**CSER HARMONIZED MEASURE REPOSITORY: Quality of Life (PedsQL Generic Core scale--Parent Proxy Form)**

| **Template topic** | **Definition/Note** |
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| **Measure name and acronym** | Quality of Life (PedsQL Generic Core scale) |
| **Source citation for original measure** | Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL™: measurement model for the pediatric quality of life inventory. *Medical care*, 126-139.  Versions used in CSER are licensed and are shown here: <http://www.pedsql.org/> |
| **Category of assessment (construct/ CSER framework location)** | Pediatric patient self-reported health-related quality of life/CSER2 Framework: Outcomes |
| **Description of measure** | PedsQL is a brief, standardized, generic measure that assesses patients’ and parents’ perceptions of quality of life in pediatric patients with chronic health conditions. It consists of a core measure (with different versions for children in different age groups) and has eight supplemental models that assess specific symptoms or treatment domains. It was empirically derived from data collected from cancer patients and their parents.  The core scale PedsQL is composed of two versions of two parallel forms:  1) patient self-report forms (child age range 8 to 12 years, adolescent age range 13 to 18 years)  2) parent proxy report forms with the following versions: Infant (1 - 12 months), Infant (13 – 24 months), Toddlers (age 2 - 4 years), Young Child (5 - 7 years), Child (8 - 12 years), Teenagers (13 - 18 years) |
| **Operational definition of construct** | Health-related quality of life (HRQOL) in pediatric patients. HRQOL reflects patient perceptions of the impact of disease and treatment functioning in a variety of dimensions that differ across age groups. Pediatric assessment of HRQOL incorporates consideration of child development and issues related to the accuracy and acceptability of parent-proxy ratings of child quality of life. |
| **Summary of changes made to measure for CSER (“CSER-adapted scale”), if any** | n/a |
| **Time to administer** | Not reported; assume less than 5 minutes for Core Scale |
| **Target Respondent(s)** | Pediatric patient/Parent as proxy for pediatric patient (Note: CSER is using Parent proxy version only) |
| **Age range(s) or respondents** | Infant to 18 years |
| **Number of items** | Infant (1 - 12 months): 36 items; Infant (13 – 24 months): 45 items; Toddlers (age 2 - 4 years): 21 items; Young Child (5 - 7 years): 23 items, Child (8 - 12 years): 23 items; Teenagers (13 - 18 years: 23 items |
| CSER adapted |
| **Subscales and items per subscale** | Core scale:   * Infant (1 - 12 months): physical functioning (6 items), physical symptoms (10 items), emotional functioning (12 items), social functioning (4 items), cognitive functioning (4 items) * Infant (13 - 24 months): physical functioning (9 items), physical symptoms (10 items), emotional functioning (12 items), social functioning (5 items), cognitive functioning (9 items * Toddlers (ages 2-4): physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), school functioning (optional; 3 items) * Young children (ages 5-7): physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), school functioning (5 items) * Children (ages 8-12): physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), school functioning (5 items) * Teens (ages 13-18): physical functioning (8 items), emotional functioning (5 items), social functioning (5 items), school functioning (5 items)   Modules [Note: not used in CSER]: Pain 3 items; Nausea 5 items; Procedural Anxiety 3 items; Treatment Anxiety 3 items; Worry 3 items; Cognitive Problems 7 items; Perceived Physical appearance 4 items; Physician/Nurse Communication 2 items. |
| CSER adapted: Same as original (CORE items, parent proxy version, English and Spanish) |
| **Response scale (including anchor labels)** | Original scale 4 point Likert scale scored as 0, it is never a problem; 1 it is sometimes a problem; 2, it is often a problem; 3 it is always a problem. |
| CSER adapted |
| **Scoring instructions** | 1. *Step 1: Transform Scores*. Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.  *2. Step 2: Calculate Scores*  § Dimensions**:** Mean score = Sum of the items over the number of items answered. NOTE: If more than 50% of the items in the scale are missing, the scale scores should not be computed.  § Summary scores  · *Psychosocial Health Summary Score***:** Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales  · *Physical Health Summary Score***:** Sum of the items over the number of items answered in the Physical Functioning Scale Score.  § Total Score**:** Sum of all the items over the number of items answered on all the Scales**.**  Missing data: Scoring instructions specify that a scale score cannot be computed if a respondent is missing data for more than 50% of items. If there are missing items (but at least 50% of items have responses), each missing value should be replaced with the mean of the completed items. |
| CSER adapted: Same as original |
| **Validated cutoff scores, if any** | None reported in original version |
| **Norms (if available)** | None reported for original version |
| **Contact for permission to use/adapt (associated cost)** | James W. Varni, PhD; licensed versions see PedsMetrics <https://www.pedsql.org/about_pedsql.html>; original version (not used in CSER) in public domain. |
| **Validated administration modes** | Paper and pencil/computer assisted |
| **Original measure languages available** | English, Spanish |
| **Evidence for reliability (provide type and values)** | Coefficient alpha (.83 for patient and .86 for parent-proxy) |
| **Evidence for validity (provide type and values if available)** | Known groups approach to discriminant validity demonstrated for patients on and off treatment; Small to medium positive intercorrelations among subscales supporting multidimensional measurement model; multimethod-multitrait matrix provides additional evidence for construct validity.  Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL™: measurement model for the pediatric quality of life inventory. *Medical care*, 126-139.  Also see:  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*, 800-812.  Also: <http://www.pedsql.org/> |
| **Evidence for sensitivity to change** | See Desai, A. D., Ahou, C., Stanford, S., Halland, W., Varnit, J. W., Mangione-Smith, R. M. (2014). Validity and responsiveness of the Pediatric Quality of Life Inventory (PedsQL) 4.0 generic core scales in the pediatric inpatient setting. JAMA Pediatr, 168, 114-1121. |
| **Relevant references in genetics or genomics** | See Cohen, J. S., Biesecker, B B. Quality of life in rare genetic conditions: a systematic review of the literature. Am J Med Genet A, 152A, 1136-1156. |

**Paste CSER adaptation below**

No adaptations made

**Paste or list CSER site-specific adaptation/deviation below**