The first version of the International Spinal Cord Injury (SCI) Core Data Set was developed by Michael DeVivo, Fin Biering-Sørensen, Susan Charlifue, Vanessa Noonan, Marcel Post, Thomas Stripling, Peter Wing (see DeVivo et al. 2006). Terminology and initial history of the International SCI Data Sets development is documented in the article by Biering-Sørensen et al.2006.

The second version of the International SCI Core Data Set was developed by Michael DeVivo, Yuying Chen, Susan Charlifue, Peter New, Vanessa Noonan, Marcel Post, Lawrence Vogel, and Fin Biering-Sørensen (see Biering-Sørensen F et al. 2017).

Acknowledgements
Funding and “in kind” support for the development of the first version of the International SCI Core Data Set were received from the International Spinal Cord Society, American Spinal Injury Association, Swiss Paraplegia Fund, Canadian Institutes of Health Research, Rick Hansen Man in Motion Foundation and Paralyzed Veterans of America.

Other persons who helped draft the first version of the International SCI Core Data Set were Raymond Cripps, James Harrison, Bon San Bonne Lee, Peter J. O’Connor, Renee Johnson, Lawrence C. Vogel, and Gale G. Whiteneck.

Comments and suggestions for second version of the International SCI Core Data Set were received from Annette Halvorsen, MJ Mulcahey, David Baxter, William A. Bauman, Amiram Catz, Lance L. Goetz, Linda Jones, Ronald K. Reeves, Gregory Nemunaitis and Sergio Aito.

Comments and suggestions for the third version of the International SCI Core Data Set were received from Anders Kruse, Kathy Zebracki.

Organisations that have endorsed the first version of the International SCI Core Data Set as of April 1, 2006
- International Spinal Cord Society
- American Spinal Injury Association
- International Society for Physical and Rehabilitation Medicine
- American Paraplegic Society
- Paralyzed Veterans of America
- American Academy of Physical Medicine and Rehabilitation
- National Spinal Cord Injury Association (USA)
- American Association of Spinal Cord Injury Psychologists and Social Workers
- American Association of Spinal Cord Injury Nurses
- North American Spine Society
- Rick Hansen Man in Motion Foundation (Canada)
- Ontario Neurotrauma Foundation (Canada)
- International Collaboration on Repair Discoveries
- Quadriplegic Association of South Africa
- American Congress of Rehabilitation Medicine
Using the International SCI Core Data Set

It is advised to practice with the training cases before implementing the International Spinal Cord Injury (SCI) Core Data Set in your own setting.

Revisions to the International Spinal Cord Injury Core Data Set – Version 2.0

The International SCI Core Data Set Version 1.0 has been the adopted standard for collecting and reporting minimal data on study population characteristics since it was first published in Spinal Cord (DeVivo et al. 2006). Standard methods to analyze and report descriptive statistics that would facilitate comparisons across published studies also were adopted in 2011 (DeVivo MJ et al. 2011). All International SCI Data Sets undergo periodic review to ensure continued relevance, acceptance and usage by the SCI research community. In 2015, the International SCI Data Sets Committee solicited comments and proposed revisions to the International SCI Core Data Set Version 1.0. Many comments were received, and each was reviewed by the Committee. In 2016 the International SCI Data Sets were reviewed to ensure they are relevant for pediatric SCI and some revisions were recommended. When reviewing proposed revisions, the Working Group weighed the potential benefits of the proposal against the loss of continuity resulting from any revision. Ultimately, the Committee adopted several changes to the Core Data Set and accompanying analytic and reporting standards. These changes are summarized in the ensuing narrative, followed by the revised data form and syllabus version 2.0.

List of specific revisions incorporated into the International SCI Core Data Set Version 2.0

1. Language was added to clarify the instructions for coding the date of injury. For non-traumatic cases, the date of injury should be coded as the approximate date of first physician visit related to symptoms of spinal cord dysfunction.

2. Date of Death was added as a new variable that will be included in the Core Data Set.

3. Total Days Hospitalized for Acute Care and Rehabilitation was deleted from the Core Data Set. Dates of admission and discharge remain, permitting the length of stay to be calculated, if needed.

4. Date of admission to rehabilitation has been added, as a request from several clinicians and researchers as it is found important to have this information. This is due to the fact that the acute management and the rehabilitation is separated.
in many settings. Even when not separated the date is given when the patient is considered to be transferred from the acute to the rehabilitation program. This variable will make it possible to calculate the length of stay for inpatient acute management and rehabilitation respectively.

5. A new category reflecting “transgender and other related” was added to the gender variable, in recognition that some people identify themselves as transgender, transsexual, intersex or other similar gender affiliation (New and Currie 2016; Reisner et al. 2016).

6. Several new responses were added to the etiology variable to allow basic categorization of non-traumatic cases and to include pediatric causes of SCI: congenital or genetic etiology (e.g., spina bifida); degenerative non-traumatic etiology; tumor – benign; tumor – malignant; vascular etiology (e.g., ischemia, hemorrhage, arteriovenous malformation); infection (e.g., bacterial, viral); other non-traumatic spinal cord dysfunction. An option to specify the other non-traumatic spinal cord dysfunction is included.

7. Requirements for reporting the neurologic examination results were clarified. For cross-sectional post-discharge studies, the examination to be reported should be the most recent, and the unknown code should be used whenever the patient cannot engage in the examination due to age or condition.

8. A response category was added to the variable on utilization of ventilatory assistance to reflect the use of CPAP to treat sleep apnea.

9. Under the heading Spinal Surgery for Traumatic Spinal Cord Injuries, the use of staples was added to the list of methods that may be used for internal fixation of the spine.

10. The Place of Discharge was clarified to designate the location the individual was placed upon discharge or the current residence for post-discharge cross-sectional studies; the place upon discharge was also clarified to reflect the intended final disposition, rather than the location of a temporary stay in a hospital, rehabilitation setting, or nursing home.

11. Brachial plexus injuries were an additional category of injury added to the list of qualifying associated injuries.
12. Recognizing that most general population data are published in 5 year increments of 0-4, 5-9, 10-14 years, etc., the recommended grouping for reporting and analyzing age has been changed to 0-14, 15-29, 30-44, 45-59, 60-74, and 75+ years. If necessary, as required to obtain sufficient sample size in each grouping to permit adequate data analysis, the categories could be expanded to 30-year intervals to 0-29, 30-59, and 60+ years. For studies of the pediatric SCI population, the current recommended grouping for age is 0-5, 6-12, 13-14, 15-17, and 18-21 years in order to correspond to anticipated milestones in the maturation process. Similarly, years post-injury should now be grouped <1, 1-4, 5-9, 10-14, and every 5 years thereafter, doubling the years included in each interval with categories ending in 4 or 9, as required. The recommended calendar time intervals do no need to be changed (for example 5 years intervals such as 1990-94, 1995-99, 2000-04, 2005-09, etc., with the option of collapsing the number of categories by one-half, as needed). Each of these variables still could be treated continuously in multivariate analyses. This change in the grouping should not affect the ability to compare future data with previously collected data because the intervals captured will differ by only one year from the prior intervals that had been employed.

**Revisions to the International Spinal Cord Injury Core Data Set – Version 3.0**

Suggestions for revisions of the International SCI Core Data Set have been received and discussed in the Working Group weighing the potential benefits in relation to clinical and research utility of the proposals against the loss of continuity resulting from any revision. The adopted changes to the International SCI Core Data Set are summarized below, followed by the revised syllabus and data collection form version 3.0.

1. The variable ‘Gender’ has been changed to ‘Sex assigned at birth’. The item ‘Transgender or other related category’ is changed to ‘Other, specify’, as the majority will be assigned to Male/Female. In addition, an item ‘Decline to answer’ is included. It is agreed that the individuals’ current sexual orientation is important, and this now is included in the International SCI Male Sexual Function and Female Sexual and Reproductive Function Basic Data Sets - version 2.0.

2. For the variable ‘Spinal Cord Injury Etiology’, the first item, ‘Sports or exercise during leisure time’, has been clarified in the item description that it is ‘including during leisure time.’ This was the intended definition, but not has been clear until now. For this reason, the following sentence was added: This will include a wide range of activities from professional (or college or other
school) athlete activities during an organized sporting event to exercise during leisure time.

3. For the variable ‘Vertebral injury’, the item ‘Unknown’ is reworded into two answer possibilities: ‘Not applicable (non-traumatic case)’ and ‘Unknown’ for the traumatic cases where this is actually not known. The first option to make it clear that this item is for individuals with traumatic SCI only.

4. For the same reasons, for the variable ‘Associated injuries’ the item ‘Unknown’ is reworded into two answer possibilities: ‘Not applicable (non-traumatic case)’ and ‘Unknown’.

5. Due to the fact that individuals with non-traumatic SCI constitute the majority of individuals with new SCI in many settings, and these patients can have surgery as part of the management of their SCI e.g., for spinal stenosis, slipped disc, spinal tumors, spondylodiscitis, spinal abscesses, hematomas, vascular conditions, etc. it is relevant to include these surgeries as well under the variable ‘Spinal surgery’. Therefore, the Description of the variable and the Comments section are expanded to accommodate these surgical procedures. As a consequence, the following are now included: laminotomy, laminectomy, laminoplasty, decompression due to spinal stenosis or metastasis, evacuation of hematoma or infection, removal of pathology in the spinal canal, spinal fusion, or internal fixation of the spine, as well as surgery for cysts, web, adherences or arachnoiditis, and endovascular treatment of pathology in the spinal canal. Likewise, the Comments are aligned with this expansion of possibilities.

6. For the variable ‘Utilization of ventilatory assistance’, item 4 related to Continuous Positive Airway Pressure (CPAP) for sleep apnea has been extended, thus Ventilatory support for sleep apnea may include CPAP, Bilevel Positive Airway Pressure (BiPAP) and Adaptive Servo Ventilation (ASV).

7. For the variables related to the neurologic examination using the International Standards for Neurological Classification of SCI (ISNCSCI) changes are made to the items making it clearer and easier to report, and at the same time it is realized that not all the information previously included were usable in either daily clinical practice or research in general. The change includes that the sensory and motor levels are not reported separately. This means only the neurologic level of injury (NLI) and the American Spinal Injury Association (ASIA) Impairment Scale (AIS) are to be reported at time of admission and discharge. In addition, to comply with the 2019 version of the ISNCSCI
(Rupp et al. 2021) a separate variable is included indicating whether the values for the NLI or the AIS or both are impacted by a non-SCI condition (meaning that one or both are tagged with a ‘*’).

**Training in the Use of the Core Data Set**

Training cases have been contributed by Fin Biering-Sørensen, Michael J. DeVivo, Vanessa Noonan, Pradeep Thumbikat, Peter Wing, and Lawrence Vogel.

Try first to fill in a blank scoring sheet (see International SCI Core Data Set Collection Form – Version 2.0), and then after completing the task, check your results with the completed scoring-sheet to determine if the scoring was performed correctly.

The documentation with explanations for the International SCI Core Data Set is found in the Introduction to the International SCI Core Data Set – Version 2.0.

**Questions and suggestions** regarding the International SCI Core Data Set should be directed to Vanessa Noonan Vanessa.Noonan@vch.ca or Fin Biering-Sørensen fin.biering-soerensen@regionh.dk.
INTRODUCTION

The purpose of the International Spinal Cord Injury (SCI) Core Data Set is to standardize the collection and reporting of a minimal amount of information necessary to evaluate and compare results of published studies. At minimum, published studies should include information on the age of the study population at the time of injury, the current age of the study population if different from age at injury, the length of elapsed time after injury when data are being collected, the calendar time frame during which the study was conducted, the sex of the study population, the causes of spinal cord dysfunction, and the neurologic status of the study population. In addition, studies of health services and rehabilitation outcomes should also contain information on dates of initial acute admission, rehabilitation admission, and rehabilitation discharge, date of death, whether a vertebral injury was present, whether spinal surgery was performed, whether associated injuries were present, whether patients were ventilator-dependent, and the current residence upon discharge from inpatient care. Inclusion of more detailed information will depend on the research topic.

It is vital to this initiative that data be collected in a uniform manner. For this reason, each variable and each response category within each variable have been specifically defined in a way that is designed to promote the collection and reporting of comparable minimal data.

Use of a standard coding scheme (assignment of numeric values to response categories) and format is essential for combining data from multiple investigators and locations. Therefore, all response categories within each variable have been assigned codes that can be used consistently at all locations. However, other formats and coding schemes may be equally effective and could be used in individual studies or by agreement of the collaborating investigators.

The International SCI Core Data Set will often be used together with International SCI Data Sets related to other SCI specific topics, when relevant. All these International SCI Data Sets may be seen and downloaded for free from the International Spinal Cord Society’s website: http://www.iscos.org.uk/international-sci-data-sets.
<table>
<thead>
<tr>
<th>VARIABLE NAME</th>
<th>DESCRIPTION</th>
<th>LENGTH</th>
<th>FORMAT</th>
<th>CODES</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth</td>
<td>This variable document the patient's date of birth.</td>
<td>8</td>
<td>Numeric (yyyymmd)</td>
<td>9999-99-99 Unknown</td>
<td>Record the year, month, and day of birth. If the month or day is unknown, it should be coded “99”; if the year is unknown, it should be coded “9999”. Numeric format is used rather than date format for computer storage of the data because the unknown codes are not valid dates.</td>
</tr>
<tr>
<td>Date of Injury</td>
<td>This variable specifies the date the SCI occurred.</td>
<td>8</td>
<td>Numeric (yyyymmd)</td>
<td>9999-99-99 Unknown</td>
<td>Record the year, month, and day of injury. If the month or day is unknown, it should be coded “99”; if the year is unknown, it should be coded “9999”. For non-traumatic cases, date of injury should be coded as the approximate date of the first physician visit for symptoms related to spinal cord dysfunction. Numeric format is used rather than date format for computer storage of the data because the unknown codes are not valid dates.</td>
</tr>
<tr>
<td>Date of Acute Care Hospital Admission</td>
<td>This variable specifies the date of admission to the first acute care hospital after the SCI occurred.</td>
<td>8</td>
<td>Numeric (yyyymmd)</td>
<td>9999-99-99 Unknown</td>
<td>Record the year, month, and day of first acute care hospital admission. If the month or day is unknown, it should be coded “99”; if the year is unknown, it should be coded “9999”. Numeric format is used rather than date format for computer storage of the data because the unknown codes are not valid dates.</td>
</tr>
</tbody>
</table>
VARIABLE NAME: Date of Admission to Inpatient Rehabilitation
DESCRIPTION: This variable specifies the date of admission to the inpatient rehabilitation facility from the acute facility.
LENGTH: 8
FORMAT: Numeric (yyyymmdd)
CODES: 9999-99-99 Unknown
COMMENTS: Record the year, month, and day for the inpatient rehabilitation facility admission. If the month or day is unknown, it should be coded “99”; if the year is unknown, it should be coded “9999”.

Numeric format is used rather than date format for computer storage of the data because the unknown codes are not valid dates.

In centers where there is comprehensive management, i.e. acute and rehabilitation in the same department, there will often be a distinction between the acute care program and the rehabilitation program, and the date registered when the patient is considered to be transferred from the acute to the rehabilitation program. This variable will make it possible to calculate the length of stay for inpatient acute management and rehabilitation respectively.

VARIABLE NAME: Date of Final Inpatient Discharge
DESCRIPTION: This variable specifies the date of discharge from the last inpatient hospital when all planned acute care and rehabilitation phases of treatment are completed.
LENGTH: 8
FORMAT: Numeric (yyyymmdd)
CODES: 9999-99-99 Unknown
COMMENTS: Record the year, month, and day of discharge from the last inpatient hospital when all planned acute care and rehabilitation phases of treatment are completed. If the month or day is unknown, it should be coded “99”; if the year is unknown, it should be coded “9999”.

Numeric format is used rather than date format for computer storage of the data because the unknown codes are not valid dates.

On this date, patients will typically be discharged home (with no further planned inpatient admissions) or discharged to a long-term care facility. Outpatient rehabilitation or a home rehabilitation program may continue after this date, or limited rehabilitation
therapy may continue in the long-term care facility. If the patient dies during inpatient hospitalization, this will be the date of death.

If there is a planned interruption in the inpatient hospitalization and the patient is readmitted for further care, then the date of inpatient discharge is the date of discharge for the planned readmission. An example of this would be a patient who is discharged home temporarily until he is ready for further rehabilitation and then is brought back to the hospital for completion of inpatient rehabilitation. The date of inpatient discharge is the last date of discharge with no further planned hospitalizations. Subsequent admissions and discharges for treatment of unplanned secondary medical complications such as infections or pressure sores are not to be coded in this variable.

VARIABLE NAME: Date of Death
DESCRIPTION: This variable specifies the date of death for patients who have died.
LENGTH: 8
FORMAT: Numeric (yyymmmdd)
CODES: 9999-99-99 Deceased but with unknown date
Blank (patient is thought to still be alive)
COMMENTS: Record the year, month, and day of death. If the month or day is unknown, it should be coded “99”; if the year is unknown, it should be coded “9999”.
Numeric format is used rather than date format for computer storage of the data because the unknown codes are not valid dates.

VARIABLE NAME: Sex assigned at birth
DESCRIPTION: This variable specifies the sex of the patient.
LENGTH: 1
FORMAT: Numeric
CODES: 1 Male
2 Female
3 Other, specify
4 Decline to answer
9 Unknown
COMMENTS: Record the sex to which the patient is assigned at birth (Jette AM 2020). For the individuals’ current sexual orientation, one should refer to the International SCI Male Sexual Function and Female Sexual and Reproductive Function Basic Data Sets - version 2.0 (Alexander MS, et al. 2017; https://www.iscos.org.uk/international-sci-data-sets). As the majority will be assigned male/female, any other may be specified.

VARIABLE NAME: Spinal Cord Injury Etiology
DESCRIPTION: This variable identifies the etiology of the SCI. SCI is impairment of the spinal cord or cauda equina function resulting from the application of an external force of any magnitude or a dysfunction or disease process.
LENGTH: 2
FORMAT: Numeric
CODES:
1  Sports or exercise including during leisure time
2  Assault
3  Transport
4  Fall
5  Birth injury or other traumatic cause, specify
6  Congenital or genetic etiology (e.g., spina bifida)
7  Degenerative non-traumatic etiology
8  Tumor – benign
9  Tumor – malignant
10  Vascular etiology (e.g., ischemia, hemorrhage, arteriovenous malformation)
11  Infection (e.g., bacterial, viral)
12  Other non-traumatic spinal cord dysfunction, specify
99  Unspecified or Unknown

COMMENTS: For traumatic spinal cord injuries, this variable has been adapted from the International Classification of External Causes of Injuries (ICECI). In its entirety, the ICECI provides a multi-axial description of the event that resulted in SCI. Four axes have been developed, including the External Cause of Injury Axis, the Intent of Injury Axis, the Place of Injury Axis, and the Injury Activity Axis. Use of the complete version of the ICECI (including all four axes and subcategories not included in the core data set) is recommended for injury surveillance activities or other research studies the goal of which would be to provide information useful
for the development of interventions targeted at primary prevention of spinal cord injuries.

Because it is possible that an injury event may be classifiable into more than one of these categories, the following prioritization has been established for assigning codes:

First coding priority for traumatic SCI is given to sports or exercise including during leisure time. If the injury event involved sports or exercise it should be coded as a 1 (Sports or exercise including during leisure time) regardless of whether it involved assault, transport or a fall. Code 1 would be appropriate whenever the ICECI Injury Activity Axis would be coded as “sports and exercise during leisure time” (ICECI Injury Activity code 4), regardless of coding on other ICECI Axes.

Second priority for traumatic SCI is given to Assault. If the event did not involve sports but it did involve an assault, then the event should be coded as a 2 (Assault) regardless of whether it involved transport or a fall. Code 2 would be appropriate whenever the ICECI Intent of Injury Axis would be coded as “assault” (ICECI Intent of Injury code 3) and the ICECI Injury Activity Axis would not be coded as “sports and exercise during leisure time” (ICECI Injury Activity code 4), regardless of other ICECI Axes.

Third priority for traumatic SCI is given to Transport. If the event was neither sports nor assault related but it involved transport, then the event should be coded as 3 (Transport), regardless of whether it involved a fall. Code 3 would be appropriate whenever the ICECI External Cause of Injury Axis would be coded as “transport injury event” (ICECI External Cause of Injury code 1.1) and ICECI Intent of Injury Axis would not be coded as “assault” (ICECI Intent of Injury code 3) and ICECI Injury Activity Axis would not be coded as “sports and exercise during leisure time” (ICECI Injury Activity code 4).

Fourth priority for traumatic SCI is given to Fall. If the event was neither sports-, assault- nor transport-related and it involved a fall then it should be coded as 4 (Fall). Code 4 would be appropriate whenever the ICECI External Cause of Injury Axis would be coded as “falling, stumbling, or jumping” (ICECI External Cause of Injury code 1.5) and the ICECI External Cause of Injury Axis would not be coded as “transport injury event” (ICECI External Cause of Injury code 1.1), the ICECI Intent of Injury Axis would not be coded as “assault” (ICECI Intent of Injury code 3), and the
ICECI Injury Activity Axis would not be coded as “sports and exercise during leisure time” (ICECI Injury Activity code 4).

Use code 5 (other traumatic cause) for birth injuries or all other known (specified) or unknown traumatic causes whenever codes 1 through 4 of this etiology variable do not apply. Paralysis secondary to surgical procedures when the patient does not have a neurological deficit prior to surgery would be coded in this category. It is possible to specify the cause.

Use codes 6 through 12 (non-traumatic causes) if there is impairment of the spinal cord or cauda equina function that is not caused either directly or indirectly by an external event.

Codes 6-11 include the most common non-traumatic causes as classified by the non-traumatic SCI datasets classification to the second level (New and Marshall 2014).

Code 12 should be used for all other less common causes of non-traumatic spinal cord damage and cases of non-traumatic spinal cord damage where the exact etiology is unknown. It is possible to specify the cause, e.g., with International Classification of Disease (ICD) code.

If more detailed information is needed pertaining to non-traumatic causes of SCI, additional variables can be selected from the International SCI Non-traumatic Data Set (New and Marshall 2014).

<table>
<thead>
<tr>
<th>VARIABLE NAME:</th>
<th>Vertebral Injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>DESCRIPTION:</td>
<td>This variable document whether there was a spinal fracture and/or dislocation in addition to the SCI.</td>
</tr>
<tr>
<td>LENGTH:</td>
<td>1</td>
</tr>
<tr>
<td>FORMAT:</td>
<td>Numeric</td>
</tr>
<tr>
<td>CODES:</td>
<td>0  No</td>
</tr>
<tr>
<td></td>
<td>1  Yes</td>
</tr>
<tr>
<td></td>
<td>2  Not applicable (non-traumatic case)</td>
</tr>
<tr>
<td></td>
<td>9  Unknown</td>
</tr>
<tr>
<td>COMMENTS:</td>
<td>Spinal fracture or dislocation is defined as any break, rupture, or crack through or between any part(s) of the vertebral column from the occiput to the coccyx. Thus, this is applicable for individuals</td>
</tr>
</tbody>
</table>
with traumatic SCI only. ‘Unknown’ is for the traumatic cases where it is not known if a vertebral injury is present.

If more detailed information is needed pertaining to vertebral injury, including information on non-continuous vertebral injuries, additional variables can be selected from the International SCI Spinal Column Injury Data Set (Dvorak et al. 2012).

VARIABLE NAME: Associated Injury
DESCRIPTION: This variable documents whether any of the following pre-specified major traumatic injuries occurred at the same time as the SCI: moderate to severe traumatic brain injury (Glasgow Coma Scale 12 or below at discharge), non-vertebral fractures requiring surgery, severe facial injuries affecting sense organs, major chest injury requiring chest-tube or mechanical ventilation, traumatic amputations of an arm or leg (or injuries severe enough to require surgical amputation), severe hemorrhaging, brachial plexus injuries, or damage to any internal organ requiring surgery.

LENGTH: 1
FORMAT: Numeric
CODES: 0 No
1 Yes
2 Not applicable (non-traumatic case)
9 Unknown
COMMENTS: Do not include other associated injuries not listed above, negative findings from exploratory surgery, and do not include injuries that pre-date the SCI. Thus, this is applicable for individuals with traumatic SCI only. ‘Unknown’ is for the traumatic cases where it is not known if associated injuries are present.

VARIABLE NAME: Spinal Surgery
DESCRIPTION: This variable documents whether any spinal surgical procedures were performed during the inpatient hospitalization following a traumatic or non-traumatic SCI, including laminotomy, laminectomy, laminoplasty, decompression due to spinal stenosis or metastasis, evacuation of hematoma or infection, removal of pathology in the spinal canal, spinal fusion, or internal fixation of the spine, as well as surgery for cysts, web, adherences or arachnoiditis, and endovascular treatment of pathology in the spinal canal.
LENGTH: 1
FORMAT: Numeric
CODES: 0 No 1 Yes 9 Unknown

COMMENTS: Laminotomy is defined as the partial removal of the lamina.
Laminectomy is defined as removal of the lamina or foreign body at the site of spinal cord damage.
Laminoplasty is defined as a temporary removal and then replacement of the lamina (often used to treat cervical degenerative myelopathy).
Removal of pathology in the spinal is defined as the removal of bone or disk fragments, hematoma/blood clots, intraspinal tumor, malformations, or foreign bodies (such as bullet fragments) from the spinal canal.
Reduction is defined as surgical replacement of one or more dislocated, subluxated or angulated vertebra into anatomic or near anatomic alignment.
Spinal fusion is defined as the addition of a bone graft to the vertebrae for the purpose of achieving intervertebral fusion or stability.
Internal fixation of the spine is defined as attaching rods, plates, wires, staples, cages, semirigid fixation and arthroplasty etc. to the spine (individually or in combination) to provide internal surgical stabilization of the vertebral column.
Endovascular treatment of pathology in the spinal canal including embolization or stenting for vascular malformation or tumors etc.
If more detailed information is needed pertaining to surgical procedures for individuals with traumatic SCI, additional variables can be selected from the International SCI Spinal Interventions and Surgical Procedures Data Set (Dvorak et al. 2015).

VARIABLE NAME: Utilization of Ventilatory Assistance
DESCRIPTION: This variable documents any use of any type of ventilatory assistance used to sustain respiration on the date of final inpatient discharge (the date of discharge from the last inpatient rehabilitation hospital or discharge from the last acute care hospital if the patient is not admitted to a rehabilitation hospital). For cross-sectional post-discharge studies, this variable documents current use of ventilatory assistance.

LENGTH: 1
FORMAT: Numeric
CODES:
0 No
1 Yes, less than 24 hours per day at discharge
2 Yes, 24 hours per day at discharge
3 Yes, unknown number of hours per day at discharge
4 Ventilatory support for sleep disordered breathing only
9 Unknown

COMMENTS: Ventilatory assistance includes, but is not limited to, mechanical ventilators, phrenic nerve stimulators, diaphragmatic pacing, external negative pressure devices, and Bilevel Positive Airway Pressure (BiPAP).
Ventilatory support for sleep disordered breathing may include Continuous Positive Airway Pressure (CPAP), BiPAP and Adaptive Servo Ventilation (ASV).
Do not include routine administration of oxygen or periodic Intermittent Positive Pressure Breathing (IPPB) administration.

VARIABLE NAME: Place upon Discharge or Current Residence
DESCRIPTION: This variable specifies either the discharge disposition or the current residence of the patient.

LENGTH: 2
FORMAT: Numeric
CODES:
01 Private residence: includes house, condominium, mobile home, apartment, or houseboat
02 Hospital includes mental hospital or other acute care hospital for management of continuing medical issues after SCI-related care and/or rehabilitation is completed
03 Nursing home includes skilled nursing facilities and institutions providing essentially long-term, custodial, chronic disease care
04 Assisted living residence includes residential non-institutional locations in which some level of support for activities of daily living is provided
05 Group living situation includes transitional living facility or any residence shared by non-family members
06 Correctional institution includes prison, penitentiary, jail, correctional center, etc.
07 Hotel or motel
08 Homeless includes cave, car, tent, etc.
09 Deceased
10 Other, unclassified
99 Unknown

COMMENTS: If the patient’s place of residence does not fit into any of the above classifications, document it as “other, unclassified”.

Place of residence at time of discharge should indicate the intended final disposition. If the patient is discharged to a hospital or nursing home temporarily for custodial care only pending home renovations or for other reasons, then the intended final destination should be coded, rather than coding a temporary destination, such as a “hospital,” “rehabilitation facility,” or “nursing home”.

For cross-sectional post-discharge studies, this variable document current place of residence. When the person is currently hospitalized on a temporary basis, the usual place of residence should be coded rather than “hospital”.

VARIABLE NAME: Dates of the Neurologic Examinations
DESCRIPTION: These variables document the dates on which the neurologic examinations were performed:
1) at initial acute care hospital examination
2) at discharge from the last inpatient hospital
LENGTH: 8 for each entry
FORMAT: Numeric (yyyyymmdd)
CODES: Any valid date
8888-88-88 Not Done
9999-99-99 Unknown
COMMENTS: Record the year, month, and day. If the month or day is unknown, it should be coded “99”; if the year is unknown, it should be coded “9999”.

Use the unknown code (“9999-99-99”) when it is not known if there was a neurologic examination, or when the patient cannot engage in an examination due to age or condition.
Date format is not used because the unknown and not done codes are not valid dates.

The International Standards for Neurological Classification of SCI (ISNCSCI) (Rupp et al. 2021) cannot be conducted in children five years of age and younger (Mulcahey and Biering-Sørensen 2014; Mulcahey et al. 2011), thus for these children, the date should be recorded as 8888-88-88.

When parts of the examination are done on different dates, the date of the examination should be the day on which most parts of the examination were done.

All admission and discharge examinations should be performed within 72 hours of the corresponding admission or discharge date; however, data for examinations performed later than 72 hours after admission or more than 72 hours before discharge can be included in the database. For cross-sectional post-discharge studies, this variable document the date of the most recent neurologic examination.

The complete neurologic examination consists of the Neurological level of injury (NLI) and the American Spinal Injury Association Impairment Scale (AIS). This examination must be performed by a qualified health care professional who has been trained using the ISNCSCI guidelines, e.g. by using the International Standards Training e-Learning Program (InSTeP) (http://lms3.learnshare.com/home.aspx). In general, refer to the latest published version of ISNCSCI for complete information on the sensory, motor examination etc.

**VARIABLE NAME:** Neurological Level of Injury (NLI)

**DESCRIPTION:** The NLI is the most caudal segment of the spinal cord with normal sensory and antigravity motor function on both sides of the body, provided that there is normal (intact) sensory and motor function rostrally. This is documented:

1) at initial acute care hospital examination
2) at discharge from the last inpatient hospital

**LENGTH:** 3 for each entry

**FORMAT:** Character

**CODES**

- C01-C08 Cervical (C1 - C8)
- T01-T12 Thoracic (Dorsal, T1 - T12)
L01-L05  Lumbar (L1 - L5)  
S01-S03  Sacral (S1 – S3)  
X00  Normal neurologic examination  
X99  Unknown or Not Done  

COMMENTS: If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code "99". Use code X99 if the level is completely unknown, the examination was not done due to age, condition, or other reason, or there was no corresponding admission or discharge.  

The ISNCSIC (Rupp et al 2021) cannot be conducted in children five years of age and younger (Mulcahey and Biering-Sorensen 2014; Mulcahey et al. 2011), thus for these children, the NLI should be recorded as X99.  

For cross-sectional post-discharge studies, this variable document the NLI from the most recent neurologic examination.  

---  

VARIABLE NAME:  American Spinal Injury Association Impairment Scale (AIS)  
DESCRIPTION:  This variable attempt to quantitate the degree of impairment:  
1) at initial acute care hospital examination  
2) at discharge from the last inpatient hospital  
LENGTH:  1 for each entry  
FORMAT:  Character:  
CODES:  
A  Complete Injury.  
   No sensory or motor function is preserved in the sacral segments S4-S5.  
B  Sensory Incomplete.  
   Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-5 (light touch or pin prick at S4-5 or deep anal pressure) AND no motor function is preserved more than three levels below the motor level on either side of the body.  
C  Motor Incomplete.  
   Motor function is preserved at the most caudal sacral segments for voluntary anal contraction (VAC) OR the patient meets the criteria for sensory incomplete status (sensory function preserved at the most caudal sacral segments S4-5 by light touch (LT), pin prick (PP), or deep anal pressure (DAP)), and has some sparing of motor function more than three levels below the ipsilateral motor level on either side of the body. (This includes key or non-key muscle functions to determine motor incomplete status.) For AIS C – less than half of key
muscle functions below the single NLI have a muscle grade ≥ 3.

D Motor Incomplete.
Motor incomplete status as defined above, with at least half (half or more) of key muscle functions below the single NLI having a muscle grade ≥ 3.

E Normal.
If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without an initial SCI does not receive an AIS grade.

U Unknown or not applicable.

COMMENTS: When an associated injury (e.g., traumatic brain injury) or certain non-neurologic impairments interfere with the ability to perform a complete neurological examination, or the examination is not performed due to age, condition, or other reason, the AIS should be coded Unknown.

The ISNCSCI (Rupp et al 2021) cannot be conducted in children five years of age and younger (Mulcahey and Biering-Sorensen 2014; Mulcahey et al. 2011), thus for these children, AIS grade should be recorded as U.

For cross-sectional post-discharge studies, this variable document the AIS from the most recent neurological examination.

VARIABLE NAME: The NLI / AIS are impacted by a non-SCI condition (i.e. one or both are tagged with a ‘*’)
DESCRIPTION: This describe whether the NLI / AIS are impacted by a non-SCI condition (i.e., one or both are tagged with a ‘*’) and is documented:
1) at initial acute care hospital examination
3) at discharge from the last inpatient hospital

LENGTH: 1 for each entry
FORMAT: Numeric
CODES
0 No
1 Yes
9 Unknown

COMMENTS To comply with the 2019 version of the ISNCSCI (Rupp et al. 2021) this variable indicate whether the values for the NLI or the AIS or both are impacted by a non-SCI condition (meaning that one or both are tagged with a ‘*’) as introduced in the 2019 version of the ISNCSCI (Rupp et al. 2021).
References


Jette AM. The Importance of Collecting Data on Sexual Orientation and Gender Identity (SOGI) in Rehabilitation Research. Phys Ther. 2020 Aug 12;100(8):1235-1236. doi: 10.1093/ptj/pzaa104. PMID: 32785647


INTERNATIONAL SPINAL CORD INJURY CORE DATA SET
(VERSION 3.0) – DATA COLLECTION FORM

Dates (YYYYMMDD)

Birth date ________ / ______ / ______
Injury date ________ / ______ / ______
Acute Admission ________ / ______ / ______
Rehabilitation Admission ________ / ______ / ______
Final Inpatient Discharge ________ / ______ / ______
Date of Death ________ / ______ / ______

Sex assigned at birth: □ Male □ Female □ Other, specify______________
□ Decline to answer □ Unknown

Injury Etiology:
□ Sports and exercise including during leisure time; □ Assault; □ Transport;
□ Fall; □ Birth injury or other traumatic cause;
□ Congenital or genetic etiology (e.g., spina bifida), Specify:____________________;
□ Degenerative non-traumatic etiology;
□ Tumor – benign; □ Tumor – malignant;
□ Vascular etiology (e.g., ischemia, hemorrhage, arteriovenous malformation);
□ Infection (e.g., bacterial, viral);
□ Other non-traumatic spinal cord dysfunction, Specify:________________________;
□ Unspecified or Unknown

Vertebral Injury: □ No □ Yes □ Not applicable (non-traumatic case)
□ Unknown

Associated Injury: □ No □ Yes □ Not applicable (non-traumatic case)
□ Unknown

Spinal Surgery: □ No □ Yes □ Unknown

Ventilatory Assistance:
□ No; □ Yes, less than 24 hours per day at discharge;
□ Yes, 24 hours per day at discharge;
Yes, unknown number of hours per day at discharge;
Ventilatory support for sleep disordered breathing only;
Unknown

**Place upon Discharge/Current Residence:**
- Private residence: includes house, condominium, mobile home, apartment, or houseboat;
- Hospital: includes mental hospital or other acute care hospital for management of continuing medical issues after spinal cord injury-related care and/or rehabilitation is completed;
- Nursing home: includes skilled nursing facilities and institutions providing essentially long-term, custodial, chronic disease care;
- Assisted living residence: includes residential non-institutional locations in which some level of support for activities of daily living is provided;
- Group living situation: includes transitional living facility or any residence shared by non-family members;
- Correctional institution: includes prison, penitentiary, jail, correctional center, etc.;
- Hotel or motel; Homeless: includes cave, car, tent, etc.; Deceased;
- Other, unclassified; Unknown

### Neurological Data

<table>
<thead>
<tr>
<th>Acute Admission</th>
<th>Final Inpatient Discharge</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Examination</td>
<td>Date of Examination</td>
</tr>
<tr>
<td>_ _ _ _/ _ / _ _</td>
<td>_ _ _ _/ _ / _ _</td>
</tr>
<tr>
<td>Neurological Level of Injury (NLI)</td>
<td>Neurological Level of Injury (NLI)</td>
</tr>
<tr>
<td>______</td>
<td>______</td>
</tr>
<tr>
<td>ASIA Impairment Scale (AIS)</td>
<td>ASIA Impairment Scale (AIS)</td>
</tr>
<tr>
<td>_____</td>
<td>_____</td>
</tr>
</tbody>
</table>

The NLI / AIS are impacted by a non-SCI condition (i.e. one or both are tagged with a '*)
- No
- Yes
- Unknown

The NLI / AIS are impacted by a non-SCI condition (i.e. one or both are tagged with a '*)
- No
- Yes
- Unknown