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International Spinal Cord Injury Core Data Set (version 3.0)— including standardization of reporting

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STUDY DESIGN: Expert opinion, feedback, revisions and final consensus.
OBJECTIVES: To update the International Spinal Cord Injury (SCI) Core Data Set while still retaining recommended standardization of data reporting.
SETTING: International.
METHODS: Comments on the data elements received from the SCI community were discussed in the International Core Data Set working group. The suggestions from this group were iteratively reviewed. The final version was circulated for final approval.
RESULTS: The International SCI Core Data Set (Version 3.0) consists of 21 variables. The variable 'Gender' has been changed to 'Sex assigned at birth'; for the variable 'Spinal Cord Injury Etiology', the item, 'Sports or exercise during leisure time', has been clarified as 'including during leisure time'; for the variables 'Vertebral injury' and 'Associated injuries', the item 'Unknown' is reworded into: 'Not applicable (non-traumatic case)' and 'Unknown'; the variable 'Spinal surgery' has been expanded to include surgeries for individuals with non-traumatic SCI; for the variables related to the International Standards for Neurological Classification of SCI only the neurological level of injury (NLI) and the American Spinal Injury Association (ASIA) Impairment Scale (AIS) are to be reported, and a separate variable is included indicating if the NLI or the AIS or both are impacted by a non-SCI condition.
CONCLUSION: The International SCI Core Data Set (Version 3.0) should be collected and reported for all studies of SCI to facilitate uniform descriptions of SCI populations and facilitate comparison of results collected worldwide.

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INTRODUCTION

The ongoing purpose of the International Spinal Cord Injury (SCI) Core Data Set is to facilitate standardized collection and reporting of data on the most necessary information for evaluation and comparison of results when published [1].

When publishing studies on SCI, at least basic information about individuals with SCI should be given including age at the time of injury and time after injury at study inclusion as well as sex, cause of SCI and neurologic status [1].

The International SCI Core Data Set (Version 1) was adopted as a standardized way for collection and reporting of minimal data, as documented when publishing the International SCI Core Data Set (Version 2) [2]. The International SCI Core Data Set, like the other International SCI Data Sets, is overseen by the International Spinal Cord Society (ISCoS) and endorsed by the American Spinal Injury Association (ASIA) and linked to the National Institutes of Health (NIH), National Institute for Neurological Disorders and Stroke (NINDS), SCI Common Data Elements (CDE) to promote

data standards internationally. To illustrate the impact of the International SCI Core Data Set version 1 [1] and 2 [2] these were, according to Google Scholar by October 23, 2022, cited 249 and 130 times respectively.

Depending on gained experience and knowledge, it is intended that all the International SCI Data Sets are reviewed and revised periodically to ensure their ongoing acceptance for use in clinical and research SCI settings [3].

This article includes the revisions made to the International SCI Core Data Set (Version 3).

MATERIALS AND METHODS

The SCI community provided suggestions and comments to the International SCI Core Data Set (Version 2.0) since it was published in 2017 [2].

All comments were reviewed and discussed by the International SCI Core Data Set working group in an iterative way by email correspondence. Changes to the data set were considered, weighing the potential benefits

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Table 1. Recommend standardized reporting for age at injury, time since injury, length of stay, calendar time, and neurological level and severity of spinal cord injury [2].

Age at injury	Mean (s.d.) and for non-normal distributions median (IQR)
When grouped:	0–14, 15–29, 30–44, 45–59, 60–74 and 75+ years
For small samples:	0–29, 30–59 and 60+ years
For pediatric SCI:	0–5, 6–12, 13–14, 15–17 and 18–21 years
Time since injury	Mean (s.d.) and for non-normal distributions median (IQR)
When grouped:	<1, 1–4, 5–9, 10–14 and every 5 years thereafter
Length of stay	Mean (s.d.) and for non-normal distributions median (IQR)
Calendar time	Years during which the study is conducted
When grouped:	By either 5- or 10-year increments with years ending in 4 or 9
Level and severity of SCI	Distribution of NLI and AIS
When grouped:	C1–4 AIS A, B and C
	C5–8 AIS A, B and C
	T1–S3 AIS A, B, and C
	AIS D at any NLI
	Ventilator dependent at any NLI or with any AIS grade

SCI spinal cord injury, s.d. standard deviation, IQR interquartile range, NLI neurological level of injury, AIS American Spinal Injury Association Impairment Scale.

in relation to clinical and research utility of the proposals against the loss of continuity resulting from any revision.

The revised International SCI Core Data Set (Version 3) was then reviewed by the International SCI Data Sets Committee, the ISCoS Executive and Scientific Committees and the ASIA Board. Organizations and individuals interested in reviewing the International SCI Data Sets received a targeted email and the data set revisions were also posted on the ISCoS and ASIA websites for at least one month. During this process, some issues were discussed, and further revisions were adopted by the International SCI Core Data Set working group.

RESULTS

All variables of the International SCI Core Data Set (Version 3.0) are available in Appendix A. The changes adopted are described below:

The variable 'Gender' has been changed to 'Sex assigned at birth' [4]. The category 'Transgender or other related category' is changed to 'Other, specify', as the majority will be assigned to Male/Female. In addition, an item 'Decline to answer' is included. It is agreed that the individuals' gender identity as well as current sexual orientation are important, and the latter is included in the International SCI Male Sexual Function and Female Sexual and Reproductive Function Basic Data Sets (Version 2.0) [5].

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

For the item 'Birth injury or other traumatic cause, specify' it has been changed to 'Other traumatic cause, including birth injury, specify' to have less emphasis on the birth injuries and have the option to identify the specific cause.

For the variable 'Vertebral injury', the item 'Unknown' is reworded into two response options: 'Not applicable (non-traumatic case)' and 'Unknown' for the traumatic cases where this actually is not known. The first option is to make it clear that this variable is to be used in individuals with traumatic SCI only.

For the same reasons, for the variable 'Associated injuries' the item 'Unknown' is reworded into two response options: 'Not applicable (non-traumatic case)' and 'Unknown'.

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

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

For the variables related to the sensorimotor examination using the International Standards for Neurological Classification of SCI (ISNCSCI) [6] changes were made to the items making reporting simpler. At the same time, it is realized that not all the information included in the previous versions were needed for clinical decision making or in research not specifically addressing sensorimotor aspects. This resulted in the change that the sensory and motor levels are not reported separately anymore, but only the neurological level of injury (NLI) and the ASIA Impairment Scale (AIS) are documented at time of admission and discharge. In addition, to comply with the 2019 version of the ISNCSCI [6] a separate variable is included indicating whether the NLI or the AIS or both are impacted by a non-SCI condition (meaning that one or both are tagged with a '*').

STANDARDIZED REPORTING

It is essential to be able to compare the data from published studies on SCI. To facilitate this endeavor, standardized methods for analyzing and reporting descriptive statistics were introduced

in 2011 [7], and further developed when publishing the International SCI Core Data Set (Version 2.0) in 2017 [2]. Table 1 shows the recommendations agreed upon and are unchanged from version 2.

The continuous variables age at injury, time since injury, and length of stay, are to be described by mean and standard deviation (s.d.). When the distribution is skewed, median and interquartile range (IQR) also are to be reported. Likewise, the range should be provided when there may be concerns related to generalization of the results. The recommended age groupings are provided in Table 1 and further described in 2017 [2]. For calendar time intervals, these may be collapsed if appropriate.

It is recommended to report the level/severity of SCI described by the NLI/AIS as shown in Table 1 [7]. If few individuals required a ventilator, they are to be included in the group C1-4 AIS A, B and C. If the sample still is considered too small, they could be in one group C1-8 AIS A, B, and C. Depending on the specific study, other groupings may be more meaningful, e.g., studies on neurological recovery may consider separating each AIS grade, if studying autonomic dysreflexia, NLI at or above T6 versus T7 or below may be more appropriate, and when analyzing data related to pressure injuries comparing AIS A with AIS B, C or D could be more relevant [7].

DISCUSSION
The International SCI Core Data Set (version 3.0) has been developed and revised based on input from clinicians and researchers working in different fields of SCI medicine and rehabilitation. It has continuously been the aim only to adopt changes that most important and relevant for SCI clinical practice and research, i.e., their assessment should fit into the clinical routine and they should be meaningful in daily work. It is intended that, as with previous versions, the International SCI Core Data Set (Version 3.0) will be relevant in clinical as well research settings and be used together with other International SCI Data Sets, depending on the SCI topic to be clinically evaluated or systematically studied.

The forms of the International SCI Data Sets can be downloaded from the ISCoS website (https://www.iscos.org.uk/international-sci-data-sets) free of charge together with the original publications. The International SCI Data Sets also are integrated into the NIH, NINDS, CDEs [8, 9], and therefore downloadable from their website: https://www.commondataelements.ninds.nih.gov/Spinal%20Cord%20Injury.

Other NINDS CDEs are available and can help when initiating new SCI studies and trials.

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COMPETING INTERESTS
The authors declare no competing interests.

ADDITIONAL INFORMATION
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APPENDIX A

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

Dates (YYYYMMDD)

Birth date   __ __ __ __/ __ __/ __ __

Injury date   __ __ __ __/ __ __/ __ __

Acute Admission   __ __ __ __/ __ __/ __ __

Rehabilitation Admission   __ __ __ __/ __ __/ __ __

Final Inpatient Discharge   __ __ __ __/ __ __/ __ __

Date of Death   __ __ __ __/ __ __/ __ __

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

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

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

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

Spinal Surgery: □ No   □ Yes   □ Unknown

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

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

Neurological Data

Acute Admission	Final Inpatient Discharge
Date of Examination	Date of Examination
__ __ __ __/ __ __/ __ __	__ __ __ __/ __ __/ __ __
Neurological Level of Injury (NLI)	Neurological Level of Injury (NLI)
_____	_____
ASIA Impairment Scale (AIS)	ASIA Impairment Scale (AIS)
_____	_____
The NLI / AIS are impacted by a non-SCI condition (i.e. one or both are tagged with a '*') □ No □ Yes □ Unknown	The NLI / AIS are impacted by a non-SCI condition (i.e. one or both are tagged with a '*') □ No □ Yes □ Unknown