

#### **SCALING AND SCORING OF THE**

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

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## **PedsQL** TM **4.0 Generic Core Scales**

#### **PARENT Report for Toddlers (ages 2-4)**

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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	_

#### **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 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	<ul> <li>Score by Dimensions:</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul>
	<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.

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

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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	

#### **SCORING OF DIMENSIONS:**

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	Step 1: Transform 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.

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## YOUNG ADULT and PARENT Report for Young Adult (ages 18-25), ADULT and PARENT Report for Adult (ages over 26)

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The Parent, 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	

#### **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 on a scale from 0 to 100.
Scoring Procedure	Step 1: Transform 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	not be computed.  If 50% or more items are completed: Impute the mean of the completed items in a scale.

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### **PedsQL** TM 4.0 SF15 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), Young Adults (ages 18-25) and Adults (ages over 26)

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The Child and Parent Reports of the PedsQL™ 4.0 SF15 Generic Core Scales for

- Toddlers (ages 2-4),
- Young Children (ages 5-7)
- Children (ages 8-12),
- Teens (ages 13-18),
- Young Adults (ages 18-25),
- And Adults (ages over 26)

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	_

#### **SCORING OF DIMENSIONS:**

Weighting of Items  Extension of the Scoring Scale  Step 1: T  Items are 0=100, 1  Score by	re transformed on a scale from 0 to 100.  Transform Score
Extension of the Scoring Scale  Step 1: T  Items are 0=100, 1  Step 2: 0  Score by	ransform Score
the Scoring Scale  Step 1: T  Items are 0=100, 1  Step 2: 0  Score by	ransform Score
Items are 0=100, 1	
• Mea	e reversed scored and linearly transformed to a 0-100 scale as follows: =75, 2=50, 3=25, 4=0.  Calculate Scores  Dimensions:  ore than 50% of the items in the scale are missing, the scale scores ld not be computed,  n score = Sum of the items over the number of items answered.  Ocial Health Summary Score = Sum of the items over the number of swered in the Emotional, Social, and School Functioning Scales.

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	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.

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## **PedsQL** TM 3.0 Arthritis Module

#### **PARENT Report for Toddlers (ages 2-4)**

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The Parent Report for Toddlers (ages 2-4) of the PedsQL <sup>™</sup> 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	

#### **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 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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed</li> <li>Mean score = Sum of the items over the number of items answered</li> </ul>
	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.
	items in a soale.

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

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The Child and Parent Reports of the PedsQL <sup>™</sup> 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	_

#### **SCORING OF DIMENSIONS:**

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.
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.
	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> 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.

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

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

- Children (ages 8-12),
- And Teens (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	
Communication	3	1-3	1-3	

#### **SCORING OF DIMENSIONS:**

Item Scaling	5-point Likert scale from 0 (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 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.		

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## **PedsQL** TM 3.0 Asthma Module

#### **PARENT Report for Toddlers (ages 2-4)**

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The Parent Report for Toddlers (ages 2-4) of the PedsQL <sup>™</sup> 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	

#### **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 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
	• If more than 50% of the items in the scale are missing, the scale scores should not be computed,
	<ul> <li>Mean score = Sum of the items over the number of items answered.</li> </ul>
	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.

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

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The Child and Parent Reports of the PedsQL <sup>™</sup> 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	

#### **SCORING OF DIMENSIONS:**

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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul>
	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.

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## PedsQL <sup>TM</sup> 3.0 SF22 Asthma Module

#### **PARENT Report for Toddlers (ages 2-4)**

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The Parent Report for Toddlers (ages 2-4) of the PedsQL <sup>TM</sup> 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.

#### **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 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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul>
	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.

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

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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.

#### **SCORING OF DIMENSIONS:**

	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 R
	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.

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## **PedsQL** TM Brain Tumor Module

#### **PARENT Report for Toddlers (ages 2-4)**

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The Parent Report for Toddlers (ages 2-4) of the PedsQL™ 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	<u> </u>

#### **SCORING OF DIMENSIONS:**

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	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.</li> <li>Step 2: Calculate Scores by Dimensions         <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>There is no Total Score</li> </ul>
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.

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

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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	_

#### **SCORING OF DIMENSIONS:**

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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> 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.

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

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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	_

#### **SCORING OF DIMENSIONS:**

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	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.</li> <li>Step 2: Calculate Scores by Dimensions         <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>There is no Total Score</li> </ul>
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.

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## **PedsQL** TM 3.0 Cancer Module

#### **PARENT Report for Toddlers (ages 2-4)**

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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	<ul> <li>Higher scores indicate lower problems.</li> </ul>
Cognitive Problems	3	1-3	1-3	
Perceived Physical Appearance	3	1-3	1-3	
Communication	3	1-3	1-3	

#### **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.
Scoring Procedure	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.</li> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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

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The **Child and Parent Reports** of the **PedsQL<sup>TM</sup> 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	<ul><li>Higher scores indicate lower problems.</li></ul>
Worry	3	1-3	1-3	
Cognitive Problems	4	1-4	1-4	
Perceived Physical Appearance	3	1-3	1-3	
Communication	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18), Young Adults (ages 18-25), and ADULT Report (ages over 26)

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

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

and the Adult Report (ages over 26)

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	<ul> <li>Higher scores indicate lower problems.</li> </ul>
Cognitive Problems	5	1-5	1-5	_
Perceived Physical Appearance	3	1-3	1-3	_
Communication	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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# **PedsQL** TM 3.0 Cardiac Module

### **PARENT Report for Toddlers (ages 2-4)**

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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 lower problems.
Treatment Anxiety	4	1-4	1-4	— lower problems.
Cognitive Problems	3	1-3	1-3	
Communication	3	1-3	1-3	

### **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.
Scoring Procedure	<ul> <li>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.     </li> <li>Step 2: Calculate scores by Dimensions         <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>There is no Total Score.</li> </ul>
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.

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

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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	_

### **SCORING OF DIMENSIONS:**

E point Likert and from 0 (Never) to 4 (Almost alveys)			
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)			
N			
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			
10110W5. 0=100, 1=73, 2=30, 3=23, 4=0			
Ston 2: Calculate Secree by Dimensions			
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,			
<ul> <li>Mean score = Sum of the items over the number of items answered.</li> </ul>			
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.			

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CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18), Young Adults (ages 18-25), and Adults (ages over 26)

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

- Children (ages 8-12),
- Teens (ages 13-18),
- Young Adults (ages 18-25),
- Adults (ages over 26)

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	<ul><li>lower problems.</li></ul>
Cognitive Problems	5	1-5	1-5	
Communication	3	1-3	1-3	

### **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 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.

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# **PedsQL** TM 3.0 Cerebral Palsy Module

### **PARENT Report for Toddlers (ages 2-4)**

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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	

### **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.
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.

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

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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	
Eating Activities	5	1-5	1-5	_
Speech and Communication	4	1-4	1-4	

#### **SCORING OF DIMENSIONS:**

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.     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.

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# **PedsQL** TM Cognitive Functioning Scale

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The **PedsQL<sup>TM</sup> 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

### **SCORING OF DIMENSIONS:**

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.

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# **PedsQL** TM 3.0 Diabetes Module

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The **PedsQL<sup>TM</sup>** 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	

### **SCORING OF DIMENSIONS:**

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) 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	<ul> <li>Step 2: Calculate scores by Dimension</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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# **PedsQL** TM **3.2 Diabetes Module**

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The **PedsQL<sup>™</sup>** 3.2 Diabetes Module is composed of 33 items comprising 5 dimensions for ages 8-45 years. For ages 2-7 years, the **PedsQL<sup>™</sup>** 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 Symptoms	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	3	1-3	1-3	
·	(2 ages 2-7)	(or 1-2)	(or 1-2)	
Communication	4	1-4	1-4	_

#### **SCORING OF DIMENSIONS:**

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.		
Scoring Procedure	Step 1: Transform 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.		

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# PedsQL TM 3.0 Duchenne Muscular Dystrophy Module

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## PARENT Report for Young Children (ages 5-7)

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The **Parent Report** of the **PedsQL<sup>™</sup> 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	— Higher scores indicate
Worry	6	1-6	1-6	lower problems.
Communication	3	1-3	1-3	_

### **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 on a scale from 0 to 100.
Scoring Procedure	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</li> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>No Total Score</li> </ul>
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.

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

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The Child and Parent Reports of the PedsQL<sup>TM</sup> 3.0 Duchenne Muscular Dystrophy Module for:

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

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	— Higher scores indicate
Worry	6	1-6	1-6	lower problems.
Communication	3	1-3	1-3	

### **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 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.     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.

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# PedsQL <sup>TM</sup> 3.0 End Stage Renal Disease Module

### **PARENT Report for Toddlers (ages 2-4)**

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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	

### **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.
Scoring Procedure	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.</li> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>Total Score: Sum of all the items over the number of items answered on all</li> </ul>
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.

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CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens (ages 13-18), and Young Adults (ages 18-25)

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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),
- Young Adults (ages 18-25)

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	<del></del>

#### **SCORING OF DIMENSIONS:**

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 Children (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	Step 1: Transform 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.

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# PedsQL TM 3.0 Eosinophilic Esophagitis Module

### **PARENT Report for Toddlers (ages 2-4)**

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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	— — Higher scores indicate lower problems.
Treatment	4	1-4	1-4	
Worry	4	1-4	1-4	
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	<ul> <li>Step 2: Calculate scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul>
	<u>Symptoms Total Scale Score</u> = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales.
	<u>Total Score</u> : 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,

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

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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	_
Worry	4	1-4	1-4	Higher scores indicate lower problems.
Communication	4	1-4	1-4	_
Food and Eating	4	1-4	1-4	_
Food Feelings	3	1-3	1-3	_

<sup>\*</sup>Symptoms II Scale not scored for child self-report ages 5-7 years.

Note: Feeding Tube Scale not scored.

### **SCORING OF DIMENSIONS:**

	T
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	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</li> <li>Step 2: Calculate Scores by Dimensions <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>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.</li> </ul>
	Total Score: 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.

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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.

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

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The Child and Parent Reports of the PedsQL<sup>TM</sup> 3.0 Eosinophilic Esophagitis Module for:

- Children (ages 8-12),And Teens (ages 13-1 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	<u> </u>
Food and Eating	4	1-4	1-4	_
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 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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>Symptoms Total Scale Score = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales.</li> <li>Total Score: Sum of all the items over the number of items answered on all</li> </ul>
Internated as	the Scales except Feeding Tube Scale.
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.

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# PedsQL TM Eosinophilic Esophagitis Symptoms Scales

**PARENT Report for Toddlers (ages 2-4)** 

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The Parent Report for Toddlers (age 2-4) of the PedsQL™ Eosinophilic Esophagitis Symptoms Scales is composed of 7 items comprising 2 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	Higher scores indicate
Symptoms II	4	1-4	1-4	lower problems.

#### **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.
Scoring Procedure	<ul> <li>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.     </li> <li>Step 2: Calculate scores by Dimensions         <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Symptoms Total Scale Score = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales.</li> </ul>
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.

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## **PARENT Reports for Young Children (ages 5-7)**

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The Parent Reports of the PedsQL™ Eosinophilic Esophagitis Symptoms Scales for Young Children (ages 5-7) are composed of 7 items comprising 2 dimensions. Please note that there is no child self-report for ages 5-7.

#### **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	Higher scores indicate
Symptoms II	4	1-4	1-4	lower problems.

#### **SCORING OF DIMENSIONS:**

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	<ul> <li>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     </li> <li>Step 2: Calculate Scores by Dimensions         <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Symptoms Total Scale Score = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales.</li> </ul>
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.

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

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The Child and Parent Reports of the PedsQL<sup>TM</sup> Eosinophilic Esophagitis Symptoms Scales for:

- Children (ages 8-12),And Teens (ages 13-1 And Teens (ages 13-18)

are composed of 10 items comprising 2 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	Higher scores indicate
Symptoms II	4	1-4	1-4	lower problems.

#### **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 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	If more than 50% of the items in the scale are missing, the scale		
Procedure	scores should not be computed,		
	Mean score = Sum of the items over the number of items answered.		
	<u>Symptoms Total Scale Score</u> = Sum of the items over the number of items		
	answered in the Symptoms I and Symptoms II 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.		

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## **PedsQL** TM 3.0 Epilepsy Module

## **PARENT Report for Toddlers (ages 2-4)**

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

#### **DESCRIPTION OF THE EPILEPSY MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Impact	6	1-6	1-6	
Cognitive Functioning	5	1-5	1-5	_
Sleep/Rest	2	1-2	1-2	Higher scores indicate lower problems.
Executive Functioning	4	1-4	1-4	
Mood/Behavior	5	1-5	1-5	

#### **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.
Scoring Procedure	Step 1: Transform 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.

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## **CHILD Reports for Young Children (ages 5-7)**

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The **Child Reports** of the **PedsQL**<sup>™</sup> 3.0 Epilepsy Module for:
- Young Children (ages 5-7)
are composed of 28 items comprising 5 dimensions.

#### **DESCRIPTION OF THE EPILEPSY MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Impact	8	1-8	1-8	
Cognitive Functioning	6	1-6	1-6	
Sleep/Rest	3	1-3	1-3	Higher scores indicate lower problems.
Executive Functioning	6	1-6	1-6	
Mood/Behavior	5	1-5	1-5	

#### **SCORING OF DIMENSIONS:**

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.
Scoring Procedure	Step 1: Transform Score     Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 2=50, 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.

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## **PARENT Reports for Young Children (ages 5-7)**

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The Parent Reports of the PedsQL™ 3.0 Epilepsy Module for:

Young Children (ages 5-7)
 are composed of 29 items comprising 5 dimensions.

#### **DESCRIPTION OF THE EPILEPSY MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Impact	9	1-9	1-9	
Cognitive Functioning	6	1-6	1-6	
Sleep/Rest	3	1-3	1-3	Higher scores indicate lower problems.
Executive Functioning	6	1-6	1-6	
Mood/Behavior	5	1-5	1-5	

#### **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 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.		

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

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The **Child and Parent Reports** of the **PedsQL™**3.0 Epilepsy Module for:
- Children (ages 8-12),

- Teens (ages 13-10) Young Adults (18-25)

are composed of 29 items comprising 5 dimensions.

#### **DESCRIPTION OF THE EPILEPSY MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Impact	9	1-9	1-9	
Cognitive Functioning	6	1-6	1-6	
Sleep/Rest	3	1-3	1-3	Higher scores indicate lower problems.
Executive Functioning	6	1-6	1-6	
Mood/Behavior	5	1-5	1-5	

#### **SCORING OF DIMENSIONS:**

	T
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.

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## **PedsQL TM 2.0 Family Impact Module**

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## **PARENT Report**

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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	_
Social Functioning	4	1-4	1-4	
Cognitive Functioning	5	1-5	1-5	- Higher scores indicate better
Communication	3	1-3	1-3	functioning.
Worry	5	1-5	1-5	-
Daily Activities	3	1-3	1-3	-
Family Relationships	5	1-5	1-5	-

#### **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.			
Scoring Procedure	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</li> <li>Step 2: Calculate Scores by Dimensions         <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Step 3: Total Scores         <ul> <li>The Total Score is the sum of all 36 items divided by the number of items answered</li> <li>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.</li> <li>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.</li> </ul> </li> </ul>			

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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.

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## PedsQL <sup>TM</sup> 3.0 Gastrointestinal Symptoms Module

## **PARENT Report for Toddlers (ages 2-4)**

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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	_
Nausea and Vomiting	4	1-4	1-4	_
Gas and Bloating	7	1-7	1-7	Higher scores indicate lower problems.
Constipation	14	1-14	1-14	— lower problems.
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	_

#### **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
Scoring Procedure	follows: 0=100, 1=75, 2=50, 3=25, 4=0.  Step 2: Calculate scores by Dimensions
	<ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul>

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	Symptoms Total Scales Score = Sum of the items over the number of items answered in the 10 Symptoms Scales.  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.

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

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The **Child and Parent Reports** of the **PedsQL<sup>TM</sup>** 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	
Nausea and Vomiting	4	1-4	1-4	
Gas and Bloating	7	1-7	1-7	Higher scores indicate
Constipation	14	1-14	1-14	<ul><li>lower problems.</li></ul>
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	

#### **SCORING OF DIMENSIONS:**

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 Scores by Dimensions				
	If more than 50% of the items in the scale are missing, the scale scores				

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	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	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.

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

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The **Child and Parent Reports** of the **PedsQL™** 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	
Gas and Bloating	7	1-7	1-7	
Constipation	14	1-14	1-14	<ul> <li>Higher scores indicate lower problems.</li> </ul>
Blood in Poop (Bowel Movement)	2	1-2	1-2	
Diarrhea	7	1-7	1-7	
Worry About Going Poop (Bowel Movements)	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	

#### **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.
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.

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	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 Dat	

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## PedsQL TM 3.0 Gastrointestinal Symptoms ScalesTM

## **PARENT Report for Toddlers (ages 2-4)**

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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	
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	Higher scores indicate Iower problems.
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	

#### **SCORING OF DIMENSIONS:**

	<del>-</del>
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
Interpretation	answered in the 10 Symptoms 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.

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

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The **Child and Parent Reports** of the **PedsQL<sup>™</sup>** 3.0 Gastrointestinal Symptoms Scales <sup>™</sup> 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	_
Stomach Discomfort When Eating	5	1-5	1-5	Higher scores indicate lower problems.
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	_

#### **SCORING OF DIMENSIONS:**

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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>Symptoms Total Scales Score = Sum of the items over the number of items answered in the 10 Symptoms Scales.</li> </ul>				
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.				

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

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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	

#### **SCORING OF DIMENSIONS:**

COMING OF DIVIDIN	0101101
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.
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.

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## **PedsQL** TM General Well-Being Scale

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

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The **PedsQL<sup>TM</sup>** 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.

#### **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 on a scale from 0 to 100.
Scoring Procedure	<ul> <li>Step 1: Transform Score</li> <li>Items are linearly transformed to a 0-100 scale as follows: 0=0, 1=25, 2=50, 3=75, 4=100.</li> <li>Step 2: Calculate Scores</li> <li>Score by Dimensions: <ul> <li>If more than 50% of the items in the scale are missing, the scale score should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>The General Health item is not included in the scale score, but is reported separately.</li> </ul> </li> </ul>
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.

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# **PedsQL**<sup>TM</sup> **Healthcare Satisfaction Generic Module**

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The **PedsQL<sup>TM</sup>** 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		

#### **SCORING OF DIMENSIONS:**

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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If 50% or more items are completed, the Mean score = Sum of the items divided by the number of items answered in the scale,</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> </ul>		
	<u>Total Score</u> : 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 of Missing Data	should not be computed.  If 50% or more items are completed: Impute the mean of the completed items in the scale.		

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# **PedsQL<sup>TM</sup> Healthcare Satisfaction Hematology / Oncology Module**

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The **PedsQL<sup>TM</sup>** 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		l limb on account in disease
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		

## **SCORING OF DIMENSIONS:**

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
	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.
Scoring Procedure	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If 50% or more items are completed, the Mean score = Sum of the items divided by the number of items answered in the scale,</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> </ul>
	<u>Total Score</u> : 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.

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# **PedsQL** TM Infant Scales

**PARENT Report for Infants (ages 1-24 months)** 

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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	_

## **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 on a scale from 0 to 100.

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	Ston 1: Transform Score
	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	<ul> <li>Score by Dimensions:</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul>
	<u>Psychosocial Health Summary Score</u> = 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.
	<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.

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# **PedsQL** TM Multidimensional Fatigue Scale

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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	

## **SCORING OF DIMENSIONS:**

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
oooning i roocaare	• 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.

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## **PedsQL** TM 3.0 Neurofibromatosis Module

CHILD and PARENT Reports for Young Children (ages 5-7), Children (ages 8-12), Teens (ages 13-18), Young Adults (ages 18-25), and Adults (ages over 26)

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

- Young Children (ages 5-7)
- Children (ages 8-12),
- Teens (ages 13-18),
- Young Adults (ages 18-25),
- Adults (ages over 26)

are composed of 104 items comprising 18 dimensions.

#### **DESCRIPTION OF THE NEUROFIBROMATOSIS MODULE:**

	Number of	Cluster of	Reversed	Direction of Dimensions
Dimensions	Items	Items	Scoring	Direction of Dimensions
Skin Itch Bother	6	1-6	1-6	
Skin Sensations	3	1-3	1-3	
Pain	6	1-6	1-6	
Pain Impact	16	1-16	1-16	<u> </u>
Pain Management	2	1-2	1-2	<del>_</del>
Cognitive Functioning	15	1-15	1-15	<del>_</del>
Speech	4	1-4	1-4	<del>_</del>
Fine Motor	6	1-6	1-6	<del>_</del>
Balance	5	1-5	1-5	
Vision	5	1-5	1-5	<ul><li>Higher scores indicate lower problems.</li></ul>
Perceived Physical Appearance	3	1-3	1-3	
Communication	6	1-6	1-6	<u> </u>
Worry	10	1-10	1-10	<del>_</del>
Treatment	6	1-6	1-6	<del>_</del>
Medicines	3	1-3	1-3	_
Stomach Discomfort	3	1-3	1-3	_
Constipaton	3	1-3	1-3	_
Diarrhea	2	1-2	1-2	<u> </u>

## **SCORING OF DIMENSIONS:**

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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	<ul> <li>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. </li> <li>Step 2: Calculate Scores by Dimensions <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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# **PedsQL** TM 3.0 Neuromuscular Module

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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	_

## **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 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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul>
	<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.

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# **PedsQL** TM **Oral Health Scale**

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The **PedsQL<sup>TM</sup>** 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

## **SCORING OF DIMENSIONS:**

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.

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# 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)

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

The Child Reports of the **PedsQL<sup>™</sup> Pediatric Pain Coping Inventory<sup>™</sup>** 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		

#### **SCORING OF DIMENSIONS:**

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

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# PedsQL TM Pediatric Pain Questionnaire TM (PPQ)

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The **PedsQL<sup>™</sup> Pediatric Pain Questionnaire<sup>™</sup> 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	NI-	Higher score = higher
Worst Pain	1	2	No	pain intensity.

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

## **SCORING OF DIMENSIONS:**

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.

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

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

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The **PedsQL<sup>TM</sup>** 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 Functioning	6	1-6	No	Higher score = higher distress or intensity.

## **SCORING OF DIMENSIONS:**

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

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## **PedsQL** TM 3.0 Rheumatology Module

## **PARENT Report for Toddlers (ages 2-4)**

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The Parent Report for Toddlers (age 2-4) of the PedsQL™ 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	

## **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.
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.

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

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The **Child and Parent Reports** of the **PedsQL<sup>TM</sup> 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	<u> </u>
Communication	3	1-3	1-3	

## **SCORING OF DIMENSIONS:**

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.     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.

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

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The Child and Parent Reports of the PedsQL<sup>TM</sup> 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	

## **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 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.

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## **PedsQL** TM 3.0 Sickle Cell Disease Module

## **PARENT Report for Toddlers (ages 2-4)**

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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	<del>_</del>
Worry I	5	1-5	1-5	<u> </u>
Worry II	2	1-2	1-2	Higher scores indicate lower problems.
Emotions	2	1-2	1-2	
Treatment	6	1-6	1-6	<del>_</del>
Communication I	3	1-3	1-3	<u> </u>
Communication II	3	1-3	1-3	<del>_</del>

## **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.
Scoring Procedure	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.</li> <li>Step 2: Calculate scores by Dimensions         <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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

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The Child and Parent Reports for Young Children (ages 5-7) of the PedsQL™ 3.0 Sickle Cell Disease Module are composed of 40 items for the child report and 42 items for the parent report, 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	<del>_</del>
Worry I	5	1-5	1-5	<u> </u>
Worry II*	2	1-2	1-2	Higher scores indicate lower problems.
Emotions	2	1-2	1-2	
Treatment	6	1-6	1-6	<del>_</del>
Communication I	3	1-3	1-3	<u> </u>
Communication II	3	1-3	1-3	<del>_</del>

<sup>\*</sup>Note: Worry II Scale is not included for child self-report for ages 5-7.

## **SCORING OF DIMENSIONS:**

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
<b>3</b>	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	<ul> <li>Step 2: Calculate Scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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CHILD and PARENT Reports for Children (ages 8-12), Teens (ages 13-18), Young Adults (ages 18-25), and Adults (ages over 26)

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The **Child and Parent Reports** of the **PedsQL™** 3.0 Sickle Cell Disease Module for:

- Children (ages 8-12)
- Teens (ages 13-18)
- Young Adults (ages 18-25)
- And Adults (ages over 26)

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	
Worry II	2	1-2	1-2	Higher scores indicate lower problems.
Emotions	2	1-2	1-2	<u> </u>
Treatment	7	1-7	1-7	_
Communication I	3	1-3	1-3	_
Communication II	3	1-3	1-3	_

#### **SCORING OF DIMENSIONS:**

	<del>,</del>
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	<ul> <li>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     </li> <li>Step 2: Calculate Scores by Dimensions         <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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# **PedsQL** TM **1.0 Stem Cell Transplant Module**

## **PARENT Report for Toddlers (ages 2-4)**

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The Parent Report for Toddlers (age 2-4) of the PedsQL™ 1.0 Stem Cell Transplant Module is composed of 31 items comprising 8 dimensions.

## **DESCRIPTION OF THE STEM CELL TRANSPLANT MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Fatigue and Sleep	5	1-5	1-5	_
Nausea	4	1-4	1-4	
Worry	2	1-2	1-2	— Higher scores indicate
Nutrition	5	1-5	1-5	lower problems.
Thinking	4	1-4	1-4	<del></del>
Communication	3	1-3	1-3	_
Other Complaints	6	1-6	1-6	<u> </u>

## **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	<ul> <li>Step 2: Calculate scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> <li>Total Score: Sum of all the items over the number of items answered on all</li> </ul>
lata manatatia m	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.
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## PARENT Report for Young Children (ages 5-7)

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The Parent Report for Young Children (ages 5-7) of the PedsQL™ 1.0 Stem Cell Transplant Module is composed of 39 items comprising 8 dimensions.

## **DESCRIPTION OF THE STEM CELL TRANSPLANT MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Fatigue and Sleep	5	1-5	1-5	
Nausea	4	1-4	1-4	
Worry	10	1-10	1-10	— Higher scores indicate
Nutrition	5	1-5	1-5	lower problems.
Thinking	4	1-4	1-4	<u> </u>
Communication	3	1-3	1-3	<u> </u>
Other Complaints	6	1-6	1-6	_

## **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 on a scale from 0 to 100.
Scoring Procedure	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</li> <li>Step 2: Calculate Scores by Dimensions <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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## **CHILD and PARENT Reports for Children (ages 8-12)**

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The Child and Parent Reports for Children (ages 8-12) of the PedsQL™ 1.0 Stem Cell Transplant Module are composed of 39 items comprising 8 dimensions.

DESCRIPTION OF THE STEM CELL TRANSPLANT MODULE:

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Fatigue and Sleep	5	1-5	1-5	_
Nausea	4	1-4	1-4	
Worry	10	1-10	1-10	Higher scores indicate lower problems.
Nutrition	5	1-5	1-5	
Thinking	4	1-4	1-4	
Communication	3	1-3	1-3	
Other Complaints	6	1-6	1-6	_

#### **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 on a scale from 0 to 100.
Scoring Procedure	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</li> <li>Step 2: Calculate Scores by Dimensions <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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## **TEEN and PARENT Reports for Teens (ages 13-18)**

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The Teen and Parent Reports for Teens (ages 13-18) of the PedsQL™ 1.0 Stem Cell Transplant Module are composed of 41 items comprising 8 dimensions.

#### **DESCRIPTION OF THE STEM CELL TRANSPLANT MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Fatigue and Sleep	5	1-5	1-5	_
Nausea	4	1-4	1-4	_
Worry	12	1-12	1-12	— Higher scores indicate
Nutrition	5	1-5	1-5	lower problems.
Thinking	4	1-4	1-4	_
Communication	3	1-3	1-3	_
Other Complaints	6	1-6	1-6	

#### **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 on a scale from 0 to 100.
Scoring Procedure	<ul> <li>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     </li> <li>Step 2: Calculate Scores by Dimensions         <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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# **PedsQL** TM **1.0 Stem Cell Transplant Module Acute Version**

### **PARENT Report for Toddlers (ages 2-4)**

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The Parent Report for Toddlers (age 2-4) of the PedsQL™ 1.0 Stem Cell Transplant Module Acute Version is composed of 31 items comprising 8 dimensions.

#### **DESCRIPTION OF THE STEM CELL TRANSPLANT MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Fatigue and Sleep	5	1-5	1-5	
Nausea	4	1-4	1-4	
Worry	2	1-2	1-2	Higher scores indicate lower problems.
Nutrition	5	1-5	1-5	
Thinking	4	1-4	1-4	
Communication	3	1-3	1-3	
Other Complaints	6	1-6	1-6	_

#### **SCORING OF DIMENSIONS:**

	I
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	<ul> <li>Step 2: Calculate scores by Dimensions</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> Total Score: Sum of all the items over the number of items answered on all
lata manatatia m	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.

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## **PARENT Report for Young Children (ages 5-7)**

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The Parent Report for Young Children (ages 5-7) of the PedsQL<sup>TM</sup> 1.0 Stem Cell Transplant Module Acute Version is composed of 39 items comprising 8 dimensions.

#### **DESCRIPTION OF THE STEM CELL TRANSPLANT MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Fatigue and Sleep	5	1-5	1-5	
Nausea	4	1-4	1-4	
Worry	10	1-10	1-10	— Higher scores indicate
Nutrition	5	1-5	1-5	lower problems.
Thinking	4	1-4	1-4	_
Communication	3	1-3	1-3	_
Other Complaints	6	1-6	1-6	

#### **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 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.				
	<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.				

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## **CHILD and PARENT Reports for Children (ages 8-12)**

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The Child and Parent Reports for Children (ages 8-12) of the PedsQL™ 1.0 Stem Cell Transplant Module Acute Version are composed of 39 items comprising 8 dimensions.

#### **DESCRIPTION OF THE STEM CELL TRANSPLANT MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Fatigue and Sleep	5	1-5	1-5	
Nausea	4	1-4	1-4	
Worry	10	1-10	1-10	Higher scores indicate lower problems.
Nutrition	5	1-5	1-5	
Thinking	4	1-4	1-4	
Communication	3	1-3	1-3	
Other Complaints	6	1-6	1-6	<u> </u>

#### **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 on a scale from 0 to 100.
Scoring Procedure	<ul> <li>Step 1: Transform Score</li> <li>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</li> <li>Step 2: Calculate Scores by Dimensions <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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## **TEEN and PARENT Reports for Teens (ages 13-18)**

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The **Teen and Parent Reports for Teens (ages 13-18)** of the **PedsQL<sup>TM</sup>** 1.0 Stem Cell Transplant Module Acute Version are composed of 41 items comprising 8 dimensions.

#### **DESCRIPTION OF THE STEM CELL TRANSPLANT MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	
Fatigue and Sleep	5	1-5	1-5	
Nausea	4	1-4	1-4	
Worry	12	1-12	1-12	Higher scores indicate lower problems.
Nutrition	5	1-5	1-5	
Thinking	4	1-4	1-4	
Communication	3	1-3	1-3	
Other Complaints	6	1-6	1-6	<u> </u>

#### **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 on a scale from 0 to 100.
Scoring Procedure	<ul> <li>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     </li> <li>Step 2: Calculate Scores by Dimensions         <ul> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed.</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> </li> <li>Total Score: Sum of all the items over the number of items answered on all the Scales.</li> </ul>
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.

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## **PedsQL** TM 3.0 Transplant Module

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The PedsQLTM 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	_

#### **SCORING OF DIMENSIONS:**

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	<ul> <li>Step 2: Calculate scores by Dimension</li> <li>If more than 50% of the items in the scale are missing, the scale scores should not be computed,</li> <li>Mean score = Sum of the items over the number of items answered.</li> </ul> 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.		

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