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## Cohort profile of the International Spinal Cord Injury (InSCI) Community Survey implemented in 22 countries

--Manuscript Draft--

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<b>Abstract:</b>	<p><b>Objective:</b> 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.</p> <p><b>Design:</b> Cross-sectional survey.</p> <p><b>Setting:</b> 22 countries representing all six WHO regions, community setting.</p> <p><b>Participants:</b> n=12,591 persons with traumatic or non-traumatic SCI aged ≥18 years.</p> <p><b>Interventions:</b> NA.</p> <p><b>Main Outcomes:</b> Recruitment and data collection procedures; recruitment results; basic participants' characteristics.</p> <p><b>Results:</b> Eight countries used predefined sampling frames and 14 countries applied convenience sampling for recruitment. Most countries recruited participants through specialized rehabilitation facilities, patient organizations, and/or acute and general hospitals. Modes of approaching potential participants depended on the sampling strategy and multiple response modes were offered to maximize participation. Contact rates ranged from 33%-98%; cooperation rates from 29%-90%, and response rates from 23%-54%. The majority of participants were males (73%), median age was 52 (IQR 40-63), 60% had a partner, 8% reported that they were born in another country than currently residing, and median education was 12 years (IQR 9-15). Paraplegia was the main diagnosis (63%), traumatic etiologies the major cause of injury (81%), and median time since injury (TSI) was 9 years (IQR 4-19). Participants from higher income quartiles were overrepresented, in general they were older, more often diagnosed with tetraplegia, had a longer TSI and a higher education, and were more often born in a foreign country to their current residing country than participants from lower quartiles.</p> <p><b>Conclusions:</b> The successful implementation of the InSCI survey enables to compare the lived experience of persons with SCI across the globe and constitutes a crucial starting point for an international learning experience in SCI.</p>



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## International SCI Survey (InSCI) articles – Second Revision “Cohort profile of the International Spinal Cord Injury (InSCI) Community Survey implemented in 22 countries”

Dear Glenn

As agreed with Prof. Allen Heinemann, we are currently passing over to you the six papers that are based on the results of the InSCI survey conducted in 22 countries. We are extremely satisfied with the quality of the data, and the huge potential it has for providing a firm, empirical basis, for a comprehensive understanding of the lived experience of spinal cord injury.

We herewith submit the second revision of the “Cohort profile of the International Spinal Cord Injury (InSCI) Community Survey implemented in 22 countries” paper by Christine Fekete.

We are very much looking forward to receiving your feedback.

1	Cohort profile of the International Spinal Cord Injury (InSCI) Community Survey implemented in 22 countries	Christine Fekete	Second revision submitted
2	Describing functioning in people living with spinal cord injury across countries – a graphical modelling approach	Cristina Ehrmann	Submitted
3	Comparison of the social response to functioning needs of people with SCI across over 20 countries	Diana Pacheco Barzallo	Reviews received
4	Work participation across the InSCI countries	Marcel Post	Submitted
5	Prevalence and associated factors of environmental barriers across countries	Jan D. Reinhardt	Reviews received
6	The way forward	Jerome Bickenbach	

Yours sincerely  
Swiss Paraplegic Research

Prof. Dr. Jerome Bickenbach  
Scientific Advisor, International Spinal  
Cord Injury Survey (InSCI)

Second revision of the manuscript entitled  
**‘Cohort profile of the International Spinal Cord Injury (InSCI) Community Survey’**  
(ARCHIVES-PMR-D-19-01164R1)

Dear Dr. Deutsch, dear Reviewers

We would like to thank you again for the helpful comments to improve our manuscript. Please find a point-to-point reply of your comments below.

Yours sincerely,

The authors

## **Editors comments**

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Additionally, while it is usually easy to follow your thoughts, a number of areas remain where unusual word choices or awkward English usage detracts from the value of your findings. While the Archives can provide some editing at the copyediting level, your paper requires a higher level of review. I recommend that it undergo a careful editing by a skilled writer of medical English. (This resource may be available through your institution or a commercial source.)

- Thank you, we have now carefully checked the manuscript together with native English speaking colleagues.

## **Reviewers' comments**

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Reviewer #1: no additional comments

Reviewer #2: The reviewer appreciates the efforts of the authors to improve this document. The authors took reviewer comments seriously and made substantial narrative changes in the document. As a result, the document is much more cohesive and coherent. This work substantially expands knowledge of spinal cord injury treatment across many areas of the globe and provides a foundation for improving outcomes for persons with spinal cord injuries in countries that have had limited access to emerging knowledge of SCI and its treatments.

- Thank you, we are very pleased that you acknowledge our efforts to improve the manuscript.

My comments are largely focused on coherence of the document. In just a few places, I found it necessary to request clarification of language and purpose. I think these changes will be made efficiently, based on the efforts made in response to comments on the first document.

Overall comments:

Below, the reviewer will comment on concepts that require further discussion. There will be no further comments on areas that have been improved. The reviewer appreciates the response to initial comments. Only comments that raise additional concerns are discussed below. These concerns are raised in the order that they appear and do not necessarily conform to the line numbers that the authors used in the revisions.

1. “With these unique features, the InSCI survey constitutes a crucial starting point for identifying how societies can respond to the needs of persons with a chronic health condition, such as SCI, and enables to

describe the lived experience of persons with SCI among diverging health systems.” It is unclear to this reviewer what “enables to describe” means. Please clarify the sentence. Thank you.

*- We have now revised the sentence to clarify its meaning (p. 2, line 44ff.): “With these unique features, the InSCI survey provides the database to describe the lived experience of persons with SCI among diverging health systems and constitutes a crucial starting point for identifying how societies can respond to the needs of persons with a chronic health condition, such as SCI.”*

2. More specifically, the availability of data on self-reported health, functioning, contextual factors, and well-being of persons 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, for improved lives of persons with SCI. [Suggest this change to clarify the focus of improved lives of persons with SCI.]

*- This is a good suggestion which we have now included.*

3. Suggested change: 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.

*- Thank you, we have changed the sentence according to your suggestion.*

4. Several items in the Measurement Section would benefit from some clarification: a) The meaning of the sentence “Emphasis was put on the feasibility in terms of understandability” is not clear nor is the rest of the sentence “and difficult constructs were defined to enhance accuracy of data.” Also, I think the term, “foreign country of birth” is confusing. This comes up several times in the measurement section. Is it possible to simply refer to the country of birth. Individuals only have one birth country....I’m confused about why the word “foreign” is needed.

*- We agree with the reviewer that the sentence on the ‘feasibility in terms of understandability’ is complex and we therefore revised it into: “Constructs that were potentially difficult to understand for participants were defined and explained in the questionnaire to enhance data quality.”*

*- However, we would like to stick to the term ‘foreign country of birth’ as we cannot think of a term that better describes what we measured. We have now revised the sentence describing the meaning of the variable ‘foreign country of birth’ reduce confusion: “Foreign country of birth was evaluated with a free text question asking participants in which country they were born. Persons who indicated being born in another country than the country where they currently resided were coded as having ‘foreign country of birth’.”*

5. Minor issue: Under line 4 of the Statistical Analysis section, there should be an “and” before the word “interquartile.” So the sentence would end, “and interquartile range....”).

*- We have realized that the sentence reads not very fluent and have revised it: “Frequency statistics were used to describe basic characteristics of participants. Number of participants and proportions (%) were indicated for categorical variables, and medians and first and third quartiles (Q1, Q3; and interquartile range IQR) were indicated for continuous variables.”*

6. In the last paragraph before the Discussion section, a sentence begins, “We observed....” I suggest that the first-person pronoun be dropped since it doesn’t occur anywhere else in the document. Perhaps something like, “There were inconsistent patterns....”

*- Thank you for detecting this inconsistency, which we have now changed into “Inconsistent patterns in the distribution of gender, age at time of injury, etiology, and partnership status across the four income quartiles were observed (Table 3)”.*

7. In the third section of the Discussion section, there is a sentence that that “public authorities may not allow to track persons who moved away.” The meaning of the “may not allow to track persons...” is not clear. Please clarify. Thank you.

*- We have now changed the wording in order to make it clearer: “...public authorities may not allow to release updated contact information on persons who moved away.”*

8. The second sentence in the section on “Developmental opportunities and operational challenges” uses the term “rehabilitative” systems. Should it not be “rehabilitation” systems?

*- Thank you, we have changed the term into ‘rehabilitation systems’.*

9. Please do “spell-check.” A few words have letters left out. Thanks.

*- We have used the spell-check function and could identify the typos left.*

Overall Comment: It is a genuine pleasure to work with individuals who take comments seriously and who make significant changes to the documents. I hope my comments are helpful, and I look forward to continuing to follow this important project. Congratulations on your achievements to date.

*- Thank you very much.*

**Running head:** InSCI community survey cohort profile

## **Cohort profile of the International Spinal Cord Injury (InSCI) Community Survey implemented in 22 countries**

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The members of the InSCI Steering Committee are: Julia Patrick Engkasan (ISPRM representative; Malaysia), James Middleton (ISCoS representative; Member Scientific Committee; Australia), Gerold Stucki (Chair Scientific Committee; Switzerland), Mirjam Brach (Representative Coordinating Institute; Switzerland), Jerome Bickenbach (Member Scientific Committee; Switzerland), Christine Fekete (Member Scientific Committee;

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75 **Conflict of interest**

76 The authors declare no conflict of interest.



# **Cohort profile of the International Spinal Cord Injury (InSCI) Community Survey implemented in 22 countries**

## **Abstract**

**Objective:** 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:** 22 countries representing all six WHO regions, community setting.

**Participants:** n=12,591 persons with traumatic or non-traumatic SCI aged  $\geq 18$  years.

**Interventions:** NA.

**Main Outcomes:** Recruitment and data collection procedures; recruitment results; basic participants' characteristics.

**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, and/or acute and general hospitals. Modes of approaching potential participants depended on the sampling strategy and multiple response modes were offered to maximize participation. Contact rates ranged from 33%-98%; cooperation rates from 29%-90%, and response rates from 23%-54%. The majority of participants were males (73%), median age was 52 (IQR 40-63), 60% had a partner, 8% reported that they were born in another country than currently residing, and median education was 12 years (IQR 9-15). Paraplegia was the main diagnosis (63%), traumatic etiologies the major cause of injury (81%), and median time since injury (TSI) was 9 years (IQR 4-19). Participants from higher income quartiles were overrepresented, in general they were older, more often diagnosed with tetraplegia, had a longer TSI and a higher education, and were more often born in a foreign country to their current residing country than participants from lower quartiles.

**Conclusions:** The successful implementation of the InSCI survey enables to compare the lived experience of persons with SCI across the globe and constitutes a crucial starting point for an international learning experience in SCI.

**List of Abbreviations:** ICF: International Classification of Functioning, Disability and Health; InSCI: International Spinal Cord Injury community survey; ISCoS: International Spinal Cord Society; ISPRM: International Society of Physical Rehabilitation and Medicine; SCI: spinal cord injury; TSI: Time since injury; WHO: World Health Organization

The International Spinal Cord Injury (InSCI) community survey presents the first international effort to systematically collect information on the lived experience of persons with spinal cord injury (SCI) across the globe.<sup>1,2</sup> As stated in a recent WHO report,<sup>3</sup> a comprehensive description of the situation of persons living with SCI across nations, different settings of economic development, and different health care and rehabilitation systems is currently lacking.<sup>3</sup> Moreover, a comprehensive understanding of the individual's lived experience – conceptualized by the notion of functioning – has rarely been implemented in research.<sup>4</sup> Functioning is understood as the outcome of a dynamic interaction between an individual's health condition and contextual factors, i.e. personal factors and the environment in which she or he lives. With these unique features, the InSCI survey provides the database to describe the lived experience of persons with SCI among diverse health systems and constitutes a crucial starting point for identifying how societies can respond to the needs of persons 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 persons 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 persons with SCI. The initiative of the InSCI survey should further strengthen efforts to systematically collect data on persons with SCI in order to provide a sound basis for epidemiological reporting on basic characteristics of the population living with SCI, and 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 paper is to describe the methodology of the InSCI survey, recruitment results and basic characteristics of study participants. More specifically, we aim to 1) describe recruitment and data collection procedures; 2) provide details on recruitment results including participation rates for the

different countries, with the reporting of sampling frames; and 3) report on basic characteristics of 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 six WHO world regions between 01/2017-05/2019. Participating countries were recruited through the networks of the International Society of Physical Rehabilitation and Medicine (ISPRM) 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 and/or clinical affiliation), and 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.<sup>1</sup> Persons having traumatic or non-traumatic SCI (including cauda equina syndrome), being aged  $\geq 18$  years, living in the community, and being able to respond in one of the available language versions of the questionnaire were eligible for study participation. Persons with congenital etiologies (e.g., spina bifida), neurodegenerative disorders (e.g., multiple sclerosis, amyotrophic lateral sclerosis) or peripheral nerve damage (Guillain Barré syndrome) were excluded.<sup>1</sup> A hierarchy to define sampling frames was proposed, assuming greater representativeness of samples from higher order sampling strategies: 1) national or regional registries of persons 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 sampling frames 1-5 cited above.<sup>1</sup> Convenience samples among persons visiting health

care facilities or joining patient organization events were drawn in countries with limited access to databases of hospitals or patient organizations.

In order 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 de-identification, harmonization and central storage on a password-protected database server. Response modes included paper-pencil or online questionnaires, and telephone or 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 way of data collection, but in countries where illiteracy was prevalent (e.g. Morocco, China) personal interviews were additionally 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).<sup>5</sup> 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',<sup>6</sup> the 'ICF rehabilitation set',<sup>7</sup> selected categories on personal factors,<sup>8</sup> and additionally contains measures for experienced health and well-being. Constructs that were potentially difficult to understand for participants were defined and explained in the questionnaire to enhance data quality. Details on the questionnaire development and included data collection tools are reported elsewhere<sup>9</sup> and the questionnaire can be downloaded at 'insci.network/insci/T1/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 is 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,<sup>10</sup> 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 indicating being married, cohabiting or living in a partnership were grouped into the category ‘in partnership’ and others into ‘not in partnership’. Foreign country of birth was evaluated with a free text question asking participants in which country they were born. Persons who indicated being born in another country than the country where they currently resided were coded as having ‘foreign country of birth’. Lesion severity was assessed with one item on SCI level (paraplegia; tetraplegia) and one 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.<sup>11</sup>

## **Statistical analysis**

Analyses were performed using R version 3.5.0 (The R Foundation for Statistical Computing). Frequency statistics were used to describe basic characteristics of participants. Number of participants and percentages (%) were indicated for categorical variables, and medians and first and third quartiles (Q1, Q3; and interquartile range IQR) 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 income setting and countries were classified into quartiles according to GDP (PPP) in 2017.<sup>12</sup> Participation rates were calculated based on international guidelines<sup>13</sup> if countries based the recruitment on predefined sampling frames and were able to document relevant numbers.

## **Results**

### **1) Recruitment and data collection procedures**

Figure 1 gives 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, i.e. 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 (n=17 countries; 77%), followed by patient organizations (n=14; 64%), acute and general hospitals (n=12; 55%), government agencies (n=3; 14%), and preexisting study databases (n=2; 9%). Six countries based the recruitment uniquely on one source for contacting potential participants (mainly specialized rehabilitation facilities), while 16 countries used multiple sources for initial recruitment.

Modes of first contact with potential participants included postal invitations, email invitations, telephone calls, face-to-face contacts or mobile text messages. Ten countries used one mode and 12 countries used multiple modes for recruitment. The initial recruitment mode largely depended on the applied sampling strategy, i.e., all countries using predefined sampling frames sent written invitations or called potential participants, and 11 out of 14 countries using convenience sampling recruiting potential participants face-to-face, i.e. 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 email if applicable, and 6 did not apply any reminding strategy since eligible persons either completed the survey on-site or refused participation. All countries (except one) offered multiple response modes to maximize participation, with 91% offering paper-pencil questionnaires, 68% online questionnaires and 82% personal or telephone interviews.

[Figure 1 around here]

## **2) Recruitment results**

A total of 12,591 persons participated in the first InSCI community survey (Figure 2). While four countries recruited over 1,000 participants in order to enable more complex country-specific analysis, 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.

[Figure 2 around here]

Participation status and participation rates were calculated for the subgroup of countries with predefined sampling frames (Table 1). Contact rates indicate the percentage of eligible persons who could be contacted. Contact rates varied considerably between countries, ranging from 33% (China) to over 90% (Australia, Netherlands, Norway), pointing at large differences in the availability of updated contact information. Cooperation rates specify the percentage of persons who participated of those who were successfully contacted. Cooperation rates ranged from around 30% in Australia, 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 could be established. Response rates indicate the percentage of persons 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, hereby the relatively low response rate in China and Poland can be partly explained by the high percentage of persons who could not be contacted.

[Table 1 around here]

### 3) Participants characteristics

Basic sociodemographic and lesion characteristics of participants by country are presented in Table 2. The majority of participants in all countries were males, and the median age at time of survey was 52 years, with lowest in Malaysia, Morocco, Romania and South Africa (37 years), and highest in Australia, Netherlands and Norway (59-60 years). Median age at time of injury was 36 years, lowest age at injury was observed in Lithuania and South Africa (25 years) and highest in Netherlands and China (45-46 years). Nearly 60% of participants indicated living in a partnership, with large variations between countries (22% in South Africa to 85% in China). Less 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, up to 19% in Switzerland and 23% in Australia. Overall, median years of education was 12, with lowest medians in China,

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

Median TSI was 9 years, with an overall IQR of 4-19 years, indicating that 25% of the total InSCI sample reported less than 4 years of education and 25% of the total sample reported having more than 19 years of education. Lowest TSI was observed in Brazil (median 2), followed by China and Morocco (median 4); 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 persons with the most severe lesion (complete tetraplegia) was lowest in all countries, except in Japan. Overall, 38% reported complete and 62% incomplete lesions and the trend towards more frequent incomplete lesions was observed in 18 out of 22 countries. With 81%, traumatic SCI was the major cause of injury in the InSCI population. Lowest rates of traumatic cases were observed in the Netherlands and China (63% and 67%, respectively) and rates of over 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 (below 2% for gender, age, partnership, foreign country of birth; below 5% for TSI, lesion severity, etiology; 6% for total years of education).

[Table 2 around here]

Participants from countries in the highest GDP PPP quartile are overrepresented in the InSCI study population. Participants from the lower income quartiles were in general 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 countries. Inconsistent patterns in the distribution of gender, age at time of injury, etiology, and partnership status across the four income quartiles were observed (Table 3).

[Table 3 around here]



## Discussion

The successful implementation of the InSCI community survey in 22 countries worldwide is a first step in describing the lived experience of persons with SCI across nations, different settings of economic development, and different health care and rehabilitation systems. Besides descriptions of the study population and recruitment results, this paper 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 recruitment and data collection procedures, as well as recruitment results largely depended 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 prior to recruitment due to a lack of available and updated databases of persons with SCI was identified as the main reason why two thirds of 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 persons with SCI in most world regions,<sup>3</sup> 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% males in the InSCI sample and a mean age of 52 across countries follow a gender and age-distribution that is in line with current evidence,<sup>14</sup> at least for higher income settings. Moreover, the younger age, lower lesion level, shorter TSI, and lower education of participants from the lower income quartiles supports previous findings and may be explained by two reasons. First, the differences in age at 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.<sup>15</sup> Second, contacting persons who sustained the SCI a longer time

ago is supposed 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 on persons who moved away. 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.

#### *Strength and limitations of the survey*

For some of the collaborating countries, the InSCI survey is the first comprehensive and systematic collection of information on community-dwelling persons with SCI. A comprehensive description of persons with SCI across nations is currently lacking;<sup>3</sup> however, the use of one data collection tool enables comparability of information on the lived experience of persons with SCI in all six WHO world 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 the limitation in validity of prevalence estimates of self-reported health, functioning, contextual factors and well-being. In addition, basic characteristics of non-respondents were unknown in most countries, making it difficult to compare differences with responders. Furthermore, the likelihood of survival after SCI depends on a country's income level,<sup>15</sup> 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 (e.g. more health complications in individuals recruited through acute hospitals). This limitation might be however attenuated by the fact that 16 out of 22 countries relied on multiple recruitment sources. The limitations related to sampling, non-response and mortality bias need to be considered when interpreting results and potential sampling bias needs, whenever possible, a critical evaluation by comparing available information on SCI populations with key characteristics of the InSCI sample. For example, the US sample only consists of traumatic cases, which restricts the

generalizability to non-traumatic 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 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. Further, 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 persons, policy makers and researchers. This is particularly important in countries with poorly developed rehabilitation systems, as the availability of data on persons 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, or provides an internal review for scientific proposals to enhance the scientific capacity of collaborators and the scientific quality of projects using InSCI data.

Accessing the target population was the main operational challenge to survey implementation as there is limited routine collection worldwide of epidemiological data on persons with SCI. In addition, national registries on persons with SCI do not exist. Moreover, persons 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.<sup>3</sup> The initiative of the InSCI network will help strengthen efforts to identify information on persons with SCI within countries in the network so that there is sound epidemiological data in the future. First promising learning experiences were made in China, where despite challenging conditions, over 1300 persons with SCI completed the InSCI survey. Given that rehabilitative services are underdeveloped or non-existent in lower income settings,

collaborations could not be established yet. Further efforts will be made to include low-income countries as collaborating partners by intensifying networking activities in the framework of the two supporting societies ISCoS and ISPRM.

## **Conclusions**

The successful implementation of the InSCI community survey contributes to reducing the knowledge gap about 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.

## **Data availability & collaboration**

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@paraplegie.ch](mailto:insci@paraplegie.ch).

## **Keywords**

Spinal cord injury; Community survey; Survey methodology; Response rates

## **References**

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## **Supplier**

R version 3.5.0 (The R Foundation for Statistical Computing).

## **Figure Legends**

**Figure 1.** Recruitment and data collection procedures in the InSCI community survey: Sampling strategies, recruitment sources, initial recruitment modes, reminder strategies and offered response modes

**Figure 2.** Number of participants in the InSCI community survey by country, total N=12,591

# Cohort profile of the International Spinal Cord Injury (InSCI) Community Survey implemented in 22 countries

## Abstract

**Objective:** To detail ~~on~~ the methodological features of [the first International Spinal Cord Injury \(InSCI\) community survey by describing](#) recruitment and data collection procedures ~~of the first International Spinal Cord Injury (InSCI) community survey,~~ and to report on the recruitment results and basic characteristics of participants by country and income setting.

**Design:** Cross-sectional survey.

**Setting:** 22 countries representing all six WHO regions, community setting.

**Participants:** n=12,591 persons with traumatic or non-traumatic SCI aged  $\geq 18$  years.

**Interventions:** NA.

**Main Outcomes:** Recruitment and data collection procedures; recruitment results; basic participants' characteristics.

**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, and/or acute and general hospitals. Modes of approaching potential participants depended on the sampling strategy and multiple response modes were offered to maximize participation. Contact rates ranged from 33%-98%; cooperation rates from 29%-90%, and response rates from 23%-54%. The majority of participants were males (73%), median age was 52 (IQR 40-63), 60% had a partner, 8% reported that they were born in another country than currently residing, and median education was 12 years (IQR 9-15). Paraplegia was the main diagnosis (63%), traumatic etiologies the major cause of injury (81%), and median time since injury (TSI) was 9 years (IQR 4-19). Participants from higher income quartiles were overrepresented, [in general they were](#) ~~and~~ older, more often diagnosed with tetraplegia, [with had a longer TSI and a](#) higher education, and [were more often born in a foreign country to their current residing country](#) ~~often foreign country of birth~~ than participants from lower quartiles.

**Conclusions:** The successful implementation of the InSCI survey enables to compare the lived experience of persons with SCI across the globe and constitutes a crucial starting point for an international learning experience in SCI.

**List of Abbreviations:** ICF: International Classification of Functioning, Disability and Health; InSCI: International Spinal Cord Injury community survey; ISCoS: International Spinal Cord Society; ISPRM: International Society of Physical Rehabilitation and Medicine; SCI: spinal cord injury; TSI: Time since injury; WHO: World Health Organization

The International Spinal Cord Injury (InSCI) community survey presents the first international effort to systematically collect information on the lived experience of persons with spinal cord injury (SCI) across the globe.<sup>1,2</sup> As stated in a recent WHO report,<sup>3</sup> a comprehensive description of the situation of persons living with SCI across nations, different settings of economic development, and different health care and rehabilitation systems is currently lacking.<sup>3</sup> Moreover, a comprehensive understanding of the individual's lived experience – conceptualized by the notion of functioning ~~understood as an outcome of a dynamic interaction between an individual's health condition and personal factors, and the environment in which she or he lives~~ – has rarely been implemented in research.<sup>4</sup> Functioning is understood as the outcome of a dynamic interaction between an individual's health condition and contextual factors, i.e. personal factors and the environment in which she or he lives. With these unique features, the InSCI survey provides the database to describe the lived experience of persons with SCI among diverging~~diverse~~ health systems and constitutes a crucial starting point for identifying how societies can respond to the needs of persons with a chronic health condition, such as SCI, ~~and enables to describe the lived experience of persons with SCI among diverging health systems.~~ More specifically, the availability of data on self-reported health, functioning, contextual factors, and well-being of persons 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, the improved lives of persons with SCI. The initiative of the InSCI survey should further strengthen efforts ~~to~~ systematically collect data on persons with SCI in order to



provide a sound basis for epidemiological reporting on basic characteristics of the population living with SCI, and 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 paper is to describe the methodology of the InSCI survey, recruitment results and basic characteristics of study participants. More specifically, we aim to 1) describe recruitment and data collection procedures; 2) provide details on recruitment results including participation rates for the ~~subgroup of different~~ countries, with ~~the~~ reporting of sampling frames; and 3) report on basic characteristics of 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 six WHO world regions between 01/2017-05/2019. Participating countries were recruited through the networks of the International Society of Physical Rehabilitation and Medicine (ISPRM) 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 and/or clinical affiliation), and additional supporting personnel. The responsibility for recruitment, data collection, and the organization of resources to execute the survey lies within the National Study Centers, ~~and~~ 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.<sup>1</sup> Persons having traumatic or non-traumatic SCI (including cauda equina syndrome), being aged  $\geq 18$  years, living in the community, and being able to respond in one of the available language versions of the questionnaire were eligible for study participation. Persons with congenital etiologies (e.g., spina bifida), neurodegenerative disorders (e.g., multiple sclerosis, amyotrophic lateral sclerosis)

or peripheral nerve damage (Guillain Barré syndrome) were excluded.<sup>1</sup> A hierarchy to define sampling frames was proposed, assuming ~~higher-greater~~ representativeness of samples ~~in-from~~ higher order sampling strategies: 1) national or regional registries of persons 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 sampling frames 1-5 cited above.<sup>1</sup> Convenience samples among persons visiting health care facilities or joining patient organizations events were drawn in countries with limited access to databases of hospitals or patient organizations.

In order 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 de-identification, harmonization and central storage on a password-protected database server. Response modes included paper-pencil or online questionnaires, ~~and~~ telephone or 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 way of data collection, but in countries ~~where with prevalent~~ illiteracy ~~was prevalent~~ (e.g. Morocco, China) personal interviews were additionally offered to increase response. Compliance with national laws and regulatory approvals by Institutional Review Boards or Ethical Committees ~~were-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).<sup>5</sup> 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,<sup>6</sup> the 'ICF rehabilitation set',<sup>7</sup> selected categories on personal factors,<sup>8</sup> and additionally contains measures for experienced health and well-being. ~~Emphasis was put on the~~

~~feasibility in terms of understandability and~~ Constructs that were potentially difficult to understand for participants were defined and explained in the questionnaire ~~difficult constructs were defined to~~ enhance ~~data quality, accuracy of data~~. Details on the questionnaire development and included data collection tools are reported elsewhere<sup>9</sup> and the questionnaire can be downloaded at 'insci.network/insci/T1/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 is 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,<sup>10</sup> 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); ~~whereby~~ ~~p~~Participants indicating being married, cohabiting or living in a partnership were grouped into the category 'in partnership' and others into 'not in partnership'. Foreign country of birth was evaluated with a free text question asking participants ~~in which country they were born, on their country of birth.~~ ~~Persons who indicated being born in another country than the country where they currently resided were coded as having 'foreign country of birth'.~~ Lesion severity was assessed with one item on SCI level (paraplegia; tetraplegia) and one 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.<sup>11</sup>

## Statistical analysis

Analyses were performed using R version 3.5.0 (The R Foundation for Statistical Computing). Frequency statistics were used to describe basic characteristics of participants, ~~including #~~Number of participants and ~~proportions percentages~~ (%) ~~were indicated~~ for categorical variables, and medians and first and third quartiles (Q1, Q3; ~~and~~ interquartile range IQR) ~~were indicated for continuous variables, 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 income setting and countries were classified into

quartiles according to GDP (PPP) in 2017.<sup>12</sup> Participation rates were calculated based on international guidelines<sup>13</sup> if countries based the recruitment on predefined sampling frames and were able to document relevant numbers.

## Results

### 1) Recruitment and data collection procedures

[Figure 1](#) gives an overview of the main methodological features of the recruitment and data collection procedures in collaborating countries ~~are presented in Figure 1~~. Eight countries (36%) relied on predefined sampling frames for recruitment and 14 countries (64%) applied convenience sampling, i.e. 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 (n=17 countries; 77%), followed by patient organizations (n=14; 64%), acute and general hospitals (n=12; 55%), government agencies (n=3; 14%), and preexisting study databases (n=2; 9%). Six countries based the recruitment uniquely on one source for contacting potential participants (mainly specialized rehabilitation facilities), while 16 countries used multiple sources for initial recruitment.

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

[Figure 1 around here]

## 2) Recruitment results

A total of 12,591 persons participated in the first InSCI community survey (Figure 2). While four countries recruited over 1,000 participants in order to enable more complex country-specific analysis, 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.

[Figure 2 around here]

Participation status and participation rates were calculated for the subgroup of countries with predefined sampling frames (Table 1). Contact rates indicate the percentage of eligible persons who could be contacted. Contact rates varied considerably between countries, ranging from 33% (China) to over 90% (Australia, Netherlands, Norway), pointing at large differences in the availability of updated contact information. Cooperation rates specify the percentage of persons who participated of those who were successfully contacted. Cooperation rates ranged from around 30% in Australia, 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 could be established. Response rates indicate the percentage of persons 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, hereby the relatively low response rate in China and Poland can be partly explained by the high percentage of persons who could not be contacted.

[Table 1 around here]

### 3) Participants characteristics

Basic sociodemographic and lesion characteristics of participants by country are presented in Table 2. The majority of participants in all countries were males, and the median age at time of survey was 52 years, with lowest in Malaysia, Morocco, Romania and South Africa (37 years), and highest in Australia, Netherlands and Norway (59-60 years). Median age at time of injury was 36 years, lowest age at injury was observed in Lithuania and South Africa (25 years) and highest in Netherlands and China (45-46 years). Nearly 60% of participants indicated living in a partnership, with large variations between countries (22% in South Africa to 85% in China). Less 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, up to 19% in Switzerland and 23% in Australia. Overall, median years of education was 12, with lowest medians in China, Indonesia, Morocco and Thailand (9 years) and highest in France, the Netherlands (14 years), and the United States (16 years).

Median TSI was 9 years, with an overall IQR of 4-19 years, indicating that 25% of the total InSCI sample reported less than 4 years of education and 25% of the total sample reported having more than 19 years of education. Lowest TSI was observed in Brazil (median 2), followed by China and Morocco (median 4); 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 persons with the most severe lesion (complete tetraplegia) was lowest in all countries, except in Japan. Overall, 38% reported complete and 62% incomplete lesions and the trend towards more frequent incomplete lesions was observed in 18 out of 22 countries. With 81%, traumatic SCI was the major cause of injury in the InSCI population. Lowest rates of traumatic cases were observed in the Netherlands and China (63% and 67%, respectively) and rates of over 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 (below 2% for gender, age, partnership, foreign country of birth; below 5% for TSI, lesion severity, etiology; 6% for total years of education).

[Table 2 around here]

Participants from countries in the highest GDP PPP quartile are overrepresented in the InSCI study population. Participants from the lower income quartiles were in ~~tendency general~~ younger, less often diagnosed with tetraplegia, ~~and~~ had shorter TSI, lower education and ~~were~~ less often ~~from a~~ foreign country of birth than participants from higher income countries. ~~We observed in~~ Inconsistent patterns in the distribution of gender, age at time of injury, etiology, and partnership status across the four income quartiles ~~were observed~~ (Table 3).

[Table 3 around here]

## Discussion

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

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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 persons with SCI in most world regions,<sup>3</sup> some patterns of key sociodemographic and lesion characteristics observed for the InSCI sample ~~indicate suggest satisfying satisfactory~~ face validity. For instance, face validity is supported by the fact that the overall proportion of 73% males in the InSCI sample and a mean age of 52 across countries follows a gender and age-distribution that is in line with current evidence,<sup>14</sup> at least for higher income settings. Moreover, the younger age, lower lesion level, shorter TSI, and lower education of participants from the lower income quartiles supports previous findings and may be explained by two reasons. First, the differences in age at 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.<sup>15</sup> Second, contacting persons who sustained the SCI a longer time ago is supposed to be more difficult in lower income settings as regular medical check-ups might not take place and public authorities may not allow ~~to the release of~~ updated contact information on track persons who moved away. 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.

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and well-being. In addition, basic characteristics of non-respondents were unknown in most countries, making it difficult to compare differences with responders. Furthermore, the likelihood of survival after SCI depends on a country's income level,<sup>15</sup> 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 (e.g. more health complications in individuals recruited through acute hospitals). This limitation might be however attenuated by the fact that 16 out of 22 countries relied on multiple recruitment sources. The limitations related to sampling, non-response and mortality bias need to be considered when interpreting results and potential sampling bias needs, whenever possible, a critical evaluation by comparing available information on SCI populations with key characteristics of the InSCI sample. For example, the US sample only consists of traumatic cases, which restricts the generalizability to non-traumatic 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 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. Further, the self-report nature of information collected in InSCI might be prone to reporting bias.

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## 320 **Conclusions**

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## 326 **Data availability & collaboration**

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## 331 **Keywords**

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334 **References**

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## Supplier

R version 3.5.0 (The R Foundation for Statistical Computing).

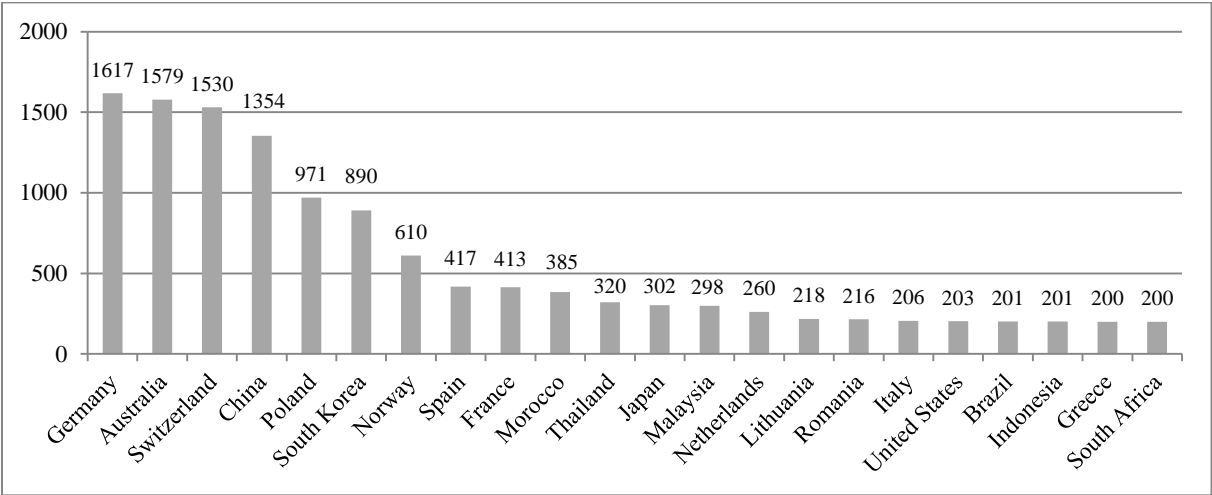
## Figure Legends

**Figure 1.** Recruitment and data collection procedures in the InSCI community survey: Sampling strategies, recruitment sources, initial recruitment modes, reminder strategies and offered response modes

**Figure 2.** Number of participants in the InSCI community survey by country, total N=12,591

[illegible]

Figure 2



**Table 1:** Participation status of invited persons and participation rates in countries with defined sampling frames

Participation status of invited persons							Participation rates <sup>a</sup>		
	Invited	Eligible	Non-eligible	No contact	Refusal	Participants	Contact rates	Cooperation rates	Response rates
Abbreviation/	I+R+NC+N	E	NE	NC	R	I	[(I+R)/(I+R+NC)]*100	[I/I+R]*100	[I/(I+R+NC)]
Calculation	E	E	NE	NC	R	I	NC)]*100		*100
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	Rate in %	Rate in %	Rate in %
Australia	6,123	5,925	198	563	3,783	1,579	90.5	29.4	26.6
China	7,478	5,931	1,549	3,946	629	1,354	33.4	68.3	22.8
Germany	5,598	5,359	239	681	2,822	1,617	86.7	36.4	31.6
Netherlands	847	787	60	16	511	260	98.0	33.7	33.0
Norway	1,456	1,446	10	55	781	610	96.2	43.9	42.2
Poland	3,600	3,069	531	1,583	515	971	48.4	65.3	31.6
South Africa	426	387	39	150	23	200	59.8	89.7	53.6
Switzerland	4,493	3,959	534	740	1,689	1,530	81.3	47.5	38.6

<sup>a</sup> Contact rates indicate % of eligible persons who could be contacted; Cooperation rates indicate % of persons who participated of those who could be contacted; Response rates indicate % of persons who participated of the total number of eligible persons (note that persons who could not be contacted are counted as eligible). Persons having received an invitation but did not react were coded as ‘refusals’, only persons who could not be contacted due to wrong or inexistent contact details were coded as no contact.

Table 2

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

Country	Total	Female gender	Age at time of survey (years)	Age at time of injury (years)	Years since injury	In partnership	Foreign country of birth	Years of education	Paraplegia complete	Paraplegia incomplete	Tetraplegia complete	Tetraplegia incomplete	Traumatic etiology
	N (%)	N (%)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	N (%)	N (%)	Median (Q1, Q3)	N (%)	N (%)	N (%)	N (%)	N (%)
Missing values	N (% of total pop)	33 (0.3)	78 (0.6)	405 (3.2)	92 (0.7)	343 (2.7)	139 (1.1)	769 (6.1)			546 (4.3)		546 (4.3)
Total	12,591 (100.0)	3,393 (27.0)	52 (40, 63)	36 (24, 51)	9 (4, 19)	7,380 (59)	951 (7.6)	12 (9, 15)	3,381 (28.1)	4,155 (34.5)	1,225 (10.2)	3,284 (27.3)	9,991 (80.6)
Australia	1,579 (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)
Brazil	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)
China	1,354 (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)
France	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)
Germany	1,617 (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)
Greece	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)
Indonesia	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)
Italy	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)
Japan	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)
Lithuania	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)	13 (6.0)	202 (93.5)
Malaysia	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)	252 (85.4)
Morocco	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)
Netherlands	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)
Norway	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)
Poland	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)
Romania	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)
South Africa	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)	38 (19.5)	185 (92.5)
South Korea	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)
Spain	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)
Switzerland	1,530 (12.2)	440 (28.8)	58 (47, 68)	35 (23, 52)	16 (8, 28)	893 (58.6)	281 (18.6)	13 (12, 16)	370 (27.6)	562 (41.9)	114 (8.5)	296 (22.1)	1,199 (79.4)
Thailand	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)
United States	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)

*Note:* N=Number of persons; %= percent in relation to the total population; Median = the ‘middle of the dataset’; Q1= first quartile; 25% of data are smaller or equal this value; Q3 = third quartile: 75% of data are smaller or equal this value. The interquartile range (IQR) indicates that 50% of the sample are placed within the range between Q1 and Q3.



Table 3

**Table 3:** Basic characteristics of study participants by quartiles of Gross Domestic Product based on purchasing power parity (GDP PPP)

	Total	Female gender	Age at time of survey (years)	Years since injury	Age at time of injury (years)	In partnership	Foreign country of birth	Years of education	Paraplegia complete	Paraplegia incomplete	Tetraplegia complete	Tetraplegia incomplete	Traumatic etiology
Income quartiles based on GDP PPP	N (%)	N (%)	Median (Q1, Q3)	Median (Q1, Q3)	Median (Q1, Q3)	N (%)	N (%)	Median (Q1, Q3)	N (%)	N (%)	N (%)	N (%)	N (%)
Q1: Lowest	2,661 (21.1)	747 (28.1)	46 (34, 56)	4 (2, 8)	39 (26, 51)	1,744 (65.6)	10 (0.4)	9 (6, 12)	700 (26.5)	1137 (43.0)	187 (7.1)	620 (23.4)	1,942 (74.4)
Q2: 2 <sup>nd</sup> lowest	1,903 (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)	1,654 (88.1)
Q3: 2 <sup>nd</sup> highest	2,228 (17.7)	552 (24.9)	51 (41, 60)	14 (6, 23)	31 (22, 44)	1,189 (53.8)	70 (3.2)	12 (11, 16)	778 (35.8)	562 (25.9)	343 (15.8)	488 (22.5)	1,875 (85.0)
Q4: Highest	5,799 (46.1)	1,673 (28.9)	58 (46, 67)	11 (5, 22)	40 (25, 56)	3,484 (60.7)	833 (14.6)	14 (11, 17)	1,249 (23.3)	1,967 (36.7)	476 (8.9)	1,672 (31.2)	4,520 (79.4)
<i>p-value</i>	<i>&lt;0.001</i>	<i>&lt;0.001</i>	<i>&lt;0.001</i>	<i>&lt;0.001</i>	<i>&lt;0.001</i>	<i>&lt;0.001</i>	<i>0.100</i>	<i>&lt;0.001</i>	<i>&lt;0.001</i>	<i>&lt;0.001</i>	<i>&lt;0.001</i>	<i>&lt;0.001</i>	<i>&lt;0.001</i>

Q1: Brazil, China, Indonesia, Morocco, South Africa, Thailand.

Q2: Greece, Lithuania, Malaysia, Poland, Romania.

Q3: France, Italy, Japan, South Korea, Spain.

Q4: Australia, Germany, Netherlands, Norway, Switzerland, United States.

Note: *p*-values for the comparison of countries from chi-squared tests (for categorical variables) and Kruskal-Wallis tests (for continuous variables age, education, years since injury).



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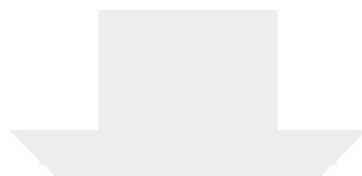
STROBE Statement—Checklist of items that should be included in reports of *cross-sectional studies***Cohort profile of the International Spinal Cord Injury (InSCI) community survey**

	<b>Item No</b>	<b>Recommendation</b>	<b>Page No</b>
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	1
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2
Objectives	3	State specific objectives, including any prespecified hypotheses	2, last paragraph – this is a descriptive paper thus no hypothesis
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	3-4
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants	3
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	4
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4
Bias	9	Describe any efforts to address potential sources of bias	Only descriptive analysis
Study size	10	Explain how the study size was arrived at	4, see reference 1 for power analysis
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	NA
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	5, see comment above on confounding
		(b) Describe any methods used to examine subgroups and interactions	5
		(c) Explain how missing data were addressed	5
		(d) If applicable, describe analytical methods taking account of sampling strategy	NA
		(e) Describe any sensitivity analyses	NA
<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed	7

		eligible, included in the study, completing follow-up, and analysed	
		(b) Give reasons for non-participation at each stage	NA
		(c) Consider use of a flow diagram	NA
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	7-8
		(b) Indicate number of participants with missing data for each variable of interest	Table 3
Outcome data	15*	Report numbers of outcome events or summary measures	NA
Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	NA
		(b) Report category boundaries when continuous variables were categorized	NA
		(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	NA
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	Table 4
<b>Discussion</b>			
Key results	18	Summarise key results with reference to study objectives	9
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	10
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	9-10
Generalisability	21	Discuss the generalisability (external validity) of the study results	10
<b>Other information</b>			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	This is a non-funded study

\*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at [www.strobe-statement.org](http://www.strobe-statement.org).



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