INTERNATIONAL SPINAL CORD INJURY DATA SET
NON-TRAUMATIC SPINAL CORD INJURY DATA SETS (Version 1.0)

The International Spinal Cord Injury Data Sets for Non-Traumatic Spinal Cord Injury (NTSCI) was developed by Peter New and Ruth Marshall (see New PW, Marshall R. International Spinal Cord Injury Data Sets for Non-Traumatic Spinal Cord Injury. Spinal Cord. In Press). For the terminology of the International Spinal Cord Injury Data sets see Biering-Sørensen el al. The International Spinal Cord Injury Data Set. Spinal Cord 2006;44(9):530-4

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Organisations that have endorsed the International Non-Traumatic Spinal Cord Injury Data Set as of January 23, 2012
International Spinal Cord Society
American Spinal Injury Association

Using the International Non-Traumatic Spinal Cord Injury Data Set
It is advised to practice with the training cases before implementing the International Non-Traumatic Spinal Cord Injury Data Set.
Try first to fill in a blank scoring sheet (see the International Non-Traumatic Spinal Cord Injury Data Set Collection Form), and afterwards check with the filled in scoring-sheet to see if the scoring has been done correctly.
The documentation with explanations for the International Non-Traumatic Spinal Cord Injury Data Set is found in the Introduction to the International Non-Traumatic Spinal Cord Injury Data Set.

The training cases have been contributed by Dr Peter New, Dr Ruth Marshall and Dr Ronald Reeves. The training cases were proof read by Dr William McKinley, Dr Claire Weeks and Dr Peter Wing.

Questions and suggestions regarding the International Non-Traumatic Spinal Cord Injury Data Set should be directed to Peter New p.new@cgmc.org.au or Ruth Marshall Ruth.Marshall@health.sa.gov.au

INTERNATIONAL SPINAL CORD INJURY DATA SETS

NON-TRAUMATIC SPINAL CORD INJURY DATA SETS (Version 1.0) – DATA FORM

BASIC DATA SET

Date performed: YYYYMMDD □ Unknown

Classification of aetiology of Non-Traumatic Spinal Cord Injury (NTSCI):
Axis 1
Level 1 Level 2
_____ _____

EXTENDED DATA SET

Date performed: YYYYMMDD □ Unknown

Timeframe of onset of NTSCI: □ acute (≤ 1 day) □ sub-acute (> 1 day but ≤ 7 days)
□ prolonged (> 7 days but ≤ month) □ lengthy (> 1 month)

Iatrogenic role in aetiology: □ yes □no □ Unknown

Classification of aetiology of NTSCI:
Axis 1
Level 1 Level 2 Level 3 Level 4 Level 5
_____ _____ _____ _____ _____

Axis 2:
ICD version: __ __

ICD codes:

__ __ __ __ __ __ __ __ __ __ __ __ __ __ __
Letter Numerical code Letter Numerical code Letter Numerical code

Classification of the aetiology of Non-Traumatic Spinal Cord Injury – Axis 1

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 Related			
	Radiation Myelitis		
Toxic			
	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		

INTRODUCTION TO THE INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS

It is well known that damage to the neural elements in the spinal canal (spinal cord and cauda equina) resulting in resolving or permanent neurological deficit can arise from many causes other than trauma. Although there is no universally accepted term for spinal cord damage not due to trauma (often referred to as non-traumatic spinal cord injury [NTSCI] – but better alternatives may be 'spinal cord damage' or 'spinal cord myelopathy') this field is an important aspect of spinal cord medicine. International consensus on a classification system for NTSCI is essential in order to have good epidemiological studies, prevention, treatment, and outcomes research and to facilitate comparative studies across different settings.

One of items in the International SCI Core Data Set is the aetiology of the SCI. The Core Data Set classifies the aetiology of SCI into 7 categories. One of these is NTSCI. There is, however, no further sub-categorization of the numerous possible causes of NTSCI within the Core Data Set. The International Data Sets for NTSCI includes a classification system for the aetiology of NTSCI.

We have presented the classification system in such a way that allows a degree of flexibility that we feel achieves the necessary balance for the multiple potential users. We have presented here the content of both the Basic and Extended NTSCI Data Sets.

VARIABLE NAME: Date of collection

DESCRIPTION: This variable documents the date of data collection

CODES: YYYYMMDD
Unknown

COMMENTS: This collection of data on non-traumatic spinal cord injury may be carried out at any time after the spinal cord injury.
Therefore the date of data collection is imperative to be able to identify the data collected in relation to other data collected on the same individual at various time points. In addition, the date is likewise important to calculate the time interval from date of birth (age), and time interval from date of spinal cord injury (time since lesion).

VARIABLE NAME: Timeframe of onset of NTSCI.

DESCRIPTION: This variable specifies the timeframe over which the clinical features of non-traumatic spinal cord injury developed. It does not relate to the timeframe associated with the period following diagnosis of NTSCI.

CODES: acute (≤ 1 day)
sub-acute (> 1 day but ≤ 7 days)
prolonged (>7 days but ≤ month)
lengthy (> 1 month)

COMMENTS: In many cases of non-traumatic spinal cord the timeframe for the onset is not instantaneous as typically is the case with traumatic spinal cord injury. Some diseases that cause NTSCI can have an onset of symptoms of minutes (e.g. cord infarction), hours (e.g. transverse myelitis), days (e.g. spinal abscess) or weeks to months (e.g. spinal canal stenosis). The timeframe over which the clinical features developed which are attributable to the onset of the non-traumatic spinal cord injury should be recorded.

No specific internationally recognised classification for the timeframes of disease symptom onset has been located. The specific time periods are indicated so that there will be consistency in classification of this item. The time periods are chosen to match the typical periods seen in various NTSCI aetiologies. The terms chosen are descriptive only and it is suggested that they would be useful in reporting results in the text of manuscripts that choose to report this item.

VARIABLE NAME: Iatrogenic role in aetiology.

DESCRIPTION: This variable specifies whether there was the presence of iatrogenicity in the aetiology of the non-traumatic spinal cord injury.

CODES: yes
no
unknown

COMMENTS: 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 (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 tumour causing NTSCI with neurological symptoms and signs due to spinal cord compression (from the tumour), the spinal cord damage can worsen as a result of radiotherapy, chemotherapy or surgery carried out in an attempt to treat the tumour. 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 aetiology 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 standardise 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.

VARIABLE NAME: Classification of aetiology of NTSCI – Axis 1

DESCRIPTION: Cause of non-traumatic SCI.

CODES: Aetiology of NTSCI is indicated in the accompanying table. If the aetiology is being classified in a project to a level of detail that does not have any corresponding item in the table for that aetiology then 'NA' (not applicable) should be entered to indicate that the detail is not missing.

COMMENTS: 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 aetiology. The Basic Data Set codes the aetiology of NTSCI using Levels 1 and 2 of Axis 1. The Extended Data Set can code the aetiology 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. Aetiology 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 aetiological process responsible for the NTSCI.

<u>Classification principles</u>

- Only one single aetiology is coded for any case.
- If a patient has NTSCI 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 aetiology 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 aetiology listed in the classification, then this specific cause is coded. The transverse myelitis aetiology is only selected where the cause is idiopathic.

In developing the classification system, it was realised that there were a number of approaches that could be taken regarding how to classify certain groups of conditions that cause NTSCI, in particular, a number of conditions in the genetic group and Motor Neurone Disease. We recognize that a number of different classification systems for these conditions are in use. The approach taken here was to develop a classification that is believed to be the most appropriate for spinal cord medicine settings. It was also desired to develop a classification that could also be used in countries with constraints on resources, particularly regarding genetic testing. In addition, for the various causes we identified, it was decided to group conditions in a way that would help direct preventative strategies, where these are possible. Furthermore, some level 3 and 4 conditions could potentially be further sub-divided, but this was deliberately not done for those that are rare in spinal cord medicine settings.

VARIABLE NAME: Axis 2: ICD version

DESCRIPTION: ICD version used to classify triggering diseases or process that eventuated in the NTSCI

CODES:
09
10
11
00

COMMENTS: Diseases or processes can be coded using the International Statistical Classification of Diseases and related Health Problems (ICD). (http://www.who.int/classifications/icd/en/). Some countries are still using the 9th edition of the ICD, but most are using the 10th edition. An 11th edition is currently at the planning stage. This coding is only used where the axis 1 classification does not include relevant detail regarding processes or diseases that had a role in the aetiology.

09 is used to indicate that the 9th edition of the ICD was used to code aetiology of the NTSCI

10 is used to indicate that the 10th edition of the ICD was used to code aetiology of the NTSCI

11 is used to indicate that the 11th edition of the ICD was used to code aetiology of the NTSCI (when it is finalised)

00 is used to indicate that no coding of triggering diseases or processes was undertaken

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VARIABLE NAME: Axis 2: ICD codes

DESCRIPTION: ICD codes are used to classify triggering diseases or process that eventuated in the NTSCI.

CODES:
Letter code:
Numerical code:

COMMENTS: In some circumstances NTSCI can be caused by a cascade of events. For these situations, and if it is desired to collect this level of detail, Axis 2 is proposed to document the triggering diseases or processes indirectly responsible for the NTSCI using the relevant ICD codes. It is suggested that up to 3 disease processes could be recorded, if relevant, to code the initiating event(s) that resulted in the NTSCI. This coding is only used where the axis 1 classification does not include relevant detail regarding processes or diseases that had a role in the aetiology.

The ICD codes for diseases comprise of a letter and numerical component. These should be entered as appropriate and indicated.

CASES FOR TRAINING OF THE INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS

CASE 1 FOR NON-TRAUMATIC SPINAL CORD INJURY DATA SET TRAINING

25 year old man with type 2 diabetes mellitus and morbid obesity was admitted to hospital with a hyperosmolar non-ketotic coma. He was transferred to the intensive care unit. He had a prolonged period of hypotension lasting several hours before inotrope support was effective in restoring his blood pressure to an adequate level. Other resuscitation measures were also implemented and effective in stabilising his condition over the first 12 – 18 hours following admission.

The day after admission in the afternoon he started to regain consciousnesses. It was subsequently observed that he was not moving his legs. On examination the tone was reduced, reflexes were absent, and there was no response to painful stimuli. A MRI scan with Gadolinium contrast was performed of his spinal cord and brain that revealed findings consistent with a spinal cord infarction in the anterior portion of the spinal cord in the region from T8 to the conus.

INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS – FORM

CASE 1

Date performed: 20110505

Timeframe of onset of NTSCI: acute (≤ 1 day) **X** sub-acute (> 1 day but ≤ 7 days) □ prolonged (> 1 week but ≤ month) □ lengthy (> 1 month) □

Iatrogenic role in aetiology: yes □ no **X** Unknown □

Classification of aetiology of NTSCI:

Axis 1

Level 1	Level 2	Level 3	Level 4	Level 5
Acquired	Vascular	Ischaemia	Hypotensive-hypoperfusion	NA

Axis 2:
ICD version: 10

ICD codes:

E	1 1 0 __ __ __		E	6 6 __ __ __ __			__ __ __ __ __		
Letter	Numerical code		Letter	Numerical code			Letter	Numerical code	

Comments: The obesity and diabetes were felt to be relevant contributing factors and are therefore coded in axis 2.

CASES FOR TRAINING OF THE INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS

CASE 2 FOR NON-TRAUMATIC SPINAL CORD INJURY DATA SET TRAINING

50 year old man with lung cancer presented with 6 days of progressive leg weakness, pain radiating down both legs, and increasing problems with loss of urinary and faecal continence. A month earlier he completed thoracic spine radiation for a T9 metastasis. His examination revealed marked lower extremity weakness, reduced sensation, loss of reflexes, and a flaccid, insensate anal sphincter. MRI of the entire spine with contrast revealed diffuse bone metastases and extensive abnormal enhancement of cauda equina nerve roots and along distal thoracic cord consistent with leptomeningeal carcinomatosis. There was no signal abnormality noted in the thoracic spinal cord.

INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS – FORM

CASE 2

Date performed: 20110523

Timeframe of onset of NTSCI: acute (≤ 1 day) □ sub-acute (> 1 day but ≤ 7 days) **X** prolonged (> 7 days but ≤ month) □ lengthy (> 1 month) □

Iatrogenic role in aetiology: yes □ no **X** Unknown □

Classification of aetiology of NTSCI:

Axis 1

Level 1	Level 2	Level 3	Level 4	Level 5
Acquired	Neoplastic	Malignant	Leptomeningeal disease	Lung

Axis 2:

ICD version: 0 0

ICD codes:

__	__ __ __ __ __	__	__ __ __ __ __	__	__ __ __ __ __
Letter	Numerical code	Letter	Numerical code	Letter	Numerical code

Comments: Nil

CASES FOR TRAINING OF THE INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS

CASE 3 FOR NON-TRAUMATIC SPINAL CORD INJURY DATA SET TRAINING

A 78 year old woman presented to her general practitioner on a number of occasions over a 4 month period complaining of increasing difficulty in walking. She had started using a neighbour's walking frame to help her walk around her house in the previous month. On examination she had an extensor Babinski and abnormally increased reflexes, lower limb power of 4/5 in all muscle groups and 4/5 weakness in both upper limbs involving the biceps, wrist and fingers and abnormally increased biceps reflex. She had a MRI scan performed of her brain and spinal cord which revealed severe canal stenosis at C5 – C6 due to osteophytes and facet joint hypertrophy that was causing cord compression. She had consultation with a neurosurgeon the following day who recommended surgery but she declined.

Three weeks later she was admitted to the emergency department with incontinence of bladder and bowel due to absent awareness and 3/5 in L2-3 bilaterally and 4/5 in distal muscles and 3/5 in C6-T1. She denied any trauma or falls. She agreed to surgery but postoperatively had weakness of 1/5 in L1-4 and 2/5 in distal muscles. A repeat MRI was performed and no cause for the deterioration was apparent. She was admitted to rehabilitation and after 4 months was discharged continent of bladder and bowel and walking with a walking stick.

INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS – FORM

CASE 3

Date performed: 20110715

Timeframe of onset of NTSCI: acute (≤ 1 day) □ sub-acute (> 1 day but ≤ 7 days) □ prolonged (> 7 days but ≤ month) □ lengthy (> 1 month) **X**

Iatrogenic role in aetiology: yes **X** no □ Unknown □

Classification of aetiology of NTSCI:

Axis 1

Level 1	Level 2	Level 3	Level 4	Level 5
Acquired	Vertebral column degenerative disorders	combination of factors	NA	NA

Axis 2:

ICD version: 0 0

ICD codes:

__	__ __ __ __ __	__	__ __ __ __ __	__	__ __ __ __ __
Letter	Numerical code	Letter	Numerical code	Letter	Numerical code

Comments: There was no reported trauma and she had features of spinal cord damage from degenerative canal stenosis prior to the surgery. There are potentially two iatrogenic factors in this case: the passive omission of the general practitioner to respond to her symptoms and the active iatrogenic effect of the surgery. The surgery did exacerbate the spinal damage but it was not the primary cause of her spinal cord injury. Therefore, this case is considered to be non-traumatic but with iatrogenic components.

CASES FOR TRAINING OF THE INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS

CASE 4 FOR NON-TRAUMATIC SPINAL CORD INJURY DATA SET TRAINING

A 65 year old man presented to hospital with a 2 week history of increasing fevers, feeling unwell, left knee pain and increasing weakness in all four limbs . On examination he had a temperature of 38.5 Celsius, C5 AIS C, and a red, hot swollen left knee joint and an associated effusion. He had no history of trauma or surgery in recent months. He reported to drink about 1,500ml of wine a day for a number of years. It was believed that this resulted in immune compromise. On investigation he was found to have multiple septic foci including septic arthritis (left knee). A moderate aortic regurgitation murmur was noted. MRI revealed 2 epidural abscesses, one in the lumbar spine associated with L4/5 discitis which was not compressing the cauda equina and one from C3-C6 causing cord compression. Cord signal was normal. Pus aspirated from the knee grew Staph aureus sensitive to flucloxacillin. Blood cultures also grew this organism. Trans oesophageal echocardiagram did not indicate any septic vegetations. Intravenous antibiotics for 6 weeks followed by 12 months of oral dicloxacillin. Decompression of the cervical epidural abscess was delayed and pus was sterile when cultured. He made an almost full recovery but has been left with a minor gait abnormality requiring a walking stick for community mobility. Cardiac abnormality resolved.

INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS – FORM

CASE 4

Date performed: 20110607

Timeframe of onset of NTSCI: acute (≤ 1 day) □ sub-acute (> 1 day but ≤ 7 days) □ prolonged (>7 days but ≤ month) **X** lengthy (> 1 month) □

Iatrogenic role in aetiology: yes □ no **X** Unknown □

Classification of aetiology of NTSCI:

Axis 1

Level 1	Level 2	Level 3	Level 4	Level 5
Acquired	Infection	Bacterial	Staph Aureus	Extradural abscess

Axis 2:

ICD version: 0 9

ICD codes:

0	3 0 5.0	__	__ __ __ __ __	__	__ __ __ __ __
Letter	Numerical code	Letter	Numerical code	Letter	Numerical code

Comments: The alcohol consumption was felt to be a factor contributing to the development of the abscesses so was coded in axis 2.

CASES FOR TRAINING OF THE INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS

CASE 5 FOR NON-TRAUMATIC SPINAL CORD INJURY DATA SET TRAINING

A 35 year old man with known HIV-AIDS complex disease including previously diagnosed cerebral involvement and only intermittent access to his anti-retroviral medication presented with severe weakness in both lower limbs and sphincter disturbance over a 4 – 6 week period. Upper limbs were normal on examination. History was difficult to obtain but this presentation was thought to be a recurrence based on medical record documentation and no other cause was identified after thorough investigation including lumbar puncture and MRI scan.

Following recommencement of anti-retroviral medication and 2 months of rehabilitation he regained independent gait with 2 elbow crutches and continence. He refused to use a wheelchair for longer distance mobility although this was advised.

INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS – FORM

CASE 5

Date performed: 20110628

Timeframe of onset of NTSCI: acute (≤ 1 day) □ sub-acute (> 1 day but ≤ 7 days) □ prolonged (>7 days but ≤ month) □ lenghty (> 1 month) **X**

Iatrogenic role in aetiology: yes □ no **X** Unknown □

Classification of aetiology of NTSCI:

Axis 1

Level 1	Level 2	Level 3	Level 4	Level 5
Acquired	Infection	Viral	Retrovirus	Human Immunodeficiency Virus

Axis 2:

ICD version: 0.0

ICD codes:

__	__ __ __ __ __	__	__ __ __ __ __	__	__ __ __ __ __
Letter	Numerical code	Letter	Numerical code	Letter	Numerical code

Comments: Nil

CASES FOR TRAINING OF THE INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS

CASE 6 FOR NON-TRAUMATIC SPINAL CORD INJURY DATA SET TRAINING

A 69 year old man presented to hospital with severe abdominal pain. While in the emergency department he collapsed and became unconscious. He was resuscitated and a CT scan revealed a dissecting aortic aneurysm involving the descending aorta, which involving the supra-renal region. He was noted to have flaccid tone in his legs and absent reflexes and was incontinent of urine during the course of his resuscitation. He had an urgent repair of the aneurysm but had persisting AIS A paraplegia despite rehabilitation.

INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS – FORM

CASE 6

Date performed: 20110206

Timeframe of onset of NTSCI: acute (≤ 1 day) **X** sub-acute (> 1 day but ≤ 7 days) □ prolonged (>7 days but ≤ month) □ lengthy (> 1 month) □

Iatrogenic role in aetiology: yes □ no **X** Unknown □

Classification of aetiology of NTSCI:

Axis 1

Level 1	Level 2	Level 3	Level 4	Level 5
Acquired	Vascular	Ischaemia	Aortic Dissection	NA

Axis 2:

ICD version: 0.0

ICD codes:

__	__ __ __ __ __	__	__ __ __ __ __	__	__ __ __ __ __
Letter	Numerical code	Letter	Numerical code	Letter	Numerical code

Comments: The clinical presentation given above describes the onset of paraplegia due to the aortic aneurysm dissection. This particular case is not iatrogenic.

Similar clinical features of paraplegia due to a spinal cord infarction can arise following elective or emergency aneurysm repair. In these situations, however, the case would be considered to be a traumatic SCI, because there were no clinical features of spinal cord damage prior to the surgery. Therefore, this situation would not be coded using this dataset.

CASES FOR TRAINING OF THE INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS

CASE 7 FOR NON-TRAUMATIC SPINAL CORD INJURY DATA SET TRAINING

A 24 year old woman presented with gradual onset of leg weakness, more so on the left than right, over a period of 2 – 3 weeks. Investigations revealed an arterio-venous malformation (AVM) in the T12 – L1 region. She had endo-vascular embolisation but immediately post-operatively had worsening of her leg weakness, spasm and incontinence. A MRI scan showed no abnormality apart from the residual AVM.

INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS – FORM

CASE 7

Date performed: 20110504

Timeframe of onset of NTSCI: acute (≤ 1 day) □ sub-acute (> 1 day but ≤ 7 days) □ prolonged (>7 days but ≤ month) **X** lengthy (> 1 month) □

Iatrogenic role in aetiology: yes **X** no □ Unknown □

Classification of aetiology of NTSCI:

Axis 1

Level 1	Level 2	Level 3	Level 4	Level 5
Acquired	Vascular	Vascular Malformations	Arterio-vascular malformation	NA

Axis 2:

ICD version: 0 0

ICD codes:

__	__ __ __ __ __	__	__ __ __ __ __	__	__ __ __ __ __
Letter	Numerical code	Letter	Numerical code	Letter	Numerical code

Comments: The case describes a clinical situation where there where features of spinal cord damage prior to the medical treatment. There was a clear iatrogenic component, but this was on the background of an existing pathological process causing spinal cord damage. Therefore, this case is considered to be non-traumatic with an iatrogenic component.

CASES FOR TRAINING OF THE INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS

CASE 8 FOR NON-TRAUMATIC SPINAL CORD INJURY DATA SET TRAINING

A 69 year old man with chronic atrial fibrillation managed with warfarin developed a viral respiratory tract infection. After about 5 days he had a sudden onset of back pain over a few minutes after sneezing while seated and subsequently collapsed.

He was taken to hospital where he was found to have an AIS D T9 paraplegia. Investigations revealed a large epidural haematoma extending from T10 – T12. His prothrombin time (International Normalized Ratio) was elevated excessively. This was corrected and the haematoma evacuated.

INTERNATIONAL NON-TRAUMATIC SPINAL CORD INJURY DATA SETS – FORM

CASE 8

Date performed: 20110131

Timeframe of onset of NTSCI: acute (≤ 1 day) **X** sub-acute (> 1 day but ≤ 7 days) □ prolonged (>7 days but ≤ month) □ lengthy (> 1 month) □

Iatrogenic role in aetiology: yes **X** no □ Unknown □

Classification of aetiology of NTSCI:

Axis 1

Level 1	Level 2	Level 3	Level 4	Level 5
Acquired	Vascular	Haemorrhage	Epidural Haematoma	Medication

Axis 2:

ICD version: 10

ICD codes:

I	48	Y	44.2	__	__ __ __ __ __
Letter	Numerical code	Letter	Numerical code	Letter	Numerical code

Comments: This case is clearly iatrogenic. The warfarin was directly responsible for the haematoma and SCI. This case would be considered as a trauma by strictly applying the ICECI classification. However, although there was an external cause, there is no force involved in the aetiology of his SCI. It is felt that this clinical scenario is more appropriate for classification as a NTSCI.