



The International Spinal Cord Injury Pediatric Activity and Participation Basic Data Set

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Abstract

Study design International focus groups.

Objectives The objective of this project was to develop the International Spinal Cord Injury (SCI) Pediatric Activity and Participation (A&P) Basic Data Set.

Methods A focus group of experts in pediatric and adult SCI, and contributors of the existing adult International SCI Adult A&P Basic Data Set convened to develop an initial draft of the data set, which was iteratively refined over a 12 month period based on relevant literature and existing outcome measures that evaluate pediatric activity and participation. The draft was reviewed and approved by the larger project working group and then distributed to the International Spinal Cord Society (ISCoS), American Spinal Injury Association (ASIA), and relevant expert groups for review. Feedback received was considered before the final data set was approved.

Results The International SCI Pediatric A&P Basic Data Set is comprised of 13 variables: administration date, mobility, dressing, feeding, toileting, communication, family outings, spending time with friends, being out with friends, participating in team or club activity, paid work, dating, and physical activity. It is intended for children between 6 and 17 years of age, who have been discharged from initial rehabilitation/hospitalization for a minimum of 3 months.

Conclusion The International SCI Pediatric A&P Basic Data Set was developed to standardize the recording of a minimal amount of information about activities and participation in children with SCI. Further work on reliability and cultural validation is needed.

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Introduction

The International Spinal Cord Injury (SCI) Basic Data Sets were developed to collect the minimal amount of necessary

information in areas relevant to an individual's medical concerns and psychosocial experience living with a SCI [1]. The Basic Data Sets have been developed on topics with high clinical relevance to the SCI community in order to

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promote standardized recording of clinical information, which can facilitate comparisons of injuries, treatments, and outcomes among individuals with SCI, treatment centers, and countries [2–4]. To date, one Core Data Set, which documents demographic and injury-related variables, and 20 basic data sets have been developed [2]. Efforts have been made to ensure that the international SCI basic data sets are applicable to pediatric age groups. This has been accomplished by having pediatric content experts serve on the working groups and via a formal review of each of the data sets for pediatric relevance [5].

The upper age limit defined for “pediatrics” ranges between 17 and 24, depending on source and context [6, 7]. An important consideration when conducting pediatric assessment and collection of clinical data, such as those collected by the international SCI basic data sets, is growth and development. Variables/responses that may be relevant to school-aged children and adolescent ages may have less relevance or not be relevant at all to preschool children. As an example, in the International SCI Basic Bowel Data Set Version 2.0 [8], the variable “awareness of need to defecate” is not appropriate for children who are not at the age at which continence is usually achieved (3–4 years old). On the other hand, some variables/responses may be relevant to each age across the pediatric ages, such as those in the spinal column and musculoskeletal basic data sets [9, 10]. Growth and development must also be considered when deciding who (child, parent, and both) responds to questionnaires and interviews. For all of these reasons, one standard pediatric age cannot be defined for all variables across all data sets.

While many of the existing data sets can be used in pediatrics, following the review by Carroll et al., it was determined that several were not applicable to children of pediatric age groups [5]. Notably, the International Activity and Participation (A&P) Basic Data Set [11] was considered inadequate for monitoring activity and participation in children 17 years of age and younger, and hence catalyzed the development of the data set described within this paper. The primary objective of the existing adult International SCI A&P Basic Data Set Data Set [11] is to assess A&P in the following domains of the International Classification of Functioning, Disability, and Health (ICF) [12]: mobility; self-care; domestic life; social interactions and relationships; major life areas; community, social, and civic life. Development of a pediatric-specific activity and participation basic data set was recommended to better capture relevant and developmentally appropriate experiences of activity and participation of children [5]. The aim of this paper is to present the International SCI Pediatric A&P Basic Data Set Version 1.0, discuss the process by which it was developed and the rationale for domains and variables.

Methods

An international interdisciplinary group of individuals with expertise in pediatric SCI care and research, and those who contributed to the development of the existing (adult) International Activity and Participation Basic Data Set was formed through invitation by the Principal Investigator (MJM). Work group members included individuals from Australia (1), the Netherlands (1), Norway (1), South Korea (1), Sweden (1), and the United States (5). The process used to develop the International Pediatric SCI A&P Basic Data Set followed the iterative process used for developing all of the other International SCI Basic Data Sets [1]. Specifically:

1. Existing instruments for measurement of pediatric activity and participation [13–25] were reviewed from which an initial draft data set was developed. The initial draft contained three domains, activities of daily living (ADLs), physical activities, and participation, comprised of items adapted from The Spinal Cord Independence Measure Self-Report for Youth (SCIM-III SR-Y) [18], the Physical Activity Questionnaire for Older Children (PAQ-C) [16, 24], and the Pediatric Measure of Participation short forms [25]. Because an International SCI Education Basic Data Set [26] was being developed in parallel to the development of the International SCI Pediatric Activity and Participation, school participation variables were not included on the A&P data set.
2. The group met face to face in a focus group format, and continued to review iterative drafts of the data set via biweekly conference calls and frequent email communications over a 1 year period (2017–2018).
3. A full draft was vetted during a follow up face-to-face meeting of the larger workgroup for development of Pediatric SCI/D Basic Data Sets, held in Philadelphia PA in February 2018, during which the larger pediatric work group reviewed and made recommendations to draft variables and their descriptions. Specifically, changes were made in content and wording of the variables to allow for ease of comprehension by both child and caregiver respondents, as well as to have greater applicability to the international community. The age criteria for several participation variables, specifically “go out with friends”, “be on a team or club”, “dating”, and “paid work” was also discussed until there was consensus on age applicability for the majority of children living in regions across the globe.
4. The draft was sent to the American Spinal Injury Association (ASIA) Board and the International Spinal Cord Society (ISCoS) Executive and Scientific Committees, with a request to make the draft available

on the respective websites for membership feedback. No additional suggestions or comments were made.

5. The Data Set was approved by ASIA Board and the ISCoS Executive and Scientific Committees.

Results

The final International SCI Pediatric A&P Basic Data Set contains 13 variables corresponding to one of three domains: ADLs, participation, and physical activities. It was developed for children between 6 and 17 years of age, with traumatic or nontraumatic acquired SCI and who have been discharged from initial hospitalization/rehabilitation for at least 3 months. The 3 month period is a criteria for the PMoP [25] so that children have opportunities to perform activities to better aide in self-report. The data set can be administered through an interview, or by self-report (completing it via paper/pencil without an interviewer).

Based on previous cognitive interviewing studies including two that were conducted on the SCIM-III SR-Y [18] and PMoP [27], it is expected that children 8 years of age and older will be able to self-report and respond to variables on the International SCI Pediatric A&P Data Set independently, and for children younger than 8, a parent or caregiver proxy will respond on their child’s behalf. As seen in clinical practice, parent or caregiver report may be used in combination with child report (in children 8–12 years of age) or be supplemental to child report (children 13–14 years of age). Parent input is optional when administrating the data set to children aged 15–17, assuming cognition and development are at age levels. At aged 18 the existing adult

International SCI A&P Basic Data Set should be used. Together, these two data sets provide the opportunity to monitor activity and participation using standardized methods over the course of the child’s lifetime.

As shown in Table 1, the International SCI Pediatric A&P Basic Data Set contain domains that are similar to the domains on the adult A&P Basic Data Set, however the variables, variable descriptors, and/or metrics differ. For instance, the ADL variables in both data sets record information about level of independence in mobility, dressing, feeding, and toileting activities, however the description for the pediatric variables and coding metrics are adopted from the SCIM-III SR-Y [18]. The ADL variables in the International SCI Pediatric A&P Basic Set can be classified within the Mobility (d4) and Self-care (d5) domains of the International Classification of Disability for Children and Youth (ICF-CY) [28].

The Participation domain records areas important to community participation and psychosocial development in children and assesses the following domains of the ICF-CYF [28]: communication (d3), interpersonal interactions and relationships (d7), major life areas (d8), and community, social, and civic life (d9) [29–31]. The physical activities domain considers the significant implications of participating in physical activity for both cardiovascular fitness and psychosocial health and wellness in children with disabilities [32–35]. The single physical activities variable was adapted from the PAQ-C [16, 24] and, can be defined by the Recreation and leisure category (d930) within the Community, social, and civic life domain (d9) of ICF-CY [28].

Each of the variables on the International SCI Pediatric A&P Basic Data Set are described below.

Table 1 Comparison of items and performance metrics in the existing and Pediatric Activities and Participation International SCI Basic Data Sets

The International SCI Activities and Participation Basic Data Set		The International SCI Pediatric Activities and Participation Basic Data Set	
Item	Performance metric	Item	Performance metric
Mobility	Task execution	Mobility	Task execution
Dressing	Task execution	Lower body dressing	Task execution
Feeding	Task execution	Feeding	Task execution
Toileting	Task execution	Toileting	Task execution
Household Work	Hours a week	Physical activities	Times per week
Volunteer Work	Hours a week	Communication	Frequency compared with peers
Family Relationships	Number of contacts	Family outings	Frequency compared with peers
Friends Relationships	Number of contacts	Time spent with friends	Frequency compared with peers
Education	Hours a week	Outings with friends	Frequency compared with peers
Spare time activities	Hours a week	Team activities	Frequency compared with peers
Spousal relationships	Presence and type of relationship	Dating	Presence
Paid work	Hours a week	Paid work	Frequency compared with peers

Date of data collection

The International Pediatric SCI Basic Data Set can be administered any time after 3 months post-discharge from initial rehabilitation/hospitalization. Three months was selected as this amount of time is considered minimal for children to have an opportunity to engage in activities to aide in self-report.

Activities of daily living

A 4-week recall is used for the ADL variables; the 4-week recall is also used for the existing adult International SCI A&P Basic Data set. The ADL variables were obtained from the SCIM-III SR-Y [18]. The SCIM-III SR-Y was developed based on cognitive interview studies on the widely-implemented SCIM-III [36, 37] to evaluate level of self-reported independence by children with SCI. Only the four SCIM-III SR-Y items that correspond to the variables on the existing adult International SCI A&P Basic Data Set were included in the pediatric A&P data set This was done to provide a mechanism for monitoring ADL performance across the pediatric-adult lifespan.

Mobility

This variable records the mode of mobility used to move medium distances (10–100 m) in the last 4 weeks. Either “*I use a wheelchair to move around*” or “*I walk medium distances*” is selected. Walking can only be selected if the child can walk *medium distances*. *Medium distances* correlates to the distance between classrooms at school, length of a gymnasium, or a city block. Once the mode of mobility is established, the variable records the level of assistance that is required to move medium distances.

Dressing

This variable records level of independence in dressing/undressing the lower body (clothes, shoes, and braces) in the last 4 weeks.

Feeding

This variable records level of independence in feeding (eating and drinking) in the last 4 weeks. Feeding (eating and drinking) is defined as cutting food, opening containers/bags, pouring, bringing food to mouth, or holding a cup with fluid. The code “*I eat nothing with my mouth*” is used to record feeding via a gastrostomy or other type of parenteral feeding.

Toileting

This variable records the level of independence in toileting in the last 4 weeks. Toileting can occur either on the toilet or in bed and involves personal hygiene, adjusting clothes, using napkins, or diapers.

Participation

A 4 week recall is also used for the seven participation variables. The participation variables are drawn from the PMoP [25], which is a SCI-specific pediatric patient reported outcome instrument developed using item response theory [38, 39]. While the PMoP evaluates participation based both on what the child desires and as compared with friends’ participation, the International SCI Pediatric A&P Basic Data Set only uses the comparison with friends. With the exception of the dating, each of the participation variables are coded as follows:

- (1) I don’t do it.
- (2) I do it a lot less than my friends.
- (3) I do it a little less than my friends.
- (4) I do it as much as my friends.

Communication

This variable records the child’s frequency (compared with friends) to which the internet and electronic devices are used to communicate with others. Electronic devices include, but are not limited to, computers, tablets, smartphones, game consoles, etc. Internet use via an electronic device for communication may include texting, email, messaging applications (such as Snapchat, WhatsApp, Messenger, etc.), and social media (such as Twitter, Facebook, Instagram, etc.). This variable may be coded not applicable (N/A) if the child does not have access to the internet or an internet-accessible electronic device.

Family outings

This variable records the frequency (compared with friends) to which the child goes places with family. Places may include restaurants, theater, sports events, holiday travel, etc.

Spending time with friends

This variable records the frequency (compared with friends) to which the child plays or hangs out at a friend’s house.

Being out with friends

This variable records the frequency (compared with friends) to which the child goes out with friends to eat, watch movies, attend concerts, or sports events. If the child is too young to be out without a parent or guardian the variable may be coded as N/A.

Participating in team or club activity

This variable records the frequency (compared with friends) to which the child participates on a community team or club. Community team or club activities include any sports leagues, girl/boy scouts, choir, theater, etc. This variable may be coded N/A if the child is less than 6 years of age.

Dating

This variable documents whether or not the child with SCI dates and/or has a girlfriend/boyfriend. The code “I do not date” means the individual does not go on dates or does not have a boyfriend/girlfriend, whereas the code “I date” means the individual dates or has a girlfriend or boyfriend. This variable may be coded as N/A if the child is too young to date or in cultures where dating is not usual (for example, arranged marriages).

Paid work

This variable records the frequency (compared with friends) to which the child engages in gainful employment or work. The preamble to this question (A job means doing something to get paid) highlights the requirement of “gainful” or “paid” employment/work. Examples of paid work can include activities such as babysitting, dog-walking, newspaper delivery, etc. Allowances for household chores are not considered paid work. If the child is too young to perform paid work or in cultures where paid employment is not usual, this can be coded as N/A.

Physical activities

This variable records the level of physical activity in the last 7 days. *Things that involve little physical effort* include sedentary activities such as reading, watching television, playing games, etc. This variable was adapted from the PAQ-C [16, 24], The 7-day recall period is unique to this variable; it is the same recall period used in the PAQ-C as well as other validated physical activity measures noted in the literature, including the Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury and the International Physical Activity Questionnaire [33, 40, 41].

Discussion

The International SCI Pediatric A&P Basic Data Set records the minimum amount of clinically relevant information on activities and participation of children with SCI between 6 and 17 years of age. The data set can be administered in conjunction with the newly developed International SCI Pediatric Education Data Set [26] to record the most relevant areas of function and participation in children with SCI.

None of the International SCI Basic Data Sets, including the International SCI Pediatric A&P Basic Data Set were developed as assessments or outcome instruments. However, because they contain standardized methods for recording variables and are designed to facilitate pooling of clinical data, they should be validated and tested for reliability. Likewise, while the process by which the international SCI basic data sets are developed provides face validity, further evaluation for cultural relevance is necessary. Thus, future field testing of the International SCI Pediatric A&P Basic Data Set is warranted, particularly for cultural relevance and feasibility of administration. If translated, it should be done so in accordance with the procedures outlined by Biering-Sørensen et al. [42]. As has been done for the other international SCI basic data sets, we anticipate that this data set will be exposed to a formal review sometime in the future after the field has had an opportunity to use it, and as our understanding and ability to measure activity and participation in children with SCI advance.

Conclusion

The International SCI Pediatric A&P Basic Data Set provides an important addition to the library of international SCI basic data sets. It provides a mechanism to record activity and participation in a standardized fashion and therefore supports the pooling of clinical information from across the globe. The International Spinal Cord Injury Pediatric Activity and Participation Data Basic Data Set can be found on the ISCoS website (<https://www.iscos.org.uk/international-sci-data-sets>).

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Compliance with ethical standards

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Ethics approval All the authors affirm that the paper is an authentic, accurate, and transparent account of the study; no aspects of the study have been omitted; and the incongruities from the planned study have been explained. Ethical standards for this human subject’s research were strictly followed.

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