

International Spinal Cord Injury Socio-Demographic Basic Data Set (Version 1.0)

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The International Spinal Cord Injury (SCI) Socio-Demographic Basic Data Set was produced under the umbrella of the International Spinal Cord Society (ISCoS) and the American Spinal Injury Association (ASIA). In addition, the work carried out by the present working group has been running in parallel with a similar endeavor within the National Institute of Neurological Disorders and Stroke (NINDS), the Common Data Elements (CDE) project, at the National Institutes of Health.¹ Therefore, there is, on purpose and as appropriate, an overlap in variable recommendations between the NINDS SCI CDE and the International SCI Socio-Demographic Basic Data Set.

Introduction

Profound physical, psychological, and economic consequences, as well as the lack of a cure, underscore the importance of primary prevention of SCI. Understanding the socio-demographic profile of new SCI is the key for the development of effective prevention strategies that are targeted to persons at greatest risk for injury. By providing socio-demographic information about people living with SCI, the needs for health services organization and research could also be better assessed.

As socio-demographic characteristics are known to be associated with many physical and psychosocial outcomes after SCI, there has been great interest in documenting these indicators in people with SCI in different communities to facilitate comparisons with the general population. Most nations in the world collect socio-demographic information of their populations on a regular basis, which typically includes questions such as age, gender, education, family situation, area where they live, and job status. Some of these questions are universal (such as age and gender), but some are challenging regarding an international standard to capture the global picture such as race/ethnicity, education, disposable income, and other socioeconomic status.

With focus on common socio-demographic variables or measures included in population surveys, as well as SCI registries and clinical studies, this document seeks to include variables that are a) universally applicable, b) easy to ask and operationalize, c) fairly short in length, and d) applicable in different types of health care settings. In accordance with the aims of the International SCI Data Sets,² it is the hope of this socio-demographic working group to

standardize data collection and reporting of a minimal amount of socio-demographic information at the time of injury as well as at post-injury follow-ups to facilitate the evaluation and comparisons across studies. The International SCI Socio-Demographic Basic Data Set is developed for adults with traumatic or non-traumatic supraconal, conal or cauda equina lesions.

Summary of recommendations

The International SCI Socio-Demographic Basic Data Set consists of 4 items:

1. Marital status (6 categories)
2. Number of persons living in the household
3. Years of education
4. Primary occupation (7 categories)

Appendix 1 contains the data form. Appendix 2 contains the syllabus, with instructions for all items and definitions.

Please note the International SCI Socio-Demographic Basic Data Set has to be used in conjunction with the background information within the International SCI Core Data Set³ that includes date of birth, age, and gender as well as the Activities and Participation Basic Data set⁴ that includes hours of paid and unpaid work. It is also to be noted that questions related to race, ethnicity, family income, home ownership, disability benefits, area of residence, secondary occupation, type of occupation, citizenship, birth country, and religion are not recommended for the basic dataset. These are important questions, but some are challenging to obtain universally and reliably, given the sensitive nature of these questions and variations across cultures and countries. These items will be considered for a planned SCI Socio-Demographic Extended Data Set in the future.

Appendix 1: Data Collection Form

International Spinal Cord Injury Socio-Demographic Basic Data Set (Version 1.0)

Date of data collection: ____/____/____ (YYYY/MM/DD)

1. Marital status

- Never married
- Married
- Domestic partnership
- Divorced
- Separated
- Widowed
- Unknown

2. Household member

How many members are there in your household (including yourself): _____

- Unknown

3. Years of formal education

Number of years of education: _____ years

- Unknown

4. Primary occupation (*choose one*)

- Working, competitive labor market (employed/self-employed/family business, including military)
- Homemaker
- Student (including on the job training)
- Retired (age-related/age pension)
- Volunteer
- Unemployed (none of the above)
- Other, specify _____
- Unknown

Appendix 2: SYLLABUS (instructions)

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Each variable and each response category within each variable has been defined specifically in a way that is designed to facilitate the collection of a uniform basic data set.

VARIABLE NAME: **Date of data collection**

DESCRIPTION: This variable documents the date of data collection

CODES: YYYY/MM/DD

COMMENTS: The collection of socio-demographic data may be carried out at any time after the spinal cord injury. The *Date of data collection* variable is necessary in order to identify when the data were collected. This variable provides a way to relate the collected data to other data collected on the same individual at various time points.

VARIABLE NAME: **Marital status**

DESCRIPTION: This variable documents the marital/partnership status

CODES: Never married
Married
Domestic partnership
Divorced
Separated
Widowed
Unknown

COMMENTS: Marital status is a self-identified variable with a minimum number of categories. For reason of simplicity and because of the decision made on the household composition variable, it was decided to include domestic partnership outside of marriage. The domestic partnership category is applicable if the person with SCI is living together with a significant other but not legally married, irrespective of the presence of some type of legal partnership arrangement (other than marriage). Being married/living together with a significant other is an important aspect of the living situation of a person with SCI, and is related to support, participation and quality of life⁵⁻⁷. This variable is in accordance with NINDS SCI CDE – Demographics (http://www.commondataelements.ninds.nih.gov/SCI.aspx#tab=Data_Standards).

VARIABLE NAME: Household member

DESCRIPTION: This variable documents the number of members in the household (including yourself):

CODES: Number of household members: _____
Unknown

COMMENTS: Household members are individuals dependent on the household income. This is not related to those living in group homes, extended care or assisted-living facilities. Number of individuals in the household is related to financial situation (how many earn money, how many depend on those monies), possible caregiver tasks for the person with SCI (e.g. caring for young children or elderly individuals),⁸ and possible care received by the person with SCI from other members of the household (e.g., spouse, older children).^{9:10} This variable is of obvious importance for children with SCI.¹¹ This variable is in accordance with NINDS SCI CDE – Demographics (http://www.commondataelements.ninds.nih.gov/SCI.aspx#tab=Data_Standards).

VARIABLE NAME: Years of formal education

DESCRIPTION: This variable documents the number of years of education

CODES: Number of years of education _____
Unknown

COMMENTS: This includes years of formal education completed, starting from the age of 6. The counting of years should be normed to someone studying through schooling full time at the usual pace. For example, a typical one-year full-time in school completed over several years will still be counted as one year. A repeated school year should be excluded. Certificate, technical training, internship, residency, and fellowship are NOT counted. For an incomplete year, round up to next year, if it is more than 6 months. No formal education is the reality in several places around the world, thus necessary to include in a global measure. As the boundary between primary and secondary education varies between countries (and even within countries), years of education are more universally comparable than the categories of education level.

Low education impacts upon the ability to gain knowledge and new skills after SCI.¹² Education can further be used as a proxy for socio-economic status, with higher education being associated with a healthier lifestyle, better living conditions, easier access to care, and a number of outcomes of SCI rehabilitation, including fewer secondary health conditions and improved participation and quality of life.¹³⁻¹⁶

This variable is in accordance with NINDS SCI CDE – General Core (http://www.commondataelements.ninds.nih.gov/SCI.aspx#tab=Data_Standards).

VARIABLE NAME: Primary occupation

DESCRIPTION: This variable documents a person’s primary occupational and employment status (choose one below)

CODES: Working, competitive labor market (employed/self-employed/family business, including military)
Homemaker
Student (including on the job training)
Retired (age-related/age pension)
Volunteer
Unemployed (none of the above)
Other, specify _____
Unknown

COMMENTS: This question documents a person’s main occupational role and employment status. Since these sub-categories are not mutually exclusive, determine primary status using respondent’s definition.
Ignore non-employment sources of income or reasons for not working, such as settlement or disability income support, when coding “Unemployed” status.
If the individual's primary occupation does not fit into any of the above classifications, document it as "Other" and specify the occupational role. A more extensive standardized registration of participation, including questions on number of working hours (paid work, volunteer work and household work) is available from in the *International SCI Activities and Participation Basic Data Set*¹⁷ (<http://www.iscos.org.uk/international-sci-data-sets>)

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