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

INTERNATIONAL SPINAL CORD INJURY DATA SETS

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

TABLE #1

BASIC DATA SET

Date performed: YYYYMMDD Unknown NTSCIDT

Classification of aetiology of Non-Traumatic Spinal Cord Injury (NTSCI):
Axis 1
Level 1 Level 2
NTSCILV1 NTSCILV2

EXTENDED DATA SET

Date performed: YYYYMMDD □ Unknown NTSCIDT

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

Iatrogenic role in aetiology: □ yes □no □ Unknown IATROGEN

Classification of aetiology of NTSCI:
Axis 1
Level 1 Level 2 Level 3 Level 4 Level 5
NTSCILV1 NTSCILV2 NTSCILV3 NTSCILV4 NTSCILV5

Axis 2:
ICD version: __ __ NTSCICDV

ICD codes:
__ __ __ __ __ __ __ NTSCICD1 __ __ __ __ __ __ __ NTSCICD2 __ __ __ __ __ __ __ NTSCICD3
Letter Numerical code Letter Numerical code Letter Numerical code

Proposed 8 Character Variables:	NON-TRAUMATIC SPINAL CORD INJURY BASIC AND EXTENDED DATA SETS - TABLE #1					
	NON-TRAUMATIC SPINAL CORD INJURY BASIC DATA SET					
	NON-TRAUMATIC SPINAL CORD INJURY EXTENDED DATA SET					
Data Element	Site	Subject	Date performed	Classification of aetiology of Non-Traumatic Spinal Cord Injury (NTSCI)- Axis 1- Level 1:	Classification of aetiology of Non-Traumatic Spinal Cord Injury (NTSCI)- Axis 1- Level 2:	Classification of aetiology of Non-Traumatic Spinal Cord Injury (NTSCI)- Axis 1- Level 3:
Format/ Codes			99999999 = Unknown	CONGENITAL; GENETIC DISORDERS; ACQUIRED ABNORMALITIES; NA	[Refer to Level 2 accepted codes on Aetiology worksheet] NA	[Refer to Level 3 accepted codes on Aetiology worksheet] NA
Variable	SITE	SUBJECT	NTSCIDT	NTSCILV1	NTSCILV2	NTSCILV3
Comments	**KEY**	**KEY**	**KEY**	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.	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.	Collected ONLY for NTSCI Extended Data Sets 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.
				Should refer to the Aetiology Classification Table. Provide for reference in 'Aetiology Classifications Table' tab. Please refer to ISCoS web site for the most accurate classifications.	Should refer to the Aetiology Classification Table. Provide for reference in 'Aetiology Classifications Table' tab. Please refer to ISCoS web site for the most accurate classifications.	Should refer to the Aetiology Classification Table. Provide for reference in 'Aetiology Classifications Table' tab. Please refer to ISCoS web site for the most accurate classifications.

Proposed 8 Character Variables:	NON-TRAUMATIC SPINAL CORD INJURY BASIC AN										
	NON-TRAUMATIC SPINAL CORD INJURY BASIC DAT										
	NON-TRAUMATIC SPINAL CORD INJURY EXTENDED										
Data Element	Site	Subject	Date performed	Classification of aetiology of Non-Traumatic Spinal Cord Injury (NTSCI)- Axis 1- Level 4:	Classification of aetiology of Non-Traumatic Spinal Cord Injury (NTSCI)- Axis 1- Level 5:	Timeframe of onset of NTSCI:	Iatrogenic role in aetiology:	Axis 2-ICD version:	ICD code #1	ICD code #2	ICD code #3
Format/ Codes			99999999 = Unknown	[Refer to Level 4 accepted codes on Aetiology worksheet] NA	[Refer to Level 5 accepted codes on Aetiology worksheet] NA	acute (≤ 1 day); sub-acute (> 1 day but ≤ 7 days); prolonged (> 7 days but ≤ month); lengthy (> 1 month)	Yes; No; Unknown	09; 10; 11; 00	Alphanumeric: Letter followed by up to 5 numbers	Alphanumeric: Letter followed by up to 5 numbers	Alphanumeric: Letter followed by up to 5 numbers
Variable	SITE	SUBJECT	NTSCIDT	NTSCILV4	NTSCILV5	NTSCIOTM	IATROGEN	NTSCICDV	NTSCICD1	NTSCICD2	NTSCICD3
Comments	**KEY**	**KEY**	**KEY**	Collected ONLY for NTSCI Extended Data Sets 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.	Collected ONLY for NTSCI Extended Data Sets 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.	Collected ONLY for NTSCI Extended Data Sets	Collected ONLY for NTSCI Extended Data Sets	Collected ONLY for NTSCI Extended Data Sets	If ICD Letter code is collected then MUST have ICD Numeric code collected Collected ONLY for NTSCI Extended Data Sets		If ICD Numeric code is collected then MUST have ICD Letter code collected Collected ONLY for NTSCI Extended Data Sets
				Should refer to the Aetiology Classification Table. Provide for reference in 'Aetiology Classifications Table' tab. Please refer to ISCoS web site for the most accurate classifications.	Should refer to the Aetiology Classification Table. Provide for reference in 'Aetiology Classifications Table' tab. Please refer to ISCoS web site for the most accurate classifications.						

Aetiology Classification Table

Level 1	Level 2	Level 3	Level 4	Level 5
CONGENITAL	Spinal Dysraphism	Spina bifida occulta Myelomeningocoele Tethered cord syndrome Spinal dysraphism - other	Lipomeningocoele Anterior sacral meningocoele Diastometamyelia Hypertrophied filum terminale	
	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 Atlanto-axial instability (Down's Syndrome) Achondroplasia Muco-polysaccharididosis Klippel-Feil syndrome Osteogenesis Imperfecta Lumbosacral agenesis Other congenital skeletal malformations	Os odontoideum Hypoplastic dens Laxity of transverse atlantal - ligament	
	Other congenital	Congenital Syringomyelia		
GENETIC DISORDERS	Hereditary spastic paraparesis	HSP pure HSP complicated		
	Spino-cerebellar ataxias	Dominant Recessive	Specified Unspecified Friedreich's Other recessive spinocerebellar ataxias - genetically confirmed/identified Presumed recessive spinocerebellar ataxias - genetic type undetermined	
	Adreno-myeloneuropathy			
	Other leukodystrophies			
	Spinal muscular atrophies	Dominant Recessive	Specific genetic types Unspecified genetic subtype	
	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 Spinal cord compression due to combination of multiple developmental and/or acquired factors listed above Other vertebral column degenerative disorders	Idiopathic Acromegaly Fluorosis Lipomatosis	
	Metabolic Disorders	Deficiency Osteoporosis Paget's Disease Osteomalacia Other metabolic	Vitamin B12 deficiency Folate deficiency Copper deficiency Rickets Other deficiency	
	Vascular Disorders	Haemorrhage Vascular Malformations Ischaemia	Epidural Haematoma Other haemorrhage Dural arterio-venous (AV) fistula Arterio-venous malformation (AVM) with or without haemorrhage Atherosclerosis Aortic Dissection Takayasu's arteritis Atheromatous emboli Thromboemboli Fibrocartilaginous emboli Decompression sickness Venous Infarction Hypotensive-hypoperfusion Fat embolism Idiopathic Other ischaemic	Bleeding Diathesis Medication Other
	Inflammatory and Auto-immune Diseases	Demyelination Collagen Vascular Disease Sarcoidosis Paraneoplastic Arachnoiditis Other inflammatory-immune	Transverse Myelitis - idiopathic Multiple Sclerosis Neuromyelitis Optica Systemic lupus erythematosis Sjogren's disease Rheumatoid Arthritis Ankylosing Spondylitis Vasculitis Other inflammatory	Atlanto-axial instability
	Radiation Related	Radiation Myelitis		
	Toxic	Organophosphates Konzo Lathyrism Pharmacological agents	Nitrous Oxide Other	

Level 1	Level 2	Level 3	Level 4	Level 5
		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		