

**Welcome to the second round on Patient Reported Outcome (PRO) measures for use with children who have a Brachial Plexus Birth Injury (BPBI).**

We were pleased to analyse results from 36 centers worldwide that completed the first PRO round. The moderator team decided that only the top 3 ranked questionnaires will be selected for the second PRO round. In some categories the ranking in the alternative age group was decisive.

The results of the first round will be presented to anchor you to the collective groups' opinion. The mean ratings for each PRO measure will be calculated as final score. Scores between 7-9 are defined as 'in favour' / 'agree', while scores between 1-3 are defined as 'not in favour' / 'disagree'. Scores between 4-6 are considered 'neutral' opinions.

Additionally, you will find the free-text comments that participants entered during the previous round.

It is – again – expected that you discuss the questions within your multidisciplinary team and answer the questions **as a team**. To facilitate this a PDF file has been prepared that includes all questions.

<< link >>

In this PDF you'll also find the answers to the previous round on PRO measures. **It is intended that you print this PDF file double-sided so that the results from the last round are on the left page, while the questions are repeated on the right page.**

Please avoid to score 'no opinion'. In the PDF of the previous PRO round we included sample pages from each questionnaire and weblinks to gain insight in each questionnaire.

<https://iplutodotorg.files.wordpress.com/2018/12/questions-round-52.pdf>

This PDF includes a general outline of the rounds evaluating PRO measures.



## General questions

### Question 1.

Assessment of outcome using PROs is useful for clinical evaluation and patient treatment.

#### *Results of the previous round for Question 1*

Mean score: 7.0  
Scores 1-3 (disagree) 0%  
Scores 4-6 (neutral) 33%  
Scores 7-9 (agree) 67%

*Please indicate your opinion...*

	1	2	3	4	5	6	7	8	9	
fully disagree	( )	( )	( )	( )	( )	( )	( )	( )	( )	fully agree

### Question 2.

Assessment of outcome using PROs is useful for scientific evaluation (e.g. research, audit, quality improvement).

#### *Results of the previous round for Question 2*

Mean score: 7.08  
Scores 1-3 (disagree) 14%  
Scores 4-6 (neutral) 14%  
Scores 7-9 (agree) 72%

*Please indicate your opinion...*

	1	2	3	4	5	6	7	8	9	
fully disagree	( )	( )	( )	( )	( )	( )	( )	( )	( )	fully agree

## **Summary of answers from the previous round - Functional status**

		average	CHEQ	PODCI	HUH	PROMISue	BPOM	DASH
<b>responsiveness</b>	<b><i>no opinion</i></b>	<b>15%</b>	9%	13%	24%	24%	9%	9%
	<b><i>mean</i></b>	<b>4,92</b>	4,94	4,31	5,21	5,07	5,58	4,39
	<b><i>score 7-9</i></b>	<b>38%</b>	36%	31%	45%	34%	55%	27%
	<b><i>score 1-3</i></b>	<b>33%</b>	30%	44%	28%	28%	24%	45%
<b>current state</b>	<b><i>no opinion</i></b>	<b>15%</b>	9%	13%	24%	24%	9%	9%
	<b><i>mean</i></b>	<b>5,37</b>	5,27	4,91	5,66	5,41	5,97	5,03
	<b><i>score 7-9</i></b>	<b>48%</b>	45%	44%	55%	41%	61%	39%
	<b><i>score 1-3</i></b>	<b>26%</b>	27%	34%	21%	21%	18%	36%
<b>applicability</b>	<b><i>no opinion</i></b>	<b>16%</b>	9%	13%	33%	29%	9%	6%
	<b><i>mean</i></b>	<b>6,09</b>	5,88	5,19	6,70	5,71	7,21	5,85
	<b><i>score 7-9</i></b>	<b>51%</b>	48%	34%	67%	39%	73%	47%
	<b><i>score 1-3</i></b>	<b>17%</b>	18%	31%	7%	21%	6%	18%
<b>specificity</b>	<b><i>no opinion</i></b>	<b>15%</b>	9%	13%	29%	24%	9%	6%
	<b><i>mean</i></b>	<b>5,28</b>	5,70	3,88	5,75	4,52	7,33	4,53
	<b><i>score 7-9</i></b>	<b>36%</b>	42%	22%	43%	17%	73%	21%
	<b><i>score 1-3</i></b>	<b>29%</b>	18%	59%	18%	38%	6%	32%
<b>ages</b>	<b>1</b>	<b>2%</b>	2%	3%	5%	3%	0%	0%
	<b>3</b>	<b>10%</b>	5%	12%	25%	7%	10%	0%
	<b>5</b>	<b>18%</b>	19%	24%	28%	19%	17%	0%
	<b>7</b>	<b>26%</b>	30%	28%	28%	31%	33%	5%
	<b>15</b>	<b>28%</b>	28%	27%	9%	28%	29%	49%
	<b>adult</b>	<b>14%</b>	14%	4%	4%	10%	11%	44%
	<b>other</b>	<b>2%</b>	2%	3%	1%	1%	0%	2%
	<b><i>no opinion (n)</i></b>	<b>7,33</b>	6	8	10	10	6	4

*Shaded: items that scored above average or > 20% (in the age groups)*

What is the best PRO to evaluate Functional status for **children (<10 years)** in your opinion, when taking into account all merits and drawbacks.

**CHEQ** 9

**PODCI** 7

**HUH** 6

**BPOM** 6

**PROMIS-UE** 4

ABILHAND 3

DASH 1

PEM-CY 0

MHQ 0

WOSI 0

What is the best PRO to evaluate Functional status for **teens / adolescents (> 10 years)** in your opinion, when taking into account all merits and drawbacks.

**BPOM** 10

**PROMIS-UE** 6

**DASH** 6

CHEQ 5

ABILHAND 3

PODCI 2

HUH 1

PEM-CY 1

MHQ 1

WOSI 1

*In **bold** the PRO measures that made it to the next round.*

<b>Measure (abb)</b>	<b>CHEQ</b>
<b>Measure (full)</b>	Children's Hand-use Experience Questionnaire
<b>Reference</b>	<a href="https://www.ncbi.nlm.nih.gov/pubmed/26610725">https://www.ncbi.nlm.nih.gov/pubmed/26610725</a>
<b>Description</b>	The CHEQ is a questionnaire developed for children and adolescents with decreased function in one hand (e.g., hemiplegic cerebral palsy, obstetric brachial plexus palsy) and for their parents. The questionnaire was developed to evaluate the experience of children and adolescents in using their affected hand in activities where usually two hands are needed. The experience of hand use are measured in three domains: grasp efficiency, time taken, and feeling bothered for bimanual activities.
<b>No of items / questions</b>	27 (Cheq 2.0), 29 (Cheq 1.0)
<b>Target</b>	Self-reported hand use for bimanual activities
<b>Questionnaire (direct link)</b>	<a href="http://www.cheq.se/">http://www.cheq.se/</a>
<b>Validated or used for BPBI</b>	Skold 2011 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/21413973">https://www.ncbi.nlm.nih.gov/pubmed/21413973</a>
<b>Availability</b>	free
<b>Ages</b>	6-18
<b>Languages</b>	Arabic, Portuguese, Dutch, English, German, French, Hebrew, Italian, Japanese, Norwegian, Spanish, Swedish, Turkish
<b>Classification (Isoquol)</b>	Functional Status PRO-children
<b>ICF domains</b>	ICF - Activities
<b>PDF available</b>	yes

**CHEQ** Free text comments from the previous round

- This PRO seems overly concerned about the flexibilities of the hand, while attention to the functions of shoulder and elbow is not sufficient.
- Ignores shoulder and elbow functions, seems this would only be applicable to global injuries
- The assessment of this(and subsequent PROM's) in infants has been taken as assessment in the < 2yr old group - hence the poor scores for the initial questions re responsiveness in assessment of Rx and current level of function
- Difficult for me to implement
- Would be interesting to have some test exploring geometrical capacities (using rule)
- The CHEQ measures bimanual activities for hand function that take place in front of the body, it does not measure positioning the hand in space. Hence it is more a function for children with C7/C8/T1 dysfunction, while most children are limited in shoulder function and lack range of shoulder function.
- use it as goal setting exercise with clients prior to therapy intervention block or pre/post op
- Mini Cheq for younger Children 3-8 yoa
- Although the CHEQ is an excellent questionnaire with appropriate content, our team's primary concern is that you do not have access to your own patient data when entered online. Therefore, this is not practical or useful for our clinic.

## **CHEQ - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score:	4.94
Scores 7-9 (useful)	36%
Scores 1-3 (not useful)	30%
No opinion	8%

### Usefulness to evaluate current state

Mean score:	5.27
Scores 7-9 (useful)	45%
Scores 1-3 (not useful)	27%
No opinion	8%

### Clinical applicability / feasibility.

Mean score:	5.88
Scores 7-9 (easy)	48%
Scores 1-3 (not easy)	18%
No opinion	8%

### Specificity for BPBI:

Mean score:	5.70
Scores 7-9 (specific)	42%
Scores 1-3 (not specific)	18%
No opinion	8%

"This PRO measure should be employed at..."

1	2%
3	5%
5	19%
7	30%
15	28%
adult	14%
other	2%

no opinion (n)6

## **CHEQ - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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<b>Measure (abb)</b>	<b>PODCI</b>
<b>Measure (full)</b>	Pediatric Outcomes Data Collection Instrument
<b>Reference</b>	<a href="https://www.ncbi.nlm.nih.gov/pubmed/8773720">https://www.ncbi.nlm.nih.gov/pubmed/8773720</a>
<b>Description</b>	A questionnaire which quantifies functional health status with a focus on musculoskeletal health in children and adolescents through four domains. The instrument includes seven dimensions: upper extremity and physical function, transfers and basic mobility, sports and physical functioning, pain and comfort, happiness, satisfaction, and expectations.
<b>No of items / questions</b>	86
<b>Target</b>	functional health status
<b>Questionnaire (direct link)</b>	<a href="https://www.aaos.org/research/outcomes/Pediatric.pdf">https://www.aaos.org/research/outcomes/Pediatric.pdf</a>
<b>Validated or used for BPBI</b>	Huffman 2005 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/15832163">https://www.ncbi.nlm.nih.gov/pubmed/15832163</a> Bae 2008 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/18580377">https://www.ncbi.nlm.nih.gov/pubmed/18580377</a> Eismann 2014 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/24599198">https://www.ncbi.nlm.nih.gov/pubmed/24599198</a>
<b>Availability</b>	free
<b>Ages</b>	2-18
<b>Languages</b>	English, Dutch, Korean, Spanish
<b>Classification (Isoquol)</b>	Functional Status PRO-children
<b>ICF domains</b>	ICF - Body functions & structures
	ICF - Activities
	ICF - Participation
	ICF - Personal Factors
	ICF - Environmental Factors
<b>PDF available</b>	yes

**PODCI** - Free text comments from the previous round

- Much emphasis to lower extremities, this is the PRO that can be administered at the youngest age (2y). Also lots of historical data available using this measure.
- please see above, the PODCI was not felt to be useful in our hands
- Difficult to implement.
- To wide and generalist.
- Advantage of PODCI is that it also contains questions concerning shoulder function / positioning in space.
- we do not use in infants hence answered 2 to first two questions.
- we use it in children/teens
- We do not use this instrument.
- Not applicable for this population. Primary concern - poor specificity.

## **PODCI - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score:	4.31
Scores 7-9 (useful)	31%
Scores 1-3 (not useful)	44%
No opinion	13%

### Usefulness to evaluate current state

Mean score:	4.91
Scores 7-9 (useful)	44%
Scores 1-3 (not useful)	34%
No opinion	13%

### Clinical applicability / feasibility.

Mean score:	5.19
Scores 7-9 (easy)	34%
Scores 1-3 (not easy)	31%
No opinion	13%

### Specificity for BPBI:

Mean score:	3.88
Scores 7-9 (specific)	22%
Scores 1-3 (not specific)	59%
No opinion	13%

"This PRO measure should be employed at..."

1	3%
3	12%
5	24%
7	28%
15	27%
adult	4%
other	3%

no opinion (n)8

## **PODCI - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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<b>Measure (abb)</b>	<b>HUH</b>
<b>Measure (full)</b>	Hand Use at Home questionnaire
<b>Reference</b>	<a href="https://www.ncbi.nlm.nih.gov/pubmed/28555780">https://www.ncbi.nlm.nih.gov/pubmed/28555780</a>
<b>Description</b>	A parent-rated questionnaire to assess the amount of spontaneous use of the affected hand in children with unilateral upper-limb paresis.
<b>No of items / questions</b>	18
<b>Target</b>	spontaneous use of affected arm
<b>Questionnaire (direct link)</b>	<a href="http://journals.sagepub.com/doi/suppl/10.1177/0269215518775156">http://journals.sagepub.com/doi/suppl/10.1177/0269215518775156</a>
<b>Validated or used for BPBI</b>	vanderHolst 2018 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/29756465">https://www.ncbi.nlm.nih.gov/pubmed/29756465</a>
<b>Availability</b>	free
<b>Ages</b>	3-10
<b>Languages</b>	English, Dutch
<b>Classification (Isoquol)</b>	Functional Status PRO-children
<b>ICF domains</b>	ICF - Activities
<b>PDF available</b>	yes

## **HUH** - Free text comments from the previous round

- Not suitable for older children or long time follow-up
- Difficult to implement
- Seems good because of the assessment of affected hand use and the quickness of realization
- Measures actual hand use, as observed by parents.
- We don't use this instrument.
- Narrow age range. Not tested at our department
- This is a parent report questionnaire. Concern that patients are not evaluated in the context of their own environment.
- It's not in spanish

## **HUH - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score: 5.21  
Scores 7-9 (useful) 45%  
Scores 1-3 (not useful) 28%  
No opinion 24%

### Usefulness to evaluate current state

Mean score: 5.66  
Scores 7-9 (useful) 55%  
Scores 1-3 (not useful) 21%  
No opinion 24%

### Clinical applicability / feasibility.

Mean score: 6.70  
Scores 7-9 (easy) 67%  
Scores 1-3 (not easy) 7%  
No opinion 33%

### Specificity for BPBI:

Mean score: 5.75  
Scores 7-9 (specific) 43%  
Scores 1-3 (not specific) 18%  
No opinion 29%

"This PRO measure should be employed at..."

1 5%  
3 25%  
5 28%  
7 28%  
15 9%  
adult 4%  
other 1%

no opinion (n)10

## **HUH - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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<b>Measure (abb)</b>	<b>PROMIS - Upper Extremity</b>
<b>Measure (full)</b>	Patient-Reported Outcomes Measurement Information System - Pediatric upper extremity
<b>Reference</b>	<a href="http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-pediatric-measures">http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-pediatric-measures</a>
<b>Description</b>	Activities that require use of the upper extremity including shoulder, arm, and hand activities.
<b>No of items / questions</b>	34 (patients) 29 (parents)
<b>Target</b>	activities
<b>Questionnaire (direct link)</b>	<a href="http://www.healthmeasures.net/search-view-measures">http://www.healthmeasures.net/search-view-measures</a>
<b>Validated or used for BPBI</b>	
<b>Availability</b>	free on paper, paid electronically
<b>Ages</b>	
<b>Languages</b>	Dutch, Portuguese-Brazilian, Spanish
<b>Classification (Isoquol)</b>	Functional Status PRO-children
<b>ICF domains</b>	ICF - Activities
<b>PDF available</b>	yes

**PROMIS UE** - Free text comments from the previous round

- expensive to translate
- allmost omitted shoulder and elbow
- very easy to administer. easy to compare results to other conditions.
- No comment
- Too wide
- Affected hand impairment may easlyly not appear because of adaptations efficiency,
- We don't use this instrument
- Few bimanual activities. We can´t see that the questions specify usage of your injured hand (for example "I could hold a full cup)
- 8 years of age
- infants by parental proxy

## **PROMIS UE - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score:	5.07
Scores 7-9 (useful)	34%
Scores 1-3 (not useful)	28%
No opinion	24%

### Usefulness to evaluate current state

Mean score:	5.41
Scores 7-9 (useful)	41%
Scores 1-3 (not useful)	21%
No opinion	24%

### Clinical applicability / feasibility.

Mean score:	5.71
Scores 7-9 (easy)	39%
Scores 1-3 (not easy)	21%
No opinion	29%

### Specificity for BPBI:

Mean score:	4.52
Scores 7-9 (specific)	17%
Scores 1-3 (not specific)	38%
No opinion	24%

"This PRO measure should be employed at..."

1	3%
3	7%
5	19%
7	31%
15	28%
adult	10%
other	1%

no opinion (n)10

## **PROMIS UE - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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<b>Measure (abb)</b>	<b>BPOM</b>
<b>Measure (full)</b>	Brachial Plexus Outcome Measurement - self evaluation scales
<b>Reference</b>	<a href="https://www.ncbi.nlm.nih.gov/pubmed/22818900">https://www.ncbi.nlm.nih.gov/pubmed/22818900</a>
<b>Description</b>	The Brachial Plexus Outcome Measure (BPOM) Self-evaluation Scale is a PRO measure completed by children > 6 years that screens whether their perception of upper extremity function and appearance hinders or enhances his/her participation in daily activities. It consists of 3 (100 mm) visual analog scales that evaluate the perceived arm function, perceived hand function and perceived appearance of the upper limb.
<b>No of items / questions</b>	3
<b>Target</b>	use of arm / use of hand / appearance of arm & hand
<b>Questionnaire (direct link)</b>	<a href="https://www.vll.se/VLL/Filer/BPOM%20Manual%20v.%202.0%20e-version.pdf">https://www.vll.se/VLL/Filer/BPOM%20Manual%20v.%202.0%20e-version.pdf</a>
<b>Validated or used for BPBI</b>	Hosbay 2018 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/29395601">https://www.ncbi.nlm.nih.gov/pubmed/29395601</a>
<b>Availability</b>	free
<b>Ages</b>	
<b>Languages</b>	english
<b>Classification (Isoquol)</b>	Functional Status PRO-children
<b>ICF domains</b>	ICF - Participation
	ICF - Personal Factors
<b>PDF available</b>	yes

**BPOM** - Free text comments from the previous round

- difficult scoring
- many confounding factors which change over ages.
- Not suitable as the only prom
- Perhaps worthwhile
- Good
- Functional and PRO Mallet type evaluation including appearance, but quite poor
- again we do not use in infants but find it useful for children/teens.
- We use this tool occasionally
- only measure that considers appearance, not designed for infants.
- would need parental proxy for infants

## **BPOM - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score: 5.58  
Scores 7-9 (useful) 55%  
Scores 1-3 (not useful) 24%  
No opinion 9%

### Usefulness to evaluate current state

Mean score: 5.97  
Scores 7-9 (useful) 61%  
Scores 1-3 (not useful) 18%  
No opinion 9%

### Clinical applicability / feasibility.

Mean score: 7.21  
Scores 7-9 (easy) 73%  
Scores 1-3 (not easy) 6%  
No opinion 9%

### Specificity for BPBI:

Mean score: 7.33  
Scores 7-9 (specific) 73%  
Scores 1-3 (not specific) 6%  
No opinion 3%

"This PRO measure should be employed at..."

1 0%  
3 10%  
5 17%  
7 33%  
15 29%  
adult 11%  
other 0%

no opinion (n)6

## **BPOM - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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<b>Measure (abb)</b>	<b>DASH</b>
<b>Measure (full)</b>	Disability of the Arm, Shoulder, and Hand
<b>Reference</b>	<a href="http://www.dash.iwh.on.ca/">http://www.dash.iwh.on.ca/</a>
<b>Description</b>	A PRO measure that measures the ability to do a number of activities in the last week (21 items) and the severity of symptoms in the last week (5 items).
<b>No of items / questions</b>	30 plus work and play modules
<b>Target</b>	physical function and symptoms in the UL
<b>Questionnaire (direct link)</b>	<a href="http://www.dash.iwh.on.ca/about-dash">http://www.dash.iwh.on.ca/about-dash</a>
<b>Validated or used for BPBI</b>	Butler 2017 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/28719549">https://www.ncbi.nlm.nih.gov/pubmed/28719549</a> de Heer 2015 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/25332088">https://www.ncbi.nlm.nih.gov/pubmed/25332088</a>
<b>Availability</b>	free
<b>Ages</b>	16 – 18 10 - 18 however problems with understanding of some terminology/words by younger children (Heyworth 2018)
<b>Languages</b>	52 languages
<b>Classification (Isoquol)</b>	Functional Status PRO- teens and adults
<b>ICF domains</b>	ICF - Body functions & structures
	ICF - Activities
	ICF - Participation
<b>PDF available</b>	yes

**DASH** - Free text comments from the previous round

- Generally not applicable with children
- Not useful
- To wide and unspecific about the side to used in performing activities
- Many questions concerning adult activities
- Useful, but adult oriented
- Non specific for these patients
- 16+
- Please consider adding the DASH short version as a consideration

## **DASH - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score: 4.39  
Scores 7-9 (useful) 27%  
Scores 1-3 (not useful) 45%  
No opinion 9%

### Usefulness to evaluate current state

Mean score: 5.03  
Scores 7-9 (useful) 39%  
Scores 1-3 (not useful) 36%  
No opinion 9%

### Clinical applicability / feasibility.

Mean score: 5.85  
Scores 7-9 (easy) 47%  
Scores 1-3 (not easy) 18%  
No opinion 6%

### Specificity for BPBI:

Mean score: 4.53  
Scores 7-9 (specific) 21%  
Scores 1-3 (not specific) 32%  
No opinion 6%

"This PRO measure should be employed at..."

1 0%  
3 0%  
5 0%  
7 5%  
15 49%  
adult 44%  
other 2%

no opinion (n)4

## **DASH - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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### **Answers from the previous round**

What is the best PRO to evaluate Functional status for children (<10 years) in your opinion, when taking into account all merits and drawbacks.

CHEQ 9

PODCI 7

HUH 6

BPOM 6

PROMIS-UE 4

What is the best PRO to evaluate Functional status for teens / adolescents (> 10 years) in your opinion, when taking into account all merits and drawbacks.

BPOM 10

PROMIS-UE 6

DASH 6

## Questions current round

What is the best PRO to evaluate **Functional status for children** (<10 years) in your opinion, when taking into account all merits and drawbacks.

- ( ) CHEQ - Children's Hand-use Experience Questionnaire
- ( ) PODCI -Pediatric Outcomes Data Collection Instrument
- ( ) HUH - Hand Use at Home questionnaire
- ( ) BPOM - Brachial Plexus Outcome Measurement - self evaluation scales
- ( ) PROMIS - Upper Extremity

What is the best PRO to evaluate **Functional status for teens / adolescents** (> 10 years) in your opinion, when taking into account all merits and drawbacks.

- ( ) BPOM - Brachial Plexus Outcome Measurement - self evaluation scales
- ( ) PROMIS - Upper Extremity
- ( ) DASH - Disability of the Arm, Shoulder, and Hand

### **Summary of answers from the previous round - Global Health status**

		average	PROMIS_gh	PEDS_QL	EQ5D_Y
<b>responsiveness</b>	<b><i>no opinion</i></b>	<b>27%</b>	33%	20%	29%
	<b><i>mean</i></b>	<b>3,46</b>	3,37	3,50	3,50
	<b><i>score 7-9</i></b>	<b>17%</b>	19%	13%	18%
	<b><i>score 1-3</i></b>	<b>55%</b>	59%	50%	57%
<b>current state</b>	<b><i>no opinion</i></b>	<b>27%</b>	33%	20%	29%
	<b><i>mean</i></b>	<b>3,92</b>	3,96	4,13	3,68
	<b><i>score 7-9</i></b>	<b>15%</b>	15%	20%	11%
	<b><i>score 1-3</i></b>	<b>47%</b>	52%	37%	54%
<b>applicability</b>	<b><i>no opinion</i></b>	<b>27%</b>	29%	24%	29%
	<b><i>mean</i></b>	<b>5,80</b>	5,64	5,66	6,11
	<b><i>score 7-9</i></b>	<b>45%</b>	39%	41%	54%
	<b><i>score 1-3</i></b>	<b>14%</b>	21%	14%	7%
<b>specificity</b>	<b><i>no opinion</i></b>	<b>29%</b>	33%	24%	29%
	<b><i>mean</i></b>	<b>3,10</b>	3,19	3,41	2,71
	<b><i>score 7-9</i></b>	<b>10%</b>	11%	10%	7%
	<b><i>score 1-3</i></b>	<b>67%</b>	67%	59%	75%
<b>ages</b>	<b>1</b>		0%	0%	0%
	<b>3</b>		4%	2%	2%
	<b>5</b>		16%	12%	17%
	<b>7</b>		25%	37%	32%
	<b>15</b>		38%	39%	40%
	<b><i>adult</i></b>		16%	6%	6%
	<b><i>other</i></b>		2%	4%	2%
	<b><i>no opinion</i></b>				
	<b><i>(n)</i></b>		15	10	16

*Shaded: items that scored above average or > 20% (in the age groups)*

What is the best PRO to evaluate Health related Quality of life for children (< 10 years) in your opinion, when taking into account all merits and drawbacks.

**PedsQL** **16**

**EQ5D-Y** **10**

**PROMIS\_gl\_health 6**

CHQ 3

PROMIS\_peer\_rel 1

What is the best PRO to evaluate Health related Quality of life for teens / adolescents (> 10 years) in your opinion, when taking into account all merits and drawbacks.

**PedsQL** **13**

**EQ5D-Y** **9**

**PROMIS\_gl\_health 5**

CHQ 5

PROMIS\_peer\_rel 4

*In **bold** the PRO measures that made it to the next round.*

<b>Measure (abb)</b>	<b>PROMIS - Global Health Scale</b>
<b>Measure (full)</b>	Patient-Reported Outcomes Measurement Information System Global Health Scale
<b>Reference</b>	<a href="http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-pediatric-measures">http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-pediatric-measures</a>
<b>Description</b>	Overall evaluation of the child's physical and mental health.
<b>No of items / questions</b>	9 (patients) 7 (parents)
<b>Target</b>	QoL physical and MH
<b>Questionnaire (direct link)</b>	<a href="http://www.healthmeasures.net/search-view-measures">http://www.healthmeasures.net/search-view-measures</a>
<b>Validated or used for BPBI</b>	
<b>Availability</b>	PDF free licence for electronic submissions
<b>Ages</b>	(patient) 8 - 17 (parent) 5 - 17
<b>Languages</b>	English - Spanish - others available via online request
<b>Classification (Isoquol)</b>	HRQOL PRO - children
<b>ICF domains</b>	ICF - Body functions & structures
	ICF - Participation
	ICF - Personal Factors
	ICF - Environmental Factors
<b>PDF available</b>	yes

**PROMIS – Global Health** - Free text comments from the previous round

- expensive to translate
- We don't use this instrument
- no practical experience
- 8 years
- Please also consider putting an option of using the PROMIS global short form
- It has a version for parental proxy, which is good. But I advise against using a scale for global assessment of functioning, as it is not condition-specific.

## **PROMIS Global Health - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score:	3.37
Scores 7-9 (useful)	19%
Scores 1-3 (not useful)	59%
No opinion	33%

### Usefulness to evaluate current state

Mean score:	3.96
Scores 7-9 (useful)	15%
Scores 1-3 (not useful)	52%
No opinion	33%

### Clinical applicability / feasibility.

Mean score:	5.64
Scores 7-9 (easy)	39%
Scores 1-3 (not easy)	21%
No opinion	29%

### Specificity for BPBI:

Mean score:	3.19
Scores 7-9 (specific)	11%
Scores 1-3 (not specific)	67%
No opinion	9%

"This PRO measure should be employed at..."

1	0%
3	4%
5	16%
7	25%
15	38%
adult	16%
other	2%

no opinion (n)15

## **PROMIS Global Health - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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<b>Measure (abb)</b>	<b>PedsQL</b>
<b>Measure (full)</b>	Pediatric Quality of Life Inventory
<b>Reference</b>	<a href="http://www.pedsql.org/">http://www.pedsql.org/</a>
<b>Description</b>	The PedsQL Measurement Model is a modular approach to measuring health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions.
<b>No of items / questions</b>	23 (child) 23 (teen) 23 (parent)
<b>Target</b>	QoL
<b>Questionnaire (direct link)</b>	
<b>Validated or used for BPBI</b>	Butler 2017 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/28719549">https://www.ncbi.nlm.nih.gov/pubmed/28719549</a>
<b>Availability</b>	licence
<b>Ages</b>	8 - 12 (child) 13 - 18 (teen) 8 - 12 (parent)
<b>Languages</b>	28 languages (English - Spanish - German - French - Dutch - Portuguese - mandarin - Croatian - Czech - Danish - Finnish - Swedish - Greek - Cantonese - Hungarian - Arabic - Russian - Hebrew - Italian - Japanese - Lithuanian - Norwegian - Polish - Serbian - Malay - Slovak - Thai - Turkish)
<b>Classification (Isoquol)</b>	HRQOL PRO - children
<b>ICF domains</b>	ICF - Body functions & structures
	ICF - Activities
	ICF - Participation
	ICF - Personal Factors
	ICF - Environmental Factors
<b>PDF available</b>	yes

**Peds QL** – Free text comments from the previous round

- Again not suitable for infants, but can be used as required
- we do not tend to use in BPP population but do sometimes in CP population
- this is our 2nd choice for this category
- developed for cancer population
- our team has a strong preference not to adopt this measure for BPBI

### **Peds QL - Results of the previous round**

#### Usefulness to evaluate responsiveness

Mean score:	3.50
Scores 7-9 (useful)	13%
Scores 1-3 (not useful)	50%
No opinion	20%

#### Usefulness to evaluate current state

Mean score:	4.13
Scores 7-9 (useful)	20%
Scores 1-3 (not useful)	37%
No opinion	20%

#### Clinical applicability / feasibility.

Mean score:	5.66
Scores 7-9 (easy)	41%
Scores 1-3 (not easy)	14%
No opinion	24%

#### Specificity for BPBI:

Mean score:	3.41
Scores 7-9 (specific)	10%
Scores 1-3 (not specific)	59%
No opinion	24%

"This PRO measure should be employed at..."

1	0%
3	2%
5	12%
7	37%
15	39%
adult	6%
other	4%

no opinion (n)10

## **Peds QL - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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<b>Measure (abb)</b>	<b>EQ5D-Y</b>
<b>Measure (full)</b>	EuroQol five Dimensional scale - Youth edition
<b>Reference</b>	<a href="https://euroqol.org/eq-5d-instruments/eq-5d-y-about/">https://euroqol.org/eq-5d-instruments/eq-5d-y-about/</a>
<b>Description</b>	<p>The child-friendly EQ-5D version (EQ-5D-Y) was introduced by the EuroQol Group in 2009 as a more comprehensible instrument suitable for children and adolescents. The EQ-5D-Y is based on the EQ-5D-3L and essentially consists of 2 pages: the EQ-5D descriptive system and the EQ visual analogue scale (EQ VAS).</p> <p>The EQ-5D-Y descriptive system comprises the following five dimensions: mobility, looking after myself, doing usual activities, having pain or discomfort and feeling worried, sad or unhappy. Each dimension has 3 levels: no problems, some problems and a lot of problems. The younger patient is asked to indicate his/her health state by ticking the box next to the most appropriate statement in each of the five dimensions. This decision results in a 1-digit number that expresses the level selected for that dimension</p>
<b>No of items / questions</b>	6
<b>Target</b>	QoL
<b>Questionnaire (direct link)</b>	<a href="https://euroqol.org/support/how-to-obtain-eq-5d/">https://euroqol.org/support/how-to-obtain-eq-5d/</a>
<b>Validated or used for BPBI</b>	nil found
<b>Availability</b>	licence
<b>Ages</b>	"children and youth"
<b>Languages</b>	40 languages
<b>Classification (Isoquol)</b>	HRQOL PRO - children
<b>ICF domains</b>	ICF - Body functions & structures
	ICF - Activities
	ICF - Participation
	ICF - Personal Factors
<b>PDF available</b>	yes

**EQ5D-Y** – Free text comments from the previous round

- Our team has a strong preference not to use this measure for BPBI.
- Too vague for BPBI and was developed for cancer patients

## **EQ5D Y - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score:	3.50
Scores 7-9 (useful)	18%
Scores 1-3 (not useful)	57%
No opinion	29%

### Usefulness to evaluate current state

Mean score:	3.68
Scores 7-9 (useful)	11%
Scores 1-3 (not useful)	57%
No opinion	29%

### Clinical applicability / feasibility.

Mean score:	6.11
Scores 7-9 (easy)	54%
Scores 1-3 (not easy)	7%
No opinion	29%

### Specificity for BPBI:

Mean score:	2.71
Scores 7-9 (specific)	7%
Scores 1-3 (not specific)	75%
No opinion	29%

"This PRO measure should be employed at..."

1	0%
3	2%
5	17%
7	32%
15	40%
adult	6%
other	2%

no opinion (n)16

## **EQ5D Y - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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### **Answers from the previous round**

What is the best PRO to evaluate Health related Quality of life for children (< 10 years) in your opinion, when taking into account all merits and drawbacks..

PedsQL 16

EQ5D-Y 10

PROMIS\_gl\_health 6

What is the best PRO to evaluate Health related Quality of life for teens / adolescents (> 10 years) in your opinion, when taking into account all merits and drawbacks.

PedsQL 13

EQ5D-Y 9

PROMIS\_gl\_health 5

## Questions current round

What is the best PRO to evaluate **Health related Quality of life** for children (< 10 years)in your opinion, when taking into account all merits and drawbacks.

- ( ) PedsQL (3) - Pediatric Quality of Life Inventory
- ( ) EQ5D-Y - EuroQol five Dimensional scale - Youth edition
- ( ) PROMIS - Global Health Scale

What is the best PRO to evaluate **Health related Quality of life** for teens / adolescents (> 10 years)in your opinion, when taking into account all merits and drawbacks.

- ( ) PedsQL (3) - Pediatric Quality of Life Inventory
- ( ) EQ5D-Y - EuroQol five Dimensional scale - Youth edition
- ( ) PROMIS - Global Health Scale

## **Summary of answers from the previous round - Pain**

		average	VAS	FPS	APPT	BPI
<b>responsiveness</b>	<b><i>no opinion</i></b>	16%	6%	9%	33%	16%
	<b><i>mean</i></b>	4,93	5,29	4,91	5,15	4,39
	<b><i>score 7-9</i></b>	36%	44%	30%	37%	32%
	<b><i>score 1-3</i></b>	34%	26%	33%	30%	48%
<b>current state</b>	<b><i>no opinion</i></b>	15%	6%	9%	29%	16%
	<b><i>mean</i></b>	4,93	5,03	5,00	5,21	4,48
	<b><i>score 7-9</i></b>	35%	41%	30%	32%	35%
	<b><i>score 1-3</i></b>	36%	35%	33%	25%	48%
<b>applicability</b>	<b><i>no opinion</i></b>	14%	3%	3%	33%	16%
	<b><i>mean</i></b>	6,41	7,40	7,20	6,04	5,00
	<b><i>score 7-9</i></b>	57%	80%	71%	44%	32%
	<b><i>score 1-3</i></b>	12%	6%	3%	11%	29%
<b>specificity</b>	<b><i>no opinion</i></b>	14%	6%	6%	29%	16%
	<b><i>mean</i></b>	3,06	2,79	3,09	3,54	2,84
	<b><i>score 7-9</i></b>	9%	9%	12%	11%	3%
	<b><i>score 1-3</i></b>	65%	71%	68%	50%	71%
<b>ages</b>	<b><i>1</i></b>		1%	3%	0%	0%
	<b><i>3</i></b>		9%	16%	0%	2%
	<b><i>5</i></b>		17%	27%	6%	7%
	<b><i>7</i></b>		23%	24%	28%	20%
	<b><i>15</i></b>		30%	19%	47%	41%
	<b><i>adult</i></b>		18%	9%	17%	29%
	<b><i>other</i></b>		2%	2%	2%	2%
<b><i>no opinion (n)</i></b>		2	6	12	11	

*Shaded: items that scored above average or > 20% (in the age groups)*

What is the best symptom PRO to evaluate Pain for children (< 10 years) in your opinion, when taking into account all merits and drawbacks.

**FPS** **17**

**BPI** **5**

**VAS** **4**

PROMIS\_pain\_interf 4

NRS 2

APP 2

PROMIS\_pain\_intens 2

PROMIS\_pain\_qual 0

What is the best symptom PRO to evaluate Pain for teens / adolescents (> 10 years) in your opinion, when taking into account all merits and drawbacks.

**BPI** **9**

**VAS** **8**

**APPT** **8**

NRS 7

PROMIS\_pain\_qual 2

PROMIS\_pain\_intens 1

PROMIS\_pain\_interf 1

FPS 0

*In **bold** the PRO measures that made it to the next round.*

<b>Measure (abb)</b>	<b>VAS for pain</b>
<b>Measure (full)</b>	Visual Analogue Scale
<b>Reference</b>	
<b>Description</b>	Visual Analogue Scale (VAS) is a PRO measure completed by children >3 years that measures pain intensity. This scale ranks the child's severity of pain on a 100 mm line, where greater values represent greater intensity in pain.
<b>No of items / questions</b>	
<b>Target</b>	
<b>Questionnaire (direct link)</b>	
<b>Validated or used for BPBI</b>	de Heer 2015 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/25332088">https://www.ncbi.nlm.nih.gov/pubmed/25332088</a>
<b>Availability</b>	
<b>Ages</b>	
<b>Languages</b>	
<b>Classification (Isoquol)</b>	Symptom PRO (Pain)
<b>ICF domains</b>	ICF - Body functions & structures
<b>PDF available</b>	no

**VAS** - Free text comments from the previous round

- some simple measure of pain (VAS, NRS, Faces) should be administered at each visit
- we use it as required not routinely

## **VAS - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score:	5.29
Scores 7-9 (useful)	44%
Scores 1-3 (not useful)	26%
No opinion	6%

### Usefulness to evaluate current state

Mean score:	5.03
Scores 7-9 (useful)	41%
Scores 1-3 (not useful)	35%
No opinion	6%

### Clinical applicability / feasibility.

Mean score:	7.40
Scores 7-9 (easy)	80%
Scores 1-3 (not easy)	6%
No opinion	3%

### Specificity for BPBI:

Mean score:	2.79
Scores 7-9 (specific)	9%
Scores 1-3 (not specific)	71%
No opinion	6%

"This PRO measure should be employed at..."

1	1%
3	9%
5	17%
7	23%
15	30%
adult	18%
other	2%

no opinion (n)2

## **VAS - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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<b>Measure (abb)</b>	<b>FPS</b>
<b>Measure (full)</b>	Faces Pain Scale - Revised
<b>Reference</b>	
<b>Description</b>	The Faces Pain Scale - Revised (FPS-R) is a PRO measure that measures pain intensity in children > 3 years. It consists of 6 faces that show how much something can hurt, where the left-most face shows no pain and the right-most face shows a lot of pain.
<b>No of items / questions</b>	
<b>Target</b>	
<b>Questionnaire (direct link)</b>	<a href="https://s3.amazonaws.com/rdcms-iasp/files/production/public/Content/ContentFolders/Resources2/FPSR/facepainscale_english_eng-au-ca.pdf">https://s3.amazonaws.com/rdcms-iasp/files/production/public/Content/ContentFolders/Resources2/FPSR/facepainscale_english_eng-au-ca.pdf</a>
<b>Validated or used for BPBI</b>	Ho 2015 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/25817754">https://www.ncbi.nlm.nih.gov/pubmed/25817754</a> Ho 2018 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/30042027">https://www.ncbi.nlm.nih.gov/pubmed/30042027</a>
<b>Availability</b>	
<b>Ages</b>	
<b>Languages</b>	
<b>Classification (Isoquol)</b>	Symptom PRO (Pain)
<b>ICF domains</b>	ICF - Body functions & structures
<b>PDF available</b>	yes

**FPS** - Free text comments from the previous round

- i know this scale but i have never use it. so i make suppositions
- only use as required
- Do not think that this is a good tool prefer lego faces

## **FPS - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score: 4.91  
Scores 7-9 (useful) 30%  
Scores 1-3 (not useful) 33%  
No opinion 9%

### Usefulness to evaluate current state

Mean score: 5.00  
Scores 7-9 (useful) 30%  
Scores 1-3 (not useful) 33%  
No opinion 9%

### Clinical applicability / feasibility.

Mean score: 7.20  
Scores 7-9 (easy) 71%  
Scores 1-3 (not easy) 3%  
No opinion 3%

### Specificity for BPBI:

Mean score: 3.09  
Scores 7-9 (specific) 12%  
Scores 1-3 (not specific) 68%  
No opinion 6%

"This PRO measure should be employed at..."

1 3%  
3 16%  
5 27%  
7 24%  
15 19%  
adult 9%  
other 2%

no opinion (n)6

## **FPS - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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<b>Measure (abb)</b>	<b>APPT</b>
<b>Measure (full)</b>	Adolescent Pediatric Pain Tool
<b>Reference</b>	<a href="https://www.ncbi.nlm.nih.gov/pubmed/24950413">https://www.ncbi.nlm.nih.gov/pubmed/24950413</a>
<b>Description</b>	The Adolescent Pediatric Pain Tool (APPT) is a multidimensional pain assessment tool designed to assess pain location (body outline diagram), intensity (word graphic rating scale) and quality (list of pain descriptors) in children aged 8 to 17 years old.
<b>No of items / questions</b>	3
<b>Target</b>	multidimensional pain assessment
<b>Questionnaire (direct link)</b>	<a href="http://www.allcare.org/CancerPain-and-SymptomManagement/comfort/cfm3/appt.pdf">http://www.allcare.org/CancerPain-and-SymptomManagement/comfort/cfm3/appt.pdf</a>
<b>Validated or used for BPBI</b>	Ho 2015 - <a href="https://www.ncbi.nlm.nih.gov/pubmed/25817754">https://www.ncbi.nlm.nih.gov/pubmed/25817754</a>
<b>Availability</b>	free
<b>Ages</b>	8-17
<b>Languages</b>	English
<b>Classification (Isoquol)</b>	Symptom PRO (Pain)
<b>ICF domains</b>	ICF - Body functions & structures
	ICF - Personal Factors
<b>PDF available</b>	yes

**APPT** - Free text comments from the previous round

- Part 1 (drawing) and 2 (VAS) are more suitable than part 3
- would need to understand scoring to track data
- never used but seems more detailed
- Seems difficult to have in a quality register
- Team's concerns - APPT should be not be used with every child in clinic, only after pain has been identified
- It's not in spanish

## **APPT - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score:	5.15
Scores 7-9 (useful)	37%
Scores 1-3 (not useful)	30%
No opinion	33%

### Usefulness to evaluate current state

Mean score:	5.21
Scores 7-9 (useful)	32%
Scores 1-3 (not useful)	25%
No opinion	29%

### Clinical applicability / feasibility.

Mean score:	6.04
Scores 7-9 (easy)	44%
Scores 1-3 (not easy)	11%
No opinion	33%

### Specificity for BPBI:

Mean score:	3.54
Scores 7-9 (specific)	11%
Scores 1-3 (not specific)	50%
No opinion	29%

"This PRO measure should be employed at..."

1	0%
3	0%
5	6%
7	28%
15	47%
adult	17%
other	2%

no opinion (n)12

## **APPT - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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<b>Measure (abb)</b>	<b>BPI</b>
<b>Measure (full)</b>	Brief Pain Inventory
<b>Reference</b>	<a href="https://www.journalofphysiotherapy.com/article/S1836-9553(15)00075-2/pdf">https://www.journalofphysiotherapy.com/article/S1836-9553(15)00075-2/pdf</a>
<b>Description</b>	The Brief Pain Inventory (BPI), previously known as the Brief Pain Questionnaire, is a self-administered questionnaire that was originally designed to assess cancer pain. It is now also used as a generic pain questionnaire for other chronic pain conditions. It is available in a short (nine items) and long (17 items) form. The BPI short form is more frequently used. The first, optional, item is a screening question about the respondent's pain on the day. The questionnaire is then composed of pain drawing diagrams, four items about pain intensity (worst pain, least pain, average pain, pain right now), two items on pain relief treatment or medication, and one item on pain interference, with seven sub-items (general activity, mood, walking ability, normal walk, relations with other people, sleep, and enjoyment of life).
<b>No of items / questions</b>	9
<b>Target</b>	Pain
<b>Questionnaire (direct link)</b>	<a href="https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0015/212910/Brief%20Pain%20Inventory%20Final.pdf">https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0015/212910/Brief Pain Inventory Final.pdf</a>
<b>Validated or used for BPBI</b>	no
<b>Availability</b>	free
<b>Ages</b>	has been used from age 6+ in CP
<b>Languages</b>	translated into 12 languages
<b>Classification (Isoquol)</b>	Symptom PRO (Pain)
<b>ICF domains</b>	ICF - Body functions & structures ICF - Activities ICF - Participation ICF - Personal Factors ICF - Environmental Factors
<b>PDF available</b>	yes

**BPI** - Free text comments from the previous round

- We find it applicable and brief and informative, even not specific of BPP, but available after 10 years old
- never used
- Past 24 hours - good time span
- only if patient identifies that they have pain

## **BPI - Results of the previous round**

### Usefulness to evaluate responsiveness

Mean score:	4.39
Scores 7-9 (useful)	32%
Scores 1-3 (not useful)	48%
No opinion	16%

### Usefulness to evaluate current state

Mean score:	4.48
Scores 7-9 (useful)	35%
Scores 1-3 (not useful)	48%
No opinion	16%

### Clinical applicability / feasibility.

Mean score:	5.00
Scores 7-9 (easy)	32%
Scores 1-3 (not easy)	29%
No opinion	16%

### Specificity for BPBI:

Mean score:	2.84
Scores 7-9 (specific)	3%
Scores 1-3 (not specific)	71%
No opinion	16%

"This PRO measure should be employed at..."

1	0%
3	2%
5	7%
7	20%
15	41%
adult	29%
other	2%

no opinion (n)11

## **BPI - Questions current round**

### Usefulness:

"This PRO measure is useful for the evaluation of BPBI infants *before and after a therapeutic intervention* (such as surgery, botulinum toxin, physiotherapy or occupational therapy)"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

"This PRO measure is useful for the evaluation of *current state of functioning* of BPBI infants."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not useful at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most useful

### Clinical applicability / feasibility.

"This PRO measure is easy to administer in daily practice"

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not easy at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most easy

### Specificity for BPBI:

"This PRO measure contains items specific to BPBI."

*Please indicate your opinion...*

*(1-9 will be used for calculation; zero = no opinion)*

	0	1	2	3	4	5	6	7	8	9	
not specific at all	( )	( )	( )	( )	( )	( )	( )	( )	( )	( )	most specific

"This PRO measure should be employed at..." (multiple answers possible)

- ( ) 1 year of age
- ( ) 3 years of age
- ( ) 5 years of age
- ( ) 7 years of age
- ( ) 15 years of age (/ adolescent 10-19)
- ( ) adult age
- ( ) other (please specify below)
- ( ) no opinion

Please provide your comments. (facultative)

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**Answers from the previous round.**

What is the best symptom PRO to evaluate Pain for children (< 10 years) in your opinion, when taking into account all merits and drawbacks.

FPS	17
BPI	5
VAS	4

What is the best symptom PRO to evaluate Pain for teens / adolescents (> 10 years) in your opinion, when taking into account all merits and drawbacks.

BPI	9
VAS	8
APPT	8

## **Questions current round**

What is the best symptom PRO to evaluate **Pain** for children (< 10 years) in your opinion, when taking into account all merits and drawbacks.

- FPS - Faces Pain Scale - Revised
- BPI - Brief Pain Inventory
- VAS for pain - Visual Analogue Scale

What is the best symptom PRO to evaluate **Pain** for teens / adolescents (> 10 years) in your opinion, when taking into account all merits and drawbacks.

- BPI - Brief Pain Inventory
- VAS for pain - Visual Analogue Scale
- APPT - Adolescent Pediatric Pain Tool