

**SCALING AND SCORING for the Acute and  
Standard versions OF THE**

**Pediatric Quality of Life Inventory<sup>TM</sup>**

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

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# **PedsQL™ 4.0 Generic Core Scales**

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

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

### **DESCRIPTION OF THE QUESTIONNAIRE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Physical Functioning	8	1-8	1-8	Higher scores = Better HRQOL
Emotional Functioning	5	1-5	1-5	
Social Functioning	5	1-5	1-5	
School Functioning	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions:</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Psychosocial Health Summary Score</u></b> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales</p> <p><b><u>Physical Health Summary Score</u></b> = Physical Functioning Scale Score</p> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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**CHILD and PARENT Reports for Young Children (ages 5-7),  
Children (ages 8-12), and 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)
- 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	Higher scores = Better HRQOL
Emotional Functioning	5	1-5	1-5	
Social Functioning	5	1-5	1-5	
School Functioning	5	1-5	1-5	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Young Child (ages 5-7) child report
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores</u></b></p> <p><b><u>Score by Dimensions:</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Psychosocial Health Summary Score</u></b> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales</p> <p><b><u>Physical Health Summary Score</u></b> = Physical Functioning Scale Score</p> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in</p>

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of Missing Data	a scale.
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**YOUNG ADULT, ADULT, and PARENT Reports for Young  
Adults (ages 18-25) and Adults (ages over 26)**

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The **Young Adult, Adult, and Parent** Reports of the **PedsQL<sup>TM</sup> 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	Higher scores = Better HRQOL
Emotional Functioning	5	1-5	1-5	
Social Functioning	5	1-5	1-5	
School Functioning	5	1-5	1-5	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions:</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Psychosocial Health Summary Score</u></b> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales</p> <p><b><u>Physical Health Summary Score</u></b> = Physical Functioning Scale Score</p> <p><b><u>Total Score</u></b>: Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL<sup>™</sup> 4.0 SF15 Generic Core Scales**

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

The **Parent** Report for Toddlers (ages 2-4) of the **PedsQLTM 4.0 SF15 Generic Core Scales** are composed of 15 items comprising 4 dimensions.

#### **DESCRIPTION OF THE SF15 QUESTIONNAIRE:**

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

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions:</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Psychosocial Health Summary Score</u></b> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales</p> <p><b><u>Physical Health Summary Score</u></b> = Physical Functioning Scale Score</p> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

**CHILD, YOUNG ADULT, ADULT, 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),**

The **Child, Young Adult, Adult, and Parent** Reports of the **PedsQL<sup>TM</sup> 4.0 SF15 Generic Core Scales** 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 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	Higher scores = Better HRQOL
Emotional Functioning	4	1-4	1-4	
Social Functioning	3	1-3	1-3	
School Functioning	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes), and 4 (A lot) for the Young Child self-report
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions:</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Psychosocial Health Summary Score</u></b> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales</p> <p><b><u>Physical Health Summary Score</u></b> = Physical Functioning Scale Score</p> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the</p>



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

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# **PedsQL<sup>™</sup> 3.0 Arthritis Module**

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

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

#### **DESCRIPTION OF THE ARTHRITIS MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	4	1-4	1-4	Higher scores = Better HRQOL and fewer problems or symptoms
Daily Activities	5	1-5	1-5	
Treatment	5	1-5	1-5	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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<sup>TM</sup> 3.0 Arthritis Module** 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	Higher scores = Better HRQOL and fewer problems or symptoms
Daily Activities	5	1-5	1-5	
Treatment	5	1-5	1-5	
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) for the parent report 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the child report
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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 Arthritis Module** for:

- Children (ages 8-12)
- 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	Higher scores = Better HRQOL and fewer problems or symptoms
Daily Activities	5	1-5	1-5	
Treatment	7	1-7	1-7	
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of missing data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

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



The **Parent** Report for Toddlers (ages 2-4) of the **PedsQL<sup>TM</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	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment	9	1-9	1-9	
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100.
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

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

- Young Children (ages 5-7)
- Children (ages 8-12)
- 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	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment	11	1-11	1-11	
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the child report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

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

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

#### **DESCRIPTION OF THE SF22 ASTHMA MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Asthma	11	1-11	1-11	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment	9	1-9	1-9	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

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

- Young Children (ages 5-7)
- Children (ages 8-12)
- 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 = Better HRQOL and fewer problems or symptoms
Treatment	11	1-11	1-11	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child R Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL<sup>™</sup> 1.0 Brain Tumor Module**

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



The **Parent** Report for Toddlers (ages 2-4) of the **PedsQL<sup>TM</sup> 1.0 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	Higher scores = Better HRQOL and fewer problems or symptoms
Movement and Balance	3	1-3	1-3	
Procedural Anxiety	3	1-3	1-3	
Nausea	5	1-5	1-5	
Worry	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never a problem) to 4 (Almost always a problem)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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™ 1.0 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	Higher scores = Better HRQOL and fewer problems or symptoms
Pain and Hurt	3	1-3	1-3	
Movement and Balance	3	1-3	1-3	
Procedural Anxiety	3	1-3	1-3	
Nausea	5	1-5	1-5	
Worry	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

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The **Child, Young Adult, and Parent** Reports for Children (ages 8-12) and Teens (ages 13-18), Young Adult (ages 18-25) of the **PedsQL™ 1.0 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	Higher scores = Better HRQOL
Pain and Hurt	3	1-3	1-3	
Movement and Balance	3	1-3	1-3	
Procedural Anxiety	3	1-3	1-3	
Nausea	5	1-5	1-5	
Worry	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never a problem) to 4 (Almost always a problem)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# PedsQL<sup>™</sup> 3.0 Cancer Module

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

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

### **DESCRIPTION OF THE CANCER MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	2	1-2	1-2	Higher scores = Better HRQOL and fewer problems or symptoms
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	
Cognitive Problems	3	1-3	1-3	
Perceived Physical Appearance	3	1-3	1-3	
Communication	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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 Cancer Module** 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	Higher scores = Better HRQOL and fewer problems or symptoms
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	
Cognitive Problems	4	1-4	1-4	
Perceived Physical Appearance	3	1-3	1-3	
Communication	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

The **Child, Young Adult, Adult, and Parent** Reports of the **PedsQL™ 3.0 Cancer 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 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	Higher scores = Better HRQOL and fewer problems or symptoms
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	
Cognitive Problems	5	1-5	1-5	
Perceived Physical Appearance	3	1-3	1-3	
Communication	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis</b>	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.

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<b>of Missing Data</b>	If 50% or more items are completed: Impute the mean of the completed items in a scale.
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# PedsQL<sup>™</sup> 3.0 Cardiac Module

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

The **Parent** Report for Toddlers (age 2-4) of the **PedsQL<sup>TM</sup> 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	Higher scores = Better HRQOL and fewer symptoms and problems
Treatment II	3	1-3	1-3	
Perceived Physical Appearance	3	1-3	1-3	
Treatment Anxiety	4	1-4	1-4	
Cognitive Problems	3	1-3	1-3	
Communication	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>There is no Total Score</u></b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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 Cardiac Module** 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	Higher scores = Better HRQOL and fewer problems and symptoms
Treatment II	3	1-3	1-3	
Perceived Physical Appearance	3	1-3	1-3	
Treatment Anxiety	4	1-4	1-4	
Cognitive Problems	5	1-5	1-5	
Communication	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>



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

The **Child, Young Adult, Adult, 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	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment II	5	1-5	1-5	
Perceived Physical Appearance	3	1-3	1-3	
Treatment Anxiety	4	1-4	1-4	
Cognitive Problems	5	1-5	1-5	
Communication	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL<sup>™</sup> 3.0 Cerebral Palsy Module**

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

The **Parent** Report for Toddlers (ages 2-4) of the **PedsQL<sup>TM</sup> 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	Higher scores = Better HRQOL and fewer problems or symptoms
Movement and Balance	5	1-5	1-5	
Pain and Hurt	4	1-4	1-4	
Fatigue	4	1-4	1-4	
Eating Activities	4	1-4	1-4	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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**CHILD and PARENT Reports for Young Children (ages 5-7),  
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 Cerebral Palsy Module** for:

- Young Children (ages 5-7)
- Children (ages 8-12)
- 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	Higher scores = Better HRQOL and fewer problems or symptoms
School Activities	4	1-4	1-4	
Movement and Balance	5	1-5	1-5	
Pain and Hurt	4	1-4	1-4	
Fatigue	4	1-4	1-4	
Eating Activities	5	1-5	1-5	
Speech and Communication	4	1-4	1-4	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b> Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL<sup>™</sup> 3.0 Cognitive Functioning Scale**

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

The **Parent** Report for Toddlers (ages 2-4) of the **PedsQL<sup>TM</sup> 3.0 Cognitive Functioning Scale** is composed of 6 items comprising 1 dimension.

#### **DESCRIPTION OF THE COGNITIVE FUNCTIONING SCALE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Cognitive Functioning	6	1-6	1-6	Higher scores = Better HRQOL and fewer problems or symptoms

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

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



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

The **Child, Young Adult, Adult, and Parent** Reports of the **PedsQL<sup>TM</sup> 3.0 Cognitive Functioning Scale**:

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

is composed of 6 items comprising 1 dimension.

#### **DESCRIPTION OF THE COGNITIVE FUNCTIONING SCALE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Cognitive Functioning	6	1-6	1-6	Higher scores = Better HRQOL and fewer problems or symptoms

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

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

# **PedsQL<sup>™</sup> 3.0 Diabetes Module**

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

The **Parent** Report for Toddlers (ages 2-4) of the **PedsQL™ 3.0 Diabetes Module** is composed of 28 items comprising 5 dimensions.

#### **DESCRIPTION OF THE DIABETES MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Diabetes	11	1-11	1-11	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment I	4	1-4	1-4	
Treatment II	7	1-7	1-7	
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimension</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

The **Child, Young Adult, and Parent** Reports of the **PedsQL™ 3.0 Diabetes Module**:

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

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	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment I	4	1-4	1-4	
Treatment II	7	1-7	1-7	
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimension</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL<sup>™</sup> 3.2 Diabetes Module**

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

The **Parent** Report for Toddlers (ages 2-4) of the **PedsQL™ 3.2 Diabetes Module** is composed of 32 items comprising 5 dimensions.

### **DESCRIPTION OF THE DIABETES MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Diabetes Symptoms	15	1-15	1-15	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment I	5	1-5	1-5	
Treatment II	6	1-6	1-6	
Worry	2	1-2	1-2	
Communication	4	1-4	1-4	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point scale from: 0 (Never) to 4 (Almost always) for Parent report for Toddlers (ages 2-4)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b> Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores</u></b> <b><u>Score by Dimensions:</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Diabetes Symptoms Summary Score</u></b> = Diabetes Symptoms Scale Score</p> <p><b><u>Diabetes Management Summary Score</u></b> = Sum of the items over the number of items answered in the Treatment I, Treatment II, Worry, and Communication Scales</p> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>



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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™ 3.2 Diabetes Module** is composed of 32 items comprising 5 dimensions.

#### **DESCRIPTION OF THE DIABETES MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Diabetes Symptoms	15	1-15	1-15	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment I	5	1-5	1-5	
Treatment II	6	1-6	1-6	
Worry	2	1-2	1-2	
Communication	4	1-4	1-4	

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

<b>Item Scaling</b>	3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b> Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores</u></b> <b><u>Score by Dimensions:</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Diabetes Symptoms Summary Score</u></b> = Diabetes Symptoms Scale Score</p> <p><b><u>Diabetes Management Summary Score</u></b> = Sum of the items over the number of items answered in the Treatment I, Treatment II, Worry, and Communication Scales</p> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

The **Child, Young Adult, Adult, and Parent** Reports of the **PedsQL™ 3.2 Diabetes Module**:

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

is composed of 33 items comprising 5 dimensions for ages 8-45 years.

#### **DESCRIPTION OF THE DIABETES MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Diabetes Symptoms	15	1-15	1-15	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment I	5	1-5	1-5	
Treatment II	6	1-6	1-6	
Worry	3	1-3	1-3	
Communication	4	1-4	1-4	

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

<b>Item Scaling</b>	5-point scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Diabetes Symptoms Summary Score</u></b> = Diabetes Symptoms Scale Score</p> <p><b><u>Diabetes Management Summary Score</u></b> = Sum of the items over the number of items answered in the Treatment I, Treatment II, Worry, and Communication Scales</p> <p><b><u>Total Score</u></b>: Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and</b>	If more than 50% of the items in the scale are missing, the Scale Scores

<b>Analysis of Missing Data</b>	<p>should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>
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# **PedsQL<sup>™</sup> 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™ 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	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment	4	1-4	1-4	
Worry	6	1-6	1-6	
Communication	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>No Total Score</u></b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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



The **Child, Young Adult, Adult, 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)
- Adults (ages over 26)

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	Higher scores = Better HRQOL and fewer problems or symptoms
Treatment	4	1-4	1-4	
Worry	6	1-6	1-6	
Communication	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>No Total Score</u></b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

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## **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 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	Higher scores = Better HRQOL and fewer problems or symptoms
About My Kidney Disease	4	1-4	1-4	
Treatment Problems	3	1-3	1-3	
Worry	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

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

- Young Children (ages 5-7)
- Children (ages 8-12)
- 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	Higher scores = Better HRQOL and fewer problems or symptoms
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	
Worry	10	1-10	1-10	
Perceived Physical Appearance	3	1-3	1-3	
Communication	5	1-5	1-5	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Young Children (ages 5-7) child report
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b> Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL™ 3.0 Eosinophilic Esophagitis Module**

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

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

### **DESCRIPTION OF THE EOSINOPHILIC ESOPHAGITIS MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Symptoms I	3	1-3	1-3	Higher scores = Better HRQOL and fewer problems or symptoms
Symptoms II	4	1-4	1-4	
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:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Symptoms Total Scale Score</u></b> = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales</p> <p><b><u>Total Score</u></b>: Sum of all the items over the number of items answered on all the Scales except the Feeding Tube Scale</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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 for Young Children (ages 5-7) of the **PedsQL™ 3.0 Eosinophilic Esophagitis Module** 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	Higher scores = Better HRQOL and fewer problems and symptoms
Symptoms II*	4	1-4	1-4	
Treatment	4	1-4	1-4	
Worry	4	1-4	1-4	
Communication	4	1-4	1-4	
Food and Eating	4	1-4	1-4	
Food Feelings	3	1-3	1-3	

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

Note: Feeding Tube Scale not scored.

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Symptoms Total Scale Score</u></b> = 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</p> <p><b><u>Total Score</u></b>: Sum of all the items over the number of items answered on all the Scales for parent report except the Feeding Tube Scale. For child self-report ages 5-7, sum all the items over the number of items answered on all Scales except for the Symptoms II and Feeding Tube Scale</p>

<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>
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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™ 3.0 Eosinophilic Esophagitis Module** for:

- Children (ages 8-12)
- 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	Higher scores = Better HRQOL and fewer problem and symptoms
Symptoms II	4	1-4	1-4	
Treatment	5	1-5	1-5	
Worry	6	1-6	1-6	
Communication	5	1-5	1-5	
Food and Eating	4	1-4	1-4	
Food Feelings	3	1-3	1-3	

Note: Feeding Tube Scale not scored.

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Symptoms Total Scale Score</u></b> = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales</p> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales except the Feeding Tube Scale</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL<sup>TM</sup> 3.0 Eosinophilic Esophagitis Symptoms Scales**

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

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The **Parent** Report for Toddlers (age 2-4) of the **PedsQL<sup>TM</sup> 3.0 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 = Better HRQOL and fewer problems and symptoms
Symptoms II	4	1-4	1-4	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Symptoms Total Scale Score</u></b> = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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<sup>TM</sup> 3.0 Eosinophilic Esophagitis Symptoms Scales** are composed of 7 items comprising 2 dimensions.

#### **DESCRIPTION OF THE EOSINOPHILIC ESOPHAGITIS SYMPTOMS MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Symptoms I	3	1-3	1-3	Higher scores = Better HRQOL and fewer problems and symptoms
Symptoms II	4	1-4	1-4	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) for Parent Report for Young Children (ages 5-7) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Symptoms Total Scale Score</u></b> = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales.</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>



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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™ Eosinophilic Esophagitis Symptoms Scales** for:

- Children (ages 8-12)
- 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 = Better HRQOL and fewer problems and symptoms
Symptoms II	4	1-4	1-4	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Symptoms Total Scale Score</u></b> = Sum of the items over the number of items answered in the Symptoms I and Symptoms II Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL™ 3.0 Epilepsy Module**

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

The **Parent** Report for Toddlers (ages 2-4) of the **PedsQL<sup>TM</sup> 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	Higher scores = Better HRQOL and fewer problems or symptoms
Cognitive Functioning	5	1-5	1-5	
Sleep/Rest	2	1-2	1-2	
Executive Functioning	4	1-4	1-4	
Mood/Behavior	5	1-5	1-5	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>There is no Total score</u></b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

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The **Child** Report for Young Children (ages 5-7) of the **PedsQL™ 3.0 Epilepsy Module** is 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	Higher scores = Better HRQOL and fewer problems or symptoms
Cognitive Functioning	6	1-6	1-6	
Sleep/Rest	3	1-3	1-3	
Executive Functioning	6	1-6	1-6	
Mood/Behavior	5	1-5	1-5	

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

<b>Item Scaling</b>	3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b> Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 2=50, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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™ 3.0 Epilepsy Module** is 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	Higher scores = Better HRQOL and fewer problems or symptoms
Cognitive Functioning	6	1-6	1-6	
Sleep/Rest	3	1-3	1-3	
Executive Functioning	6	1-6	1-6	
Mood/Behavior	5	1-5	1-5	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b> Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>



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

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The **Child, Young Adult, and Parent** Reports of the **PedsQL™ 3.0 Epilepsy Module** for:

- Children (ages 8-12)
- Teens (ages 13-18)
- 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	Higher scores = Better HRQOL and fewer problems or symptoms
Cognitive Functioning	6	1-6	1-6	
Sleep/Rest	3	1-3	1-3	
Executive Functioning	6	1-6	1-6	
Mood/Behavior	5	1-5	1-5	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b> Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# PedsQL<sup>™</sup> 2.0 Family Impact Module

## PARENT Report for all ages

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	Higher scores = Better functioning
Emotional Functioning	5	1-5	1-5	
Social Functioning	4	1-4	1-4	
Cognitive Functioning	5	1-5	1-5	
Communication	3	1-3	1-3	
Worry	5	1-5	1-5	
Daily Activities	3	1-3	1-3	
Family Relationships	5	1-5	1-5	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Step 3: Total Scores</u></b></p> <ul style="list-style-type: none"> <li><b><u>The Total Score</u></b> is the sum of all 36 items divided by the number of items answered</li> <li><b><u>The Parent HRQL Summary Score</u></b> (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><b><u>The Family Functioning Summary Score</u></b> (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>
<b>Interpretation</b>	If more than 50% of the items in the scale are missing, the Scale Scores

<b>and Analysis of Missing Data</b>	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>™</sup> 3.0 Family Information Form**

## **PARENT Report for all ages**

The **Parent** Report of the **PedsQL™ 3.0 Family Information Form** contains items regarding demographic information about the parent (and or caregiver) and child. Only 2 items are scored.

#### **DESCRIPTION OF THE FAMILY INFORMATION FORM:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Family Impact	2	1-2	1-2	Higher scores = Lower impact or better functioning

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

<b>Item Scaling</b>	5-point scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100.
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0.</p> <p><b><u>Step 2: Calculate scores by Dimension</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales.</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

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



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

#### **DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS MODULE:**

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <li>If more than 50% of the items in the scale are missing, the scale scores</li> </ul>

	<p>should not be computed</p> <ul style="list-style-type: none"> <li>• Mean score = Sum of the items over the number of items answered</li> </ul> <p><b><u>Symptoms Total Scales Score</u></b>: Sum of the items over the number of items answered in the 10 Symptoms Scales</p> <p><b><u>Total Score</u></b>: Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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 Gastrointestinal Symptoms Module** are composed of 74 items comprising 14 dimensions.

#### **DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS MODULE:**

<b>Dimensions</b>	<b>Number of Items</b>	<b>Cluster of Items</b>	<b>Reversed Scoring</b>	<b>Direction of Dimensions</b>
Stomach Pain and Hurt	6	1-6	1-6	Higher scores = Better HRQOL and fewer problems or symptoms
Stomach Discomfort When Eating	5	1-5	1-5	
Food and Drink Limits	6	1-6	1-6	
Trouble Swallowing	3	1-3	1-3	
Heart Burn and Reflux	4	1-4	1-4	
Nausea and Vomiting	4	1-4	1-4	
Gas and Bloating	7	1-7	1-7	
Constipation	14	1-14	1-14	
Blood in Poop	2	1-2	1-2	
Diarrhea	7	1-7	1-7	
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:**

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

	<p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Symptoms Total Scales Score:</u></b> Sum of the items over the number of items answered in the 10 Symptoms Scales</p> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

The **Child, Young Adult, Adult, 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)
- Adults (ages over 26)

are composed of 74 items comprising 14 dimensions.

#### **DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS MODULE:**

<b>Dimensions</b>	<b>Number of Items</b>	<b>Cluster of Items</b>	<b>Reversed Scoring</b>	<b>Direction of Dimensions</b>
Stomach Pain and Hurt	6	1-6	1-6	Higher scores = Better HRQOL and fewer problems or symptoms
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	
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:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No

<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Symptoms Total Scales Score</u></b>: Sum of the items over the number of items answered in the 10 Symptoms Scales</p> <p><b><u>Total Score</u></b>: Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>



# **PedsQL<sup>™</sup> 3.0 Gastrointestinal Symptoms Scales**

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

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

#### **DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS SCALES:**

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

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Symptoms Total Scales Score:</u></b> Sum of the items over the number of items answered in the 10 Symptoms Scales</p>
<b>Interpretation and Analysis</b>	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.

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<b>of Missing Data</b>	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 Gastrointestinal Symptoms Scales** 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 = Better HRQOL and fewer problems or symptoms
Stomach Discomfort When Eating	5	1-5	1-5	
Food and Drink Limits	6	1-6	1-6	
Trouble Swallowing	3	1-3	1-3	
Heart Burn and Reflux	4	1-4	1-4	
Nausea and Vomiting	4	1-4	1-4	
Gas and Bloating	7	1-7	1-7	
Constipation	14	1-14	1-14	
Blood in Poop	2	1-2	1-2	
Diarrhea	7	1-7	1-7	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) for Parent Report for Young Children (ages 5-7) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Symptoms Total Scales Score:</u></b> Sum of the items over the number of items</p>

	answered in the 10 Symptoms Scales
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

The **Child, Young Adult, Adult, 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)
- Adults (ages over 26)

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 = Better HRQOL and fewer problems or symptoms
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:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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>



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

# **PedsQL<sup>™</sup> 3.0 General Well-Being Scale**

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

The **Child** and **Young Adult** Reports of the **PedsQL™ General Well-Being Scale** for:

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

are composed of 7 items comprising 2 dimensions.

#### **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 = better HRQOL

  

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
General Health	1	1	No	Higher scores = better HRQOL

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are linearly transformed to a 0-100 scale as follows: 0=0, 1=25, 2=50, 3=75, 4=100</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Score should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL<sup>™</sup> 3.0 Healthcare Satisfaction Generic Module**

## **PARENT Report for all ages**

The **Parent** Report of the **PedsQL™ Healthcare Satisfaction Generic Module** is composed of 24 items comprising 6 dimensions.

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

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

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale: 0 (Never) to 4 (Always) and Not Applicable
<b>Weighting of items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are scored and linearly transformed to a 0-100 scale as follows: 0=0, 1=25, 2=50, 3=75, 4=100</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Mean score = Sum of all the items in all scales divided by the number of items answered on all the scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in the scale.</p>

# **PedsQL<sup>™</sup> 3.0 Healthcare Satisfaction Hematology/Oncology Module**

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## **PARENT Report for all ages**

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The **Parent** Report of the **PedsQL™ 3.0 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	No	Higher scores = Higher satisfaction
Information	5	1-5		
Inclusion of Family	4	1-4		
Communication	5	1-5		
Technical Skills	4	1-4		
Emotional Needs	4	1-4		

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

<b>Item Scaling</b>	5-point Likert scale: 1 (Very dissatisfied) to 5 (Very satisfied)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are scored and linearly transformed to a 0-100 scale as follows: 1=0, 2=25, 3=50, 4=75, 5=100</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Mean score = Sum of all the items in all scales divided by the number of items answered on all the scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in the scale.</p>

# PedsQL<sup>™</sup> 1.0 Infant Scales

## PARENT Report for Infants (ages 1-12 months)



The **Parent** Report for Infants (ages 1-22 months) of the **PedsQL™ 1.0 Infant Scales** is composed of 36 items 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	Higher scores = Better HRQOL and fewer problems or symptoms
Physical Symptoms	10	1-10	1-10	
Emotional Functioning	12	1-12	1-12	
Social Functioning	4	1-4	1-4	
Cognitive Functioning	4	1-4	1-4	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Psychosocial Health Summary Score:</u></b> Sum of the items over the number of items answered in the Emotional, Social, and Cognitive Functioning Scales</p> <p><b><u>Physical Health Summary Score:</u></b> Sum of the items over the number of items answered in the Physical Functioning and Physical Symptoms Scales</p> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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## **PARENT Report for Infants (ages 13-24 months)**

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The **Parent** Report for Infants (ages 13-24 months) of the **PedsQL™ 1.0 Infant Scales** is composed of 45 items comprising 5 dimensions.

#### **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	Higher scores = Better HRQOL and fewer problems or symptoms
Physical Symptoms	10	1-10	1-10	
Emotional Functioning	12	1-12	1-12	
Social Functioning	5	1-5	1-5	
Cognitive Functioning	9	1-9	1-9	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Psychosocial Health Summary Score:</u></b> Sum of the items over the number of items answered in the Emotional, Social, and Cognitive Functioning Scales</p> <p><b><u>Physical Health Summary Score:</u></b> Sum of the items over the number of items answered in the Physical Functioning and Physical Symptoms Scales</p> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL<sup>™</sup> 3.0 Multidimensional Fatigue Scale**

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

The **Parent** Report for Toddlers (ages 2-4) of the **PedsQL™ 3.0 Multidimensional Fatigue Scale** are 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	Higher scores = Better HRQOL and fewer problems or symptoms
Sleep/Rest Fatigue	6	1-6	1-6	
Cognitive Fatigue	6	1-6	1-6	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

**CHILD, YOUNG ADULT, ADULT, and PARENT Report for Young  
Children (ages 5-7), Children (ages 8-12), Teens (age 13-18),  
Young Adults (ages 18-25), and Adults (ages over 26)**

The **Child, Young Adult, Adult, and Parent** Reports of the **PedsQL<sup>TM</sup> 3.0 Multidimensional Fatigue Scale**:

- Young Child (ages 5-7)
- Child (ages 8-12)
- Teen (ages 13-18)
- Young Adult (ages 18-25)
- Adult (ages over 26)

are 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	Higher scores = Better HRQOL and fewer problems or symptoms
Sleep/Rest Fatigue	6	1-6	1-6	
Cognitive Fatigue	6	1-6	1-6	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL<sup>TM</sup> 3.0 Neurofibromatosis Module**

**CHILD, YOUNG ADULT, ADULT, 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)**



The **Child, Young Adult, Adult, 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:**

<b>Dimensions</b>	<b>Number of Items</b>	<b>Cluster of Items</b>	<b>Reversed Scoring</b>	<b>Direction of Dimensions</b>
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	
Pain Management	2	1-2	1-2	
Cognitive Functioning	15	1-15	1-15	
Speech	4	1-4	1-4	
Fine Motor	6	1-6	1-6	
Balance	5	1-5	1-5	Higher scores = Better HRQOL and fewer problems or symptoms
Vision	5	1-5	1-5	
Perceived Physical Appearance	3	1-3	1-3	
Communication	6	1-6	1-6	
Worry	10	1-10	1-10	
Treatment	6	1-6	1-6	
Medicines	3	1-3	1-3	
Stomach Discomfort	3	1-3	1-3	
Constipation	3	1-3	1-3	
Diarrhea	2	1-2	1-2	

**SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Young Child (ages 5-7) child report
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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# **PedsQLTM 3.0 Neuromuscular Module**

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## **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 Neuromuscular Module** are composed of 25 items comprising 3 dimensions.

#### **DESCRIPTION OF THE NEUROMUSCULAR MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
About Neuromuscular Disease	17	1-17	1-17	Higher scores = Better HRQOL and fewer problems or symptoms
Communication	3	1-3	1-3	
About Our Family Resources	5	1-5	1-5	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of missing data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

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**Child** Report for Young Children (ages 5-7) of the **PedsQL™ 3.0 Neuromuscular Module** is composed of 17 items comprising 1 dimension.

#### **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 = Better HRQOL and fewer problems or symptoms

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

<b>Item Scaling</b>	3-point Likert scale: 0 (Not at all), 2 (Sometimes), 4 (A lot)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of missing data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

**CHILD, YOUNG ADULT, ADULT, 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)**

The **Child, Young Adult, Adult, and Parent** Reports of the **PedsQL™ 3.0 Neuromuscular Module**:

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

are composed of 25 items comprising 3 dimensions.

#### **DESCRIPTION OF THE NEUROMUSCULAR MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
About Neuromuscular Disease	17	1-17	1-17	Higher scores = Better HRQOL and fewer problems or symptoms
Communication	3	1-3	1-3	
About Our Family Resources	5	1-5	1-5	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of missing data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>



# PedsQL<sup>™</sup> 3.0 Oral Health Scale

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

The **Parent** Report for Toddlers (ages 2-4) of the **PedsQL™ 3.0 Oral Health Scale** are 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 = Better HRQOL and fewer problems or symptoms

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

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

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**CHILD and PARENT Reports for Young Children (ages 5-7), 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 Oral Health Scale**:

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

are 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 = Better HRQOL and fewer problems or symptoms

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

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

# **PedsQL™ Pediatric Pain Coping Inventory™ (PPCI)**

## **PARENT Report for Children-Teens (ages 5-18)**

The **Parent** Report for Children-Teens (ages 5-18) of the **PedsQL™ Pediatric Pain Coping Inventory (PPCI)** are composed of 41 items comprising 5 dimensions.

See Varni, J.W. et al. (1996). Development of the Waldron/Varni Pediatric Pain Coping Inventory. Pain, 67, 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	No	Higher scores = Greater use of the coping strategy
Problem-Solving	10	1, 2, 11, 15, 26, 27, 30, 33, 34, 35		
Distraction	9	6, 8, 9, 10, 14, 16, 17, 18, 19		
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:**

<b>Item Scaling</b>	3-point Likert scale from: 0 (Never) to 2 (Often)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 2
<b>Scoring Procedure</b>	<b><u>Calculate Scale Scores:</u></b> Sum of all the items over the number of items answered for each Scale
<b>Interpretation and Analysis of Missing Data</b>	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.

## **CHILD Report for Children (ages 5-12) and Teens (ages 13-18)**

The **Child** Report of the **PedsQL™ Pediatric Pain Coping Inventory (PPCI)**:

- Children (ages 5-12)
- 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. Pain, 67, 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	No	Higher scores = Greater use of the coping strategy
Problem-Solving	10	1, 2, 11, 15, 26, 27, 30, 33, 34, 35		
Distraction	9	6, 8, 9, 10, 14, 16, 17, 18, 19		
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:**

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



# **PedsQL™ 3.0 Pediatric Pain Questionnaire (PPQ)™**

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## **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 Pediatric Pain Questionnaire<sup>TM</sup>** are composed of 3 items comprising 2 domains.

#### **DESCRIPTION OF THE QUESTIONNAIRE:**

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

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

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

<b>Item Scaling</b>	10cm (100mm) VAS scales from: 0cm/mm (Not hurting/No discomfort/No pain) to 10cm (100mm) (Hurting a whole lot/Very uncomfortable/Severe pain)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	0-10cm or 0-100mm
<b>Scoring Procedure</b>	<ul style="list-style-type: none"> <li>• Present pain and worst pain are scored separately</li> <li>• The score is based on the line length to the nearest 0.5 cm (5mm)</li> </ul>
<b>Interpretation and Analysis of Missing Data</b>	There is no imputation process since these are single item VAS scales.

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

The **Child** and **Parent** Reports of the **PedsQL<sup>TM</sup> 3.0 Pediatric Pain Questionnaire<sup>TM</sup>**:

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

are composed of 3 items comprising 2 domains.

#### **DESCRIPTION OF THE QUESTIONNAIRE:**

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

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

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

<b>Item Scaling</b>	10cm (100mm) VAS scales from: 0cm/mm (Not hurting/No discomfort/No pain) to 10cm (100mm) (Hurting a whole lot/Very uncomfortable/Severe pain)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	0-10cm or 0-100mm
<b>Scoring Procedure</b>	<ul style="list-style-type: none"> <li>• Present pain and worst pain are scored separately</li> <li>• The score is based on the line length to the nearest 0.5 cm (5mm)</li> </ul>
<b>Interpretation and Analysis of Missing Data</b>	There is no imputation process since these are single item VAS scales.

# **PedsQL™ 3.0 Present Functioning Visual Analogue Scale (PedsQL™ VAS)**

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**CHILD and PARENT Reports for Children-Teens (ages 5-18)**

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The **Child** and **Parent** Reports for Children (ages 5-18) **PedsQL™ 3.0 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:**

<b>Item Scaling</b>	100mm VAS scales from 0 to 100
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	0-100
<b>Scoring Procedure</b>	<ul style="list-style-type: none"> <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>
<b>Interpretation and Analysis of Missing Data</b>	There is no imputation process since these are single item VAS scales.

# PedsQL™ 3.0 Rheumatology Module

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

The **Parent** Report for Toddlers (age 2-4) of the **PedsQL<sup>TM</sup> 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	Higher scores = Better HRQOL and fewer problems or symptoms
Daily Activities	5	1-5	1-5	
Treatment	5	1-5	1-5	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>There is no Total Score</u></b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>



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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 Rheumatology Module** 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	Higher scores = Better HRQOL and fewer problems or symptoms
Daily Activities	5	1-5	1-5	
Treatment	5	1-5	1-5	
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the child report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b> Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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 RheumatologyModule** for:

- Children (ages 8-12)
- 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	Higher scores = Better HRQOL and fewer problems or symptoms
Daily Activities	5	1-5	1-5	
Treatment	7	1-5	1-5	
Worry	3	1-3	1-3	
Communication	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b> Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b>There is no Total Score</b></p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# **PedsQL<sup>™</sup> 3.0 Sickle Cell Disease Module**

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

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

#### **DESCRIPTION OF THE SICKLE CELL DISEASE MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Pain and Hurt	9	1-9	1-9	Higher scores = Better HRQOL and fewer problems or symptoms
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	
Emotions	2	1-2	1-2	
Treatment	6	1-6	1-6	
Communication I	3	1-3	1-3	
Communication II	3	1-3	1-3	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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	Higher scores = Better HRQOL and fewer problems or symptoms
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	
Emotions	2	1-2	1-2	
Treatment	6	1-6	1-6	
Communication I	3	1-3	1-3	
Communication II	3	1-3	1-3	

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

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales.</p>
<b>Interpretation and Analysis</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items</p>



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of Missing Data	in a scale.
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**CHILD, YOUNG ADULT, ADULT, and PARENT Reports for  
Children (ages 8-12), Teens (ages 13-18), Young Adults (ages  
18-25), and Adults (ages over 26)**

The **Child, Young Adult, Adult, 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)
- 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	Higher scores = Better HRQOL and fewer problems or symptoms
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	
Emotions	2	1-2	1-2	
Treatment	7	1-7	1-7	
Communication I	3	1-3	1-3	
Communication II	3	1-3	1-3	

### **SCORING OF DIMENSIONS:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation</b>	If more than 50% of the items in the scale are missing, the Scale Scores

<b>and Analysis of Missing Data</b>	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>™</sup> 3.0 Spinal Cord Injury Module**

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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> 3.0 Spinal Cord Injury Module** are composed of 42 items comprising 9 dimensions.

#### **DESCRIPTION OF THE SPINAL CORD INJURY MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Daily Activities	6	1-6	1-6	Higher scores = Better HRQOL and fewer problems or symptoms
Mobility	6	1-6	1-6	
Bladder Function	6	1-6	1-6	
Bowel Function	5	1-5	1-5	
Pain Interference	3	1-3	1-3	
Social Participation	4	1-4	1-4	
Worry Social	3	1-3	1-3	
Worry Bladder Bowel	3	1-3	1-3	
Pressure Injury	2	1-2	1-2	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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

The **Child, Adult** and **Parent** Reports of the **PedsQL™ 3.0 Spinal Cord Injury Module**:

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

are composed of 42 items comprising 9 dimensions.

#### **DESCRIPTION OF THE SPINAL CORD INJURY MODULE:**

Dimensions	Number of Items	Cluster of Items	Reversed Scoring	Direction of Dimensions
Daily Activities	6	1-6	1-6	Higher scores = Better HRQOL and fewer problems or symptoms
Mobility	6	1-6	1-6	
Bladder Function	6	1-6	1-6	
Bowel Function	5	1-5	1-5	
Pain Interference	3	1-3	1-3	
Social Participation	4	1-4	1-4	
Worry Social	3	1-3	1-3	
Worry Bladder Bowel	3	1-3	1-3	
Pressure Injury	2	1-2	1-2	

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

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis</b>	If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.



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<b>of Missing Data</b>	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> 1.0 Stem Cell Transplant Module**

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

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	Higher scores = Better HRQOL and fewer problems or symptoms
Fatigue and Sleep	5	1-5	1-5	
Nausea	4	1-4	1-4	
Worry	2	1-2	1-2	
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:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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	Higher scores = Better HRQOL and fewer problems or symptoms
Fatigue and Sleep	5	1-5	1-5	
Nausea	4	1-4	1-4	
Worry	10	1-10	1-10	
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:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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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	Higher scores = Better HRQOL and fewer problems or symptoms
Fatigue and Sleep	5	1-5	1-5	
Nausea	4	1-4	1-4	
Worry	10	1-10	1-10	
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:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

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



The **Child** 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	Higher scores = Better HRQOL and fewer problems or symptoms
Fatigue and Sleep	5	1-5	1-5	
Nausea	4	1-4	1-4	
Worry	12	1-12	1-12	
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:**

<b>Item Scaling</b>	5-point Likert scale from: 0 (Never) to 4 (Almost always)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate Scores by Dimensions</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>

# PedsQL<sup>™</sup> 3.0 Transplant Module

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

The **Parent** Reports of the **PedsQ<sup>TM</sup> 3.0 Transplant Module:**

- Toddlers (ages 2-4)
- Young Children (ages 5-7)
- Children (ages 8-12)
- Teens (ages 13-18)

are 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	Higher scores = Better HRQOL and fewer problems or symptoms
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	
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:**

<b>Item Scaling</b>	5-point scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimension</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>

<b>Interpretation and Analysis of Missing Data</b>	<p>If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>
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**CHILD Report for Young Children (ages 5-7), Children  
(ages 8-12), and Teens (ages 13-18)**

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The **Child** Reports of the **PedsQ™ 3.0 Transplant Module:**

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

are 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	Higher scores = Better HRQOL and fewer problems or symptoms
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	
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:**

<b>Item Scaling</b>	5-point scale from: 0 (Never) to 4 (Almost always) 3-point Likert scale from: 0 (Not at all), 2 (Sometimes) and 4 (A lot) for the Child Report for Young Children (ages 5-7)
<b>Weighting of Items</b>	No
<b>Extension of the Scoring Scale</b>	Scores are transformed on a scale from 0 to 100
<b>Scoring Procedure</b>	<p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reverse scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b><u>Step 2: Calculate scores by Dimension</u></b></p> <ul style="list-style-type: none"> <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> <p><b><u>Total Score:</u></b> Sum of all the items over the number of items answered on all the Scales</p>
<b>Interpretation and</b>	If more than 50% of the items in the scale are missing, the Scale Scores

<b>Analysis of Missing Data</b>	<p>should not be computed.</p> <p>If 50% or more items are completed: Impute the mean of the completed items in a scale.</p>
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