## Injury Timeframe

1. \*Date of visit:
2. \*Date of injury1: Unknown
3. \*\*Time of injury: Unknown
4. \*\*Timeframe of onset of non-traumatic spinal cord injury2:

acute (≤ 1 day)

sub-acute (> 1 day but ≤ 7 days)

prolonged (> 7 days but ≤ 1 month)

lengthy (> 1 month)

## Injury Etiology

1. \*\*Iatrogenic role in etiology2:

No  Yes  Unknown

1. \*Traumatic injury etiology1:

Sports/leisure (1st priority)

Assault (2nd priority)

Transport (3rd priority)

Fall (4th priority)

Other traumatic causes

Unspecified or Unknown

Not applicable

1. \*\* Traumatic injury - Penetrating/blunt injury3:

Blunt Penetrating Unknown

1. \*Non-traumatic injury etiology:

(Note: Complete question 9 if a detailed description of the non-traumatic injury is needed)

Congenital or genetic etiology (e.g. spinal bifida)

Degenerative

Tumor – benign

Tumor – malignant

Vascular etiology (e.g. ischemia, hemorrhagic, malformations)

Infection etiology (e.g. bacterial, viral)

Other non-traumatic spinal cord dysfunction

Not applicable

Unspecified or Unknown

1. \*\*\*Injury etiology – Detailed classification of etiology of Non-Traumatic Spinal Cord Injury (NTSCI)2

Axis 1 (See Table 1 on pages 6-13 and consider question #8 if a detailed description is not required):

Level 1 :

Level 2 :

Level 3 :

Level 4 :

Level 5 :

Axis 2:

ICD version:

ICD codes (collect up to three codes):

## General Instructions

Important note: Four data elements included on this CRF are considered Core (i.e., strongly recommended for all studies to collect). The remaining data elements are either Supplemental or Exploratory, as indicated. Supplemental elements should be collected in clinical research only if the research team considers them appropriate for their study. The Exploratory elements are additional recommendations that may be collected if needed.

## Specific Instructions

* Date of injury - If date is not known, suggest using the first month as a default and then the closet month.
* Special Note: These elements are from the ISCoS International SCI Data Sets:

[1International SCI Core Data Set (Version 1.1)](http://www.iscos.org.uk/international-sci-core-data-sets)

[2International SCI Non-Traumatic SCI Basic and Extended Data Sets (Version 1.0)](http://www.iscos.org.uk/international-sci-non-traumatic-sci-data-sets-)

[3International SCI Spinal Column Injury Basic Data Set (Version 1.0)](http://www.iscos.org.uk/international-sci-spinal-column-injury-data-sets)

* Injury etiology: See Data Dictionary for definitions
* **Iatrogenic role in etiology:** A major challenge in developing the data sets was dealing with iatrogenic causes of SCI. There were two schools of thought expressed during the development of the dataset regarding this issue.

One felt that iatrogenic conditions should be included in the NTSCI classification system if there was no direct external force involved. The other highlighted the approach taken by the International Classification of External Causes of Injury (ICECI), developed by the WHO ([International Classification of External Causes of Injuries (ICECI](http://www.rivm.nl/who-fic/ICECI/ICECI_1-2_2004July.pdf)), and advocated the need to follow their standard. The ICECI directs that iatrogenic injury be considered traumatic if it had an external cause. This includes complications of health care, either medical or surgical, unintentionally leading to injury or other harm, and acts of omission as well as acts of commission.

There are a number of concerns, however, regarding the use of the ICECI framework, for classifying all iatrogenic SCI as traumatic. The following scenarios illustrate these concerns (and additional examples are provided in the case studies section). In patients with a tumor causing NTSCI with neurological symptoms and signs due to spinal cord compression (from the tumor), the spinal cord damage can worsen as a result of radiotherapy, chemotherapy or surgery carried out in an attempt to treat the tumor. Likewise, patients presenting with canal stenosis causing cord myelopathy can have spinal cord damage symptoms pre-surgery and worsening of these signs post-operatively without any direct operative trauma to the cord. Each of the above would be classified as iatrogenic but it is believed to be misleading to classify the etiology as traumatic. SCI trauma prevention would have no impact on the occurrence of these types of SCI. Most SCI intervention trials would not include these patients as traumatic SCI. Finally, in cases of a bacterial epidural abscess causing spinal cord compression, it can be argued that there are few difference in outcomes between cases in which no cause is found, cases that occurred following immune suppression for a medical condition, or a surgical wound or a fall (i.e. a trauma) and resulted in a scratch which became infected and progressed to septicaemia and subsequent an epidural abscess. Again, prevention programs would have no direct bearing on the occurrence.

Feedback from participants in the Data Set development process indicated that there is a wide range in what different people consider to be traumatic or non-traumatic in these examples. The enormous challenge faced in developing an approach for dealing with iatrogenic SCI has resulted in the belief that it is almost impossible to develop a framework to completely standardize the classification of these conditions because of the nuances of clinical cases, the subjective nature of how clinicians interpret key events and contributing factors in the non-traumatic SCI cases, and the influence of legal and cultural factors. It is therefore recommend that in using this dataset classification the ICECI be used as the overall guiding framework but clinicians make the final decision regarding whether they consider the SCI to be traumatic or non-traumatic. It is suggested that when the iatrogenic component is a direct ‘cause’ involving an ‘unintentional cut, puncture, perforation during a surgical intervention (ICECI 20.4), the case should be considered a traumatic SCI. If the iatrogenic component involves medication (i.e. iatrogenic but no direct external force), or is only a factor in an already established clinical case of NTSCI even if there is some progression in severity of SCI as a result of the iatrogenic component, then these should be classified as NTSCI and the iatrogenic component is indicated as being present. It is acknowledged that further refinements to this approach will be required over time.

* **Classification of etiology for non-traumatic SCI:** A detailed classification for NTSCI is presented that consists of two axes. Axis 1 provides a hierarchical classification of NTSCI using clinical classes and pathological mechanisms in two major tiers: ‘congenital – genetic’ and ‘acquired’. Five levels are provided within the axis to allow for increasing levels of detail to be recorded about the etiology. The Basic Data Set codes the etiology of NTSCI using Levels 1 and 2 of Axis 1. The Extended Data Set can code the etiology through a further 3 levels i.e. levels 3 to 5. Researchers can use as many levels beyond the basic level as they deem appropriate for their project. Etiology categories can be left out of research reports if there are no participants with these disorders.

For congenital or genetic categories, when there are small numbers in a particular group, they can be collapsed to level 1 (i.e. reported simply as ‘genetic’ or ‘congenital’, if the researchers deem this appropriate. Acquired disorders should always be described, however, to level 2 at a minimum. If there are very small numbers of some disorders then these can be collapsed into an ‘other’ category, if the researchers deem this appropriate.

It is intended that the Axis 1 be used to classify the final etiological process responsible for the NTSCI.

Classification principles

* Only one single etiology is coded for any case.
* If a patient has non-traumatic SCI lesions that occurs as a result of different causes during the course of the same admission then the condition that causes the more severe neurological impairment is the condition that should be classified. E.g. a patient that had a mild thoracic myelopathy from a meningioma, then while in rehabilitation the patient had an epidural bleed from sub-cutaneous heparin for DVT prevention. The myelopathy was much worse after the bleed. Thus in this case, the epidural bleed was the more severe causative factor and the one coded, even though the meningioma was indirectly responsible (could be coded as Axis 2, if Extended Data Set is used).
* If a patient has a single cause of non-traumatic SCI that could possibly be placed in two (or more) different aetiological groups in the classification then the more specific etiology should be selected. E.g. Achondroplasia that leads to compression of multiple regions of the thoracic cord is classified as “CONGENITAL:Skeletal malformations-Achondroplasia” and not "ACQUIRED:Vertebral column degenerative disorders-spinal cord compression due to combination of multiple developmental and/or acquired factors” as a matter of routine, unless there are “acquired factors” that are also responsible for cord compression.
* If a patient has transverse myelitis from an etiology listed in the classification, then this specific cause is coded. The transverse myelitis etiology is only selected where the cause is idiopathic.

\*Element is classified as Core.

\*\*Element is classified as Supplemental.

\*\*\*Element is classified as Exploratory.

Table 1 History of Injury Levels

| **Level 1** | **Level 2** | **Level 3** | **Level 4** | | **Level 5** |
| --- | --- | --- | --- | --- | --- |
| **CONGENITAL** | - | - | - | | - |
| - | **Spinal Dysraphism** | - | - | | - |
| - | - | Spina bifida occulta | - | | - |
| - | - | Myelomeningocoele | - | | - |
| - | - | Tethered cord syndrome | - | | - |
| - | - | - | Lipomeningocoele | | - |
| - | - | - | Anterior sacral meningocoele | | - |
| - | - | - | Diastometamyelia | | - |
| - | - | - | Hypertrophied filum terminale | | - |
| - | - | Spinal dysraphism - other | - | | - |
| - | **Arnold-Chiari Malformation** | - | - | | - |
| - | - | Type 1: Abnormal extension of the cerebellar tonsils below the foramen magnum | - | | - |
| - | - | Type 2: Plus caudal displacement of the medulla and the 4th ventricle | - | | - |
| - | - | Type 3: Displaced cerebellar and brainstem tissue extends into an infra tentorial meningoencephalocoele | - | | - |
| - | - | Type 4: Cerebellar and brainstem hypoplasia - variant of Dandy Walker Malformation | - | | - |
| - | **Skeletal malformations** | - | - | | - |
| - | - | Atlanto-axial dislocation | - | | - |
| - | - | - | Os odontoideum | | - |
| - | - | - | Hypoplastic dens | | - |
| - | - | - | Laxity of transverse atlantal - ligament | | - |
| - | - | Atlanto-axial instability (Down’s Syndrome | - | | - |
| - | - | Achondroplasia | - | | - |
| - | - | Muco-polysaccharididosis | - | | - |
| - | - | Klippel-Feil syndrome | - | | - |
| - | - | Osteogenesis Imperfecta | - | | - |
| - | - | Lumbosacral agenesis | - | | - |
| - | - | Other congenital skeletal malformations | - | | - |
| - | **Other congenital** | - | - | | - |
| - | - | Congenital Syringomyelia | - | | - |
| **GENETIC DISORDERS** | - | - | - | | - |
| - | **Hereditary spastic paraparesis** | - | - | | - |
| - | - | HSP pure | - | | - |
| - | - | HSP complicated | - | | - |
| - | **Spino-cerebellar ataxias** | - | - | | - |
| - | - | Dominant | - | | - |
| - | - | - | Specified | | - |
| - | - | - | Unspecified | | - |
| - | - | Recessive | - | | - |
| - | - | - | Friedreich's | | - |
| - | - | - | Other recessive spinocerebellar ataxias - genetically confirmed/identified | | - |
| - | - | - | Presumed recessive spinocerebellar ataxias - genetic type undetermined | | - |
| - | **Adreno-myeloneuropathy** | - | - | | - |
| - | **Other leukodystrophies** | - | - | | - |
| - | **Spinal muscular atrophies** | - | - | | - |
| - | - | Dominant | - | | - |
| - | - | - | Specific genetic types | | - |
| - | - | - | Unspecified genetic subtype | | - |
| - | - | Recessive | - | | - |
| - | **Genetic - other** | - | - | | - |
| **ACQUIRED ABNORMALITIES** | - | - | - | | - |
| - | **Vertebral column degenerative disorders** | - | - | | - |
| - | - | Disc prolapse | - | | - |
| - | - | Ligamentum flavum hypertrophy | - | | - |
| - | - | Ossification of the posterior longitudinal ligament | - | | - |
| - | - | Spinal osteophytosis | - | | - |
| - | - | Spondylolisthesis | - | | - |
| - | - | Spondylosis | - | | - |
| - | - | Spinal stenosis | - | | - |
| - | - | - | Idiopathic | | - |
| - | - | - | Acromegaly | | - |
| - | - | - | Fluorosis | | - |
| - | - | - | lipomatosis | | - |
| - | - | Spinal cord compression due to combination of multiple developmental and/or acquired factors listed above | - | | - |
| - | - | Other vertebral column degenerative disorders | - | | - |
| - | **Metabolic Disorders** | - | - | | - |
| - | - | Deficiency | - | | - |
| - | - | - | Vitamin B12 deficiency | | - |
| - | - | - | Folate deficiency | | - |
| - | - | - | Copper deficiency | | - |
| - | - | - | Rickets | | - |
| - | - | - | Other deficiency | | - |
| - | - | Osteoporosis | - | | - |
| - | - | Paget’s Disease | - | | - |
| - | - | Osteomalacia | - | | - |
| - | - | Other metabolic | - | | - |
| - | **Vascular Disorders** | - | - | | - |
| - | - | Haemorrhage | - | | - |
| - | - | - | Epidural Haematoma | |  |
| - | - | - | - | | Bleeding Diathesis |
| - | - | - | - | | Medication |
| - | - | - | - | | Other |
| - | - | - | Other haemorrhage | | - |
| - | - | Vascular Malformations | - | | - |
| - | - |  | Dural arterio-venous (AV) fistula | | - |
| - | - | - | Arterio-venous malformation (AVM) with or without haemorrhage | | - |
| - | - | Ischaemia |  | | - |
| - | - | - | Atherosclerosis | | - |
| - | - | - | Aortic Dissection | | - |
| - | - | - | Takayasu's arteritis | | - |
| - | - | - | Atheromatous emboli | | - |
| - | - | - | Thromboemboli | | - |
| - | - | - | Fibrocartilaginous emboli | | - |
| - | - | - | Decompression sickness | | - |
| - | - | - | Venous Infarction | | - |
| - | - | - | Hypotensive-hypoperfusion | | - |
| - | - | - | Fat embolism | | - |
| - | - | - | Idiopathic | | - |
| - | - | - | Other ischaemic | | - |
| - | **Inflammatory and**  **Auto-immune Diseases** | - | - | | - |
| - | - | Demyelination | - | | - |
| - | - | - | Transverse Myelitis - idiopathic | | - |
| - | - | - | Multiple Sclerosis | | - |
| - | - | - | Neuromyelitis Optica | | - |
| - | - | - | - | | - |
| - | - | Collagen Vascular Disease | - | | - |
| - | - | - | Systemic lupus erythematosis | | - |
| - | - | - | Sjogren’s disease | | - |
| - | - | - | Rheumatoid Arthritis | | - |
| - | - | - | - | | Atlanto-axial instability |
| - | - | - | Ankylosing Spondylitis | | - |
| - | - | - | Vasculitis | | - |
| - | - | - | Other inflammatory | | - |
| - | - | Sarcoidosis | - | | - |
| - | - | Paraneoplastic | - | | - |
| - | - | Arachnoiditis | - | | - |
| - | - | Other inflammatory-immune | - | | - |
| - | - | - | - | | - |
| - | - | Radiation Myelitis | - | | - |
| - | - | - | - | | - |
| - | - | Organophosphates | - | | - |
| - | - | Konzo | - | | - |
| - | - | Lathyrism | - | | - |
| - | - | Pharmacological agents | - | | - |
| - | - | - | Nitrous Oxide | | - |
| - | - | - | Other | | - |
| - | - | Chronic liver disease | - | | - |
| - | - | Other toxic | - | | - |
| - | **Neoplastic** | - | - | | - |
| - | - | Benign | - | | - |
| - | - | - | Primary vertebral lesions | | - |
| - | - | - | - | | Osteoma |
| - | - | - | - | | Osteochondroma |
| - | - | - | - | | Osteoid osteoma |
| - | - | - | - | | Haemangioma |
| - | - | - | - | | Aneurysmal bone cyst |
| - | - | - | Extradural space | | - |
| - | - | - | | - | Lipoma |
| - | - | - | | Intradural (extramedullary) | - |
| - | - | - | | - | Neurofibroma |
| - | - | - | | - | Meningioma |
| - | - | - | | - | Schwannomas |
| - | - | - | | - | Chordoma - benign |
| - | - | - | | Intramedullary | - |
| - | - | - | | - | Astrocytoma - benign |
| - | - | - | | - | Oligodendroglioma |
| - | - | - | | - | Ependymoma |
| - | - | - | | - | Cavernoma |
| - | - | - | | Other benign | - |
| - | - | Malignant | | - | - |
| - | - | - | | Neural | - |
| - | - | - | | - | Chordoma - malignant |
| - | - | - | | - | Astrocytoma - malignant |
| - | - | - | | Primary vertebral lesions | - |
| - | - | - | | - | Osteosarcoma |
| - | - | - | | - | Other |
| - | - | - | | Leptomeningeal disease (not associated with other spinal cord lesions) | - |
| - | - | - | | Secondary vertebral lesions | - |
| - | - | - | | - | Breast |
| - | - | - | | - | Bronchus |
| - | - | - | | - | Lung |
| - | - | - | | - | Prostate |
| - | - | - | | - | Renal |
| - | - | - | | - | Thyroid |
| - | - | - | | - | Ewing's sarcoma |
| - | - | - | | - | Melanoma |
| - | - | - | | - | other |
| - | - | - | | Haematological | - |
| - | - | - | | - | Myeloma |
| - | - | - | | - | Leukaemia |
| - | - | - | | - | Non-Hodgkins Lymphoma |
| - | - | - | | - | Hodgkin's Lymphoma |
| - | - | - | | Other malignant | - |
| - | **Infection** | - | | - | - |
| - | - | Viral | | - | - |
| - | - | - | | Herpes group | - |
| - | - | - | | - | Herpes simplex |
| - | - | - | | - | Herpes zoster |
| - | - | - | | - | Cytomegalovirus (CMV) |
| - | - | - | | - | Epstein Barr |
| - | - | - | | Retrovirus | - |
| - | - | - | | - | Human Immunodeficiency Virus |
| - | - | - | | - | Human T-cell Leukaemia Virus Type1 |
| - | - | - | | - | - |
| - | - | - | | Enterovirus | - |
| - | - | - | | - | Polio virus |
| - | - | - | | - | Coxsackievirus |
| - | - | - | | - | Other enterovirus |
| - | - | - | | Polyomavirus | - |
| - | - | - | | - | John Cunningham virus |
| - | - | - | | Other viruses | - |
| - | - | Bacterial | | - | - |
| - | - | - | | S aureus | - |
| - | - | - | | - | Extradural abscess |
| - | - | - | | - | vertebral ostemyelitis with septic discitis |
| - | - | - | | Strep | - |
| - | - | - | | - | Extradural abscess |
| - | - | - | | - | vertebral ostemyelitis with septic discitis |
| - | - | - | | Other pyogenic | - |
| - | - | - | | - | Extradural abscess |
| - | - | - | | - | vertebral ostemyelitis with septic discitis |
| - | - | - | | Mycobacterium tuberculosis (TB) | - |
| - | - | - | | - | vertebral ostemyelitis with septic discitis |
| - | - | - | | - | Extradural disease |
| - | - | - | | - | Spinal arachnoiditis |
| - | - | - | | - | Intramedullary tuberculoma |
| - | - | - | | - | - |
| - | - | - | | Brucellosis | - |
| - | - | - | | - | Brucella spondylitis |
| - | - | - | | Melioidosis | - |
| - | - | - | | Borreliosis | - |
| - | - | Spirochaetal | | - | - |
| - | - | - | | Treponema pallidum | - |
| - | - | - | | - | Meningomyelitis |
| - | - | - | | - | Vasculitis |
| - | - | - | | - | Gumma |
| - | - | - | | - | Tabes dorsalis |
| - | - | Fungal | | - | - |
| - | - | - | | Cryptococcal | - |
| - | - | - | | Actinomycosis | - |
| - | - | - | | Other fungal | - |
| - | - | Parasitic | | - | - |
| - | - | - | | Cysticercosis | - |
| - | - | - | | Hydatid | - |
| - | - | - | | Toxoplasmosis | - |
| - | - | - | | Schistosomiasis | - |
| - | - | - | | Other parasitic | - |
| - | **Miscellaneous** | - | | - | - |
| - | - | Motor Neurone Disease | | - | - |
| - | - | - | | Amyotrophic lateral sclerosis | - |
| - | - | - | | Primary lateral sclerosis | - |
| - | - | - | | Progressive muscular atrophy | - |
| - | - | Syringomyelia | | - | - |
| - | - | - | | Communicating | - |
| - | - | - | | - | Basilar arachnoiditis |
| - | - | - | | Non-communicating | - |
| - | - | - | | - | Post infectious |
| - | - | - | | - | Post inflammatory |
| - | - | - | | - | Tumour associated |
| - | - | - | | - | Idiopathic |
| - | - | Other miscellaneous diseases not otherwise specified | | - | - |