INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET
Version 2.0

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This interdisciplinary working group was assembled based on published research expertise in the area of spinal cord injury (SCI) 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 SCI (Stensman 1994; Westgren & Levi, 1998). Pain taxonomies for SCI (Siddall et al., 2000; Bryce & Ragnarsson, 2001; Bryce et al., 2012a,b) 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 ISCIPDS: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 ISCIPDS:E is primarily intended to be used for research purposes. The overall purpose of the ISCIPDS 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 International 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 complementary 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 ISCIPDS: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 include a pain intensity rating and a classification for each specific pain. Pain interference is addressed using three questions specifically addressing pain interference with activities, mood and sleep.

Version changes of the International SCI Pain Basic Data Set.
Version 1.0 to Version 1.1:
The only change made was related to the variable **Type of pain**, where the option *"At- and below-level (Neuropathic)"* was removed and merged with the "Below-level (Neuropathic)" pain. The revised "B*elow-level (Neuropathic)"* pain category now includes pain that may be experienced below the level of injury and extends to the level of injury. This modification was made since no current evidence suggests the underlying mechanisms differ between the two categories.

The International SCI Pain Basic Data Set (ISCIPBDS) published in 2008 was Version 1.1: Widerström-Noga E, Biering-Sørensen F, Bryce T, Cardenas DD, Finnerup NB, Jensen MP, Richards S, Siddall PJ. The International Spinal Cord Injury Pain Basic Data Set. Spinal Cord 2008;46:818-23.

Version 1.1 to Version 2.0 (2.0 version finalized 21 May, 2013):
Several changes have been made due to both updates to the pain classification scheme and desires from the field to shorten the International SCI Pain Basic Data Set to facilitate its clinical usefulness:

1. Related to the variable **Type of pain**, an extra option *"Other"* is inserted, in accordance with the changes made in the International Spinal Cord Injury Pain (ISCIP) Classification (Bryce et al. 2012a). Also only one choice of pain type should now be chosen. This manual has been updated with more detail to facilitate the pain classification according to the ISCIP Classification.

2. The variable **Number of days with pain in the last 7 days including today** has been deleted to shorten the International SCI Pain Basic Data Set.

3. The variable **How long does your pain usually last?** has been deleted to shorten the International SCI Pain Basic Data Set.

4. The variable **When is the pain most intense?** has been deleted to shorten the International SCI Pain Basic Data Set.

5. The variable **How much do you limit your activities in order to keep your pain from getting worse?** has been deleted to shorten the International SCI Pain Basic Data Set.

6. The variable **How much has your pain changed your ability to take part in recreational and other social activities?** has been deleted to shorten the International SCI Pain Basic Data Set.

7. The variable **How much has your pain changed the amount of satisfaction or enjoyment you get from family-related activities?** has been deleted to shorten the International SCI Pain Basic Data Set.

8. The 3 remaining **Pain Interference questions** shall be applied for overall pain rather than differentiated for up to 3 pain types and be scored on a 0 to 10 scale instead of 0 to 6 for consistency with the pain intensity item. Please note that the psychometric properties were evaluated with these items scored between 0 and 6. We expect minimal to no effects on these properties with the revision.

Endorsement:

The International SCI Pain Basic Data Set Version 1.1 has been officially endorsed by the ISCoS, ASIA, IASP and the APS.

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SYLLABUS (instructions) – Version 2.0

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.

Pain Interference

The three 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 on physical activity; and (2) the need to ensure assessment of pain interference on mood and sleep, two key interference domains. Widerstrom-Noga et al, 2002; Hirsch et al., 2011. Based on the results from a study testing the psychometric properties of a self-reported version of the International SCI Pain Basic Data Set (Jensen et al., 2010) the 6 interference items exhibited excellent reliability (0.94). However, a reliability coefficient in this range suggests that some items may provide similar information and could therefore be dropped. Thus, all items were examined regarding internal reliability and validity. Three items asking about interference with day-to-day activities, mood and sleep (AMS) were selected based upon excellent reliability (0.89) and on strong association with the validity criteria (psychological functioning -0.60 and Sleep problems 0.68). Each item has been revised and is now scored on a numerical rating scale from 0 to 10. Please note that the psychometric properties were evaluated with these items scored between 0 and 6. We expect minimal to no effects on these properties with the revision.

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

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 – 10 Numerical Rating Scale (ranging from 0 = "No interference" to a maximum of 10 = "Extreme interference") of pain interference with general activity.

CODES: 0
                 1
                 2
                 3
                 4
                 5
                 6
                 7
                 8
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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.

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

DESCRIPTION: A 0 – 10 Numerical Rating Scale (ranging from 0 = "No interference" to a maximum of 10 = "Extreme interference") of pain interference of mood.

CODES: 0
                 1
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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.

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

DESCRIPTION: A 0 – 10 Numerical Rating Scale (ranging from 0 = "No interference" to a maximum of 10 = "Extreme interference") of pain interference of mood.

CODES: 0
                 1
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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.

_____

VARIABLE NAME**:** **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: **Head** right side, midline and/or left side
Neck/shoulders
     throat right side, midline and/or left side
     neck right side, midline and/or left side
     shoulder right and/or left side

Arms/hands

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

Frontal torso/genitals

chest	right side, midline and/or left side
abdomen	right side, midline and/or left side
pelvis/gentalia	right side, midline and/or left side

Back

upper back	right side, midline and/or left side
lower back	right side, midline and/or left side

Buttocks/hips

buttocks	right and/or left side
hip	right and/or left side
anus	midline

Upper legs/thighs   right and/or left side

Lower legs/feet

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 SCI (Neuropathic)
Below-level SCI (Neuropathic)
Other (Neuropathic)
Other
Unknown

COMMENTS: Seven 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; Bryce et al., 2012a,b) and based on prevalence in the SCI population. ***Please note that the ASIA Impairment scale (AIS) and the associated dermatomal map (Kirshblum et al., 2011) are to be used as integral parts 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)*". Pains that are not associated with a lesion or disease affecting the spinal cord or nerve roots yet are nevertheless neuropathic can be classified as "*Other (Neuropathic)*". "*Unknown*" should be used when it is not possible to classify the pain into one of the categories listed above. "*Unknown*" pain refers only to pain of unknown etiology and not to pains with both nociceptive and neuropathic qualities, nor to defined pain syndromes of unknown etiology, like fibromyalgia. For pains that seem to have both nociceptive and neuropathic qualities the two components should be classified separately. Defined pain syndromes of unknown etiology (for example, fibromyalgia) should be coded as *"Other"*.

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 or opioid 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, abdomen, or pelvis and believed to be generated in visceral structures. The presence of this type of pain is suggested by characteristics such as dull, tender, 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; Bryce et al., 2012a). 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).

At-level SCI (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 hot-burning, tingling, pricking, pins and needles, squeezing, cold, electric, or shooting. Sensory changes such as allodynia, hypoalgesia, or hyperalgesia within the pain distribution are often found. The pain may be unilateral or bilateral (Siddall et al., 2000; Bryce & Ragnarsson, 2001; Bryce et al., 2012a). 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 SCI (Neuropathic) pain refers to neuropathic pain that is present more than three dermatomes below the dermatome of the neurological level of injury; it may in addition be perceived up to the dermatome representing the neurological level of injury and the three dermatomes just below this. A necessary condition for this to occur is that there is a lesion or disease affecting the spinal cord and that the pain is believed to arise as a result of this damage. 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 is often characterized as hot-burning, tingling, pricking, pins and needles, squeezing, cold, electric, or shooting; it usually has a regional distribution. Sensory changes such as allodynia, hypoalgesia, or hyperalgesia may be present. If two distinct pains are distinguishable in the same region, the two pain types must be classified and documented as separate pains.

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).

Other pain refers to pain that occurs when there is no identifiable noxious stimulus nor any detectable inflammation or damage to the nervous system responsible for the pain and the pain is thought to be unrelated to the underlying SCI, both temporally and mechanistically. It is unclear what causes the pain to develop or persist. Examples include: Complex Regional Pain Syndrome type I, interstitial cystitis pain, irritable bowel syndrome pain and fibromyalgia.

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.*

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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: **Are you using or receiving any <u>treatment</u> 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 PAIN BASIC DATA SET

DATA COLLECTION FORM – Version 2.0

Date of data collection: YYYY/MM/DD

Have you had any pain during the last seven days including today:
        ☐ No   ☐ Yes

If yes:

Please note that the time period during the <u>last week</u> applies to all pain interference questions.

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 - ☐ 7 - ☐ 8 - ☐ 9 - ☐ 10 Extreme interference

In general, how much has pain interfered with your overall mood in the last week?
No interference ☐ 0 - ☐ 1 - ☐ 2 - ☐ 3 - ☐ 4 - ☐ 5 - ☐ 6 - ☐ 7 - ☐ 8 - ☐ 9 - ☐ 10 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 - ☐ 7 - ☐ 8 - ☐ 9 - ☐ 10 Extreme interference

How many different pain problems do you have?
       ☐ 1; ☐ 2; ☐ 3; ☐ 4; ☐ ≥5

Please describe your <u>three</u> 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 Intensity and duration of pain Treatment of pain
Head				**Type of pain (check one):**
Neck/shoulders				**Nociceptive**
throat				☐ Musculoskeletal
neck				☐ Visceral
shoulder				☐ Other
Arms/hands				
upper arm				**Neuropathic**
elbow				☐ At-level SCI
forearm				☐ Below-level SCI
wrist				☐ Other
hand/fingers				
Frontal torso/genitals				☐ **Other**
chest				
abdomen				☐ **Unknown**
pelvis/genitalia				
Back				
upper back				**Intensity** and **duration of pain:**
lower back				**Average pain intensity in the last week:**
Buttocks/hips				0 = no pain; 10 = pain as bad as you can imagine
buttocks				☐ 0; ☐ 1; ☐ 2; ☐ 3; ☐ 4; ☐ 5;
hip				☐ 6; ☐ 7; ☐ 8; ☐ 9; ☐ 10
anus				
Upper leg/thigh				**Date of onset:** YYYY/MM/DD
Lower legs/feet				
knee				**Are you using or receiving any <u>treatment</u> for your pain problem:**
shin				☐ No ☐ Yes
calf				
ankle				
foot/toes				

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 Intensity and duration of pain Treatment of pain
Head				**Type of pain (check one):**
Neck/shoulders				**Nociceptive**
throat				☐ Musculoskeletal
neck				☐ Visceral
shoulder				☐ Other
Arms/hands				
upper arm				**Neuropathic**
elbow				☐ At-level SCI
forearm				☐ Below-level SCI
wrist				☐ Other
hand/fingers				
Frontal torso/genitals				☐ **Other**
chest				
abdomen				☐ **Unknown**
pelvis/genitalia				
Back				**Intensity** and **duration of pain:**
upper back				**Average pain intensity in the last week:**
lower back				0 = no pain; 10 = pain as bad as you can imagine
Buttocks/hips				☐ 0; ☐ 1; ☐ 2; ☐ 3; ☐ 4; ☐ 5;
buttocks				☐ 6; ☐ 7; ☐ 8; ☐ 9; ☐ 10
hip				
anus				
Upper leg/thigh				**Date of onset:** YYYY/MM/DD
Lower legs/feet				
knee				**Are you using or receiving any <u>treatment</u> for your pain problem:**
shin				☐ No ☐ Yes
calf				
ankle				
foot/toes				

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 **Intensity** and **duration of pain** **Treatment of pain**
Head				**Type of pain (check one):**
Neck/shoulders				**Nociceptive**
throat				☐ Musculoskeletal
neck				☐ Visceral
shoulder				☐ Other
Arms/hands				
upper arm				**Neuropathic**
elbow				☐ At-level SCI
forearm				☐ Below-level SCI
wrist				☐ Other
hand/fingers				
Frontal torso/genitals				☐ **Other**
chest				
abdomen				☐ **Unknown**
pelvis/genitalia				
Back				**Intensity** and **duration of pain:**
upper back				**Average pain intensity in the last week:**
lower back				0 = no pain; 10 = pain as bad as you can imagine
Buttocks/hips				☐ 0; ☐ 1; ☐ 2; ☐ 3; ☐ 4; ☐ 5;
buttocks				☐ 6; ☐ 7; ☐ 8; ☐ 9; ☐ 10
hip				
anus				
Upper leg/thigh				**Date of onset:** YYYY/MM/DD
Lower legs/feet				
knee				**Are you using or receiving any <u>treatment</u> for your pain problem:**
shin				☐ No ☐ Yes
calf				
ankle				
foot/toes				

INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET
Version 2.0

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.

He does not feel that pain affects his overall day-to-day activities and upon inquiry he rates interference with activities as very low, perhaps 1/10. He also does not feel that his mood is affected and rates the influence of mood as 0/10. He does, however, mention that he frequently wakes up but that this is not related to his pain, and he rates sleep interference as 0/10.

Note: 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.

INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET – FORM - Version 2.0
CASE 1

Date of data collection: 2008/05/26

Have you had any pain during the last 7 days including today:
☐ **No   X Yes**

If yes:

Please note that the time period during the <u>last week</u> applies to all pain interference questions.

In general, how much has pain interfered with your day-to-day activities in the last week?
No interference ☐ 0 - **X 1** - ☐ 2 - ☐ 3 - ☐ 4 - ☐ 5 - ☐ 6 - ☐ 7 - ☐ 8- ☐ 9 - ☐ 10 Extreme interference

In general, how much has pain interfered with your overall mood in the last week?
No interference **X 0** - ☐ 1 - ☐ 2 - ☐ 3 - ☐ 4 - ☐ 5 - ☐ 6 - ☐ 7 - ☐ 8- ☐ 9 - ☐ 10 Extreme interference

In general, how much has pain interfered with your ability to get a good night's sleep?
No interference **X 0** - ☐ 1 - ☐ 2 - ☐ 3 - ☐ 4 - ☐ 5 - ☐ 6 - ☐ 7 - ☐ 8- ☐ 9 - ☐ 10 Extreme interference

How many different pain problems do you have?
☐ **1; X 2;** ☐ **3;** ☐ **4;** ☐ **>5**

Please describe your <u>three</u> 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 Intensity and duration of pain Treatment of pain
Head				**Type of pain (check one):**
Neck/shoulders				**Nociceptive**
throat				☐ Musculoskeletal
neck				**X** Visceral
shoulder				☐ Other
Arms/hands				
upper arm				**Neuropathic**
elbow				☐ At-level SCI
forearm				☐ Below-level SCI
wrist				☐ Other
hand/fingers				
Frontal torso/genitals				☐ **Other**
chest				
abdomen		**X**		☐ **Unknown**
pelvis/genitalia				
Back				**Intensity** and **duration of pain:**
upper back				**Average pain intensity in the last week:**
lower back				0 = no pain; 10 = pain as bad as you can imagine
Buttocks/hips				☐ 0; ☐ 1; ☐ 2; ☐ 3; ☐ 4; ☐ 5;
buttocks				☐ 6; **X** 7; ☐ 8; ☐ 9; ☐ 10
hip				
anus				
Upper leg/thigh				**Date of onset: 2006/**99/99
Lower legs/feet				
knee				**Are you using or receiving any <u>treatment</u> for your pain problem:**
shin				☐ No **X** Yes
calf				
ankle				
foot/toes				

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 Intensity and duration of pain Treatment of pain
Head				**Type of pain (check one):**
Neck/shoulders				**Nociceptive**
throat				**X** Musculoskeletal
neck				☐ Visceral
shoulder				☐ Other
Arms/hands				
upper arm				**Neuropathic**
elbow				☐ At-level SCI
forearm				☐ Below-level SCI
wrist				☐ Other
hand/fingers				
Frontal torso/genitals				☐ **Other**
chest				
abdomen				☐ **Unknown**
pelvis/genitalia				
Back				**Intensity** and **duration of pain:**
upper back				**Average pain intensity in the last week:**
lower back				0 = no pain; 10 = pain as bad as you can imagine
Buttocks/hips				☐ 0; **X** 1; ☐ 2; ☐ 3; ☐ 4; ☐ 5;
buttocks				☐ 6; ☐ 7; ☐ 8; ☐ 9; ☐ 10
hip				
anus				
Upper leg/thigh	X		X	**Date of onset: 2000**/99/99
Lower legs/feet				
knee	X		X	**Are you using or receiving any treatment for your pain problem:**
shin	X		X	☐ No **X** Yes
calf	X		X	
ankle	X		X	
foot/toes	X		X	

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.

She reports that her pain interferes with her activities every day and she rates this interference as 8/10. Similarly, she also mentions that her pain makes her feel sad on a daily basis and she rates it as 7/10 interfering significantly with mood. She wakes up several times every night because of pain and this is a very difficult problem for her. She rates it as 10/10.

Note: 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.

INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET – FORM - Version 2.0
CASE 2

Date of data collection: 2008/10/26

Have you had any pain during the last 7 days including today:
☐ **No   X Yes**

If yes:

Please note that the time period during the <u>*last week*</u> *applies to all pain interference questions.*

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 - ☐ 7 - **X 8**- ☐ 9 - ☐ 10 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 - **X 7** - ☐ 8 - ☐ 9 - ☐ 10 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 - ☐ 7 - ☐ 8 - ☐ 9 - **X 10** Extreme interference

How many different pain problems do you have?
☐ **1;** ☐**2; X 3;** ☐ **4;** ☐ **>5**

Please describe your <u>**three**</u> **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 Intensity and duration of pain Treatment of pain
Head				**Type of pain (check one):**
Neck/shoulders				**Nociceptive**
throat				☐ Musculoskeletal
neck				☐ Visceral
shoulder				☐ Other
Arms/hands				
upper arm	X		X	**Neuropathic**
elbow	X		X	**X** At-level SCI
forearm	X		X	☐ Below-level SCI
wrist	X		X	☐ Other
hand/fingers	X		X	
	X		X	
Frontal torso/genitals				☐ **Other**
chest				
abdomen				☐ **Unknown**
pelvis/genitalia				
Back				**Intensity** and **duration of pain:**
upper back				**Average pain intensity in the last week:**
lower back				0 = no pain; 10 = pain as bad as you can imagine
Buttocks/hips				☐ 0; ☐ 1; ☐ 2; ☐ 3; ☐ 4; ☐ 5;
buttocks				☐ 6; ☐ 7; **X** 8; ☐ 9; ☐ 10
hip				
anus				
Upper leg/thigh				**Date of onset: 2005/09/99**
Lower legs/feet				
knee				**Are you using or receiving any <u>treatment</u> for your pain problem:**
shin				☐ No **X** Yes
calf				
ankle				
foot/toes				

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 **Intensity** and **duration of pain** **Treatment of pain**
Head				**Type of pain (check one):**
Neck/shoulders				**Nociceptive**
throat				☐ Musculoskeletal
neck				☐ Visceral
shoulder				☐ Other
Arms/hands				
upper arm				**Neuropathic**
elbow				☐ At-level SCI
forearm				**X** Below-level SCI
wrist				☐ Other
hand/fingers				
Frontal torso/genitals				☐ **Other**
chest				
abdomen				☐ **Unknown**
pelvis/genitalia				
Back				**Intensity** and **duration of pain:**
upper back				**Average pain intensity in the last week:**
lower back				0 = no pain; 10 = pain as bad as you can imagine
Buttocks/hips				☐ 0; ☐ 1; ☐ 2; ☐ 3; ☐ 4; ☐ 5;
buttocks	X		X	☐ 6; **X** 7; ☐ 8; ☐ 9; ☐ 10
hip				
anus				
Upper leg/thigh	X		X	**Date of onset: 2006/08**/99
Lower legs/feet				
knee				**Are you using or receiving any treatment for your pain problem:**
shin				☐ No **X** Yes*
calf				*She is taking an anticonvulsant although this
ankle				medication is not effective for this pain.
foot/toes				

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 / Intensity and duration of pain / Treatment of pain
Head				**Type of pain (check one):**
Neck/shoulders				**Nociceptive**
throat				**X** Musculoskeletal
neck				☐ Visceral
shoulder	X		X	☐ Other
Arms/hands				
upper arm				**Neuropathic**
elbow				☐ At-level SCI
forearm				☐ Below-level SCI
wrist				☐ Other
hand/fingers				
Frontal torso/genitals				☐ **Other**
chest				
abdomen				☐ **Unknown**
pelvis/genitalia				
Back				**Intensity** and **duration of pain:**
upper back				**Average pain intensity in the last week:**
lower back				0 = no pain; 10 = pain as bad as you can imagine
Buttocks/hips				☐ 0; ☐ 1; ☐ 2; ☐ 3; **X** 4; ☐ 5;
buttocks				☐ 6; ☐ 7; ☐ 8; ☐ 9; ☐ 10
hip				
anus				
Upper leg/thigh				**Date of onset: 2007**/99/99
Lower legs/feet				
knee				**Are you using or receiving any <u>treatment</u> for your pain problem:**
shin				☐ No **X** Yes
calf				
ankle				
foot/toes				

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.

She describes that pain does not really affect her day-to-day activities since she has to "get things done." She rates the pain interference with activities as 1/10. She does, however, mention that pain affects her mood to a moderate degree and rates the pain interference as 5/10 since she does not feel that way every day. Sleep is also interrupted by pain and she rates sleep interference as 5/10.

Note: 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.

INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET – FORM - Version 2.0
CASE 3

Date of data collection: 2008/09/03

Have you had any pain during the last 7 days including today:
☐ **No   X Yes**

If yes:

Please note that the time period during the <u>last week</u> applies to all pain interference questions.

In general, how much has pain interfered with your day-to-day activities in the last week?
No interference ☐ 0 - **X 1** - ☐ 2 - ☐ 3 - ☐ 4 - ☐ 5 - ☐ 6 - ☐ 7 - ☐ 8 - ☐ 9 - ☐ 10 Extreme interference

In general, how much has pain interfered with your overall mood in the past week?
No interference ☐ 0 - ☐ 1 - ☐ 2 - ☐ 3 - ☐ 4 - **X 5** - ☐ 6 - ☐ 7 - ☐ 8 - ☐ 9 - ☐ 10 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 - **X 5** - ☐ 6 - ☐ 7 - ☐ 8 - ☐ 9 - ☐ 10 Extreme interference

How many different pain problems do you have?
☐ **1; X 2; ☐ 3; ☐ 4; ☐ >5**

Please describe your <u>three</u> 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 Intensity and duration of pain Treatment of pain
Head				**Type of pain (check one):**
Neck/shoulders				**Nociceptive**
throat				**X** Musculoskeletal
neck				☐ Visceral
shoulder				☐ Other
Arms/hands				
upper arm				**Neuropathic**
elbow				☐ At-level SCI
forearm				☐ Below-level SCI
wrist				☐ Other
hand/fingers				
Frontal torso/genitals				☐ **Other**
chest				
abdomen				☐ **Unknown**
pelvis/genitalia				
Back				**Intensity** and **duration of pain:**
upper back				**Average pain intensity in the last week:**
lower back	X	X	X	0 = no pain; 10 = pain as bad as you can imagine
Buttocks/hips				☐ 0; ☐ 1; ☐ 2; ☐ 3; ☐ 4; ☐ 5;
buttocks				☐ 6; ☐ 7; **X** 8; ☐ 9; ☐ 10
hip				
anus				
Upper leg/thigh				**Date of onset: 2007**/99/99
Lower legs/feet				
knee				**Are you using or receiving any _treatment_ for your pain problem:**
shin				☐ No **X** Yes
calf				
ankle				
foot/toes				

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 **Intensity** and **duration of pain** **Treatment of pain**
Head				**Type of pain (check one):**
Neck/shoulders				**Nociceptive**
throat				☐ Musculoskeletal
neck				☐ Visceral
shoulder				☐ Other
Arms/hands				
upper arm				**Neuropathic**
elbow				**X** At-level SCI
forearm				☐ Below-level SCI
wrist				☐ Other
hand/fingers				
Frontal torso/genitals				☐ **Other**
chest				
abdomen	X	X	X	☐ **Unknown**
pelvis/genitalia				
Back				**Intensity** and **duration of pain:**
upper back				**Average pain intensity in the last week:**
lower back				0 = no pain; 10 = pain as bad as you can imagine
Buttocks/hips				☐ 0; ☐ 1; ☐ 2; ☐ 3; **X** 4; ☐ 5;
buttocks				☐ 6; ☐ 7; ☐ 8; ☐ 9; ☐ 10
hip				
anus				
Upper leg/thigh				**Date of onset: 2004/08/08**
Lower legs/feet				
knee				**Are you using or receiving any <u>treatment</u> for your pain problem:**
shin				☐ No **X** Yes*
calf				*the opioid medication she is taking has no effect on this pain.
ankle				
foot/toes				