INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET
Version 3.0

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This interdisciplinary working group was assembled based on published research expertise in spinal cord injury (SCI) related pain. We have expertise in SCI and in the clinical condition of pain, pain taxonomy, psychophysics of pain, psychology, epidemiology, and assessment of pain.

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 the neurological level of injury. 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 often collected in idiosyncratic ways that is important for treatment decisions concerning the pain condition. However, to expedite the development of beneficial treatments, it would be ideal to evaluate the outcomes of treatments in a consistent manner across settings. 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 **basic** (ISCIPBDS) and **extended** (ISCIPEDS) components. The ISCIPBDS contains the necessary clinically relevant information concerning pain that can be collected in the daily practice of healthcare professionals with expertise in SCI. It was designed to be logistically feasible across different settings and countries. The intent of the ISCIPBDS is to make it possible to evaluate either a single distinct pain problem (e.g., "neuropathic pain.," "shoulder pain," or "worst" pain problem), it was also designed to make it possible to assess more than one pain problem. The specific items can therefore be adapted, as needed, depending on the specific clinical or research needs of the assessment. The overall purpose of the ISCIPDS however, aligns with the purpose and vision of the International Spinal Cord Injury Data Sets (Biering-Sørensen et al., 2006) and should be used together with sensorimotor data regarding the spinal injury cord injury severity and the neurological level or injury determined by the International Standards for Neurological Classification of SCI (ISNCSCI) (Rupp et al. 2021).

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). Specifically, it was suggested that pain severity, physical and emotional functioning should be assessed as these measures would best capture the multidimensional nature of pain. However, the IMMPACT consensus group 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 sensorimotor 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 studies, clinical trials, and clinical practice.

The questions in the ISCIPBDS 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 in version 1.0 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 then included pain that may be experienced below the level of injury and extends to the level of injury. This modification was made because no evidence suggested that 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 were made in version 1.1 in 2013 because of updates made to the pain classification scheme and desires from the field to shorten the International SCI Pain Basic Data Set to facilitate its clinical utility:

1. Related to the variable **Type of pain**, an extra option *"Other"* was inserted, in accordance with the changes made in the International Spinal Cord Injury Pain (ISCIP) Classification (Bryce et al. 2012a). Also, we determined that only one choice of pain type should be chosen. The manual was 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** was deleted to shorten the International SCI Pain Basic Data Set.

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

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

8. We determined that the 3 remaining **Pain Interference questions** should 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 of the SCI Pain Basic Data Set were originally evaluated with these items scored between 0 and 6. We expected minimal to no effects on these properties with the revision.

Version 2.0 to Version 3.0 (3.0 version finalized xx/xx, 2022):

1. We updated recommendations regarding how to use the ISCIBPDS items. Specifically, our intent was to make the dataset more flexible and useful. We clarified that although the initial intent of the ISCIPBDS was to evaluate the 3 worst pain problems, a greater number of distinct pain problems may also be evaluated if needed. The assessment can be based on the patient's perception of several of his/her "worst" pain(s) especially for clinical practice, or on one or several pain types of specific interest. The selection of pain problem(s) may also be determined by a clinical or research question. For example, for longitudinal follow-up of a specific pain, pain type or a combination of labels may be used e.g., pain location (e.g., shoulder, legs), temporal pattern (e.g., continuous, intermittent), pain quality (e.g., burning, electric) or evoked pain (e.g., mechanical allodynia). Similarly, if a research project aims to evaluate the prevalence or mechanisms of a particular type of pain, e.g., neuropathic pain, the use of the 3 worst pain problems could be misleading. In those cases, neuropathic pain should always be evaluated. There might also be situations, where a research aim is best addressed by first examining if each pain type, e.g., neuropathic pain, musculoskeletal pain, visceral pain and other pain, is present or not, and if present, described for each type separately.

2. Pain interference is recommended to be assessed for overall pain because it is very difficult for many individuals to distinguish the unique and distinct impact of one pain problem on quality of life when more than one pain problem is present. However, there may be situations where a clinician or a specific research question may determine that one or more pain interference questions are relevant for one or all pain types present. For example, this could be the case if a research project focuses on one specific pain type or aims to assess which type of pain has most impact on a specific outcome, e.g., mood or sleep. However, validity data regarding the assessment of pain interference separately for specific pain problems when in individuals who experience multiple pain problems are currently lacking.

3. We added an optional pain drawing with a frontal and dorsal view to complement the pain location check boxes, given feedback from some clinicians that they find a pain drawing more useful than a pain checklist. The pain drawing can also be used when discussing the pains with the patient or research individual. Furthermore, the dermatome map from the ISNCSCI exam can be used to determine at- and below-level pain based on the drawing as previously shown (Rosner et al., 2021).

4. Treatment: Because there are detailed treatment options in the ISCIPEDS (Widerstrom-Noga et al., 2016), we added a few check boxes for the categories listed in Appendix C of the ISCIPEDS so that the assessor can decide whether more details should be collected within each of these categories, depending on the research or clinical focus. In the extended data set we have the following categories: 1. Physiotherapy (e.g., exercise); 2. Passive and stimulation therapy (e.g., massage, transcutaneous electrical nerve, spinal cord stimulation); 3. Relaxation and Psychotherapy (e.g., meditation, cognitive behavioural therapy); 4. Oral and topical medication (e.g., antiepileptics, NSAIDs); 5. Procedural intervention (e.g., acupuncture, nerve block, epidural spinal cord stimulation); 6. Surgical interventions; 7. Other

More detailed instructions and examples regarding the use of the ISCIBPDS are provided in the training cases.

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ISCIPBDS v3.0:

Endorsement:

ISCIPBDS v1.0 and v2.0: The International SCI Pain Basic Data Set Versions 1.0 and 2.0 were officially endorsed by the ISCoS, ASIA, IASP and the APS.

ISCIPBDS v3.0:

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SYLLABUS (instructions) – Version 3.0

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, or resembling that associated with, actual or potential tissue damage" (Raja et al., 2020).

The seven-day interval was chosen 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 a Basic Pain Question in other questionnaires, i.e., gate or screening 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. 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) (Jensen et al., 2010). Each item is scored on a numerical rating scale from 0 to 10. Please note that the psychometric properties were evaluated in a previous version where these items were scored between 0 and 6. We do not expect the psychometric properties to be different for the scoring range of 0-10.

In this section pain interference ***during the last week*** apply to all questions. The 3 interference items can be assessed for individual pains or for overall pain. To ensure comparability across studies, even when a user allows respondents to rate pain interference for more than one pain problem, we recommend that respondents still be invited to rate overall pain interference." Although validity data regarding the use of the pain interference items for each individual pain in a person who experiences several concomitants pains is currently lacking, there may be situations where there is a clinical or research interest in assessing pain interference separately for individual pain problems.

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
9
10

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 dataset to provide a summary rating of interference with various activities.

VARIABLE NAME: **In general, how much has pain interfered with your overall mood 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 of mood.

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

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
2
3
4
5
6
7
8
9
10

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 pain problems an individual perceives that he or she has that are different from each other (e.g., quality, temporal pattern, intensity, impact on life) and that are 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. There may also be cases where a patient experiences pain in several different locations and these pains are diagnosed by a clinician to be the same pain type (e.g., rheumatoid arthritis). Similarly, a patient may have bilateral shoulder pain of the same origin (e.g., musculoskeletal). In these cases, these pains should be documented as one pain.

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.

Use of the data set to assess one or several distinct pain problems

COMMENTS: Most people with SCI experience several pain problems. Each person is asked to describe one or several of his/her pains experienced within the last 7 days. The pain problems could include one or several of the worst pains as defined by the patient or one or more pain type of particular interest depending on a clinical or research question. Each person can also be asked to describe all pain types present, e.g. neuropathic, musculoskeletal, visceral and other pain. The selection

of pain problem(s) may also be determined by a clinical or research question. For example, for longitudinal follow-up of a specific pain, pain type or a combination of labels may be used e.g., pain location (e.g., shoulder, legs), temporal pattern (e.g., continuous, intermittent), pain quality (e.g., burning, electric) or evoked pain (e.g., mechanical allodynia). 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. Please note that one or more area can apply.

CODES:

Head	☐ right side ☐ midline ☐ left side
Neck/shoulders	
throat	☐ right side ☐ midline ☐ left side
neck	☐ right side ☐ midline ☐ left side
shoulder	☐ right side ☐ left side
Arms/hands	
upper arm	☐ right side ☐ left side
elbow	☐ right side ☐ left side
forearm	☐ right side ☐ left side
wrist	☐ right side ☐ left side
hand/fingers	☐ right side ☐ left side
Frontal torso/genitals	
chest	☐ right side ☐ midline ☐ left side
abdomen	☐ right side ☐ midline ☐ left side
pelvis/genitalia	☐ right side ☐ midline ☐ left side
Back	
upper back	☐ right side ☐ midline ☐ left side
lower back	☐ right side ☐ midline ☐ left side
Buttocks/hips	
buttocks	☐ right side ☐ left side
hip	☐ right side ☐ left side
anus	☐ midline
Upper legs/thighs	☐ right side ☐ left side
Lower legs/feet	
knee	☐ right side ☐ left side
shin	☐ right side ☐ left side
calf	☐ right side ☐ left side
ankle	☐ right side ☐ left side
foot/toes	☐ right side ☐ 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 their pain. Please indicate right (R), midline (M) and/or left (L) side. We have included an optional pain drawing that can be used for more detail if needed.

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), the neurological level of injury, and the associated dermatomal map (Rupp et al., 2021) are to be used as complementary 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, e.g. pain in the skin related to an ulcer, 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 or weight bearing, 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 neurological level of injury and three dermatomes below. 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 one or more pain problems. 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 a particular pain problem or type started.

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: **Treatments used to reduce this pain**

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

CODES: **None**
Physiotherapy (e.g., exercise)
Passive and stimulation therapy (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)
Relaxation and Psychotherapy (e.g., meditation, cognitive behavioural therapy)
Oral and topical medication (e.g., antiepileptics, NSAIDs)
Procedural intervention (e.g., acupuncture, nerve block, epidural spinal cord stimulation)
Surgical interventions
Other

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.

If a person is using or receiving a treatment for pain, the categories are consistent with appendix C in the ISCIPEDS that can be used to record specific treatment options under each category if needed.

INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET

DATA COLLECTION FORM – Version 3.0

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 do you have?
□ 1; □ 2; □ 3; □ 4; □ ≥5

Please describe one or several pain problems or specific pain types of interest with respect to pain interference
The pain interference items can be used to describe overall pain or individual pains. To encourage comparability across studies, even when a user allows respondents to rate pain interference for more than one pain problem, we recommend that respondents still be invited to rate overall pain interference.

Please note that the time period during the last week 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

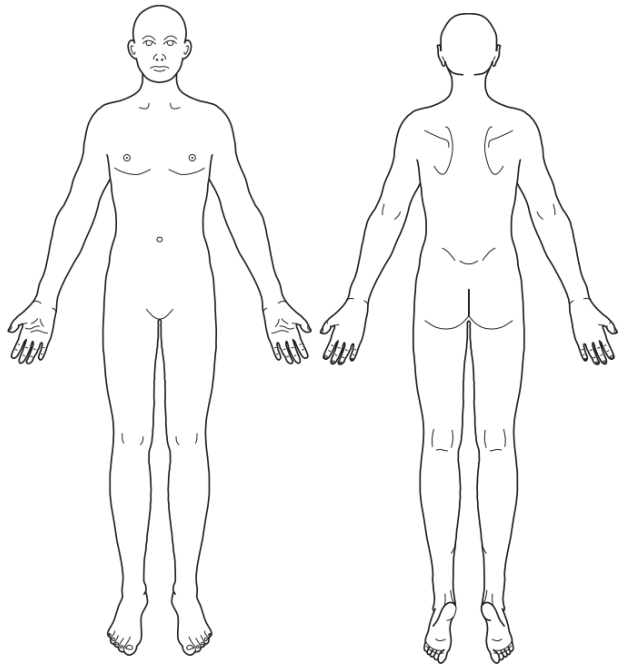
In general, how much has pain interfered with your overall mood in the last week?
No interference □ 0 - □ 1 - □ 2 - □ 3 - □ 4 - □ 5 - □ 6 - □ 7 - □ 8 - □ 9 - □ 10 Extreme interference

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

Pain problem/pain type (please add one sheet per pain):

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	**R**	**M**	**L**
Head			
Neck/shoulders			
throat			
neck			
shoulder			
Arms/hands			
upper arm			
elbow			
forearm			
wrist			
hand/fingers			
Frontal torso/genitals			
chest			
abdomen			
pelvis/genitalia			
Back			
upper back			
lower back			
Buttocks/hips			
buttocks			
hip			
anus			
Upper leg/thigh			
Lower legs/feet			
knee			
shin			
calf			
ankle			
foot/toes			

Optional Pain drawing



Type of pain
Intensity and **duration of pain**
Treatment of pain

Type of pain (check one):

Nociceptive
- ☐ Musculoskeletal
- ☐ Visceral
- ☐ Other

Neuropathic
- ☐ At-level SCI
- ☐ Below-level SCI
- ☐ Other

☐ **Other**

☐ **Unknown**

Intensity and **onset of pain:**
Average pain intensity in the last week:
0 = no pain; 10 = pain as bad as you can imagine
☐ 0; ☐ 1; ☐ 2; ☐ 3; ☐ 4; ☐ 5;
☐ 6; ☐ 7; ☐ 8; ☐ 9; ☐ 10

Date of onset: YYYY/MM/DD

Treatment used to reduce this pain
☐ None

☐ **Physiotherapy** (e.g., exercise)

☐ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)

☐ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)

☐ **Oral and topical medication** (e.g., antiepileptics, NSAIDs)

☐ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)

☐ **Surgical interventions**

☐ **Other**

INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET
DATA COLLECTION FORM – Version 3.0

Training case 1

Date: December 21, 2021

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 about 6 years after his SCI (duration 15 years) 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 on 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
DATA COLLECTION FORM – Version 3.0

Training case 1

Date of data collection: 2021/12/21

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

If yes:

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

Please describe one or several pain problems or specific pain types of interest with respect to pain interference
The pain interference items can be used to describe overall pain or individual pains. To encourage comparability across studies, even when a user allows respondents to rate pain interference for more than one pain problem, we recommend that respondents still be invited to rate overall pain interference.

Please note that the time period during the last week 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

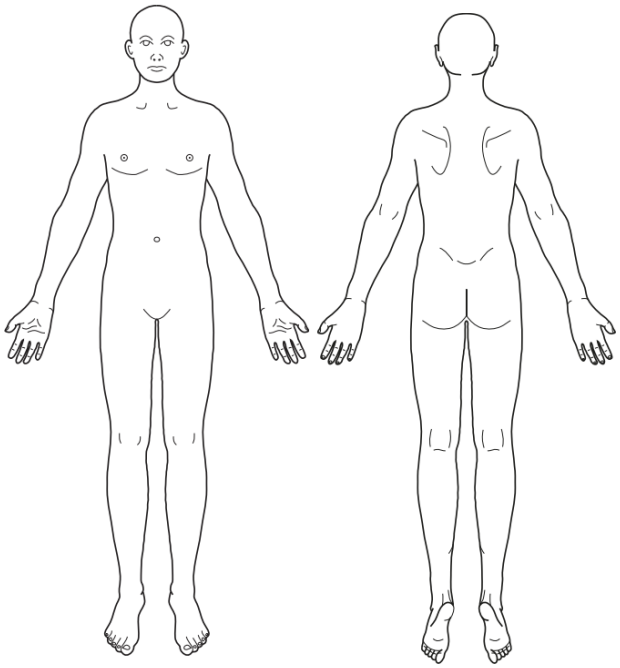
In general, how much has pain interfered with your ability to get a good night's sleep?
No interference **X 0** - □ 1 - □ 2 - □ 3 - □ 4 - □ 5 - □ 6 - □ 7 - □ 8- □ 9 - □ 10 Extreme interference

Please describe one or several pain problems or specific pain types of interest with respect to location and other characteristics:

Pain problem/pain type: Worst pain

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	**R**	**M**	**L**
Head			
Neck/shoulders			
throat			
neck			
shoulder			
Arms/hands			
upper arm			
elbow			
forearm			
wrist			
hand/fingers			
Frontal torso/genitals			
chest			
abdomen		**X**	
pelvis/genitalia			
Back			
upper back			
lower back			
Buttocks/hips			
buttocks			
hip			
anus			
Upper leg/thigh			
Lower legs/feet			
knee			
shin			
calf			
ankle			
foot/toes			

Optional Pain drawing



Type of pain
Intensity and **duration of pain**
Treatment of pain

Type of pain (check one):

Nociceptive
- □ Musculoskeletal
- **X** Visceral
- □ Other

Neuropathic
- □ At-level SCI
- □ Below-level SCI
- □ Other

□ **Other**

□ **Unknown**

Intensity and **onset of pain:**
Average pain intensity in the last week:
0 = no pain; 10 = pain as bad as you can imagine
□ 0; □ 1; □ 2; □ 3; □ 4; □ 5; □ 6; **X** 7; □ 8; □ 9; □ 10

Date of onset: 2006/99/99

Treatment used to reduce this pain
□ **None**

□ **Physiotherapy** (e.g., exercise)

□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)

□ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)

X Oral and topical medication (e.g., antiepileptics, NSAIDs)

□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)

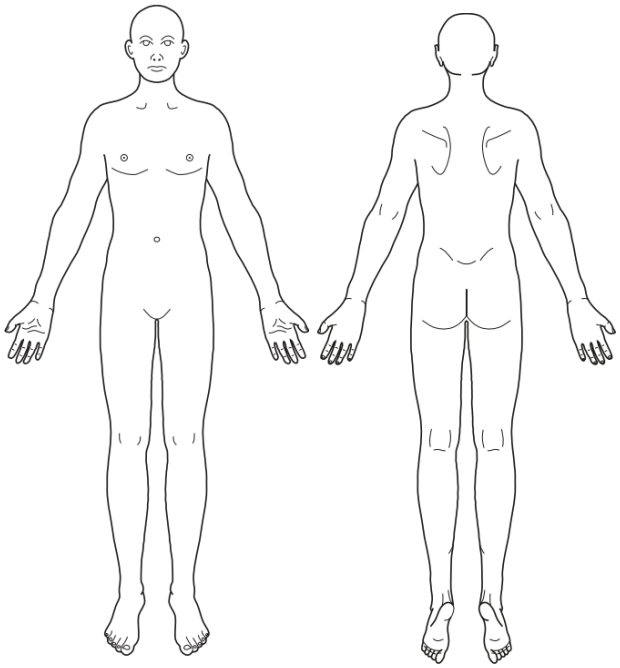
□ **Surgical interventions**

□ **Other**

Pain problem/pain type: Second worst pain

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	**R**	**M**	**L**
Head			
Neck/shoulders			
throat			
neck			
shoulder			
Arms/hands			
upper arm			
elbow			
forearm			
wrist			
hand/fingers			
Frontal torso/genitals			
chest			
abdomen			
pelvis/genitalia			
Back			
upper back			
lower back			
Buttocks/hips			
buttocks			
hip			
anus			
Upper leg/thigh	**X**		**X**
Lower legs/feet			
knee	**X**		**X**
shin	**X**		**X**
calf	**X**		**X**
ankle	**X**		**X**
foot/toes	**X**		**X**

Optional Pain drawing



Type of pain
Intensity and **duration of pain**
Treatment of pain

Type of pain (check one):

Nociceptive
X Musculoskeletal
□ Visceral
□ Other

Neuropathic
□ At-level SCI
□ Below-level SCI
□ Other

□ **Other**

□ **Unknown**

Intensity and **onset of pain:**
Average pain intensity in the last week:
0 = no pain; 10 = pain as bad as you can imagine
□ 0; **X** 1; □ 2; □ 3; □ 4; □ 5; □ 6; □ 7; □ 8; □ 9; □ 10

Date of onset: 2000/99/99

Treatment used to reduce this pain
□ **None**

□ **Physiotherapy** (e.g., exercise)

□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)

□ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)

X Oral and topical medication (e.g., antiepileptics, NSAIDs)

□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)

□ **Surgical interventions**

□ **Other**

INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET

DATA COLLECTION FORM – Version 3.0

Training case 2

Date: October 26, 2008
This is a 25-year-old woman with a C4 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 medications somewhat helpful for the shoulder pain.

She reports that her pain interferes with her activities every day and rates this interference as 8/10. Similarly, she also mentions that her pain makes her feel sad daily 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

DATA COLLECTION FORM – Version 3.0

Training 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:

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

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

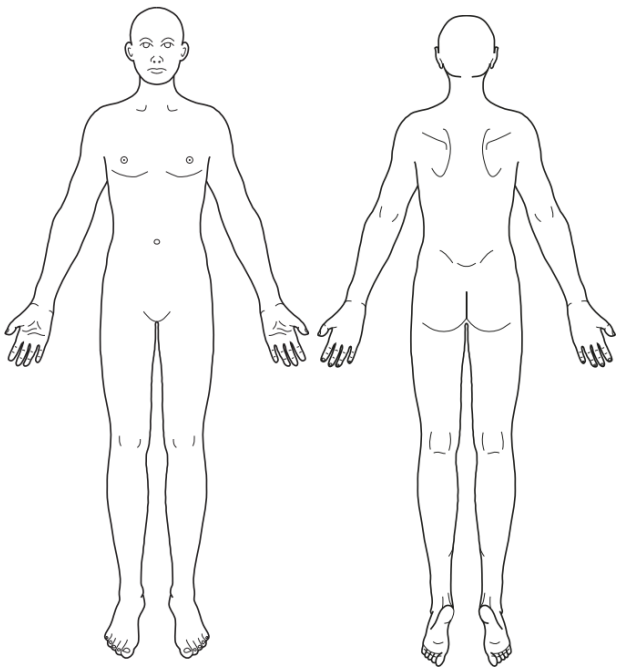
In general, how much has pain interfered with your day-to-day activities in the last week?
No interference □ 0 - □ 1 - □ 2 - □ 3 - □ 4 - □ 5 - □ 6 - □ 7 - **X 8**- □ 9 - □ 10 Extreme interference

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

Please describe one or several pain problems or specific pain types of interest with respect to location and other characteristics

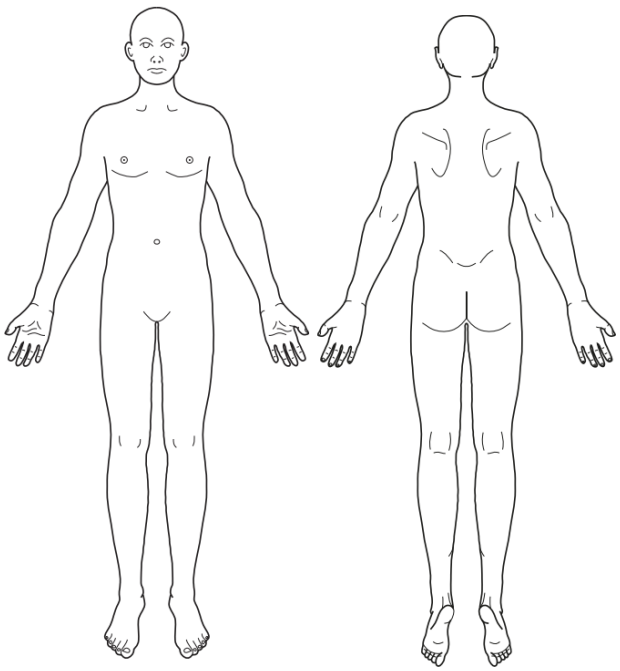
Pain problem/pain type: Worst pain

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				
throat				**Nociceptive**
neck				□ Musculoskeletal
shoulder				□ Visceral
Arms/hands				□ Other
upper arm	**X**		**X**	
elbow	**X**		**X**	**Neuropathic**
forearm	**X**		**X**	**X** At-level SCI
wrist	**X**		**X**	□ Below-level SCI
hand/fingers	**X**		**X**	□ Other
Frontal torso/genitals				□ **Other**
chest				
abdomen				□ **Unknown**
pelvis/genitalia				
Back				**Intensity** and **onset 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				**Date of onset:** 2005/09/99
Upper leg/thigh				
Lower legs/feet				**Treatment used to reduce this pain**
knee				□ **None**
shin				
calf				□ **Physiotherapy** (e.g., exercise)
ankle				
foot/toes				□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)
Optional Pain drawing				**X Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)
				**X Oral and topical medication** (e.g., antiepileptics, NSAIDs)
				□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)
				□ **Surgical interventions**
				□ **Other**

Pain problem/pain type: Second worst pain

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	**R**	**M**	**L**
Head			
Neck/shoulders			
throat			
neck			
shoulder			
Arms/hands			
upper arm			
elbow			
forearm			
wrist			
hand/fingers			
Frontal torso/genitals			
chest			
abdomen			
pelvis/genitalia			
Back			
upper back			
lower back			
Buttocks/hips			
buttocks	**X**		**X**
hip			
anus			
Upper leg/thigh	**X**		**X**
Lower legs/feet			
knee			
shin			
calf			
ankle			
foot/toes			

Optional Pain drawing



Type of pain
Intensity and **duration of pain**
Treatment of pain

Type of pain (check one):

Nociceptive
- □ Musculoskeletal
- □ Visceral
- □ Other

Neuropathic
- □ At-level SCI
- **X** Below-level SCI
- □ Other

□ **Other**

□ **Unknown**

Intensity and **onset of pain:**
Average pain intensity in the last week:
0 = no pain; 10 = pain as bad as you can imagine
□ 0; □ 1; □ 2; □ 3; □ 4; □ 5; □ 6; **X** 7; x 8; □ 9; □ 10

Date of onset: 2006/08/99

Treatment used to reduce this pain

□ **None**

□ **Physiotherapy** (e.g., exercise)

□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)

□ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)

X Oral and topical medication (e.g., antiepileptics, NSAIDs)
She is taking an anticonvulsant although this medication is not effective for this pain.

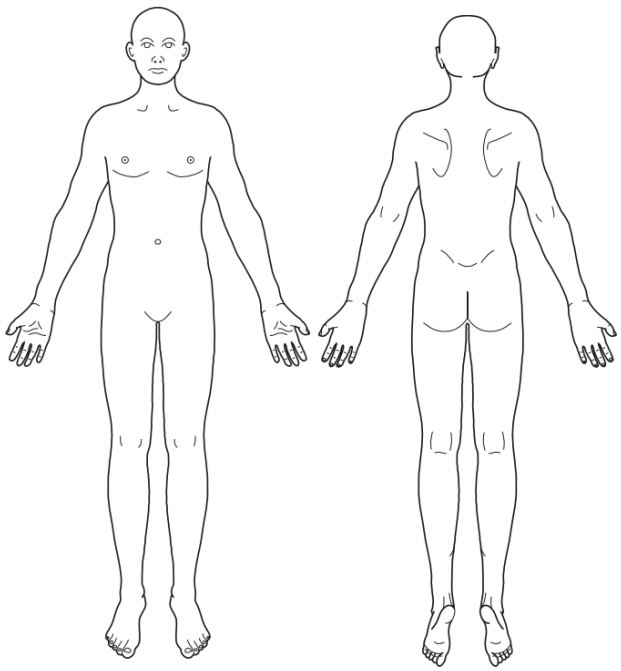
□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)

□ **Surgical interventions**

□ **Other**

Pain problem/pain type: Third worst pain

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				
throat				**Nociceptive**
neck				**X** Musculoskeletal
shoulder	**X**		**X**	□ Visceral
				□ 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 **onset 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; □ 6; □ 7; □ 8; □ 9; □ 10
buttocks				
hip				
anus				**Date of onset:** 2007/99/99
Upper leg/thigh				
Lower legs/feet				**Treatment used to reduce this pain**
knee				□ **None**
shin				
calf				□ **Physiotherapy** (e.g., exercise)
ankle				
foot/toes				□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)
Optional Pain drawing				□ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)
				X Oral and topical medication (e.g., antiepileptics, NSAIDs)
				□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)
				□ **Surgical interventions**
				□ **Other**



INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET
DATA COLLECTION FORM – Version 3.0

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 3.0
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:

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

Please note that the time period during the last week 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

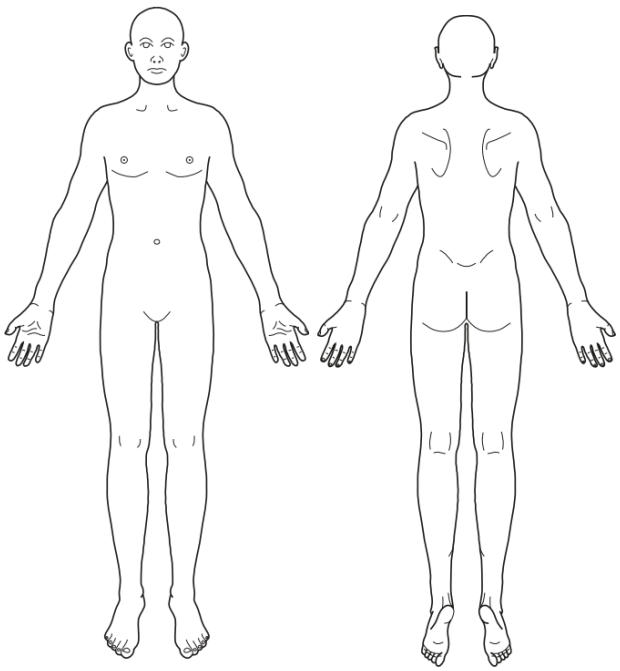
In general, how much has pain interfered with your ability to get a good night's sleep?
No interference □ 0 - □ 1 - □ 2 - □ 3 - □ 4 - **X 5** - □ 6 - □ 7 - □ 8 - □ 9 - □ 10 Extreme interference

Please describe one or several pain problems or specific pain types of interest with respect to location and other characteristics

Pain problem/pain type: Worst pain

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				
throat				**Nociceptive**
neck				**X** Musculoskeletal
shoulder				□ Visceral
Arms/hands				□ Other
upper arm				
elbow				**Neuropathic**
forearm				□ At-level SCI
wrist				□ Below-level SCI
hand/fingers				□ Other
Frontal torso/genitals				
chest				□ **Other**
abdomen				
pelvis/genitalia				□ **Unknown**
Back				
upper back				**Intensity** and **onset of pain:**
lower back	**X**	**X**	**X**	**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; **X** 8; □ 9; □ 10
anus				
Upper leg/thigh				**Date of onset:** 2007/99/99
Lower legs/feet				
knee				**Treatment used to reduce this pain**
shin				□ **None**
calf				
ankle				□ **Physiotherapy** (e.g., exercise)
foot/toes				
				□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)
				□ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)
				X Oral and topical medication (e.g., antiepileptics, NSAIDs)
				□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)
				□ **Surgical interventions**
				□ **Other**

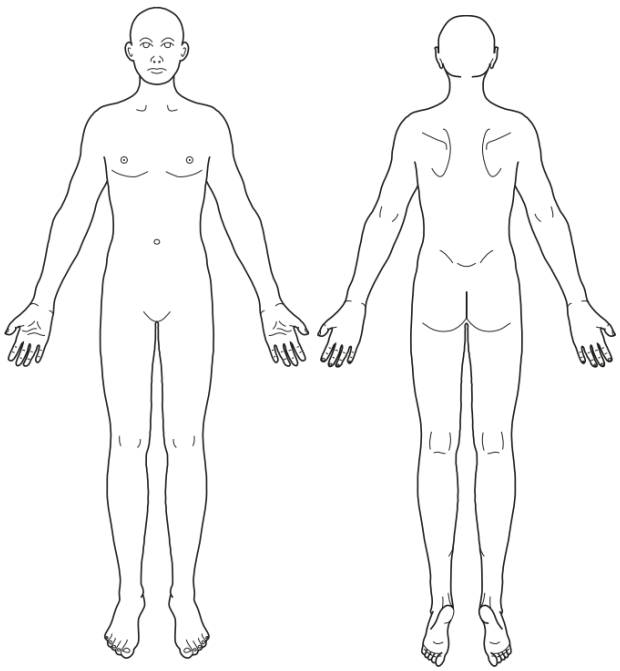
Optional Pain drawing



Pain problem/pain type: Second worst pain

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	**R**	**M**	**L**
Head			
Neck/shoulders			
throat			
neck			
shoulder			
Arms/hands			
upper arm			
elbow			
forearm			
wrist			
hand/fingers			
Frontal torso/genitals			
chest			
abdomen	**X**	**X**	**X**
pelvis/genitalia			
Back			
upper back			
lower back			
Buttocks/hips			
buttocks			
hip			
anus			
Upper leg/thigh			
Lower legs/feet			
knee			
shin			
calf			
ankle			
foot/toes			

Optional Pain drawing



Type of pain
Intensity and **duration of pain**
Treatment of pain

Type of pain (check one):

Nociceptive
- □ Musculoskeletal
- □ Visceral
- □ Other

Neuropathic
- **X** At-level SCI
- □ Below-level SCI
- □ Other

□ **Other**

□ **Unknown**

Intensity and **onset of pain:**
Average pain intensity in the last week:
0 = no pain; 10 = pain as bad as you can imagine
□ 0; □ 1; □ 2; □ 3; **X** 4; □ 5; □ 6; □ 7; □ 8; □ 9; □ 10

Date of onset: 2004/08/08

Treatment used to reduce this pain
□ **None**

□ **Physiotherapy** (e.g., exercise)

□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)

□ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)

X Oral and topical medication (e.g., antiepileptics, NSAIDs) The opioid medication she is taking has no effect on this pain

□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)

□ **Surgical interventions**

□ **Other**

INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET
DATA COLLECTION FORM – Version 3.0

Training case 4

Date: 2020/07/03

A 37-year-old man enrolls in a clinical trial investigating the safety and efficacy of a novel drug for the treatment of neuropathic pain (at- and below level) following spinal cord injury. Among the primary outcome measures is mean pain intensity of neuropathic pain on a numerical rating scale (NRS) after 4 weeks. Other pain types were not followed up longitudinally.

He sustained a C5 AIS B cervical injury following a skiing accident in February 2010. He experiences three different pains. His hands are hypersensitive to touch, and he experiences severe discomfort touching cold objects such as a metal door handle. At times he feels spontaneous pain with an intensity of 2/10 in his hands, but mostly a slight tingling sensation. In addition, he suffers from pelvic pain located around his bladder and in the perineal region. The pain has a burning quality with an average intensity of 6/10. It fluctuates during the day, and pain episodes are related to bladder filling. The most problematic pain interfering with his activities of daily living is a bilateral, shooting, squeezing and ice-like pain in his thighs, upper and lower legs.

The pain in his hands started almost immediately after his accident. The evoked pain occurs daily, but the spontaneous pain is intermittent, often worse in the evening. The evoked pain component responded a little to anticonvulsants, but currently he takes no medication for this pain.

The pain in the pelvic area developed only recently and the emergence coincided with a pressure sore that has now completed healed. There is no consistent temporal pattern to this pain; it tends to occur throughout the day with no specific time period being better or worse. Sometimes he takes NSAIDs for this pain, but he is not sure if this really helps.

The pain in his lower legs is most troublesome. It started about a year after the accident. The pain is constant with slight fluctuations depending on the body position, i.e., it gets worse after sitting in the wheelchair for longer periods of time. This pain affects his overall day-to-day activities and upon inquiry he rates interference with activities 4/10. Sometimes also his mood is affected and he rates the influence on mood as 2/10. He rates sleep interference as 2/10.

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

DATA COLLECTION FORM – Version 3.0

Training case 4

Date of data collection: 2020/07/03

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

If yes:

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

Please note that the time period during the last week 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

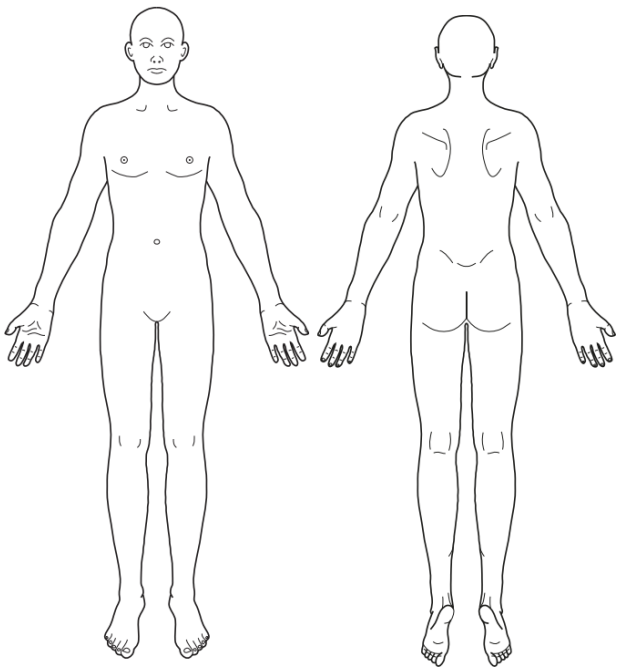
In general, how much has pain interfered with your ability to get a good night's sleep?
No interference **X 0** - □ 1 - □ 2 - □ 3 - □ 4 - □ 5 - □ 6 - □ 7 - □ 8- □ 9 - □ 10 Extreme interference

Please describe one or several pain problems or specific pain types of interest with respect to location and other characteristics

Pain problem/pain type: At-level Neuropathic pain

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	**R**	**M**	**L**
Head			
Neck/shoulders			
throat			
neck			
shoulder			
Arms/hands			
upper arm			
elbow			
forearm	**X**		**X**
wrist	**X**		**X**
hand/fingers	**X**		**X**
Frontal torso/genitals			
chest			
abdomen			
pelvis/genitalia			
Back			
upper back			
lower back			
Buttocks/hips			
buttocks			
hip			
anus			
Upper leg/thigh			
Lower legs/feet			
knee			
shin			
calf			
ankle			
foot/toes			

Optional Pain drawing



Type of pain
Intensity and **duration of pain**
Treatment of pain

Type of pain (check one):

Nociceptive
- □ Musculoskeletal
- □ Visceral
- □ Other

Neuropathic
- **X** At-level SCI
- □ Below-level SCI
- □ Other

□ **Other**

□ **Unknown**

Intensity and **onset of pain:**
Average pain intensity in the last week:
0 = no pain; 10 = pain as bad as you can imagine
□ 0; □ 1; X 2; □ 3; □ 4; □ 5; □ 6; □ 7; □ 8; □ 9; □ 10

Date of onset: 2010/99/99

Treatment used to reduce this pain
X None

□ **Physiotherapy** (e.g., exercise)

□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)

□ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)

X Oral and topical medication (e.g., antiepileptics, NSAIDs)

□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)

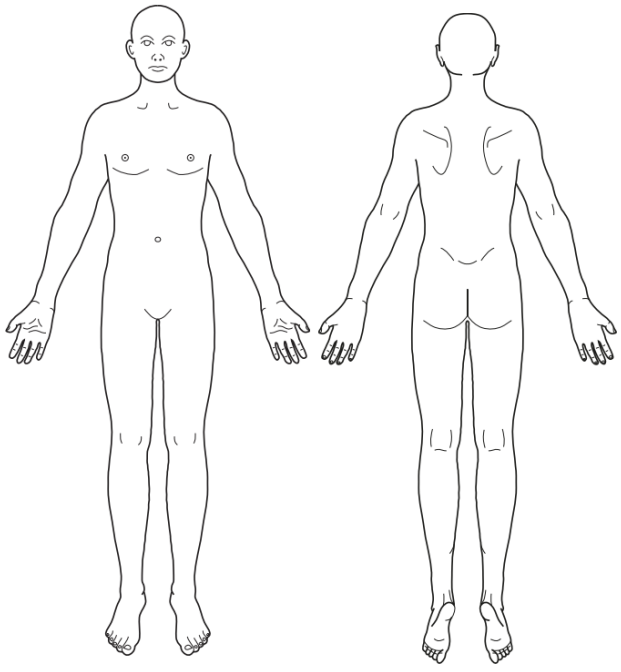
□ **Surgical interventions**

□ **Other**

Pain problem/pain type: Below-level Neuropathic pain

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	**R**	**M**	**L**
Head			
Neck/shoulders			
throat			
neck			
shoulder			
Arms/hands			
upper arm			
elbow			
forearm			
wrist			
hand/fingers			
Frontal torso/genitals			
chest			
abdomen			
pelvis/genitalia			
Back			
upper back			
lower back			
Buttocks/hips			
buttocks			
hip			
anus			
Upper leg/thigh	**X**		**X**
Lower legs/feet			
knee	**X**		**X**
shin	**X**		**X**
calf	**X**		**X**
ankle	**X**		**X**
foot/toes	**X**		**X**

Optional Pain drawing



Type of pain
Intensity and **duration of pain**
Treatment of pain

Type of pain (check one):

Nociceptive
- □ Musculoskeletal
- □ Visceral
- □ Other

Neuropathic
- □ At-level SCI
- **X** Below-level SCI
- □ Other

□ **Other**

□ **Unknown**

Intensity and **onset of pain:**
Average pain intensity in the last week:
0 = no pain; 10 = pain as bad as you can imagine
□ 0; □ 1; □ 2; □ 3; □ 4; □ 5;
X 6; □ 7; □ 8; □ 9; □ 10

Date of onset: 2011/99/99

Treatment used to reduce this pain
X None

□ **Physiotherapy** (e.g., exercise)

□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)

□ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)

□ **Oral and topical medication** (e.g., antiepileptics, NSAIDs)

□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)

□ **Surgical interventions**

□ **Other**

INTERNATIONAL SPINAL CORD INJURY PAIN BASIC DATA SET
DATA COLLECTION FORM – Version 3.0

Training case 5

Date: 2022/06/01

A 57-year-old woman was interviewed by telephone after completion of the ISCIP pain map which illustrated the major pain problems present during the previous 7 days. The subject had previously been diagnosed with neuropathic at- and below-level SCI pain following a cavernous C7-Th6 spinal haemangioma in 2006. Non-evoked pain was present within the T6 dermatome and lower legs. A T2 Susceptibility Weighted Imaging MRI sequence detected an extensive haemosiderin-rich deposit between the C7 and Th5/6 spinal level. Cold allodynia was detected below the spinal haemangioma in the left L5 dermatome, while tonic thermal stimuli applied to the T6, T10 and C7 dermatomes revealed widespread heat and cold allodynia.

During the follow-up interview the subject complained of three main pain types in the chest, legs and feet, and in the pelvic area (see pain map below). Despite having experienced neuropathic pain during the previous years, in 2016 pain intensity increased with the development of pain within the area of the pelvis. In the previous 1-2 months pain in the chest area has increased to intolerable levels. Although Pregabalin and Duloxetine has been well tolerated and had previously improved pain intensity, recently this treatment is not effective in controlling pain in the trunk area. Pain intensity often increases when the subject is nervous, with some relief present during relaxation.

The pain map now indicates that neuropathic at and below-level pain is contiguous as compared to the clear separation of the pain types that were observed in a previous visit. Ongoing at-level neuropathic pain was as bad as she could imagine (10/10) and interfered extremely with general day-to-day activities (10/10). The pain is described as a tightening belt sensation but not as electrical, pins and needles or as heat/cold. At-level pain is aggravated by contact with clothing and with movement. Neuropathic below-level pain/dysesthesia in the legs and feet has a pain intensity of 8/10 and extremely interferes with general day-to-day activities (10/10). Some thermal and tactile sensation is present in the left leg. The pain is described as a burning and pressure sensation, but not as electrical or as pins and needles. Changes in temperature (e.g., cold weather) often increase the below-level neuropathic pain.

Since 2016 discomfort/pain in the pelvic area has developed with an intensity of 5/10. Referred pain from the pelvic area was reported in the buttocks and hips. This dysesthesia/pain also highly interferes with general day-to-day activities (8/10). The pain is continuous and is increased during bladder and bowel voiding, and buildup of flatus. The sensation of this pain type is described as pressure and numbness.

The subject rates the pain in the chest area as her worst pain problem, followed by pain in the legs and feet, and then in the pelvic area. No musculoskeletal pain was reported. The subject clearly distinguishes between the three pain types reported recently, even after 15 years after the SCI. The high intensity and interference of each pain type urgently require a revised pain management plan.

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.*

Training case 5

Date of data collection: 2020/06/01

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

If yes:

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

Please note that the time period during the last week 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

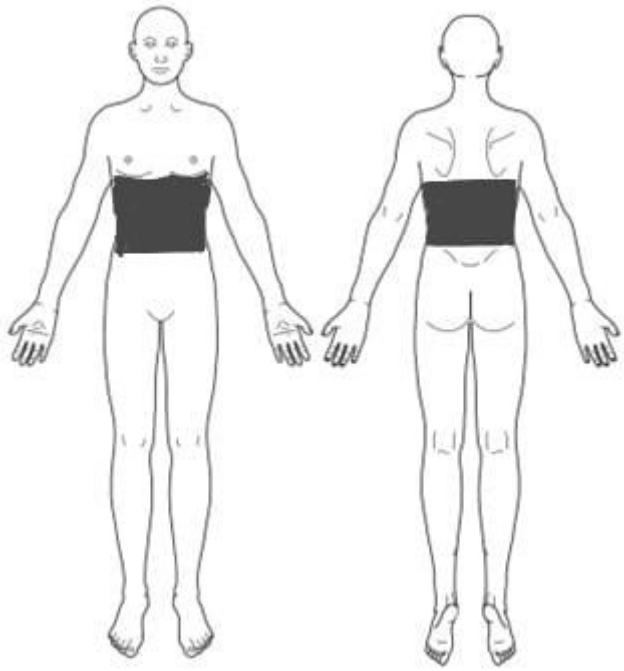
In general, how much has pain interfered with your ability to get a good night's sleep?
No interference □ 0 - □ 1 - □ 2 - □ 3 - □ 4 - □ 5 - □ 6 - □ 7 - □ 8 - □ 9 - **X 10** Extreme interference

Please describe one or several pain problems or specific pain types of interest with respect to location and other characteristics

This real training case is based on the SCI pain case reported by Gómez-Soriano et al. (2012). During a telephone interview (June 2022) the subject was asked to draw the pain problems present during the previous 7 days. The subject described the characteristics of each pain problem (as prioritised by the patient) using the ISCIP basic data set version 3.0. The subject was guided by the researcher to provide information related to the presence of neuropathic at and below-level SCI pain, and to nociceptive musculoskeletal and visceral SCI pain. Pain interference with day-to-day activities was also assessed for each pain.

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	**R**	**M**	**L**
Head			
Neck/shoulders			
throat			
neck			
shoulder			
Arms/hands			
upper arm			
elbow			
forearm			
wrist			
hand/fingers			
Frontal torso/genitals			
chest	**X**	**X**	**X**
abdomen			
pelvis/genitalia			
Back			
upper back			
lower back			
Buttocks/hips			
buttocks			
hip			
anus			
Upper leg/thigh			
Lower legs/feet			
knee			
shin			
calf			
ankle			
foot/toes			

Optional Pain drawing – continuous pain in the chest



Type of pain
Intensity and **duration of pain**
Treatment of pain

Type of pain (check one):

Nociceptive
- □ Musculoskeletal
- □ Visceral
- □ Other

Neuropathic
- **X** At-level SCI
- □ Below-level SCI
- □ Other

□ **Other**

□ **Unknown**

Intensity and **onset of pain:**
Average pain intensity in the last week:
0 = no pain; 10 = pain as bad as you can imagine
□ 0; □ 1; □ 2; □ 3; □ 4; □ 5; □ 6; □ 7; x 8; □ 9; **X** 10

Date of onset: 2006/09/28

Treatment used to reduce this pain
□ **None**

□ **Physiotherapy** (e.g., exercise)

□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)

□ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)

X Oral and topical medication (e.g., antiepileptics, NSAIDs)

□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)

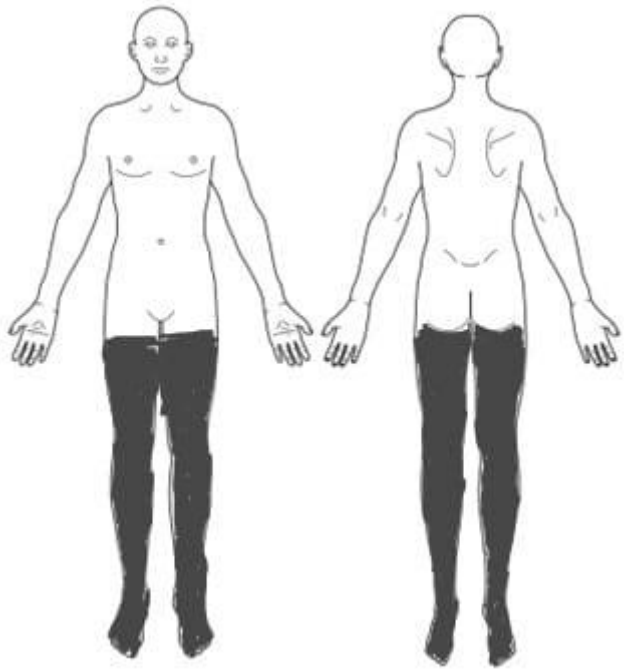
□ **Surgical interventions**

□ **Other**

Pain problem/pain type: Below-level Neuropathic Pain

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	**R**	**M**	**L**
Head			
Neck/shoulders			
throat			
neck			
shoulder			
Arms/hands			
upper arm			
elbow			
forearm			
wrist			
hand/fingers			
Frontal torso/genitals			
chest			
abdomen			
pelvis/genitalia			
Back			
upper back			
lower back			
Buttocks/hips			
buttocks			
hip			
anus			
Upper leg/thigh	**X**		**X**
Lower legs/feet			
knee	**X**		**X**
shin	**X**		**X**
calf	**X**		**X**
ankle	**X**		**X**
foot/toes	**X**		**X**

Optional Pain drawing - continuous pain in the legs and feet



Type of pain
Intensity and **duration of pain**
Treatment of pain

Type of pain (check one):

Nociceptive
□ Musculoskeletal
□ Visceral
□ Other

Neuropathic
□ At-level SCI
X Below-level SCI
□ Other

□ **Other**

□ **Unknown**

Intensity and **onset of pain:**
Average pain intensity in the last week:
0 = no pain; 10 = pain as bad as you can imagine
□ 0; □ 1; □ 2; □ 3; □ 4; □ 5; □ 6; □ 7; **X** 8; □ 9; □ 10

Date of onset: 2006/09/28

Treatment used to reduce this pain
□ **None**

□ **Physiotherapy** (e.g., exercise)

□ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)

□ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)

X Oral and topical medication (e.g., antiepileptics, NSAIDs)
She is taking an anticonvulsant although this medication is not effective for this pain.

□ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)

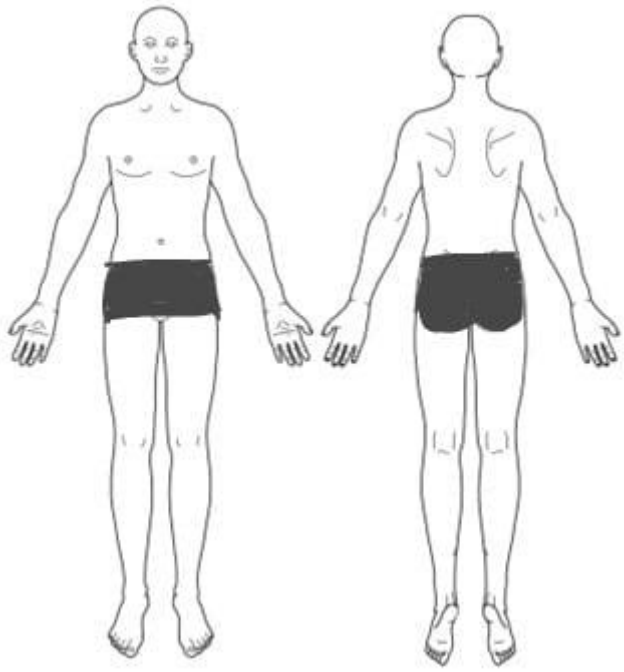
□ **Surgical interventions**

□ **Other**

Pain problem/pain type: Nociceptive Visceral Pain

Pain locations /sites (can be more than one, so check all that apply): right (R), midline (M), or left (L)	**R**	**M**	**L**
Head			
Neck/shoulders			
throat			
neck			
shoulder			
Arms/hands			
upper arm			
elbow			
forearm			
wrist			
hand/fingers			
Frontal torso/genitals			
chest			
abdomen			
pelvis/genitalia	**X**	**X**	**X**
Back			
upper back			
lower back			
Buttocks/hips			
buttocks	**X**		**X**
hip	**X**		**X**
anus			
Upper leg/thigh			
Lower legs/feet			
knee			
shin			
calf			
ankle			
foot/toes			

Optional Pain drawing - continuous pain in the pelvic area



Type of pain
Intensity and **duration of pain**
Treatment of pain

Type of pain (check one):

Nociceptive
☐ Musculoskeletal
X Visceral
☐ Other

Neuropathic
☐ At-level SCI
☐ Below-level SCI
☐ Other

☐ **Other**

☐ **Unknown**

Intensity and **onset of pain:**
Average pain intensity in the last week:
0 = no pain; 10 = pain as bad as you can imagine
☐ 0; ☐ 1; ☐ 2; ☐ 3; **X** 4; ☐ 5; ☐ 6; ☐ 7; ☐ 8; ☐ 9; ☐ 10

Date of onset: 2006/09/28

Treatment used to reduce this pain
☐ **None**

☐ **Physiotherapy** (e.g., exercise)

☐ **Passive and stimulation therapy** (e.g., massage, transcutaneous electrical nerve, or spinal cord stimulation)

☐ **Relaxation and Psychotherapy** (e.g., meditation, cognitive behavioural therapy)

X Oral and topical medication (e.g., antiepileptics, NSAIDs)

☐ **Procedural intervention** (e.g., acupuncture, nerve block, epidural spinal cord stimulation)

☐ **Surgical interventions**

☐ **Other**