

Note: It is recommended that this Data Set have two additional key variables:
 - SITE (to distinguish the location where the data are recorded) and
 - SUBJECT (to distinguish the patient/study participant)

INTERNATIONAL SPINAL CORD INJURY PAIN EXTENDED DATA SET (Version 1.0)

1. Pain Symptoms

TABLE 1

Note: This is inclusive of all pain experienced

Date for collection of data

YYYY.MM.DD

PAINEXDT

A. Overall pain

Number of days with pain in the last 7 days including today

☐ None ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Unknown

PNDAYNO

Worst pain intensity in the last week

0 = no pain; 10 = the most intense pain imaginable

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

PNINWEEK

Average pain unpleasantness in the last week

0 = not at all unpleasant; 10 = the most unpleasant pain imaginable

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

PNAVUNPL

Number of days with manageable/tolerable pain in the last 7 days including today

☐ None ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ Unknown

PNMGDNO

B. Worst pain problem (#1)

TABLE 2

Please note that if there is more than one pain, this section should be consistent with the International Spinal Cord Injury Pain Basic Data Set and apply to Worst, 2nd Worst and 3rd Worst pains.

Date for collection of data

YYYY.MM.DD

PAINEXDT

Worst pain #1:

WRSTPAIN

Pain intensity in the present moment

0 = no pain; 10 = the most intense pain imaginable:

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

WPNINTPR

How long does your pain usually last?

☐ <1 min; ☐ > 1 min but < 1 hr; ☐ >1hr but < 24hrs; ☐ constant or continuous; ☐ Unknown

WPNDUR

When during the day is the pain the most intense?

☐ Morning (06.01-12:00)

☐ afternoon (12.01-18:00)

☐ evening (18.01-24.00)

☐ night (00.01-06.00)

☐ unpredictable (pain is not consistently more intense at any one time of day)

WPNTIME

TABLE 2

C. Second worst pain problem (#2)

Please note that this section should only be completed if there is a pain problem in addition to the Worst Pain Problem documented in the previous section.

Second worst pain #2:

2WSTPAIN

Pain intensity in the present moment

0 = no pain; 10 = the most intense pain imaginable:

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

2NDINTPR

How long does your pain usually last?

☐ <1 min; ☐ > 1 min but < 1 hr; ☐ >1hr but < 24hrs; ☐ constant or continuous; ☐ Unknown

2NDDUR

When during the day is the pain the most intense?

☐ Morning (06.01-12:00)

☐ afternoon (12.01-18:00)

☐ evening (18.01-24.00)

☐ night (00.01-06.00)

☐ unpredictable (pain is not consistently more intense at any one time of day)

2NDTIME

A. Third pain problem (#3)

TABLE 2

Please note that this section should be completed only if there are two other pain problems documented in the previous sections.

Please note that this section should be completed only if there are two other pain problems documented in the previous sections.

Third worst pain #3:

3WSTPAIN

Pain intensity in the present moment

0 = no pain; 10 = the most intense pain imaginable:

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

3RDINTPR

How long does your pain usually last?

☐ <1 min; ☐ > 1 min but < 1 hr; ☐ >1hr but < 24hrs; ☐ constant or continuous; ☐ Unknown

3RDDUR

When during the day is the pain the most intense?

☐ Morning (06.01-12:00)

☐ afternoon (12.01-18:00)

☐ evening (18.01-24.00)

☐ night (00.01-06.00)

☐ unpredictable (pain is not consistently more intense at any one time of day)

3RDTIME

TABLE 3

2. Sensory Assessment

The sensory bedside assessment includes abnormal responses to light touch, pinprick and cold sensation compared with a non-affected control area above the level of injury. The sensory measures were intentionally selected to be appropriate for bedside examination and to detect and quantify sensory abnormalities: mechanical allodynia (pain in response to an innocuous mechanical stimulus), mechanical hyperalgesia (exaggerated response to a painful mechanical stimulus) and thermal allodynia (pain in response to an innocuous thermal stimulus) commonly associated with neuropathic pain types.

Date for collection of data

YYYY.MM.DD

PAINEXTD

A. Dynamic light touch

| | | | | | |
|--|---|---------------------------------------|--|------------------------------------|--------------------------------------|
| DLTANRM | At level of injury | DLTAHYPO | DLTAHYPR | DLTAALLO | |
| DLTAABS | <input type="checkbox"/> Normal | <input type="checkbox"/> Hypoesthesia | <input type="checkbox"/> Hyperesthesia | <input type="checkbox"/> Allodynia | <input type="checkbox"/> Other _____ |
| | <input type="checkbox"/> Absent | | | | DLTAOTHR |
| | If allodynia, rate the intensity: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 10 | | | | DLTASP |
| | DLTAINTA | | | | |
| DLTBNRM | Below level of injury | DLTBHYPO | DLTBHYPR | DLTBALLO | |
| DLTBABS | <input type="checkbox"/> Normal | <input type="checkbox"/> Hypoesthesia | <input type="checkbox"/> Hyperesthesia | <input type="checkbox"/> Allodynia | <input type="checkbox"/> Other _____ |
| | <input type="checkbox"/> Absent | | | | DLTBOTHR |
| | If allodynia, rate the intensity: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 10 | | | | DLTBSP |
| DLTBINTA | | | | | |
| Notes: Left or right side can be noted here | | | | | |
| | DLTLAT | | | | |

B. Pinprick

| | | | | |
|--|--|--------------------------------------|---------------------------------------|--------------------------------------|
| PPANRM | At level of injury | PPAHYPOA | PPAHYPR | |
| PPAABS | <input type="checkbox"/> Normal | <input type="checkbox"/> Hypoalgesia | <input type="checkbox"/> Hyperalgesia | <input type="checkbox"/> Other _____ |
| | <input type="checkbox"/> Absent | | | PPAOTHR |
| | If hyperalgesia, rate the intensity: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 10 | | | PPASP |
| | PPAINTHR | | | |
| PPBNRM | Below level of injury | PPBHYPOA | PPBHYPR | |
| PPBABS | <input type="checkbox"/> Normal | <input type="checkbox"/> Hypoalgesia | <input type="checkbox"/> Hyperalgesia | <input type="checkbox"/> Other _____ |
| | <input type="checkbox"/> Absent | | | PPBOTHR |
| | If hyperalgesia, rate the intensity: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 10 | | | PPBSP |
| | PPBINTHR | | | |
| Notes: Left or right side can be noted here | | | | |
| | PPLAT | | | |

C. Cold

| | | | | | |
|--|---|---------------------------------------|--|------------------------------------|--------------------------------------|
| CLDANRM | At level of injury | CLDAHYP | CLDAHYP | CLDAALLO | |
| CLDAABS | <input type="checkbox"/> Normal | <input type="checkbox"/> Hypoesthesia | <input type="checkbox"/> Hyperesthesia | <input type="checkbox"/> Allodynia | <input type="checkbox"/> Other _____ |
| | <input type="checkbox"/> Absent | | | | CLDAOTHR |
| | If allodynia, rate the intensity: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 10 | | | | CLDASP |
| | CLDAINTA | | | | |
| CLDBNRM | Below level of injury | CLDBHYPO | CLDBHYPR | CLDBALLO | |
| CLDBABS | <input type="checkbox"/> Normal | <input type="checkbox"/> Hypoesthesia | <input type="checkbox"/> Hyperesthesia | <input type="checkbox"/> Allodynia | <input type="checkbox"/> Other _____ |
| | <input type="checkbox"/> Absent | | | | CLDBOTHR |
| | If allodynia, rate the intensity: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> 6 <input type="checkbox"/> 7 <input type="checkbox"/> 8 <input type="checkbox"/> 9 <input type="checkbox"/> 10 | | | | CLDBSP |
| | CLDBINTA | | | | |
| Notes: Left or right side can be noted here | | | | | |
| | CLDLAT | | | | |

3. Treatments

A. Past treatments

This section can either be filled out for overall pain or for each separate pain component (Overall, Worst, 2nd Worst, 3rd Worst). Please indicate previous treatments (over the last 12 months) and whether the treatment was helpful with Y (yes, helpful), N (Not helpful) or U (Uncertain/Unknown). Leave blank if treatment was not performed.

Date for collection of data

YYYY.MM.DD

PAINEXDT

TABLE 4

| Physiotherapy | Overall Pain | Worst | 2 nd Worst | 3 rd Worst |
|-----------------------------------|--------------|----------|-----------------------|-----------------------|
| Aerobic Exercise | OPAEROEX | WPAEROEX | 2PAEROEX | 3PAEROEX |
| Passive exercise | OPPASSEX | WPPASSEX | 2PPASSEX | 3PPASSEX |
| Resistance exercise | OPRESEX | WPRESEX | 2PRESEX | 3PRESEX |
| Position adjustment | OPPOSADJ | WPPOSADJ | 2PPOSADJ | 3PPOSADJ |
| Joint mobilization / manipulation | OPJTMOBP | WPJTMOBP | 2PJTMOBP | 3PJTMOBP |
| Other, specify | OPPHOTH | WPPHOTH | 2PPHOTH | 3PPHOTH |
| | OPPHSP | WPPHSP | 2PPHSP | 3PPHSP |

Aerobic exercise: low to moderate intensity

Passive exercise: non-weight-bearing or against resistance, e.g., stretching

Resistance exercise: strength building, e.g., weight training

Position adjustment: in wheelchair, bed, etc.

Joint mobilization/manipulation: including chiropractic, osteopathic

Date for collection of data

YYYY.MM.DD

PAINEXDT

TABLE 5

| Passive and stimulation therapy | Overall pain | Worst | 2 nd Worst | 3 rd Worst |
|---------------------------------|--------------|---------|-----------------------|-----------------------|
| Massage | OPMASSG | WPMASSG | 2WMASSG | 3WMASSG |
| Acupressure | OPACPRS | WACPRS | 2WACPRS | 3WACPRS |
| TES, TNS, TENS | OPTENS | WTENS | 2WTENS | 3WTENS |
| Ultrasound | OPULTRSN | WULTRSN | 2WULTRSN | 3WULTRSN |
| Laser | OPLASER | WLASER | 2WLASER | 3WLASER |
| Heat therapy | OPHTTHRP | WHTTHRP | 2WHTTHRP | 3WHTTHRP |
| Other, specify | OPASOTH | WPASOTH | 2WPASOTH | 3WPASOTH |
| | OPASSP | WPASSP | 2WPASSP | 3WPASSP |

TES/TNS/TENS: Transcutaneous electrical nerve stimulation

Heat therapy: including heat-packs, shortwave

| Date for collection of data | | YYYY.MM.DD | | PAINEXDT | TABLE 6 |
|-----------------------------------|--------------|------------|-----------------------|-----------------------|---------|
| Relaxation and Psychotherapy | Overall Pain | Worst | 2 nd Worst | 3 rd Worst | |
| Biofeedback / Relaxation Training | OPBFRT | WBFRT | 2WBFRT | 3WBFRT | |
| Relaxation | OPRELAX | WRELAX | 2WRELAX | 3WRELAX | |
| Meditation | OPMEDT | WMEDT | 2WMEDT | 3WMEDT | |
| Mindfulness meditation | OPMIND | WMIND | 2WMIND | 3WMIND | |
| Hypnosis | OPHYPNOS | WHYPNOS | 2WHYPNOS | 3WHYPNOS | |
| Cognitive / Behavioral therapy | OPCGBVT | WCGBVT | 2WCGBVT | 3WCGBVT | |
| Other psychotherapy | OPOTHPSY | WOTHPSY | 2WOTHPSY | 3WOTHPSY | |
| Other, specify | OPRELOTH | OPRELSP | WRELOTH | WRELSP | |
| | | | 2WRELOTH | 3WRELOTH | |
| | | | 2WRELSP | 3WRELSP | |

Relaxation: relaxation techniques, e.g., muscle relaxation or deep breathing
Meditation: meditation techniques, e.g., contrative, religious
Mindfulness meditation: meditation using mindfulness technique

| Date for collection of data | | YYYY.MM.DD | | PAINEXDT | TABLE 7 |
|-----------------------------|--------------|------------|-----------------------|-----------------------|---------|
| Oral and topical medication | Overall Pain | Worst | 2 nd Worst | 3 rd Worst | |
| Antidepressants | OPANTDP | WANTDP | 2WANTDP | 3WANTDP | |
| Antiepileptics | OPANTEP | WANTEP | 2WANTEP | 3WANTEP | |
| Tramadol | OPTRMDL | WTRMDL | 2WTRMDL | 3WTRMDL | |
| Opioids | OPOPIOID | WOPIOID | 2WOPIOID | 3WOPIOID | |
| Cannabinoids | OPCANN | WCANN | 2WCANN | 3WCANN | |
| Acetaminophen | OPACET | WACET | 2WACET | 3WACET | |
| NSAIDS / aspirin | OPNSAID | WNSAID | 2WNSAID | 3WNSAID | |
| Benzodiazepines | OPBENZ | WBENZ | 2WBENZ | 3WBENZ | |
| Antispasticity drugs | OPANTSPD | WANTSPD | 2WANTSPD | 3WANTSPD | |
| Topical anesthetics | OPTPAN | WTPAN | 2WTPAN | 3WTPAN | |
| Topical capsaicin | OPTPCPN | WTPCPN | 2WTPCPN | 3WTPCPN | |
| Other, specify | OPMEDOTH | WMEDOTH | 2WMEDOTH | 3WMEDOTH | |
| | OPMEDSP | WMEDSP | 2WMEDSP | 3WMEDSP | |

Antidepressants: amitriptyline, nortriptyline, duloxetine
Antiepileptics: pregabalin, gabapentin, carbamazepine
Opioids: morphine, oxycodone, buprenorphine, fentanyl
Cannabinoids: e.g., marijuana
NSAIDS/aspirin: ibuprofen, naproxen, celecoxib, meloxicam
Benzodiazepines: e.g., diazepam
Antispasticity drugs: e.g., baclofen, tizanidine
Topical anesthetics: e.g., lidocaine/lignocaine

| Date for collection of data | | YYYY.MM.DD | | PAINEXDT | TABLE 8 |
|---|--------------|------------|-----------------------|-----------------------|---------|
| Procedural interventions | Overall Pain | Worst | 2 nd Worst | 3 rd Worst | |
| Trigger point injection / dry needling | OPTPTINJ | WTPTINJ | 2WTPTINJ | 3WTPTINJ | |
| Acupuncture | OPACUPN | WACUPN | 2WACUPN | 3WACUPN | |
| Peripheral nerve / motor block | OPPNMB | WPNMB | 2WPNMB | 3WPNMB | |
| Joint injections | OPJTINJ | WJTINJ | 2WJTINJ | 3WJTINJ | |
| Intravenous lidocaine | OPINTLD | WINTLD | 2WINTLD | 3WINTLD | |
| Intravenous ketamine | OPKETMN | WKETMN | 2WKETMN | 3WKETMN | |
| Epidural block | OPEPBLCK | WEPBLCK | 2WEPBLCK | 3WEPBLCK | |
| Intrathecal pumps | OPINTPMP | WINTPMP | 2WINTPMP | 3WINTPMP | |
| Spinal cord stimulator | OPSPCSTM | WSPCSTM | 2WSPCSTM | 3WSPCSTM | |
| tDCS or rTMS | OPTDCS | WTDCS | 2WTDCS | 3WTDCS | |
| Percutaneous Peripheral Nerve Stimulation | OPPPNS | WPPNS | 2WPPNS | 3WPPNS | |
| | OPINTOTH | WPINTOTH | 2WINTOTH | 3WINTOTH | |
| Other, specify | OPINTSP | WPINTSP | 2WINTSP | 3WINTSP | |

Peripheral nerve/motor point block: including alcohol, phenol, steroid, anesthetic blocks, botulinum toxin injection
 Joint injections: including shoulder, knee, facet joint, ilio-sacral
 Intrathecal pumps: including morphine, ziconotide, clonidine, baclofen
 tDCS/rTMS: Transcranial brain stimulation

| Date for collection of data | | YYYY.MM.DD | | PAINEXDT | TABLE 9 |
|-------------------------------|--------------|------------|-----------------------|-----------------------|---------|
| Surgical interventions | Overall pain | Worst | 2 nd Worst | 3 rd Worst | |
| Dorsal root entry zone lesion | OPDREZL | WDREZL | 2WDREZL | 3WDREZL | |
| Spinal surgery | OPSPSURG | WSPSURG | 2WSPSURG | 3WSPSURG | |
| Deep brain stimulation | OPDBSTIM | WDBSTIM | 2WDBSTIM | 3WDBSTIM | |
| | OPSRGOTH | WSRGOTH | 2WSRGOTH | 3WSRGOTH | |
| Other, specify | OPSRGSP | WSRGSP | 2WSRGSP | 3WSRGSP | |

Spinal surgery: including stabilization, rod removal, untethering the cord, shunt
 Deep brain stimulation: implanted brain electrodes

| Date for collection of data | | YYYY.MM.DD | | PAINEXDT | TABLE 10 |
|-----------------------------|--------------|------------|-----------------------|-----------------------|----------|
| Other treatments | Overall pain | Worst | 2 nd Worst | 3 rd Worst | |
| Specify | OPOTTXSP | WOTTXSP | 2WOTTXSP | 3WOTTXSP | |

TABLE 11

B. Current treatments For examples of treatments please see previous section (A. Past treatments)

Date for collection of data

YYYYMMDD

PAINEXT

| Treatment | Dose | How Often | PGIC* | Side effects / Adverse events |
|-----------|-------|-----------|-------|-------------------------------|
| CURRTX1 | DOSE1 | FREQ1 | PGIC1 | SEADVEV1 |
| CURRTX2 | DOSE2 | FREQ2 | PGIC2 | SEADVEV2 |
| CURRTX3 | DOSE3 | FREQ3 | PGIC3 | SEADVEV3 |
| CURRTX4 | DOSE4 | FREQ4 | PGIC4 | SEADVEV4 |
| CURRTX5 | DOSE5 | FREQ5 | PGIC5 | SEADVEV5 |
| CURRTX6 | DOSE6 | FREQ6 | PGIC6 | SEADVEV6 |
| CURRTX7 | DOSE7 | FREQ7 | PGIC7 | SEADVEV7 |

*PGIC – Patient Global Impression of Change: Indicate the effect of the treatment on your global well-being using one of the following descriptors:

(1) – Very much improved; (2) – Much improved; (3) – Minimally improved; (4) – No change; (5) – Minimally worse; (6) – Much worse; (7) – Very much worse