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Published in:
Journal of Neurotrauma

DOI:
[10.1089/neu.2017.5036](https://doi.org/10.1089/neu.2017.5036)

Publication date:
2018

Document version
Publisher's PDF, also known as Version of record

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Citation for published version (APA):
Noonan, V. K., Chan, E., Bassett-Spiers, K., Berlowitz, D. J., Biering-Sørensen, F., Charlifue, S., ... Brown, D. J. (2018). Facilitators and Barriers to International Collaboration in Spinal Cord Injury: Results from a Survey of Clinicians and Researchers. *Journal of Neurotrauma*, 35(3), 478-485. <https://doi.org/10.1089/neu.2017.5036>

Facilitators and Barriers to International Collaboration in Spinal Cord Injury: Results from a Survey of Clinicians and Researchers

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Abstract

International collaboration in spinal cord injury (SCI) research is necessary to overcome the challenges often encountered by clinicians and researchers, including participant recruitment, high cost, and the need for specialized expertise. However, international collaboration poses its own obstacles. The objective of this study was to conduct an international online survey to assess barriers and facilitators to international SCI clinical research, potential initiatives to facilitate future collaborations, and the use of SCI-specific data sets and standards. Results were analyzed using descriptive statistics. Of 364 total respondents, 213 completed the survey, with the majority of these participants based in North America (38%), Asia (22%), Europe (18%), and Oceania (16%). Over half had more than 10 years of experience in SCI research or clinical practice (57%) and 60% had previous experience with international collaborations. Funding was identified as a top barrier (82%), a facilitator (93%), and a proposed future initiative (97%). Communication and technology were also identified as strong facilitators and proposed future initiatives. The International Standards for Neurological Classification of SCI were used by 69% of participants, the International Standards to document remaining Autonomic Function after SCI by 13% of participants, and the International SCI Data Sets by 45% of participants. As the need for international collaborations in SCI research increases, it is important to identify how clinicians and researchers can be supported by SCI consumer and professional organizations, funders, and networks. Furthermore, unique solutions to overcome modifiable barriers and creation of new facilitators are also needed.

Keywords: clinical research; international collaboration; spinal cord injury; standardization

Introduction

CLINICAL RESEARCH in a health condition such as spinal cord injury (SCI) can be challenging.^{1,2} The lower incidence and prevalence of SCI, compared with other major health conditions such as stroke or cancer, poses inherent challenges to participant recruitment.^{3,4} In addition, the cost of conducting clinical studies is high and the expertise required to execute them is highly specialized. These challenges often result in small study samples with low statistical power, increased competition for limited funding, and mul-

iple studies targeting a small population of individuals with SCI. To overcome these problems, international collaboration is emerging as a critical factor to leverage existing funding, personnel, and study participants. International collaborations also provide an opportunity to exchange knowledge and experience, improve the generalizability of research to an international setting, and train the next generation of clinical researchers.

The International Spinal Cord Society (ISCoS) has a mandate to promote the highest standard of care in the practice of SCI and to foster education, research, and clinical excellence.⁵ The annual

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scientific meetings of ISCoS have provided a venue for clinicians and researchers from across the world to explore the feasibility and logistics of expanding international collaborations in clinical research and best practice implementation. Through ISCoS, there have been multiple collaborations, such as the “E-Learning” training modules, which were developed and deployed with input from more than 36 countries and 332 SCI experts worldwide.⁶ In addition, national and local SCI networks also are expanding beyond their native country and forming successful collaborations. Examples of SCI clinical and research networks around the world include Europe (e.g., European Multicenter Study about SCI^{7,8}), North America (e.g., Rick Hansen Institute,⁹ Ontario Neurotrauma Foundation,¹⁰ Spinal Cord Injury Model Systems¹¹), Australia (e.g., Spinal Research Institute,¹² Australasian Spinal Cord Injury Network¹³), and Asia (e.g., ISCoS Database: Asian Spinal Cord Network Pilot Project¹⁴). There are also a number of organizations that fund SCI research and have international collaborations including: the Christopher and Dana Reeve Foundation,¹⁵ the Craig H. Neilsen Foundation,¹⁶ the Miami Project to Cure Paralysis,¹⁷ and the Institute for Safety, Compensation and Recovery Research.¹⁸ Other initiatives working towards international data standardization and harmonization include the International SCI Data Sets,^{19,20} and the National Institute of Neurological Disorders and Stroke SCI Common Data Elements.^{21–23}

It is evident that, along with benefits, international collaborations pose unique challenges. Cultural and language barriers may hinder effective communication among team members, ethical complications with security and privacy for sharing data may arise, and technical resources for international communication must be provided. Addressing these potential challenges, or at least considering them in the planning stage, is crucial for projects to be successful.

In 2013, at the 52nd ISCoS Annual Scientific Meeting in Istanbul, Turkey, a workshop was held to share experiences and lessons learned from leading international multi-center trials and collaborations, as well as to discuss the benefits and barriers to participation in international collaborations in SCI clinical research. The workshop featured presentations on successful international collaborations from the perspective of researchers, clinicians, and consumers followed by small group discussions, and ended with a panel discussion. As a result of the workshop, two surveys—one directed to individuals with SCI (consumer survey) and the other to SCI clinicians and researchers—were proposed to gain further insights into what individuals perceived as the prominent facilitators and barriers to participating in international collaborations in SCI clinical research. The consumer survey included 802 participants; the number one facilitator for participating in clinical research was the possibility of improving functionality and the number one barrier was the possibility of a decline in functionality.²⁴ While these results may have been expected, the unexpected facilitators and barriers that emerged from the survey include the possibility to learn more about their general health/SCI and potential out-of-pocket expenses, respectively.²⁴ The main goal of performing these surveys was to determine how SCI consumers, researchers, and organizations can work together to best support, design and conduct international SCI clinical research collaborations. The objective of the present article is to describe the results from a survey completed by clinicians and researchers on the barriers and facilitators to international collaborations in SCI clinical research.

Methods

Survey development

The ISCoS 2013 workshop identified the following key themes for international collaboration: 1) breaking down fund-

ing barriers; 2) improving communication and transparency; and 3) finding future innovative solutions for collaborations. Using these key themes, expert input, and a literature review of relevant studies, the authors developed a 50-question survey. The survey consisted of five parts: 1) current barriers to international collaboration; 2) current facilitators of international collaboration; 3) proposed initiatives to facilitate future international collaboration; 4) SCI-specific international standards and data sets; and 5) demographics and expertise of the participant. (For the complete survey, see the online Supplementary Material at www.liebertpub.com). Parts 1, 2, and 3 included questions with five response options that ranged from “strongly agree” to “strongly disagree.” Participants who identified as having no experience with international collaborations were directed to skip part 1. Parts 4 and 5 of the survey included questions regarding the participants’ use of the International SCI Standards and Data Sets and about their educational and research/clinical background, respectively. Many questions included a comments box for free text. The survey was tested for clarity by members of the research team. Three individuals with varying amounts of international expertise in conducting SCI research also piloted the survey and provided feedback.

Participants

Individuals were eligible to participate in the survey if they fulfilled the following inclusion criteria: 1) were 18 years or older at the time the survey was conducted; 2) had worked in either SCI clinical practice or SCI research; and 3) understood written English. Respondents were recruited through email invitations and newsletters sent to members, subscribers, collaborators and partners of various SCI organizations (e.g., Rick Hansen Institute; Ontario Neurotrauma Foundation; Institute for Safety, Compensation and Recovery Research; ISCoS). Flyers advertising the survey were also distributed at relevant conferences. Participants were offered the chance to be included in a draw for three \$25.00 (CAD) gift certificates if they completed the survey. Ethical approval to conduct this study was obtained from the Veritas Independent Review Board.²⁵

Data collection

Data collection was performed by the Mustel Group,²⁶ a market research organization that specializes in online surveys. The survey data were collected using a web-based format. Materials were available in English. Demographic information and expertise (both with SCI and international collaborations) were monitored in an attempt to minimize any sampling biases and ensure representation from diverse backgrounds and regions.

Analysis

Data from the survey were analyzed using descriptive statistics. The top barriers, facilitators and initiatives were determined by adding together the percentage of participants who “somewhat agree” and “strongly agree.” Barriers that were potentially modifiable by an international initiative (e.g., a new funding opportunity), in contrast to a barrier that is specific to a particular country (e.g., language, privacy regulations) and cannot be easily influenced by an international initiative from an external organization, were identified by the authors. The comments in parts 1, 2, and 3 were reviewed for each question. The comments in part 4 describing why participants did not use the International SCI Data Sets or Standards were grouped into the following categories: inaccessibility, capacity (e.g., personnel/funding/time constraints), lack of knowledge/training, unmet research needs, lack of opportunity, not relevant to their type of research, not part of their role in the study, unnecessary for their study, and “other.” The countries

of residence of the participants were grouped into the following geographical regions: Africa, Asia, Europe, North America, South America, and Oceania.

Results

Participant demographics

The survey was completed by 213 (referred to as “participants”) out of 364 total respondents who attempted the survey (59%) between June 2014 and February 2015. For the 151 respondents who were excluded, 114 (76%) did not complete the survey, 30 (20%) were ineligible, and seven (< 5%) were duplicates. Participation was geographically diverse, with the majority from North America (38%), Asia (22%), Europe (18%), and Oceania (16%). Over half of the participants (57%) had more than 10 years of experience in SCI research and/or clinical practice and 60% had previous international collaboration experience. The majority of participants identified clinical rehabilitation as one of their areas of research focus (80%) followed by clinical acute (35%). The most common organizational research environment was hospital rehabilitation (62%) followed by academic (58%; Table 1).

Barriers, facilitators and initiatives

Results from part 1 of the survey, completed by 127 participants with previous international collaboration experience, indicated the most frequent barriers to international collaborations were funding availability (82% agreed) followed by insufficient time to dedicate to research (73%), funding timelines (67%) and differences in standards of care/health care system differences (67%; Fig. 1). The importance of funding was reiterated many times in the comments; for example, “Start-up of collaborative projects is very expensive and public funding/granting agencies do not fund the real cost of initiating collaborative studies,” “[It is] difficult to assign personnel if you don’t have sustainable funding,” and “[Insufficient time to dedicate to the project] is not a problem if there is enough money.” Of the 16 barriers included, seven were identified as being potentially modifiable and could be addressed in a future international initiative led by SCI organizations (funding availability; insufficient time to dedicate to the project/collaboration; funding timelines; research capacity; study participant recruitment; technological infrastructure; and knowledge and experience of conducting clinical trials). All seven of the modifiable barriers were identified in the top 10 barriers to international collaborations.

The majority of responses (> 75%) from the 213 participants in part 2 of the survey agreed that all six of the suggested factors influencing participation have facilitated or could facilitate international SCI research collaborations (Fig. 2). The paucity of current facilitators was reflected by the comment of one participant who noted that, “in my opinion, the lack of facilitators is a bigger barrier than any of the barriers listed in this study.” Top facilitators were personal relationships (94% agreed), funding that can be used to support international research (93%), and networks (90%).

Similarly to the responses about the facilitators, the majority of participants (> 75%) agreed that all the proposed future initiatives would also facilitate international SCI research collaborations (Fig. 3). The initiative that most participants agreed would facilitate future collaborations was additional international funding sources (97% agreed). More opportunities to develop personal relationships (93%) and participate in inter-

TABLE 1. DESCRIPTION OF INCLUDED PARTICIPANTS

Variable	Description	Value (n=213)
Level of experience with international collaborations	Very experienced	36 (17%)
	Some experience	91 (43%)
	None	86 (40%)
Highest level of education*	Diploma	12 (6%)
	Bachelor or undergraduate degree	29 (14%)
	Degree in medicine	71 (35%)
	Masters	58 (28%)
	Doctorate	72 (35%)
Country of residence by region	Other	27 (13%)
	North America	81 (38%)
	Asia	46 (22%)
	Europe	39 (18%)
	Oceania	33 (16%)
	Africa	11 (5%)
South America	South America	2 (< 1%)
	Missing	1 (< 1%)
Years of experience in SCI research and/or clinical practice	0 to <2	13 (6%)
	2 to <5	29 (14%)
	5 to 10	50 (23%)
	> 10	121 (57%)
Primary research area*	Pre-clinical	20 (10%)
	Clinical (patient-focused) - acute	71 (35%)
	Clinical (patient-focused) - rehab	163 (80%)
	Population (epidemiology)	42 (21%)
	Policy (administration)	14 (7%)
Type of organizational research environment*	Academic (affiliated with a university)	119 (58%)
	Industry	12 (6%)
	Non-profit	26 (13%)
	Hospital—acute	61 (30%)
	Hospital—rehabilitation	126 (62%)
	Hospital—longer-term care	24 (12%)
	Other	16 (8%)

*Participants can select more than one option.
SCI, spinal cord injury.

national research exchanges specific for SCI (91%) as well as technology-related factors including a database of available clinical trials or studies that require additional sites (91%), and an international information technology platform for data collection and management (90%) were identified. Other ideas provided by the participants of future initiatives to facilitate international collaboration included “workshops on how it works, successful examples, and what one would have to do to successfully conduct an international research collaboration,” and “organizing small groups with common interests and goals and providing funding for group collaboration, communication and exchange is a necessary first step for development of collaborative research teams.”

International SCI Standards and Data Sets

The International Standards for Neurological Classification of SCI (ISNCSCI) were reported to be used by 69% of participants

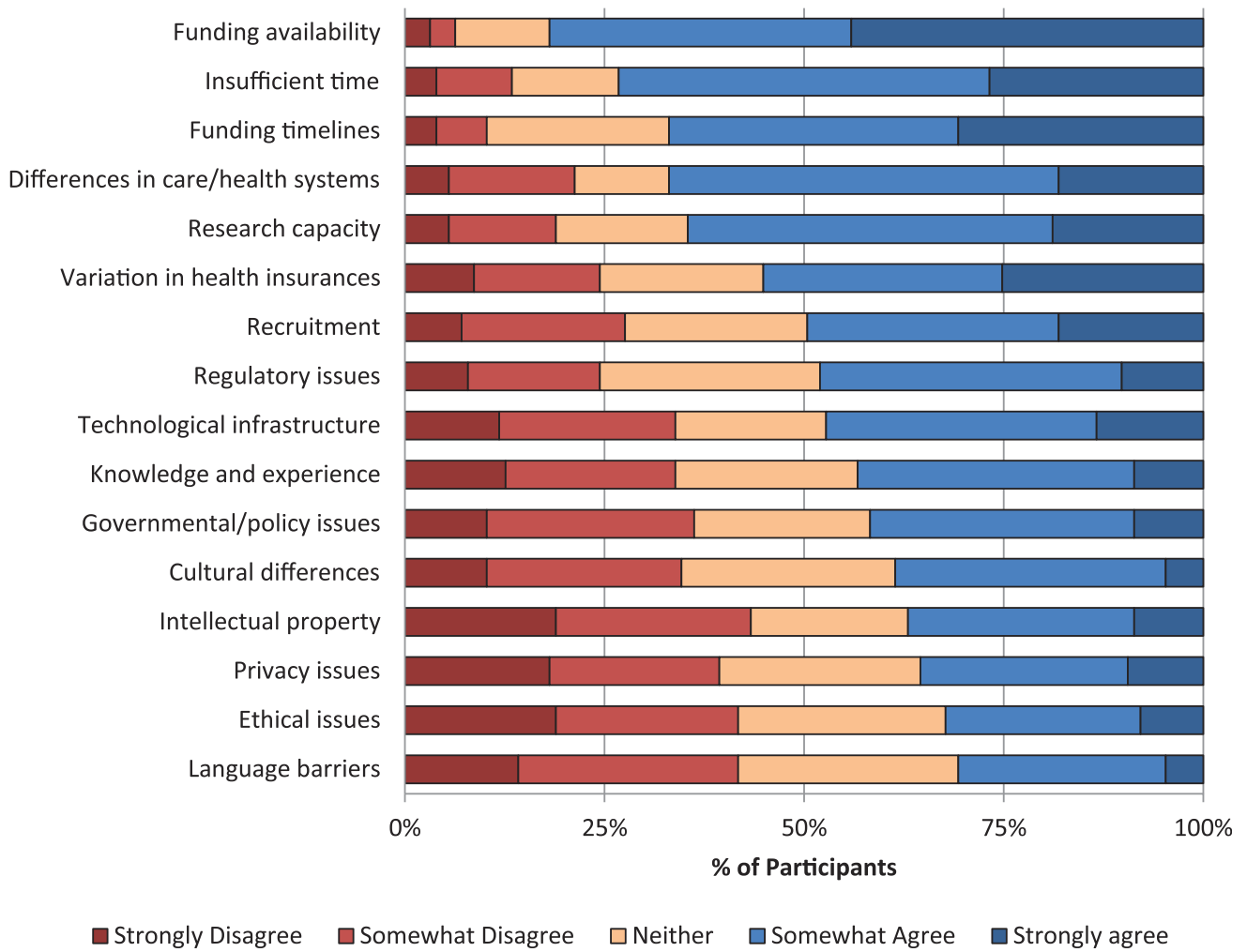


FIG. 1. Barriers to International Spinal Cord Injury Research Collaborations. Barriers are listed by the percentage of participants who agree.

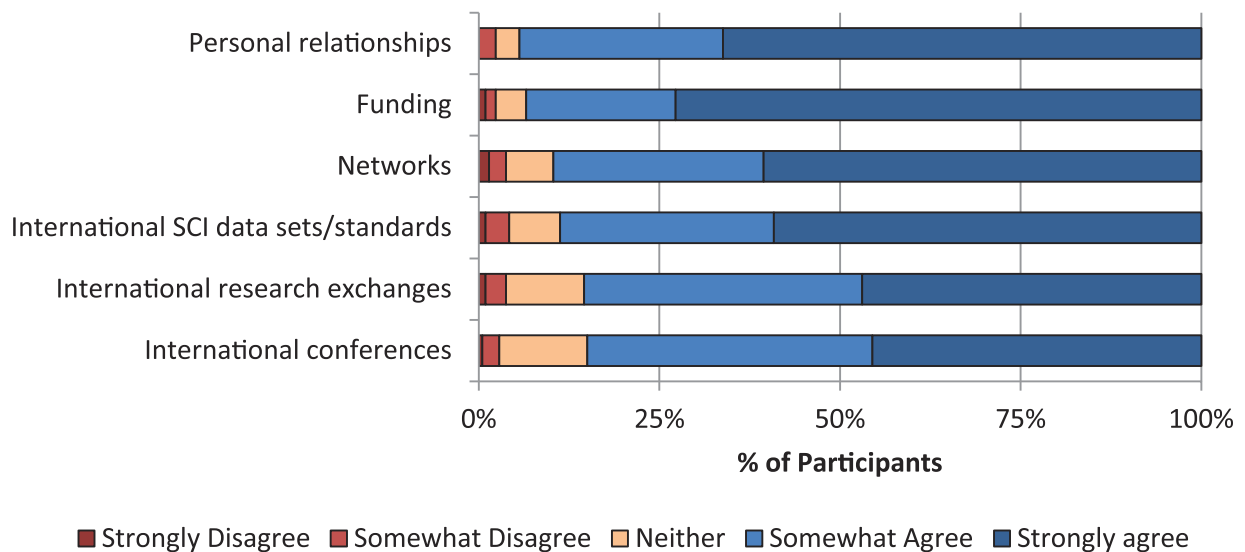


FIG. 2. Facilitators for International Spinal Cord Injury Research Collaborations. Facilitators are listed by the percentage of participants who agree.

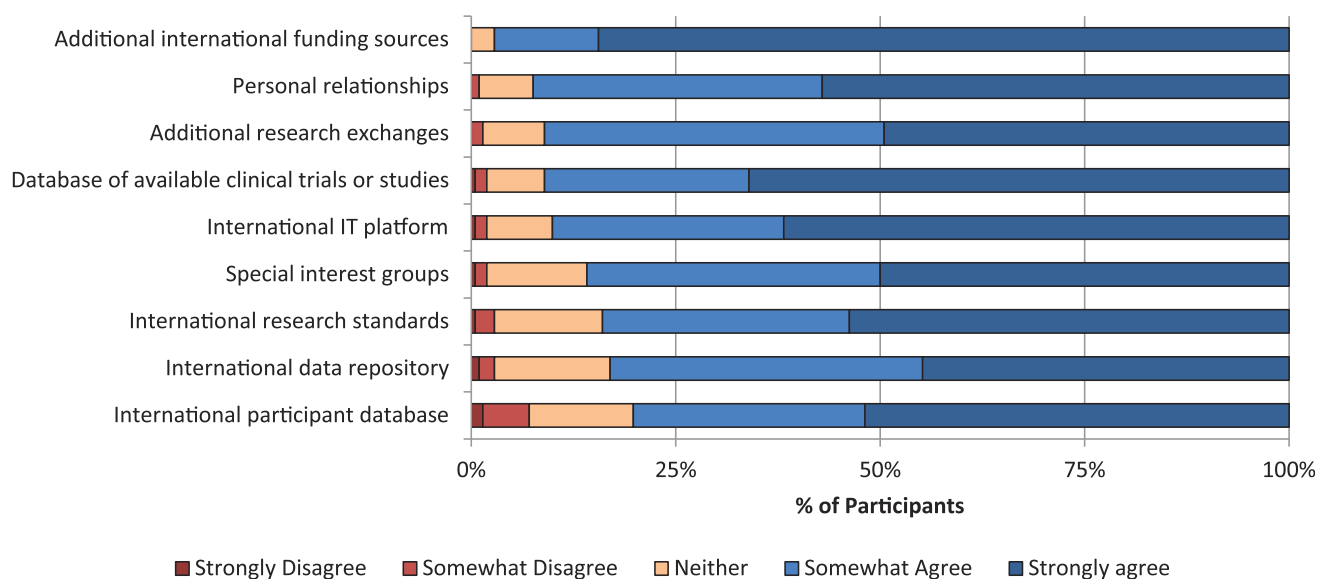


FIG. 3. Initiatives to facilitate future International Spinal Cord Injury Research Collaborations. Initiatives are listed by the percentage of participants who agree. IT, information technology.

(147/213) and the International Standards to document remaining Autonomic Function after SCI (ISAFSCI) by 13% (28/213; Table 2). Most participants who reported using the ISNCSCI did so for research and clinical purposes concurrently (46%), followed by for research purposes only (31%), and for clinical purposes only (22%). Of the 30% of participants (64/213) who reported not using ISNCSCI or ISAFSCI, more than half were unaware of the International Standards altogether (55%). Of the 29 participants who were aware of the standards but did not use them, the most common reason given (35%) was the nature of the participants' work (e.g., "our work involves evidence syntheses and knowledge translation rather than direct patient research").

The International SCI Data Sets were used by 45% (95/213) of the participants. Approximately one-third (36%) reported using the International SCI Data Sets for clinical purposes only, 31% for research only, and 30% concurrently for research and clinical purposes. Awareness of International SCI Data Sets among those currently not using them were similar to that of International Standards, with only 52% (61/118) aware. Again, the most common reason specified in the comments for not using the International SCI Data Sets despite being aware of them (18/61, 30%) was because they are beyond the scope of or are not relevant to participants' current research. For example, "for experimental research the International SCI Data Sets is not always of use."

Discussion

This paper describes the results of an international survey that was conducted to identify the barriers to and facilitators of international collaborations in SCI clinical research. It was not surprising that funding was recognized as a barrier and a facilitator, as well as a recommended future initiative.

To our knowledge, this is the first international survey of clinicians and researchers in the SCI field to systematically explore the perceived barriers and facilitators of international collaborations, even though barriers and facilitators to conducting research in SCI

TABLE 2. USE OF INTERNATIONAL SPINAL CORD INJURY (SCI) STANDARDS AND DATA SETS

	Frequency	Percentage
Use of International SCI Standards (<i>n</i> =213)		
Yes - ISNCSCI only	121	57%
Yes - ISAFSCI only	2	1%
Yes - both	26	12%
No	64	30%
Use of ISNCSCI (<i>n</i> =147)		
Research only	46	31%
Clinical only	32	22%
Research and Clinical	67	46%
Research, clinical, and other	1	<1%
Other only	1	<1%
Use of ISAFSCI (<i>n</i> =28)		
Research only	13	46%
Clinical only	8	29%
Research and clinical	6	21%
Other only	1	4%
Aware of International SCI Standards (if do not use them) (<i>n</i> =64)		
Yes	29	45%
No	35	55%
Use of International SCI Data Sets (<i>n</i> =213)		
Yes	95	45%
No	118	55%
How data sets are used		
Research only	29	31%
Clinical only	34	36%
Research and clinical	28	30%
Clinical and other	3	3%
Research, clinical and other	1	1%
Aware of data sets (if do not use them) (<i>n</i> =118)		
Yes	61	52%
No	57	48%

ISNCSCI, International Standards for Neurological Classification of SCI; ISAFSCI, International Standards to document remaining Autonomic Function after SCI.

are frequently cited in the literature. For example, the challenges with the translation of cellular therapies for SCI was explored by an international group of stakeholders²⁷ and a systematic review of knowledge translation interventions identified barriers and facilitators to implementation.²⁸ Work has also been done to investigate the state of international collaborations in the area of science and provide recommendations for supporting collaboration.^{29,30} From this survey and from the literature cited above, the theme of funding appears to be a common challenge.^{27–30} Additionally, when discussing barriers to international collaborations in SCI research, it is also important to keep in mind the challenges faced by prospective research participants, which include the possibility of decrease in functionality and out-of-pocket expenses as identified in the consumer survey.²⁴

Encouragingly, seven of the top 10 barriers identified in this survey are potentially modifiable by an international initiative. In SCI, there have been recent attempts for funding organizations such as the Craig H. Nielsen Foundation, Rick Hansen Institute, and Wings for Life to partner on funding workshops and research studies. For example, in October 2015, a workshop titled “International Spinal Data Network” (ISDN) was held to explore how SCI registries can partner to align data standards and to share data. These types of initiatives require funding agencies to address differences in their reporting/accountability, areas of priority and funding timelines. Pilot projects such as the ISDN will be important in establishing new precedents on funding international initiatives and there will also be an opportunity to learn from other organizations, such as the International Initiative for Traumatic Brain Injury Research.³¹

Communication- and technology-related factors were also reported as strong facilitators and initiatives. Factors related to communication, such as personal relationships, networks, and research exchanges, were all agreed upon as top facilitators or initiatives. Specifically, 94% of participants agreed that personal relationships were a facilitator of international collaborations and 92% agreed that additional opportunities to develop personal relationships (e.g., mentors) would facilitate future international collaborations. These relationships are crucial to finding individuals to collaborate with and to build trust. Similarly, in the consumer survey, recommendation from SCI peers was identified as a strong facilitator to participation in clinical research.²⁴ In the present survey, 91% and 90% of participants agreed that a database of available clinical trials or studies that require additional sites and an international IT platform for data collection and management, respectively, would be initiatives to facilitate future collaborations. Examples of databases of available clinical trials include the World Health Organization’s clinical trial registry,³² the National Institutes of Health (NIH) World RePORT of funded research projects³³ and ClinicalTrials.gov website,³⁴ and the Spinal Cord Outcomes Partnership Endeavor’s catalogues of clinical trials.³⁵ One example of an existing international electronic data collection platform is the Rick Hansen Institute’s Global Research Platform.³⁶ However, further work is needed to select (or create) relevant resources and adapt or expand these for use in international SCI research.

The use of internationally recognized standards was first proposed for the assessment of neurological impairment following SCI. The first version of the ISNCSCI was released in 1982 and was most recently revised in 2011.^{37,38} In the present survey, 69% of participants reported using the ISNCSCI. Reasons for not using the ISNCSCI included that the standards were not relevant to the

type of research being conducted or more surprisingly, unawareness of the standards. The more recent publication to document autonomic function (ISAFSCI) was reported to be used by 13% of participants. Given that the ISAFSCI was first published in 2009, it is encouraging to see the initiation of its international adoption.³⁹

In SCI, the international community has developed data sets to accompany the recommended standards (ISNCSCI and ISAFSCI). The first data set, the Core SCI Data Set was published in 2006.⁴⁰ Development of the data sets was based on the International Classification of Functioning, Disability, and Health (ICF) framework¹⁹ and can include both basic and expanded versions. As per the ICF, the data sets cover body functions and structures (e.g., Lower Urinary Tract and Bowel Basic Data Set), and activities and participation (e.g., Activities and Participation Basic Data Set). Thus far, 19 International SCI Basic Data Sets in addition to the International SCI Core Data Set, as well as a few International SCI Extended Data Sets, are freely available on the ISCoS website.^{20,41–43} Participants in this survey identified that these data sets and standards are an important facilitator (89% agreed) but they are not fully being utilized, as only 45% of participants reported using them. However, some participants stated in the comments section that they did not use them because they were not relevant to the type of research they conduct. More recently, the requirement by the NIH and the National Institute of Neurological Disease and Stroke (NINDS) to use the NINDS SCI Common Data Elements (which align to the International SCI Data Sets)²³ if researchers receive funding by organizations such as the NIH²² will assist in the implementation of data standards and data sets and accelerate the sharing of data internationally.

In considering the results from the survey, it is also important to consider the limitations. Given that the authors were from Canada, the United States, Europe, and Australia, a large number of respondents were also from these developed countries. The authors attempted to recruit from other developing countries by contacting colleagues working in SCI centres and SCI organizations but one difficulty was the requirement to read English. As a result, the study findings may not be generalizable to developing countries. Additionally, the majority of participants agreed (> 75%) that all the choices in part 2 (current facilitators of international collaborations) and part 3 (proposed initiatives to facilitate collaborations) of the survey were facilitators or initiatives that could facilitate international collaborations in SCI research, respectively. This made it difficult to interpret which facilitators or initiatives were the most important. Further, it is difficult to determine a precise response rate as it was not possible to track all of the persons who were aware of the survey but did not complete it. Lastly, considering that the survey was conducted over a span of nine months, we acknowledge the possibility that the institutional affiliations of participants may have changed following their completion of the survey.

The need for international collaborations in SCI research is becoming increasingly evident. Therefore it is important to identify how clinicians and researchers can be supported by SCI consumer and professional organizations, funders, and networks to encourage this type of collaboration. Unique solutions to overcome modifiable barriers and the creation of new facilitators to conducting international collaborations are needed, especially for funding, communication and engagement, and technology. To do this effectively it will require time and commitment from a wide range of stakeholders within the SCI community.

Author Disclosure Statement

Vanessa K. Noonan, Elaine Chan, Phalgun Joshi, and Zeina Waheed are employees of the Rick Hansen Institute. Keith C. Hayes and Kent Bassett-Spiers are employees of the Ontario Neurotrauma Foundation. Verna Smith and Debora Markelis were employees of the Institute for Safety, Compensation and Recovery Research. David J. Berlowitz and Marnie Graco are recipients of grant funding from the Institute for Safety, Compensation and Recovery Research and the Australasian Spinal Cord Injury Network. David J. Berlowitz is a Director and Board member of the Spinal Research Institute. Douglas J. Brown is Executive Director of the Spinal Research Institute and a Board member of the Rick Hansen Institute.

For Fin Biering-Sørensen, Susan Charlifue, and Jane Horsewell, no competing financial interests exist.

This study was supported by financial contributions from the Rick Hansen Institute, Health Canada and Western Economic Diversification Canada.

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