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ORIGINAL RESEARCH

Cohort Profile of the International Spinal Cord Injury Community Survey Implemented in 22 Countries

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Abstract

Objectives: To detail the methodological features of the first International Spinal Cord Injury (InSCI) Community Survey by describing recruitment and data collection procedures, and to report on the recruitment results and basic characteristics of participants by country and income setting.

Design: Cross-sectional survey.

Setting: Community setting in 22 countries representing all 6 World Health Organization regions.

Participants: Individuals (N = 12,591) with traumatic or non-traumatic spinal cord injury (SCI) aged over 18 years.

Interventions: Not applicable.

Main Outcome Measures: Recruitment and data collection procedures, recruitment results, and basic sociodemographic and lesion characteristics of participants.

Results: Eight countries used predefined sampling frames and 14 countries applied convenience sampling for recruitment. Most countries recruited participants through specialized rehabilitation facilities, patient organizations, or acute and general hospitals. Modes of approaching

Disclosures: none.

potential participants depended on the sampling strategy and multiple response modes were offered to maximize participation. Contact rates ranged from 33% to 98%, cooperation rates ranged from 29% to 90%, and response rates ranged from 23% to 54%. The majority of participants were men (73%), the median age was 52 years (interquartile range, 40-63y), 60% had a partner, 8% reported that they were born in another country than where they were currently residing, and the median length of education was 12 years (interquartile range, 9-15y). Paraplegia was the main diagnosis (63%), traumatic etiologies were the major cause of injury (81%), and the median time since injury (TSI) was 9 years (interquartile range, 4-19y). Compared with participants from lower income settings, participants from higher income settings were over-represented and, in general, were older, more often diagnosed with tetraplegia, had a longer TSI, higher education, and were more often born in a country different than their current residence country.

Conclusions: The successful implementation of the InSCI survey enables the comparison of the situation of individuals with SCI around the world and constitutes a crucial starting point for an international learning experience.

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The International Spinal Cord Injury (InSCI) Community Survey presents the first international effort to systematically collect information on the lived experience of individuals with spinal cord injury (SCI) across the globe.^{1,2} As stated in a recent World Health Organization (WHO) report,³ a comprehensive description of the situation of individuals living with SCI across nations, different settings of economic development, and different health care and rehabilitation systems is currently lacking.³ Moreover, a comprehensive understanding of the individual's lived experience, conceptualized by the notion of functioning, has rarely been implemented in research.⁴ Functioning is understood as the outcome of a dynamic interaction between an individual's health condition and contextual factors (ie, personal factors and the environment in which an individual lives). With these unique features, the InSCI survey provides the database to describe the situation of individuals with SCI among diverse health systems and constitutes a crucial starting point for identifying how societies can respond to the needs of individuals with a chronic health condition, such as SCI. More specifically, the availability of data on self-reported health, functioning, contextual factors, and well-being of individuals with SCI allows for a comparison of the situation of persons with SCI across countries and helps to identify potential targets for improved health systems, and ultimately, improved lives of individuals with SCI. The initiative of the InSCI survey should further strengthen efforts to systematically collect data on individuals with SCI to provide a sound basis for epidemiological reporting on basic characteristics of the population living with SCI, as well as the study of factors that explain functioning and well-being in this population.

The first InSCI survey was successfully completed in 22 countries between 2017 and 2019 and will be repeated at 5-year intervals to obtain longitudinal and updated data. The overall objective of this study is to describe the methodology of the InSCI survey, recruitment results, and basic characteristics of the study participants. More specifically, we aim to (1) describe the recruitment and data

collection procedures; (2) provide details on recruitment results, including participation rates for the countries that used predefined sampling frames; and (3) report on basic characteristics of the study participants by country and income setting.

Methods

Design and recruitment of collaborating countries

The first InSCI survey was implemented in 22 countries across all 6 WHO regions between January 2017 and May 2019. Participating countries were recruited through the networks of the International Society of Physical Rehabilitation and Medicine and the International Spinal Cord Society (ISCoS). A kick-off meeting with potential collaborators was held in February 2015 in Switzerland. National Study Centers consist of national leaders and study coordinators (mostly academic or clinical affiliation), as well as additional supporting personnel. The responsibility for recruitment, data collection, and the organization of resources to execute the survey lies within the National Study Centers. Swiss Paraplegic Research, Switzerland, acts as coordinating institute, guiding and supporting National Centers in methodological and operational issues.

Population and recruitment of participants

Based on a power analysis, a minimal sample size of 200 participants per country was required.¹ Individuals with traumatic or non-traumatic SCI (including cauda equina syndrome) who were aged 18 years or older, living in the community, and being able to respond in one of the available language versions of the questionnaire were eligible for study participation. Individuals with congenital etiologies (eg, spina bifida), neurodegenerative disorders (eg, multiple sclerosis, amyotrophic lateral sclerosis), or peripheral nerve damage (Guillain Barré syndrome) were excluded.¹ A hierarchy to define sampling frames was proposed, assuming greater representativeness of samples from higher order sampling strategies: (1) national or regional registries of individuals with SCI; (2) databases of academic or level I trauma hospitals; (3) databases from specialized rehabilitation centers; (4) databases from disabled person's organizations or insurance agencies; (5) samples from previous SCI cohort studies; or a combination of the 5 sampling frames cited above.¹ Convenience samples among individuals visiting health care facilities or joining patient organization events were drawn in countries with limited access to databases of hospitals or patient organizations.

List of abbreviations:

GDP PPP	gross domestic product based on purchasing power parity
ICF	International Classification of Functioning, Disability and Health
InSCI	International Spinal Cord Injury
ISCoS	International Spinal Cord Society
Q	quartile
SCI	spinal cord injury
TSI	time since injury
WHO	World Health Organization

To standardize procedures of data collection and entry between countries, descriptions of standard operational procedures were established and implemented. Data storage followed high quality standards, including deidentification, harmonization and central storage on a password-protected database server. Response modes included paper-pencil questionnaires, online questionnaires, telephone interviews and personal interviews. According to local circumstances, countries decided on the offered response modes of the questionnaire. For example, most countries offered online and paper-pencil versions as a cost-effective method of data collection. However, in countries where illiteracy was prevalent (eg, Morocco, China), personal interviews were offered to increase response. Compliance with national laws and regulatory approvals by Institutional Review Boards or Ethical Committees was mandatory for all countries and conform to the Helsinki Declaration. Informed consent was sought from each participant in accordance with national regulations.

Measurement

The 125-item self-report questionnaire was developed by researchers of the coordinating institute (Swiss Paraplegic Research) relying on the International Classification of Functioning, Disability and Health (ICF).⁵ The InSCI data model consists of the components body functions and structures, activities and participation, environmental and personal factors, lesion characteristics, and appraisal of health and well-being. The questionnaire covers categories from the brief ICF core set for SCI in the long-term context,⁶ the ICF rehabilitation set,⁷ selected categories on personal factors,⁸ and measures for general health and well-being. To enhance data quality, constructs that were potentially difficult to understand were defined and explained in the questionnaire. Details on the questionnaire development and included data collection tools are reported elsewhere,⁹ and the questionnaire can be downloaded at: insci.network/insci/TT/en/download.php.

Information on age in years, sex, education, partnership status, foreign country of birth, lesion severity, time since injury (TSI), age at injury, and etiology was used to describe the study population. Education was assessed in line with the International Standard Classification of Education, summing up total years of formal education, including school and vocational training,¹⁰ and potential vocational retraining after SCI. Partnership status was assessed by asking participants about their current marital status (single, married, cohabiting or in a partnership, separated or divorced, widowed). Participants who indicated they were married, cohabiting, or living in a partnership were grouped into the "in partnership" category and others were grouped into the "not in partnership" category. Foreign country of birth was evaluated with a free text question asking participants in which country they were born. Individuals who indicated being born in a country other than the country where they currently resided were coded as having a foreign country of birth. Lesion severity was assessed with 1 item on the SCI level (paraplegia, tetraplegia) and 1 item on injury completeness (complete, incomplete). TSI in years was deduced from information on the injury date and the date of questionnaire completion. Etiology was measured with an item on the SCI cause, based on the ISCoS classification.¹¹

Statistical analysis

Analyses were performed using R version 3.5.0.³ Frequency statistics were used to describe the basic characteristics of

participants. The number of participants and percentages were indicated for categorical variables, and medians and first and third quartiles (Q1, Q3) were indicated for continuous variables. Stratified descriptions of basic characteristics by country and by income setting were provided to describe the sample. Gross domestic product based on purchasing power parity (GDP PPP) was used to define the income setting and countries were classified into quartiles according to their GDP PPP in 2017.¹² Participation rates were calculated based on international guidelines¹³ if countries based the recruitment on predefined sampling frames and were able to document relevant numbers.

Results

Recruitment and data collection procedures

Figure 1 provides an overview of the main methodological features of the recruitment and data collection procedures in collaborating countries. Eight countries (36%) relied on predefined sampling frames for recruitment and 14 countries (64%) applied convenience sampling (ie, asking eligible visitors of healthcare facilities or patient organization events to participate in the study). Overall, specialized rehabilitation facilities were the most frequently used recruitment source (17 countries; 77%), followed by patient organizations (14 countries; 64%), acute and general hospitals (12 countries; 55%), government agencies (3 countries; 14%), and preexisting study databases (2 countries; 9%). Six countries based the recruitment uniquely on 1 source for contacting potential participants (mainly specialized rehabilitation facilities), whereas 16 countries used multiple sources for initial recruitment.

Modes of first contact with potential participants included postal invitations, e-mail invitations, telephone calls, face-to-face contacts, or mobile text messages. Ten countries used 1 mode and 12 countries used multiple modes for recruitment. The initial recruitment mode largely depended on the applied sampling strategy (ie, all countries using predefined sampling frames sent written invitations or called potential participants via telephone); 11 out of 14 countries using convenience sampling recruiting potential participants face-to-face (ie, invited persons who visited the outpatient clinic or a patient organization event). All countries with predefined sampling frames reminded non-responders by written reminders or phone calls. Out of 14 convenience sampling countries, 8 reminded potential participants by telephone or e-mail if applicable, and 6 did not apply any reminder strategy because eligible individuals either completed the survey on-site or actively refused participation in the direct contact. All countries except 1 offered multiple response modes to maximize participation, with 91% offering paper and pencil questionnaires, 68% online questionnaires, and 82% personal or telephone interviews.

Recruitment results

A total of 12,591 persons participated in the first InSCI Community Survey (fig 2). Four countries recruited more than 1000 participants to enable more complex country-specific analysis, and 10 countries recruited between 200 and 300 participants. Additional countries were interested in implementing the InSCI survey but were unable to reach the required sample size of 200.

Participation status and participation rates were calculated for the subgroup of countries with predefined sampling frames

	Australia	Brazil	China	France	Germany	Greece	Indonesia	Italy	Japan	Lithuania	Malaysia	Morocco	Netherlands	Norway	Poland	Romania	South Africa	South Korea	Spain	Switzerland	Thailand	United States
Sampling strategies																						
Defined sampling frame																						
Convenience sampling																						
Recruitment sources																						
Rehabilitation facility	6	2		1	8	2		4		1	1	8	3	3	3	2		1		4	1	2
Acute & general hospital			29			2	9		3		7	6			1	2	3		4		3	2
Patient organization	3				3	4	7	1	1	1	3				1	1	1	1		2		2
Government agency	1					1					3											
Pre-existing study database				7													1					
Initial recruitment modes																						
Postal invitation																						
Email invitation																						
Telephone call																						
Face to face																						
Text message mobile phone																						
Reminder strategies																						
Written reminder																						
Second written reminder																						
Email reminder																						
Text message mobile phone																						
Telephone reminder																						
Offered response modes for questionnaire completion																						
Paper-pencil																						
Online																						
Smart phone																						
Personal interview																						
Telephone interview																						

Fig 1 Recruitment and data collection procedures in the InSCI Community Survey, including sampling strategies, recruitment sources, initial recruitment modes, reminder strategies and offered response modes.

(table 1). Contact rates indicate the percentage of eligible individuals who could be contacted. Contact rates varied considerably between countries, ranging from 33% (China) to more than 90% (Australia, the Netherlands, Norway), pointing at large differences in the availability of updated contact information. Cooperation rates specify the percentage of individuals who participated among those who were successfully contacted. Cooperation rates ranged from approximately 30% in Australia, the Netherlands, and Germany to 65% in Poland, 68% in China, and nearly 90% in South Africa, indicating that the willingness to participate varied largely by country and was high for the latter countries once contact was established. Response rates indicate the percentage of individuals who participated of the total number of eligible persons, assuming that those who could not be contacted would have been eligible. Response rates ranged from 23% in China to 54% in South Africa. The relatively low response rate in China and Poland can be partly explained by the high percentage of individuals who could not be contacted.

Characteristics of study participants

Basic sociodemographic and lesion characteristics of participants by country are presented in table 2. The majority of participants in all countries were men, and the median age at the time of the survey was 52 years, with youngest age in Malaysia, Morocco, Romania, and South Africa (37y) and the oldest in Australia, the Netherlands, and Norway (59-60y). The median age at the time of injury was 36 years, with the youngest age at injury observed in Lithuania and South Africa (25y) and the oldest in the Netherlands and China (45-46y). Nearly 60% of participants indicated living in a partnership, with large variations between countries (22% in South Africa to 85% in China). Fewer than 10% of participants reported a foreign country of birth. However, proportions of participants indicating a foreign country of birth varied markedly between countries, from 0% in Brazil, China, and Indonesia to 19% in Switzerland and 23% in Australia. Overall, the median years of education was 12, with the lowest medians in China,

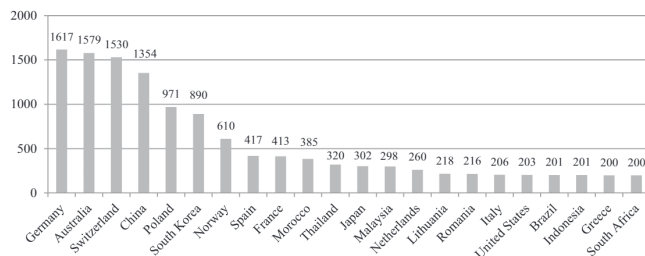


Fig 2 Number of participants in the InSCI Community Survey by country, N = 12,591.

Indonesia, Morocco, and Thailand (9y) and the highest in France (14y), the Netherlands (14y), and the United States (16y).

The median TSI was 9 years, with an overall interquartile range of 4 to 19 years, indicating that 25% of the total InSCI sample reported fewer than 4 years of education and 25% of the total sample reported having more than 19 years of education. The lowest TSI was observed in Brazil (median, 2), followed by China and Morocco (median, 4). The highest TSI was found in Japan, Lithuania, and Switzerland (median, 16). In all countries except Japan, more participants were diagnosed with paraplegia (63%) than with tetraplegia (38%). The proportion of individuals with the most severe lesion (complete tetraplegia) was lowest in all countries, except in Japan. Overall, 38% reported complete and 62% reported incomplete lesions, and the trend towards more frequent incomplete lesions was observed in 18 out of 22 countries. At 81%, traumatic SCI was the major cause of injury in the InSCI population. The lowest rates of traumatic cases were observed in the Netherlands and China (63% and 67%, respectively) and rates of more than 90% of traumatic cases were reported in South Africa, South Korea, and the United States. Missing values were generally low for sociodemographic and lesion characteristics (less than 2% for sex, age, partnership, foreign country of birth; less than 5% for TSI, lesion severity, etiology; 6% for total years of education).

Participants from countries in the highest GDP PPP quartile were over-represented in the InSCI study population. Participants from lower income settings were generally younger, less often diagnosed with tetraplegia, had shorter TSI, lower education, and were less often from a foreign country of birth than participants from higher income settings. Inconsistent patterns in the distribution of sex, age at time of injury, etiology, and partnership status were observed across the 4 income quartiles (table 3).

Discussion

The successful implementation of the InSCI Community Survey in 22 countries worldwide is a first step in describing the lived experience of individuals with SCI across nations, different settings of economic development, and different health care and rehabilitation systems. In addition to descriptions of the study population and recruitment results, this study provides an account of the methodology of recruitment and data collection, as well as a valuable reference for upcoming studies using InSCI data.

The reporting on applied methodologies in this cohort profile highlights the fact that the recruitment and data collection procedures, as well as recruitment results, depended largely on available opportunities and local circumstances in the collaborating countries. More specifically, the existence of collaborations with key stakeholders, the availability of updated patient databases, and the availability of adequate measures to track patients after the last contact with a health care facility were identified as decisive factors for the selection of the sampling strategy and the recruitment and data collection procedures. The difficulty of establishing a sampling frame before recruitment due to a lack of available and updated databases of individuals with SCI was identified as the primary reason why two-thirds of the countries relied on convenience sampling. Moreover, most countries only had limited financial and human resources to conduct the survey, which certainly constituted an additional challenge to the survey implementation.

Although basic characteristics of the InSCI population can hardly be compared and interpreted in terms of representativeness given the lack of population-based data on individuals with SCI in most world regions,³ some patterns of key sociodemographic and lesion characteristics observed for the InSCI sample suggest satisfactory face validity. For instance, face validity is supported by the fact that the overall proportion of 73% men in the InSCI sample and a mean age of 52 across countries follow a sex- and age-distribution that is in line with current evidence,¹⁴ at least for higher income settings. Moreover, the younger age, lower lesion level, shorter TSI, and lower education of participants from the lower income settings supports previous findings and may be explained by 2 reasons. First, the differences in age at the time of the survey and TSI between income settings reflect global differences in survival and life expectancy after SCI, which mainly emerge from the large inequalities in the quality and availability of health care facilities.¹⁵ Second, contacting individuals who sustained a SCI a longer time ago is expected to be more difficult in lower income settings as regular medical check-ups might not take place and public authorities may not allow the release of updated contact information for individuals who moved. A more detailed analysis of the generalizability of the samples in the different countries is not within the scope of this manuscript and will be discussed in upcoming country reports describing recruitment results and sample characteristics for each country, as well as providing information on envisioned implementation goals.

Table 1 Participation status of invited individuals and participation rates in countries with defined sampling frames

Abbreviation/Calculation	Participation Status of Invited Individuals						Participation Rates*			
	Invited		Eligible		Non-eligible		Refusal		Participation Rates	
	I+R+NC+NE n (%)	E n (%)	NE n (%)	NC n (%)	R n (%)	I n (%)	[(I+R)/(I+R+NC)] × 100 Rate, %	Cooperation Rates (I/I+R) × 100 Rate, %	Response Rates [I/(I+R+NC)] × 100 Rate, %	
Australia	6123	5925	198	563	3783	1579	90.5	29.4	26.6	
China	7478	5931	1549	3946	629	1354	33.4	68.3	22.8	
Germany	5998	5359	239	681	2822	1617	86.7	36.4	31.6	
Netherlands	847	787	60	16	511	260	98.0	33.7	33.0	
Norway	1456	1446	10	55	781	610	96.2	43.9	42.2	
Poland	3600	3069	531	1583	515	971	48.4	65.3	31.6	
South Africa	426	387	39	150	23	200	59.8	89.7	53.6	
Switzerland	4493	3959	534	740	1689	1530	81.3	47.5	38.6	

* Contact rates indicate the percentage of eligible individuals who could be contacted. Cooperation rates indicate the percentage of individuals who participated among those who could be contacted. Response rates indicate the percentage of individuals who participated among the total number of eligible individuals (note that individuals who could not be contacted are counted as eligible). Individuals who received an invitation but did not react were coded as refusals, and only individuals who could not be contacted due to wrong or inexistent contact details were coded as no contact.

Study limitations

For some of the collaborating countries, the InSCI survey is the first comprehensive and systematic collection of information on community-dwelling individuals with SCI. A comprehensive description of individuals with SCI across nations is currently lacking³ and the use of a common data collection tool enables comparability of information on the lived experience of individuals with SCI in all 6 WHO regions. Furthermore, high quality standards were met in data collection and storage.

The operational difficulties in accessing the target population and defining sound sampling frames limits the comparability between countries and the generalizability of results for countries using convenience sampling. Those difficulties in establishing representative samples lead to potentially limited validity of prevalence estimates of self-reported health, functioning, contextual factors, and well-being. In addition, basic characteristics of nonrespondents were unknown in most countries, making it difficult to compare differences with responders to assess potential nonresponse bias. Furthermore, the likelihood of survival after SCI depends on a country's income level,¹⁵ and mortality bias may affect comparability between countries. Also, the different sources for initial recruitment could lead to potential sampling bias as it cannot be excluded that individuals recruited through specific sources have certain characteristics in common (eg, more health complications in individuals recruited through acute hospitals). This limitation, however, might be attenuated by the fact that 16 out of 22 countries relied on multiple recruitment sources. The limitations related to sampling, nonresponse, and mortality bias need to be considered when interpreting results and potential sampling bias needs and, whenever possible, critical evaluation by comparing available information on SCI populations with key characteristics of the InSCI sample. For example, the United States sample consists only of traumatic cases, which restricts the generalizability to nontraumatic SCI populations. Given that evidence derived from the InSCI data might not be fully generalizable due to selection biases and, thus, limited representativeness, findings based on InSCI data often present the best evidence available that can lead to conclusions that have relevance for entire SCI populations of a country. For example, if environmental barriers were observed to restrict participation, it is still meaningful to conclude that environmental barriers need to be tackled, even for a sample with limited representativeness. Furthermore, the self-report nature of information collected in InSCI might be prone to reporting bias.

Developmental opportunities and operational challenges

From a developmental perspective, results of the InSCI Community Survey may support countries to raise awareness on the topic of rehabilitation and to strengthen the collaboration and exchange within community networks of relevant stakeholders, such as health care providers, affected individuals, policy makers, and researchers. This is particularly important in countries with poorly developed rehabilitation systems, as the availability of data on individuals with SCI is highly relevant in supporting any policy action. Furthermore, the InSCI collaborating network emphasizes the importance of collaborator support in developing scientific capacity. For example, the InSCI Scientific Committee supports regular workshops to teach methodological skills, provide individual statistical counseling, and provides an internal review for

Table 2 Basic sociodemographic and lesion characteristics of study participants by collaborating country

Country	N (%)	Female Sex		Age at Time of Survey, y of Injury, y		Years Since Injury		In Partnership		Foreign Country of Birth		Years of Education		Paraplegia Incomplete		Tetraplegia Complete		Tetraplegia Incomplete		Traumatic Etiology		
		n (%)	n (%)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
Total	12,591 (100.0)	3393 (27.0)	52 (40.63)	36 (24, 51)	9 (4, 19)	7380 (59)	951 (7.6)	12 (9, 15)	3381 (28.1)	4155 (34.5)	1225 (10.2)	3284 (27.3)	9991 (80.6)	546 (4.3)	546 (4.3)	1225 (10.2)	3284 (27.3)	9991 (80.6)	546 (4.3)	546 (4.3)	546 (4.3)	
Missing values N (% of total population)	1579 (12.5)	422 (26.7)	59 (48.68)	38 (24, 55)	13 (6, 25)	931 (59.1)	359 (23.0)	12 (9, 16)	362 (24.4)	542 (36.6)	128 (8.6)	449 (30.3)	1305 (83.5)			128 (8.6)	449 (30.3)	1305 (83.5)				
Australia	201 (1.6)	42 (20.9)	43 (30, 57)	40 (27, 53)	2 (1, 3)	103 (51.2)	0 (0.0)	11 (8, 14)	27 (13.4)	93 (46.3)	15 (7.5)	66 (32.8)	141 (70.1)			15 (7.5)	66 (32.8)	141 (70.1)				
Brazil	1354 (10.8)	391 (28.9)	50 (41, 59)	46 (36, 54)	4 (2, 5)	1,153 (85.2)	0 (0.0)	9 (6, 12)	277 (20.5)	629 (46.5)	68 (5.0)	380 (28.1)	869 (66.5)			68 (5.0)	380 (28.1)	869 (66.5)				
China	413 (3.3)	113 (27.4)	53 (41, 62)	28 (20, 44)	16 (6, 26)	231 (56.3)	26 (6.3)	14 (11, 17)	135 (33.5)	132 (32.8)	37 (9.2)	99 (24.6)	330 (80.9)			37 (9.2)	99 (24.6)	330 (80.9)				
France	1617 (12.8)	447 (28.0)	56 (46, 65)	42 (25, 56)	9 (4, 17)	981 (62.4)	111 (7.0)	13 (12, 16)	357 (23.5)	414 (27.3)	159 (10.5)	586 (38.7)	1,234 (79.1)			159 (10.5)	586 (38.7)	1,234 (79.1)				
Germany	200 (1.6)	54 (27.0)	47 (38, 56)	28 (20, 40)	13 (6, 22)	93 (46.7)	25 (12.6)	12 (12, 16)	73 (37.1)	61 (31.0)	18 (9.1)	45 (22.8)	159 (85.0)			18 (9.1)	45 (22.8)	159 (85.0)				
Greece	201 (1.6)	66 (32.8)	44 (35, 52)	31 (22, 41)	12 (3, 12)	138 (69.3)	0 (0.0)	12 (6, 12)	74 (37.9)	101 (51.8)	8 (4.1)	12 (6.2)	173 (87.8)			8 (4.1)	12 (6.2)	173 (87.8)				
Indonesia	206 (1.6)	53 (25.7)	51 (40, 60)	36 (25, 51)	10 (5, 17)	105 (51)	14 (6.8)	13 (8, 13)	61 (30.5)	87 (43.5)	15 (7.5)	37 (18.5)	141 (69.8)			15 (7.5)	37 (18.5)	141 (69.8)				
Italy	302 (2.4)	47 (15.9)	55 (44, 67)	31 (22, 49)	16 (8, 30)	179 (60.5)	1 (0.3)	12 (12, 14)	105 (35.8)	40 (13.7)	80 (27.3)	68 (23.2)	268 (89.9)			40 (13.7)	80 (27.3)	68 (23.2)	268 (89.9)			
Japan	218 (1.7)	81 (37.2)	42 (35, 49)	25 (20, 33)	16 (7, 22)	132 (60.6)	2 (0.9)	13 (12, 16)	110 (50.7)	42 (19.4)	52 (24.0)	202 (93.5)			42 (19.4)	52 (24.0)	202 (93.5)					
Lithuania	298 (2.4)	62 (20.8)	38 (29, 50)	28 (20, 40)	6 (3, 13)	141 (47.5)	3 (1.0)	11 (8, 13)	87 (30.4)	112 (39.2)	31 (10.8)	56 (19.6)	232 (85.4)			31 (10.8)	56 (19.6)	232 (85.4)				
Malaysia	385 (3.1)	106 (27.5)	37 (28, 47)	28 (22, 40)	4 (2, 9)	165 (42.9)	2 (0.5)	9 (4, 12)	137 (35.6)	148 (38.4)	35 (9.1)	65 (16.9)	298 (77.4)			35 (9.1)	65 (16.9)	298 (77.4)				
Morocco	260 (2.1)	87 (33.5)	59 (51, 69)	45 (28, 56)	10 (4, 22)	179 (69.4)	20 (7.7)	14 (11, 18)	50 (19.6)	107 (42.0)	22 (8.6)	76 (29.8)	159 (62.6)			22 (8.6)	76 (29.8)	159 (62.6)				
Netherlands	610 (4.8)	192 (31.5)	60 (45, 70)	51 (36, 62)	8 (4, 12)	394 (65.1)	46 (7.7)	13 (9, 15)	71 (12.5)	258 (45.3)	34 (6.0)	206 (36.2)	420 (69.7)			34 (6.0)	206 (36.2)	420 (69.7)				
Norway	971 (7.7)	164 (16.9)	45 (37, 57)	29 (22, 43)	11 (6, 19)	508 (52.6)	7 (0.7)	13 (11, 15)	322 (33.9)	187 (19.7)	110 (11.6)	332 (34.9)	861 (89.2)			110 (11.6)	332 (34.9)	861 (89.2)				
Poland	216 (1.7)	60 (27.8)	37 (30, 46)	28 (21, 38)	5 (2, 13)	89 (41.2)	1 (0.5)	12 (10, 14)	62 (28.8)	87 (40.5)	8 (3.7)	58 (27.0)	180 (83.7)			8 (3.7)	58 (27.0)	180 (83.7)				
Romania	200 (1.6)	50 (25.0)	37 (28, 47)	25 (20, 32)	7 (4, 16)	44 (22.1)	7 (3.5)	12 (10, 14)	67 (34.4)	52 (26.7)	38 (19.5)	185 (92.5)			38 (19.5)	185 (92.5)						
South Africa	890 (7.1)	214 (24.1)	49 (40, 57)	31 (23, 41)	15 (7, 22)	432 (49)	2 (0.2)	12 (11, 15)	348 (39.8)	178 (20.4)	157 (18.0)	191 (21.9)	815 (92.2)			157 (18.0)	191 (21.9)	815 (92.2)				
South Korea	417 (3.3)	125 (30.0)	51 (42, 61)	32 (22, 47)	14 (5, 24)	242 (58)	27 (6.6)	12 (8, 17)	129 (32.2)	125 (31.2)	54 (13.5)	93 (23.2)	321 (77.5)			54 (13.5)	93 (23.2)	321 (77.5)				
Spain	1530 (12.2)	440 (28.8)	58 (47, 68)	35 (23, 52)	16 (8, 28)	893 (58.6)	281 (18.6)	13 (12, 16)	370 (27.2)	562 (41.9)	114 (8.5)	296 (22.1)	1199 (79.4)			114 (8.5)	296 (22.1)	1199 (79.4)				
Switzerland	320 (2.5)	92 (28.8)	43 (33, 58)	32 (23, 50)	5 (2, 12)	141 (44.1)	1 (0.3)	9 (4, 14)	118 (37.6)	114 (36.3)	23 (7.3)	59 (18.8)	276 (86.2)			23 (7.3)	59 (18.8)	276 (86.2)				
Thailand	203 (1.6)	85 (41.9)	43 (32, 57)	26 (19, 47)	10 (4, 18)	106 (52.5)	16 (7.9)	16 (12, 18)	39 (19.4)	84 (41.8)	19 (9.5)	59 (29.4)	203 (100.0)			19 (9.5)	59 (29.4)	203 (100.0)				
United States																						

NOTE: Q1 indicates the first quartile, meaning that 25% of the data are smaller than or equal to this value. Q3 indicates the third quartile, meaning that 75% of the data are smaller than or equal to this value. The interquartile range indicates that 50% of the sample are placed within the range between Q1 and Q3.

Table 3 Basic characteristics of study participants by quartiles of GDP PPP

Income Quartiles Based on GDP PPP	Total		Female Sex		Age at Time of Survey, y		Years Since Injury		Age at Time of Injury, y		Partnership		Foreign Country of Birth		Years of Education		Paraplegia		Tetraplegia		Traumatic Etiology		
	N (%)	n (%)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	n (%)	n (%)	Median (Q1, Q3)	Median (Q1, Q3)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
Q1: lowest	2661 (21.1)	747 (28.1)	46 (34, 56)	4 (2, 8)	39 (26, 51)	1744 (65.6)	10 (0, 4)	9 (6, 12)	700 (26.5)	1137 (43.0)	187 (7.1)	620 (23.4)	1942 (74.4)	504 (27.0)	1654 (88.1)	488 (22.5)	1875 (85.0)	1672 (31.2)	4620 (79.4)	<.001	<.001	<.001	<.001
Q2: 2nd lowest	1903 (15.1)	421 (22.1)	43 (34, 54)	10 (5, 18)	28 (21, 40)	963 (50.8)	38 (2, 0)	13 (11, 16)	654 (35.0)	489 (26.2)	219 (11.7)	504 (27.0)	1654 (88.1)	488 (22.5)	1875 (85.0)	1672 (31.2)	4620 (79.4)	<.001	<.001	<.001	<.001	<.001	
Q3: 2nd highest	2228 (17.7)	552 (24.9)	51 (41, 60)	14 (6, 23)	31 (22, 44)	1189 (53.8)	70 (3, 2)	12 (11, 16)	778 (35.8)	562 (25.9)	343 (15.8)	488 (22.5)	1875 (85.0)	1672 (31.2)	4620 (79.4)	<.001	<.001	<.001	<.001	<.001	<.001	<.001	
Q4: highest	5799 (46.1)	1,673 (28.9)	58 (46, 67)	11 (5, 22)	40 (25, 56)	3484 (60.7)	833 (14.6)	14 (11, 17)	1249 (23.3)	1967 (36.7)	476 (8.9)	620 (23.4)	1942 (74.4)	504 (27.0)	1654 (88.1)	488 (22.5)	1875 (85.0)	1672 (31.2)	4620 (79.4)	<.001	<.001	<.001	<.001
P value	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001	

NOTE. P values for the comparison of countries from χ^2 tests (for categorical variables) and Kruskal-Wallis tests (for continuous variables age, education, years since injury). Q1 included Brazil, China, Indonesia, Morocco, South Africa, and Thailand. Q2 included Greece, Lithuania, Malaysia, Poland, and Romania. Q3 included France, Italy, Japan, South Korea, and Spain. Q4 included Australia, Germany, the Netherlands, Norway, Switzerland, and the United States.

scientific proposals to enhance the scientific capacity of collaborators and the scientific quality of projects using InSCI data.

Accessing the target population was the primary operational challenge to survey implementation, as there is limited routine collection worldwide of epidemiological data on individuals with SCI. In addition, national registries on individuals with SCI do not exist. Moreover, individuals with SCI are treated, if at all, in different health care settings, and databases across care settings are not coordinated or linked and often lack updated contact information.³ The initiative of the InSCI network will help strengthen efforts to identify information on individuals with SCI within countries in the network to provide sound epidemiological data in the future. Promising learning experiences were made in China, where despite challenging conditions, more than 1300 individuals with SCI completed the InSCI survey. Given that rehabilitative services are underdeveloped or nonexistent in lower income settings, collaborations could not yet be established. Further efforts will be made to include low-income countries as collaborating partners by intensifying networking activities in the framework of the 2 supporting societies, ISCoS and the International Society of Physical Rehabilitation and Medicine.

Conclusions

The successful implementation of the InSCI Community Survey contributes to reducing the knowledge gap regarding SCI and enables the comparability of the lived experience of persons with SCI across the globe. The InSCI data constitute a crucial starting point for an international learning experience in SCI.

Supplier

a. The R Foundation for Statistical Computing.

Keywords

Rehabilitation; Spinal cord injuries; Surveys and questionnaires

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The members of the InSCI Steering Committee are: Julia Patrick Engkasan (International Society of Physical Rehabilitation and Medicine representative, Malaysia), James Middleton (ISCoS representative, Member Scientific Committee, Australia), Gerold

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The use of InSCI survey data is currently restricted to participating countries. For further information or any request on future collaboration, please contact the InSCI study center at insci@paraplegic.ch.

References

- Gross-Hemmi MH, Post MW, Ehrmann C, et al. Study protocol of the International Spinal Cord Injury (InSCI) Community Survey. *Am J Phys Med Rehabil* 2017;96:S23-34.
- Stucki G, Bickenbach J. The International Spinal Cord Injury Survey and the Learning Health System for Spinal Cord Injury. *Am J Phys Med Rehabil* 2017;96:S2-4.
- World Health Organization. International perspectives on spinal cord injury. Geneva: World Health Organization; 2013.
- Stucki G, Bickenbach J, Melvin J. Strengthening rehabilitation in health systems worldwide by integrating information on functioning in National Health Information Systems. *Am J Phys Med Rehabil* 2017; 96:677-81.
- World Health Organization. International classification of functioning, disability and health: ICF. Geneva: World Health Organization; 2001.
- Cieza A, Kirchberger I, Biering-Sorensen F, et al. ICF core sets for individuals with spinal cord injury in the long-term context. *Spinal Cord* 2010;48:305-12.
- Proding B, Cieza A, Oberhauser C, Bickenbach J, Üstün TB, Chatterji S, Stucki G. Toward the ICF rehabilitation set: a minimal generic set of domains for rehabilitation as a health strategy. *Arch Phys Med Rehabil* 2016;97:875-84.
- Geyh S, Müller R, Peter C, Bickenbach JE, Post MW, Stucki G, Cieza A. Capturing the psychologic-personal perspective in spinal cord injury. *Am J Phys Med Rehabil* 2011;90:S79-96.
- Fekete C, Post MW, Bickenbach J, Middleton J, Proding B, Selb M, Stucki G. A structured approach to capture the lived experience of spinal cord injury: Data model and questionnaire of the International Spinal Cord Injury Community Survey. *Am J Phys Med Rehabil* 2017; 96:S5-16.
- United Nations Educational, Scientific and Cultural Organization. International standard classification of education (ISCED). Paris: United Nations Educational, Scientific and Cultural Organization; 1997.
- Biering-Sorensen F, DeVivo MJ, Charlifue S, et al. International Spinal Cord Injury Core Data Set (version 2.0)-including standardization of reporting. *Spinal Cord* 2017;55:759-64.
- World Bank. Gross domestic product based on purchasing power parity (GDP PPP) by countries. Available at: <https://data.worldbank.org/indicator/ny.gdp.mktpp.cd>. Accessed September 10, 2019.
- American Association for Public Opinion Research. Standard definitions: final dispositions of case codes and outcome rates for surveys 2016. Available at: https://www.aapor.org/AAPOR_Main/media/publications/Standard-Definitions20169theditionfinal.pdf. Accessed September 10, 2019.
- Bickenbach J, Boldt I, Brinkhof MW, et al. A global picture of spinal cord injury. In: Bickenbach J, et al., editors. International perspectives on spinal cord injury. Geneva: World Health Organization; 2013.
- Chamberlain JD, Meier S, Mader L, von Groote PM, Brinkhof MW. Mortality and longevity after a spinal cord injury: systematic review and meta-analysis. *Neuroepidemiology* 2015;44:182-98.