

SCALING AND SCORING OF THE

Pediatric Quality of Life Inventory $^{\text{TM}}$ $\text{PedsQL}^{^{\text{TM}}}$

Mapi Research Trust 27 rue de la Villette 69003 Lyon France

Phone: +33 (0) 4 72 13 65 75 Fax: +33 (0) 4 72 13 66 82

Email: PROinformation@mapi-trust.org

James W. Varni, Ph.D.
Professor
Department of Pediatrics, College of Medicine
Professor, Department of Landscape
Architecture and Urban Planning, College of
Architecture
3137 TAMU

College Station, Texas 77843-3137

USA

Email: jvarni@arch.tamu.edu



PedsQL TM 4.0 Generic Core Scales	5
PARENT Report for Toddlers (ages 2-4)	
PedsQL TM 4.0 Generic Core Scales	
CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens (ag	ges
13-18)	7
PedsQL TM 4.0 Generic Core Scales	9
YOUNG ADULT Report (ages 18-25) and ADULT Report (ages over 26)	
PedsQL TM Infant Scales	
PARENT Report for Infants (ages 1-24 months)	
PedsQL TM 4.0 SF15 Short Form Generic Core Scales	14
PARENT Report for Toddlers (ages 2-4) CHILD and PARENT Reports for Young Children	
(ages 5-7), Children (ages 8-12), Teens (ages 13-18)	
PedsQL TM General Well-Being Scale	17
CHILD, ADOLESCENT and YOUNG ADULT Report (ages 8-25 years of age)	17
PedsQL $^{ m TM}$ 3.0 Arthritis Module	19
PARENT Report for Toddlers (ages 2-4)	19
PedsQL TM 3.0 Arthritis Module	21
CHILD and PARENT Reports for Young Children (ages 5-7)	21
PedsQL $^{ m TM}$ 3.0 Arthritis Module	
CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18)	23
PedsQL TM 3.0 Asthma Module	25
PARENT Report for Toddlers (ages 2-4)	
PedsQL TM 3.0 Asthma Module	27
CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens (ages	ges
13-18)	
PedsQL $^{ m TM}$ 3.0 SF22 Short Form Asthma Module	
PARENT Report for Toddlers (ages 2-4)	
PedsQL TM 3.0 SF22 Short Form Asthma Module	31
CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens (ages	ges
13-18)	
PedsQL $^{ m TM}$ Brain Tumor Module	
PARENT Report for Toddlers (ages 2-4)	
PedsQL $^{ m TM}$ Brain Tumor Module	
CHILD and PARENT Reports for Young Children (ages 5-7)	35
PedsQL $^{ m TM}$ Brain Tumor Module	37
CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18)	
PedsQL TM 3.0 Cancer Module	
PARENT Report for Toddlers (ages 2-4)	39
PedsQL TM 3.0 Cancer Module	41
CHILD and PARENT Reports for Young Children (ages 5-7)	
PedsQL TM 3.0 Cancer Module	43
CHILD and PARENT Reports for Children (ages 8-12), and Teens (ages 13-18), and Young	
Adults Report (ages 18-25)	
PedsQL TM 3.0 Cardiac Module	
PARENT Report for Toddlers (ages 2-4)	45
PedsQL TM 3.0 Cardiac Module	47
CHILD and PARENT Reports for Young Children (ages 5-7) PedsQL TM 3.0 Cardiac Module	



CHILD and PARENT Reports for Children (ages 8-12) and Teens (ages 13-18)	49
PedsQL TM 3.0 Cerebral Palsy Module	51
PARENT Report for Toddlers (ages 2-4)	
PedsQL TM 3.0 Cerebral Palsy Module	53
CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens	
13-18)	53
PedsQL TM Cognitive Functioning Scale	55
PedsQL TM 3.0 Diabetes Module	57
PedsQL TM 3.2 Diabetes Module	59
PedsQL TM 3.0 Duchenne Muscular Dystrophy Module	61
PARENT Report for Young Children (ages 5-7)	
PedsQL TM 3.0 Duchenne Muscular Dystrophy Module	63
CHILD and PARENT Reports for Children (ages 8-12) and Teens (ages 13-18)	
PedsQL TM 3.0 Eosinophilic Esophagitis Module	
PARENT Report for Toddlers (ages 2-4)	
PedsQL TM 3.0 Eosinophilic Esophagitis Module	
CHILD and PARENT Reports for Young Children (ages 5-7)	
PedsQL TM 3.0 Eosinophilic Esophagitis Module	
CHILD and PARENT Reports for Children (ages 8-12) and Teens (ages 13-18)	
PedsQL TM 3.0 End Stage Renal Disease Module	
PARENT Report for Toddlers (ages 2-4)	
PedsQL TM 3.0 End Stage Renal Disease Module	76
CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens	
13-18)	
PedsQL TM 2.0 Family Impact Module	78
PARENT Report	78
PedsQL TM 3.0 Gastrointestinal Symptoms Module	81
PARENT Report for Toddlers (ages 2-4)	81
PedsQL TM 3.0 Gastrointestinal Symptoms Module	84
CHILD and PARENT Reports for Young Children (ages 5-7)	
PedsQL TM 3.0 Gastrointestinal Symptoms Module	87
CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18) and Young Ad	
(18-25)	87
PedsQL TM 3.0 Gastrointestinal Symptoms Scales TM	
PARENT Report for Toddlers (ages 2-4)	
PedsQL TM 3.0 Gastrointestinal Symptoms Scales TM	
CHILD and PARENT Reports for Young Children (ages 5-7)	
PedsQL TM 3.0 Gastrointestinal Symptoms Scales TM	
CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18) and Young Ad	
(18-25) PedsQL TM Healthcare Satisfaction Generic Module	95
PedsQL TM Healthcare Satisfaction Generic Module	98
PedsQL TM Healthcare Satisfaction Hematology / Oncology Module	100
PedsQL TM Multidimensional Fatigue Scale	102
PedsQL TM 1.0 Neurofibromatosis Type 1 Module	104
PedsQL TM 3.0 Neuromuscular Module	107
PedsQL TM Oral Health Scale	109
PedsQL TM Pediatric Pain Coping Inventory (PPCI)	
PARENT Report for Children and Teens (ages 5-18)	
CHILD Report for Children (ages 5-12), Teens (ages 13-18)	111



PedsQL TM Pediatric Pain Questionnaire TM (PPQ)	113
PedsQL TM Present Functioning Visual Analogue Scale (PedsQL TM VAS)	
CHILD and PARENT reports for CHILD (ages 5-18)	
PedsQL TM 3.0 Rheumatology Module	
PARENT Report for Toddlers (ages 2-4)	
PedsQL TM 3.0 Rheumatology Module	
CHILD and PARENT reports for Young Children (ages 5-7)	
PedsQL TM 3.0 Rheumatology Module	
CHILD and PARENT reports for Children (ages 8-12) and Teens (ages 13-18)	
PedsQL TM 3.0 Sickle Cell Disease Module	
PARENT Report for Toddlers (ages 2-4)	
PedsQL TM 3.0 Sickle Cell Disease Module	
CHILD and PARENT Reports for Young Children (ages 5-7)	
PedsQL TM 3.0 Sickle Cell Disease Module	
CHILD and PARENT Reports for Children (ages 8-12) and Teens (ages 13-18)	
PedsQL TM 3.0 Transplant Module	



PedsQL TM **4.0 Generic Core Scales**

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (ages 2-4) of the PedsQL™ 4.0 Generic Core Scales is composed of 21 items comprising 4 dimensions.

DESCRIPTION OF THE QUESTIONNAIRE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Physical Functioning	8	1-8	1-8	
Emotional Functioning	5	1-5	1-5	Higher scores indicate
Social Functioning	5	1-5	1-5	better HRQOL.
School Functioning	3	1-3	1-3	_

Itom Cooling	5 point Likert cools from 0 (Never) to 4 (Almost shape)
Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
	Step 2: Calculate Scores
Scoring Procedure	 Score by Dimensions: If more than 50% of the items in the scale are missing, the scale scores should not be computed. Mean score = Sum of the items over the number of items answered.
	<u>Psychosocial Health Summary Score</u> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales.
	Physical Health Summary Score = Physical Functioning Scale Score
	<u>Total Score</u> : Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM **4.0** Generic Core Scales

CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens (ages 13-18)



The Child and Parent Reports of the PedsQL[™] 4.0 Generic Core Scales for:

- Young Children (ages 5-7),Children (ages 8-12),
- And Teens (ages 13-18),

are composed of 23 items comprising 4 dimensions.

DESCRIPTION OF THE QUESTIONNAIRE:

Dimensions	Number of Items	Cluster of Items	Reversed scoring	Direction of Dimensions
Physical Functioning	8	1-8	1-8	
Emotional Functioning	5	1-5	1-5	Higher scores indicate
Social Functioning	5	1-5	1-5	better HRQOL.
School Functioning	5	1-5	1-5	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Young Child (ages 5-7) child report
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores Score by Dimensions: If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. 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 = Physical Functioning Scale Score Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM **4.0** Generic Core Scales

YOUNG ADULT Report (ages 18-25) and ADULT Report (ages over 26)



The Young Adult and Adult Reports of the PedsQL™ 4.0 Generic Core Scales for:

- Young Adults (ages 18-25),
- Adults (ages over 26),

are composed of 23 items comprising 4 dimensions.

DESCRIPTION OF THE QUESTIONNAIRE:

Dimensions	Number of Items	Cluster of Items	Reversed scoring	Direction of Dimensions
Physical Functioning	8	1-8	1-8	
Emotional Functioning	5	1-5	1-5	Higher scores indicate
Social Functioning	5	1-5	1-5	better HRQOL.
School Functioning	5	1-5	1-5	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores Score by Dimensions: If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. 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 = Physical Functioning Scale Score Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores should
and Analysis of Missing Data	not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM Infant Scales

PARENT Report for Infants (ages 1-24 months)



The Parent Report for Infants (ages 1-24 months) of the PedsQL[™] Infant Scales is composed of 36 items for infants ages 1-12 months and 45 items for infants ages 13-24 months comprising 5 dimensions.

DESCRIPTION OF THE QUESTIONNAIRE (INFANTS 1-12 MONTHS):

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Physical Functioning	6	1-6	1-6	_
Physical Symptoms	10	1-10	1-10	
Emotional Functioning	12	1-12	1-12	Higher scores indicate better HRQOL.
Social Functioning	4	1-4	1-4	
Cognitive Functioning	4	1-4	1-4	

DESCRIPTION OF THE QUESTIONNAIRE (INFANTS 13-24 MONTHS):

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Physical Functioning	9	1-9	1-9	_
Physical Symptoms	10	1-10	1-10	
Emotional Functioning	12	1-12	1-12	Higher scores indicate better HRQOL.
Social Functioning	5	1-5	1-5	_
Cognitive Functioning	9	1-9	1-9	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of	No
Items	IVO
Extension of	
the	Scores are transformed on a scale from 0 to 100.
Scoring Scale	



	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
	Step 2: Calculate Scores
Scoring Procedure	 Score by Dimensions: If more than 50% of the items in the scale are missing, the scale scores should not be computed. Mean score = Sum of the items over the number of items answered.
	Psychosocial Health Summary Score = Sum of the items over the number of items answered in the Emotional, Social, and Cognitive Functioning Scales.
	Physical Health Summary Score = Sum of the items over the number of items answered in the Physical Functioning and Physical Symptoms Scales.
	Total Score : Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 4.0 SF15 Short Form Generic Core Scales

PARENT Report for Toddlers (ages 2-4)
CHILD and PARENT Reports for Young Children (ages 5-7),
Children (ages 8-12), Teens (ages 13-18)



The Parent Report for Toddlers (ages 2-4) and the Child & Parent Reports for Young Children (ages 5-7), Children (ages 8-12) and Teens (ages 13-18) of the PedsQLTM 4.0 SF15 Generic Core Scales are composed of 15 items comprising 4 dimensions.

DESCRIPTION OF THE SF15 QUESTIONNAIRE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Physical Functioning	5	1-5	1-5	
Emotional Functioning	4	1-4	1-4	Higher scores indicate
Social Functioning	3	1-3	1-3	better HRQOL.
School Functioning	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scales: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Young Child self-report
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores Score by Dimensions: If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. 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 = Physical Functioning Scale Score Total Score: Sum of all the items over the number of items answered on all the Scales.



Interpretation
and Analysis
of Missing Data

If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.

If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQLTM **General Well-Being Scale**

CHILD, ADOLESCENT and YOUNG ADULT Report (ages 8-25 years of age)



The **PedsQL[™] General Well-Being Scale** is composed of 6 items for ages 8-25 years of age, and 1 overall General Health item.

DESCRIPTION OF THE QUESTIONNAIRE (ages 8-25 years):

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
General Well- Being	6	1-6	No	Higher scores indicate better HRQOL.
Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
General Health	1	1	No	Higher scores indicate better HRQOL.

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	 Step 1: Transform Score Items are linearly transformed to a 0-100 scale as follows: 0=0, 1=25, 2=50, 3=75, 4=100. Step 2: Calculate Scores Score by Dimensions: If more than 50% of the items in the scale are missing, the scale score should not be computed. Mean score = Sum of the items over the number of items answered. The General Health item is not included in the scale score, but is reported separately.
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Score should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Arthritis Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (ages 2-4) of the PedsQL [™] 3.0 Arthritis Module is composed of 14 items comprising 3 dimensions.

DESCRIPTION OF THE ARTHRITIS MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	4	1-4	1-4	
Daily Activities	5	1-5	1-5	Higher scores indicate lower problems.
Treatment	5	1-5	1-5	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)		
Weighting of Items	No		
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.		
	Step 1: Transform Score		
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.		
Scoring Procedure	 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores 		
	should not be computed		
	Mean score = Sum of the items over the number of items answered		
	There is no Total Score		
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores		
Analysis	should not be computed.		
of Missing Data	If 50% or more items are completed: Impute the mean of the completed		
	items in a scale.		



PedsQL TM 3.0 Arthritis Module

CHILD and PARENT Reports for Young Children (ages 5-7)



The **Child and Parent Reports** of the **PedsQL** [™] 3.0 Arthritis Module for **Young Children** (ages 5-7) are composed of 20 items comprising 5 dimensions.

DESCRIPTION OF THE ARTHRITIS MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	4	1-4	1-4	
Daily Activities	5	1-5	1-5	
Treatment	5	1-5	1-5	Higher scores indicate lower problems.
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) for the parent report 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the child report
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
Scoring Procedure	 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. There is no Total Score
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores
Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Arthritis Module

CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18)



The Child and Parent Reports of the PedsQL TM 3.0 Arthritis Module for:

- Children (ages 8-12),
- And Teen's (ages 13-18),

are composed of 22 items comprising 5 dimensions.

DESCRIPTION OF THE ARTHRITIS MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	4	1-4	1-4	
Daily Activities	5	1-5	1-5	
Treatment	7	1-7	1-7	Higher scores indicate lower problems.
Worry	3	1-3	1-3	<u> </u>
Communication	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)			
	3-point Likert scale from 6 (Never) to 4 (Almost always)			
Weighting of	No			
Items				
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.			
	Step 1: Transform Score			
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.			
Scoring Procedure	Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale score			
	should not be computed,			
	Mean score = Sum of the items over the number of items answered.			
	There is no Total Score			
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores			
Analysis	should not be computed.			
of missing data	If 50% or more items are completed: Impute the mean of the completed			
or impomy data	items in a scale.			



PedsQL TM 3.0 Asthma Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (ages 2-4) of the PedsQL TM 3.0 Asthma Module is composed of 26 items comprising 4 dimensions.

DESCRIPTION OF THE ASTHMA MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Asthma	11	1-11	1-11	
Treatment	9	1-9	1-9	— Higher scores indicate
Worry	3	1-3	1-3	lower problems.
Communication	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	 Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. There is no Total Score
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Asthma Module

CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens (ages 13-18)



The Child and Parent Reports of the PedsQL ™ 3.0 Asthma Module for:

- Young Children (ages 5-7),Children (ages 8-12),
- And Teens (ages 13-18),

are composed of 28 items comprising 4 dimensions.

DESCRIPTION OF THE ASTHMA MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Asthma	11	1-11	1-11	
Treatment	11	1-11	1-11	— Higher scores indicate
Worry	3	1-3	1-3	lower problems.
Communication	3	1-3	1-3	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the child report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
Scoring Procedure	 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores
	 should not be computed, Mean score = Sum of the items over the number of items answered.
	There is no Total Score
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores
Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 SF22 Short Form Asthma Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (ages 2-4) of the PedsQL [™] 3.0 SF22 Asthma Module is composed of 20 items comprising 2 dimensions.

DESCRIPTION OF THE SF22 ASTHMA MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Asthma	11	1-11	1-11	
				Higher scores indicate
Treatment	9	1-9	1-9	lower problems.

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)		
Weighting of Items	No		
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.		
	Step 1: Transform Score		
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.		
Scoring Procedure	 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores 		
	should not be computed,		
	 Mean score = Sum of the items over the number of items answered. 		
	There is no Total Score		
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores		
Analysis	should not be computed.		
of Missing Data	If 50% or more items are completed: Impute the mean of the completed		
	items in a scale.		



PedsQL TM 3.0 SF22 Short Form Asthma Module

CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens (ages 13-18)



The Child and Parent Reports of the PedsQL™ 3.0 SF22 Asthma Module for:

- Young Children (ages 5-7),Children (ages 8-12),
- And Teens (ages 13-18)

are composed of 22 items comprising 2 dimensions.

DESCRIPTION OF THE SF22 ASTHMA MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Asthma	11	1-11	1-11	
				Higher scores indicate
Treatment	11	1-11	1-11	lower problems.

T
5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child R Report for Young Children (ages 5-7)
No
Scores are transformed on a scale from 0 to 100.
Step 1: Transform Score
Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. There is no Total Score
If more than 50% of the items in the scale are missing, the Scale Scores
should not be computed.
If 50% or more items are completed: Impute the mean of the completed
items in a scale.



PedsQL TM Brain Tumor Module

PARENT Report for Toddlers (ages 2-4)



The **Parent Report for Toddlers** (ages 2-4) of the **PedsQLTM Brain Tumor Module** is composed of 17 items comprising 5 dimensions.

DESCRIPTION OF THE BRAIN TUMOR MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	3	1-3	1-3	
Movement and Balance	3	1-3	1-3	
Procedural Anxiety	3	1-3	1-3	Higher scores indicate lower problems.
Nausea	5	1-5	1-5	
Worry	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never a problem) to 4 (Almost always a problem)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	 Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. There is no Total Score
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores
Analysis of Missing Data	should not be computed. If 50% or more items are completed: Impute the mean of the completed
	items in a scale.



PedsQL TM Brain Tumor Module

CHILD and PARENT Reports for Young Children (ages 5-7)



The Parent and Child Reports for Young Children (ages 5-7) of the PedsQL ™ Brain Tumor Module are composed of 23 items comprising 6 dimensions.

DESCRIPTION OF THE BRAIN TUMOR MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Cognitive Problems	6	1-6	1-6	
Pain and Hurt	3	1-3	1-3	
Movement and Balance	3	1-3	1-3	— Higher scores indicate
Procedural Anxiety	3	1-3	1-3	lower problems.
Nausea	5	1-5	1-5	
Worry	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
Scoring Procedure	 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. There is no Total Score
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores
Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM Brain Tumor Module

CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18)



The Parent and Child Reports for Children (ages 8-12) and Teens (ages 13-18) of the PedsQL™ Brain Tumor Module are composed of 24 items comprising 6 dimensions.

DESCRIPTION OF THE BRAIN TUMOR MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Cognitive Problems	7	1-7	1-7	
Pain and Hurt	3	1-3	1-3	
Movement and Balance	3	1-3	1-3	— Higher scores indicate
Procedural Anxiety	3	1-3	1-3	lower problems
Nausea	5	1-5	1-5	
Worry	3	1-3	1-3	_

Item Scaling	5-point Likert scale from 0 (Never a problem) to 4 (Almost always a problem)		
Weighting of Items	No		
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.		
	Step 1: Transform Score		
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.		
Scoring Procedure	 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. 		
	There is no Total Score		
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores		
Analysis	should not be computed.		
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.		



PedsQL TM 3.0 Cancer Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (ages 2-4) of the PedsQL[™] 3.0 Cancer Module is composed of 25 items comprising 8 dimensions.

DESCRIPTION OF THE CANCER MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Nausea	5	1-5	1-5	
Procedural Anxiety	3	1-3	1-3	
Treatment Anxiety	3	1-3	1-3	
Worry	3	1-3	1-3	 Higher scores indicate lower problems.
Cognitive Problems	3	1-3	1-3	_
Perceived Physical Appearance	3	1-3	1-3	
Communication	3	1-3	1-3	_

14 0 11	
Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.
Scoring Procedure	 Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered.
Interpretation and Analysis of Missing Data	Total Score: Sum of all the items over the number of items answered on all the Scales. If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Cancer Module

CHILD and PARENT Reports for Young Children (ages 5-7)



The **Child and Parent Reports** of the **PedsQL™** 3.0 Cancer Module for Young Children (ages 5-7), are composed of 26 items comprising 8 dimensions.

DESCRIPTION OF THE CANCER MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Nausea	5	1-5	1-5	
Procedural Anxiety	3	1-3	1-3	
Treatment Anxiety	3	1-3	1-3	
Worry	3	1-3	1-3	 Higher scores indicate lower problems.
Cognitive Problems	4	1-4	1-4	
Perceived Physical Appearance	3	1-3	1-3	
Communication	3	1-3	1-3	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
Scoring Procedure	 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores
and Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Cancer Module

CHILD and PARENT Reports for Children (ages 8-12), and Teens (ages 13-18), and Young Adults Report (ages 18-25)



The Child and Parent Reports of the PedsQL [™] 3.0 Cancer Module for:

- Children (ages 8-12),Teens (ages 13-18)

and the Young Adults report (ages 18-25)

are composed of 27 items comprising 8 dimensions.

DESCRIPTION OF THE CANCER MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Nausea	5	1-5	1-5	_
Procedural Anxiety	3	1-3	1-3	
Treatment Anxiety	3	1-3	1-3	
Worry	3	1-3	1-3	 Higher scores indicate lower problems.
Cognitive Problems	5	1-5	1-5	_
Perceived Physical Appearance	3	1-3	1-3	
Communication	3	1-3	1-3	_

	5-point Likert scale from 0 (Never) to 4 (Almost always)
Item Scaling	3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
Scoring	Step 2: Calculate Scores by Dimensions
Procedure	If more than 50% of the items in the scale are missing, the scale scores should not be computed,
	Mean score = Sum of the items over the number of items answered.
	Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores
and Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Cardiac Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (age 2-4) of the PedsQL™ 3.0 Cardiac Module is composed of 23 items comprising 6 dimensions.

DESCRIPTION OF THE CARDIAC MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Heart problems and Treatment	7	1-7	1-7	
Treatment II	3	1-3	1-3	_
Perceived Physical Appearance	3	1-3	1-3	Higher scores indicate
Treatment Anxiety	4	1-4	1-4	lower problems.
Cognitive Problems	3	1-3	1-3	
Communication	3	1-3	1-3	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.
Scoring Procedure	Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. There is no Total Score.
Interpretation and Analysis	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Cardiac Module

CHILD and PARENT Reports for Young Children (ages 5-7)



The **Child and Parent Reports** of the **PedsQL[™] 3.0 Cardiac Module** for Young Children (ages 5-7) are composed of 25 items comprising 6 dimensions.

DESCRIPTION OF THE CARDIAC MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Heart Problems and Treatment	7	1-7	1-7	
Treatment II	3	1-3	1-3	
Perceived Physical Appearance	3	1-3	1-3	— Higher scores indicate — lower problems.
Treatment Anxiety	4	1-4	1-4	— lower problems.
Cognitive Problems	5	1-5	1-5	_
Communication	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0
Scoring Procedure	 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered.
_	There is no Total Score
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores
and Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Cardiac Module

CHILD and PARENT Reports for Children (ages 8-12) and Teens (ages 13-18)



The Child and Parent Reports of the PedsQL™ 3.0 Cardiac Module for:

- Children (ages 8-12),And Teens (ages 13-18)

are composed of 27 items comprising 6 dimensions.

DESCRIPTION OF THE CARDIAC MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Heart Problems and Treatment	7	1-7	1-7	
Treatment II	5	1-5	1-5	
Perceived Physical Appearance	3	1-3	1-3	Higher scores indicate
Treatment Anxiety	4	1-4	1-4	lower problems.
Cognitive Problems	5	1-5	1-5	
Communication	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)		
Weighting of Items	No		
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.		
Scoring Procedure	 Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. There is no Total Score 		
Interpretation and Analysis	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.		
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.		



PedsQL TM 3.0 Cerebral Palsy Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (ages 2-4) of the PedsQL™ 3.0 Cerebral Palsy Module is composed of 22 items comprising 5 dimensions.

DESCRIPTION OF THE CEREBRAL PALSY MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Daily Activities	5	1-5	1-5	
Movement and Balance	5	1-5	1-5	
Pain and Hurt	4	1-4	1-4	Higher scores indicate lower problems.
Fatigue	4	1-4	1-4	
Eating Activities	4	1-4	1-4	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.
Scoring Procedure	Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. There is no Total score
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Cerebral Palsy Module

CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens (ages 13-18)



The Child and Parent Reports of the PedsQL™ 3.0 Cerebral Palsy Module for:

- Young Children (ages 5-7),Children (ages 8-12),
- And Teens (ages 13-18)

are composed of 35 items comprising 7 dimensions.

DESCRIPTION OF THE CEREBRAL PALSY MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Daily Activities	9	1-9	1-9	
School Activities	4	1-4	1-4	_
Movement and Balance	5	1-5	1-5	_
Pain and Hurt	4	1-4	1-4	Higher scores indicate lower problems.
Fatigue	4	1-4	1-4	<u> </u>
Eating Activities	5	1-5	1-5	
Speech and Communication	4	1-4	1-4	

-				
Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report			
item Scaming	for Young Children (ages 5-7)			
Weighting of Items	No			
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.			
	Step 1: Transform Score			
	Items are reversed scored and linearly transformed to a 0-100 scale as			
	follows: 0=100, 1=75, 2=50, 3=25, 4=0.			
	Stan 2. Calculate Coorea hu Dimonaiana			
Scoring	Step 2: Calculate Scores by Dimensions			
Procedure	• If more than 50% of the items in the scale are missing, the scale scores should not be computed,			
	Mean score = Sum of the items over the number of items answered.			
	There is no Total score			
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores			
and Analysis	should not be computed.			
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items			
	in a scale.			



PedsQL TM Cognitive Functioning Scale



The **PedsQLTM Cognitive Functioning Scale** is composed of 6 items comprising 1 dimension.

DESCRIPTION OF THE COGNITIVE FUNTIONING SCALE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Cognitive Functioning	6	1-6	1-6	Higher scores indicate lower problems

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
Scoring Procedure	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
	Step 2: Calculate Total Score
	Sum of all the items over the number of items answered
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Score
Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed
	items in a scale.



PedsQL TM 3.0 Diabetes Module



The PedsQL™ 3.0 Diabetes Module is composed of 28 items comprising 5 dimensions.

DESCRIPTION OF THE DIABETES MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Diabetes	11	1-11	1-11	
Treatment I	4	1-4	1-4	
Treatment II	7	1-7	1-7	Higher scores indicate lower problems.
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	

Item Scaling	5-point scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
Scoring Procedure	 Step 2: Calculate scores by Dimension If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores
Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.2 Diabetes Module



The **PedsQL[™] 3.2 Diabetes Module** is composed of 33 items comprising 5 dimensions for ages 13-45 years. For ages 2-12 years, the **PedsQL[™] 3.2 Diabetes Module** is composed of 32 items comprising 5 dimensions (one less item for the Worry Scale).

DESCRIPTION OF THE DIABETES MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Diabetes	15	1-15	1-15	
Treatment I	5	1-5	1-5	_
Treatment II	6	1-6	1-6	Higher scores indicate lower problems.
Worry	2 (3 for teens and adults)	1-2 or 1-3	1-2 or 1-3	
Communication	4	1-4	1-4	

Item Scaling Weighting of	5-point scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
Scoring Procedure	 Step 2: Calculate scores by Dimension If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Duchenne Muscular Dystrophy Module

PARENT Report for Young Children (ages 5-7)



The **Parent Report** of the **PedsQL[™] 3.0 Duchenne Muscular Dystrophy Module** for Young Children (ages 5-7) is composed of 18 items comprising 4 dimensions.

DESCRIPTION OF THE DUCHENNE MUSCULAR DYSTROPHY MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Daily Activities	5	1-5	1-5	
Treatment	4	1-4	1-4	
Worry	6	1-6	1-6	Higher scores indicate lower problems.
Communication	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)				
Weighting of	No				
Items	TNO				
Extension of the					
Scoring Scale	Scores are transformed on a scale from 0 to 100.				
	Step 1: Transform Score				
	Items are reversed scored and linearly transformed to a 0-100 scale as				
	follows: 0=100, 1=75, 2=50, 3=25, 4=0				
	10110W3. 0-100, 1-10, 2-00, 0-20, 4-0				
Scoring	Step 2: Calculate Scores by Dimensions				
Procedure	If more than 50% of the items in the scale are missing, the scale				
	scores should not be computed,				
	Mean score = Sum of the items over the number of items answered.				
	Would book - built of the forme over the hamber of forme answered.				
	No Total Score				
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores				
and Analysis	should not be computed.				
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items				
	in a scale.				



PedsQL TM 3.0 Duchenne Muscular Dystrophy Module

CHILD and PARENT Reports for Children (ages 8-12) and Teens (ages 13-18)



The Child and Parent Reports of the PedsQL[™] 3.0 Duchenne Muscular Dystrophy Module for:

- Children (ages 8-12),
- And Teens (ages 13-18)

are composed of 18 items comprising 4 dimensions.

DESCRIPTION OF THE DUCHENNE MUSCULAR DYSTROPHY MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Daily Activities	5	1-5	1-5	
Treatment	4	1-4	1-4	_
Worry	6	1-6	1-6	Higher scores indicate lower problems.
Communication	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)				
Weighting of					
Items	No				
Extension of the					
Scoring Scale	Scores are transformed on a scale from 0 to 100.				
	Step 1: Transform Score				
	Items are reversed scored and linearly transformed to a 0-100 scale as				
	follows: 0=100, 1=75, 2=50, 3=25, 4=0				
Scoring	Step 2: Calculate Scores by Dimensions				
Procedure	If more than 50% of the items in the scale are missing, the scale				
	scores should not be computed,				
	Mean score = Sum of the items over the number of items answered.				
	No Total Score				
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores				
and Analysis	should not be computed.				
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items				
	in a scale.				



PedsQL TM 3.0 Eosinophilic Esophagitis Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (age 2-4) of the PedsQL™ 3.0 Eosinophilic Esophagitis Module is composed of 21 items comprising 6 dimensions.

DESCRIPTION OF THE EOSINOPHILIC ESOPHAGITIS MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Symptoms I	3	1-3	1-3	
Symptoms II	4	1-4	1-4	_
Treatment	4	1-4	1-4	— Higher scores indicate
Worry	4	1-4	1-4	lower problems.
Food and Eating	3	1-3	1-3	
Food Feelings	3	1-3	1-3	

Note: Feeding Tube Scale not scored.

SCORING OF DIMENSIONS:

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)			
Weighting of Items	No			
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.			
	Step 1: Transform Score			
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.			
Scoring Procedure	 Step 2: Calculate scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. Symptoms Total Scale Score = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales. Total Score: Sum of all the items over the number of items answered on all the Scales except Feeding Tube Scale. 			
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores			
and Analysis	should not be computed.			
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.			

REFERENCES:

Franciosi, J.P., Hommel, K.A., Bendo, C.B., King, E.C., Collins, M.H., Eby, M.D., Marsolo, K., Abonia, J.P., von Tiehl, K.F., Putnam, P.E., Greenler, A.J., Greenberg, A.B., Bryson,



R.A., Davis, C.M., Olive, A.P., Gupta, S.K., Erwin, E.A., Klinnert, M.D., Spergel, J.M., Denham, J.M., Furuta, G.T., Rothenberg, M.E., & Varni, J.W. (2012). PedsQL™ Eosinophilic Esophagitis Module: Feasibility, reliability and validity. Manuscript submitted for publication.

Franciosi, J.P., Hommel, K.A., Greenberg, A.B., Debrosse, C.W., Greenler, A.J., Abonia, J.P., Rothenberg, M.E., & Varni, J.W. (2012). Development of the Pediatric Quality of Life Inventory™ Eosinophilic Esophagitis Module items: Qualitative methods. Manuscript submitted for publication.

Franciosi J.P., Hommel, K.A., Debrosse, C.W., Greenberg, A.B., Greenler, A.J., Abonia, J.P., Rothenberg, M.E., & Varni, J.W. (2012). Quality of life in paediatric eosinophilic oesophagitis: What is important to patients? Child: Care, Health and Development, 38, 477–483.



PedsQL TM 3.0 Eosinophilic Esophagitis Module

CHILD and PARENT Reports for Young Children (ages 5-7)



The **Child and Parent Reports** of the **PedsQL**[™] 3.0 Eosinophilic Esophagitis Module for Young Children (ages 5-7) are composed of 26 items comprising 7 dimensions.

DESCRIPTION OF THE EOSINOPHILIC ESOPHAGITIS MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Symptoms I	3	1-3	1-3	
Symptoms II*	4	1-4	1-4	
Treatment	4	1-4	1-4	Higher scores indicate lower problems.
Worry	4	1-4	1-4	
Communication	4	1-4	1-4	
Food and Eating	4	1-4	1-4	
Food Feelings	3	1-3	1-3	_

^{*}Symptoms II Scale not scored for child self-report ages 5-7 years.

Note: Feeding Tube Scale not scored.

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0
	Step 2: Calculate Scores by Dimensions
Scoring Procedure	If more than 50% of the items in the scale are missing, the scale scores should not be computed,
	Mean score = Sum of the items over the number of items answered.
	Symptoms Total Scale Score = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales. No Symptoms Total Scale Score for child self-report ages 5-7 years.
	<u>Total Score</u> : Sum of all the items over the number of items answered on all the Scales for parent report except Feeding Tube Scale. For child self-report ages 5-7, sum all of the items over the number of items answered on all Scales except for Symptoms II and Feeding Tube Scale.



Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores		
and Analysis	should not be computed.		
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items		
	in a scale.		

REFERENCES:

Franciosi, J.P., Hommel, K.A., Bendo, C.B., King, E.C., Collins, M.H., Eby, M.D., Marsolo, K., Abonia, J.P., von Tiehl, K.F., Putnam, P.E., Greenler, A.J., Greenberg, A.B., Bryson, R.A., Davis, C.M., Olive, A.P., Gupta, S.K., Erwin, E.A., Klinnert, M.D., Spergel, J.M., Denham, J.M., Furuta, G.T., Rothenberg, M.E., & Varni, J.W. (2012). PedsQL™ Eosinophilic Esophagitis Module: Feasibility, reliability and validity. Manuscript submitted for publication.

Franciosi, J.P., Hommel, K.A., Greenberg, A.B., Debrosse, C.W., Greenler, A.J., Abonia, J.P., Rothenberg, M.E., & Varni, J.W. (2012). Development of the Pediatric Quality of Life Inventory™ Eosinophilic Esophagitis Module items: Qualitative methods. Manuscript submitted for publication.

Franciosi J.P., Hommel, K.A., Debrosse, C.W., Greenberg, A.B., Greenler, A.J., Abonia, J.P., Rothenberg, M.E., & Varni, J.W. (2012). Quality of life in paediatric eosinophilic oesophagitis: What is important to patients? Child: Care, Health and Development, 38, 477–483.



PedsQL TM 3.0 Eosinophilic Esophagitis Module

CHILD and PARENT Reports for Children (ages 8-12) and Teens (ages 13-18)



The **Child and Parent Reports** of the **PedsQL**[™] 3.0 Eosinophilic Esophagitis Module for:

- Children (ages 8-12),
- And Teens (ages 13-18)

are composed of 33 items comprising 7 dimensions.

DESCRIPTION OF THE EOSINOPHILIC ESOPHAGITIS MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Symptoms I	6	1-6	1-6	
Symptoms II	4	1-4	1-4	
Treatment	5	1-5	1-5	_
Worry	6	1-6	1-6	Higher scores indicate lower problems.
Communication	5	1-5	1-5	
Food and Eating	4	1-4	1-4	
Food Feelings	3	1-3	1-3	

Note: Feeding Tube Scale not scored.

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0
Scoring Procedure	 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. Symptoms Total Scale Score = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales. Total Score: Sum of all the items over the number of items answered on all the Scales except Feeding Tube Scale.
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores
and Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



REFERENCES:

Franciosi, J.P., Hommel, K.A., Bendo, C.B., King, E.C., Collins, M.H., Eby, M.D., Marsolo, K., Abonia, J.P., von Tiehl, K.F., Putnam, P.E., Greenler, A.J., Greenberg, A.B., Bryson, R.A., Davis, C.M., Olive, A.P., Gupta, S.K., Erwin, E.A., Klinnert, M.D., Spergel, J.M., Denham, J.M., Furuta, G.T., Rothenberg, M.E., & Varni, J.W. (2012). PedsQL™ Eosinophilic Esophagitis Module: Feasibility, reliability and validity. Manuscript submitted for publication.

Franciosi, J.P., Hommel, K.A., Greenberg, A.B., Debrosse, C.W., Greenler, A.J., Abonia, J.P., Rothenberg, M.E., & Varni, J.W. (2012). Development of the Pediatric Quality of Life Inventory™ Eosinophilic Esophagitis Module items: Qualitative methods. Manuscript submitted for publication.

Franciosi J.P., Hommel, K.A., Debrosse, C.W., Greenberg, A.B., Greenler, A.J., Abonia, J.P., Rothenberg, M.E., & Varni, J.W. (2012). Quality of life in paediatric eosinophilic oesophagitis: What is important to patients? Child: Care, Health and Development, 38, 477–483.



PedsQL TM 3.0 End Stage Renal Disease Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (ages 2-4) of the PedsQL™ 3.0 End Stage Renal Disease Module is composed of 13 items comprising 4 dimensions.

DESCRIPTION OF THE END STAGE RENAL DISEASE MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
General Fatigue	3	1-3	1-3	
About My Kidney Disease	4	1-4	1-4	Higher scores indicate
Treatment Problems	3	1-3	1-3	lower problems.
Worry	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)		
Weighting of Items	No		
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.		
Scoring Procedure	 Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. Total Score: Sum of all the items over the number of items answered on all the Scales. 		
Interpretation and Analysis	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.		
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.		



PedsQL TM 3.0 End Stage Renal Disease Module

CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens (ages 13-18)



The Child and Parent Reports of the PedsQL™ 3.0 End Stage Renal Disease Module for:

- Young Children (ages 5-7),
- Children (ages 8-12),
- And Teens ages (13-18)

are composed of 34 items comprising 7 dimensions.

DESCRIPTION OF THE END STAGE RENAL DISEASE MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
General Fatigue	4	1-4	1-4	
About My Kidney Disease	5	1-5	1-5	
Treatment Problems	4	1-4	1-4	
Family and Peer Interaction	3	1-3	1-3	Higher scores indicate lower problems.
Worry	10	1-10	1-10	<u> </u>
Perceived Physical Appearance	3	1-3	1-3	
Communication	5	1-5	1-5	_

5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Young Children (ages 5-7) child report
No
Scores are transformed on a scale from 0 to 100.
Step 1: Transform Score
If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM **2.0** Family Impact Module

PARENT Report



The Parent report of the PedsQL[™] 2.0 Family impact Module is composed of 36 items comprising 8 dimensions.

DESCRIPTION OF THE FAMILY IMPACT MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Physical Functioning	6	1-6	1-6	_
Emotional Functioning	5	1-5	1-5	- - - Higher scores indicate better functioning.
Social Functioning	4	1-4	1-4	
Cognitive Functioning	5	1-5	1-5	
Communication	3	1-3	1-3	
Worry	5	1-5	1-5	-
Daily Activities	3	1-3	1-3	-
Family Relationships	5	1-5	1-5	-

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)		
Weighting of Items	No		
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.		
	Step 1: Transform Score		
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0		
Scoring	 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. 		
Procedure	 Step 3: Total Scores The Total Score is the sum of all 36 items divided by the number of items answered The Parent HRQL Summary Score (20 items) is computed as the sum of the items divided by the number of items answered in the Physical, Emotional, Social, and Cognitive Functioning scales. The Family Functioning Summary Score (8 items) is computed as the sum of the items divided by the number of items answered in the Daily Activities and family Relationships scales. 		



Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores
and Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items
	in a scale.



PedsQL TM 3.0 Gastrointestinal Symptoms Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (age 2-4) of the PedsQL™ 3.0 Gastrointestinal Symptoms Module is composed of 74 items comprising 14 dimensions.

DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Stomach Pain and Hurt	6	1-6	1-6	
Stomach Discomfort When Eating	5	1-5	1-5	
Food and Drink Limits	6	1-6	1-6	
Trouble Swallowing	3	1-3	1-3	
Heart Burn and Reflux	4	1-4	1-4	— Higher scores indicate — lower problems.
Nausea and Vomiting	4	1-4	1-4	
Gas and Bloating	7	1-7	1-7	
Constipation	14	1-14	1-14	
Blood in Poop	2	1-2	1-2	
Diarrhea	7	1-7	1-7	
Worry About Going Poop	5	1-5	1-5	_
Worry About Stomach Aches	2	1-2	1-2	_
Medicines	4	1-4	1-4	
Communication	5	1-5	1-5	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.
	Step 1: Transform Score
Scoring Procedure	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
	Step 2: Calculate scores by Dimensions
	 If more than 50% of the items in the scale are missing, the scale scores should not be computed,



	Mean score = Sum of the items over the number of items answered.
	<u>Symptoms Total Scales Score</u> = Sum of the items over the number of items answered in the 10 Symptoms Scales.
	<u>Total Score</u> : Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items
	in a scale.



PedsQL TM 3.0 Gastrointestinal Symptoms Module

CHILD and PARENT Reports for Young Children (ages 5-7)



The **Child and Parent Reports** of the **PedsQLTM** 3.0 Gastrointestinal Symptoms Module for Young Children (ages 5-7) are composed of 74 items comprising 14 dimensions.

DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Stomach Pain and Hurt	6	1-6	1-6	_
Stomach Discomfort When Eating	5	1-5	1-5	
Food and Drink Limits	6	1-6	1-6	
Trouble Swallowing	3	1-3	1-3	
Heart Burn and Reflux	4	1-4	1-4	— Higher scores indicate — lower problems.
Nausea and Vomiting	4	1-4	1-4	
Gas and Bloating	7	1-7	1-7	
Constipation	14	1-14	1-14	
Blood in Poop	2	1-2	1-2	
Diarrhea	7	1-7	1-7	_
Worry About Going Poop	5	1-5	1-5	
Worry About Stomach Aches	2	1-2	1-2	
Medicines	4	1-4	1-4	_
Communication	5	1-5	1-5	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0
	Step 2: Calculate Scores by Dimensions



	 If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered.
	<u>Symptoms Total Scales Score</u> = Sum of the items over the number of items answered in the 10 Symptoms Scales.
	<u>Total Score</u> : Sum of all the items over the number of items answered on all the Scales.
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores
and Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items
	in a scale.



PedsQL TM 3.0 Gastrointestinal Symptoms Module

CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18) and Young Adults (18-25)



The **Child and Parent Reports** of the **PedsQLTM** 3.0 Gastrointestinal Symptoms Module for:

- Children (ages 8-12),
- Teens (ages 13-18),
- Young Adults (ages 18-25)

are composed of 74 items comprising 14 dimensions.

DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Stomach Pain and Hurt	6	1-6	1-6	
Stomach Discomfort When Eating	5	1-5	1-5	
Food and Drink Limits	6	1-6	1-6	
Trouble Swallowing	3	1-3	1-3	
Heart Burn and Reflux	4	1-4	1-4	
Nausea and Vomiting	4	1-4	1-4	Higher scores indicate lower problems.
Gas and Bloating	7	1-7	1-7	
Constipation	14	1-14	1-14	
Blood in Poop (Bowel Movement)	2	1-2	1-2	
Diarrhea	7	1-7	1-7	<u> </u>
Worry About Going Poop (Bowel Movements)	5	1-5	1-5	
Worry About Stomach Aches	2	1-2	1-2	<u> </u>
Medicines	4	1-4	1-4	_
Communication	5	1-5	1-5	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.
Scoring Procedure	Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.



	 Step 2: Calculate scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. Symptoms Total Scales Score = Sum of the items over the number of items answered in the 10 Symptoms Scales.
	<u>Total Score</u> : Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Gastrointestinal Symptoms Scales TM

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (age 2-4) of the PedsQL™ 3.0 Gastrointestinal Symptoms Scales™ is composed of 58 items comprising 10 dimensions.

DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS SCALES™:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Stomach Pain and Hurt	6	1-6	1-6	Higher scores indicate lower problems.
Stomach Discomfort When Eating	5	1-5	1-5	
Food and Drink Limits	6	1-6	1-6	
Trouble Swallowing	3	1-3	1-3	
Heart Burn and Reflux	4	1-4	1-4	
Nausea and Vomiting	4	1-4	1-4	
Gas and Bloating	7	1-7	1-7	
Constipation	14	1-14	1-14	
Blood in Poop	2	1-2	1-2	
Diarrhea	7	1-7	1-7	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)		
Weighting of Items	No		
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.		
	Step 1: Transform Score		
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.		
Scoring	Step 2: Calculate scores by Dimensions		
Procedure	• If more than 50% of the items in the scale are missing, the scale scores should not be computed,		
	Mean score = Sum of the items over the number of items answered.		
	Symptoms Total Scales Score = Sum of the items over the number of items answered in the 10 Symptoms Scales.		
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores		
and Analysis	should not be computed.		
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.		



PedsQL TM 3.0 Gastrointestinal Symptoms ScalesTM

CHILD and PARENT Reports for Young Children (ages 5-7)



The **Child and Parent Reports** of the **PedsQL**[™] 3.0 Gastrointestinal Symptoms Scales for Young Children (ages 5-7) are composed of 58 items comprising 10 dimensions.

DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS SCALES™:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Stomach Pain and Hurt	6	1-6	1-6	Higher scores indicate lower problems.
Stomach Discomfort When Eating	5	1-5	1-5	
Food and Drink Limits	6	1-6	1-6	
Trouble Swallowing	3	1-3	1-3	
Heart Burn and Reflux	4	1-4	1-4	
Nausea and Vomiting	4	1-4	1-4	
Gas and Bloating	7	1-7	1-7	
Constipation	14	1-14	1-14	
Blood in Poop	2	1-2	1-2	
Diarrhea	7	1-7	1-7	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	Step 1: Transform Score
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores



and Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items
_	in a scale.



PedsQL TM 3.0 Gastrointestinal Symptoms Scales TM

CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18) and Young Adults (18-25)



The **Child and Parent Reports** of the **PedsQL**[™] 3.0 Gastrointestinal Symptoms Scales for:

- Children (ages 8-12),
- Teens (ages 13-18),
- Young Adults (ages 18-25)

are composed of 58 items comprising 10 dimensions.

DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS SCALES™:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Stomach Pain and Hurt	6	1-6	1-6	Higher scores indicate lower problems.
Stomach Discomfort When Eating	5	1-5	1-5	
Food and Drink Limits	6	1-6	1-6	
Trouble Swallowing	3	1-3	1-3	
Heart Burn and Reflux	4	1-4	1-4	
Nausea and Vomiting	4	1-4	1-4	
Gas and Bloating	7	1-7	1-7	
Constipation	14	1-14	1-14	
Blood in Poop (Bowel Movement)	2	1-2	1-2	
Diarrhea	7	1-7	1-7	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
Scoring	Step 2: Calculate scores by Dimensions
Procedure	If more than 50% of the items in the scale are missing, the scale scores
	should not be computed,
	Mean score = Sum of the items over the number of items answered.
	<u>Symptoms Total Scales Score</u> = Sum of the items over the number of items answered in the 10 Symptoms Scales.
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores



•	should not be computed. If 50% or more items are completed: Impute the mean of the completed items
or missing Data	in a scale.



PedsQLTM Healthcare Satisfaction Generic Module



The **PedsQL[™] Healthcare Satisfaction Generic Module** is composed of 24 items comprising 6 dimensions.

DESCRIPTION OF THE MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Information	5	1-5		
Inclusion of Family	4	1-4		
Communication	5	1-5	No	Higher scores indicate
Technical Skills	3	1-3		higher satisfaction.
Emotional Needs	4	1-4		
Overall Satisfaction	3	1-3		

Item Scaling	5-point Likert scale: 0 (Never) to 4 (Always) and Not Applicable		
Weighting of items	No		
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.		
	Step 1: Transform Score		
	Items are scored and linearly transformed to a 0-100 scale as follows: 0=0, 1=25, 2=50, 3=75, 4=100		
Scoring Procedure	 Step 2: Calculate Scores by Dimensions If 50% or more items are completed, the Mean score = Sum of the items divided by the number of items answered in the scale, If more than 50% of the items in the scale are missing, the scale scores should not be computed. 		
	Total Score : Mean score = Sum of all the items in all scales divided by the number of items answered on all the scales.		
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores		
Analysis	should not be computed.		
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in the scale.		



PedsQLTM **Healthcare Satisfaction Hematology / Oncology Module**



The PedsQL[™] Healthcare Satisfaction Hematology / Oncology Module is composed of 25 items comprising 6 dimensions.

DESCRIPTION OF THE MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
General Satisfaction	3	1-3		
Information	5	1-5		
Inclusion of Family	4	1-4	No	Higher scores indicate
Communication	5	1-5		higher satisfaction.
Technical Skills	4	1-4		
Emotional Needs	4	1-4		

Item Scaling	5-point Likert scale: 1 (Very dissatisfied) to 5 (Very satisfied)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100
Scoring Procedure	 Step 1: Transform Score Items are scored and linearly transformed to a 0-100 scale as follows: 1=0, 2=25, 3=50, 4=75, 5=100. Step 2: Calculate Scores by Dimensions If 50% or more items are completed, the Mean score = Sum of the items divided by the number of items answered in the scale, If more than 50% of the items in the scale are missing, the scale scores should not be computed. Total Score: Mean score = Sum of all the items in all scales divided by the number of items answered on all the scales.
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in the scale.



PedsQL TM Multidimensional Fatigue Scale



The PedsQL™ Multidimensional Fatigue Scale is composed of 18 items comprising 3 dimensions.

DESCRIPTION OF THE MULTIDIMENSIONAL FATIGUE MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
General Fatigue	6	1-6	1-6	
Sleep/Rest Fatigue	6	1-6	1-6	Higher scores indicate lower problems.
Cognitive Fatigue	6	1-6	1-6	_

	-		
Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)		
Weighting of Items	No		
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.		
	Step 1: Transform Score		
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.		
Scoring Procedure	Step 2: Calculate Scores by Dimensions		
Scoring Procedure	 If more than 50% of the items in the scale are missing, the scale scores should not be computed, 		
	Mean score= Sum of the items over the number of items answered.		
	<u>Total Score</u> : Sum of all the items over the number of items answered on all the Scales		
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores		
Analysis	should not be computed.		
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.		
	ILCITIS III a Scale.		



PedsQL TM 1.0 Neurofibromatosis Type 1 Module

ADULT Report (≥ 26)



The **Adult Report** of the **PedsQL[™]** 1.0 Neurofibromatosis Type 1 Module for:

- Adults (ages ≥ 26) are composed of 70 items comprising 16 dimensions.

DESCRIPTION OF THE CEREBRAL PALSY MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Physical	7	1-7	1-7	
Functioning				
Emotional	5	1-5	1-5	
Functioning				<u> </u>
Social	2	1-2	1-2	
Functioning				<u> </u>
Cognitive	5	1-5	1-5	
Functioning				<u> </u>
Communication	3	1-3	1-3	
Worry	6	1-6	1-6	
Perceived Physical Appearance	3	1-3	1-3	Higher scores indicate lower problems.
Pain and Hurt	3	1-3	1-3	
Paresthesias	2	1-2	1-2	
Skin Irritation	5	1-5	1-5	
Sensation	4	1-4	1-4	
Movement and Balance	4	1-4	1-4	
Daily Activities	12	1-12	1-12	
Feeling	3	1-3	1-3	
Treatment Anxiety	3	1-3	1-3	
Sexual Functioning	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)		
Weighting of Items	No		
Extension of the	Scores are transformed on a scale from 0 to 100.		



Scoring Scale	
Scoring Procedure	 Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores
and Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Neuromuscular Module



Child and Parent Reports of the PedsQL™ 3.0 Neuromuscular Module for:

- Children (ages 8-12),
- And Teens (ages 13-18),

are composed of 25 items comprising 3 dimensions.

- Young Child Report (ages 5-7) only consists of the 17-item About My Neuromuscular Disease Scale, Parent Report for ages 2-18 includes all 3 dimensions and all 25 items,

DESCRIPTION OF THE NEUROMUSCULAR MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
About My Neuromuscular Disease	17	1-17	1-17	_ Higher scores indicate
Communication	3	1-3	1-3	lower problems.
About Our Family Resources	5	1-5	1-5	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)		
Weighting of Items	No		
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.		
Scoring Procedure	Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered.		
	<u>Total Score</u> : Sum of all the items over the number of items answered on all the Scales.		
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores		
Analysis	should not be computed.		
of missing data	If 50% or more items are completed: Impute the mean of the completed items in a scale.		



PedsQL TM **Oral Health Scale**



The PedsQL[™] Oral Health Scale is composed of 5 items comprising 1 dimension.

DESCRIPTION OF THE ORAL HEALTH SCALE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Oral Health	5	1-5	1-5	Higher scores indicate lower problems

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
Scoring Procedure	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
	Step 2: Calculate Total Score
	Sum of all the items over the number of items answered
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Score
Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed
	items in a scale.



PedsQL TM Pediatric Pain Coping Inventory (PPCI)

PARENT Report for Children and Teens (ages 5-18)
CHILD Report for Children (ages 5-12), Teens (ages 13-18)



The Parent Report of the **PedsQL[™] Pediatric Pain Coping Inventory[™]** for Children (ages 5-12) and Teens (ages 13-18) is composed of 41 items comprising 5 dimensions.

The Child Reports of the **PedsQL[™] Pediatric Pain Coping Inventory[™]** for:

- Children (ages 5-12)
- And teens (ages 13-18)

are composed of 41 items comprising 5 dimensions.

See Varni, J.W. et al. (1996). Development of the Waldron/Varni Pediatric Pain Coping Inventory. <u>Pain</u>, <u>67</u>, 141-150, for scoring instructions for the *a priori* and *empirically-derived* scale scores.

DESCRIPTION OF THE PEDIATRIC PAIN COPING INVENTORY:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Cognitive Self- Instruction	7	12, 22, 23, 24, 31, 32, 40		
Problem-Solving	10	1, 2, 11, 15, 26, 27, 30, 33, 34, 35		Higher scores indicate
Distraction	9	6, 8, 9, 10, 14, 16, 17, 18, 19	No	greater use of the coping strategy.
Seeks Social Support	9	3, 4, 7, 13, 28, 29, 37, 38,39		
Catastrophizing / Helplessness	6	5, 20, 21, 25, 36, 41		

Item Scaling	3-point Likert scale from 0 (Never) to 2 (Often)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 2.
Scoring Procedure	Calculate Scale Scores Sum of all the items over the number of items answered for each Scale.
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM Pediatric Pain Questionnaire TM (PPQ)



The **PedsQL**[™] Pediatric Pain Questionnaire [™] is composed of 3 items.

DESCRIPTION OF THE QUESTIONNAIRE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Present Pain	1	1	NIa	Higher score = higher
Worst Pain	1	2	No	pain intensity.

The third item refers to the localisation of pain and is not scored.

Item Scaling	10cm (100mm) VAS scales from 0 (Not hurting / No discomfort / No pain) to 10 (100) (Hurting a whole lot / Very uncomfortable / Severe pain)
Weighting of Items	No
Extension of the Scoring Scale	0-10cm or 0-100mm
Scoring Procedure	Present pain and worst pain are scored separately. The score is based on line length to the nearest 0.5 cm (5mm).
Interpretation and Analysis of Missing Data	There is no imputation process since these are single item VAS scales.



PedsQL TM Present Functioning Visual Analogue Scale (PedsQL TM VAS)

CHILD and PARENT reports for CHILD (ages 5-18)



The **PedsQLTM** Present Functioning Visual Analogue Scale is composed of 6 items.

DESCRIPTION OF THE SCALE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Present	6	1-6	No	Higher score = higher
Functioning				distress or intensity.

Item Scaling	100mm VAS scales from 0 to 100
Weighting of Items	No
Extension of the Scoring Scale	0-100
Scoring Procedure	 PedsQL VAS Total Symptom Score = average of all six items PedsQL VAS Emotional Distress Summary Score = mean of the anxiety, sadness, anger, and worry items
Interpretation and Analysis of Missing Data	There is no imputation process since these are single item VAS scales.



PedsQL TM 3.0 Rheumatology Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (age 2-4) of the PedsQLTM 3.0 Rheumatology Module is composed of 14 items comprising 3 dimensions.

DESCRIPTION OF THE RHEUMATOLOGY MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	4	1-4	1-4	
Daily Activities	5	1-5	1-5	Higher scores indicate lower problems.
Treatment	5	1-5	1-5	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)		
Weighting of Items	No		
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.		
Scoring Procedure	Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. There is no Total Score		
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores		
and Analysis of Missing Data	should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.		



PedsQL TM 3.0 Rheumatology Module

CHILD and PARENT reports for Young Children (ages 5-7)



The **Child and Parent Reports** of the **PedsQL[™] 3.0** Rheumatology Module for Young Children (ages 5-7) are composed of 20 items comprising 5 dimensions.

DESCRIPTION OF THE RHEUMATOLOGY MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	4	1-4	1-4	
Daily Activities	5	1-5	1-5	_
Treatment	5	1-5	1-5	Higher scores indicate lower problems.
Worry	3	1-3	1-3	_
Communication	3	1-3	1-3	

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the child report for			
	Young Children (ages 5-7)			
Weighting of Items	No			
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.			
	Step 1: Transform Score			
	Items are reversed scored and linearly transformed to a 0-100 scale as			
	follows: 0=100, 1=75, 2=50, 3=25, 4=0.			
Scoring	Step 2: Calculate Scores by Dimensions			
Procedure	If more than 50% of the items in the scale are missing, the scale scores			
1 1 0 0 0 d d l o	should not be computed,			
	Mean score = Sum of the items over the number of items answered.			
	mean education and the terms of the manner of terms and world.			
	There is no Total Score			
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores			
and Analysis	should not be computed.			
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items			
	in a scale.			



PedsQL TM 3.0 Rheumatology Module

CHILD and PARENT reports for Children (ages 8-12) and Teens (ages 13-18)



The Child and Parent Reports of the PedsQL™ 3.0 Rheumatology Module for:

- Children (ages 8-12),And Teens (ages 13-18)

are composed of 22 items comprising 5 dimensions.

DESCRIPTION OF THE RHEUMATOLOGY MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	4	1-4	1-4	
Daily Activities	5	1-5	1-5	
Treatment	7	1-5	1-5	Higher scores indicate lower problems.
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. There is no Total Score
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores
and Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Sickle Cell Disease Module

PARENT Report for Toddlers (ages 2-4)



The Parent Report for Toddlers (age 2-4) of the PedsQL™ 3.0 Sickle Cell Disease Module is composed of 42 items comprising 9 dimensions.

DESCRIPTION OF THE SICKLE CELL DISEASE MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	9	1-9	1-9	
Pain Impact	10	1-10	1-10	_
Pain Management	2	1-2	1-2	
Worry I	5	1-5	1-5	_
Worry II	2	1-2	1-2	Higher scores indicate lower problems.
Emotions	2	1-2	1-2	
Treatment	6	1-6	1-6	_
Communication I	3	1-3	1-3	_
Communication II	3	1-3	1-3	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No No
Extension of the Scoring Scale	Scores are transformed to a 0 to 100 scale.
Scoring Procedure	 Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0. Step 2: Calculate scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed. Mean score = Sum of the items over the number of items answered. Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis of Missing Data	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed. If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Sickle Cell Disease Module

CHILD and PARENT Reports for Young Children (ages 5-7)



The Child and Parent Reports for Young Children (ages 5-7) of the PedsQLTM 3.0 Sickle Cell Disease Module are composed of 42 items comprising 9 dimensions.

DESCRIPTION OF THE SICKLE CELL DISEASE MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	9	1-9	1-9	
Pain Impact	10	1-10	1-10	_
Pain Management	2	1-2	1-2	_
Worry I	5	1-5	1-5	_
Worry II*	2	1-2	1-2	Higher scores indicate lower problems.
Emotions	2	1-2	1-2	<u> </u>
Treatment	6	1-6	1-6	_
Communication I	3	1-3	1-3	_
Communication II	3	1-3	1-3	_

^{*}Note: Worry II Scale is not included for child self-report for ages 5-7.

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	 Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed. Mean score = Sum of the items over the number of items answered. Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation and Analysis	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Sickle Cell Disease Module

CHILD and PARENT Reports for Children (ages 8-12) and Teens (ages 13-18)



The Child and Parent Reports for Children (ages 8-12) and Teens (ages 13-18) of the PedsQLTM 3.0 Sickle Cell Disease Module are composed of 43 items comprising 9 dimensions. DESCRIPTION OF THE SICKLE CELL DISEASE MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	9	1-9	1-9	
Pain Impact	10	1-10	1-10	_
Pain Management	2	1-2	1-2	_
Worry I	5	1-5	1-5	— Higher scores indicate lower problems.
Worry II	2	1-2	1-2	
Emotions	2	1-2	1-2	_
Treatment	7	1-7	1-7	<u> </u>
Communication I	3	1-3	1-3	
Communication II	3	1-3	1-3	_

Item Scaling	5-point Likert scale from 0 (Never) to 4 (Almost always)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
Scoring Procedure	 Step 1: Transform Score Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0 Step 2: Calculate Scores by Dimensions If more than 50% of the items in the scale are missing, the scale scores should not be computed. Mean score = Sum of the items over the number of items answered. Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation	If more than 50% of the items in the scale are missing, the Scale Scores
and Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.



PedsQL TM 3.0 Transplant Module



The PedsQL™ 3.0 Transplant Module is composed of 46 items comprising 8 dimensions.

DESCRIPTION OF THE TRANSPLANT MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
About My Medicines I	9	1-9	1-9	_
About My Medicines II	8	1-8	1-8	
My Transplant and Others	8	1-8	1-8	_
Pain and Hurt	3	1-3	1-3	Higher scores indicate lower problems.
Worry	7	1-7	1-7	
Treatment Anxiety	4	1-4	1-4	
How I Look	3	1-3	1-3	
Communication	4	1-4	1-4	

Item Scaling	5-point scale from 0 (Never) to 4 (Almost always) 3-point scale: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
Weighting of Items	No
Extension of the Scoring Scale	Scores are transformed on a scale from 0 to 100.
	Step 1: Transform Score
	Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.
Scoring Procedure	 Step 2: Calculate scores by Dimension If more than 50% of the items in the scale are missing, the scale scores should not be computed, Mean score = Sum of the items over the number of items answered. Total Score: Sum of all the items over the number of items answered on all the Scales.
Interpretation and	If more than 50% of the items in the scale are missing, the Scale Scores
Analysis	should not be computed.
of Missing Data	If 50% or more items are completed: Impute the mean of the completed items in a scale.