A Structured Approach to Capture the Lived Experience of Spinal Cord Injury

Data Model and Questionnaire of the International Spinal Cord Injury Community Survey

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Abstract: The International Spinal Cord Injury (InSCI) community survey has been developed to collect internationally comparable data on the lived experience of persons with spinal cord injury (SCI) in all 6 WHO regions. The InSCI survey provides a crucial first step to generate evidence on functioning, health maintenance, and subjective well-being in persons with SCI globally. A major challenge in setting up the InSCI community survey was to develop a data model and questionnaire that comprehensively captures what matters to people and, at the same time, is feasible and parsimonious in terms of participant's burden. This paper outlines the components of the InSCI data model and presents the question selection to operationalize the data model along the 4 guiding principles of efficiency, feasibility, comparability, and truth and discrimination. The data model consists of 6 components operationalized with 125 questions including functioning (n = 28 body functions and structures; n = 42 activities and participation), contextual factors (n = 26 environmental; n = 19 personal factors), lesion characteristics (n = 2), and appraisal of health and well-being (n = 8). The InSCI questionnaire presents an efficient and feasible solution with satisfying comparability to other populations; however, its validity and reliability still needs to be confirmed.

Key Words: Spinal Cord Injury, Data Collection, Questionnaire Design, Community Survey, Survey Methodology, International Classification of Functioning, Disability and Health

(*Am J Phys Med Rehabil* 2017;96(Suppl):S5–S16)

The World Health Organization's (WHO's) Global Disability Action Plan 2014–2021 *Better Health For All People With Disability*[1] identifies as 2 objectives the reduction of barriers to access to health services, assistive technology, and community-based rehabilitation, and the strengthening of data collection to enable international comparative analysis of information about disability. The Learning Health System for Spinal Cord Injury (LHS-SCI) is an initiative aligned with these objectives of the action plan and consists of 3 complementary pillars: generating evidence, implementing recommendations, and building capacity. The International Spinal Cord Injury (InSCI) community survey has been developed as a crucial first step to support the LHS-SCI initiative through the collection of internationally comparable data on the lived experience of community-dwelling persons with spinal cord injury (SCI) globally and to describe their situation in relation to functioning, health maintenance, and subjective well-being.

A major challenge in setting up the InSCI community survey is that of developing a data model that comprehensively captures what matters to people and, at the same time, is feasible in participant burden. As a result, the definition of what to measure and how to measure is crucial, and this requires a well-defined and structured approach in order to develop a comprehensive and parsimonious questionnaire. The International Classification of Functioning, Disability and Health (ICF)[2] provides a valuable framework to guide researchers in selecting the most relevant ICF components (ie, sets of variables) to measure, ensuring that appropriate data on relevant aspects of people's lived experience are collected.[3,4] Since the ICF is built on a comprehensive model, it is a practical tool for determining a data model by means of selecting ICF categories that are relevant for the specific health condition.[5] Once the components and specific ICF categories to be included in the data model are defined, researchers then face the challenge of operationalization, that is, the selection of data collection tools that adequately represent each of the predefined categories.

The objective of this paper was to report on the development of the InSCI data model and the InSCI questionnaire. More specifically, we aim to 1) present the components of the

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The authors declare that they do not receive any financial benefits for this study. This manuscript or abstract has not been presented in any form elsewhere.

Financial disclosure statements have been obtained, and no conflicts of interest have been reported by the authors or by any individuals in control of the content of this article.

ISSN: 0894-9115
DOI: 10.1097/PHM.0000000000000622

InSCI data model and the resulting ICF categories; 2) outline the selection of questions that operationalize the InSCI data model based on guiding principles; and 3) describe the operational procedures and key process steps in the InSCI questionnaire development.

METHODS

The InSCI Data Model: Defining Components and Categories of "What To Measure"

The process of determining what to measure in the ICF components body functions and structures, activities and participation, and environmental factors was guided by the conceptually and scientifically driven selection of health condition–specific ICF categories in the ICF core sets. The ICF core sets are short lists of categories from the entire ICF classification that have been demonstrated through the core set methodology to be the most relevant for describing the functioning of persons with specific health conditions (www.icf-core-sets.org). Brief ICF core sets include a minimal set of categories to describe the typical spectrum of functioning in persons with specific health conditions.[5,6] As the comprehensive core sets tend to be too large to be feasible for survey purposes, the brief core sets were selected. For the InSCI data model, all ICF categories defined in the brief ICF core set for SCI, long-term context,[5] were selected. Importantly, the process of developing health condition–specific core sets also includes affected persons, thus reflecting their subjective perspective on the relevance of domains for their lives.[7] In addition, the ICF rehabilitation set,[8] including a minimal set of categories most relevant across health conditions, was selected to enable comparisons with general and clinical populations. The ICF rehabilitation set was developed as reference framework to harmonize information on disability across clinical populations.[8] In addition, the ICF rehabilitation set includes 7 categories from the ICF generic set[9] relevant for general populations, thus providing information for general population comparisons. Information on ICF categories of the InSCI data model as well as their source (ICF core set for SCI; ICF rehabilitation set) is provided in Tables 2 to 4 in the "Results" section.

As the component of personal factors is not classified in the ICF, although it should be measured in the context of functioning, a recent systematic literature review by Geyh et al.[10] was relied on for the identification of plausible categories to be included. The authors extracted data from a pool of 1246 items from SCI studies to establish a psychologic personal factor structure that includes relevant research constructs. The result of a preliminary classification proposal resulted in the identification of 7 categories, which were included in the InSCI data model (see "Results" section). Further components of the InSCI data model include lesion characteristics and the appraisal of health and well-being (Fig. 1).

As defined in the InSCI study protocol (Gross-Hemmi et al.[11] in this issue), the collaborating countries are invited to add national modules on key topics they wish to assess in more detail. The development of national modules is not the subject of this paper and is described in each of the national study protocols. In addition, design issues such as the operational implementation of the questionnaire in data collection are described in detail elsewhere in this issue (Gross-Hemmi et al.[11] for general guidelines; national study protocols for description of country-specific implementation of the survey).

Operationalization of the Data Model: Defining "How To Measure" and Selecting Questions

Based on earlier work on guiding principles to select data collection tools for epidemiological studies on functioning,[4]

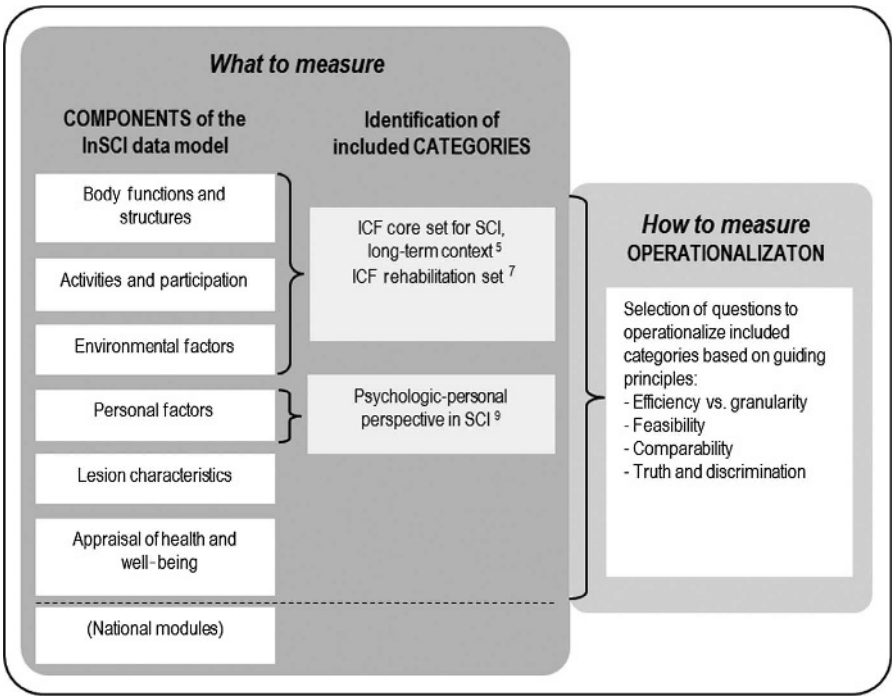

FIGURE 1. The structured approach of the InSCI data model and questionnaire development.

the four principles that guided the argumentative process of question selection are presented below.

Efficiency Versus Granularity

The procedure of linking questions to an ICF category[12–14] (or just a category in case no ICF category exists) provides a useful tool to assess measurement efficiency. For example, the ICF category *d850 Remunerative employment* is assessed with 11 questions, thus indicating high granularity of information (ie, a high level of detail of information), but low efficiency, as 11 questions only cover a single ICF category. An example of efficient measurement would be the assessment of category *e225 Climate*, where a single question is used to capture the impact of unfavorable climatic conditions on a persons' life. The granularity of the information from this single question is limited, but the coverage of the ICF category is most efficient, as only one question is used to assess the category. However, the decision on a suitable number of questions to include per category, and therefore the efficiency of assessment, largely depends on the topic prioritization and study objective, with the trade-off between granularity and efficiency needing careful consideration.

Feasibility

Feasibility concerns include issues important for researchers (eg, legal aspects and availability of translations) and participants (eg, length and comprehensibility). The length of the questionnaire is one of the most important feasibility issues since willingness to complete a survey varies considerably by its length.[15,16] Besides length, other factors such as question complexity and structure may add to participant's cognitive burden and affect data quality and completion. For example, simplicity can be enhanced by using similar style and response options throughout a section and by using a language that is familiar to participants (eg, avoiding technical terms).

Comparability

In addition to using condition-specific instruments, it is important to incorporate established generic data collection tools that allow the pooling and comparison of data with reference values from general populations. Moreover, interpretation of results and communication with the scientific community may be facilitated if well-known tools are used. Comparisons with SCI populations will be more relevant in some cases than in others. For example, a SCI-specific tool is needed for the assessment of body functions, since prevalent problems such as pressure sores or spasticity are usually not assessed in generic tools. However, the challenge remains that as there is no criterion standard in data collection, widely used tools, might not be the best ones or do not meet the needs of a specific survey. In some cases, it is useful to introduce newer or less frequently used tools that are shorter (and thus more efficient). Again, the use of newly developed questions may violate the principle of comparability and needs careful considerations.

Truth and Discrimination

Data collection tools should meet required standards for validity and reliability, summarized as truth and discrimination criteria by a recent initiative on the improvement of Outcome Measures in Rheumatology.[17] Validity is the extent to which a tool measures what is intended. Content and face validity assess whether questions adequately address the domain of interest, and reliability concerns whether a tool is internally consistent, reproducible, and free from measurement error (ie, the difference of responses and real values). Sensitivity to change is another aspect of reliability that should be taken into account.[17] There are numerous approaches to assess these psychometric properties; extensive literature exists that describes these approaches in detail.[18,19] However, validity and reliability should not be seen as fixed properties and must be assessed in relation to the specific population and measurement objectives. Again, there is a trade-off between using psychometrically tested data collection tools and new tools with less evidence of validity and reliability that may be preferred because of feasibility or efficiency reasons or a better fit to research questions. A pilot test of the InSCI questionnaire with the focus on inter-rater reliability of the ratings and cognitive debriefing of the questions has been performed (see also Gross-Hemmi et al.[11] in this issue).

Furthermore, a high standard of translation and cultural appropriateness must be ensured.[20] To attain appropriate linguistic translation and cultural adaptation and to maintain consistency and content validity of the InSCI questionnaire across different countries, guidelines for cross-cultural adaptation suggested by Beaton et al. and Epstein et al.[21,22] are applied. These guidelines are designed to maximize semantic, idiomatic, experiential, and conceptual equivalence between the reference InSCI questionnaire (English version) and its translated versions. The order of questions and response categories cannot be changed, and altering content or design components are only allowed if substantial improvement in a specific sociocultural context is attained. In general, the maintenance of the semantics equivalence of a phrase has priority over literal translation. The questions are translated in a process involving 2 independent translations, which are then harmonized, discussed and approved by the Expert Committee of each National Study Group.[21,22]

Development of the InSCI Questionnaire: Operational Procedure

A first draft of the InSCI questionnaire was developed by researchers from the InSCI Study Center at Swiss Paraplegic Research (Nottwil, Switzerland), the chair of the Scientific Committee of InSCI, and 2 international advisors in March and April 2015. This draft was then been discussed with the national leaders and coordinators of participating InSCI countries at the conferences of the International Spinal Cord Society (ISCOS, Montréal, May 2015) and the International Society of Physical and Rehabilitation Medicine (ISPRM, Berlin, June 2015). There was general agreement on the inclusion of established data collection tools such as SF-36 or Brief Pain Inventory (see "Results" section); however, most critical feedback was related to newly designed questions or questions that have been adapted from existing tools in case of nonexistence of any suitable tool. In addition, the selection of questions to cover key topics (ie, the work situation and health care services) was discussed. Feedback from these discussions was incorporated in a revised version of the questionnaire and a final draft

discussed with experts in respective fields in July 2015. All participating countries received a final version of the questionnaire and had the opportunity to give feedback again. The translation process in all participating countries and the U.S. pilot test of the English reference questionnaire with SCI persons provided additional feedback that helped to improve the InSCI questionnaire. The pilot test included focus group interviews to test content validity, and the assessment of test-retest reliability. Based on the issues raised during translation and pilot testing, decisions on the final version of the InSCI questionnaire have been taken by researchers from the InSCI Study Center (Swiss Paraplegic Research, Nottwil, Switzerland), the chair of the Scientific Committee, and 2 international advisors by the end of August 2016. The development of the InSCI questionnaire has therefore been an iterative consensus process in which experts from different countries as well as persons with SCI have been involved.

RESULTS

In this section, the operationalization of the InSCI data model is presented with regard to the six components (Fig. 1). The source of the question, the category covered, and the rationale for the selection based on the guiding principles are given. The InSCI questionnaire as well as detailed information on the original questions and the ICF linking (if applicable) are all available on request at insci@paraplegie.ch.

Table 1 provides a summary on the total number of questions per component, the number of questions that assess categories from the InSCI data model, and the number of questions that assess categories beyond the InSCI data model. In total, the InSCI questionnaire includes 125 questions, of which n = 70 (56.0%) assess functioning (n = 28, body functions and structures; n = 42, activities and participation); n = 45 (36.0%) contextual factors (n = 26, environmental factors; n = 19, personal factors); n = 2 (1.6%) lesion characteristics, and n = 8 (6.4%) appraisal of health and well-being. Whereas an average of 1.9 questions were used to assess ICF categories on functioning, environmental factors were assessed more efficiently with an average of 1.5 questions per category as defined in the data model. However, approximately one quarter of the questions assessing body functions and environmental factors cover ICF categories that are not part of the data model. With only one question covering an ICF category that is not in the data model, the component activities and participation is assessed most efficiently. The 19 personal factors questions covered 7 categories, thus indicating an average of 2.7 questions to cover one category.

Body Functions

A total of 12 ICF categories from the component of body functions are included in the InSCI data model, operationalized with 21 questions. Seven questions address ICF categories that are not part of the InSCI data model; therefore, a total of 28 questions address body functions (Tables 1 and 2). The selected data collection tools to operationalize the component of body functions are presented below.

SF-36 Mental Health and Vitality Subscale (Version 2)

The SF-36 is one of the most widely used generic data collection tools to assess health aspects including 8 dimensions of physical functioning, social functioning, role limitations due to physical problems, role limitations due to emotional problems, mental health, vitality, pain, and general health perceptions.[23–26] The 4 questions from the SF-36 Vitality Subscale were selected to cover the ICF category *b130 Energy and drive functions*, and the 5 questions from the SF-36 Mental Health Subscale were chosen to assess the ICF category *b152 Emotional functions*. The main reason for the inclusion of the 2 SF-36 subscales is not only its international comparability and the availability of general population reference values but also the availability of comparable data for SCI populations.[27] In addition, the SF-36 subscales were validated and translated into different languages, thus providing feasible and culturally adequate versions for most of the participating InSCI countries.

TABLE 1. Components, questions, and measurement efficiency in the InSCI questionnaire

		No. Questions…			Efficiency	
Component	ICF Categories in Data Model	Total	…Assessing ICF Categories in Data Model	…Assessing Extra ICF Categories (Not in Data Model)	Average of Questions to Assess One ICF Category From Data Model	% of Questions to Assess Additional Category (Not in Data Model)
Body functions	12	28	21	7	21/12 = 1.8	(7/28) × 100 = 25.0%
[Body structures][a]	[4]	—		—	—	—
Activity and participation	22	42	41	1	41/22 = 1.9	(1/41) × 100 = 2.4%
Environmental factors	13	26	20	6	20/13 = 1.5	(6/26) × 100 = 23.1%
Personal factors	7[b]	19	19	0	19/7 = 2.7	0.0%
Lesion characteristics	N.d.	3	N.d.	—	—	—
Appraisal of health and well-being	N.d.	8	N.d.	—	—	—
Total	47	125				

[a]Assessed by body functions as indicators for body structures.

[b]Personal factors are not classified in the ICF. Selection of categories based on Geyh et al. (2011).[9]

N.d., not defined.

TABLE 2. Overview of the InSCI questions to assess body functions

ICF Code	RS	SCI LT	ICF Category	Data Collection Tool	No. Questions	Operationalization of Category
b130	✓		Energy and drive functions	SF-36 vitality subscale	4	Frequency of feelings of vitality
b134	✓		Sleep problems	New (SCI-SCS format)	1	Sleep problem and treatment
b152	✓	✓	Emotional functions	SF-36 Mental Health Subscale	5	Frequency of positive and negative emotions
b270			Sensory functions related to temperature and other stimuli	SCI-SCS	1	Problem and treatment of injury caused by loss of sensation
b280	✓	✓	Sensation of pain	Brief Pain Inventory (BPI); Spinal Cord Injury Secondary Conditions Scale (SCI-SCS)	2	Pain severity (BPI); Problem of pain interference and treatment (SCI-SCS)
b410–b429			Functions of the cardiovascular system	SCI-SCS	1	Problem and treatment of autonomic dysreflexia
b420			Blood pressure functions	SCI-SCS	1	Problem and treatment of postural hypotension
b430			Hematological system functions	SCI-SCS	1	Problem and treatment of circulatory problems
b440			Respiration functions	SCI-SCS	1	Problem and treatment of respiratory problems
b455	✓		Exercise tolerance functions	Model Disability Survey (MDS)[a]	1	Problem and treatment of shortness of breath during physical exertion
b525		✓	Defecation functions	Spinal Cord Injury Secondary Conditions Scale (SCI-SCS)[b]	1	Problem and treatment of bowel dysfunction
b620	✓	✓	Urination functions	SCI-SCS	2	Problem and treatment of urinary tract infections; Problem and treatment of bladder dysfunction
b640	✓	✓	Sexual functions	SCI-SCS	1	Problem and treatment of sexual dysfunction
b710	✓	✓	Mobility of joint functions	SCI-SCS	1	Problem and treatment of contractures
b735		✓	Muscle tone functions	SCI-SCS	1	Problem and treatment of spasticity
b810		✓	Protective functions of the skin	SCI-SCS	1	Problem and treatment of pressure sores
b730	✓	✓	Muscle power functions	New	2	Level and completeness of lesion
N.a.			N.a.	New	1	Additional health problems
				Total number	**28**	

ICF categories printed in **bold** are part of the InSCI data model.

[a]To group questions with the same style and response options, this question is placed in the section "Activity and Participation" within a sequence of MDS items.

[b]Questions on joint and muscle pain; heterotopic bone ossification; and diabetes mellitus were dropped for feasibility reasons.

N.a., not applicable; RS, ICF rehabilitation set[7]; SCI LT, brief ICF core set for SCI, long-term context.[5]

Question from the Brief Pain Inventory (BPI)

Similar to the SF-36, the BPI is a generic tool to assess pain in different settings (eg, clinical, epidemiologic, or effectiveness research) and populations (eg, general population, populations with specific conditions) that is widely used all over the world.[28] A single question on pain severity from the BPI was selected to assess *b280 Sensation of pain*. As outlined below, pain interference is assessed with an additional question. By using a BPI question, the availability of population reference values as well as reference values from SCI populations is largely given and presents an efficient and feasible solution. The fact that the BPI is translated into more than 40 languages is an additional advantage of the tool, as many InSCI countries can rely on available translations.

Questions from the Spinal Cord Injury Secondary Conditions Scale (SCI-SCS)

The Spinal Cord Injury Secondary Conditions Scale (SCI-SCS) was specifically developed for the self-report of the prevalence and severity of secondary conditions in persons with SCI.[29] The SCI-SCS measures 16 SCI-relevant conditions, from which 9 questions cover ICF categories from the InSCI data model. For feasibility reasons, 2 questions that assess ICF categories beyond the InSCI data model were covered elsewhere ("diabetes" was gathered by an open question on additional health conditions, and "joint and muscle pain" was captured by a question on pain more generally), and one question was removed ("heterotopic bone ossification" as it is an uncommon condition). To harmonize the question style and reduce the number of response options, new questions on *b134 Sleep functions,* and *b280 Sensation of pain* (interference with day-to-day activities) were added to the group of questions derived from the SCI-SCS. As the original response options of the SCI-SCS were identified as problematic (severity and frequency in one option; difficulties in translation), the 5-point response options suggested by the Model Disability Survey (see below) ranging from 1, "no problem," to 5, "extreme problem" were chosen. In addition to the modified 5-point scale on the extent of a problem, the question on "do/did you receive treatment for it?" was derived from the Self-Administered Comorbidity Questionnaire (SCQ).[30] This treatment-question may provide important information on the quality of a health care system. For example, highly prevalent problems that are rarely treated may point to unmet health care needs.

To cover additional health problems that are not part of the SCI-SCS, a question was added that gives respondents the option of listing up to 5 additional health problems in free text format. The free text format was chosen, as health problems vary considerably between persons and countries.

Body Structures

From the component of body structures, 4 ICF categories from the brief ICF core set for SCI[5] are included in the InSCI data model. These 4 ICF categories are covered as follows: *s120 Spinal cord and related structures* is assessed with 2 questions on level and severity of the spinal cord lesion; *s430 Structure of respiratory system* is measured with a question from SCI-SCS[29] on the severity and treatment of respiratory problems; *s610 Structure of urinary system* is covered with a question from Spinal Cord Independence Measure for Self-Report (SCIM-SR)[31] on the independence and the use of assistive devices in bladder management; and *s810 Structure of areas of skin* is assessed with an SCI-SCS[29] question on the severity and treatment of pressure sores.

Activities and Participation

Twenty-two categories from the component of activities and participation are part of the InSCI data model. These 22 categories are operationalized with 41 questions. One extra category that is covered by a single question has been added, resulting in a total of 42 questions addressing activities and participation (Tables 1 and 3).

Questions from the Model Disability Survey (MDS)

The Model Disability Survey (MDS) was developed by the WHO and the World Bank to provide a platform to collect comprehensive, generic, comparable, and relevant information on disability for a variety of national purposes, including to monitor the United Nations Convention on the Rights of Persons with Disabilities in the general population.[32–34] Eleven MDS questions were selected to cover *d* categories from the InSCI data model as they present an efficient and feasible solution. For 2 ICF categories where no MDS questions and no feasible alternatives were available, new questions in MDS format were developed (Table 3). By collaborating with the coordinators of the MDS, synergistic effects may be created during the period of translation and cultural adaptation. Furthermore, the use of MDS questions creates the opportunity to obtain data for SCI that is internationally comparable with the general population.

Questions from Spinal Cord Independence Measure for Self-Report (SCIM-SR)

The Spinal Cord Independence Measure (SCIM) III was specifically designed to assess independence in self-care, mobility, and respiration/sphincter management in persons with SCI.[35,36] Originally developed for the clinical setting, it is also available as self-report version for the community setting (SCIM-SR).[31] The SCIM for Self-Report (SCIM-SR) has been prioritized over other data collection tools, as it is recommended by ISCoS[37] and is used in SCI research worldwide. The SCIM-SR provides international comparability and captures more granular information than other tools, including information on the use of assistive devices in activity performance. To reach highly efficient coverage of ICF categories from the InSCI data model, 7 SCIM-SR questions that cover ICF categories that are not part of the data model were omitted.

Questions from Spinal Cord Injury-Functional Index, Assistive Technologies (SCI-FI AT)

The Spinal Cord Injury-Functional Index (SCI-FI) is an SCI-specific data collection tool to assess activity limitations in persons with SCI and the impact of assistive technology (AT) in 5 distinct functional domains.[38] Two of the categories, *d445 Hand and arm use,* and *d410 Changing basic body position*, have a potentially high impact on the independence of a person with SCI and the reason why 3 questions were selected from the SCI-FI AT item battery for more granular information.

TABLE 3. Overview on the InSCI questions to assess activities and participation

ICF Code	RS	SCI LT	ICF Category	Data Collection Tool	No. Questions	Operationalization of Category
d230	✓	✓	Carrying out daily routine	New (Model Disability Survey, MDS-format)	1	Problem in carrying out daily routine
d240	✓	✓	Handling stress and other psychological demands	MDS	1	Problem in handling stress
d410	✓	✓	Changing basic body position	SCIM-SR; SCI-FI AT	3	Independence in moving body positions (SCIM-SR); Get up from lying; Get up from sitting to lying (SCI-FI AT)
d415	✓	✓	Maintaining a body position	MDS	2	Ability to sit (MDS modified); ability to stand (MDS)
d420	✓	✓	Transferring oneself	SCIM-SR	1	Independence in transfer from bed to wheelchair
d445		✓	Hand and arm use	MDS; Spinal Cord Injury-Functional Index – Assistive Technology (SCI-FI AT)	2	Problems in hand and finger use (MDS); Problem in opening a door (SCI-FI AT)
d450	✓		Walking	SCIM-SR	[1, same as d455]	Independence in moving around moderate distances
d455	✓	✓	Moving around	MDS; Spinal Cord Independence Measure for Self-Report (SCIM-SR)	2	Problem in getting where one wants to go (MDS); Independence in moving around moderate distances (SCIM-SR)
d465	✓	✓	Moving around using equipment	SCIM-SR	[1, same as d455]	Independence in moving around moderate distances
d470	✓	✓	Using transportation	MDS	2	Problem in using public transportation; private transportation
d510	✓		Washing oneself	SCIM-SR	2	Independence in washing upper body and head; independence in washing lower body
d520	✓	✓	Caring for body parts	SCIM-SR	1	Independence in grooming
d530	✓	✓	Toileting	SCIM-SR	3	Independence in bladder management; independence in bowel management; Use of the toilet
d540	✓		Dressing	SCIM-SR	2	Independence in dressing upper body; independence in dressing lower body
d550	✓	✓	Eating	SCIM-SR	1	Eating & drinking
d570	✓		Looking after one's health	MDS; new	2	Problem of looking after one's health; smoking status
d640	✓		Doing housework	MDS	1	Problem in getting household tasks done
d660	✓		Assisting others	MDS	1	Problem in providing care or support for others
d710	✓		Basic interpersonal interactions	New (MDS-format)	1	Problem in interaction with people
d770	✓		Intimate relationships	MDS	1	Problem in intimate relationships
d845			Acquiring, keeping and terminating a job	MDS	1	Problems in job fulfillment
d850	✓		Remunerative employment	SwiSCI community survey; MDS; Effort-Reward Imbalance Questionnaire (ERI)	11	Description of job before SCI (SwiSCI modified); duration until job entry after SCI (SwiSCI); current work situation (MDS modified); paid work yes/no (SwiSCI). *Persons in paid work:* Description of current job (SwiSCI modified); desired amount of work (SwiSCI modified); reward at work (2 items, ERI); *Persons without paid work*: wish to work (SwiSCI); work ability (SwiSCI); reasons for unemployment (MDS modified)
d920	✓		Recreation and leisure	MDS	1	Problem in doing things for relaxation
				Total number	**42**	

ICF categories printed in **bold** are part of the InSCI data model.

RS, ICF rehabilitation set[7]; SCI LT, Brief ICF core set for SCI, long-term context.[5]

Question to Assess d570, Looking After One's Health

As evidence points to the detrimental effect of smoking on health, a single question on current smoking status is used to assessed health behavior linked to *d570 Looking after one's health*.

Questions to Assess the Work Situation

As highlighted in the WHO report International Perspectives on Spinal Cord Injury (IPSCI), paid employment is a major determinant of health and well-being in persons with SCI[39] and therefore a key topic of the InSCI community survey. In total, 6 questions assess the work situation in all persons, irrespective of their work status. An additional 7 questions are only asked in employed persons and 3 questions in persons who are not employed. Questions are drawn from several sources. Four MDS questions are used to collect basic information on the work situation, and 7 questions are assumed from the Swiss Spinal Cord Injury Cohort Study (SwiSCI).[40] The SwiSCI survey has been developed by SCI experts, thus providing valid questions that allow for comparison to other SCI populations. As an input from the conferences in Berlin and Montreal, a measure of work stress is included. Two questions from the internationally established Effort-Reward Imbalance Questionnaire[41] that were used in its 2-question composition[42] are selected to assess reward at work as an indicator for psychosocial work stress. In total, 11 work questions are linked to ICF category *d850 Remunerative employment*, 1 to *d845 Acquiring, keeping and terminating a job* (Table 3) and 4 questions to environmental factors (Table 4).

Environmental Factors

The InSCI data model includes 13 categories from the component of environmental factors. A total of 26 questions are used to operationalize the identified ICF categories of which 20 assess ICF categories in the data model and 6 questions assess additional ICF categories (Tables 1 and 4).

Questions from the Nottwil Environmental Factors Inventory Short Form (NEFI-S)

Based on the ICF core set for SCI, the Nottwil Environmental Factors Inventory Short Form (NEFI-S) was developed to assess perceived environmental barriers.[43] The NEFI-S is the only validated instrument specifically designed for SCI, covering a large spectrum of ICF categories defined in the InSCI data model. Therefore, it offers an efficient and feasible tool to assess *e* categories and allows for comparisons with other SCI populations such as the SwiSCI population.[44]

Questions on Health Care Services (e355, e450, e580)

As stated in the Global Disability Action Plan[1] and the IPSCI report,[45,46] improving the access and quality of health care services is a major target of future health policy. Assessment of health care services is therefore a key topic in the InSCI survey requiring more granularity. In addition to NEFI-S questions, MDS questions were selected to gather information on health care services. MDS questions offer the advantage of comparability with the general population. Based on expert feedback from Montreal and Berlin, a single question on support from other persons in activities of daily living was created.

Personal Factors

Seven categories determined as essential for capturing the psychological-personal perspective in SCI research are included the InSCI data model.[10] A total of 19 questions were included to assess these 7 categories (Table 5).

Sociodemographic and Personal Characteristics

Model Disability Survey questions are used to assess basic sociodemographic and socioeconomic characteristics including age, country of birth, highest level of education, and household income. A new item on total years of education was created, separating years of education before and after SCI. The country-specific response options for a highest level of education are based on the United Nations Educational, Scientific and Cultural Organization's guidelines for categorizing education into primary, secondary, and tertiary education.[47] Similarly, the 10 country-specific response categories for household income are based on the recommendations published by the European Social Survey 2012.[48]

Position in the Immediate Social and Physical Context

Subjective social status is described with the McArthur Scale of subjective social status, using a 10-rung ladder to visualize social position.[49] Information on marital status is collected by using an MDS item with modified response options. A new item on household composition was created to weight household income based on the age cutoffs presented by the Organisation for Economic Co-operation and Development.[50]

Personal History and Biography

Since most data collection tools to capture critical life events are lengthy, a single question with an open answer format was developed to assess critical life events during the past 12 months as operationalization of the category personal history and biography.

Feelings

This category is covered by the SF-36 Mental Health Subscale on *b152 Emotional functions* (see "Results", body functions).

Thoughts and Beliefs

Self-efficacy, personal growth, optimism, and autonomy were chosen to operationalize the category of thoughts and beliefs. The Generalized Self-Efficacy Scale (GSES) is a widely used tool that delivers comparable and reliable data,[51] and the Moorong Self-Efficacy Scale (MSES) was developed specifically for SCI.[52] Two GSES and 2 MSES questions were selected to assess self-efficacy, thus providing a feasible solution with good comparability both to the general population and SCI populations. With 4 questions, the concept of self-efficacy is assessed with more granularity, as evidence shows its importance for health and well-being in persons with SCI.[53–55] Model Disability Survey questions are used to assess personal growth and optimism with one question each, an efficient solution. The single question on autonomy originates from the WHOQoL disabilities module[56] and is also used in the MDS.

TABLE 4. Overview on the InSCI questions to assess environmental factors

ICF Code	RS	SCI LT	ICF Category	Data Collection Tool	No. Questions	Operationalization of Category
e110 e115	✓	✓	Products or substances for personal consumption; Products and technology for personal use in daily living	Nottwil Environmental Factors Inventory short form (NEFI-S)	1	Insufficient medication, medical aid and supplies
e120	✓	✓	Products and technology for personal indoor and outdoor mobility and transportation	NEFI-S	2	Insufficiently adapted assistive technology for moving around short distances; Insufficiently adapted means of transportation for long distances
e125			Products and technology for communication	NEFI-S	1	Insufficient communication devices
e135	✓		Products and technology for employment	Swiss Spinal Cord Injury Cohort Study (SwiSCI)	1	Coverage of assistive work devices
e150	✓	✓	Design, construction and building products and technology of buildings for public use	SwiSCI; NEFI-S	2	Problem in accessing workplace (SwiSCI); Insufficient accessibility of public places (NEFI-S)
e155	✓	✓	Design, construction and building products and technology of buildings for private use	NEFI-S	1	Insufficient accessibility to homes of friends and relatives
e165			Assets	NEFI-S	1	Problematic financial situation
e225	✓		Climate	NEFI-S	1	Unfavorable climatic conditions
e310	✓	✓	Immediate family	NEFI-S	1	Negative attitudes of family and relatives
e320	✓		Friends	NEFI-S	1	Negative attitudes of friends
e340		✓	Personal care providers and personal assistants	NEFI-S; New	2	Insufficient nursing care and support services (NEFI-S); home care situation (New)
e355	✓	✓	Health professionals	Model Disability Survey (MDS)	2	Visited health care providers; explanation received by health care providers
e460			Societal attitudes	NEFI-S	1	Negative societal attitudes
e425			Individual attitudes of acquaintances, peers, colleagues, neighbors and community members	NEFI-S	1	Negative attitudes of neighbors, acquaintances and work colleagues
e450	✓		Individual attitudes of health professionals	MDS	2	Experience of respectful treatment; involvement in decision making for treatment
e580	✓	✓	Health services, systems and policies	MDS; NEFI-S	4	Frequency of inpatient hospitalization (MDS); unmet health care needs (MDS); satisfaction with health care services (MDS); insufficient state services (NEFI-S)
e570				MDS	1	Disability pension (MDS modified)
e590				SwiSCI	1	Vocational rehabilitation (SwiSCI modified)
				Total number	**26**	

ICF categories printed in **bold** are part of the InSCI data model.

RS, ICF rehabilitation set[7]; SCI LT: Brief ICF core set for SCI, long-term context.[5]

TABLE 5. Overview on InSCI questions to assess personal factors

Category[9]	Data Collection Tool	No. Questions	Operationalization of Category
Sociodemographic personal characteristics	New	1	Gender
	New	1	Total years of education or training before and after SCI
	Model Disability Survey (MDS)	4	Age; country of birth. highest level of education (country-specific response options according to UNESCO guidelines); household income (country-specific response options according to European Social Survey 2012)
Position in the immediate social and physical context	McArthur Scale of subjective social status	1	Subjective social position
	New	1	Living situation
	MDS, modified	1	Marital status
Personal history and biography	New	1	Major adverse life events
Feelings	N.a.	N.a.	(covered by b152 emotional functions)
Thoughts and beliefs	Moorong Self-Efficacy Scale (MSES)	2	Self-efficacy in maintaining contacts; Self-efficacy in maintaining health
	General Self-Efficacy Scale (GSES)	2	General self-efficacy
	MDS	1	Personal growth
	MDS	1	Optimism
	WHOQoL-Disability	1	Autonomy
Motives	MDS	1	Purpose in life
Patterns of experience and behavior	General Belongingness Scale (GBS)	1	Belongingness
	Total number	**19**	

Motives

A single question on purpose in life was selected from the MDS to operationalize the category of motives. Selecting this question was mainly based on feasibility and efficiency reasons, as many established measures of purpose in life contain several questions.

Patterns of Experience and Behavior

Patterns of experience and behavior are covered by a question from the General Belongingness Scale (GBS).[57] The GBS is a valid and reliable tool that was used in the general population to assess belongingness. For feasibility and efficiency reasons, a single question from the GBS was selected by expert discussion.

To reduce participant burden and to enhance cross-cultural validity, the same response options, derived from the MDS (1 'not at all' to 5 'completely') were chosen for all the questions on thoughts and beliefs, motives, and patterns of experience and behavior.

Lesion Characteristics

Besides the assessment of level and completeness of lesion level (paraplegia; tetraplegia; complete lesion; incomplete lesion) described in body functions and structures (*b730 Muscle power functions; s120 Spinal cord and related structures*), information on etiology and date of SCI is collected. Etiology of SCI is assessed based on the Spinal Cord Injury Demographics Template developed by the International Spinal Cord Society (ISCoS).

Appraisal of Health and Well-Being

Questions on General Health

The SF-36 questions on general health and health transition are used in the InSCI questionnaire owing to their comparability with population reference values and ability to deliver reliable and valid data[23,26] (see "Results", body functions).

Questions on Subjective Well-Being

The WHO Quality of Life (WHOQoL)-BREF was developed by the WHO and provides an internationally and cross-culturally comparable assessment of well-being consisting of 26 questions. Owing to feasibility and efficiency reasons, a 5-question selection that showed good reliability and validity within the SCI-community is used.[58] Additionally, a question on the satisfaction with oneself is added from the WHOQoL BREF, as this dimension seems particularly important for persons with disabilities.

DISCUSSION

Implementing the InSCI community survey is a first step to support the LHS-SCI initiative through the collection of internationally comparable data on the lived experience of persons with SCI and to describe their situation in relation to functioning, health maintenance, and subjective well-being on a global level. In this paper, a structured approach to capture what matters to persons with SCI is described by providing details on the development of the InSCI data model and the InSCI questionnaire. In summary, the InSCI data model consists of 6 components (body functions and structures; activities and

participation; environmental factors; personal factors; lesion characteristics; and appraisal of health and well-being) and includes ICF categories from the brief ICF core set for SCI long-term context,[5] the ICF rehabilitation set,[8] and 7 categories for personal factors.[10] Although the ICF[2] provides a valuable framework to guide the selection of relevant components to measure,[3,4] the major challenge was to develop a questionnaire that comprehensively captures the most relevant aspects and, at the same time, is feasible and parsimonious with regard to participant burden. To attain this goal, the guiding principles of efficiency, feasibility, comparability, and truth and discrimination were defined and applied.

Two sets of limitations need to be addressed: limitations related to the approach of selecting questions based on guiding principles, and second, methodological limitations of the InSCI questionnaire. Although guiding principles provide a valuable tool to direct the decision-making process in question selection, some challenges concerning their application remain. Guiding principles cannot be prioritized in importance, and prioritization largely depends on the purpose of a study and its key topics. In addition, guiding principles strongly interact, and the decision for specific questions often claims a trade-off between different guiding principles, as already highlighted for the efficiency versus granularity issue. In the InSCI questionnaire development, efficiency and feasibility issues were oftentimes prioritized, which led to the violation of comparability or truth and discrimination issues. This situation arose whenever new items were created to efficiently cover a category with a single question in case established data collection tools were too comprehensive and thus not feasible in the context of the InSCI survey. These trade-offs need careful consideration, and justification for prioritization should be provided by the questionnaire developers.

The main limitation of the resulting InSCI questionnaire described in this paper, however, concerns truth and discrimination issues. As a result of the effort to enhance feasibility and efficiency, single questions were chosen from existing and psychometrically tested data collection tools. This might be criticized, as validity is not confirmed for the use of single questions. In addition, questions from the MDS were designed for the general population and have not yet been validated. However, MDS questions provided an efficient and feasible solution in the context of the InSCI community survey and have the advantage of worldwide comparability with general population data. Furthermore, the modification of style and response options of some questions to reduce complexity for participants (and thus enhance feasibility) limits comparability to other surveys. Consequently, the modified questions lack validation, and their comparability with other data sources is decreased. Statistical methods of calibration of response options present a potential solution to address the comparability issue in upcoming data analysis. However, there are reasons to believe that the cognitive debriefing in the pilot test of the questionnaire would have identified critical issues.

Besides these limitations, our approach to develop the InSCI data model and questionnaire has several strengths. The selection of what to measure, that is, the definition of the InSCI data model, was based on established ICF core sets and thus presents a structured, transparent, and reasoned selection of relevant categories. By additionally involving worldwide experts, the iterative decision-making process reduced the risk of missing important categories. In addition, the application of guiding principles to operationalize the data model stimulated an argumentative process in which pros and cons of different questions were carefully considered. In conclusion, the InSCI community survey comprehensively captures what matters to people and, at the same time, is feasible and parsimonious with regard to participant burden. Moreover, the InSCI questionnaire offers satisfying comparability to general and SCI populations, although its validity and reliability still need to be confirmed.

ACKNOWLEDGMENTS

The authors thank the valuable input and support of the following researchers: Mirjam Brach, Martin Brinkhof, Jonviea Chamberlain, Armin Gemperli, Mirja Gross-Hemmi, Sonja Meier, Rachel Müller, Diana Pacheco Barzallo, Claudio Peter, Urban Schwegler, Vegard Strom, Denise Tate, Piotr Tederko, and Bruno Trezzini. The authors are very grateful to Reuben Escorpizo who led the pilot test of the InSCI questionnaire. In addition, special thanks go to all the country leaders and coordinators who provided input during the ISCoS and ISPRM conferences in 2015.

InSCI is part of The Learning Health System for Spinal Cord Injury, an initiative embedded in WHO's Global Disability Action Plan 2014–2021. The members of the InSCI Steering Committee are the following: Christoph Gutenbrunner (ISPRM representative), Doug Brown (ISCoS representative), Gerold Stucki (Chair Scientific Committee), Jianan Li (Co-Chair Scientific Committee), Mirjam Brach (Representative Coordinating Institute, Switzerland), Christine Thyrian (Representative Study Center, Switzerland), Marcel W.M. Post (Scientific Advisor), Jerome Edmond Bickenbach (Scientific Advisor), Marcelo Riberto (Brazil), Juan Manuel Guzmán González (Mexico), Reuben Escorpizo (USA), James Middleton (Australia), Jianan Li (China), Eiichi Saitoh (Japan), Zee-A Han (Korea), Nazirah Binti Hasnan (Malaysia), Xiang-Hu (Shaun) Xiong (New Zealand), Luh Karunia Wahyuni (Indonesia), Apichana Kovindha (Thailand), Abderrazak Hajjioui (Morocco), Conran Joseph (South Africa), Brigitte Perrouin-Verbe (France), Christoph Gutenbrunner (Germany), Christina-Anastasia Rapidi (Greece), Iuly Treger (Israel), Mauro Zampolini (Italy), Anda Nulle (Latvia), Alvydas Juocevicius (Lithuania), Marcel Post (the Netherlands), Johan K. Stanghelle (Norway), Piotr Tederko (Poland), Jorge Laíns (Portugal), Mercè Avellanet (Spain), Per Ertzgaard (Sweden), Micheal Baumberger (Switzerland).

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