

Outcome Measure	Pediatric Quality of Life Initiative (PEDS QL)
Sensitivity to Change	Yes
Population	Paediatrics
Domain	Health-Related Quality of Life (for full scale) Social Role Participation and Social Competence (for Social Subscale)
Type of Measure	Parent-report & self-report
ICF-Code/s	d710-d729
Description	<p>The Pediatric Quality of Life Initiative (PEDS QL) version 4.0 Generic Core Scales consists of 23 items with 5 response selections that range from “never” to “almost always.” The scales include:</p> <ol style="list-style-type: none"> 1) Physical Functioning (8 items), 2) Emotional Functioning (5 items), 3) Social Functioning (5 items), and 4) School Functioning (5 items). <p>The Generic Core Scales are comprised of parallel child self-report and parent proxy-report formats. Child self-report includes ages 5 to 7, 8 to 12, and 13 to 18 years. Parent proxy-report includes ages 2 to 4 (toddler), 5 to 7 (young child), 8 to 12 (child), and 13 to 18 (adolescent), and assesses parent's perceptions of their child's HRQOL.</p> <p>The items for each of the forms are essentially identical, differing in developmentally appropriate language, or first or third person tense. The instructions ask how much of a problem each item has been during the past 1 month. A 5-point response scale is utilized across child self-report for ages 8 to 18 and parent proxy-report (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). To further increase the ease of use for the young child self-report (ages 5-7), the response scale is reworded and simplified to a 3-point scale (0 = not at all a problem; 2 = some-times a problem; 4 = a lot of a problem), with each response choice anchored to a happy to sad faces scale.</p> <p>Parent proxy-report also includes the toddler age range (ages 2-4), which does not include a self-report form given developmental limitations on self-report for children younger than 5 years of age, and includes only 3 items for the school functioning scale. Items are reverse-scored and linearly transformed to a 0 to 100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate better HRQOL. Scale Scores are computed as the sum of the items divided by the number of items answered (this accounts for missing data). If more than 50% of the items in the scale are missing, the Scale Score is not computed.</p> <p>Psychosocial Health Summary Score (15 items) can be computed as the</p>

	sum of the items divided by the number of items answered in the Emotional, Social, and School Functioning Subscales.
Properties	<p>PURPOSE</p> <p>The PedsQL Measurement Model is a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. The PedsQL Measurement Model integrates seamlessly both generic core scales and disease-specific modules into one measurement system.</p> <p>ADMINISTRATION</p> <ol style="list-style-type: none"> 1) The parent/child should first complete the PedsQL™ Generic Core Scales and then complete any additional PedsQL™ Module. 2) Parents, Children (8-12) and Teens (13-18) may self-administer the PedsQL™ after introductory instructions from the administrator. 3) If the administrator determines that the child or teen is unable to self-administer the PedsQL (e.g., due to illness, fatigue, reading difficulties), the PedsQL should be read aloud to the child or teen. 4) For the Young Child (5-7), the PedsQL™ should be administered by reading the instructions and each item to the young child word for word. 5) At the beginning of each subscale repeat the recall interval instructions (one month or 7 days) to remind the young child to respond only for that specific recall interval. 6) Use the separate page with the three faces response choices to help the young child understand how to answer. 7) When reading items aloud to a child, intonation should be kept neutral to avoid suggesting an answer. 8) If a child has difficulty understanding the age-appropriate PedsQL®, the preceding age group version may be administered to the child (e.g., administering the Young Child (5-7) Self-Report version with the three faces response choices to an 8 year old). However, if a child presents with severe cognitive impairments (as determined by the administrator), the PedsQL may not be appropriate for that child. In such cases, only the Parent-Proxy Report should be administered to the child's parent. 9) The parent and child must complete the questionnaires <i>independently</i> of one another. Discourage the parent, child, or other family members from consulting with one another during the completion of the questionnaire. Let them know that they can feel free to discuss their answers following completion of the questionnaires, but that it is important to get both the parent's and the child's <i>individual</i> perspectives. If you are administering the questionnaire to the child, the child should be facing away from the

parent.

- 10) If the child or parent has a question about what an item means or how they should answer it, do not interpret the question for them. Repeat the item to them verbatim. Ask them to answer the item according to what *they think the question means*. If they have trouble deciding on an answer, ask them to choose the response that comes closest to how they feel. The child and/or the parent has the option of not answering a question if they truly do not understand the question.
- 11) If a parent/child asks you to interpret the responses, tell her/him that you are not trained to interpret or provide a score for the answers given. If the PedsQL™ is being used for a clinical study, let the parent/child know that their answers will be combined with other participants' answers and analysed as a group rather than as individual respondents.
- 12) Document all reasons for refusals and non-completions of the PedsQL™.

SCORING

The PedsQL **Generic Core Scales** are easy to score. The items of the four Scales (Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning) are grouped together on the actual questionnaire, so it is easy to create Scale Scores.

1. On the PedsQL **Generic Core Scales**, for ease of interpretability, items are reversed scored and linearly transformed to a 0-100 scale, so that higher scores indicate better HRQOL (Health-Related Quality of Life).
2. To reverse score, transform the 0-4 scale items to 0-100 as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
3. To create **Scale Scores**, the mean is computed as the sum of the items over the number of items answered (this accounts for missing data). If more than 50% of the items in the scale are missing, the Scale Score should not be computed. Imputing the mean of the completed items in a scale when 50% or more are completed is generally the most unbiased and precise method. To do this, count the number of missing values in the scale (call it nmiss). Next, sum the item scores and divide by the number of items in the scale minus nmiss. Alternatively, use the Compute command in SPSS to compute the MEAN.
4. To create the **Psychosocial Health Summary Score**, the mean is computed as the sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales.

The **Physical Health Summary Score** is the same as the Physical Functioning Scale Score.

5. To create the **Total Scale Score**, the mean is computed as the sum of all the items over the number of items answered on all the Scales.

Response Choices	Never	Almost Never	Some- times	Often	Almost Always
Raw Scores	0	1	2	3	4
0-100 Scale Scores	100	75	50	25	0

PSYCHOMETRIC PROPERTIES

STUDY 1

The PedsQL™: Measurement Model for the Paediatric Quality of Life Inventory

James W. Varni , Michael Seid and Cheryl A. Rode *Medical Care* Vol. 37, No. 2 (Feb., 1999), pp. 126-139

Background. Paediatric patients' self-report of health-related quality of life (HRQOL) has emerged as an important patient-based health outcome. A practical, validated generic measure of HRQOL facilitates assessing risk, tracking health status, and measuring treatment outcomes in paediatric populations. Methods. The PedsQL is a brief, standardised, generic assessment instrument that systematically assesses patients' and parents' perceptions of HRQOL in paediatric patients with chronic health conditions using paediatric cancer as an exemplary model. The PedsQL is based on a modular approach to measuring HRQOL and consists of a 15-item core measure of global HRQOL and eight supplemental modules assessing specific symptom or treatment domains. The PedsQL was empirically derived from data collected from 291 paediatric cancer patients and their parents at various stages of treatment. Results. Both reliability and validity were determined. Cronbach's alpha coefficients for the core measure ($\alpha = .83$ for patient and $\alpha = .86$ for parent) were acceptable for group comparisons. Alphas for the patient self-report modules generally ranged from .70 to .89. Discriminant or clinical validity, using the known-groups approach, was demonstrated for patients on- versus off-treatments. The 11 scales showed small-to-medium positive inter-correlations, supporting the multidimensional measurement model. Further construct validity was demonstrated via a multimethod-multitrait matrix using standardised psychosocial questionnaires. **Conclusion. The results support the PedsQL**

as a reliable and valid measure of HRQOL. The PedsQL core and modular design makes it flexible enough to be used in a variety of research and clinical applications for paediatric chronic health conditions.

STUDY 2

PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations.

[Varni JW](#)¹, [Seid M](#), [Kurtin PS](#) .[Med Care](#). 2001 Aug;39(8):800-12.

BACKGROUND:

Paediatric patients' self-report of health-related quality of life (HRQOL) has emerged as an important patient-based health outcome. A practical, validated generic measure of HRQOL facilitates assessing risk, tracking health status, and measuring treatment outcomes in pediatric populations.

METHODS:

The PedsQL is a brief, standardised, generic assessment instrument that systematically assesses patients' and parents' perceptions of HRQOL in paediatric patients with chronic health conditions using paediatric cancer as an exemplary model. The PedsQL is based on a modular approach to measuring HRQOL and consists of a 15-item core measure of global HRQOL and eight supplemental modules assessing specific symptom or treatment domains. The PedsQL was empirically derived from data collected from 291 paediatric cancer patients and their parents at various stages of treatment.

RESULTS:

Both reliability and validity were determined. Cronbach's alpha coefficients for the core measure ($\alpha = .83$ for patient and $\alpha = .86$ for parent) were acceptable for group comparisons. Alphas for the patient self-report modules generally ranged from .70 to .89. Discriminant or clinical validity, using the known-groups approach, was demonstrated for patients on-versus off-treatments. The 11 scales showed small-to-medium positive intercorrelations, supporting the multidimensional measurement model. Further construct validity was demonstrated via a multimethod-multitrait matrix using standardised psychosocial questionnaires.

CONCLUSION:

The results support the PedsQL as a reliable and valid measure of HRQOL. The PedsQL core and modular design makes it flexible enough to be used in a variety of research and clinical applications for pediatric chronic health conditions.

STUDY 3

Validity and responsiveness of the pediatric quality of life inventory (PedsQL) 4.0 generic core scales in the pediatric inpatient setting.

[Desai AD](#), [Zhou C](#), [Stanford S](#), [Haaland W](#), [Varni JW](#), [Mangione-Smith RM](#).

IMPORTANCE:

Validated patient-reported outcomes responsive to clinical change are needed to evaluate the effectiveness of quality improvement interventions.

OBJECTIVES:

To evaluate responsiveness, construct validity, and predictive validity of the Paediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales in the paediatric inpatient setting.

DESIGN, SETTING, AND PARTICIPANTS:

Prospective, cohort study of parents and caregivers of patients 1 month to 18 years old (n = 4637) and patients 13 to 18 years old (n = 359) admitted to Seattle Children's Hospital between October 1, 2011, and December 31, 2013. Of 7184 eligible participants invited to complete the survey, 4637 (64.5%) completed the PedsQL on admission, and of these 2694 (58.1%) completed the follow-up survey 2 to 8 weeks after discharge.

MAIN OUTCOMES AND MEASURES:

Responsiveness was assessed by calculating improvement scores (difference between follow-up and admission scores). Construct validity was examined by comparing the mean improvement scores for known groups differing by medical complexity. Predictive validity was assessed using Poisson regression to examine associations among admission scores, prolonged length of stay (≥ 3 days), and 30-day readmissions or emergency department (ED) return visits. Similar models examined the association between improvement scores and risk for 30-day readmissions or ED return visits.

RESULTS:

The mean (SD) PedsQL improvement scores (scale, 0-100) were 22.1 (22.7) for total, 29.4 (32.4) for physical, and 17.1 (21.0) for psychosocial. The mean PedsQL total improvement scores were lower for patients with medically complex conditions compared with patients without chronic conditions (13.7 [95% CI, 11.6-15.8] vs. 24.1 [95% CI, 22.4-25.7], $P < .001$). A 10-point decrement in the PedsQL total admission score below the established community-based mean was associated with an increase in risk

	<p>for prolonged length of stay (15% [95% CI, 13%-17%]), 30-day readmissions (8% [95% CI, 3%-14%]), and ED return visits (13% [95% CI, 6%-20%]). A 5-point decrement in the PedsQL total improvement score below the study sample mean improvement score was associated with an increase in risk for 30-day readmissions or ED return visits (9% [95% CI, -1% to 19%]).</p> <p>CONCLUSIONS AND RELEVANCE:</p> <p>The PedsQL demonstrated responsiveness, construct validity, and predictive validity in hospitalized pediatric patients. The PedsQL may be a useful patient-reported outcome for hospital-based clinical effectiveness research.</p> <p>See Varni et al. (1999, 2001, 2003). Measure selected for CDE by the inter-agency Pediatrics TBI Outcomes Workgroup.</p> <p>The reliability and validity of the Peds-QL has been demonstrated in both healthy children and children with physical illness who range in age from 2 to 18 years.</p> <p>see Crichton et al for details.</p>
Advantages	<ol style="list-style-type: none"> 1) Normative data available 2) best measure currently to QoL in children 3) Multiple languages, wide age range, parent and child report versions 4) Used in published child TBI studies 5) CORE for NIH CDE measures 6) Brief (23 items) 7) Practical (Less than 4 minutes to complete) 8) Flexible (Designed for use with community, school, and clinical pediatric populations) 9) Developmentally Appropriate (Ages 2-18; Child Self-Report Ages 5-7, 8-12, 13-18; Parent Proxy-Report Ages 2-4, 5-7, 8-12, 13-18) 10) Multidimensional (Physical, Emotional, Social, School Functioning). 11) Reliable (Total Scale Score: 0.88 Child Self-Report; 0.90 Parent Proxy-Report). 12) Valid (Distinguishes between healthy children and children with acute and chronic health conditions; distinguishes disease severity within a chronic health condition). 13) Responsive to clinical change over time.
Disadvantages	<ol style="list-style-type: none"> 1) Expensive, 2) likely not sensitive to some aspects of QoL post-TBI
Additional Information	<ol style="list-style-type: none"> 1) The PedsQL (generic core) is a Core Measure in the Health-Related Quality of Life Domain in McCauley et al (2012).

	<p>2) The PedsQL is also a Supplemental measure in the Global Outcome Domain in McCauley.</p> <p>3) The PedsQL (Social Subscale) is a Core Measure in the Social Role Participation and Social Competence Domain in McCauley.</p>
Reviewers	<p>Vicki Anderson</p> <p>Cathy Catroppa</p>

References

Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL (TM): Measurement model for the pediatric quality of life inventory. *Medical care*, 37(2), 126-139.