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Development of Items that Assess Physical Function in Children who Use Wheelchairs

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Abstract

Purpose—To assess the content, format, and comprehension of the Patient Reported Outcomes Measurement Information System (PROMIS) pediatric physical function related to mobility items for children who use wheelchairs (WCs).

Methods—During a cognitive interview, 14 children, ages 8 to 12 years, who use WCs, verbalized their thoughts when answering PROMIS items. Questionnaire Appraisal System was used to code summarized text from the interviews.

Results—The children requested items be more specific and include options for reporting adaptive ways of performing and participating. How they would answer the item depended on the situation and specific environmental supports and constraints they may have experienced.

Conclusions—As rehabilitation professionals develop and use self-reported outcome measures, they should explore what is important to children who use WCs regarding their views on physical functioning, the influences of the environment, and variability in the use of devices to assist with functional mobility.

Keywords

assistive technology; child; cognition; disability evaluation; environment; female; humans; interviews as topic; male; psychometrics; self-report; severity of illness index; social environment; wheelchairs

INTRODUCTION AND PURPOSE

Physical function is a commonly used construct in pediatric rehabilitation. It is implicitly described within the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF)¹ activities and participation domains. Evaluation of pediatric physical function explores and measures capacity and performance, levels of independence, and environmental and equipment needs of children in their daily living routines.²

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Self-reported outcome measures can play a large role in the evaluation of physical function by obtaining information from children about their abilities to do what they want to do and how they do it in their home and community settings. Children, properly queried, can be the best source of information about their health and treatment effects,³ and self-reporting can also be a means to facilitate children's participation in their own healthcare.⁴

A common assumption in many measures of physical function is that the capacity to engage in functional activities is essential to the formation of a sense of well-being and satisfaction in life.⁵ However, adults with disabilities often report their quality of life (QOL) as good and that their QOL is only moderately correlated with their symptoms or impairments.⁶ Similarly, it should not be assumed that children who use a wheelchair (WC) for mobility have poor health or diminished QOL.

Therefore, the common challenge in developing self-reported outcome measures is to assure that the constructs being measured are well understood and the foundation of the measures is grounded in the expertise of the respondents, thereby making the questions asked clearly understood and appropriate.⁷ Cognitive interviewing (CI), a technique used to obtain respondent feedback on potential questions, is considered important in the development of self-reported outcome measures that are psychometrically sound and valid.⁸ The intents of CI are to be aware of what the respondent understands a particular question to be asking; the processes used by each person to retrieve relevant information from memory; and the decisions used to arrive at an answer.⁹

Available CI research with individuals who use WCs is very limited. Meyers and Anderson¹⁰ administered the SF-36, a 36-item questionnaire that is widely used to examine functional health and wellbeing, to a sample of adults who use WCs. Respondents rejected words such as "walk" and "climb". However, when the word "go" was substituted and the questions changed to reflect function using assistive devices, results suggested that this version could be successfully used to measure performance among adults who had mobility impairments, including those who use WCs.¹¹

Cognitive interviewing was used by Dumas,² to assess the content, format, and comprehension of questions and responses developed for use in a parent-report of physical function measure for children with cerebral palsy (CP). Respondents commented that certain questions had limited applicability to their children (e.g., advanced physical activities for children with severe physical function limitations) and were unsure how to factor in (or not) level of assistance when responding to questions. Tucker et al.¹² examined the psychometric properties of a computer adaptive test (CAT) using parent-report of physical function in children with CP. They found a lack of questions related to assistive devices and WC use for mobility; though it was believed the inclusion of these questions would improve the responsiveness of the measure.

The Patient Reported Outcomes Measurement Information System (PROMIS)^{13, 14} is a multi-center project funded under the National Institutes of Health¹⁵ to develop a psychometrically sound and clinically meaningful measurement system of self-reported outcomes. Using state-of-the-art qualitative and quantitative methods, PROMIS personnel have developed a set of item banks for children and adults that allow the assessment of key symptoms and health concepts relevant to both community and clinical populations, including people with chronic conditions.¹³ The PROMIS pediatric physical function related to mobility (PFM) item bank was developed through a step-wise item review and extensive field testing. For this domain, CAT and short-form formats are available.¹⁶ Greater detail about the PROMIS qualitative and quantitative analytic plan is publicly available.¹³

The pediatric PFM domain satisfies general criteria for unidimensionality, the assumption that the construct being measured can be expressed as a range of ability on a definable continuum characterized by a number of items that can be ordered from low to high, or easy to difficult.¹⁶ However, a conceptual and practical problem suggests that a unidimensional model might not be a valid representation when disability is present.¹⁷ The PROMIS pediatric PFM item bank was developed through focus groups and CI of children with asthma and children without medical conditions or disabilities and it was noted that the assistive device items included in the item bank (i.e., questions about using a walker or WC) did not apply to a large number of those children.⁹

The outcome measurement field would benefit from further study and application of the PROMIS pediatric PFM item bank with children having a greater variety of diseases and disabilities, including those at the extreme ends of physical functioning. The purpose of this study was to use CI to assess the content, format, and comprehension of the PROMIS pediatric PFM items and appraise responses from children who use WCs.

METHODS

This study was approved by the Seattle Children's Hospital Institutional Review Boards prior to initiation of study procedures.

Participants

A sample of 14 children, ages 8 to 12 years, who used a WC participated in CI. The children were recruited through professional contacts, consumer organizations for children with disabilities, and flyers posted in the community. Inclusion criteria required that each child had used a WC as their primary means of mobility for at least 3 prior consecutive months and had one of the following parent-reported diagnoses: CP, spinal cord injury, spina bifida, Duchenne's muscular dystrophy, or other chronic physical disabilities. Each child also had to read English at the second grade level and parents had to report that the child could meaningfully answer the questions on the survey during the study screening. All participants and their parents provided written informed assent and consent before the children's participation in the study.

Measure

Based on the WHO definition of health: "a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity",¹⁸ PROMIS defines physical function as "one's ability to carry out various activities, ranging from self-care (activities of daily living) to more challenging and vigorous activities that require increasing degrees of mobility, strength, or endurance".¹³ PROMIS further describes the pediatric PFM item banks as focusing on "activities of physical mobility such as getting out of bed or a chair to activities such as running". These are reported¹³ to be "consistent with the International Classification of Functioning for Children (ICF-CY)".¹⁹

PROMIS pediatric PFM items are framed as "capability" (i.e., what a child "can do") rather than "performance" (i.e., what a child "does do").¹³ It emphasizes walking without accommodations or environmental adaptations as the highest probable level of functioning.¹⁶ Table 1 presents the PROMIS pediatric PFM item bank including the item context, stem, and response scale.

Procedures

This study closely followed the PROMIS Qualitative Item Review (QIR) CI protocol.²⁰ The 23 PROMIS PFM items were initially reviewed by the lead investigator, a pediatric physical

therapist who has worked with children with disabilities for over 20 years, and an expert panel comprised of 2 pediatric physical therapists, 1 occupational therapist, and an educational psychology researcher of children with disabilities. The lead investigator conducted all of the CI with participants. CI sessions were conducted in the child's home, at the hospital or over the telephone, based on child/parent preference. Each child's reading level was assessed through the reading section of the Wide Range Achievement Test 3 (WRAT3), a commonly used and reliable assessment of reading level.²¹

The children first read and responded to all of the 23 PROMIS PFM items in paper and pencil format. Then the primary investigator, using the PROMIS CI protocol of questions (See Table 2) and spontaneous probes encouraged the children to verbalize their thoughts when answering each item. The questions and probes were based on previous PROMIS research and addressed 4 main topics: item clarity, time frame, item content, and response format.⁹

The primary investigator and a research assistant took detailed notes throughout each interview about the child's responses to the probes; questions or concerns about the items that arose during the interviews; and thoughts about the interview format and interaction. When permission was given, the interviews were audio recorded to ensure accuracy of interviewers' notes. All concerns identified by the children were considered potential problem areas. An a priori decision was made to stop data collection when saturation was perceived (i.e., no new responses were elicited).

Data Analysis

Following each child's CI, field notes were compiled into a single text document including each item and the child's comments. After completion of all CI, all comments for a single item were generated. In addition to following the PROMIS QIR CI protocol, we used the Questionnaire Appraisal System (QAS)²² that provided a structured systematic review of the children's comments for each of the items. The goal of using the QAS was to improve the efficiency of the questionnaire review process by providing an easy-to-use method for categorizing concerns the participants may have with the items.²²

Five categories of the modified version of the QAS (Clarity, Assumptions, Knowledge, Sensitivity/Bias, and Response Categories) were used to code each of the item's summarized text documents. Two QAS categories (Problems with Reading the Question and Problems with Instructions) and the Open-Ended Question subcategory were excluded as they did not apply. Table 3 presents the 5 categories and 20 subcategories that were used for coding. When coding disagreements occurred they were resolved by consensus of the 2 coders and expert panel. Additional item concerns not readily captured by the QAS were also identified and recorded.

RESULTS

CI's were completed with 14 children and all but 1 gave permission to have their interviews audio recorded. Participant demographics are summarized in Table 4. Each CI took approximately 90 minutes. The saturation requirement was met. Of the 322 comments that were coded, 4 disagreements required further discussion by the 2 coders and expert panel before achieving consensus.

Item Context

The item context used the time frame in the past 7 days. The children were asked what time frame they thought of when responding to these items. Of those who indicated using the requested time frame (n = 4) they reported either thinking about the last week of school,

Monday to Monday, or counted back 7 days. Others reported using a time frame other than the past week or not using a time frame at all ($n = 10$). Two children read right through in the past 7 days saying that it would be the same if they had been asked “in the last month.” Two children said it would be better to ask in the past 1 month because of recent special circumstances, 1 child being in the hospital and 1 at a camp, and that answers would be different depending on the time frame.

Item Response

Although some children ($n = 5$) felt the response options made sense to them and they would not change the options, a majority ($n = 9$) felt that response categories overlapped. With a little trouble and with some trouble seemed the same and they preferred to have 4 response options rather than 5. Most of the children were comfortable with the use of the word trouble. Only 1 child felt that the response should use the word difficulty rather than trouble.

QAS Results

QAS analysis identified 3 broad themes surrounding the categories of clarity, assumptions, and sensitivity of the PROMIS PFM related to mobility items (Table 5).

Clarity—During the analysis, clarity problems were identified with items related to communicating the intent of meaning of the question to the respondent. All of the children ($n = 14$) expressed concerns about some individual items being vague, that there were multiple ways to interpret the question or to decide what was to be included or excluded.

Six children wondered if the kids in the question I could keep up when I played with other kids could walk or if they too used a WC, which would affect the way they would respond. Many of the children’s answers had nothing to do with their functional ability, but more to do with the limitations placed on them by the environment (e.g., terrain). When an item was too general some said that they would answer with the middle choice “with some trouble”.

Other items on which children asked for clarification included I could bend over to pick something up. Answers varied depending on where the object was located. All of the children in one way or another wondered if they could use assistance to accomplish some of the other items such as I could move my legs, I can get up from the floor and I can stand up by myself.

Regarding getting up from the floor and standing the children said they could do it if they could use their hands, WC, walker, or when someone holds on to them. The children consistently asked for clarification regarding the questions I could get in and out of a car, I could get into or out of bed by myself, and I could ride a bike. They wanted more specific information such as type of car, bed height and characteristics of the bike.

Assumptions—The children expressed concerns about the inappropriate assumptions that some items made about them or about their situation. These included the following items: I could walk across the room, I could walk more than one block, I could run a mile, and I could get up from a regular toilet. Many of these items assume the respondent is ambulatory. The children said they would answer differently if the wording were changed. Many said they get around in different ways, using a variety of assistive devices/WC, depending on the destination and activity. Some of their answers would depend on the environment in which they were performing the activity.

Sensitivity of Items—Finally, the QAS analysis assessed the items for sensitive nature or wording, and for bias. Many of the children were not bothered with answering the questions

that had nothing to do with how they moved or played. Three children, however, commented that they were not happy answering not able to do on several of the questions. Nevertheless, many were pleased they could express how to change the wording of the questions. For example instead of I could walk across the room a child changed the wording to “I could wheel across the room.” With that small change many of the children’s responses changed from 0, not able to do, to 4, with no trouble. The children were forthcoming about suggestions of what they would like to be asked about their PFM, taking into account what they “can do” with their WC.

DISCUSSION

CI provided valuable information about the PROMIS pediatric PFM items for children ages 8 to 12 years who use WCs. The items were easily comprehended by the children in this study. The children, in meaningful and insightful ways, provided feedback on the PROMIS items they thought were not applicable to them and offered suggestions for personally important items that would better capture their perspectives of PFM. These findings are consistent with other studies examining the development of self-reported outcome measures for children⁹ and populations that use WCs for their PFM.^{2,23}

The children had a variety of responses when asked what the phrase in the past 7 days meant to them. The selection of the recall period is an important decision in the development of a self-reported outcome measures. In general, researchers have suggested shorter recall periods (e.g., 24 hours, or 1 week at most) can be preferable to longer recall periods. Longer recall data can be heavily biased by current health and any significant events. Choice of an optimal recall period may depend on a number of other factors such as the measure’s purpose and intended use; the variability, duration, frequency, and intensity of the concept measured, and the disease or condition’s characteristics.²⁴ Interestingly, in our study, some of the children’s responses were influenced by the environment in which they were present during the recall period.

Unlike the PROMIS CI study,⁹ the children in this study expressed difficulty with differentiating between 2 of the 5 response options and suggested that 4 response options would be sufficient. Previous research has shown that 8-year-old children have accurately used the full range of 5–7 point Likert scales to rate their health whereas younger children seem to respond more easily to a 3-point Likert scale.²⁵ Our study’s qualitative findings regarding the optimal recall period and number of response options should be explored further using quantitative methods similar to the PROMIS recommended item development methodology.

Participants identified items containing vague concepts, unclear assumptions, or were otherwise sensitive in nature. All of the children expressed concerns about the items being vague, with many ways to interpret and answer a question. The difficulty answering a question was not due to their functional limitations, but rather due to environmental limitations and the uncertainty about how to take these into account when reporting. Their functioning also depended on whether or not they were allowed to use their WC or other kinds of assistance. Despite the acknowledged role of environmental and personal factors to compensate for physical functioning limitations or environmental barriers in characterizing physical functioning, most self-reported outcome measures of PFM do not appear to take these factors into account.²⁶

Tieman²⁷ examined variability of mobility methods of children with CP in different Gross Motor Function Classification System (GMFCS) categories. Results indicated that children within the same GMFCS category exhibited differences in their mobility independence that

varied by environment, especially in the school and outdoors/community settings. Certain personal factors of the child, such as preferences, personality (e.g. sense of adventure, cautiousness), cognition, and health condition may also affect mobility. For instance, some children may want to walk despite the slow speed and high energy cost, whereas others may prefer wheeled mobility.

Of the 100 physical function measures commonly used in rehabilitation research reviewed by Rust,²⁸ few measures addressed use of assistive technology (AT) and if included, AT use tended to lower the overall score. This suggests that using AT reflects a negative rehabilitation outcome and must be addressed to reconcile different conceptual models of disability and physical functioning measures.

Participants also expressed concerns about the type of questions that were being asked, with particular reference to walking and performing activities using one's legs. Many stated that their answers would differ by changing the word walk to wheel. This suggests that it is important to measure PFM from multiple perspectives and has implications for the development of valid outcome measures for specific populations.

In the context of health, the ICF defines activities and participation as 'the execution of a task or action' and 'involvement in a range of life situations'.¹ The authors of the ICF indicated that it is impossible to differentiate between the domains that represented individual (activity) and societal (participation) perspectives given international variations and varying professional approaches.¹ The absence of clear definitions for these 2 constructs can create a dilemma for measurement. Different measures may be developed that identify themselves as measures of activity or participation, while actually representing quite distinct definitions of these constructs.

Researchers and clinicians also continue to debate the difference between the 2 ICF Activity and Participation qualifiers: capacity (child's ability in a standard environment) and performance (what the child does in his or her current environment).^{1, 29, 30} The decision to measure capacity, performance, or both should depend on what the researcher or clinician plans to do with the data. Treatment is sometimes intended to improve capacity, and ultimately to improve performance. In other situations the intent of treatment is to improve the quality of existing functions so that activities can be performed more easily.

One potential advantage of using ICF defined performance measures is that they provide a direct assessment of home or community functions, and assess limitations of direct relevance to children. Since home, school and play environments are most meaningful to children the use of performance measures in these settings may be more appropriate.³¹ Some argue that both capacity and performance should be measured. This strategy may identify specific areas of differences between capacity and performance and thereby may identify environmental factors that limit performance. This ultimately may lead to alternative intervention strategies such as environmental modifications.³²

The "capability" definition used for the PROMIS PFM item banks appears to be similar to the ICF Activity and Participation capacity rather than performance qualifier. For PROMIS, gathering information about one's inability to walk or climb stairs is a valuable measure for children who use WCs. Since the PROMIS PFM items exist as part of a calibrated item bank, when given to participants using a CAT, children who use WCs would not be given the walking items.

Although this may capture the physical capacity of a child, it may not provide insight into the child's overall functional abilities when using a WC. It is possible for a child who uses a WC to have better functional mobility than a child who ambulates without assistive devices.

This suggests the potential need for a PFM item bank that is specifically for children who use WCs, possibly 1 for manual WCs and 1 for power WCs.

In 2008, PROMIS developed a physical function item bank appropriate for adults who use WCs, mobility aids, and other AT. The expert panel working on the item bank recommended that physical function should include what people with chronic conditions can accomplish using AT, any device that would assist participants in independently accomplishing physical tasks and chores.³³ Subsequent analysis of this item bank indicated that the added items substantially improved the precision of the item bank, particularly for use with individuals with low physical function.³³

The selection of a self-reported outcome measure should be concept driven and/or include what is most meaningful and important to the individuals reporting. The children participating in our study requested that items be more specific and include more options for reporting adaptive ways of performing and participating, saying their answers to items depended on the situation and the environmental supports and barriers. The children also suggested other items they would like to be asked about their functional mobility, however, these items likely represent a different construct(s) than the one used to develop the PROMIS pediatric PFM item bank. To develop these suggested items into a new self-reported outcome measure for children who use WCs, they need rigorous review and further development.

Table 6 provides potential items to consider including in an item bank that measures PFM of children who use WCs. For this item bank, PFM of children who use WCs can be defined as the child's ability to move within the environment in a purposeful way for activities of daily living with modifications and equipment needed. Clearly, these items would need to be carefully trialed and amended as needed using the PROMIS mixed method (qualitative and quantitative) analyses based on a larger and more diverse sample of children who use WCs.

Limitations

As guidelines for interpreting CI results are not yet standardized in the research literature, the primary investigator and expert panel made judgments regarding the importance of a QAS item problem. Given the small sample size the results may not be representative of all children who use WCs.

CONCLUSIONS

Overall, children as young as 8 years old who use WCs are able to respond to items and discuss aspects of their PFM in meaningful ways. They comprehended varying response options and accurately understood a 7-day recall period. The children resoundingly wanted to share about what they were able to do, as evidenced in their suggested items regarding PFM. Most current self-reported PFM outcome measures do not capture the activity/participation of children who use WCs. Although the data from the cognitive interviews suggested items for a PFM outcome measure for children who use WCs, further development including qualitative and quantitative analyses using a larger sample is needed.

In the future, integrating pediatric outcome measurement within the context of the ICF framework may clarify the relationship between physical function, activities/participation, and capacity/performance. As pediatric rehabilitation professionals develop and increasingly use sound self-reported outcome measures, they should continue to explore the authentic reflections made by children who are wheelchair users regarding their physical functioning, the influences of environments, and the variability in the use of devices to assist with mobility. Suggested enhancements should result in continued refinement and successive

generations of measures in which children who use WCs can become central reporters about their experiences and needs.

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Table 1

PROMIS pediatric physical function related to mobility item bank

Item Context:	Item Stem:	Item Response:
In the past 7 days...	I could do sports and exercise that other kids my age could do.	4 = With no trouble 3 = With a little trouble 2 = With some trouble 1 = With a lot of trouble 0 = Not able to do
	I could get up from the floor.	
	I could keep up when I played with other kids.	
	I could move my legs.	
	I could stand up by myself.	
	I could stand up on my tiptoes.	
	I could walk up stairs without holding on to anything.	
	I have been physically able to do the activities I enjoy most.	
	I could bend over to pick something up.	
	I could carry my books in my backpack.	
	I could get down on my knees without holding on to something.	
	I could get in and out of a car.	
	I could get into bed by myself.	
	I could get out of bed by myself.	
	I could get up from a regular toilet.	
	I could go up one step.	
	I could ride a bike.	
	I could run a mile.	
	I could turn my head all the way to the side.	
	I could walk across the room.	
	I could walk more than one block.	
	I used a walker, cane or crutches to get around.	
	I used a wheelchair to get around.	

Table 2**Cognitive Interview Questions and Probes**

How would you ask this question in your own words?
How easy or hard was it to answer this question? (If the child finds it hard to answer) How would you change the question to make it easier to answer?
How easy or hard was it to tell the difference between each answer choice? (i.e., no, little, some, a lot of trouble or unable to do)
You picked (quote their choice) as your answer. What does (quote their choice) mean to you?
If you could change the answers to this question to make them easier to understand, what if anything would you do? If the question was changed what would be your answer?
When you read the words “past 7 days” which days did you think of? (e.g. from which day to which day?)
Did you think mostly about what you did on certain days or what you usually did over the last 7 days (If certain days, “can you tell me more about what made you think about those certain days?”)
Would you have answered differently if we asked you about what had happened over the last 30 days instead of only the last 7 days?
Finally, what could we do, if anything, to improve these questions when we use them in the future with children who use a WC to get around?

Table 3

Questionnaire Appraisal System (QAS) coding definitions

Categories	Definition
1. Clarity:	Identify problems related to communicating the intent or meaning of the question to the respondent.
1a. Wording:	Question is lengthy, awkward, ungrammatical, or contains complicated syntax.
1b. Technical Terms	are undefined, unclear, or complex.
1c. Vague	There are multiple ways to interpret the question or to decide what is to be included or excluded.
1d. Reference Periods	are missing, not well specified, or problematic.
2. Assumptions:	Determine if there are problems with assumptions made or the underlying logic.
2a. Inappropriate Assumptions	are made about the respondent or about his/her situation.
2b. Assumes Constant Behavior	or experience for situations that vary.
2c. Double-Barreled:	Contains more than one implicit question.
3. Knowledge/ Memory:	Check whether respondents are likely to not know or have trouble remembering information.
3a. Knowledge	may not exist: Respondent is unlikely to know the answer to a factual question.
3b. Attitude	may not exist: Respondent is unlikely to have formed the attitude being asked about.
3c. Recall	failure: Respondent may not remember the information asked for.
3d. Computation	problem: The question requires a difficult mental calculation.
4. Sensitivity/ Bias:	Assess questions for sensitive nature or wording, and for bias.
4a. Sensitive Content:	The question asks about a topic that is embarrassing, very private, or that involves illegal behavior.
4b. Sensitive Wording:	Given that the general topic is sensitive, the wording should be improved to minimize sensitivity.
4c. Socially Acceptable	response is implied by the question.
5. Response Categories	Assess the adequacy of the range of responses to be recorded.
5a. Mismatch	between question and response categories.
5b. Technical Terms	are undefined, unclear, or complex.
5c. Vague	response categories are subject to multiple interpretations.
5d. Overlapping	response categories.
5e. Missing	eligible responses in response categories.
5f. Illogical Order	of response categories.

Table 4

Participant Demographics

ID #	Age (yrs)	Sex	DX	Type of WC Other Mobility	Where	Other
1	12	F	CMD	Power	HSC	Urban
2	8	M	CP	Crawls Manual 1 Arm Pushed	H S C	Urban
3	10	M	SB	Manual	HSC	Rural
4	12	F	SB	Manual	HSC	Rural
5	12	F	Olliers AKA	Power	HSC	Rural
6	10	M	CP	Walker Manual Power	H HSC SC	Urban
7	11	M	SB	Manual	HSC	Rural
8	9	M	SB	Manual	HSC	Rural
9	10	M	SB	Manual	HSC	Rural
10	10	M	SMA	Power	HSC	Urban
11	11	M	CP	Power	HSC	Urban
12	12	F	CP	Walker Manual	H SC	Urban
13	12	F	SCI T3	Manual	HSC Rehab	Rural
14	11	M	SB	Manual	HSC	Urban

ID# = Child's study ID number, Sex = Female (F), Male (M), DX = Diagnosis: spinal bifida (SB), cerebral palsy (CP), spinal cord injury (SCI), congenital muscular dystrophy (CMD), spinal muscular atrophy (SMA), Olliers disease (Olliers), recent above knee amputation (AKA). Where wheelchair used = Home (H), School (S), Community (C), Currently in inpatient rehabilitation facility (Rehab).

Table 5

Samples of participant's comments related to the clarity, assumptions, and sensitivity of the PROMIS items

<p><u>Clarity</u>: Identify problems related to communicating the intent or meaning of the question to the respondent.</p> <p><u>Subset Vague</u>: There are multiple ways to interpret the question or to decide what is to be included or excluded.</p>
<p>I could do sports and exercise that other kids my age could do.</p> <p><i>"Depending on the sport or exercise I would answer a 4 with no trouble or some I would answer a 0, not able to do."</i> 7</p> <p><i>"Are these kids in WC? If they are in WC then no trouble, with kids not in WC then not able to do."</i> 2</p> <p><i>"If accessible I would do more sports. I have to travel a lot to do some sports like basketball because I haven't found a team near my home."</i> 8</p>
<p>I could bend over to pick something up.</p> <p><i>"I am confused with the question regarding bending over to pick something up. It depends on where the object is. How high up is it? Is it on a low table or the floor?"</i> 5</p>
<p>I could move my legs.</p> <p><i>"Is it okay to use my hands to move my legs, I can move some parts of my legs but sometimes I need my hands to move my whole leg"</i>. 4</p>
<p>I could get in and out of a car.</p> <p><i>"Are you talking about a WC van? I can get in and out of our van, but I need help trying to get into my friend's car."</i> 9</p>
<p>I could carry my books in my backpack.</p> <p><i>"Are you talking about carrying them in a backpack on the back of my WC?"</i> 11</p>
<p>I could get into bed by myself.</p> <p><i>"Depends on the height of the bed. I can get into my own bed because my dad lowered it, but I need help getting into beds like at a hotel or something."</i> 8</p>
<p>I could ride a bike.</p> <p><i>"Do you mean an actual bike? I own a hand bike and I can ride that."</i> 13</p>
<p><u>Assumptions</u>: Determine if there are problems with assumptions made or the underlying logic. There are multiple ways to interpret the question or to decide what is to be included or excluded.</p> <p><u>Subset Inappropriate Assumptions</u>: are made about the respondent or about his/her situation.</p>
<p>I could walk more than one block.</p> <p><i>"Why are you asking me all these questions about using my legs and walking? I use a WC to get around. Instead of using the word walk how about using the word go, wheel, or roll."</i> 14</p>
<p>I could get up from a regular toilet.</p> <p><i>"Get up from a toilet makes me think that I need to stand up. I can transfer to and from the toilet."</i> 7</p> <p><i>"I don't need to use a toilet; I go to bathroom a different way."</i> 9</p>
<p>I could ride a bike.</p> <p><i>"I would answer it differently if it said hand bike."</i> 6</p>
<p>I could walk across the room.</p> <p><i>"I scoot around the house, really fast. Want to watch me?"</i> 2</p>
<p>I could go up one step.</p> <p><i>"I can crawl up the stairs pretty easily."</i> 14</p>
<p>I could stand up by myself.</p> <p><i>"I can stand with my braces."</i> 7</p>
<p><u>Assumptions</u>: Determine if there are problems with assumptions made or the underlying logic. There are multiple ways to interpret the question or to decide what is to be included or excluded.</p> <p><u>Subset Assumes Constant Behavior</u>: or experience for situations that vary.</p>
<p>I used a WC to get around.</p> <p><i>"I have a hard time using my WC on a rug but I can on the gym floor."</i> 2</p>
<p>I could do sports and exercise that other kids my age could do.</p>

<i>"I would be able to do more of these things, but it is hard to get around my school and the parks in my town, I think you call it accessibility. I live in a small town."</i> 8
I could keep up when I played with other kids.
<i>"I can keep up with my friends unless there are stairs."</i>
<u>Sensitivity/ Bias:</u> Assess questions for sensitive nature or wording, and for bias. <u>Subset Sensitive Content:</u> The question asks about a topic that is embarrassing, very private, or that involves illegal behavior.
<i>"It only took me 5 minutes to answer the questions because so many of them were zeros. The questions upset me. Why were so many of the questions about walking?"</i> 5
Other questions that should be asked: <i>"You should ask questions about doing stuff around the house in a WC or more stuff to do with arms like brushing teeth. Also you should ask questions about doing things like shopping, going to the movies, library, out to eat."</i> 1 <i>"You should ask about getting dressed, taking care of the dog, taking a shower, ask more about how we do things."</i> 12 <i>"Kids in WC can do a lot. Ask questions about what they do, what they enjoy."</i> 14

QAS Categories, Subsets, and Definitions, underlined, **PROMIS PFM Items**, **bold**, *Examples of Children's Responses are italicized*. Numbers 1–14 at the end of the quotes correspond to the participant who made the quotes, ID number found in Table 4.

Table 6

Potential items to include in a pediatric physical function related to mobility item bank for children who use wheelchairs (WCs).

Item Context:	Item Stem:	Item Response:
In the past 7 days...	I could carry my books in my backpack on the back or underneath my WC	4 = With no trouble 3 = With a little trouble 2 = With some trouble 1 = With a lot of trouble 0 = Not able to do
	I could reach for an object from my WC	
	I could stand up using my WC	
	I could get up from the floor using my WC	
	I could transfer between my WC and another chair	
	I could transfer into and out of bed from a WC.	
	I could transfer on and off the toilet from a WC	
	I could transfer on and off the tub bench from a WC	
	I could transfer or wheel in and out of a car/van.	
	I could lock and unlock my WC brakes	
	I could manage my arm and leg rests	
	I could turn in my WC	
	I could wheel across the room.	
	I could wheel more than one block.	
	I could wheel a mile.	
	I could ride a bike, hand-bike, 3-wheeled bike.	
	I could wheel up and down inclines or ramps using my WC	
	I could wheel up and down curbs using my WC	
	I could wheel on a lawn or gravel using my WC	
	I could wheel in and out of an elevator	
	I could do a wheelie using my WC	
	I could open a door from my WC	