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**SCALING AND SCORING OF THE**

**Pediatric Quality of Life Inventory™**

**PedsQL™**

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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 indicate 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 reversed 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><u>Score by Dimensions:</u></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><u>Psychosocial Health Summary Score</u> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales.</p> <p><u>Physical Health Summary Score</u> = 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), Teens (ages 13-18)**

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

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

are composed of 23 items comprising 4 dimensions.

**DESCRIPTION OF THE QUESTIONNAIRE:**

| Dimensions            | Number of Items | Cluster of Items | Reversed scoring | Direction of Dimensions              |
|-----------------------|-----------------|------------------|------------------|--------------------------------------|
| Physical Functioning  | 8               | 1-8              | 1-8              | Higher scores indicate 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)<br>3-point scale: 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 reversed 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><u>Score by Dimensions:</u></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><u>Psychosocial Health Summary Score</u> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales.</p> <p><u>Physical Health Summary Score</u> = 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> | If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.<br>If 50% or more items are completed: Impute the mean of the completed items in a scale.   |



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

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

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

are composed of 23 items comprising 4 dimensions.

**DESCRIPTION OF THE QUESTIONNAIRE:**

| Dimensions            | Number of Items | Cluster of Items | Reversed scoring | Direction of Dimensions              |
|-----------------------|-----------------|------------------|------------------|--------------------------------------|
| Physical Functioning  | 8               | 1-8              | 1-8              | Higher scores indicate 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 reversed 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><u>Score by Dimensions:</u></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><u>Psychosocial Health Summary Score</u> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales.</p> <p><u>Physical Health Summary Score</u> = 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™ 4.0 SF15 Generic Core Scales**

**PARENT Report for Toddlers (ages 2-4),  
CHILD and PARENT Reports for Young Children (ages 5-7),  
Children (ages 8-12), Teens (ages 13-18), Young Adults (ages  
18-25) and Adults (ages over 26)**

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

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

are composed of **15 items** comprising **4 dimensions**.

**DESCRIPTION OF THE SF15 QUESTIONNAIRE:**

| Dimensions            | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions              |
|-----------------------|-----------------|------------------|------------------|--------------------------------------|
| Physical Functioning  | 5               | 1-5              | 1-5              | Higher scores indicate 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)<br>3-point scales: 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 reversed 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><u>Score by Dimensions:</u></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><u>Psychosocial Health Summary Score</u> = Sum of the items over the number of items answered in the Emotional, Social, and School Functioning Scales.</p> <p><u>Physical Health Summary Score</u> = Physical Functioning Scale Score</p> |

|   |   |
|---|---|
|   | <p><b>Total Score:</b> Sum of all the items over the number of items answered on all the Scales.</p>  |
| <p><b>Interpretation and Analysis of Missing Data</b></p> | <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 Arthritis Module

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

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

**DESCRIPTION OF THE ARTHRITIS MODULE:**

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

**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 reversed 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 of the **PedsQL™ 3.0 Arthritis Module** for Young Children (ages 5-7) are composed of 20 items comprising 5 dimensions.

**DESCRIPTION OF THE ARTHRITIS MODULE:**

| Dimensions       | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|------------------|-----------------|------------------|------------------|--|
| Pain and Hurt    | 4               | 1-4              | 1-4              | Higher scores indicate lower problems. |
| 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<br>3-point scale: 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 reversed 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 Children (ages 8-12), Teens  
(ages 13-18)**

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

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

are composed of 22 items comprising 5 dimensions.

**DESCRIPTION OF THE ARTHRITIS MODULE:**

| Dimensions       | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|------------------|-----------------|------------------|------------------|--|
| Pain and Hurt    | 4               | 1-4              | 1-4              | Higher scores indicate lower problems. |
| 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 reversed 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>   |

# PedsQL™ 3.0 Asthma Module

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

The Parent Report for Toddlers (ages 2-4) of the PedsQL™ 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 indicate lower problems. |
| 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 reversed 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), Teens (ages 13-18)**

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

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

are composed of 28 items comprising 4 dimensions.

**DESCRIPTION OF THE ASTHMA MODULE:**

| Dimensions    | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|---------------|-----------------|------------------|------------------|--|
| Asthma        | 11              | 1-11             | 1-11             | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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 reversed 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™ 3.0 SF22 Asthma Module

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



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

**DESCRIPTION OF THE SF22 ASTHMA MODULE:**

| Dimensions | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|------------|-----------------|------------------|------------------|--|
| Asthma     | 11              | 1-11             | 1-11             | Higher scores indicate lower problems. |
| 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 reversed 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), Teens (ages 13-18)**

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

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

are composed of 22 items comprising 2 dimensions.

**DESCRIPTION OF THE SF22 ASTHMA MODULE:**

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

**SCORING OF DIMENSIONS:**

|  |  |
|--|--|
| <b>Item Scaling</b>                                | 5-point Likert scale from 0 (Never) to 4 (Almost always)<br>3-point scale: 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 reversed 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™ Brain Tumor Module

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

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

**DESCRIPTION OF THE BRAIN TUMOR MODULE:**

| Dimensions           | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|----------------------|-----------------|------------------|------------------|--|
| Pain and Hurt        | 3               | 1-3              | 1-3              | Higher scores indicate lower problems. |
| 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 reversed 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 **Parent and Child Reports for Young Children** (ages 5-7) of the **PedsQL™ Brain Tumor Module** are composed of 23 items comprising 6 dimensions.

**DESCRIPTION OF THE BRAIN TUMOR MODULE:**

| Dimensions           | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|----------------------|-----------------|------------------|------------------|--|
| Cognitive Problems   | 6               | 1-6              | 1-6              | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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 reversed 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), Teens  
(ages 13-18)**

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

**DESCRIPTION OF THE BRAIN TUMOR MODULE:**

| Dimensions           | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions               |
|----------------------|-----------------|------------------|------------------|---------------------------------------|
| Cognitive Problems   | 7               | 1-7              | 1-7              | Higher scores indicate lower problems |
| 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 reversed 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™ 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:**

| <b>Dimensions</b>             | <b>Number of Items</b> | <b>Cluster of Items</b> | <b>Reversed Scoring</b> | <b>Direction of Dimensions</b>         |
|-------------------------------|------------------------|-------------------------|-------------------------|--|
| Pain and Hurt                 | 2                      | 1-2                     | 1-2                     | Higher scores indicate lower problems. |
| 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 to a 0 to 100 scale.  |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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** of the **PedsQL™ 3.0 Cancer Module** for Young Children (ages 5-7), are composed of 26 items comprising 8 dimensions.

**DESCRIPTION OF THE CANCER MODULE:**

| Dimensions                    | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-------------------------------|-----------------|------------------|------------------|--|
| Pain and Hurt                 | 2               | 1-2              | 1-2              | Higher scores indicate lower problems. |
| 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>                                | 5-point Likert scale from 0 (Never) to 4 (Almost always)<br>3-point scale: 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 reversed 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> | If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.<br>If 50% or more items are completed: Impute the mean of the completed items in a scale.   |

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

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

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

and the **Adult Report** (ages over 26) are composed of 27 items comprising 8 dimensions.

**DESCRIPTION OF THE CANCER MODULE:**

| Dimensions                    | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-------------------------------|-----------------|------------------|------------------|--|
| Pain and Hurt                 | 2               | 1-2              | 1-2              | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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 reversed 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 Cardiac Module

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



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

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

| <b>Dimensions</b>             | <b>Number of Items</b> | <b>Cluster of Items</b> | <b>Reversed Scoring</b> | <b>Direction of Dimensions</b>         |
|-------------------------------|------------------------|-------------------------|-------------------------|--|
| Heart problems and Treatment  | 7                      | 1-7                     | 1-7                     | Higher scores indicate lower 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 to a 0 to 100 scale.   |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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** of the **PedsQL™ 3.0 Cardiac Module** for Young Children (ages 5-7) are composed of 25 items comprising 6 dimensions.

**DESCRIPTION OF THE CARDIAC MODULE:**

| Dimensions                    | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-------------------------------|-----------------|------------------|------------------|--|
| Heart Problems and Treatment  | 7               | 1-7              | 1-7              | Higher scores indicate lower 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            | 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)<br>3-point scale: 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 reversed 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 Children (ages 8-12), Teens (ages 13-18), Young Adults (ages 18-25), and Adults (ages over 26)**

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

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

are composed of 27 items comprising 6 dimensions.

**DESCRIPTION OF THE CARDIAC MODULE:**

| Dimensions                    | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-------------------------------|-----------------|------------------|------------------|--|
| Heart Problems and Treatment  | 7               | 1-7              | 1-7              | Higher scores indicate lower problems. |
| 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 reversed 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™ 3.0 Cerebral Palsy Module

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

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

**DESCRIPTION OF THE CEREBRAL PALSY MODULE:**

| Dimensions           | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|----------------------|-----------------|------------------|------------------|--|
| Daily Activities     | 5               | 1-5              | 1-5              | Higher scores indicate lower problems. |
| 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 to a 0 to 100 scale.   |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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), Teens (ages 13-18)**



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

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

are composed of 35 items comprising 7 dimensions.

### **DESCRIPTION OF THE CEREBRAL PALSY MODULE:**

| <b>Dimensions</b>        | <b>Number of Items</b> | <b>Cluster of Items</b> | <b>Reversed Scoring</b> | <b>Direction of Dimensions</b>         |
|--------------------------|------------------------|-------------------------|-------------------------|--|
| Daily Activities         | 9                      | 1-9                     | 1-9                     | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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><br/>Items are reversed 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> | If more than 50% of the items in the scale are missing, the Scale Scores should not be computed.<br>If 50% or more items are completed: Impute the mean of the completed items in a scale.  |

# PedsQL™ Cognitive Functioning Scale

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

**DESCRIPTION OF THE COGNITIVE FUNTIONING SCALE:**

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

**SCORING OF DIMENSIONS:**

|  |  |
|--|--|
| <b>Item Scaling</b>                                | 5-point Likert scale from 0 (Never) to 4 (Almost always)<br>3-point scale: 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 reversed 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™ 3.0 Diabetes Module**

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

**DESCRIPTION OF THE DIABETES MODULE:**

| Dimensions    | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|---------------|-----------------|------------------|------------------|--|
| Diabetes      | 11              | 1-11             | 1-11             | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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 reversed 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™ 3.2 Diabetes Module

The **PedsQL™ 3.2 Diabetes Module** is composed of 33 items comprising 5 dimensions for ages 8-45 years. For ages 2-7 years, the **PedsQL™ 3.2 Diabetes Module** is composed of 32 items comprising 5 dimensions (one less item for the Worry Scale).

**DESCRIPTION OF THE DIABETES MODULE:**

| Dimensions        | Number of Items   | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-------------------|-------------------|------------------|------------------|--|
| Diabetes Symptoms | 15                | 1-15             | 1-15             | Higher scores indicate lower problems. |
| Treatment I       | 5                 | 1-5              | 1-5              |  |
| Treatment II      | 6                 | 1-6              | 1-6              |  |
| Worry             | 3<br>(2 ages 2-7) | 1-3<br>(or 1-2)  | 1-3<br>(or 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)<br>3-point scale: 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 reversed 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><u>Score by Dimensions:</u></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><u>Diabetes Symptoms Summary Score</u> = Diabetes Symptoms Scale Score</p> <p><u>Diabetes Management Summary Score</u> = 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>   |

# **PedsQL TM 3.0 Duchenne Muscular Dystrophy Module**



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

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

**DESCRIPTION OF THE DUCHENNE MUSCULAR DYSTROPHY MODULE:**

| Dimensions       | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|------------------|-----------------|------------------|------------------|--|
| Daily Activities | 5               | 1-5              | 1-5              | Higher scores indicate lower problems. |
| 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 reversed 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 and PARENT Reports for Children (ages 8-12), Teens  
(ages 13-18) and Young Adults (ages 18-25)**

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

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

are composed of 18 items comprising 4 dimensions.

**DESCRIPTION OF THE DUCHENNE MUSCULAR DYSTROPHY MODULE:**

| Dimensions       | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|------------------|-----------------|------------------|------------------|--|
| Daily Activities | 5               | 1-5              | 1-5              | Higher scores indicate lower problems. |
| 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 reversed 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™ 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™ 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 indicate lower problems. |
| 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 to a 0 to 100 scale.  |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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),  
Children (ages 8-12), Teens (ages 13-18), and Young Adults  
(ages 18-25)**

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

- Young Children (ages 5-7),
  - Children (ages 8-12),
  - And Teens ages (13-18),
  - Young Adults (ages 18-25)
- are composed of 34 items comprising 7 dimensions.

**DESCRIPTION OF THE END STAGE RENAL DISEASE MODULE:**

| Dimensions                    | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-------------------------------|-----------------|------------------|------------------|--|
| General Fatigue               | 4               | 1-4              | 1-4              | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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></p> <p>Items are reversed 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><u>Score by Dimensions:</u></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**

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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™ 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 indicate lower problems. |
| 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 to a 0 to 100 scale.  |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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><u>Symptoms Total Scale Score</u> = 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 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>  |

**REFERENCES:**

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

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

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

**DESCRIPTION OF THE EOSINOPHILIC ESOPHAGITIS MODULE:**

| Dimensions      | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-----------------|-----------------|------------------|------------------|--|
| Symptoms I      | 3               | 1-3              | 1-3              | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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 reversed 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 Feeding Tube Scale. For child self-report ages 5-7, sum all of the items over the number of items answered on all Scales except for Symptoms II and Feeding Tube Scale.</p> |

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|  |  |
|--|--|
| <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.<br>If 50% or more items are completed: Impute the mean of the completed items in a scale. |
|--|--|

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

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

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

are composed of 33 items comprising 7 dimensions.

**DESCRIPTION OF THE EOSINOPHILIC ESOPHAGITIS MODULE:**

| Dimensions      | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-----------------|-----------------|------------------|------------------|--|
| Symptoms I      | 6               | 1-6              | 1-6              | Higher scores indicate lower problems. |
| 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 reversed 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><u>Symptoms Total Scale Score</u> = 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 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™ 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™ Eosinophilic Esophagitis Symptoms Scales is composed of 7 items comprising 2 dimensions.

**DESCRIPTION OF THE EOSINOPHILIC ESOPHAGITIS MODULE:**

| Dimensions  | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-------------|-----------------|------------------|------------------|--|
| Symptoms I  | 3               | 1-3              | 1-3              | Higher scores indicate lower problems. |
| 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 to a 0 to 100 scale.   |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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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**PARENT Reports for Young Children (ages 5-7)**

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

**DESCRIPTION OF THE EOSINOPHILIC ESOPHAGITIS MODULE:**

| Dimensions  | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-------------|-----------------|------------------|------------------|--|
| Symptoms I  | 3               | 1-3              | 1-3              | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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 reversed 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),
- And Teens (ages 13-18)

are composed of 10 items comprising 2 dimensions.

**DESCRIPTION OF THE EOSINOPHILIC ESOPHAGITIS MODULE:**

| Dimensions  | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-------------|-----------------|------------------|------------------|--|
| Symptoms I  | 6               | 1-6              | 1-6              | Higher scores indicate lower problems. |
| 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 reversed 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<sup>™</sup> 3.0 Epilepsy 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 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 indicate lower problems. |
| 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 to a 0 to 100 scale.   |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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 Reports for Young Children (ages 5-7)**

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

**DESCRIPTION OF THE EPILEPSY MODULE:**

| Dimensions            | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-----------------------|-----------------|------------------|------------------|--|
| Impact                | 8               | 1-8              | 1-8              | Higher scores indicate lower problems. |
| 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 scale: 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><br/>                     Items are reversed 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 Reports for Young Children (ages 5-7)**

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The **Parent Reports** of the **PedsQL™ 3.0 Epilepsy Module** for:  
 - Young Children (ages 5-7)  
 are composed of 29 items comprising 5 dimensions.

**DESCRIPTION OF THE EPILEPSY MODULE:**

| Dimensions            | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-----------------------|-----------------|------------------|------------------|--|
| Impact                | 9               | 1-9              | 1-9              | Higher scores indicate lower problems. |
| 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><br/>                     Items are reversed 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), Teens  
(ages 13-18), Young Adults (ages 18-25)**

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

- Children (ages 8-12),
- Teens (ages 13-18)
- 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 indicate lower problems. |
| 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><br/>Items are reversed 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>TM</sup> 2.0 Family Impact Module**

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**PARENT Report**

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

**DESCRIPTION OF THE FAMILY IMPACT MODULE:**

| Dimensions            | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                    |
|-----------------------|-----------------|------------------|------------------|--|
| Physical Functioning  | 6               | 1-6              | 1-6              | Higher scores indicate 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 to a 0 to 100 scale.  |
| <b>Scoring Procedure</b>              | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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>• <u>The Total Score</u> is the sum of all 36 items divided by the number of items answered</li> <li>• <u>The Parent HRQL Summary Score</u> (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>• <u>The Family Functioning Summary Score</u> (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> |



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|  |  |
|--|--|
| <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.<br>If 50% or more items are completed: Impute the mean of the completed items in a scale. |
|--|--|

# **PedsQL™ 3.0 Gastrointestinal Symptoms Module**

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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™ 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 indicate lower problems. |
| Stomach Discomfort When Eating | 5               | 1-5              | 1-5              |  |
| Food and Drink Limits          | 6               | 1-6              | 1-6              |  |
| Trouble Swallowing             | 3               | 1-3              | 1-3              |  |
| Heart Burn and Reflux          | 4               | 1-4              | 1-4              |  |
| Nausea and Vomiting            | 4               | 1-4              | 1-4              |  |
| Gas and Bloating               | 7               | 1-7              | 1-7              |  |
| Constipation                   | 14              | 1-14             | 1-14             |  |
| Blood in Poop                  | 2               | 1-2              | 1-2              |  |
| Diarrhea                       | 7               | 1-7              | 1-7              |  |
| 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 to a 0 to 100 scale.  |
| <b>Scoring Procedure</b>              | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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><u>Symptoms Total Scales Score</u> = Sum of the items over the number of items answered in the 10 Symptoms Scales.</p> <p><b>Total Score:</b> Sum of all the items over the number of items answered on all the Scales.</p> |
| <p><b>Interpretation and Analysis of Missing Data</b></p> | <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 Report for Young Children (ages 5-7)**

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

**DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS MODULE:**

| Dimensions                     | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|--------------------------------|-----------------|------------------|------------------|--|
| Stomach Pain and Hurt          | 6               | 1-6              | 1-6              | Higher scores indicate lower problems. |
| Stomach Discomfort When Eating | 5               | 1-5              | 1-5              |  |
| Food and Drink Limits          | 6               | 1-6              | 1-6              |  |
| Trouble Swallowing             | 3               | 1-3              | 1-3              |  |
| Heart Burn and Reflux          | 4               | 1-4              | 1-4              |  |
| Nausea and Vomiting            | 4               | 1-4              | 1-4              |  |
| Gas and Bloating               | 7               | 1-7              | 1-7              |  |
| Constipation                   | 14              | 1-14             | 1-14             |  |
| Blood in Poop                  | 2               | 1-2              | 1-2              |  |
| Diarrhea                       | 7               | 1-7              | 1-7              |  |
| 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)<br>3-point scale: 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 reversed 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><u>Symptoms Total Scales Score</u> = Sum of the items over the number of items answered in the 10 Symptoms Scales.</p> <p><b>Total Score:</b> Sum of all the items over the number of items answered on all the Scales.</p> |
| <p><b>Interpretation and Analysis of Missing Data</b></p> | <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), Teens  
(ages 13-18) and Young Adults (18-25)**

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

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

are composed of 74 items comprising 14 dimensions.

**DESCRIPTION OF THE GASTROINTESTINAL SYMPTOMS MODULE:**

| Dimensions                               | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|--|-----------------|------------------|------------------|--|
| Stomach Pain and Hurt                    | 6               | 1-6              | 1-6              | Higher scores indicate lower problems. |
| Stomach Discomfort When Eating           | 5               | 1-5              | 1-5              |  |
| Food and Drink Limits                    | 6               | 1-6              | 1-6              |  |
| Trouble Swallowing                       | 3               | 1-3              | 1-3              |  |
| Heart Burn and Reflux                    | 4               | 1-4              | 1-4              |  |
| Nausea and Vomiting                      | 4               | 1-4              | 1-4              |  |
| Gas and Bloating                         | 7               | 1-7              | 1-7              |  |
| Constipation                             | 14              | 1-14             | 1-14             |  |
| Blood in Poop (Bowel Movement)           | 2               | 1-2              | 1-2              |  |
| Diarrhea                                 | 7               | 1-7              | 1-7              |  |
| 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 to a 0 to 100 scale.  |
| <b>Scoring Procedure</b>              | <b><u>Step 1: Transform Score</u></b><br>Items are reversed 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><u>Symptoms Total Scales Score</u> = 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> |
| <p><b>Interpretation and Analysis of Missing Data</b></p> | <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™ 3.0 Gastrointestinal 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™ 3.0 Gastrointestinal Symptoms Scales™** is composed of 58 items comprising 10 dimensions.

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

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

**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 to a 0 to 100 scale.   |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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 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** of the **PedsQL™ 3.0 Gastrointestinal Symptoms Scales™** for Young Children (ages 5-7) are composed of 58 items comprising 10 dimensions.

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

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

**SCORING OF DIMENSIONS:**

|  |   |
|--|---|
| <b>Item Scaling</b>                                | 5-point Likert scale from 0 (Never) to 4 (Almost always)<br>3-point scale: 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>Step 1: Transform Score</b></p> <p>Items are reversed scored and linearly transformed to a 0-100 scale as follows: 0=100, 1=75, 2=50, 3=25, 4=0</p> <p><b>Step 2: Calculate Scores by Dimensions</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>Symptoms Total Scales Score</b> = Sum of the items over the number of items answered in the 10 Symptoms 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), Teens  
(ages 13-18) and Young Adults (ages 18-25)**

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

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

are composed of 58 items comprising 10 dimensions.

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

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

**SCORING OF DIMENSIONS:**

|  |   |
|--|---|
| <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 to a 0 to 100 scale.   |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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 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™ General Well-Being Scale**

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

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

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

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

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

**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</u></b></p> <p><u>Score by Dimensions:</u></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™ Healthcare Satisfaction Generic Module**

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

**DESCRIPTION OF THE MODULE:**

| Dimensions           | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                     |
|----------------------|-----------------|------------------|------------------|---|
| Information          | 5               | 1-5              | No               | Higher scores indicate 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> Healthcare Satisfaction Hematology / Oncology Module**

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

**DESCRIPTION OF THE MODULE:**

| Dimensions           | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                     |
|----------------------|-----------------|------------------|------------------|---|
| General Satisfaction | 3               | 1-3              | No               | Higher scores indicate 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™ Infant Scales

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

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

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

| <b>Dimensions</b>     | <b>Number of Items</b> | <b>Cluster of Items</b> | <b>Reversed Scoring</b> | <b>Direction of Dimensions</b>       |
|-----------------------|------------------------|-------------------------|-------------------------|--------------------------------------|
| Physical Functioning  | 6                      | 1-6                     | 1-6                     | Higher scores indicate better HRQOL. |
| 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                     |                                      |

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

| <b>Dimensions</b>     | <b>Number of Items</b> | <b>Cluster of Items</b> | <b>Reversed Scoring</b> | <b>Direction of Dimensions</b>       |
|-----------------------|------------------------|-------------------------|-------------------------|--------------------------------------|
| Physical Functioning  | 9                      | 1-9                     | 1-9                     | Higher scores indicate better HRQOL. |
| 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.         |



|   |   |
|---|---|
| <p><b>Scoring Procedure</b></p>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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><u>Score by Dimensions:</u></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><u>Psychosocial Health Summary Score</u> = Sum of the items over the number of items answered in the Emotional, Social, and Cognitive Functioning Scales.</p> <p><u>Physical Health Summary Score</u> = 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> |
| <p><b>Interpretation and Analysis of Missing Data</b></p> | <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™ Multidimensional Fatigue Scale

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

### **DESCRIPTION OF THE MULTIDIMENSIONAL FATIGUE MODULE:**

| <b>Dimensions</b>  | <b>Number of Items</b> | <b>Cluster of Items</b> | <b>Reversed Scoring</b> | <b>Direction of Dimensions</b>         |
|--------------------|------------------------|-------------------------|-------------------------|--|
| General Fatigue    | 6                      | 1-6                     | 1-6                     | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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 reversed 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 Neurofibromatosis Module**

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

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

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

are composed of 104 items comprising 18 dimensions.

**DESCRIPTION OF THE NEUROFIBROMATOSIS MODULE:**

| Dimensions                    | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions |
|-------------------------------|-----------------|------------------|------------------|-------------------------|
| Skin Itch Bother              | 6               | 1-6              | 1-6              |                         |
| Skin Sensations               | 3               | 1-3              | 1-3              |                         |
| Pain                          | 6               | 1-6              | 1-6              |                         |
| Pain Impact                   | 16              | 1-16             | 1-16             |                         |
| 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              |                         |
| 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              |                         |

Higher scores indicate lower problems.

**SCORING OF DIMENSIONS:**

|  |   |
|--|---|
| <b>Item Scaling</b>                                | 5-point Likert scale from 0 (Never) to 4 (Almost always)<br>3-point scale: 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><br/>Items are reversed 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 Neuromuscular Module**

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

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

are composed of 25 items comprising 3 dimensions.

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

**DESCRIPTION OF THE NEUROMUSCULAR MODULE:**

| Dimensions                     | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|--------------------------------|-----------------|------------------|------------------|--|
| About My Neuromuscular Disease | 17              | 1-17             | 1-17             | Higher scores indicate lower problems. |
| 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 reversed 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™ Oral Health Scale

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

### **DESCRIPTION OF THE ORAL HEALTH SCALE:**

| <b>Dimensions</b> | <b>Number of Items</b> | <b>Cluster of Items</b> | <b>Reversed Scoring</b> | <b>Direction of Dimensions</b>        |
|-------------------|------------------------|-------------------------|-------------------------|---------------------------------------|
| Oral Health       | 5                      | 1-5                     | 1-5                     | Higher scores indicate lower problems |

### **SCORING OF DIMENSIONS:**

|  |  |
|--|--|
| <b>Item Scaling</b>                                | 5-point Likert scale from 0 (Never) to 4 (Almost always)<br>3-point scale: 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 reversed 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 and Teens (ages 5-18),  
CHILD Report for Children (ages 5-12), Teens (ages 13-18)**

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

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

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

are composed of 41 items comprising 5 dimensions.

See Varni, J.W. et al. (1996). Development of the Waldron/Varni Pediatric Pain Coping Inventory. *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 indicate 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><br>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.<br><br>If 50% or more items are completed: Impute the mean of the completed items in a scale. |

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

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

**DESCRIPTION OF THE QUESTIONNAIRE:**

| Dimensions   | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions               |
|--------------|-----------------|------------------|------------------|---------------------------------------|
| Present Pain | 1               | 1                | 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 0 (Not hurting / No discomfort / No pain) to 10 (100) (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>                           | Present pain and worst pain are scored separately.<br>The score is based on line length to the nearest 0.5 cm (5mm).                        |
| <b>Interpretation and Analysis of Missing Data</b> | There is no imputation process since these are single item VAS scales.  |

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

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

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The **PedsQL™ 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™ 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 indicate lower problems. |
| 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 to a 0 to 100 scale.  |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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** of the **PedsQL™ 3.0 Rheumatology Module** for Young Children (ages 5-7) are composed of 20 items comprising 5 dimensions.

**DESCRIPTION OF THE RHEUMATOLOGY MODULE:**

| Dimensions       | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|------------------|-----------------|------------------|------------------|--|
| Pain and Hurt    | 4               | 1-4              | 1-4              | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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><br/>Items are reversed 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™ 3.0 Rheumatology Module** for:

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

are composed of 22 items comprising 5 dimensions.

**DESCRIPTION OF THE RHEUMATOLOGY MODULE:**

| Dimensions       | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|------------------|-----------------|------------------|------------------|--|
| Pain and Hurt    | 4               | 1-4              | 1-4              | Higher scores indicate lower problems. |
| 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><br/>                 Items are reversed 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™ 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 indicate lower problems. |
| 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 to a 0 to 100 scale.  |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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 indicate lower problems. |
| 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)<br>3-point scale: 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 reversed 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), Teens (ages 13-18), Young Adults (ages 18-25), and Adults (ages over 26)**

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

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

are composed of 43 items comprising 9 dimensions.

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

| Dimensions       | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|------------------|-----------------|------------------|------------------|--|
| Pain and Hurt    | 9               | 1-9              | 1-9              | Higher scores indicate lower problems. |
| 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 reversed 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™ 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 indicate lower problems. |
| 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 to a 0 to 100 scale.  |
| <b>Scoring Procedure</b>                           | <p><b><u>Step 1: Transform Score</u></b></p> <p>Items are reversed 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 indicate lower problems. |
| 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 reversed 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)**

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 indicate lower problems. |
| 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 reversed 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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**TEEN and PARENT Reports for Teens (ages 13-18)**

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

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

| Dimensions        | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|-------------------|-----------------|------------------|------------------|--|
| Pain and Hurt     | 2               | 1-2              | 1-2              | Higher scores indicate lower problems. |
| 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 reversed 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 Transplant Module**

The [PedsQLTM 3.0 Transplant Module](#) is composed of 46 items comprising 8 dimensions.

**DESCRIPTION OF THE TRANSPLANT MODULE:**

| Dimensions               | Number of Items | Cluster of Items | Reversed Scoring | Direction of Dimensions                |
|--------------------------|-----------------|------------------|------------------|--|
| About My Medicines I     | 9               | 1-9              | 1-9              | Higher scores indicate lower problems. |
| 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)<br>3-point scale: 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 reversed 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>   |