Spinal Cord (2014) 52, 123–132

www.nature.com/sc

ORIGINAL ARTICLE

International Spinal Cord Injury Data Sets for non-traumatic spinal cord injury

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Study design: Multifaceted: extensive discussions at workshop and conference presentations, survey of experts and feedback.
Objectives: Present the background, purpose and development of the International Spinal Cord Injury (SCI) Data Sets for Non-Traumatic SCI (NTSCI), including a hierarchical classification of aetiology.
Setting: International.
Methods: Consultation via e-mail, presentations and discussions at ISCoS conferences (2006–2009), and workshop (1 September 2008). The consultation processes aimed to: (1) clarify aspects of the classification structure, (2) determine placement of certain aetiologies and identify important missing causes of NTSCI and (3) resolve coding issues and refine definitions. Every effort was made to consider feedback and suggestions from participants.
Results: The International Data Sets for NTSCI includes basic and an extended versions. The extended data set includes a two-axis classification system for the causes of NTSCI. Axis 1 consists of a five-level, two-tier (congenital-genetic and acquired) hierarchy that allows for increasing detail to specify the aetiology. Axis 2 uses the International Statistical Classification of Diseases (ICD) and Related Health Problems for coding the initiating diseases(s) that may have triggered the events that resulted in the axis 1 diagnosis, where appropriate. Additional items cover the timeframe of onset of NTSCI symptoms and presence of iatrogenicity. Complete instructions for data collection, data sheet and training cases are available at the websites of ISCoS (http://www.iscos.org.uk) and ASIA (http://www.asia-spinalinjury.org).
Conclusions: The data sets should facilitate comparative research involving NTSCI participants, especially epidemiological studies and prevention projects. Further work is anticipated to refine the data sets, particularly regarding iatrogenicity.
Spinal Cord (2014) **52,** 123–132; doi:10.1038/sc.2012.160; published online 8 January 2013

Keywords: spinal cord diseases; non-traumatic spinal cord injury; aetiology; classification

INTRODUCTION

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 different causes other than trauma. Although there is no universally accepted term for spinal cord damage not because of trauma[1] (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. NTSCI can occur at any age. It has been reported that the incidence of NTSCI is greater than that of traumatic spinal cord injury (SCI).[2] It is proposed that this is quite likely the case in many countries, especially developed countries, and there is evidence emerging that this is the case.[3] It is anticipated that the incidence of NTSCI will increase greatly in the coming decades because of population aging.[4]

There are many aetiologies of NTSCI reported in the literature.[5,6] Case series that have been published over the years have described the aetiologies of NTSCI using different classification systems.[7–15] It is likely that these authors formulated the classification systems used themselves because there is no consensus international classification system for NTSCI. A consensus classification is essential in order to have good epidemiological studies, prevention, treatment and outcomes research programs and especially to facilitate comparative studies across different settings.

The International SCI Data Sets have standardised the collection and reporting of information regarding SCI patients in order to facilitate comparison of results between different studies.[16] The International SCI Core Data Set describes standardised methods of collection and reporting of minimal information necessary to describe a SCI study population to allow meaningful comparison of study results and an assessment of the study population characteristics and potential sources of bias.[17] One of the items in the core data set is the aetiology of the SCI. The core data set currently classifies the causes of SCI into seven categories. One of these is NTSCI. There is, however, no further sub-categorisation of the numerous possible causes of NTSCI within the core data set. The absence of an agreed classification system for NTSCI has been recognised by ISCoS as an important deficiency.

The aim of this project was to develop an International Data Set for NTSCI, including a classification system for the causes of NTSCI.

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Received 24 January 2012; revised 16 April 2012; accepted 27 April 2012; published online 8 January 2013

MATERIALS AND METHODS

This project commenced in 2005 when the ISCoS International Data Set committee discussed the need for a system of classifying the causes of NTSCI. Over the ensuing years, a number of processes and activities occurred to develop and refine the classification presented here. These included a consultative process involving over 120 key researchers and senior clinicians involved with SCI, focusing on those active in NTSCI and the International Data Set process. This was accomplished using e-mail in three rounds of communication during 2008 and 2009 through an iterative process. Invited participants were informed that they could confer with interested colleagues, or forward on the e-mail to any other potentially interested clinician they were aware of to share an interest or expertise in the topic.

Complementing the above, presentations and discussions occurred at ISCoS conferences in 2006 (Boston), 2007 (Reykjavik), 2008 (Durban) and 2009 (Florence). A half-day workshop was held on 1 September 2008 at the ISCoS conference and a detailed presentation given at a meeting on the International SCI Data Sets in October 2008.[18] Numerous discussions between the authors were held over the course of this project.

A near final draft of the data set was circulated in December 2011 to participants in the development process and the ISCoS and American Spinal Injury Association Executive Committees for final feedback and suggestions.

The consultation processes described above aimed to clarify the following aspects of the data set: overall structure of the classification; placement of certain groupings (for example, vertebral column degenerative disorders, metabolic disorders) and certain specific aetiologies; missing aetiologies; definitions and data variables. During the course of the development of the data set, every effort was made to consider feedback and suggestions from participants.

International classification of external causes of injury

The World Health Organisation (WHO) has developed an International Classification of External Causes of Injury (ICECI)[19] Table 1. This is based on the International Statistical Classification of Diseases (ICD) and Related Health Problems 10th edition codes of external causes (chapter 20).[20] The ICECI directs that iatrogenic injury be considered traumatic. This includes complications of health care, including 'medical or surgical care, unintentionally leading to injury or other harm, acts of omission as well as acts of commission'. As a result of the approach taken by the WHO regarding classification of iatrogenic injury, it was decided that this project should adopt the ICECI as a guiding framework.

RESULTS

The International NTSCI Data Sets are presented in both basic and extended versions, with the common element including a classification of aetiology of NTSCI. The elements of the NTSCI data sets are presented below, and then the components of the basic and extended data sets are outlined.

Table 1 International classification of external causes of injury: complications of heath care

20.1 Adverse effects related to drugs, medicaments or biological substances
20.2 Foreign object left in body during surgical/medical care
20.3 Adverse incidents associated with medical devices in diagnostic/therapeutic use
20.4 Unintentional cut, puncture, perforation during surgical/medical care
20.5 Failure of sterile precaution during surgical/medical care
20.6 Abnormal reaction of the patient or later complication caused by surgical operations or other surgical/medical procedures, without mention of mis-adventure at the time of the procedure, not elsewhere classified
20.7 Non-administration of surgical/medical care
20.8 Other specified complication of health care
20.9 Unspecified complication of health care

Classification of NTSCI aetiology

In the extended data set, a detailed classification for NTSCI aetiology was developed that consists of two axis. Axis 1 provides a hierarchical classification of NTSCI using clinical classes and pathophysiological mechanisms in two major tiers: 'congenital–genetic' and 'acquired' Table 2. Five levels are provided within the axis 1 to allow for an increasing level of detail to be recorded about the aetiology. In some circumstances, NTSCI can be caused by a cascade of events. It is intended that the axis 1 be used to classify the final aetiological process responsible for the NTSCI.

A number of classification principles were developed to assist those using this data set. In addition to the case studies that are available on the ISCoS website, which provide useful guidance and an explanation of approaches to dealing with a number of scenarios, the following principles for classifying the aetiology are offered:

- Only one aetiology is coded for each case.
- If a patient has an NTSCI lesion that occurs as a result of different causes during the course of the same admission then the condition that causes the most severe neurological impairment is the condition that should be classified. For example, a patient that had a mild thoracic myelopathy from a meningioma, then while in rehabilitation the patient had an epidural bleed from subcutaneous heparin for deep venous thrombosis prevention. The myelopathy was much worse after the bleed. In this case, because the epidural bleed was the more severe causative factor it should be the one coded as the NTSCI aetiology, although the meningioma was indirectly responsible (could be coded as axis 2, if extended data set is used, see below).
- If a patient has a single-cause of NTSCI that could possibly be placed in two (or more) different aetiological groups in the classification then the more specific aetiology should be selected. For example, 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 because of 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.

Where NTSCI is caused by a cascade of events and if it is desired to collect this level of detail, a second axis, axis 2, is available to document the triggering diseases or processes using the ICD.[20] It is suggested that up to three disease processes could be recorded, if relevant, to code the initiating event(s) that resulted in the NTSCI. Currently, most countries use the 10th edition of the ICD, but a few, most notably the USA, are still using the 9th edition. An 11th edition is also in the planning phase. Therefore, the version of the ICD used should also be indicated in the data collection process.

Timeframe of onset of NTSCI

In NTSCI, the date of onset is not always clear, which is different to the situation in most cases of traumatic SCI. In many cases of NTSCI, the timeframe of the onset of neurological damage is not instantaneous as typically is the case with traumatic SCI. Some diseases that cause NTSCI can have an onset of symptoms over minutes (for example, cord infarction), hours (for example, transverse myelitis), days (for example, spinal abscess) or weeks to months (for example,

Table 2 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 paraplegia			
		Hereditary spastic paraplegia pure		
		Hereditary spastic paraplegia complicated		
	Spino-cerebellar			
		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			

Table 2 (Continued)

Level 1	*Level 2*	*Level 3*	*Level 4*	*Level 5*
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 because of 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 AV fistula	
			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		

Table 2 (Continued)

Level 1	*Level 2*	*Level 3*	*Level 4*	*Level 5*
			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	

Table 2 (Continued)

Level 1	*Level 2*	*Level 3*	*Level 4*	*Level 5*
				Myeloma
				Leukaemia
				Non-Hodgkins Lymphoma
				Hodgkin's lymphoma
			Other malignant	
	Infection			
		Viral		
			Herpes group	
				Herpes simplex
				Herpes zoster
				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		
			Staph aureus	
				Extradural abscess
				Vertebral ostemyelitis septic discitis
			Streptococcal	
				Extradural abscess
				Vertebral ostemyelitis with septic discitis
			Other pyogenic	
				Extradural abscess
				Vertebral ostemyelitis with septic discitis
			Mycobacterium 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			

Table 2 (Continued)

Level 1	*Level 2*	*Level 3*	*Level 4*	*Level 5*
		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		

Abbreviations: AV, arterio-venous; AVM, AV malformation; CMV, cytomegalovirus; TB, tuberculosis.

spinal canal stenosis). The pattern of the timeframe of NTSCI onset should be documented in the extended NTSCI data set. It is recommended that the timeframe over which clinical symptoms developed, which are attributable to the onset of the NTSCI be coded as either: acute ($\leqslant$1 day), sub-acute ($>$1 day but $\leqslant$7 days), prolonged ($>$7 days but $\leqslant$1month) or lengthy ($>$1 month). This information has relevance for prevention and treatment programs and clinical trials.

No specific internationally recognised classification for the timeframes of disease symptom onset has been located. The time periods are included along with descriptor terms so that there will be consistency in classification of this item. They were selected to match the typical time periods of onset 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 the manuscripts that choose to report this item.

Iatrogenic role in aetiology of NTSCI

Iatrogenic SCI occurring in the setting of health care is not uncommon, with one recent study reporting the proportion was 10% of all patients with SCI.[21] These cases of iatrogenic SCI should be coded to indicate the presence of this factor in the aetiological process (see Discussion section). The potential to prevent NTSCI is likely to be different in these cases, and the approaches to prevention required will also be quite different.

Basic and extended NTSCI data set

Both the basic and extended data sets are presented here because of the relatively small amount of detail needed to describe them. It is suggested that the classification of the aetiology of NTSCI can be performed at either a Basic or Extended level of detail Table 3.

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 possible further three levels, that is, levels 3–5. It is suggested that the number of levels used in any project be determined by the investigators based on the aims of the project. Researchers should list the most common aetiologies in their Table 1 of results. 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 (that is, 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.

The extended data set, in addition, includes axis 2 coding of triggering diseases or processes indirectly responsible for the NTSCI using the ICD. This coding is only used where the axis 1 classification does not include the process or disease that had a role in the aetiology. The coding of the timeframe of the pattern of onset of NTSCI symptoms and presence of iatrogenicity are also included in the extended data set. A copy of the data collection forms for the data set appears in the Appendix (Tables A1 and A2).

DISCUSSION

Data sets that include a classification for NTSCI have been developed. It is proposed that this should be used in all research involving this group of patients. During the development of the data sets, and particularly of the classification, it became apparent that the needs of potential users varied widely. In particular, some users wanted a detailed system while others indicated the need for a simple approach. For this reason, we have developed the classification system in such a way that it allows a degree of flexibility for potential users regarding the amount of specificity with which the aetiology is coded that we feel achieves the necessary balance.

Classification of NTSCI

In developing the classification system, it was realised that there were a number of approaches that could be utilised for classifying certain groups of conditions that constitute NTSCI, in particular, a number of conditions in the genetic and motor neurone disease groups. We recognise 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.

Table 3 Summary of components in the NTSCI data set

NTSCI basic data set	*NTSCI extended data set*
Axis 1: levels 1–2	Axis 1: levels 1–3, 4 or 5 Axis 2: ICD triggering diseases or processes
Data onset NTSCI (included in core SCI data set)	Date onset NTSCI (included in core SCI data set) Timeframe of the onset of clinical features of NTSCI Iatrogenic role in aetiology of NTSCI

Abbreviations: ICD, International Statistical Classification of Diseases; NTSCI, non-traumatic SCI; SCI, spinal cord injury.

It is suggested that consideration be given to including the basic data set for acquired NTSCI classification into the core data set in future revisions. It is also acknowledged that the extended data set classification is comprehensive and presents a challenge for data collection. It is planned, therefore, to develop a database proforma for the classification that could be made available via the ISCoS and spinal cord web sites to facilitate data collection.

Date of onset of NTSCI

Information on the date of onset of SCI is vital to an understanding of some research findings and is a component of the core data set.[17] In the core data set if the exact date is not known, then the year, and if known, the month, should be recorded. In recording the date of onset for patients with NTSCI, it is proposed that the date of onset should be considered to be that date, which based on the patients' history, was consistent with the onset of the neurological symptoms that were shown subsequently to be due to NTSCI. Rather than have a separate element in the NTSCI data set, it is suggested that the onset date in the core data set be modified to include the above proposed qualification. This suggestion will need to be considered by the data set committee of ISCoS, and included in a revision of the core data set.

Iatrogenic SCI

A major challenge in developing the data sets was dealing with iatrogenic causes of SCI. There were two schools of thought regarding this issue. One group, including us, felt that these conditions should be included in the NTSCI classification system if there was no direct external force involved. It was suggested that a prefix be used to indicate the occurrence of an iatrogenic component—either in the axis 1 classification or as a separate data field—for when iatrogenicity was a contributing factor in SCI. The other group highlighted the approach taken by the ICECI, and advocated strongly the need to follow their standard. Given that ICECI system was already being utilised in other areas of injury research, ultimately the decision was made to use the ICECI approach.

There are a number of concerns, however, that have been expressed regarding the use of the ICECI framework to classify all iatrogenic SCIs as traumatic. The following three clinical scenarios illustrate these concerns.

(1) In patients with a tumour-causing NTSCI, with neurological symptoms and signs because of spinal cord compression (from the tumour), the spinal damage can worsen as a result of radiotherapy, chemotherapy or surgery carried out in an attempt to treat the tumour.
(2) 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.
(3) In cases of a bacterial epidural abscess-causing spinal cord compression, there may be a known incident such as an animal scratch, trauma or surgical wound that results in an infection, immune suppression for a medical condition, which is a contributing factor, or cases in which a cause for the infection is never found.

The first and second examples could be classified as iatrogenic, but this is misleading in terms of aetiology if they were considered to be traumatic. SCI trauma prevention would have no impact on the occurrence of these types of SCI. The pathological process is not traumatic in these. Furthermore, most SCI intervention trials would not include these patients as having a traumatic SCI.

In the third example, there are few if any differences in outcome between an epidural abscess case for which no cause is found; a case that occurred following immune suppression for a medical condition; or a surgical wound, a fall or animal scratch (that is, a trauma) that resulted in a known skin break, which became infected and progressed to septicaemia and a subsequent epidural abscess?

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 the above three 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 NTSCI cases, and the influence of legal and cultural factors. It was believed that it would not be appropriate to use the Delphi process to attempt a definitive consensus approach. It is recommended that, in using this data set 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 (that is, 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 in the extended data set the iatrogenic component is indicated as being present.

The authors recommend that further work on refining the approach to the iatrogenic issue is needed in order to refine the classification of NTSCI (and, by implication, traumatic SCI). This process should involve key stakeholders, including the ISCoS, WHO ICECI subcommittee, traumatic SCI researchers, taxonomistis and nosologists. During the early phase of this project, including the

workshop at ISCoS 2008 and the preceding round of e-mail consultation, it had been proposed to include an item in the Data Sets on whether the NTSCI was progressive or not. There were very strong and opposing opinions expressed, both in favour and against this. It was decided to omit classifying NTSCI as progressive or not from this version of the Data Set in order to assist in facilitating acceptance. The need to consider classifying NTSCI in this way has recently been highlighted.[22] This is an additional issue that will need to be revisited in future revisions of these Data Sets.

In addition, a validation study of the classification system and refinement of key criteria and principles used in the classification may also be appropriate.

Limitations

Limitations to these data sets are the lack of basis is classify some[22] NTSCI conditions, in particular the subjectivity involved in considering what is an iatrogenic SCI. There will be some limitations in certain settings regarding the availability of certain investigations necessary to determine the precise aetiology of SCI. This is not a limitation of the data sets *per se*, but it does create a restriction in settings with resource limitations on the precision with which the aetiology can be specified, and thereby use the extended data set levels.

CONCLUSION

It is suggested that the basic data set be used for routine data collection and the extended version for comprehensive research projects, at the discretion of the study investigators. It is proposed that these data sets be reviewed three years after publication. The major advantage of this data set is that it provides a common language for clinicians and researchers in SCI medicine. The developers hope that it will be useful for both outcomes research and preventive programs.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

There are many people who participated in the consultative process that assisted us in developing this data set. We thank the more than 120 people who provided suggestions and feedback in the rounds of e-mail discussion and the participants at a workshop held at the 2008 ISCoS meeting in Durban, South Africa. We would especially thank Dr Claire Weeks (Division of Rehabilitation Medicine, University of British Columbia, Vancouver, Canada), Professor Peter Wing (Division of Spine, University of British Columbia, and Rick Hansen Institute, Canada), Dr Ronald Reeves (Department of Physical Medicine and Rehabilitation, Mayo Clinic College of Medicine, Rochester, MN, USA) and Professor Ahmad Bhigjee (Department of Neurology, Nelson R Mandela School of Medicine, Inkosi Albert Luthuli Central Hospital, Mayville, South Africa) for their participation in the workshop. Mr Tim Muecke provided assistance with workshop management and information technology. Dr Bonne Lee (Spinal Medicine Department, Prince of Wales Hospital, Sydney, New South Wales, Australia), Dr Marcel Post (Centre of Excellence in Rehabilitation Medicine, Rehabilitation Centre De Hoogstraat, Utrecht, The Netherlands) and especially Dr Ronald Reeves, are thanked for providing constructive suggestions on near final drafts of the data sets. Professor Elsdon Storey (Professor of Neuroscience and Director, Van Cleef Roet Centre for Nervous diseases, Monash University, and Head, Neurology Unit, Alfred Hospital, Melbourne, Australia) and Professor Ahmad Bhigjee are thanked for their valuable assistance with refining aspects of the classification.

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APPENDIX

Table A1. International spinal cord injury data sets. Non-traumatic spinal cord injury data form

Date performed:	YYYYMMDD		Unknown	
Timeframe of onset of NTSCI: (select one that best applies) ☐ Acute (⩽1 day) ☐ Sub-acute (⩽1 week) ☐ Prolonged (>1 week—month) ☐ Lengthy (>1 month)				
Classification of aetiology of NTSCI:				
Axis 1				
Level 1	Level 2	Level 3	Level 4	Level 5

(Continued)

Axis 2:					
ICD version:					
ICD codes					
Letter	Numerical code	Letter	Numerical code	Letter	Numerical code

Table A2. Basic data set

Date performed:	YYYYMMDD	Unknown
Classification of aetiology of NTSCI:		
Axis 1		
Level 1	Level 2	