

## INTERNATIONAL SPINAL CORD INJURY DATA SETS PAIN BASIC DATA SET

Widerström-Noga E, Biering-Sørensen F, Bryce T, Cardenas DD, Finnerup NB, Jensen MP, Richards JS, Siddall PJ. *Spinal Cord*. 2008;46(12):818-823.

### **The working-group consists of:**

Eva Widerström-Noga, DDS PhD (Chair) represents the International Spinal Cord Society (ISCoS) and the American Spinal Injury Association (ASIA). She is also a member of the International Association for the Study of Pain (IASP), the American Pain Society (APS) and the Academy of Spinal Cord Injury Professionals.

Fin Biering-Sørensen, MD, PhD represents The Executive Committee of the International Spinal Cord Injury Standards and Data Sets (ASIA/ISCoS).

Thomas Bryce, MD represents the ASIA. He is also a member of the IASP and the Academy of Spinal Cord Injury Professionals.

Diana D Cardenas, MD represents the ASIA and is a member of the Academy of Spinal Cord Injury Professionals.

Nanna Brix Finnerup, MD, PhD, represents the IASP.

Mark P Jensen, PhD, represents the APS. He is also a member of the IASP.

J Scott Richards, PhD, represents the ASIA. He is also a member of the Academy of Spinal Cord Injury Professionals.

Philip Siddall, MD, PhD, represents the IASP. He is also a member of the ISCoS.

This interdisciplinary working group was assembled based on published research expertise in the area of spinal cord injury related pain. Individuals with expertise in SCI with regard to the clinical condition of pain, pain taxonomy, psychophysics of pain, psychology, epidemiology and assessment of pain were recommended by the presidents of some of the major organizations with an interest in SCI-related pain (i.e., the ISCoS, ASIA, APS and IASP). Most of the committee members have memberships in several of these organizations.

Chronic pain is one of the most frequently reported reasons for reduced quality of life following spinal cord injury (SCI) (Stensman 1994; Westgren & Levi, 1998). Pain taxonomies for SCI (Siddall et al., 2000; Bryce & Ragnarsson, 2001) classify pain as neuropathic or nociceptive, and according to level of injury. The neuropathic pains are usually associated with evoked pain, such as allodynia or hyperalgesia (Eide et al., 1996; Finnerup et al., 2001). The clinical presentation of pain associated with SCI is highly complex in that different pain types are often present simultaneously. Furthermore, the refractory nature of pain following SCI and the associated psychosocial distress emphasize the need for a greater understanding of not only pathophysiological but also psychosocial mechanisms in the generation and maintenance of SCI-related pain and pain-related suffering. Ideally an effective treatment strategy should be tailored to specific pain-generating mechanisms in each individual. However, because of insufficient knowledge about the precise clinical symptoms and signs associated with a specific mechanism, this is not currently possible (Hansson, 2002).

In the clinical setting, information is collected that is important for the treatment decisions concerning the pain condition. Although physicians who treat individuals with SCI routinely collect clinical information, a standardized way to collect data concerning pain in persons with SCI is lacking. In order to expedite the development of beneficial treatments, it is important to evaluate the outcomes of treatments in a consistent manner. This would facilitate research collaboration between clinical centers and therefore result in larger well designed clinical pain trials in this population. The use of comparable sets of outcome measures in clinical practice

and in trials would increase efficiency and greatly facilitate the translation, interpretation, and application of results to enhance the successful management of SCI related pain.

The purpose of the International Spinal Cord Injury Pain Data Set (ISCIPDS) is to standardize the collection and reporting of pain in the SCI population. The ISCIPDS contains a **basic** (ISCIPDS:B) and an **extended** (ISCIPDS:E) part. The IPDS:B contains a minimal amount of clinically relevant information concerning pain that can be collected in the daily practice of healthcare professionals with expertise in SCI. In addition, the evaluation should be logistically feasible in various settings and countries. Although the intent of the ISCIPDS:B is to evaluate each separate pain problem, it may also be used to only evaluate the most significant or “worst” pain problem if there are time constraints. The IPDS:E is primarily intended to be used for research purposes. The overall purpose of the IPDS concurs with the purpose and vision of the International Spinal Cord Injury Data Sets (Biering-Sørensen et al., 2006) and should be used in conjunction with data in the International SCI Core Data Set (DeVivo et al., 2006). The SCI Core Data Set includes information on date of birth and injury, gender, the cause of spinal cord lesion, and neurological status. In addition, the Core Data Set contains information on whether a vertebral injury was present, whether spinal surgery was performed, whether associated injuries were present, whether the patient with spinal cord lesion was ventilator-dependent at the time of discharge from initial inpatient care, and the place of discharge from initial inpatient care.

## Background

The Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) has recommended that clinical pain trials designed to evaluate the effectiveness of a therapy, should **consider** including a core set of outcomes (Dworkin et al., 2005). It was suggested that the assessment of pain severity, physical and emotional functioning would best capture the multidimensional nature of pain. However, it was also emphasized that complimentary measures should be added when appropriate for specific pain populations. After SCI, a decrease in physical function may be more related to the physical impairments of SCI rather than to pain; therefore, a decrease in function **due to** pain, i.e., pain interference should be assessed (Widerström & Turk, 2004). These outcome domains are relevant both for clinical trials and clinical practice.

The questions in the IPDS:B are based upon these three domains but adapted to consider the special issues related to SCI (i.e., several simultaneous different pain problems, physical impairments, etc.). The aspects regarding the specific nature of SCI related pain includes in addition to a pain intensity rating for each specific pain, a classification of pain and questions related to temporal pattern. Pain interference is addressed using selected items from the Multidimensional Pain Inventory (the MPI-SCI) and three additional questions specifically addressing pain interference with activities, mood and sleep.

## Acknowledgement:

Pfizer Corp supported the initial work involved in developing with this Data Set with an unconditional grant.

The authors also want to thank ISCoS, ASIA, and the APS Boards and the IASP Neuropathic Pain Special Interest Group for helpful suggestions. We also want to thank the following individual reviewers for their thoughtful suggestions: Sergio Aito, Susan Charlifue, Michael deVivo, Petra Dokladal, Robert Dworkin, William Donovan, Pascal Halder, Jennifer Haythornthwaite, Steven Kirshblum, Vanessa Noonan, Lawrence Vogel and Gale Whiteneck.

## Endorsement:

The Basic Pain Dataset has been officially endorsed by the ISCoS, ASIA, IASP and the APS.

**References:**

- American Spinal Injury Association: International Standards for Neurological Classification of Spinal Cord Injury, revised 2002; Chicago, IL, American Spinal Injury Association; 2002.
- Biering-Sørensen F, Charlifue S, DeVivo M, Noonan V, Post M, Stripling T, Wing P. International spinal cord injury data sets. *Spinal Cord*. 2006;44:530-4.
- Bryce TN, Ragnarsson KT. Epidemiology and classification of pain after spinal cord injury. *Top Spinal Cord Inj Rehabil*. 2001;7:1-17.
- Bryce TN, Budh CN, Cardenas DD, Dijkers M, Felix ER, Finnerup NB, Kennedy P, Lundeberg T, Richards JS, Rintala DH, Siddall P, Widerstrom-Noga E. Pain after spinal cord injury: an evidence-based review for clinical practice and research. Report of the National Institute on Disability and Rehabilitation Research Spinal Cord Injury Measures meeting. *J Spinal Cord Med*. 2007;30:421-40.
- Cardenas DA, Turner JA, Warms CA, Marshall HM. Classification of chronic pain associated with spinal cord injuries. *Arch Phys Med Rehabil*. 2002;83:1708-14.
- 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;44:535-40.
- Donovan WH, Dimitrijevic MR, Dahm L, Dimitrijevic M. Neurophysiological approaches to chronic pain following spinal cord injury. *Paraplegia*. 1982;20:135-46.
- Dworkin RH, Turk DC, Farrar JT, Haythornthwaite JA, Jensen MP, Katz NP, Kerns RD, Stucki G, Allan RR, Bellamy N, Carr DB, Chandler J, Cowan P, Dionne R, Galer BS, Hertz S, Jadad AR, Kramer LD, Manning DC, Martin S, McCormick CG, McDermott, MP, McGrath P, Quessy S, Rappaport BA, Robbins W, Robinson JP, Rothman M, Royal MA, Simon L, Stauffer JW, Stein W, Tollett J, Wernicke J, Witter J. Core outcome measures for chronic pain clinical trials: IMMPACT recommendations. *Pain*. 2005;113:9-19.
- Eide PK, Jorum E, Stenehjelm AE. Somatosensory findings in patients with spinal cord injury and central dyesthesia pain. *J Neurol Neurosurg Psychiatry* 1996;60:411-5.
- Finnerup NB, Johannesen IL, Sindrup SH, Bach FW, Jensen TS. Pain and dysesthesia in patients with spinal cord injury: A postal survey. *Spinal Cord*. 2001;39:256-62.
- Hansson P. Neuropathic pain: clinical characteristics and diagnostic workup. *Eur J Pain*. 2002;6 Suppl A:47-50.
- Jensen MP, Karoly P. (2001). Self-report scales and procedures for assessing pain in adults. In DC Turk & R Melzack (Eds.), *Handbook of pain assessment*, 2nd edition. New York: Guilford Publications, pp. 15-34.
- Marino RJ, Barros T, Biering-Sorensen F, Burns SP, Donovan WH, Graves DE, Haak M, Hudson LM, Priebe MM. International standards for neurological classification of spinal cord injury. *J Spinal Cord Med*. 2003;26(suppl.1):S50-S56.
- Margolis RB, Chibnall JT, Tait RC. Test retest reliability of the pain drawing instrument. *Pain*. 1988;33:49-51.

Merskey H, Bogduk N. (Eds.). (1994). Classification of chronic pain: Description of chronic pain syndromes and definition of pain terms. Seattle: IASP Press.

Raichle KR, Osborne TL, Jensen MP, Cardenas D. The reliability and validity of pain interference measures in persons with spinal cord injury. *J of Pain*. 2006;7:179-86.

Rintala DH, Loubser PG, Castro J, Hart KA, Fuhrer MJ. Chronic pain in a community-based sample of men with spinal cord injury: Prevalence, severity, and relationships with impairment, disability, handicap, and subjective well-being. *Arch Phys Med Rehabil*. 1998;79:604-14.

Siddall PJ, Yeziarski RP, Loeser JD. Pain following spinal cord injury: clinical features, prevalence, and taxonomy. *International Association for the Study of Pain Newsletter*. 2000;3:3-7 ([http://www.iasp-pain.org/AM/Template.cfm?Section=Technical\\_Corner&Template=/CM/ContentDisplay.cfm&ContentID=2179](http://www.iasp-pain.org/AM/Template.cfm?Section=Technical_Corner&Template=/CM/ContentDisplay.cfm&ContentID=2179)).

Stensman R. Adjustment to traumatic spinal cord injury. A longitudinal study of self-reported quality of life. *Paraplegia*. 1994;32:416-22.

Tait RC, Chibnall JT, Krause S. The Pain Disability Index: factor structure and normative data. *Arch Phys Med Rehabil*. 1994;75:1082-6.

Westgren N, Levi R. Quality of life and traumatic spinal cord injury. *Arch Phys Med Rehabil*. 1998;79:1433-9.

Widerström-Noga EG, Felipe-Cuervo E and Yeziarski RP. Relationships among clinical characteristics of chronic pain following spinal cord injury. *Arch Phys Med Rehabil* 2001;82:1191-7.

Widerström-Noga EG, Duncan R, Felipe-Cuervo E and Turk DC, Assessment of the impact of pain and impairments associated with spinal cord injuries. *Arch Phys Med Rehabil* 2002;83:395-404.

Widerström-Noga EG and Turk DC. Outcome measures in chronic pain trials involving people with spinal cord injury. *SCI Psychosocial Process* 2004; 17:258-267.

Widerström-Noga EG, Cruz-Almeida Y, Martinez-Arizala A, Turk DC. Internal consistency, stability, and validity of the spinal cord injury version of the multidimensional pain inventory. *Arch Phys Med Rehabil* 2006;87:516-23.

**SYLLABUS (instructions) – Version 1.1**

Each variable and each response category within each variable have been specifically defined in a way that is designed to facilitate the collection of a uniform basic data set.

**VARIABLE NAME: Date of data collection**

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

**CODES:** YYYY/MM/DD

**COMMENTS:** The collection of data on Pain may be carried out at any time after the spinal cord injury. The *Date of data collection* variable is necessary in order to identify when the data were collected. This variable provides a way to relate the collected data to other data collected on the same individual at various time points.

---

**VARIABLE NAME: Have you had any pain during the last 7 days including today?**

**DESCRIPTION:** This variable documents the presence of any type of pain during the last 7 days.

**CODES:** No  
Yes

**COMMENTS:** To be able to evaluate any present, chronic, and intermittent pain related and unrelated to the spinal cord injury. Pain is defined by the International Association for the Study of Pain (IASP) as “An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Merskey & Bogduk, 1994). The seven day interval was chosen in order to be able to capture current pain and both constant and intermittent chronic pain that may be clinically relevant and to have the same time frame in all data sets.

This question can also be used as Basic Pain Question in other questionnaires, i.e. gate question to the Pain Basic Data Set.

---

**VARIABLE NAME: If yes, how many different pain problems do you have?**

**DESCRIPTION:** This variable determines how many different pain problems an individual perceives that he or she has experienced during the last seven days including today. A “pain problem” is defined by the person himself as a pain that has a specific character. Please note that one pain problem can be located in one or several areas.

**CODES:** 1 - One pain problem  
2 - Two pain problems  
3 - Three pain problems  
4 - Four pain problems  
5 - Five or more pain problems

**COMMENTS:** Data from previous studies suggest that persons with SCI rarely have more than 5 different pain problems. Persons who experience SCI related chronic pain can usually differentiate between different pain problems. Although unusual, it is possible to have two different types of pain in overlapping areas. An example would be musculoskeletal shoulder pain in a person with cervical injury and neuropathic pain at the level of injury.

---

**Description of the three worst pain problems**

COMMENTS: Each person is only required to describe the three worst pain problems he or she is currently experiencing (within the last 7 days). The reasons for this are twofold. First, most people with SCI experience three or fewer pain problems. Second, describing the details of more than three different simultaneous pain problems may induce errors in the data collection. Please note that the forms should be completed in a columnar fashion for each pain problem and not be read across.

VARIABLE NAME: **Location(s) of pain** (check all that apply including right side, midline and/or left side)

DESCRIPTION: This variable contains information concerning the location of pain.

CODES:

<b>Head</b>	right side, midline and/or left side
<b>Neck/shoulders</b>	
throat	right side, midline and/or left side
neck	right side, midline and/or left side
shoulder	right and/or left side
<b>Arms/hands</b>	
upper arm	right and/or left side
elbow	right and/or left side
forearm	right and/or left side
wrist	right and/or left side
hand/fingers	right and/or left side
<b>Frontal torso/genitals</b>	
chest	right side, midline and/or left side
abdomen	right side, midline and/or left side
pelvis/genitalia	right side, midline and/or left side
<b>Back</b>	
upper back	right side, midline and/or left side
lower back	right side, midline and/or left side
<b>Buttocks/hips</b>	
buttocks	right and/or left side
hip	right and/or left side
anus	midline
<b>Upper legs/thighs</b>	right and/or left side
<b>Lower legs/feet</b>	
knee	right and/or left side
shin	right and/or left side
calf	right and/or left side
ankle	right and/or left side
foot/toes	right and/or left side

COMMENTS: This division into pain areas is based on a pain drawing originally described by Margolis et al.,1988 but which was since recalculated into 8 principal areas (Widerström-Noga et al., 2001): (1) head; (2) neck/shoulders; (3) arms/hands; (4) frontal torso/genitals; (5) back; (6) buttocks/hips; (7) Upper legs/thighs; and (8) Lower legs/feet. Within each of these 8 pain locations, further divisions into more precise locations can be made. For example, in the “arms/hand” category specification of wrist, elbow pain etc. can be made if needed. Each individual is asked to describe the location of all present pain. Please indicate right (R), midline (M) and/or left (L) side.

The descriptions of the pain locations in the Basic Pain Data Set are meant to be based on each individual’s perception of the location of pain, and can be used to follow pain at

subsequent visits. Therefore, the delineations of these areas are not defined with precise anatomical landmarks. Several locations may be given for each pain problem, e.g., neck and either shoulders, or pain in the abdomen extending into the buttocks and thighs areas and further down to the feet.

---

VARIABLE NAME: **Type of pain**

DESCRIPTION: This variable documents the type of pain present.

CODES: Musculoskeletal (Nociceptive)  
 Visceral (Nociceptive)  
 Other (Nociceptive)  
 At-level (Neuropathic)  
 Below-level (Neuropathic)  
 Other (Neuropathic)  
 Unknown

COMMENTS: Six broad types of pain are specified based on pain types identified in previous SCI pain taxonomies (Donovan et al., 1982; Siddall et al., 2000; Bryce & Ragnarsson, 2001; Cardenas et al., 2002) and based on prevalence in the SCI population. **Please note that the ASIA Impairment scale (Marino et al., 2003) is to be used as an integral part of the SCI pain classification.** Nociceptive pains that are less prevalent or not directly related to SCI and not categorized as musculoskeletal or visceral can be classified as “*Other (Nociceptive)*”. One additional category has been added to the previous taxonomy, i.e., *Other (Neuropathic)*. This was made in order to distinguish those pains that are not associated with a lesion or disease affecting the spinal cord or nerve roots. “*Unknown*” should be used when it is not possible to classify the pain into one of the categories listed above. It is not to be used to indicate that the underlying pathology is unknown.

The type of pain should be coded using the following criteria:

**Musculoskeletal (Nociceptive)** pain refers to pain occurring in a region where there is preserved sensation above, at or below the neurological level of injury and which is believed to be arising from musculoskeletal structures. The presence of this type of pain is suggested by pain descriptors such as dull or aching, pain related to movement, tenderness of musculoskeletal structures on palpation, response to anti-inflammatory medications and evidence of skeletal pathology on imaging consistent with the pain presentation. Examples include: mechanical pain, spinal fractures, muscular injury, shoulder overuse syndromes and muscle spasm (Donovan et al., 1982; Siddall et al., 2000; Bryce & Ragnarsson, 2001; Cardenas et al., 2002).

**Visceral (Nociceptive)** pain refers to pain usually located in the thorax or abdomen and believed to be generated in visceral structures. The presence of this type of pain is suggested by characteristics such as dull, aching or cramping and a relationship to visceral pathology or dysfunction, e.g., infection or obstruction (Donovan et al., 1982; Siddall et al., 2000; Bryce & Ragnarsson, 2001; Cardenas et al., 2002). Examples include urinary tract infection, ureteric calculus and bowel impaction. Note: Failure to find evidence of visceral pathology or failure to respond to treatment directed at visceral pathology may indicate the presence of neuropathic pain (see below).

**Other (Nociceptive)** pain refers to nociceptive pains that may be present but do not fall into the musculoskeletal or visceral categories (Bryce & Ragnarsson, 2001). Examples include pain associated with ulceration of the skin and headache. These pains may be directly related to SCI (e.g., pressure areas and dysreflexic headache) or unrelated to SCI (e.g., migraine). This category has been included to provide a classification for nociceptive pains that have low prevalence or that are not specifically related to SCI.

**At-level (Neuropathic)** pain refers to neuropathic pain presenting in a segmental pattern. A necessary condition for this to occur is that there is a lesion or disease affecting the spinal cord or nerve roots. At-level neuropathic pain is perceived anywhere within the dermatome of the level of neurological injury and three dermatomes below this level. Pain

which occurs in this distribution which cannot be attributed to a lesion or disease affecting the spinal cord or nerve roots should be classified as *other (Neuropathic)*. This pain is often characterized as burning, electric or shooting. Sensory changes such as allodynia or hyperalgesia within the pain distribution are often found. The pain may be unilateral or bilateral (Siddall et al., 2000; Bryce & Ragnarsson, 2001). Note: Neuropathic pain associated with cauda equina damage is radicular in nature and therefore defined as at level (neuropathic) pain regardless of distribution.

**Below-level (Neuropathic)** pain refers to neuropathic pain that is present in the region more than three dermatomes below the neurological level of injury. A necessary condition for this to occur is that there is a lesion or disease affecting the spinal cord. Pain which occurs in this distribution which cannot be attributed to a lesion or disease affecting the spinal cord should be classified as *other (Neuropathic)*. This pain typically has characteristics such as burning, electric or shooting qualities and a diffuse, regional distribution. Sensory changes such as allodynia or hyperalgesia may be present. If the pain is present in the region within three dermatomes below the neurological level of injury as well as more than three dermatomes below the level, the pain is classified as at- and below-level (neuropathic) unless the person is able to distinguish a separate at-level (neuropathic) component. If two separate pains are distinguishable, the two pain types (at-level (neuropathic) and below-level (neuropathic)) must be classified and documented as different pains. If the neuropathic pain is present both at and below the level of injury and the patient is unable to distinguish two separate pain problems, both **At-level (Neuropathic)** and **Below-level (Neuropathic)** can be checked.

**Other (Neuropathic)** pain refers to neuropathic pains that are present above, at or below the neurological level of injury but are not directly related to the SCI. Examples include postherpetic neuralgia, pain associated with diabetic neuropathy, central post stroke pain, and compressive mononeuropathies (Siddall et al., 2000; Bryce & Ragnarsson, 2001).

---

VARIABLE NAME: **Average pain intensity in the last week**

DESCRIPTION: A 0 – 10 Numerical Rating Scale (ranging from 0 = “No pain” to a maximum of 10 = “Pain as bad as you can imagine”) of average pain intensity for (up to) three pain problems (the three worst pain problems respondents experience). Please note that “last week” specifically refers to *the last seven days including today*.

CODES: 0  
1  
2  
3  
4  
5  
6  
7  
8  
9  
10

COMMENTS: Pain intensity is the most common pain domain assessed in research and clinical settings. Although different rating scales have proven to be valid for assessing pain intensity, including the Numerical Rating Scale (NRS), the Verbal Rating Scale (VRS), and the Visual Analogue Scale (VAS), the 0 – 10 NRS has the most strengths and fewest weaknesses of available measures (Jensen & Karoly, 2001). Moreover the 0 – 10 NRS, and specifically the 0 – 10 with the endpoints listed, has been recommended by the IMMPACT consensus group for use in pain clinical trials (Dworkin et al., 2005) and by the 2006 NIDRR SCI Pain outcome measures consensus group (Bryce et al., 2007), so

using this measure will help ensure consistency in the assessment of average pain intensity across studies.

The seven day time frame was selected to balance the need to assess pain over a long enough epoch to capture usual pain, against the need to keep the time frame short enough to maximize recall accuracy.

---

**VARIABLE NAME: Date of onset**

**DESCRIPTION:** This variable specifies the date this particular pain problem started, i.e. the worst, second worst or third worst pain problem.

**CODES:** YYYY/MM/DD

**COMMENTS:** If the day of the month is unknown, record 99. If the month of the year is unknown, record 99. The year should be given as an approximation if it is not known.

---

**VARIABLE NAME: Number of days with pain in the last 7 days including today**

**DESCRIPTION:** This variable specifies the total number of days with pain during the last 7 days, including today.

**CODES:**

- 0 – none
- 1 – one day
- 2 – two days
- 3 – three days
- 4 – four days
- 5 – five days
- 6 – six days
- 7 – seven days
- Unknown

**COMMENTS:** “Today” is the day the subject answers the question regardless time of day. The duration of pain during the day does not matter in answering this question.

---

**VARIABLE NAME: How long does your pain usually last?**

**DESCRIPTION:** This variable provides an estimate of the duration of pain. Some pain types are very brief they may be felt several times per day. This question refers to the duration of each separate pain event.

**CODES:**

- One minute or less
- More than one minute but less than one hour
- At least one hour, but less than 24 hours
- At least 24 hours but not continuous
- Constant or continuous
- No pain
- Unknown

**COMMENTS:** The duration of pain can be defined when a specific pain follows a predictable pattern. If no predictable pattern for a specific pain exists, the answer “unknown” is given.

---

VARIABLE NAME: **When is the pain most intense?**

DESCRIPTION: This variable identifies the diurnal peak in pain intensity.

CODES: Morning  
 Afternoon  
 Evening  
 Night  
 Unpredictable; pain is not consistently more intense at any one time of day

COMMENTS: “Morning” is between 6.01 am and 12.00 am (06.01 and 12.00)  
 “Afternoon” is between 12.01 am and 6.00 pm (12.01 and 18.00)  
 “Evening” is between 6.01 pm and 12.00 pm (18.01 and 24.00)  
 “Night” is between 0.01am and 6.00 am (00.01 and 06.00)

---

### **Pain Interference**

This section contains three items from the Life Interference (LI) subscale of the Multidimensional Pain Inventory SCI version (MPI-SCI) evaluating impact of pain on activities in general and on recreational, social and family-related activities, and three items specifically asking about pain interference with general activities, mood and sleep.

The 8 item MPI-SCI LI subscale is recommended for assessing Pain Interference in SCI (Bryce et al., 2007). The validity and reliability of the MPI-SCI LI subscale have been established for the SCI chronic pain population (Widerström-Noga et al., 2006). This included convergent construct validity, i.e., strong correlation ( $r=0.61$ ) with a measure of a similar construct (Pain Disability Index; Tait et al., 1994), excellent internal consistency ( $r=0.90$ ) and test-retest ( $r=0.81$ ) values. In addition, a multiple regression analysis showed that LI significantly predicted satisfaction with life in persons with SCI and pain. The three selected questions had high factor loadings on the LI factor (Widerström-Noga et al., 2002). The internal consistency of these three items is 0.80 and test-retest is 0.78.

The three additional interference items were written for and included in the data set given the need for (1) the availability of a single item that could be used to assess the domain of pain interference; and (2) the need to ensure assessment of pain interference on mood and sleep (not assessed by the MPI-SCI LI), two key interference domains.

In this section pain interference *during the last week* apply to all questions.

---

### **MPI-SCI**

VARIABLE NAME: **How much do you limit your activities in order to keep your pain from getting worse?**

DESCRIPTION: This variable asks about the extent to which an individual limit his/her activities due to pain. The answers are given on a 0– 6 Numerical Rating Scale (ranging from 0=“Not at all” to 6= “Very much”).

CODES: 0  
 1  
 2  
 3  
 4  
 5  
 6

## COMMENTS:

This item had a factor loading of 0.93 on the Life Interference factor (Widerström-Noga et al., 2002).

---

**VARIABLE NAME: How much has your pain changed your ability to take part in recreational and other social activities?**

**DESCRIPTION:** This variable asks about the extent to which pain has changed an individual's ability to participate in recreational and social activities. The answers are given on a 0– 6 Numerical Rating Scale (ranging from 0="No change" to 6= "Extreme change").

**CODES:**

- 0
- 1
- 2
- 3
- 4
- 5
- 6

**COMMENTS:** This item had a factor loading of 0.91 on the Life Interference factor (Widerström-Noga et al., 2002).

---

**VARIABLE NAME: How much has your pain changed the amount of satisfaction or enjoyment you get from family-related activities?**

**DESCRIPTION:** This variable asks about the extent to which pain has changed an individual's level of satisfaction or enjoyment from family-related activities. The answers are given on a 0– 6 Numerical Rating Scale (ranging from 0="No change" to 6= "Extreme change").

**CODES:**

- 0
- 1
- 2
- 3
- 4
- 5
- 6

**COMMENTS:** This item had a factor loading of 0.85 on the Life Interference factor (Widerström-Noga et al., 2002).

---

**Pain Interference specifically related to General Activity, Mood and Sleep.**

**VARIABLE NAME: In general, how much has pain interfered with your day-to-day activities in the last week?**

**DESCRIPTION:** A 0 – 6 Numerical Rating Scale (ranging from 0 = "No interference" to a maximum of 6 = "Extreme interference") of pain interference with general activity.

**CODES:**

- 0
- 1
- 2
- 3
- 4
- 5
- 6

COMMENTS: *This question concerns how a person's specific pain problem interfered with general activity during the last seven days including today.* Pain interference (the extent to which pain interferes with functioning and mood) is a key pain domain. An interference item that assesses general activity interference was designed specifically for this data-set in order to provide a global summary interference rating. Research will be needed to determine the psychometric properties of this newly written item.

---

VARIABLE NAME: **In general, how much has pain interfered with your overall mood in the past week?**

DESCRIPTION: A 0 – 6 Numerical Rating Scale (ranging from 0 = “No interference” to a maximum of 6 = “Extreme interference”) of pain interference of mood.

CODES: 0  
1  
2  
3  
4  
5  
6

COMMENTS: *This question concerns how a person's specific pain problem interfered with mood during the last seven days including today.* An interference item that assesses mood interference was developed for this data set because pain is known to have a significant negative impact on mood for many patients, and pain's effect on mood is somewhat distinct from its effect on other functioning domains. Research will be needed to determine the psychometric properties of this newly written item.

---

VARIABLE NAME: **In general, how much has pain interfered with your ability to get a good night's sleep?**

DESCRIPTION: A 0 – 6 Numerical Rating Scale (ranging from 0 = “No interference” to a maximum of 6 = “Extreme interference”) of pain interference of mood.

CODES: 0  
1  
2  
3  
4  
5  
6

COMMENTS: *This question concerns how a person's specific pain problem interfered with his/her ability to get a good night's sleep during the last seven days including today.* An interference item that assesses sleep interference was developed for this data set because pain is known to have a significant negative impact on sleep for many patients, and pain's effect on sleep is somewhat distinct from its effect on other functioning domains. Research will be needed to determine the psychometric properties of this newly written item.

---

VARIABLE NAME: **Are you using or receiving any treatment for your pain problem?**

DESCRIPTION: This variable documents any treatment the patient is using or receiving for any pain.

CODES:           No  
                  Yes

COMMENTS:       By “treatment” is meant any prescribed or non-prescribed medical, surgical, psychological, or physical treatment that the patient is using or receiving *for pain that has been present the last seven days* to alleviate his/her pain/pains. This variable may include chronic and intermittent drug treatment, physical therapy, relaxation training, nerve blocks etc.

---

## INTERNATIONAL SPINAL CORD INJURY DATA SETS

### PAIN BASIC DATA SET – FORM – Version 1.1

**Date of data collection:** YYYY/MM/DD

**Have you had any pain during the last seven days including today:**

No     Yes

**If yes, how many different pain problems did you have?**

1;  2;  3;  4;   $\geq 5$

**Please describe your three worst pain problems:**

**Worst pain problem:**

Pain locations/sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain (check all that apply)	Intensity and temporal pattern of pain
<b>Head</b>				<b>Nociceptive</b> <input type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other  <b>Neuropathic</b> <input type="checkbox"/> At-level <input type="checkbox"/> Below-level <input type="checkbox"/> Other  <input type="checkbox"/> Unknown	<b>Average pain intensity in the last week:</b> 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10  <b>Date of onset: YYYY/MM/DD</b>  <b>Number of days with pain in the last seven days including today:</b> <input type="checkbox"/> none; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> unknown  <b>How long does your pain usually last:</b> <input type="checkbox"/> ≤ 1 min; <input type="checkbox"/> > 1 min but < 1 hr; <input type="checkbox"/> ≥ 1 hr but < 24 hrs; <input type="checkbox"/> ≥ 24 hrs; <input type="checkbox"/> constant or continuous; <input type="checkbox"/> unknown  <b>When during the day is the pain most intense:</b> <input type="checkbox"/> morning (06.01-12.00); <input type="checkbox"/> afternoon (12.01-18.00); <input type="checkbox"/> evening (18.01-24.00); <input type="checkbox"/> night (00.01-06.00) <input type="checkbox"/> unpredictable; pain is not consistently more intense at any one time of day
<b>Neck/shoulders</b> throat neck shoulder					
<b>Arms/hands</b> upper arm elbow forearm wrist hand/fingers					
<b>Frontal torso/genitals</b> chest abdomen pelvis/genitalia					
<b>Back</b> upper back lower back					
<b>Buttocks/hips</b> buttocks hip anus					
<b>Upper legs/thighs</b>					
<b>Lower legs/feet</b> knee shin calf ankle foot/toes					

*Please note that the time period during the last week apply to all pain interference questions.*

**How much do you limit your activities in order to keep your pain from getting worse?**

Not at all  0 -  1 -  2 -  3 -  4 -  5 -  6 Very much

**How much has your pain changed your ability to take part in recreational and other social activities?**

No change  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme change

**How much has your pain changed the amount of satisfaction or enjoyment you get from family-related activities?**

No change  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme change

**In general, how much has pain interfered with your day-to-day activities in the last week?**

No interference  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme interference

**In general, how much has pain interfered with your overall mood in the past week?**

No interference  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme interference

**In general, how much has pain interfered with your ability to get a good night's sleep?**

No interference  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme interference

**Are you using or receiving any Treatment for your pain problem:**  No  Yes

**Second worst pain problem:**

Pain locations/sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain (check all that apply)	Intensity and temporal pattern of pain
<b>Head</b>				<b>Nociceptive</b> <input type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other  <b>Neuropathic</b> <input type="checkbox"/> At-level <input type="checkbox"/> Below-level <input type="checkbox"/> Other  <input type="checkbox"/> Unknown	<b>Average pain intensity in the last week:</b> 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10  <b>Date of onset: YYYY/MM/DD</b>  <b>Number of days with pain in the last seven days including today:</b> <input type="checkbox"/> none; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> unknown  <b>How long does your pain usually last:</b> <input type="checkbox"/> ≤ 1 min; <input type="checkbox"/> > 1 min but < 1 hr; <input type="checkbox"/> ≥ 1 hr but < 24 hrs; <input type="checkbox"/> ≥ 24 hrs; <input type="checkbox"/> constant or continuous; <input type="checkbox"/> unknown  <b>When during the day is the pain most intense:</b> <input type="checkbox"/> morning (06.01-12.00); <input type="checkbox"/> afternoon (12.01-18.00); <input type="checkbox"/> evening (18.01-24.00); <input type="checkbox"/> night (00.01-06.00) <input type="checkbox"/> unpredictable; pain is not consistently more intense at any one time of day
<b>Neck/shoulders</b> throat neck shoulder					
<b>Arms/hands</b> arm elbow forearm wrist hand/fingers					
<b>Frontal torso/genitals</b> chest abdomen pelvis/genitalia					
<b>Back</b> upper back lower back					
<b>Buttocks/hips</b> buttocks hip anus					
<b>Upper legs/thighs</b>					
<b>Lower legs/feet</b> knee shin calf ankle foot/toes					

*Please note that the time period during the last week apply to all pain interference questions.*

**How much do you limit your activities in order to keep your pain from getting worse?**

Not at all  0 -  1 -  2 -  3 -  4 -  5 -  6 Very much

**How much has your pain changed your ability to take part in recreational and other social activities?**

No change  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme change

**How much has your pain changed the amount of satisfaction or enjoyment you get from family-related activities?**

No change  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme change

**In general, how much has pain interfered with your day-to-day activities in the last week?**

No interference  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme interference

**In general, how much has pain interfered with your overall mood in the past week?**

No interference  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme interference

**In general, how much has pain interfered with your ability to get a good night's sleep?**

No interference  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme interference

**Are you using or receiving any Treatment for your pain problem:**  No  Yes

**Third worst pain problem:**

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain (check all that apply)	Intensity and temporal pattern of pain
<b>Head</b>				<b>Nociceptive</b> <input type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other  <b>Neuropathic</b> <input type="checkbox"/> At-level <input type="checkbox"/> Below-level <input type="checkbox"/> Other  <input type="checkbox"/> Unknown	<b>Average pain intensity in the last week:</b> 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10  <b>Date of onset: YYYY/MM/DD</b>  <b>Number of days with pain in the last seven days including today:</b> <input type="checkbox"/> none; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> unknown  <b>How long does your pain usually last:</b> <input type="checkbox"/> ≤ 1 min; <input type="checkbox"/> > 1 min but < 1 hr; <input type="checkbox"/> ≥ 1 hr but < 24 hrs; <input type="checkbox"/> ≥ 24 hrs; <input type="checkbox"/> constant or continuous; <input type="checkbox"/> unknown  <b>When during the day is the pain most intense:</b> <input type="checkbox"/> morning (06.01-12.00); <input type="checkbox"/> afternoon (12.01-18.00); <input type="checkbox"/> evening (18.01-24.00); <input type="checkbox"/> night (00.01-06.00) <input type="checkbox"/> unpredictable; pain is not consistently more intense at any one time of day
<b>Neck/shoulders</b> throat neck shoulder					
<b>Arms/hands</b> upper arm elbow forearm wrist hand/fingers					
<b>Frontal torso/genitals</b> chest abdomen pelvis/genitalia					
<b>Back</b> upper back lower back					
<b>Buttocks/hips</b> buttocks hip anus					
<b>Upper leg/thigh</b>					
<b>Lower legs/feet</b> knee shin calf ankle foot/toes					

*Please note that the time period during the last week apply to all pain interference questions.*

**How much do you limit your activities in order to keep your pain from getting worse?**

Not at all  0 -  1 -  2 -  3 -  4 -  5 -  6 Very much

**How much has your pain changed your ability to take part in recreational and other social activities?**

No change  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme change

**How much has your pain changed the amount of satisfaction or enjoyment you get from family-related activities?**

No change  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme change

**In general, how much has pain interfered with your day-to-day activities in the last week?**

No interference  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme interference

**In general, how much has pain interfered with your overall mood in the past week?**

No interference  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme interference

**In general, how much has pain interfered with your ability to get a good night's sleep?**

No interference  0 -  1 -  2 -  3 -  4 -  5 -  6 Extreme interference

**Are you using or receiving any Treatment for your pain problem:**  No  Yes

## INTERNATIONAL SPINAL CORD INJURY DATA SETS

### PAIN BASIC DATA SET – TRAINING CASES – Version 1.1

#### Training case 1

Date: May 26, 2008

This is a 34 year old man with a C6 AIS B cervical injury after a diving accident in 2000. He experiences two different pains, one in the legs and the other in the center of the abdomen. The pain in his abdomen started shortly about 6 years after his SCI and is the most problematic problem of the two. He describes this pain as “cramping” and “shooting” with an average intensity of 7/10. The pain occurs daily, but is intermittent, with periods of pain “flares” followed by periods of being free from the abdominal pain. Although the hour-long pain flares are usually worse in the afternoon compared to the morning, evening, or nighttime, they seem to be related to constipation. He has tried opioids and antidepressants but does not recall the names or doses, and they did not help. He has not tried anticonvulsants. Currently, he takes no medication for this pain.

The second pain located in his legs from his thighs down to his toes is perceived as “sharp,” “aching,” and “squeezing.” This pain began 1 to 3 months after injury. The intensity of this pain is 1/10 on average, but may increase to 10/10 for brief periods (up to 5 minutes at a time). This pain is present only in relation to severe spasms, but occurs up to 10 times a day. There is no consistent temporal pattern to this pain; it tends to occur throughout the day with no time period being better or worse. He is taking baclofen for this pain and reports that this medication is very helpful.

***Note:** Information regarding pain interference has been omitted in the training case. In an assessment situation these questions and the endpoints are read verbatim to the patient and he or she answers the question by choosing the appropriate number. Please also note that this training case is not a real case. Furthermore, the treatments used in these cases do not reflect recommendations by the Pain dataset committee but are merely examples of common treatments used to relieve pain in this population.*

## Training case 2

Date: October 26, 2008

This is a 25 year old woman with a C5 AIS A spinal cord injury following a traffic accident Aug 25 2005. She experiences three different kinds of pains, one located in the arms and hands, a second pain located in the buttocks and upper legs, and a third pain located in the shoulders.

She feels that the pain that she experiences in her arms and hands (upper arms through fingers) is the worst because it has a particularly unpleasant electric quality. It began within a month after her injury. She describes the pain in her arms as very intense, rating it as 8/10, on average. Light touching of the skin, touch by clothes and taking a shower trigger an intense electric burning pain. She has this pain every day on a continuous basis, although this pain is worse in the afternoon compared to the morning or evening. The pain gets a little better when she lies down or when she is thinking about something else. She takes an anticonvulsant medication and applies topical patches including a local anesthetic for this pain with partial benefit.

She describes the pain in the upper legs and buttocks as “burning,” “pricking” and “pulsating.” This pain started about one year after injury. This pain is also very intense; she rates it as a 7/10, on average. The pain is always present, independent of movements or muscle spasms, but usually is more severe in the evening as compared to the morning or afternoon. The anticonvulsant she is taking has no effect on this pain problem.

The pain in the shoulders is aching and started about two years after injury and is not quite as intense as the other two pains. This pain is usually only present in the afternoon and evening after workout or after periods of prolonged wheelchair propulsion or working at the computer. In the last week, pain was present for a total of 5 days. It usually lasts a couple of hours, and resolves after rest. She rates it as a 4/10, on average. She takes paracetamol or NSAIDS for this pain once or twice per week; she finds both of these medications somewhat helpful for the shoulder pain.

*Note: Information regarding pain interference has been omitted in the training case. In an assessment situation these questions and the endpoints are read verbatim to the patient and he or she answers the question by choosing the appropriate number. Please also note that this training case is not a real case. Furthermore, the treatments used in these cases do not reflect recommendations by the Pain dataset committee but are merely examples of common treatments used to relieve pain in this population.*

### Training case 3

Date: September 3, 2008

This is a 20 year old female who sustained a T10 AIS A spinal cord injury on July 8, 2004. She has a one level zone of partial preservation of light touch and pinprick sensation. She underwent a three level posterior decompression with fusion and instrumentation at the time of injury. She experiences two different types of pain of which a daily “sharp” attack-like lower back pain triggered by flexion of the spine is the worst. This pain came on insidiously over the last year and she cannot identify an inciting event. She describes this pain as very intense and brief, lasting less than one minute at a time and she rates it at an average of 8/10. It is most intense in the morning, afternoon and evening and is not present when she lays flat in bed at night. On physical exam, she exhibits tenderness to palpation over the low back both centrally and adjacent to the midline in paraspinal muscles. Portions of the hardware can be palpated over her low back. Opioid medication is somewhat effective in decreasing the severity of the pain, although it does not take it away completely.

In addition, she has a second pain that she describes as a constant pressure and as a “tight girdle” that is felt about the lower abdomen. This pain has been present since approximately 4 weeks after injury and does not vary in intensity. This pain is constant and rated at 4/10. The opioid medication does not relieve this pain.

*Note: Information regarding pain interference has been omitted in the training case. In an assessment situation these questions and the endpoints are read verbatim to the patient and he or she answers the question by choosing the appropriate number. Please also note that this training case is not a real case. Furthermore, the treatments used in these cases do not reflect recommendations by the Pain dataset committee but are merely examples of common treatments used to relieve pain in this population.*

**PAIN BASIC DATA SET – FORM - Version 1.1: CASE 1**

**Date of data collection: 2008/05/26**

**Have you had any pain during the last 7 days including today:**

No  Yes

**If yes, how many different pain problems did you have?**

1;  2;  3;  4;  >5

*Please describe your worst pain problem:*

Pain locations/sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain (check all that apply)	Intensity and temporal pattern of pain
<b>Head</b>				<b>Nociceptive</b> <input type="checkbox"/> Musculoskeletal <input checked="" type="checkbox"/> Visceral <input type="checkbox"/> Other  <b>Neuropathic</b> <input type="checkbox"/> At-level <input type="checkbox"/> Below-level <input type="checkbox"/> Other  <input type="checkbox"/> <b>Unknown</b>	<b>Average pain intensity in the last week:</b> 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input checked="" type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10  <b>Date of onset: 2006/MM/DD</b>  <b>Number of days with pain in the last 7 days including today:</b> <input type="checkbox"/> none; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input checked="" type="checkbox"/> 7; <input type="checkbox"/> unknown  <b>How long does your pain usually last:</b> <input type="checkbox"/> ≤ 1 min; <input type="checkbox"/> > 1 min but < 1 hr; <input checked="" type="checkbox"/> ≥ 1 hr but < 24 hrs; <input type="checkbox"/> ≥ 24 hrs; <input type="checkbox"/> constant or continuous; <input type="checkbox"/> unknown  <b>When during the day is the pain most intense:</b> <input type="checkbox"/> morning (06.01-12.00); <input checked="" type="checkbox"/> afternoon (12.01-18.00); <input type="checkbox"/> evening (18.01-24.00); <input type="checkbox"/> night (00.01-06.00) <input type="checkbox"/> unpredictable; pain is not consistently more intense at any one time of day
<b>Neck/shoulders</b> throat neck shoulder					
<b>Arms/hands</b> upper arm elbow forearm wrist hand/fingers					
<b>Frontal torso/genitals</b> chest abdomen pelvis/genitalia					
<b>Back</b> upper back lower back					
<b>Buttocks/hips</b> buttocks hip anus					
<b>Upper legs/thighs</b>					
<b>Lower legs/feet</b> knee shin calf ankle foot/toes					

**Are you using or receiving any Treatment for your pain problem:**  No  Yes

Please describe your second worst pain problem:

Pain locations/sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain (check all that apply)	Intensity and temporal pattern of pain
<b>Head</b>				<b>Nociceptive</b> <input checked="" type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other  <b>Neuropathic</b> <input type="checkbox"/> At-level <input type="checkbox"/> Below-level <input type="checkbox"/> Other  <input type="checkbox"/> <b>Unknown</b>	<b>Average pain intensity in the last week:</b> 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input checked="" type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10  <b>Date of onset: 2000/MM/DD</b>  <b>Number of days with pain in the last 7 days including today:</b> <input type="checkbox"/> none; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input checked="" type="checkbox"/> 7; <input type="checkbox"/> unknown  <b>How long does your pain usually last:</b> <input type="checkbox"/> ≤ 1 min; <input checked="" type="checkbox"/> > 1 min but < 1 hr; <input type="checkbox"/> ≥ 1 hr but < 24 hrs; <input type="checkbox"/> ≥ 24 hrs; <input type="checkbox"/> constant or continuous; <input type="checkbox"/> unknown  <b>When during the day is the pain most intense:</b> <input type="checkbox"/> morning (06.01-12.00); <input type="checkbox"/> afternoon (12.01-18.00); <input type="checkbox"/> evening (18.01-24.00); <input type="checkbox"/> night (00.01-06.00) <input checked="" type="checkbox"/> unpredictable; pain is not consistently more intense at any one time of day
<b>Neck/shoulders</b> throat neck shoulder					
<b>Arms/hands</b> upper arm elbow forearm wrist hand/fingers					
<b>Frontal torso/genitals</b> chest abdomen pelvis/genitalia					
<b>Back</b> upper back lower back					
<b>Buttocks/hips</b> buttocks hip anus					
<b>Upper legs/thighs</b>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		
<b>Lower legs/feet</b> knee shin calf ankle foot/toes	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		

Are you using or receiving any Treatment for your pain problem:  No  Yes

**PAIN BASIC DATA SET – FORM - Version 1.1: CASE 2**

**Date of data collection: 2008/10/26**

**Have you had any pain during the last 7 days including today:**

No  Yes

**If yes, how many different pain problems did you have?**

1;  2;  3;  4;  >5

*Please describe your worst pain problem:*

Pain locations/sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain (check all that apply)	Intensity and temporal pattern of pain
<b>Head</b>				<b>Nociceptive</b> <input type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other  <b>Neuropathic</b> <input checked="" type="checkbox"/> At-level <input checked="" type="checkbox"/> Below-level <input type="checkbox"/> Other  <input type="checkbox"/> <b>Unknown</b>	<b>Average pain intensity in the last week:</b> 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input checked="" type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10  <b>Date of onset: 2005/09/DD</b>  <b>Number of days with pain in the last 7 days including today:</b> <input type="checkbox"/> none; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input checked="" type="checkbox"/> 7; <input type="checkbox"/> unknown  <b>How long does your pain usually last:</b> <input type="checkbox"/> ≤ 1 min; <input type="checkbox"/> > 1 min but < 1 hr; <input type="checkbox"/> ≥ 1 hr but < 24 hrs; <input type="checkbox"/> ≥ 24 hrs; <input checked="" type="checkbox"/> constant or continuous; <input type="checkbox"/> unknown  <b>When during the day is the pain most intense:</b> <input type="checkbox"/> morning (06.01-12.00); <input checked="" type="checkbox"/> afternoon (12.01-18.00); <input type="checkbox"/> evening (18.01-24.00); <input type="checkbox"/> night (00.01-06.00) <input type="checkbox"/> unpredictable; pain is not consistently more intense at any one time of day
<b>Neck/shoulders</b> throat neck shoulder					
<b>Arms/hands</b> upper arm elbow forearm wrist hand/fingers	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		
<b>Frontal torso/genitals</b> chest abdomen pelvis/genitalia					
<b>Back</b> upper back lower back					
<b>Buttocks/hips</b> buttocks hip anus					
<b>Upper legs/thighs</b>					
<b>Lower legs/feet</b> knee shin calf ankle foot/toes					

**Are you using or receiving any Treatment for your pain problem:**  No  Yes

*Please describe your second worst pain problem:*

Pain locations/sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain (check all that apply)	Intensity and temporal pattern of pain
<b>Head</b>				<b>Nociceptive</b> <input type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other  <b>Neuropathic</b> <input type="checkbox"/> At-level <input checked="" type="checkbox"/> Below-level <input type="checkbox"/> Other  <input type="checkbox"/> <b>Unknown</b>	<b>Average pain intensity in the last week:</b> 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input checked="" type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10  <b>Date of onset: 2006/08/DD</b>  <b>Number of days with pain in the last 7 days including today:</b> <input type="checkbox"/> none; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input checked="" type="checkbox"/> 7; <input type="checkbox"/> unknown  <b>How long does your pain usually last:</b> <input type="checkbox"/> ≤ 1 min; <input type="checkbox"/> > 1 min but < 1 hr; <input type="checkbox"/> ≥ 1 hr but < 24 hrs; <input type="checkbox"/> ≥ 24 hrs; <input checked="" type="checkbox"/> constant or continuous; <input type="checkbox"/> unknown  <b>When during the day is the pain most intense:</b> <input type="checkbox"/> morning (06.01-12.00); <input type="checkbox"/> afternoon (12.01-18.00); <input checked="" type="checkbox"/> evening (18.01-24.00); <input type="checkbox"/> night (00.01-06.00) <input type="checkbox"/> unpredictable; pain is not consistently more intense at any one time of day
<b>Neck/shoulders</b> throat neck shoulder					
<b>Arms/hands</b> upper arm elbow forearm wrist hand/fingers					
<b>Frontal torso/genitals</b> chest abdomen pelvis/genitalia					
<b>Back</b> upper back lower back					
<b>Buttocks/hips</b> buttocks hip anus	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		
<b>Upper legs/thighs</b>	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		
<b>Lower legs/feet</b> knee shin calf ankle foot/toes					

Are you using or receiving any Treatment for your pain problem:  No  Yes\*

\* She is taking an anticonvulsant although this medication is not effective for this pain.

Please describe your third worst pain problem:

Pain locations/sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain (check all that apply)	Intensity and temporal pattern of pain
<b>Head</b>				<b>Nociceptive</b> <input checked="" type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other  <b>Neuropathic</b> <input type="checkbox"/> At-level <input type="checkbox"/> Below-level <input type="checkbox"/> Other  <input type="checkbox"/> Unknown	<b>Average pain intensity in the last week:</b> 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input checked="" type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10  <b>Date of onset: 2007/MM/DD</b>  <b>Number of days with pain in the last 7 days including today:</b> <input type="checkbox"/> none; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input checked="" type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> unknown  <b>How long does your pain usually last:</b> <input type="checkbox"/> ≤ 1 min; <input type="checkbox"/> > 1 min but < 1 hr; <input checked="" type="checkbox"/> ≥ 1 hr but < 24 hrs; <input type="checkbox"/> ≥ 24 hrs; <input type="checkbox"/> constant or continuous; <input type="checkbox"/> unknown  <b>When during the day is the pain most intense:</b> <input type="checkbox"/> morning (06.01-12.00); <input checked="" type="checkbox"/> afternoon (12.01-18.00); <input checked="" type="checkbox"/> evening (18.01-24.00); <input type="checkbox"/> night (00.01-06.00) <input type="checkbox"/> unpredictable; pain is not consistently more intense at any one time of day
<b>Neck/shoulders</b>					
throat					
neck					
shoulder	<input checked="" type="checkbox"/>		<input checked="" type="checkbox"/>		
<b>Arms/hands</b>					
upper arm					
elbow					
forearm					
wrist					
hand/fingers					
<b>Frontal torso/genitals</b>					
chest					
abdomen					
pelvis/genitalia					
<b>Back</b>					
upper back					
lower back					
<b>Buttocks/hips</b>					
buttocks					
hip					
anus					
<b>Upper legs/thighs</b>					
<b>Lower legs/feet</b>					
knee					
shin					
calf					
ankle					
foot/toes					

Are you using or receiving any Treatment for your pain problem:  No  Yes

**PAIN BASIC DATA SET – FORM - Version 1.1: CASE 3**

**Date of data collection: 2008/09/03**

**Have you had any pain during the last 7 days including today:**

No  Yes

**If yes, how many different pain problems did you have?**

1;  2;  3;  4;  >5

*Please describe your worst pain problem:*

Pain locations/sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain (check all that apply)	Intensity and temporal pattern of pain
<b>Head</b>				<b>Nociceptive</b> <input checked="" type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other  <b>Neuropathic</b> <input type="checkbox"/> At-level <input type="checkbox"/> Below-level <input type="checkbox"/> Other  <input type="checkbox"/> <b>Unknown</b>	<b>Average pain intensity in the last week:</b> 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input checked="" type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10  <b>Date of onset: 2007/MM/DD</b>  <b>Number of days with pain in the last 7 days including today:</b> <input type="checkbox"/> none; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input checked="" type="checkbox"/> 7; <input type="checkbox"/> unknown  <b>How long does your pain usually last:</b> <input checked="" type="checkbox"/> ≤ 1 min; <input type="checkbox"/> > 1 min but < 1 hr; <input type="checkbox"/> ≥ 1 hr but < 24 hrs; <input type="checkbox"/> ≥ 24 hrs; <input type="checkbox"/> constant or continuous; <input type="checkbox"/> unknown  <b>When during the day is the pain most intense:</b> <input checked="" type="checkbox"/> morning (06.01-12.00); <input checked="" type="checkbox"/> afternoon (12.01-18.00); <input checked="" type="checkbox"/> evening (18.01-24.00); <input type="checkbox"/> night (00.01-06.00) <input type="checkbox"/> unpredictable; pain is not consistently more intense at any one time of day
<b>Neck/shoulders</b> throat neck shoulder					
<b>Arms/hands</b> upper arm elbow forearm wrist hand/fingers					
<b>Frontal torso/genitals</b> chest abdomen pelvis/genitalia					
<b>Back</b> upper back lower back					
<b>Buttocks/hips</b> buttocks hip anus					
<b>Upper legs/thighs</b>					
<b>Lower legs/feet</b> knee shin calf ankle foot/toes					
	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		

**Are you using or receiving any Treatment for your pain problem:**  No  Yes

Please describe your second worst pain problem:

Pain locations/sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	R	M	L	Type of pain (check all that apply)	Intensity and temporal pattern of pain
<b>Head</b>				<b>Nociceptive</b> <input type="checkbox"/> Musculoskeletal <input type="checkbox"/> Visceral <input type="checkbox"/> Other  <b>Neuropathic</b> <input checked="" type="checkbox"/> At-level <input type="checkbox"/> Below-level <input type="checkbox"/> Other  <input type="checkbox"/> <b>Unknown</b>	<b>Average pain intensity in the last week:</b> 0 = no pain; 10 = pain as bad as you can imagine <input type="checkbox"/> 0; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input checked="" type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input type="checkbox"/> 7; <input type="checkbox"/> 8; <input type="checkbox"/> 9; <input type="checkbox"/> 10  <b>Date of onset: 2004/08/08</b>  <b>Number of days with pain in the last 7 days including today:</b> <input type="checkbox"/> none; <input type="checkbox"/> 1; <input type="checkbox"/> 2; <input type="checkbox"/> 3; <input type="checkbox"/> 4; <input type="checkbox"/> 5; <input type="checkbox"/> 6; <input checked="" type="checkbox"/> 7; <input type="checkbox"/> unknown  <b>How long does your pain usually last:</b> <input type="checkbox"/> ≤ 1 min; <input type="checkbox"/> > 1 min but < 1 hr; <input type="checkbox"/> ≥ 1 hr but < 24 hrs; <input type="checkbox"/> ≥ 24 hrs; <input checked="" type="checkbox"/> constant or continuous; <input type="checkbox"/> unknown  <b>When during the day is the pain most intense:</b> <input type="checkbox"/> morning (06.01-12.00); <input type="checkbox"/> afternoon (12.01-18.00); <input type="checkbox"/> evening (18.01-24.00); <input type="checkbox"/> night (00.01-06.00) <input checked="" type="checkbox"/> unpredictable; pain is not consistently more intense at any one time of day
<b>Neck/shoulders</b> throat neck shoulder					
<b>Arms/hands</b> upper arm elbow forearm wrist hand/fingers					
<b>Frontal torso/genitals</b> chest abdomen pelvis/genitalia					
<b>Back</b> upper back lower back					
<b>Buttocks/hips</b> buttocks hip anus					
<b>Upper legs/thighs</b>					
<b>Lower legs/feet</b> knee shin calf ankle foot/toes					
	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>		

Are you using or receiving any Treatment for your pain problem:  No  Yes\*

\* the opioid medication she is taking has no effect on this pain.