

PhenX Pediatric Development Outreach Response Report

August 13, 2019

The PhenX Pediatric Development Community Outreach was available July 25 to August 8, 2019.

- 13 people responded to the outreach e-mail.
- 10 respondents completed the value section of the measures table.
- 35 unique non-RTI visitors viewed the PhenX Portal page that included the full datasheets for each measure and protocol during the outreach.
- There were no responses to the Working Group’s additional questions, which were:
 1. Can you recommend a standardized, well-validated instrument/protocol to assess sleep in the pediatric populations?
 2. Can you recommend an American English alternative (but similar) instrument to the British English Mother and Home Questionnaire from Avon Longitudinal Study of Parents and Children (ALSPAC)?

I. Protocol Rankings

The table below provides the measures and the votes received from respondents and comments about specific measures and protocols. General comments are included after the table. (Note: No Response is abbreviated in the table below as “NR”).

Proposed Pediatric Development Measures					
Measure	Description of Measurement Protocol	Yes	No	NR	Comments
1. Academic Performance and Achievement	a. Child: The Healthy Pathways – Academic Performance Child Self-Report is a five-question, self-reported questionnaire completed by the child on their grades in the past year and their schoolwork in the past month.	7	1	5	1. Not familiar with it and unable to review it. 2. I have not used this scale, but it appears useful. Lack of public access is an issue.

PhenX
Pediatric Development Outreach Response Report

	<p>b. Parent: The Healthy Pathways – Academic Performance Parent Report is a five question, self-reported questionnaire completed by a parent on their child’s grades in the past year and their schoolwork in the past month.</p>	8	0	5	<p>1. Not familiar with it and unable to review it. 2. I have not used this scale, but it appears useful. Lack of public access is an issue.</p>
2. Behavioral Inventory	<p>a. Children 1 to 5: A questionnaire on a child’s behavior providing scores on numerous scales. These include overarching Internalizing Problems, Externalizing Problems, and Total Problems, and specific syndrome scales (e.g., depressive, anxiety, autism spectrum, ADHD, aggression, sleep problems, somatic complaints, withdrawn behaviors). A supplemental Language Development Survey for ages 18-35 months is also included. Versions are available for report by the child’s parents, primary caregivers, or surrogates, or by the child’s daycare providers or teachers.</p>	9	0	4	<p>1. The externalizing component is especially important in this battery. 2. I have used this scale, and it was useful on admission and discharge to a long-term inpatient program. Lack of public access is an issue.</p>
	<p>b. Children 6 to 18: A questionnaire on a child’s behavior providing scores on numerous scales. These include overarching Internalizing Problems, Externalizing Problems, and Total Problems, and specific syndrome scales (e.g., depressive, anxiety, ADHD, ODD, conduct problems, aggressive behaviors, somatic complaints, social problems). Versions are available for report by the child’s parents, primary caregivers, or surrogates, by the child’s teachers, or by the child.</p>	9	0	4	<p>1. I have used this scale, and it was useful on admission and discharge to a long-term inpatient program. Lack of public access is an issue.</p>
3. Bullying	<p>The Olweus Bullying Questionnaire is a survey for children in grades 3-12 to respond to questions about bullying. It measures exposure to various forms of bullying, and extent to which peers, teachers, and parents respond.</p>	9	0	4	<p>1. Reviewer’s Reply: I think there are big picture and small picture considerations [for bullying or peer relations measures]. Broadly, peer relations researchers are very reluctant to buy into data based on kids’ self (as opposed to peer-) report.</p>

PhenX
Pediatric Development Outreach Response Report

					Specifically, the Olweus measure doesn't capture the forms of bullying that are now known to be relevant, and I am not sure the other measure is well known among those who study peer relationships at all. 2. I have not used this scale, but it appears useful. Lack of public access is an issue.
4. Child Care Quality	a. Younger child: Formal and Informal Child Care - An interview-administered questionnaire. For use with primary caregivers of children aged birth to 5 years old.	6	1	6	1. Eventually to be limited for toddlers (1-3 years.) 2. Out of my area of expertise. 3. These two interviews are long but comprehensive
	b. Older child: Formal Child Care/Educational Setting - An interview-administered questionnaire. For use with primary caregivers of children aged 2.9-5 years old.	6	1	6	1. Out of my area of expertise. 2. These two interviews are long but comprehensive.
5. Home Environment	Sections B & E of the Mother and Home questionnaire, to be answered by a child's mother/guardian, contain 28 questions on a child's home environment and 20 questions on their guardian's occupation and lifestyle.	6	1	6	No comments.
6. Household Chaos and Unpredictability	The Confusion, Hubbub, and Order Scale (CHAOS) is a 15-question survey of one's own home environment using a scale from one through four.	4	4	5	No comments.
7. Household Composition	Section C of the Mother and Home questionnaire, to be answered by a child's mother/guardian, contains 22 questions on a child's home environment.	6	1	6	1. Is it valid to ask just how many people are in the household and their ages? It might be helpful to researchers to be able to ask just that information rather than administer the entire questionnaire.

PhenX
 Pediatric Development Outreach Response Report

8. Interviewer-Administered Pediatric Psychiatric Assessment	An interview for parents of children 6 years old and younger divided into self-contained modules of mental health disorders to assess for DSM-IV syndromes.	6	1	6	1. Out of my area of expertise.
9. Neonatal Abstinence Syndrome (NAS) and Neonatal Opioid Withdrawal Syndrome (NOWS)	The Modified Finnegan Neonatal Abstinence Scoring System (mNASS) is a 31-line score sheet measuring 21 symptoms that are frequently observed in opiate-exposed infants. These are measured by presence/abstinence or severity at 2-4-hour intervals within a 24-hour period.	6	1	6	1. I have no experience in the field for a relevant point of view. 2. Out of my area of expertise.
10. Parenting Style	a. Child: The Alabama Parenting Questionnaire is a 42-item questionnaire that measures five dimensions of parenting that can affect the development of children. Using a Likert scale of Never to Always, the answers can be scored to assess parental involvement, positive parenting, monitoring/supervision, discipline, and corporal punishment.	10	0	3	1. A definite Yes to... Alabama Parenting Questionnaire 2. This appears to be a very useful scale that I did not know about. I will be using it from now on. Public access is a huge plus. 3. What is the age range for administration?
	b. Parent: The Alabama Parenting Questionnaire is a 42-item questionnaire that measures five dimensions of parenting that can affect the development of children. Using a Likert scale of Never to Always, the answers can be scored to assess parental involvement, positive parenting, monitoring/supervision, discipline, and corporal punishment.	10	0	3	1. A definite Yes to... Alabama Parenting Questionnaire 2. This appears to be a very useful scale that I did not know about. I will be using it from now on. Public access is a huge plus.
11. Peer Relationships	a. Proxy Reported: The PROMIS Peer Relationships item banks assess parental or self-reported quality	10	0	3	1. A definite Yes to... PROMIS

PhenX
 Pediatric Development Outreach Response Report

	of relationships with friends and other acquaintances over the past seven days.				2. Reviewer’s Reply: I think there are big picture and small picture considerations [for bullying or peer relations measures]. Broadly, peer relations researchers are very reluctant to buy into data based on kids’ self (as opposed to peer-) report. Specifically, the Olweus measure doesn’t capture the forms of bullying that are now known to be relevant, and I am not sure the other measure is well known among those who study peer relationships at all.
	b. Self-Reported: The PROMIS Peer Relationships item banks assess self-reported quality of relationships with friends and other acquaintances during the past seven days.	10	0	3	1. A definite Yes to... PROMIS
12. Psychological Resilience	Child and Youth (new alternate protocol): A 26-item measure of the resources available to children that may increase their resilience. The Child and Youth Resilience Measure (CYRM-28) has three sub-scales: individual capacities/resources, relationships with primary caregivers and contextual factors that facilitate a sense of belonging.	9	0	4	1. Note: Domain is incorrectly listed as "Geriatrics." This appears to be a very useful scale that I did not know about. I will be using it from now on. Public access is a huge plus. Note (from Lisa) this is because this is a new alternate protocol to an existing measure in the Geriatrics domain (Psychological Resilience)
13. Psychological Symptomology of Caregivers	The Adult Self-Report (ASR) is a self-report questionnaire inquiring about the respondent’s own adaptive functioning, problems, and substance use. The Adult Behavior Checklist (ABCL) is a questionnaire where an individual who knows the adult to be evaluated reports on the adult’s adaptive function, problems, and substance use.	8	1	4	1. I have not used this scale, but it appears useful. Lack of public access is an issue.

PhenX
 Pediatric Development Outreach Response Report

14. Quality of the Home Environment	The Home Observational Measurement of the Environment is a 38-item questionnaire, filled out by the child’s primary caregiver, that evaluates the quality of a child’s home environment. The questions vary based on the age of the child.	7	2	4	1. I have not used this scale, but it appears useful. Lack of public access is an issue.
15. Sustained and Selective Attention	A 7.5-minute, computer-based assessment of attention deficits in children aged 4 through 7. Images of objects that are familiar to young children require a response from the child as they appear on the screen.	5	3	5	1. Out of my area of expertise. 2. I have not used this scale, but it appears useful. Lack of public access is an issue. 3. If we are recommending NIH Toolbox, it includes measures like this.

II. General Comments

1. There is no test on development and level of participation in the present list. All are useful. But these can [be] added.