

ORIGINAL ARTICLE

Relevance of the international spinal cord injury basic data sets to youth: an Inter-Professional review with recommendations

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Study design: Mixed methods, using the Modified Delphi Technique and Expert Panel Review.

Objective: To evaluate the utility and relevance of the International Spinal Cord Injury (SCI) Core and Basic Data Sets for children and youth with SCI.

Setting: International.

Methods: Via 20 electronic surveys, an interprofessional sample of healthcare professionals with pediatric SCI experience participated in an iterative critical review of the International SCI Data Sets, and submitted suggestions for modifications for use with four pediatric age groups. A panel of 5 experts scrutinized the utility of all data sets, correlated any modifications with the developing National Institute of Neurological Disorders and Stroke (NINDS) pediatric SCI Common Data Elements (CDE) and distributed final recommendations for modifications required to the adult data sets to the International SCI Data Set Committee and the associated Working Groups.

Results: Two International SCI Data Sets were considered relevant and appropriate for use with children without any changes. Three were considered not appropriate or applicable for use with children, regardless of age. Recommendations were made for five data sets to enhance their relevance and applicability to children across the age groups, and recommendations for seven data sets were specific to infants and younger children.

Conclusions: The results of this critical review are significant in that substantive recommendations to align the International SCI Core and Basic Data Sets to pediatric practice were made.

Sponsorship: This project was funded by the Rick Hansen Institute Grant# 2015-27.

Spinal Cord (2017) **55**, 875–881; doi:10.1038/sc.2017.14; published online 28 February 2017

INTRODUCTION

Although there has been significant work on the development of spinal cord injury (SCI) outcomes instruments for adults,^{1–11} attention to instruments that are developed, validated and standardized for children with SCI remains relatively low and fragmented. The void in agreed upon and psychometrically sound outcome instruments, and the lack of standardization for collecting and recording clinical data limit the ability to evaluate treatment effectiveness, prognosticate the impact of SCI on function and compare outcomes across children and practice patterns. One way to fill this void is to evaluate existing tools that have psychometrically sound support in adult SCI for potential utility for children with SCI. For instance, the motor, sensory and anorectal examinations of the International Standards for Neurological Classification of SCI (ISNCSCI) were originally developed for adult SCI,¹² but later field-tested in children with SCI to establish reliability and define the youngest age at which administration of the examinations is feasible.¹³ Likewise, the Walking Index of Function-II¹⁴ and the Spinal Cord Independence Measure-III Self-Report (SCIM-III-SR)¹⁵ were developed and validated for adult SCI and later field-tested and

validated in children.^{16,17} Most recently, pediatric recommendations have been embedded into the National Institutes of Neurologic Disorders and Stroke (NINDS) SCI Common Data Elements.¹⁸ Advantages of expanding the applicability of robust adult SCI measures to children, when applicable, include the ability to conduct longitudinal monitoring and compare outcomes across the age span, the potential opportunity for youth to participate in clinical trials, and avoidance of exuberant costs associated with developing and validating new measures.

The International SCI Data Sets establish a standard for obtaining clinical data that aligns with the International Classification of Functioning, Disability and Health (ICF) and facilitates comparisons of health-related data among adults with SCI.¹⁹ The uniform structure of the data sets supports consistency in data collection that allows for the pooling of information worldwide. Additionally, the data sets can serve as a resource for healthcare centers or countries when developing or upgrading SCI data bases, or for clinicians advancing their SCI-related knowledge.¹⁹ The International SCI Data Sets have the potential to make a global impact and

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Received 21 October 2016; revised 29 December 2016; accepted 6 January 2017; published online 28 February 2017

are easily assessable to healthcare professionals via the International Spinal Cord Society (ISCoS) website (www.iscos.org.uk/international-sci-data-sets).

Although the existing International SCI Data Sets have a degree of applicability to children who have sustained an SCI, there are additional and different considerations that would need to be addressed for full utility when recording data specific to children aged 0–21 years. Pediatric-onset SCI has additional manifestations that are unique to children. As examples, children are vulnerable to SCIWORA (SCI without radiographic abnormality)²⁰ and the multiple physical immaturities of the spine result in susceptibility of children, especially ages 9 to 16, to multi-level, non-contiguous spinal injuries.²¹ Also, there is high occurrence of orthopedic complications such as neuromuscular scoliosis and hip dislocation/subluxation.^{22–24} Factors associated with the developmental level of the child at the time of injury also impact the ability for a child or parent to respond to questions that require comparison between current level of function and the level of function prior to injury. For instance, very young children with SCI, who would not be expected to have had achieved bowel and bladder control, walking, or sexual activity due to their young age, would not be able to respond. Additionally, at the time of data collection, the child's stage of cognitive, language and emotional development would likely impact their ability to self-report symptoms such as pain, headache associated with autonomic dysreflexia (AD) and lightheadedness secondary to orthostatic hypotensions. Similarly, children can begin self-reporting about function at approximately 8 years of age.²⁵ Finally, it would seem especially important when collecting data about children to include information related to the family/caregivers and siblings. Family/Caregivers of people who have an SCI experience lower quality of life and are at risk for depression, social isolation and financial stress.²⁶ Though pediatric SCI family/caregiver literature is limited, one study by Valenca, *et al.*,²⁷ suggests a high caregiver burden with decreased quality of life, as well as increased symptoms of anxiety and depression for caregivers of children with myelomeningocele.

The International SCI Data Sets are organized into one Core Data Set²⁸ and 19 Basic Data Sets.^{29–46} The Core Data Set standardizes the collection and reporting of the minimum clinical variables that are considered essential during the first inpatient stay after sustaining an SCI.²⁸ In contrast, the International SCI Basic Data Sets define the minimal variables that should be collected in highly relevant areas of routine clinical practice (e.g. spinal interventions and surgical procedures, bowel function, upper-extremity function), at each outpatient encounter.^{29–46} In addition to the Core and Basic Data Sets, Extended Data Sets have been developed specifically to support research within particular areas.

The International SCI Core and Basic Data Sets could be of great value to pediatric SCI clinicians. Specifically, they would provide clinicians with a common and standardized method for assessing and recording key clinical findings in children. Furthermore, implementation as part of usual care would result in benchmarking capabilities within and across centers, thereby helping to prognosticate outcomes of care. With the ability to prognosticate, clinicians' use of anticipatory guidance would be informed by evidence, and parents and youth with SCI would be better prepared for the future. The International SCI Data Sets would be equally valuable to pediatric researchers by creating a common language and by enabling aggregation of data across studies. However, since only a few of the International SCI Data Sets considered children during initial development, prior to widespread pediatric use, a systematic review for relevance of the data sets to children and youth should be conducted. Thus, this paper describes the methods used to

systematically review the International SCI Data Sets for relevance to children, and discusses the results of the review, and the recommendations for better alignment of the data sets for pediatric utility.

MATERIALS AND METHODS

The Modified Delphi Technique,⁴⁷ an iterative critical review process whereby a set of carefully selected items are presented to a field of experts in order to solicit specific information, was used to conduct an iterative review of each of the International SCI Core and Basic Data Sets. Purposeful and snowball sampling were used to recruit pediatric content experts. Health professionals (for example, physicians, psychologists, occupational therapists) with experience in SCI were identified by the investigators through their professional networks and professional organizations, including the American Spinal Injury Association, and the International Spinal Cord Society (purposeful sampling). Those identified were invited via electronic mail (e-mail) to complete a maximum of 20 surveys associated with review of one Core and 19 Basic International SCI Data Sets. Hyperlinks to each survey were sent in waves of three-to-four through individual e-mail invitations distributed over the course of 12 weeks. Participants were encouraged to forward each survey invitation to their colleagues with SCI expertise (snowballing technique) in order to increase the pool of respondents. Surveys were accessed and completed anonymously via survey monkey (<https://www.surveymonkey.com/home/>). Participants were given one month from the receipt of each survey to submit their response.

Each survey contained seven close-ended demographic questions and one open-ended demographic question (indicate the city, state and country where you practice). The data set-specific instructions included links to the specified data set and the original article associated with the development of the data set, both located within the ISCoS website. The participants were instructed to do the follows: (1) review the data set via the link, (2) consider the variables within the data set for four specified age groups: 0–5 years, 6–12 years, 13–15 years and 16–21 years, (3) submit any suggestions for deletion or addition of variables, and/or changes in how variables are coded. Include the rationale for the change and any references that support the rationale. Using this open-ended format, participants were directed to insert their responses into a content box or use an embedded link to anonymously upload a document with their responses.

The responses from round one were organized by data set, variable within the data set, and age group-specific recommendations. In round two, a table illustrating these results was distributed via a single e-mail to the survey participants in order to elicit further feedback. Two participants offered responses that were integrated into the recommendations. Due to the minimal substantive response in round two, the modified Delphi review was completed.

The final data were presented to a panel of five experts in SCI, including members of the International SCI Data Set Committee. In a two-day meeting, the panel further analyzed the recommendations gathered within the Modified Delphi Technique process. The panel scrutinized the utility of each data set and each variable within each data set, for each of the four pediatric age groups. At the same meeting, these pediatric specific modifications were correlated with the developing NINDS pediatric SCI Common Data Elements (CDE),⁴⁸ to ensure harmonization of recommendations. Final recommendations for modifications and further action items were collated and distributed to the International SCI Data Sets Committee Chair for review by the working committees associated with each data set, and integration into future-revised versions of the adult data sets.

Statement of ethics

This study was approved by the Thomas Jefferson University Institutional Review Board.

RESULTS

There were a total of 121 responses across the 20 data set surveys in round 1 of the survey distribution. The responses were submitted anonymously from among the 36 invited participants and their chosen colleagues with expertise in pediatric SCI. Participants could respond to as many as 20 surveys. When a summary of the suggested changes for all 20 round-one data set surveys were sent to participants in the

Table 1 Characteristics of the 121 responses across the 20 surveys (anonymous invited participants who responded to 1–20 surveys)

1. Profession				
Physician (60)	Psychologist (24)	Occupational Therapist (17)	Physical Therapist (9)	
Nurse (4)	Researcher (6)	Music Therapist (1)		
2. Years of experience working with people with SCI				
> 10 (101)	6–10 (10)	2–5 (6)	Less than 2 (3)	Unanswered (1)
3. Years of experience working with children with SCI				
> 10 (99)	6–10 (10)	2–5 (7)	Less than 2 (4)	Unanswered (1)
4. Number of children with SCI seen per year				
< 10 (31)	10–25 (10)	> 25 (79)	Unanswered (1)	
5. Geographic Location of respondent				
United States (71)	Denmark (14)	Sweden (5)	Australia (2)	Unanswered (26)

Abbreviation: SCI, spinal cord injury.

2nd round of the review, 2 responses were returned. As detailed in Table 1, half of all round 1 responses indicated their primary profession as physician. The majority of responses report greater than 10 years of experience working with pediatric SCI; most responses also report working with more than 25 children with SCI annually (Table 1). Four countries were represented with 60% of responses indicating a geographic location within the United States (US), although 26% of respondents did not report location. In round 2, one US-based physician and one US-based psychologist, both with over 15 years of pediatric SCI experience responded.

The Endocrine and Metabolic Functions, and Skin and Thermoregulation International Data Sets were considered relevant and appropriate, without any changes for use with children across the four age groups, whereas the Activity and Participation, Quality of Life, Pain, Female Sexuality and Reproduction, and Male Sexuality International Data Sets were considered not appropriate or applicable for use with children, regardless of age group. For items on any of the data sets that require self-report, a recommendation was made to provide explicit guidelines for who would provide the response using the following language: 'Where specified, as appropriate in pediatrics, self-report will be primarily by parent for age groups 0–5; and by primarily child for age groups 6–11 (parent report, secondary), 12–15 (parent report, supplemental) and 16 and older (parent report, optional).'

As shown in Table 2, there were recommendations for five data sets that would enhance their relevance and applicability to children across the age groups. Two new variables were recommended for the Spinal and Interventions & Procedures Basic Data Set, and one new variable was recommended for the Spinal Column Basic Data Set and Pulmonary Basic Data Set. A recommendation was also made to add response codes of 'unknown' and 'suspected' for some variables, and explicit instructions for their use. In the Pulmonary Basic Data Set, it was recommended to add a comment that provides guidance on how to obtain smoking history in children and youth.

As summarized in Table 3, there were recommended modifications to seven of the International Data Sets that were specific to infants and younger children. The majority of recommended modifications included adding a response option of 'not applicable' or 'unknown', and corresponding comments about age and developmental appropriateness of the variable. In the Urinary Tract Infection (UTI) Basic Data Set, the recommendation was made to add 'fussiness and irritability' as one of the response options for the variable 'signs and symptoms of UTI' as these are manifestations of UTI in children. Similarly, a recommendation was made to change the variable

name 'Uneasiness, headache or perspiration during defecation' (Bowel Function Basic Data Set) to 'Uneasiness, headache, fussiness and irritability.' It was recommended to add a response 'Birth Injury' for Injury Etiology in the Core Data Set, and 'Hip instability, subluxation and pelvic obliquity' to the Musculoskeletal Basic Data Set.

DISCUSSION

A systematic and iterative review of the International SCI Data Sets that were originally developed for adults was conducted by international pediatric content experts. The goal was to establish pediatric recommendations for the data sets so that they could be used to facilitate the ability to pool pediatric data worldwide and thereby provide a mechanism for comparisons and benchmarks of a relatively large number of children with SCI. As was done for the pediatric review of the SCI NINDS CDE,⁴⁸ we reviewed the International SCI Basic Data Sets for each of the four age groups defined by DeVivo and colleagues (2011),³⁸ owing to the importance of growth and development, and their influence on the relevance of each variable, and the feasibility of collecting the information using the standardized codes.

While the International Endocrine and Metabolic Functions Basic Data Set and Skin and Thermoregulation Basic Data Sets were felt to be appropriate for children without any modification, the other data sets that focus on *body functions* were viewed as highly relevant to pediatric practice, and require only a few easily achieved modifications. The addition of response codes 'Unknown' and 'Not Applicable' for variables that cannot or should not be obtained in infants and children is a simple modification that is needed for several variables in The Lower Urinary Tract Function, Urinary Tract Infection, Urodynamics, Upper Extremity, Bowel Function and Musculoskeletal Basic Data Sets. The recommended inclusion of comments that correspond with 'Unknown' and 'Not Applicable' would increase the likelihood of standardization. As an example, several variables in the Bowel Function Basic Data Set address methods and frequency of bowel programs, and frequency of fecal incontinence, which are areas of little relevance for infants and young children who developmentally would not be expected to be continent even without an SCI. A response option of 'Not Applicable', and a corresponding comment that provides an indication of the age range where continence is expected, would potentially help with recording the clinical data accurately over time. Likewise, in the Musculoskeletal Basic Data Set, a response option of 'Not Applicable' for the question 'Do any of the above musculoskeletal challenges interfere with your activities of daily

Table 2 Data Sets with recommendations applicable to all pediatric age groups, except where the entire data set is not used in the 0- to 5-year age group, as noted

<i>Data Sets</i>	<i>Variable Name</i>	<i>Pediatric Recommendation</i>
Non-traumatic Spinal cord injury	Timeframe of onset of Non-Traumatic Spinal Cord Injury	Add response: Unknown Add comment: use Unknown for pediatric patients when parent/child/caregiver cannot recall onset or if there are differing reports from child/parent/caregiver
Spinal Interventions and Procedures	Non-Surgical Treatment Cervical Traction and; Cervical Traction and Immobilization ^a Surgical Procedure: Stabilization via wire/ instrumentation without fusion ^a	Add responses: Yes, No, Unknown Response Codes Add responses: Yes, No, Unknown Include Comment: Both non-surgical and surgical options should be selected if the patient failed conservative/non-operative treatment, and had surgical management after failed conservative treatment.
Spinal Column Injury	Single or Multiple Level Spinal Column Injuries ^b Spinal Cord Injury without Radiographic Abnormality (SCIWORA) ^a	Modify the variable description to 'alternatively, multiple level injury, or non-contiguous injuries, consists of....' Add Comment: use on non-contiguous in variable description above ensures that pediatric clinicians include non-contiguous in this assessment. Response Codes: yes, no, unknown
Cardiovascular Functions Not Used in 0- to 5-year age group	Cardiovascular function history after SCI within the last three months ^b	Add a response code: <i>Suspected</i> for OH and Autonomic Dysreflexia (AD) Add comment: use Suspected for children when OH and AD may be suspected
Pulmonary Functions Not Used in 0- to 5-year age group	Smoking History ^b Pulmonary Complications and Conditions after the Spinal Cord Lesion Within the Last Year ^b Exposure to Tobacco Smoke in the Home ^a	Add comment: This question should be asked to each child age 6 and older without the parent/caregiver present Add response code: Suspected Response Code: yes, no, unknown Include comment: This variable assesses whether the patient is exposed to second-hand tobacco smoke at home. Yes is checked if someone in the home smokes, regardless of whether the patient smokes or not. No is checked if no one in the home smokes, except the patient.

Abbreviation: SCI, spinal cord injury.
^aNew variable based on pediatric review.
^bExisting adult variable.

living' would allow pediatric clinicians to systematically record musculoskeletal impairments in very young children child, without having to comment on the impact on activities of daily living (ADL). Once the child ages, and engagement in ADL is expected, the response could be recorded differently on a repeated administration. The argument is somewhat similar for adding the response option 'Suspected' for variables such as heterotrophic ossification and AD, where the condition is suspected, but difficult to confirm in children due to the inability to express symptoms such as headache in children of 5 years of age and younger. In this instance, however, it is an addition to reflect the nonspecific manifestations of AD or lack of normative references, and insufficient data.

There were other recommendations. Additional variables that are highly relevant to pediatric SCI were created for the Core Data Set (birth injury), Musculoskeletal Basic Data Set (hip instability, subluxation, pelvic obliquity), Spinal Interventions and Procedures Basic Data Set (non-surgical treatment, cervical traction and immobilization; stabilization via wire/instrumentation without fusion), Spinal Column Basic Data Set (SCIWORA) and Pulmonary Basic Data Sets (Exposure to tobacco at home). Although rare (1 per 60 000 births), birth injuries are usually due to difficult deliveries, result in tetraplegia and may be associated with a brachial plexus injury or hypoxic ischemic encephalopathy.⁴⁹ Following pediatric review of the NINDS SCI CDE,⁴⁸ birth injury was added as a variable to the domain

of 'Injury History', and a birth injury-specific case report form (CRF) was developed. Likewise, tobacco exposure at home was added to the NINDS SCI CDE following pediatric review.⁴⁸ Including these two variables in the International SCI Data Sets strengthens the harmonization of the SCI International Data Sets and the NINDS CDE. The addition of a variable to monitor hip instability/subluxation and pelvic obliquity aligns the Musculoskeletal Basic Data Set with standard of care, where routine, longitudinal surveillance of the hip is the mainstay of orthopedic management for children with SCI due to its high occurrence,^{50,51} especially in children who are injured at younger than 10 years of age.⁵² Likewise, the additional variables in the Spinal Interventions and Procedures and Spinal Column Basic Data Sets strengthen the alignment of the data sets with pediatric standard of care. Spine stabilization in young children often involves halo immobilization with or without traction and/or surgical stabilization without fusion.^{53,54} As children may undergo both immobilization and surgery, it was recommended to add a comment for the response options 'Check all that Apply.' Despite the regular use of Magnetic Resonance Imaging, and other advanced imaging, SCIWORA is still a term used in pediatric practice to describe pediatric SCI without plain radiographic or computerized tomography scan findings,²⁰ and hence it was developed as a new variable to be added to the Spinal Column Basic Data Set.

Table 3 Data Sets with specific recommendations in infants and children younger than 10 years of age

<i>Data Sets</i>	<i>Variable Name</i>	<i>Pediatric Recommendation</i>
Core	Injury Etiology ^a	Add Response Code: Birth Injury, or explicitly state in instructions that birth injury is included in 'other traumatic cause' Add Comment: The International Standards for Neurologic Classification of Spinal Cord Injury cannot be conducted in children of five years of age and younger; thus, motor level, sensory level, neurologic level and the ASIA (American Spinal Injury Association) Impairment Scale (AIS) are recorded as 8888-88-88. Add Comment: Some children up to 8 may have difficulties with the sensory and anorectal examinations and in these cases, sensory level, neurological level, AIS should be recorded as 8888-88-88
Lower Urinary Tract Function	Awareness of need to empty ^a	Add Comment: If a child was continent before the injury (i.e. aged 3 or older), all of the variables are appropriate, If the child was not continent (i.e. younger, age 0–3) use Not applicable
Urinary Tract Infection	Length of time of onset of new symptoms ^a Signs and Symptoms of urinary tract infection ^a	Add Response Code: Unknown Add Comment: Unknown is especially relevant in children 0–5 years of age Add Response Code: Fussiness and Irritability Add Comment: Fussiness and Irritability are associated with UTI in infants and young children
Urodynamics	Bladder sensation during filling cystometry ^a	Add Response: Unknown Add Comment: Use unknown if the child is too young to indicate sense of bladder filling
Upper Extremity	Basic Hand Function and Shoulder Function Classification ^a Use of Assistive Devices ^a	Add Response: Unknown Add Comment: Assign unknown if the limb is not available to assess, of if infant/child too young to demonstrate function Add Response: Not Applicable Add Comment: Use Not Applicable for infants and children who would not expect to use assistive devices because of age
Bowel	Surgical Procedures on Gastro-intestinal Tract ^a Defecation Method and Bowel Care Procedures within last Four Weeks ^a Average Time for Defecation in the last four weeks ^a Uneasiness, headache or perspiration during defecation ^a Frequency of fecal incontinence ^a Need to Wear a Pad or Plug ^a	Add Comment as introduction to Data Set: This data set is appropriate for pediatric age groups 6–11, 12–15 and 16> . For age group 0–5, the data set is appropriate for children who have reached the age 3 or older, where bowel continence is typical; some variables are not appropriate for infants and children who are not at an age where bowel continence is expected. Add Response: Antegrade Continent Enema (ACE) procedure Add Comment: ACE procedures are performed with relative frequency in children with SCI and spina bifida Add Response: Not Applicable Add Comment: Not Applicable should be used for infants and children who are not at the age where bowel continence is expected. Add Comment: Unknown would be selected for children who are not at an age where bowel continence is expected Change Variable Name to: Uneasiness, headache, fussiness and irritability Add Response: Fussiness and irritability Add Comment: For children, autonomic dysreflexia may present with fussiness and irritability Add Response: Not applicable Add Comment: Use not applicable for children who are not at an age where bowel continence is expected Add Response: Not applicable Add Comment: Use not applicable in children who are not yet at the age where fecal continence is expected. Revise Comment Section: Daily use is not appropriate as it is defined as indicating insufficient bowel management
Musculoskeletal	Do any of the above musculoskeletal challenges interfere with your activities of daily living? ^a Hip Instability, subluxation, pelvic obliquity ^b	Add: Additional activities of daily living examples that are more relevant to children such as writing, eating, phone use Add Response: Not Applicable Add Comment: Not applicable should be used for infants and children younger than 6 months old whose development would not be expected to engage in ADL; once children are 6 months, they should be reaching, hold bottles, etc. Add Variable: Hip instability, subluxation, pelvic obliquity: Response: Yes, No. If yes, check method of all that apply: observation, palpation, radiographs. Add Comment: The occurrence of hip instability and/or dislocation in children with spinal cord injury/dysfunction is high. When children are injured at younger than 10 years of age, the occurrence is greater than 90%

Abbreviation: SCI, spinal cord injury.
^aExisting adult variable.
^bNew variable based on pediatric review.

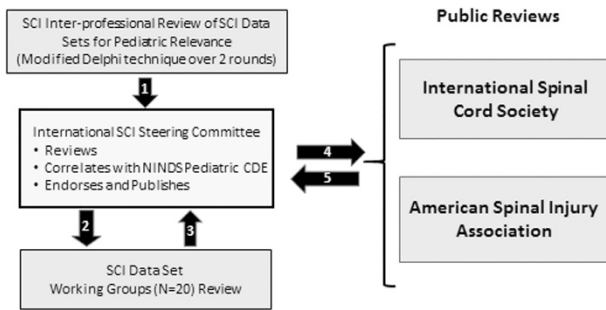


Figure 1 Iterative Review Process for International SCI Data Sets Pediatric Recommendations. CDE, Common Data Elements; NINDS, National Institute of Neurologic Disorders and Stroke; SCI, spinal cord injury.

In addition to adding new variables, recommendations were made to change the variable name 'Uneasiness, headache, or perspiration during defecation' (Bowel Function Data Set version 2.0) to 'Uneasiness, headache, fussiness, irritability during defecation', and to include 'fussiness and irritability' as a response option for 'Signs and Symptoms of UTI' (Urinary Tract Infection Basic Data Set). These recommendations were based on the work by Hickey and colleagues,⁵⁵ who studied clinical symptoms in children and adolescents with SCI during episodes of AD, and found an association between fussiness/irritability and UTI and AD in very young children.

The Pulmonary and Urinary Tract Imaging Data Sets were not recommended for the 0- to 5-year age group, and the Activity and Participation, Quality of Life, Pain, Female Sexuality and Reproduction, and Male Sexuality International Data Sets were considered inappropriate for each of the four pediatric age groups. Inclusion of pediatric expertise on the committees that review and revise the Pulmonary, Urinary Tract Imaging, Female Sexuality and Reproduction and Male Sexuality International Data Sets is planned. Development of Pain Quality of Life and Activity and Participation Data Sets for Children requires commitment from one or several people to bring together pediatric content experts and engage them in a sustaining and productive fashion, until completion of the work.

There was a glaring void in data sets for other highly relevant areas in pediatric SCI, including upright and wheeled mobility, school, caregivers and siblings. Future work on developing pediatric quality of life and activity and participation data sets could possibly include school and siblings. Adult and pediatric experts working to revise the International SCI Basic Data Sets are currently collaborating with experts associated with the NINDS CDE for SCI to develop common data sets for caregivers and mobility.

Moving forward, the pediatric recommendations will be integrated into the existing International SCI Core and Basic Data Sets through a systematic process (Figure 1) that will involve careful consideration of the pediatric recommendations by each of the appropriate International SCI Data Set working committees at the time these working committees review the adult core and basic data sets and modify them to reflect new knowledge or practice patterns. All of the new changes, including the pediatric recommendations, will be reviewed and endorsed by the international SCI community, prior to solidification of the revised data set. The Bowel Function Basic Data Set has recently been reviewed, and revisions including the pediatric recommendations from the work described in this paper were integrated and will be disseminated as version 2.0 of this data set.⁵⁶ Moreover, as a way to better facilitate pediatric considerations into the revisions of the International Core and Basic Data Sets, a pediatric content expert has been added to the International SCI Data Sets Committee, and will

serve to ensure inclusion of pediatric content experts on working groups. Work is planned to develop pediatric training cases, and to educate pediatric providers about the International SCI Data Sets, and their uses.

CONCLUSION

Recommendations to align the International SCI Core and Basic Data Sets to pediatric practice have been provided to the International SCI Data Sets Committee chair to distribute to working groups that are reviewing and updating the International SCI Core and Basic Data Sets. These working groups will review the recommendations, and embed them into subsequent versions of the data sets prior to release. Working groups to create new pediatric data sets are needed for pain, quality of life, activity and participation. Further work is needed to develop SCI data sets for school, caregiver/parent and youth, and pediatric training cases for the data sets need to be developed to support clinical uptake and use.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

Dr VKN is an employee of Rick Hansen Institute. The remaining authors declare no conflict of interest.

ACKNOWLEDGEMENTS

Professionals who participated in the Modified Delphi Technique are acknowledged for their expertise and contributions to the recommendations. The study was funded by the Rick Hansen Institute Grant #2015-27, (Mulcahey, PI).

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