INTERNATIONAL SPINAL CORD INJURY DATA SETS

**PEDIATRIC ACTIVITIES AND PARTICIPATION BASIC DATA SETS**

Version 1.0, February 2018

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**Acknowledgements**

Dr. MJ Mulcahey graciously granted permission to use items from the Spinal Cord Independence Measure-III Self Report-Youth (SCIM-III SR-Y) and the Pediatric Measure of Participation (PMoP) items.

Dr. Kent Kowalski graciously granted permission to use and modify items from the Physical Activity Questionnaire for Older Children (PAQ-C).

We thank Kathryn Dent for her invaluable efforts in coordinating our many meetings and managing the numerous project documents and materials.

This work was funded by the Rick Hansen Institute

**Introduction**

The International Spinal Cord Injury Data Sets were developed to facilitate comparisons of injuries, treatments and outcomes among individuals with SCI, treatment centers and countries.[1](#_ENREF_1),[2](#_ENREF_2) To date, one Core Data Set, which documents demographic and injury-related variables, and 20 Basic Data Sets, which collect information on pertinent clinical areas and quality of life of individuals with SCI, have been developed.[3](#_ENREF_3),[4](#_ENREF_4) The International SCI **Activity and Participation (A&P)** Basic Data Set was first published in August 2012 with the purpose of documenting clinically relevant data on independence in activities of daily living (ADL) and participation. It consists of 12 items which were taken from established measures of ADL (Spinal Cord Independence Measure, SCIM-III) and participation (Craig Handicap Assessment and Reporting Technique, CHART), and is applicable to adult individuals with traumatic or non-traumatic SCI.[2](#_ENREF_2)

Youth with SCI have unique challenges in ADL and social participation that are dependent upon their physical and cognitive development, both at the time of injury and thereafter as they mature into adulthood. Accordingly, it is imperative that outcome measures of ADL and participation for youth with SCI adequately assess issues pertinent to children and adolescents as well as allow for longitudinal evaluations. An iterative critical review of the International SCI Core and Basic Data Sets was recently conducted to determine their relevance and potential usage in the pediatric SCI population, and concluded that the A&P Basic Data Set was one of five Data Sets which were not appropriate or applicable for use with children.[5](#_ENREF_5) Such findings indicated the necessity to develop a pediatric version of the International A&P Basic Data Set, and a working group of clinicians and researchers in the field of pediatric SCI was assembled to undertake this project. This multidisciplinary group consists of 7 members from the United States, 4 international members from Europe and Asia/Australia, and an expert consultant based in Canada.

The Pediatric A&P Basic Data Set consists of 3 domains: Activities of Daily Living (ADL), Physical Activities (PA), and Participation. Items of the ADL domain closely match those of the existing A&P Basic Data Set to include mobility, dressing, feeding, and toileting. The PA domain was added as the working group considered physical activity to be an important aspect of “activity” that has significant implications for both cardiovascular fitness and psychosocial outcomes.[6](#_ENREF_6) One item was included for the PA domain to assess frequency of physical activities during a 7-day period. The Participation domain consists of seven items that assess communication, participation with family and peers in various settings, dating, and paid work.

The working group reviewed several validated outcome measures of ADL, physical activity and participation specific to the pediatric SCI population to determine which would be adoptable for the Pediatric A&P Basic Data Set. Several rounds of review and discussions were conducted before achieving a consensus for each of the selected items.

For the ADL domain, the working group chose to adopt items from the SCIM-III Self Report-Youth (SCIM-III SR-Y)[7](#_ENREF_7) as this measure consists of items identical to the SCIM-III, which had been used for the existing A&P Data Set. Considering the ongoing maturation and development in children over time, the group had discussed the inclusion of grooming and upper body dressing items in addition to mobility, feeding, lower body dressing, and toileting. However, the working group agreed that the four items of the existing A&P Data Set would be appropriate as core activities for the pediatric population and decided not to include additional items. Additional items may later be included in the Pediatric A&P Extended Data Set.

A literature search conducted by the working group and recommendations from an expert consultant (KAN) with extensive experience in physical activity of individuals with SCI resulted in the selection of several validated measures of physical activity for youth and individuals with SCI. The Physical Activity Questionnaire for Children (PAQ-C),[8](#_ENREF_8),[9](#_ENREF_9) Leisure Time Physical Activity Questionnaire for People with SCI (LTPAQ-SCI),[10](#_ENREF_10) and International Physical Activity Questionnaire – Short Form (IPAQ-SF)[11](#_ENREF_11) were reviewed for consideration of inclusion in the PA domain. Ultimately, the working group selected one item from the PAQ-C for the PA domain, as it captures *frequency* of physical activities specific to children. The PAQ-C does not specifically target individuals with SCI, however, the group agreed that the selected item would be appropriate for application in youth with SCI. Also, although intensity and duration of physical activity are important aspects of physical fitness, the group agreed inclusion of such items would be beyond the scope of the Basic Data Set.

For the Participation domain, the working group reviewed the Pediatric Measure of Participation (PMoP) items as they had been developed and validated specifically for youth with SCI.[12](#_ENREF_12) The group agreed upon 5 items from the PMoP that were considered to be core activities of participation: communication through the internet, family outings, participation with friends in the home setting, participation with friends in the community setting, team/club participation, and paid work. One additional item on dating/having a boyfriend or girlfriend was also included in the Participation domain.

The Pediatric A&P Basic Data Set thus consists of 12 items that can be completed within 10 minutes during a clinic visit. It is expected that children 8 years of age and older will be able to respond to the Pediatric A&P Basic Data Set independently; for children younger than 8 years of age, parents or caregivers will complete the Data Set based on their child’s activities. In addition, parent/caregiver report may secondary (children aged 8-12 years), supplemental (children aged 13-14 years), and optional (children aged 15 years or older) depending on the age of the child. The Pediatric A&P Basic Data Set may be administered in written/screen format or through interview.

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**APPENDIX 1**

**International Spinal Cord Injury Data Sets**

**Pediatric Activities and Participation Basic Data Set Data Form (Version 1.0)**

**Date: \_\_ \_\_ \_\_ / \_\_ \_\_ / \_\_ \_\_ (YYYY/MM / DD)**

**Activities of daily living**

1) Mobility: Do you need help moving medium distances (10-100 meters) such as down a school hallway or in a gymnasium?

 I use a wheelchair to move around and

0. I always need help to move my wheelchair

1. I need a power wheelchair or a power-assist or some help to move my manual wheelchair

2. I do not need a power wheelchair and I do not need help to move my manual wheelchair

 I walk medium distances and

3. someone is always with me

4. I walk with a walker or crutches by swinging both legs and feet together

5. I walk with a walker or crutches by moving one foot forward at a time

6. I walk with one crutch

7. I walk with braces on my legs and do not need a walker or crutches

8. I walk with nothing to help me

2) Dressing: Do you need help dressing your lower body including putting on/taking off trousers, underwear, socks, shoes?

0. I need help with all of it

1. I need help with some of it

2. I do clothes without buttons, zippers, and laces myself but use splints or something on my hand to help me

3. I only need help, a splint, or something on my hand to help me for clothes with buttons, zippers, or laces

4. I do it by myself

3) Feeding: Do you need help with eating and drinking?

0. I eat nothing with my mouth

0. I need help with all of it

1. I need help with some of it

2. I do it by myself but use a splint or something on my hand to help me eat

3. I need help with cutting or pouring only

4. I do it by myself without a splint or something on my hand to help me eat

4) Toileting: When you urinate (pee) and have a bowel movement (poop), do you need help when you wipe your private area, wash your hands, and put on and take off clothes?

0. I need help with all of it

1. I need help with some of it and cannot wipe my private area

2. I need help with some of it but can wipe my private area

3. I do it by myself but with a splint or something on my hand to help me

4. I do it by myself without any help or a splint or something on my hand to help me

**Physical activities**

5) Which *one* of the following best describes your physical activities (both scheduled and free time activities, such as playing sports, dancing, biking, swimming, etc) for the last 7 days? Read *all five* statements before deciding on the *one* answer that describes you.

0. All or most of my time was spent doing things that involve little physical effort

1. I rarely (1-2 times last week) did physical things

2. I sometimes (3-4 times last week) did physical things

3. I often (5-6 times last week) did physical things

4. I nearly always (7 or more times last week) did physical things

**Participation**

6) At home I use the internet / phone to communicate with others.

0. I don’t do it

1. I do it a lot less than my friends

2. I do it a little less than my friends

3. I do it as much as my friends

99. N/A

7) I go places with my family.

0. I don’t do it

1. I do it a lot less than my friends

2. I do it a little less than my friends

3. I do it as much as my friends

99. N/A

8) I play or hang out at my friend’s house.

0. I don’t do it

1. I do it a lot less than my friends

2. I do it a little less than my friends

3. I do it as much as my friends

99. N/A

9) I go out with my friends to eat, watch movies, attend concerts or sporting events.

0. I don’t do it

1. I do it a lot less than my friends

2. I do it a little less than my friends

3. I do it as much as my friends

99. N/A

10) I am on a community team or club.

0. I don’t do it

1. I do it a lot less than my friends

2. I do it a little less than my friends

3. I do it as much as my friends

99. N/A

11) I date.

0. I do not date

1. I date

99. N/A

12) A job means doing something to get paid. I have a job.

0. I don’t do it

1. I do it a lot less than my friends

2. I do it a little less than my friends

3. I do it as much as my friends

99. N/A

**APPENDIX 2**

**International Spinal Cord Injury Data Sets**

**Pediatric Activities and Participation Basic Data Set – Comments**

Administration and Respondents:

The Pediatric Activities and Particiation (A&P) Basic Data Set consists of 12 items that can be completed within 10 minutes during a clinic visit. It is expected that children 8 years of age and older will be able to respond to this Data Set independently; for children younger than 8 years of age, parents or caregivers will complete the Data Set based on their child’s activities. In addition, parent/caregiver report may secondary (children aged 8-12 years), supplemental (children aged 13-14 years), and optional (children aged 15 years or older) depending on the age of the child. The Pediatric A&P Basic Data Set may be administered in written/screen format or through interview.

VARIABLE NAME: **Date of data collection**

DESCRIPTION: This variable documents the date of data collection

CODES: YYYY/MM/DD

COMMENTS: The collection of data on activity and participation should be conducted at least 3 months following discharge from initial rehabilitation after sustaining the SCI, and may be administered any time thereafter.

VARIABLE NAME: **Mobility**

DESCRIPTION: Depending on the motor function of the child/adolescent, this variable describes which mode of mobility is used (i.e., wheelchair or walking) and how much assistance is required to move around for medium distances (10-100 meters) in the last 4 weeks before data collection

RESPONSE 1: I use a wheelchair to move around and

CODES: 0 I always need help to move my wheelchair

1 I need a power wheelchair or power-assist or some help to move my manual wheelchair

2 I do not need a power wheelchair and I do not need help to move my manual wheelchair

OR

RESPONSE 2: I walk medium distances and

CODES: 3 Someone is always with me

4 I walk with a walker or crutches by swinging both legs and feet together

 5 I walk with a walker or crutches by moving one foot forward at a time

 6 I walk with one crutch

 7 I walk with braces on my legs and do not need a walker or crutches

 8 I walk with nothing to help me

COMMENTS: ‘Medium distances’ correlates to the distance between classrooms at school, length of a gymnasium, or a city block.

Answer either Response 1 or Response 2. Response 1 is for children who are unable to walk and require the use of a wheelchair for mobility; Response 2 is for children who are able to walk medium distances with or without assistive devices. Code 3: ‘Someone is always with me’ refers to the need of supervision or personal assistance for walking by another person. Codes 4-8 are applicable when no supervision or assistance is necessary for walking.

 This item was adapted from the SCIM-III SR-Y.

VARIABLE NAME: **Dressing**

DESCRIPTION: This variable documents independence of the child/adolescent in lower body dressing (clothes, shoes, braces; dressing, undressing) in the last 4 weeks before data collection

CODES: 0 I need help with all of it

 1 I need help with some of it

2 I do clothes without buttons, zippers, and laces myself but use splints or something on my hand to help me

3 I only need help, a splint, or something on my hand to help me for clothes with buttons, zippers, or laces

 4 I do it by myself

COMMENTS: This is a SCIM-III SR-Y item.

VARIABLE NAME: **Feeding**

DESCRIPTION: This variable documents independence of the child/adolescent in feeding (cutting, opening containers/bags, pouring, bringing food to mouth, holding cup with fluid) in the 4 weeks before data collection.

CODES: 0 I eat nothing with my mouth

 0 I need help with all of it

 1 I need help with some of it

2 I do it by myself but use a splint or something on my hand to help me eat

 3 I need help cutting or pouring only

4 I do it by myself without a splint or something on my hand to help me eat

COMMENTS: ‘I eat nothing with my mouth’ refers to feeding through a gastrostomy or other type of parenteral feeding.

This is a SCIM-III SR-Y item.

VARIABLE NAME: **Toileting**

DESCRIPTION: This variable documents independence of the child/adolescent in toileting (on the toilet or in bed; personal hygiene, adjustment of clothes, use of napkins or diapers) in the 4 weeks before data collection.

CODES: 0 I need help with all of it

 1 I need help with some of it and cannot wipe my private area

 2 I need help with some of it but can wipe my private area

4 I do it by myself but with a splint or something on my hand to help me

5 I do it by myself without any help or a splint or something on my hand to help me

COMMENTS: This is a SCIM-III SR-Y item.

VARIABLE NAME: **Physical activities**

DESCRIPTION: This variable documents the level of physical activity of the child/ adolescent in the 7 days before data collection

CODES: 0 All or most of my time was spent doing things that involve little physical effort

1 I rarely (1-2 times last week) did physical things

 2 I sometimes (3-4 times last week) did physical things

 3 I often (5-6 last week) did physical things

 4 I almost always (7 or more times last week) did physical things

COMMENTS: ‘Things that involve little physical effort’ include sedentary activities such as reading, watching television, playing video games, etc.

 This item was adapted from the Physical Activity Questionnaire for Older Children (PAQ-C).

VARIABLE NAME: **Communication**

DESCRIPTION: This variable documents how frequently the child/adolescent uses the internet through an electronic device (e.g., computer, tablet, smart phone, game console, etc) to communicate with others in comparison to their friends

CODES: 0 I don’t do it

 1 I do it a lot less than my friends

 2 I do it a little less than my friends

 3 I do it as much as my friends

 99 N/A

COMMENTS: Internet use through electronic devices for communication may include texting, email, messaging applications (such as Snapchat, WhatsApp, Messenger, etc), and social media (such as Twitter, Facebook, Instagram, etc). This item may be coded N/A if the child does not have access to the internet or is less than 13 years of age.

 This item was adapted from the Pediatric Measure of Participation (PMoP).

VARIABLE NAME: **Family outings**

DESCRIPTION: This variable documents how frequently the child/adolescent goes places with their family in comparison to their friends

CODES: 0 I don’t do it

 1 I do it a lot less than my friends

 2 I do it a little less than my friends

 3 I do it as much as my friends

 99 N/A

COMMENTS: Going places with family such as restaurants, theater, holiday travel, etc.

This item was adapted from the Pediatric Measure of Participation (PMoP).

VARIABLE NAME: **Spend time with friends**

DESCRIPTION: This variable documents how frequently the child/adolescent plays or hangs out at their friend’s house in comparison to their friends

CODES: 0 I don’t do it

 1 I do it a lot less than my friends

 2 I do it a little less than my friends

 3 I do it as much as my friends

 99 N/A

COMMENTS: This item was adapted from the Pediatric Measure of Participation (PMoP).

VARIABLE NAME: **Be out with friends**

DESCRIPTION: This variable documents how frequently the child/adolescent goes out with friends to eat, watch movies, attend concerts or sports events in comparison to their friends

CODES: 0 I don’t do it

 1 I do it a lot less than my friends

 2 I do it a little less than my friends

 3 I do it as much as my friends

 99 N/A

COMMENTS: This item may be coded N/A if the child is too young (less than 13 years of age) to be out without a parent or guardian.

This item was adapted from the Pediatric Measure of Participation (PMoP).

VARIABLE NAME: **Participate in team or club activity**

DESCRIPTION: This variable documents how often the child participates on a community team or club in comparison to their friends

CODES: 0 I don’t do it

 1 I do it a lot less than my friends

 2 I do it a little less than my friends

 3 I do it as much as my friends

 99 N/A

COMMENTS: Community team or club activities may include sports, girl/boy scouts, choir, theater, etc. This item may be coded as N/A if the child is less than 6 years of age.

This item was adapted from the Pediatric Measure of Participation (PMoP).

VARIABLE NAME: **Dating**

DESCRIPTION: This variable documents whether or not the individual dates and/or has a girlfriend/boyfriend

CODES: 0 I do not date

 1 I date

 99 N/A

COMMENTS: Code 0 includes not having a girlfriend or boyfriend; Code 1 includes having a girlfriend or boyfriend. This item may be coded as N/A if the child is less than 13 years of age.

This item was adapted from the Pediatric Measure of Participation (PMoP).

VARIABLE NAME: **Paid work**

DESCRIPTION: This variable documents how frequently the individual with SCI gets paid to do something (a job) in comparison to their friends

CODES: 0 I don’t do it

 1 I do it a lot less than my friends

 2 I do it a little less than my friends

 3 I do it as much as my friends

 99 N/A

COMMENTS: Allowances and household chores are not considered paid work. Examples of paid work: babysitting, dog-walking, newspaper delivery, etc. This may be coded as N/A if the child is less than 13 years of age.

This item was adapted from the Pediatric Measure of Participation (PMoP).