Twomey LT. Upper limb function in persons with long term paraplegia and implications for independence: Part I. Paraplegia. 1994 Apr;32(4):211-8

Priebe MM, Sherwood AM, Thornby JI, Kharas NF, Markowski J. Clinical assessment of spasticity in spinal cord injury: a multidimensional problem. Arch Phys Med Rehabil 1996; 77: 713–716.

Rajpal S, Tubbs RS, George T, Oakes WJ, Fuchs HE, Hadley MN, Iskandar BJ. Tethered cord due to spina bifida occulta presenting in adulthood: a tricenter review of 61 patients. J Neurosurg Spine. 2007 Mar;6(3):210-5.

Sherwood AM, Graves DE, Priebe MM, Altered Motor Control and Spasticity after Spinal Cord Injury: Subjective and Objective Assessment, J Rehabil Res Dev 2000;37:41-52.

Sherwood AM, McKay WB: Assessment of Spasticity and Upper Motor Neuron Dysfunction, In: Wiley Encyclopedia of Biomedical Engineering, Metin Akay (ed), Vol. 5, pages 3306--3315. Copyright 2006 by John Wiley & Sons, Inc

Tardieu GA. La recherche d'une technique de mesure de la spasticitė `imprime' avec le periodique. Revue Neurologique 1954;91:143-4.

Terminology committee of the Scoliosis Research Society: A glossary of scoliosis terms. Spine 1976;1:57-58.

Tracy JA, Bartleson JD. Cervical spondylotic myelopathy. Neurologist. 2010 May;16(3):176-87. Review.

van Drongelen S, de Groot S, Veeger HE, Angenot EL, Dallmeijer AJ, Post MW, van der Woude LH. Upper extremity musculoskeletal pain during and after rehabilitation in wheelchair-using persons with a spinal cord injury. Spinal Cord. 2006 Mar;44(3):152-9.

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.

van Kuijk AA, Geurts AC, van Kuppevelt HJ. Neurogenic. heterotopic ossification in spinal cord injury. Spinal Cord 2002;40: 313–326.

Vogel LC, Betz RR, Mulcahey MJ: Pediatric Spinal Cord Disorders in Children and Adolescents. In: Lin V, ed. Spinal Cord Medicine Textbook. Demos, New York, New York, 2003, 851-884.

Vogel L, Krajci K and Anderson C. Adults with pediatric-onset spinal cord injury: part 2: musculoskeletal and neurological complications. Journal of Spinal Cord Medicine. 2002;25:117-123.

Yasar B, Simsek S, Er U, Yigitkanli K, Eksioglu E; Altug T, Belen D, Kars ZH, Bavbek M. Functional and clinical evaluation for the surgical treatment of degenerative stenosis of the lubar spinal canal. J Neurosurg Spine. 2009 Sep; 11(3):347-52.

INTERNATIONAL SPINAL CORD INJURY MUSCULOSKELETAL BASIC DATA SET FORM (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:

	Fractures since spinal cord lesion (only those not documented previously)				**Heterotopic ossification**		**Contracture**		**Degenerative changes / Overuse**	
	Right	Left	Date of fracture YYYY/ MM/DD	Fragility fracture	Right	Left	Right	Left	Right	Left
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