



# Guidance for the Use of Pediatric PROMIS Measures in Ambulatory Clinics

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## Background

- Patient-Reported Outcomes Information Measurement System® (PROMIS®) provides standardized pediatric patient reported outcome (PRO) measures for children 8-17 years of age, and parent proxies for children 5-17 years old
- PROMIS Pediatric measures quantify health and well-being from patient/ parent perspective, which is crucial to providing patient-centered care
- 25+ reliable, valid PROMIS Pediatric measures are currently available and embedded within common electronic health record (EHR) systems
- To realize the benefits of PROMIS measures in pediatric settings, implementation efforts must attend to unique challenges around how the measures are implemented and used
- Lack of existing guidance specific to implementation in pediatric ambulatory settings

## Objective

- To understand and address the real-world barriers to PROMIS Pediatric clinical use as identified by US clinicians and healthcare system leaders

## Methods

- 7-member Steering Committee of US experts in pediatric PROs or healthcare quality measurement
- 18 semi-structured telephone interviews to identify and address challenges to PROMIS use in the US ambulatory pediatric setting
  - Interviewees included: healthcare system leaders, PROs measurement implementers, and ambulatory pediatric clinicians
- 5 coders used thematic content analysis to analyze interview data
- Themes and subthemes were iteratively refined throughout coding and analysis
- To avoid duplicating existing guidance, topics chosen must be relevant to 1) PROMIS clinical use and 2) unique to pediatric settings
- In response to the topics identified, 8 content experts provided recommendations
  - Content experts included: health system leaders, psychometricians, and experienced ambulatory pediatric clinicians at major US academic institutions

## Results

- Analysis of the interview content yielded a coding scheme with 21 different subthemes
- Subthemes aggregated into 6 themes (topics) specific to PROMIS use in ambulatory pediatric settings (Table 1)

Table 1. Six identified topics specific to PROMIS use in ambulatory pediatric settings

Topic	Questions Addressed
Selection of PROMIS measures	<ul style="list-style-type: none"> <li>• What approaches can be taken to choose measures?</li> <li>• How can measures be selected that work across the age spectrum in the pediatric setting or for specific populations?</li> </ul>
Method of administration	<ul style="list-style-type: none"> <li>• How can response rates be optimized for children and their parents?</li> <li>• Can computer adaptive testing (CAT) increase relevancy of measures for children and precision for clinicians?</li> </ul>
Use of PROMIS proxy measures	<ul style="list-style-type: none"> <li>• When should data be collected from the child versus the parent?</li> <li>• How can clinicians interpret responses from parent proxies and self-report, including data collected over time?</li> </ul>
Privacy and confidentiality of PROMIS responses	<ul style="list-style-type: none"> <li>• How can child and adolescent PROMIS responses be kept private during data collection, storage, and clinical use, especially for sensitive topics?</li> <li>• What strategies can be used to ensure data is from the desired respondent?</li> <li>• How can this need for privacy be balanced with providing convenient access to PROMIS responses for providers?</li> </ul>
Interpretation of PROMIS scores	<ul style="list-style-type: none"> <li>• What is the current state of evidence about the interpretation of PROMIS measures in a variety of pediatric populations, including interpretation of data over time?</li> </ul>
Using PROMIS scores clinically	<ul style="list-style-type: none"> <li>• What kind of training and tools are available to prepare clinicians and clinic staff to use PROMIS measures in clinical practice?</li> <li>• How can PROMIS scores be integrated into the clinical encounter?</li> <li>• How can clinicians use PROMIS scores to inform clinical practice and decision-making?</li> </ul>

## Recommendations

### 1. Selection of PROMIS Measures

- 1) Select health concepts that are most clinically impactful, actionable, and best measured by patient-report
- 2) Consider what outcomes are important, the precision needed, and the patient/provider burden to inform measure selection
- 3) Engage a wide array of stakeholders in choosing concepts to measure
- 4) Make use of expertise from psychometricians and other non-clinicians, as well as PROMIS resources
- 5) Use PROMIS Pediatric measures when following young adult patients up to 24 years of age in pediatric clinics
- 6) Select measures available in the patient population's preferred language
- 7) Avoid modifying PROMIS Pediatric forms, items, and wording

### 2. Method of Administration

- 1) Assess collection capabilities and the available IT and EHR resources to select the appropriate method of administration
- 2) Understand your population's preferences for completing measures and your institution's feasibility to implement those preferences
- 3) Seek expertise from informatics to guide decisions about administration, including staff training
- 4) Administer measures in a manner that interfaces with the EHR, using CAT when possible
- 5) Consider additional time and effort needed to collect and embed PROMIS data into the EHR when using an electronic data capture system (e.g., REDCap) outside the EHR
- 6) If administering paper forms, have resources and processes to administer the correct measure at the right time, score the measure, and transfer data to the EHR

### 3. Use of PROMIS Proxy Measures

- 1) Collect data from the child themselves whenever possible and appropriate (see Table 2)
- 2) Carefully consider use of parent-reported data in decision-making, especially when the health concept of interest is less observable (e.g., anxiety)
- 3) Continue with same data source as the child ages to allow tracking of scores over time

Table 2. Recommendations for administration of self-report and proxy measures by clinical population characteristics

Patient population of interest	Many >8 years of age AND Willing and able to answer	Many <8 years of age OR Unwilling/cannot answer AND Construct is more observable (e.g., physical function)	Many >8 years of age AND Some are unwilling/cannot answer AND Construct is less observable (e.g., anxiety)
Consider administering	Self-report* Only	Parent Proxy Only	Self-report* and Parent Proxy

\*Choose pediatric or adult self-report, depending on patient age

### 4. Privacy and Confidentiality of PROMIS Responses

- 1) Consider available options for protecting children's privacy and confidentiality from the beginning of the implementation process
- 2) Clearly outline confidentiality policies to the child and adolescent prior to data collection
- 3) Implement strategies to ensure PROMIS responses are from the desired source
- 4) Promote access to patient information for parents, children, and adolescents by selecting an appropriate EHR patient portal model (Table 3)
- 5) Ensure PROMIS responses are stored securely but also readily retrievable for the patient/provider

Table 3. Advantages and disadvantages of patient portal options for maintaining confidentiality in the EHR

Portal Type	Advantages	Disadvantages
Parent-only portal	For children <12 years, parents act as sole proxy	Once child is >12 years, clinicians must be vigilant about not placing any sensitive information in this portal
Shared portal for parent and adolescent	For children 12-17 years, shared portal can promote health literacy and support skills for EHR use	Clinicians must be vigilant about not placing any sensitive information in this portal
Confidential portal for adolescents	For children 12-17 years, confidential portal can promote access and timely care, especially for sensitive topics	Institutional and parental buy-in needed to allow adolescents to have their own unique access

### 5. Interpretation of PROMIS Scores

- 1) Use evidence-based cut-points and responses to individual items to interpret scores (Table 4)
- 2) Provide clinicians and other end users with the training necessary to interpret PROMIS scores
- 3) Make decisions about cut points for concerning scores prior to beginning data collection, for both single scores and changes in a patient's score
- 4) Proceed with caution when assessing the magnitude in the change in scores over time for an individual patient

Table 4. Examples of scoring interpretation for 7 common PROMIS Pediatric measures\*

Health Concept	Within Normal			
	Limits	Mild	Moderate	Severe
Cognitive Function <sup>†</sup>	≥45	40-44	30-39	<29
Mobility <sup>†</sup>	≥45	40-44	30-39	<29
Fatigue	≤50	51-55	56-65	≥66
Pain Interference	≤50	51-55	56-65	≥66
Anxiety	≤50	51-55	56-65	≥66
Depressive Symptoms	≤50	51-55	56-65	≥66
Sleep Disturbance	≤50	51-55	56-65	≥66
Self-report	≤55	56-59	60-65	≥66
Parent Proxy <sup>‡</sup>	≤55	56-58	59-65	≥66

\*Source: <http://www.healthmeasures.net/score-and-interpret/interpret-scores/promis/promis-score-cut-points>

<sup>†</sup>Measure reflects level of dysfunction

<sup>‡</sup>Proxy questionnaires are available for all Pediatric PROMIS measures

### 6. Using PROMIS Scores Clinically

- 1) Use PROMIS scores to guide and direct the clinician's attention to the areas of greatest importance during a time-limited encounter
- 2) Discuss scores, even when they are not concerning, within the clinical encounter or shortly thereafter
- 3) Use the score along with the discussion with the patient/parent to decide whether to address any concerning score
- 4) Have a process and resources in place to address concerning scores

## Conclusions

- Clinicians should be confident in using PROMIS Pediatric instruments among the majority of the US pediatric population
- Challenges to PROMIS implementation and use in pediatric ambulatory settings exist within 6 priority areas
- Guidance addresses real world challenges, supporting clinicians and healthcare systems to integrate PROMIS measures into clinical practice

## Limitations

- Study was informed by US content experts and interviewees only
- Health systems' EHRs are uniquely customized and ever changing, so recommendations' relevance may vary
- Some areas lack conclusive evidence for recommendations, highlighting opportunities for future research (e.g., impact of method of administration on completion rates)

## Future Directions

- Efforts to extend PROMIS utility
  - Additional language translations
  - Validation in a breadth of populations, settings, additional ages, and health conditions
  - Additional measurement characterization, scoring algorithms, data visualization, and linking across different instruments both within and outside of PROMIS (e.g., PROsetta Stone)

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