DEVELOPMENT OF INTERNATIONAL SPINAL CORD INJURY DATA SETS

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Presented at the 6th Congress of the Romanian Society of Neurosurgery
26.09-30.09.2007 Bucharest

The purpose of the Core Data Set is to standardize the collection and reporting of a minimal amount of information necessary to evaluate and compare results of published studies. The data are included in the Core Data Set, and are recommended, as a descriptive table in most publications including individuals with SCI. The Core Data Set is available at www.iscos.org.uk, and www.asia-spinalinjury.org, including training cases.

Keywords: bony vertebral injury, spinal cord injury, spinal surgery

Common International SCI Data Sets should be collected on individuals with SCI to facilitate comparisons regarding injuries, treatments, and outcomes between patients, centres and countries. It is found increasingly important to have comparable data elements so that the services affecting worldwide outcome of SCI can be assessed and compared.

An overall structure and terminology has been developed following the format of the International Classification of Function (ICF) [1].

The Core Data Set was the first one to be developed [2]. The purpose of the Core Data Set is to standardize the collection and reporting of a minimal amount of information necessary to evaluate and compare results of published studies. At minimum, published studies should include information on the gender and age of the study population at the time of injury, the current age of the study population if different from age at injury, the length of elapsed time after injury when data are being collected, the calendar time frame during which the study was conducted, the causes of spinal cord lesion, and the neurologic status of the study population according to the International Standards for Neurological Classificaiton SCI. In addition, studies of health services and rehabilitation outcomes should also contain information on the total number of days hospitalized, whether a bony vertebral injury or associated injuries was present, whether spinal surgery was performed, whether patient was ventilator-dependent, and the place of discharge from inpatient care. These data are included in the Core Data Set, and are recommended, as a descriptive table in most publications including individuals with SCI.

Inclusion of more detailed information will depend on the research topic. This information should be provided in either table or text format for the overall study population and for each study group. It is extremely important that data be collected in a uniform manner. The Core Data Set is available at www.iscos.org.uk, and www.asia-spinalinjury.org, including training cases.

BASIC QUESTION

This is a question, which with an affirmative answer implies that it is possible to go on to one or more specific data set(s) with more detailed information on the particular topic.

There will not be such questions for all data sets.

Examples of Basic Questions:

- Bony vertebral injury: Yes/No/Unknown (from the Core Data Set), if Yes ? Bony vertebral injury Basic SCI Data Set

- Etiology of lesion: Sports/ Assault/ Transport/ Fall/ Other traumatic/ Non-traumatic (from the Core Data Set), if traumatic ? Etiology module (SCI version of International Classification of External Causes of Injury (ICECI) [5])

- Pain: Have you had any pain during the last seven days including today: Yes/No, if Yes ?

PAIN BASIC SCI DATA SET

Basic SCI Data Set. This is the minimal number of data elements, including the possible Basic Question, which together should be collected in daily clinical practice for a particular topic. This mean that the various Basic SCI Data Sets in the future may be the basis for a structured record in centres worldwide caring for persons with SCI.

Examples of Basic SCI Data Sets:
- Bony vertebral injury Basic SCI Data Set
- Spinal surgery Basic SCI Data Set
- Lower Urinary Tract Function Basic SCI Data Set
- Urodynamic Basic SCI Data Set
- Urinary tract imagine Basic SCI Data Set
- Bowel Basic SCI Data Set
- Pain Basic SCI Data Set

Expanded SCI Data Set. This is a more detailed data set, which may be used as optional for a topic, but may be recommended for specific research studies within the particular area.

Examples of possible Expanded SCI Data Sets:
- Lower urinary tract function Expanded SCI Data Set
- Bowel Expanded SCI Data Set
- Pain Expanded SCI Data Set
- ICECI (International Classification of External Causes of Injury) for SCI [5].

MODULE

A Module may consist of a basic question, a 2-level data set: Basic and Expanded SCI Data Sets, and other data (e.g. specific scoring-systems), which are appropriate for the particular module.

Possible examples of Modules:
Urological module:
- Lower Urinary Tract Function Basic SCI Data Set
- Lower Urinary Tract Function Expanded SCI Data Set
- Urodynamic Basic SCI Data Set
- Urodynamic Expanded SCI Data Set
- Urinary tract imagine Basic SCI Data Set
- Urinary tract imagine Expanded SCI Data Set
Pain module:
- Basic Pain Question (included in the Pain Basic SCI Data Set)
- Pain Basic SCI Data Set
- Pain Expanded SCI Data Set
- Pain scoring

INTERNATIONAL SCI DATA SETS DEVELOPMENTS

For development of further Data Sets the Executive Committee for the International SCI Standards and Data Sets create topic-specific expert working groups. The establishment of working groups in the various areas is done in cooperation with relevant international societies and organizations working with the respective topics.

Initially, priority has been given to the development of Basic Questions and Data Sets within the following areas:
- Bony vertebral injury
- Spinal surgery
- Non-traumatic spinal cord lesions
- Etiology/Prevention, based on the WHO International Classification of External Causes of Injury [3]
- Urology
- Bowel
- Sexual function
- Pain
- Activity, Participation and Well-being.

For each data set a syllabus including definitions, coding schemes, and instructions on how to collect each data item are developed.

ORGANIZATION

The executive committee for the International Spinal Cord Injury Standards and Data Sets is a steering committee for the specific working groups created for

developing of specific topic Modules and Data Sets. International organizations and societies within the fields of spinal cord injury, neurosurgery, orthopaedic surgery, rehabilitation and others are being invited to appoint members to join the review process for the creation and evaluation of the best possible International SCI Data Set.

Process for approval of International SCI Data Sets. A process for approval of the data sets has been established following the points below:

1. The particular SCI Data Set working group itself finalise the data set.

2. The Executive Committee of the International SCI Standards and Data Sets review the data set.

3. Comments from the Committee are discussed in the particular SCI Data Set working group and a response is made and possible adjustments of the Data Set performed.

4. ISCoS Scientific Committee and ASIA Board review the data set.

5. Comments from the Committee/Board are discussed in the particular SCI Data Set working group and a response is made and possible adjustments of the Data Set performed.

6. Relevant and interested (International) Organisations and Societies and persons review the data set and ISCoS and ASIA websites.

7. Comments are discussed in the particular SCI Data Set working group and responses are made and possible adjustments of the Data Set performed.

8. ISCoS Scientific Committee, Council and ASIA Board review the data set for final approval.

9. ISCoS and ASIA general meetings have the data set for final approval.

10. Endorsement of the data set by relevant (International) Organisations and Societies.

DATA SET PRESENTATION

As soon as a new International SCI Data Set is developed in this iterative manner, consensus has been obtained, and the final draft has been approved together with an appropriate training program, they will be disseminated at meetings, and published în international journals and through the web sites of ISCoS (www.iscos.org.uk), and ASIA (www.asia-spinalinjury.org).

Training programs. For each developed Data Set training cases will be created and made accessible through the ISCoS and ASIA web sites, from which the data guidelines will be freely available. The training cases should preferable precede download of the particular Data Set.

This training will provide examples on how to code the data set and will give a minimal introduction to those using the data sets in their own environment.

All new data sets approved will be made available with a data collection syllabus at the web sites of ISCoS (www.iscos.org.uk), and ASIA (www.asia-spinalinjury.org).

REFERENCES

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3. http://www.iceci.org/