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The use of focus groups in the development of the PROMIS pediatrics item bank

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Abstract
Purpose To understand differences in perceptions of patient-reported outcome domains between children with asthma and children from the general population. We used this information in the development of patient-reported outcome items for the Patient-Reported Outcomes Measurement Information System Pediatrics project.
Methods We conducted focus groups composed of ethnically, racially, and geographically diverse youth (8–12, 13–17 years) from the general population and youth with asthma. We performed content analysis to identify important themes.
Results We identified five unique and different challenges that may confront youth with asthma as compared to general population youth: (1) They experience more difficulties when participating in physical activities; (2) They may experience anxiety about having an asthma attack at anytime and anywhere; (3) They may experience sleep disturbances and fatigue secondary to their asthma symptoms; (4) Their health condition has a greater effect on their emotional well-being and interpersonal relationships; and (5) Youth with asthma report that asthma often leaves them with insufficient energy to complete their school activities, especially physical activities.
Conclusions The results confirm unique experiences for children with asthma across a broad range of health domains and enhance the breadth of all domains when creating an item bank.

Keywords Asthma · Children · Focus groups · Patient-reported outcomes · Pediatric

Abbreviations

NIH	National Institutes of Health
PRO(s)	Patient-reported outcome(s)
PROMIS	Patient-Reported Outcomes Measurement Information System
UNC	The University of North Carolina at Chapel Hill

Introduction

Patient-reported outcomes (PROs) provide a direct measurement of the patient experience with illnesses and treatments. The National Institutes of Health (NIH) Roadmap Initiative, PROMIS (Patient-Reported Outcomes Measurement Information System), was funded to advance PRO measurement using modern test theory and information technology (http://www.nihpromis.org). The overall mission of PROMIS is to enable researchers and clinicians to generate health status reports that will improve clinical decision-making; facilitate policy-making by health plans, systems and public programs; enhance research; and ultimately improve health and quality of life among patients [1].

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The PROMIS Pediatrics project is focused on the development of item banks across several health domains for youth ages 8–17 years. The resulting measurement system is intended for use in assessing general childhood health-related quality of life, disease-specific symptoms, and treatment effects in clinical research. Initially, PROMIS focuses on the measurement of generic health domains that are important across a variety of illnesses, including physical function, pain, fatigue, emotional distress, and social function [2].

Asthma is the most common chronic disease of childhood, and PRO measurement is an essential component of evaluation of outcomes for children with asthma [3–5]. For that reason, we felt that asthma was an excellent chronic condition for the initial development of the PROMIS pediatrics disease-specific item bank. Therefore, an asthma-specific impact domain will also be included in the PROMIS Pediatrics instrument to explore the integration of generic and disease-specific measurement in one system. Although several other instruments are available to measure asthma-specific symptoms, the advantage of PROMIS is to unify measurement to a common standard utilizing item response theory and computer adaptive testing [6]. As such, we will be able to compare the measurement of pediatric patient health and well-being across a variety of items and scales.

Although most PROs are developed for adults, several questionnaires have been developed and validated in pediatric populations [7–9]. Some pediatric PRO instruments are developed based on expert opinion and derived from adult instruments [10]. A few pediatric PRO instruments have incorporated the opinions and voices of children in the development process [11, 12]. Assessments of treatment effects in children with asthma and other chronic health conditions should account for contextual relationships such as family, peer, and school relationships that can cause diseases and their treatments to affect children differently from the way they affect adults [13].

Focus groups composed of ethnically, racially, and geographically diverse groups of youth were conducted to conceptualize pediatrics general and asthma specific PROs. Focus groups were one step in a process of qualitative item development and review prior to quantitative item testing. The entire process of qualitative item review is described elsewhere [11]. This paper describes the formative stage of the pediatrics PROMIS project starting with qualitative data collection on youth and documents the findings from these focus groups.

Methods

Participants

Youth were recruited from two sites: The University of North Carolina (UNC) in Chapel Hill, North Carolina, and The Children's Hospital at Scott and White Memorial Hospital and Clinic in Temple, Texas. The patient populations at these two sites are racially diverse. At UNC the participants were 48% white non-Hispanic, 42% African-American, and 6% Hispanic, while in Texas they were 50% white non-Hispanic, 15% African-American, and 35% spread across several other racial/ethnic categories. Youth with asthma were recruited for the focus groups through pediatric pulmonary clinics and had a confirmed asthma diagnosis in their medical records. Youth from the general population were recruited from general pediatrics clinics when they had their appointments for "well child" visits. Patients seen for "well child" visits who self-reported asthma were asked to join the asthma groups. Informed consent was obtained from parents or legal guardians of all of the participants; participating youth signed assent forms. Medical charts were abstracted after the focus groups to classify asthma severity on the participants.

Procedures

Using purposive sampling we aimed to recruit four to seven participants per focus group and we conducted eight focus groups. Four groups were held for preadolescent children (8–12 year olds), two were composed of children with asthma, and two groups were composed of children from the general population. Similarly, four groups were held for adolescents (13–17 years of age), two for adolescents with asthma, and two with adolescents from the general population. The two age groups were chosen and conducted separately as we felt some issues, especially those related to emotional and social domains, would be addressed differently among adolescents compared to younger children. All focus groups were of mixed-gender as the focus group guide did not concentrate on gender sensitive issues. For each age and health status category, one focus group was held in North Carolina and the other in Texas. At the end of each focus group each participant was given a $25 gift card for their time and participation.

Each focus group consisted of a lead moderator and a co-moderator who were all social work doctoral students experienced in working with children. All moderators were trained and supervised by an experienced, PhD-level, qualitative researcher. The lead moderators introduced the topics and guided the discussion. The co-moderators took detailed notes and interjected questions and probes to ensure that the moderators accurately interpreted children's comments. Most of the time, the co-moderators were observers, but they occasionally asked follow-up questions to clarify participants' responses. For the eight focus groups we had four teams of moderator/co-moderators. There were no outside observers in the sessions, only moderators and study participants.

The lead moderators worked from a semi-structured interview guide to elicit group participation and discussion on specific topic areas [12, 14, 15] (see Appendix). The focus group guide was developed after reviewing the current structure of child health assessment across several questionnaires, and the framework of the PedsQL was used to initiate focus group discussions with the youth in our study. The PedsQL generic core questionnaire focuses on four general domains: physical function, emotional function, social function, and school function. We anticipated that the focus group participants would identify additional domains, or facets of the general domains, that were important for consideration in the PROMIS domain framework. In addition, we anticipated that some domains would show no difference between children with asthma and children from the general population (e.g., pain).

The interview guide was not different for the different ages and we did not change the interview guide between focus groups. Because the goal of PROMIS is to develop a measurement system that can cross age ranges, we attempted to identify commonalities of experience across the ages and to recognize where differences might exist. Although some differential item functioning may occur by age, our item development procedures aimed to minimize that. Although we did not change the guide between focus groups, moderators of the groups were able to use their experience from previous groups to inform their facilitation.

Each of the focus groups lasted from 1.5 to 2 hours. The focus group leader facilitated the participants' answers, keeping the discussion on topic, but otherwise was nondirective, supportive, and nonevaluative. In all of the focus groups the discussion covered the PROMIS core generic domains of health and well-being (physical, emotional, social, pain, fatigue, and school/cognitive). In addition, more global questions about the general effects of health of children's lives were asked. In the focus groups for children with asthma, the discussions also explored problems and concerns of particular relevance to them. Further, we paid attention to the vocabulary and thinking patterns of the children to help identify new items and phrase them using words familiar to the children.

Analysis

All sessions were audio taped, transcribed verbatim, and textually analyzed using Atlas.ti software. Content and thematic analyses were conducted on participants' responses to each question [14] to identify emergent themes and to categorize them in logical groupings related to the existing core or the asthma-specific domains where possible. Specifically, theory-based codes were first developed based on the focus group questions [16]. These global codes initially included the sub-domain categories already identified by scales used in the PROMIS item bank. Second, two-person analyst teams, consisting of focus group leaders specifically trained in Atlas.ti software and qualitative data analysis compiled the responses to each question across the eight groups. They developed grounded definitions for each pre-specified sub-domains based on what participants said about those topics. Third, after the sub-domain codes were defined, one analyst coded all the transcripts. If an analyst found texts that they were uncertain how to code, these were coded as "uncertain." After coded segments for each sub-domain were compiled, the other analyst on the team reviewed them, checking to see whether the codes were applied appropriately. Texts that were coded as "uncertain" were also compiled and reviewed to determine whether they could fit within the pre-existing sub-domain categories or were too ambiguous to assign a substantive code. Analysts were encouraged to be alert for possible emergent themes as they performed their analyses, specifically focusing on texts where there was not a good fit with the theory-based codes, in texts that were coded as "uncertain," and where there were irresolvable disagreements between analysts. In general, the theory-based codes worked reasonably well. When there were disagreements, analysts usually were able to resolve them through discussions and, in a few cases, texts were recoded. In the rare cases where the analysts were unable to come to a consensus, one of the study investigators reviewed the codes and decided which code to use.

After the coding was completed, teams looked at responses to the same questions across asthma and general population groups. There were two ways that a theme could qualify for inclusion in the analysis. First, at least two participants had to make substantive comments on a topic in one group. This meant that they did more than just agree with each other, they elaborated on a common experience. This strategy allowed us to identify a few diverse cases (see discussion below on fear of dying in the emotional health domain). The second selection criterion was to use similar themes that were discussed by at least one child in at least two groups. Finally, more general themes were identified for each domain which cross-cut both age groups and child health status.

Our analytical strategy used both content analysis [17] and grounded theory [18]. We used content analysis to validate the theory-based questions. The grounded theory approach enabled us to look at the contexts (age, health status, environmental status) that affected child well-being which had the potential for identifying new domains.

Results

Participants

The overall sample totaled 41 youth. Twenty youth were diagnosed with asthma and comprised the asthma-specific group, and 21 youth were drawn from the general population without a diagnosis of asthma. The asthma group had more children who were African American and aged 8–12 and the general population group had more children who were Hispanic and aged 13–17 (Table 1).

There was a fairly equal distribution of asthma participants reporting mild intermittent (30%), mild persistent (35%), and moderate persistent (35%) severity levels of asthma symptoms. Three children in the general population sample were found to have asthma upon examination of medical records and in all cases were classified as mild intermittent; these children experienced relatively minor symptoms early in childhood. These children were not experiencing asthma symptoms at the time of the focus group.

Physical health: general

Children with symptoms of asthma related a markedly different story about how their health affected their participation in everyday activities compared to general population children. Most of the children with asthma included "my asthma" effects (insert activity or task) in this way or that way. Most of the general population children simply described what types of tasks or activities they engaged in. The most glaring and salient emergent theme that differentiated asthmatic and general population youth was the great effort that those with asthma exerted to try to be "normal" and "to be just like everyone else". For example, one child with asthma said, "like, if I didn't take my inhaler somewhere and we were doing something strenuous, like I would be kind of afraid to go just in case I did get asthma and like my inhaler wasn't there, but I would still go because I'm just like them". In contrast, one child without asthma commented, "I never think about my health, I can just go and do whatever I want whenever I want to".

Table 1 North Carolina and Texas focus group demographics of children

	Children with asthma, $N = 20$ n (%)	General population sample of children, $N = 21$ n (%)
Gender—male	9 (45)	12 (57)
Age		
8–12 years	13 (65)	8 (38)
13–17 years	7 (35)	13 (62)
Race		
Caucasian	9 (45)	9 (43)
Hispanic	2 (10)	10 (47)
African American	7 (35)	1 (5)
Other	2 (10)	1 (5)
Asthma severity		
None	0 (0)	18 (86)
Mild intermittent	6 (30)	3 (14)
Mild persistent	7 (35)	0 (0)
Moderate persistent	7 (35)	0 (0)

Physical health: pain

Children with asthma repeatedly talked about how they had used their "inhalers" when engaged in physical activities and experienced "discomfort" when playing sports. Although one child did state that "my chest gets tight and feels like my body's about to split and my head's going to go in the air", most of the responses regarding discomfort seemed more attributable to emotional or social discomfort: "In sports, I do football, soccer and track…and every time I run or do any physical activity I have some kind of asthma problem and it makes me uncomfortable because people are always in my face. Are you okay? I'm fine. It's just uncomfortable". As such, we did not identify systematic differences in reporting of pain between children with asthma and children from the general population.

Physical health: fatigue

Some of the children with asthma talked about how their asthma symptoms disrupted their sleep cycle: "I wake up in the middle of the night because I have a hard time sleeping and sometimes I can't sleep at night because I have to sleep during the day because I get tired after doing things." General population youth talked about not wanting to get up in the morning because they are tired, but they explained that they had a hard time getting up because they "don't want to go to school" or they "stayed up too late" the night before.

Emotional health

Children with asthma talked about how the symptoms of their illness affect their mood and emotional state. Evidenced by the following comments, some of the emerging themes involve children with asthma feeling different, inadequate, feeling sad due to missing out on things, and worrying about their own well-being. A sample of their comments include: "I feel mad and get upset about what asthma keeps me from doing"; "I can't go outside as much as I would like, and I can't have a pet"; "I have nightmares about dying in my

sleep". However, not all children with asthma described negative emotional experiences as a result of asthma: "I don't feel bad and it doesn't change the way I feel about myself"; "I feel kind of cool carrying around my inhaler, it makes me different." General population youth associated their mood or emotional changes with "normal kid stuff", like doing "bad in school" or "getting in trouble at home".

Social role participation

When asked about how their asthma symptoms affected how they got along with others, children with asthma most reported that their symptoms had "no affect at all" on their interpersonal relationships. However, when children with asthma were asked about how their symptoms affected their family interactions, some of the children indicated that some of their family members showed a lack of understanding towards their condition. One child with asthma commented, "My brothers and sisters get annoyed because my parents flip out and think I'm going to die or something." General population youth said very little about how their health affected their relationships with peers and family. Most general population youth simply reported their health having no effect on their interpersonal relationships.

School functioning

Most of the participants with asthma described how their symptoms of asthma are always with them no matter where they go, including when they go to school. One said, "I have to walk all the way down the hall and it's hard and P.E. is really hard because of my breathing." Interestingly, when children with asthma were asked about school, like their general population counterparts, they reported having problems with their teachers and not liking certain classes. They also mentioned liking "hanging out with friends" and their "favorite classes". General population youth seemed to focus on how feeling tired because of being physically active affected their ability to stay alert in morning classes. Other than this, most of these youth did not suggest that their physical health affected their school experience.

Table 2 depicts the crossover of the emerging themes resulting from the thematic analysis and the PROMIS domains. Table 3 summarizes themes found in the focus groups.

Discussion

Focus groups involve interactions that allow participants to utilize their own words to describe their experiences and prioritize issues [19]. Participants' comments can highlight gaps in a hypothesized PRO framework [20] and can be utilized in soliciting children's views on health related issues [21]. Although health-related quality of life is a relatively broad concept, children as young as 8 years old were able to provide useful data for PRO development. In this study, we did not attempt to examine the entire spectrum of health-related quality of life, but rather we focused on the initial domains of interest in the PROMIS study. Future phases of PROMIS may focus more on issues such as psychological well-being and other emergent domains.

The results of the focus groups with youth with asthma and those from the general population sample suggest that,

Table 2 Cross-cutting themes

Domain	Themes
General physical health	• Level of concern about health • Extent to which health problems interfere with ability to participate in physical activities
Fatigue	• Extent to which normal daily activities contribute to fatigue • Extent to which health problems interfere with sleep • Extent to which health problems contribute to fatigue during normal daily activities
Pain	• Extent of concern about pain • Extent to which health problems cause pain
Social role participation	• Extent to which health problems affect family relationships • Extent to which health problems affect peer relationships
School	• Extent to which health problems cause problems in performance at school • Extent to which health problems affect the way children are treated in school by peers and staff • Extent to which children are allowed to manage symptoms at school
Emotional health	• Extent to which health problems affect self-esteem • Extent to which health problems affect mood

Table 3 Pediatric focus group

Domain	Asthma youth	General population sample youth
General physical health	*Both age groups*	*13–17 year olds only*
	Most feel taking meds and participating in treatment of asthma was not a problem	Most feel they can do any activity they want
	Some feel asthma gives them physical problems, but usually it doesn't stop them from doing things	*Both age groups*
	Some feel that asthma inhibits physical activities	Most engage in physical activities with friends
	Some miss parts of physical activities and events due to asthma	Most generally not concerned about health
	Some use inhalers to regulate breathing during sports[a]	Most feel no physical constraints; health doesn't limit their involvement in activities
	Some know to take inhalers before physical activity, or may need to bring inhaler to game/practice[a]	Most believe health doesn't affect eating
	Some may have to stop game/physical activity and rest and/or take inhaler[a]	
Fatigue	*8–12 year olds only*	*8–12 year olds only*
	Some experience fatigue from physical activities and have difficulty distinguishing between fatigue as 'normal' or a part of asthma	Some believe health doesn't cause any sleep problems
	Some are waking up in the middle of the night feeling like they can't breathe due to factors such as weather or over-activity the day before	*13–17 year olds only*
	Some of their parents come to check on them at night when their "breathing gets loud"[a]	Some are not getting enough sleep and are tired because of early classes and busy schedules
	13–17 year olds only	Some are tired in the morning and doze off in first period classes
	Some feel extra tired because of asthma	Some sleep or take naps due to fatigue from leisure activities
Pain	*Both age groups*	*Both age groups*
	Some reported pain symptoms including side cramps, "tight head", chest pains related to coughing[a]	Most feel that their physical health doesn't result in pain
	Some feel that playing sports leads to breathing hard, but did not describe the sensation as pain	
Social role participation	*8–12 year olds only*	*13–17 year olds only*
	Some feel asthma sometimes gets in the way of joining in on family time/outings	Some feel health doesn't affect how they get along with others
	Some family members and friends make fun of or are jealous of asthmatic youth	*Both age groups*
	Some believe having asthma symptoms or having to take medications can draw unwanted attention[a]	Most believe health hasn't caused problems in family
	Some children were teased by children at school for having asthma, especially by those who did not understand the disease	
	13–17 year olds only	
	Some see themselves as the same as their friends; asthma doesn't affect their lives	
	Some felt that asthma affected their social lives	
Emotional health	*8–12 year olds only*	*13–17 year olds only*
	Some felt "cool" because they had inhalers	Some are happy that they don't have to take meds and aren't allergic to anything
	Some worry and have nightmares about dying in their sleep[a]	*Both age groups*
		Some had health related concerns, such as being overweight or small for their age

Table 3 Continued

Domain	Asthma youth	General population sample youth
	13–17 year olds only	
	Some have adjusted to having asthma and feel confident that they can do what they want to because their inhalers will prevent their having an attack	
	Some worry about the long-term consequences of asthma, including death[a]	
	Both age groups	
	Some feel bad about themselves because they have to take medications, because they are scared of asthma treatments	
	Some reported that they sometimes felt "mad," "really upset," "frustrated," or "kind of sad" because asthma limits what they can do and because they can't do what other youth do	
	Some have come to accept that they have to limit their activities to avoid having an attack. "It's just something you live with."	
	Some don't feel that their asthma affects them emotionally, or makes them feel good or bad about who they are, or how they get along with other youth at school	

[a] Emergent themes

although most youth develop along a common path and experience similar challenges, youth with asthma are faced with distinctly different obstacles compared to their general population counterparts. We identified five unique and different challenges that may confront asthmatic youth: (1) They experience more difficulties than their nonasthmatic peers when participating in physical activities; (2) They may experience anxiety about having an asthma attack at anytime and anywhere, while general population youth have few if any worries about their health; (3) They may experience sleep disturbances and fatigue secondary to their asthma symptoms, while general population youth report feeling fatigue only when exercising excessively; (4) Their health condition has a greater effect on their emotional well-being and interpersonal relationships compared to general population youth; and (5) Asthma affects how children with this condition experience school compared to general population youth whereby most children with asthma report that their condition often leaves them with insufficient energy to complete their school activities, especially physical activities. In some cases, these differences represent different places on the same latent trait, but in other cases they may represent unique experiences that belong in an asthma specific domain.

The findings of this study are similar to those of previous studies examining the physical functioning differences of youth with asthma and youth from the general population. Other researchers have also shown that children and adolescents with asthma are much more limited in engaging in physical activities and experience more feelings of alienation than general population youth [22–24]. Further, other studies have found that, because of their physical limitations, youth with asthma have more difficulty engaging in social activities that involve physical activities compared to general population youth [22, 25]. In addition, previous research has found that youth with asthma report more sleep disturbances compared to general population youth [22]. In regards to emotional functioning, some studies have shown that youth with asthma are more frequently diagnosed with anxiety and depressive disorders compared to general population youth [26, 27]. However, other research suggests youth with asthma do not experience more emotional or mood problems compared to general population youth [23].

Implications for PRO measurement

We used focus groups to improve the development of a PRO measurement system. The results confirm a unique set of concerns for youth with asthma. These results were used to develop items and wording choices of those items for inclusion in the item bank. For example, we noted that the item bank that was being created to assess perceptions of anxiety lacked an item addressing the "fear of dying". This item has now been added to capture the concerns that some children with asthma or other chronic diseases might have. This example demonstrates how we used the focus groups to broaden the scope of one of the health domains of the

PRO measurement to ensure adequate coverage across the general pediatric population as well as those with asthma. In addition, since there were specific concerns for youth with asthma, primarily related to asthma symptoms, we also developed an asthma specific item bank.

One of the strengths of this study is that it is designed to capture the voices of these youth who were living with and without asthma, thereby capturing information that may be lost in administering standardized closed ended surveys. One of the limitations of this study is that the focus groups comparing youth with asthma and youth from the general population were not equally matched by race and gender. Due to characteristics unique to a particular culture and gender, information gathered from nonmatched focused groups (asthmatic/general population) could reflect these demographic differences and not be solely attributable to asthma symptoms. Due to the small sizes of these groups (generally five participants per focus group), we probably did not capture the full extent of variations in the experiences of both youth with asthma and general population participants. Additionally, information on nonparticipants was not available, so we cannot hypothesize how nonparticipation bias may have influenced our results.

To organize the data collection for the focus groups, the framework (generic domains of physical function, emotional function, social function, and school function) of the PedsQL was used to initiate focus group discussions with the youth in our study. We anticipated that the focus group participants would identify additional domains, or facets of the general domains, that were important for consideration in the PROMIS domain framework. We hypothesized that children with asthma would have specific insights into the effects of their illness on several domains of health, which would broaden the scope of each general domain and incorporate views of chronically ill youth. It is possible that the technique of using the PedsQL framework as a starting point may have limited topics that these children felt comfortable addressing. However, we noted that even the youngest children were able to articulate their views on a variety of health-related quality of life topics.

Social interaction factors may also have constrained the range of topics arising in the discussion. Lahoux et al. [28] argue that interactional analyses of focus groups provide insights into the ways that member interactions and group dynamics influence the social construction of opinions that group members express. Although moderators explicitly encouraged children to comment on each other's statements, this occurred relatively infrequently. Usually, when the moderator posed a question, members would respond directly to the moderator. While we did not perform interaction analyses on our data, it seems likely that the leader-facilitated group setting and unfamiliarity with focus groups may have prompted the children in our groups to interpret the situation as similar to something they were familiar with—a teacher-led, semi-structured, time-limited, class discussion—and behaved accordingly. Thus, children may not have felt sufficiently empowered to raise issues or topics that had not first been mentioned by the focus group leaders. A less constrained approach to the focus group structure may have led to more domains or themes than we identified.

We noted that children with asthma used a different frame of reference than children without asthma. When discussing fatigue, children with asthma focused on the effect of their disease in performing daily activities, but children without asthma focused on issues about sleeping and what might be called "normal" tiredness. This may be partly a result of questions in the focus group that asked, "in what ways—if any—does asthma...". Although we tried to minimize this bias, children with asthma may have focused more on symptoms they attributed to asthma than other symptoms. From these data, it is hard to surmise whether responses to quality of life questionnaire items will detect this different frame of reference. Attributing symptoms to a specific illness can be difficult, especially for children. However, healthy populations lacking experience with chronic illness symptoms may use a different frame of reference when reporting quality of life outcomes compared to ill populations.

Our focus groups were facilitated by several different lead moderators. This strategy can reduce the chance of thematic saturation because the moderator will not have learned the important themes by leading the previous groups. The advantage of this method is it can lead to a broader array of themes and ideas. As we wanted to identify potential areas of importance for children with asthma and the general population, our strategy seemed appropriate.

One of the overall goals of these focus groups was to contribute to the process of developing health related quality of life items for addition to our item banks. Focus groups were just one aspect of this process. We performed an extensive literature review to obtain a comprehensive list of topics and items from which to generate new items. We also consulted the results of similar previously conducted focus groups conducted by one of the other authors (Varni). After reviewing all of these sources, we did not feel we would gain significant additional information for the creation of our items banks by conducting additional focus groups.

Implications for future research

Asthma affects about 9 million children under the age of 18 years in the United States and is one of the most prevalent childhood chronic illnesses [29]. Hence, we chose

asthma as a model chronic disease to evaluate disease specific symptoms. Focus group responses from youth with asthma provided insight into the impact of chronic childhood illness on these health-related domains. Future studies should evaluate other chronic illnesses.

When addressing health-related quality of life issues among children and adolescents with asthma, practitioners should be aware that these additional physical, psychological, and social challenges may be burdensome. However, this study underscores the fact that many youth adapt and overcome the challenges of living with asthma. Further, practitioners need to understand how important it can be for youth with asthma to be perceived as normal and high functioning. Finally, the school experience is one of the most pivotal elements of a youth's life and is essential in developing and maintaining a good overall quality of life. Therefore, when considering health-related quality of life issues among youth with asthma, practitioners must thoroughly explore issues related to school functioning for strengths as well as possible areas of impairment. Generic item banks (e.g., emotional, social, or physical) can be broadened to provide coverage of PRO related to asthma, while specific asthma-related symptoms can be covered with an asthma-specific item bank.

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Appendix: PROMIS focus group questions for children (ages 8–17)

We are trying to learn more about children—how children feel about themselves, their bodies, and their relationships with others. We are interested in finding out whether and how their health affects these feelings. By health, we mean the overall condition of the body and mind.

Physical

1. In what ways, if any, does your health keep you from doing the physical activities that you want to do?

   Probes

   - In what ways, if any, does your health get in the way of taking care of yourself?
   - In what ways, if any, does your health limit your family activities?
   - In what ways, if any, does your health affect your sleeping or eating?
   - Do you ever feel extra tired? In what ways, if any, does feeling tired affect what you do?
   - In what ways, if any, is taking medicines or participating in other treatments a problem?
   - When you have a health problem how do you know when you need to go to the doctor, hospital, or emergency room?

Asthma specific probes

- In what ways, if any, does having asthma affect what you do?
- In what ways, if any, does *being afraid of having asthma symptoms* affect what you do?
- What asthma symptoms, if any, bother you most?

Psychological/social

2. Overall, how does your health make you feel emotionally?

   Probes

   - What kinds of things, if any, make you feel extra good about yourself?
   - What kinds of things, if any, do you worry about?
   - In what ways, if any, does your health affect how you get along with other people?
   - In what ways, if any, does your health cause problems in your family?

Asthma specific probes

In what ways, if any, does having asthma make a difference how you feel emotionally?

Probes

- In what ways, if any, does having asthma make a difference whether you feel happy?
- In what ways, if any, does having asthma make a difference in whether you feel unhappy?
- In what ways, if any, does having asthma make a difference in whether you feel afraid?
- In what ways, if any, does having asthma make a difference in whether you feel angry?
- In what ways, if any, does having asthma make you feel different from your friends?
- In what ways, if any, does having asthma make you feel good or bad about who you are?

School

3. Overall, how do you like school?

   Probes

   - What do you like best about school?
   - What do you like least about school?
   - Overall, how do you get along with your classmates?
   - What problems, if any, do you have at school because of your health?

Asthma specific probes

- In what ways, if any, does asthma affect what you like or dislike about school?
- In what ways, if any, does asthma affect how you get along with other kids at school?

Other

4. What else about your health, if anything, is important in your life?

   Probes

   - So far, we've talked a lot about how a child's health can create problems for (you/your family)...Can you tell me about any good things that go along with your (having asthma/ having health problems)?
   - We have asked you a lot of questions in this session. What other questions about the ways health affects children's lives should we be asking—if any?

References

1. Reeve, B. (2006). Special issues for building computerized-adaptive tests for measuring patient-reported outcomes: The national institutes of health's investment in new technology [item banking and computerized adaptive testing: Commentary]. *Medical Care, 44*(11) Suppl 3, S198–S204.
2. Cella, D., Yount, S., Rothrock, N., et al. (2007). The patient-reported outcomes measurement information system (PROMIS): Progress of an NIH roadmap cooperative group during its first two years. *Medical Care, 45*(Suppl 1), S3–S11.
3. Chan, K. S., Mangione-Smith, R., Burwinkle, T. M., Rosen, M., & Varni, J. W. (2005). The PedsQL™: Reliability and validity of the short-form generic core scales and asthma module. *Medical Care, 43*, 256–265.
4. Guyatt, G. H., Juniper, E. F., Griffith, L. E., Feeny, D. H., & Ferrie, P. J. (1997). Children and adult perceptions of childhood asthma. *Pediatrics, 99*(2), 165–168.
5. Juniper, E. F., Guyatt, G. H., Feeny, D. H., Ferrie, P. J., Griffith, L. E, & Townsend, M. (1996). Measuring quality of life in children with asthma. *Quality of Life Research, 5*(1), 35–46.
6. Ader, D. N. (2007). Developing the patient-reported outcomes measurement information system (PROMIS). *Medical Care, 45*(Suppl 1), S1–S2.
7. Landgraf, J. M., Abetz, L., & Ware, J. E. (1999). *The CHQ: A user's manual*, 2nd printing. Boston, MA: HealthAct.
8. Ravens-Sieberer, U., Gosch, A., Rajmil, L., Erhart, M., Bruil, J., Duer, W., Auquier, P., Power, M., Abel, T., Czemy, L., Mazur, J., Czimbalmos, A., Tountas, Y., Hagquist, C., Kilroe, J., & the European KIDSCREEN Group. (2005). KIDSCREEN-52 quality-of-life measure for children and adolescents. *Expert Review of Pharmacoeconomics & Outcomes Research, 5*(3), 353–364.
9. Varni, J. W., Seid, M., & Kurtin, P. S. (2001). PedsQL™ 4.0: Reliability and validity of the Pediatric Quality of Life Inventory™ version 4.0 generic core scales in healthy and patient populations. *Medical Care, 39*, 800–812.
10. Singh, G., Athreya, B. H., Fries, J. F., & Goldsmith, D. P. (1994). Measurement of health status in children with juvenile rheumatoid arthritis. *Arthritis Rheum, 37*(12), 1761–1769.
11. DeWalt, D. A., Rothrock, N., Yount, S., Stone, A. A., & the PROMIS Cooperative Group (2007). Evaluation of item candidates: The PROMIS qualitative item review. *Medical Care, 45*(5 Suppl 1), S12–S21.
12. Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL™: Measurement model for the Pediatric Quality of Life Inventory™. *Medical Care, 37*, 126–139.
13. Matza, L. S., Swensen, A. R., Flood, E. M., Secnik, K., & Leidy, N. K. (2004). Assessment of health-related quality of life in children: A review of conceptual, methodological, and regulatory issue. *Value in Health, 7*, 79–92.
14. Krueger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage.
15. Ronen, G. M., Rosenbaum, P., Law, M., & Streiner, D. L. (2001). Health-related quality of life in childhood disorders: A modified focus group technique to involve children. *Quality of Life Research, 10*(1), 71–79.
16. Layder, D. (1998). *Sociological practice: Linking theory and social research*. London, UK: Sage.
17. Weber, R. P. (1990). *Basic content analysis*. Beverly Hills, CA: Sage.
18. Strauss, A., & Corbin, J. (1990). *Basics of qualitative research: Grounded theory procedures and techniques*. Thousand Oaks, CA: Sage.
19. Morgan, D., Krueger, R., & King, J. A. (1998). *The focus group guidebook* (Vols. 1–6). Thousand Oaks, CA: Sage.
20. Detmar, S. B., Bruil, J., Ravens-Sieberer, U., Gosch, A., Bisegger, C., & the European KIDSCREEN Group. (2006). The use of focus groups in the development of the KIDSCREEN HRQL questionnaire. *Quality of Life Research, 15*, 1345–1353.
21. Heary, C. M., & Hennessy, E. (2002). The use of focus group interviews in pediatric health care research. *Journal of Pediatric Psychology, 27*, 47–57.
22. Maier, W. C., Arrighi, H. M., Morray, B., Llewllyn, C., & Redding, G. J. (1998). The impact of asthma and asthma-like illness in Seattle school children. *Journal of Clinical Epidemiology, 51*(7), 557–568.
23. Rietveld S., & Colland, V. T. (1999). The impact of severe asthma on school children. *Journal of Asthma, 36*(5), 409–417.
24. Varni, J. W., Burwinkle, T. M., Rapoff, M. A., Kamps, J. L., & Olson, N. (2004). The PedsQL™ in pediatric asthma: Reliability and validity of the Pediatric Quality of Life Inventory™ generic core scales and asthma module. *Journal of Behavioral Medicine, 27*, 297–318.
25. Meijer, S. A., Sinnema, G., Bijstra, J. O., Mellenbergh, G. J., & Wolters, W. H. G. (2000). Social functioning in children with chronic illness. *The Journal of Child Psychology and Psychiatry and Allied Disciplines, 41*, 309–317.

26. Klinnert, M. D., McQuaid, E. L., McCormick, D., Adinoff, A. D., & Bryant, N. E. (2000). A multimethod assessment of behavioral and emotional adjustment in children with asthma. *Journal of Pediatric Psychology, 25*, 35–46.
27. Wambolt, M. A., Yancey, A. G. J., & Roseler, T. A. (1997). Cardiovascular effects of tricyclic antidepressants in childhood asthma: A case series and review. *Journal of Child Adolescent Psychopharmacolgy, 7*, 45–64.
28. Lahoux, P., Poland, B., & Daudelin, G. (2006). Focus group research and the "patient's view. *Social Science & Medicine, 63*, 2091–2104.
29. Bloom B., Cohen, R. A., Vickerie, J. L., & Wondimu, E. A. (2003). Summary health statistics for U.S. children: National health interview study, 2001. National Center for Health Statistics. *Vital Health Stat, 10*(216), 1–54.