

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

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

Measure (abb)	CHEQ
Measure (full)	Children's Hand-use Experience Questionnaire
Reference	https://www.ncbi.nlm.nih.gov/pubmed/26610725
Description	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.
No of items / questions	27 (Cheq 2.0), 29 (Cheq 1.0)
Target	Self-reported hand use for bimanual activities
Questionnaire (direct link)	http://www.cheq.se/
Validated or used for BPBI	Skold 2011 - https://www.ncbi.nlm.nih.gov/pubmed/21413973
Availability	free
Ages	6-18
Languages	Arabic, Portuguese, Dutch, English, German, French, Hebrew, Italian, Japanese, Norwegian, Spanish, Swedish, Turkish
Classification (Isoquol)	Functional Status PRO-children
ICF domains	ICF - Activities
PDF available	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)

Measure (abb)	PODCI
Measure (full)	Pediatric Outcomes Data Collection Instrument
Reference	https://www.ncbi.nlm.nih.gov/pubmed/8773720
Description	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.
No of items / questions	86
Target	functional health status
Questionnaire (direct link)	https://www.aaos.org/research/outcomes/Pediatric.pdf
Validated or used for BPBI	Huffman 2005 - https://www.ncbi.nlm.nih.gov/pubmed/15832163 Bae 2008 - https://www.ncbi.nlm.nih.gov/pubmed/18580377 Eismann 2014 - https://www.ncbi.nlm.nih.gov/pubmed/24599198
Availability	free
Ages	2-18
Languages	English, Dutch, Korean, Spanish
Classification (Isoquol)	Functional Status PRO-children
ICF domains	ICF - Body functions & structures
	ICF - Activities
	ICF - Participation
	ICF - Personal Factors
	ICF - Environmental Factors
PDF available	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.
- Too 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)

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

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

PROMIS UE - Free text comments from the previous round

- expensive to translate
- almost omitted shoulder and elbow
- very easy to administer. easy to compare results to other conditions.
- No comment
- Too wide
- Affected hand impairment may easily 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)

Measure (abb)	BPOM
Measure (full)	Brachial Plexus Outcome Measurement - self evaluation scales
Reference	https://www.ncbi.nlm.nih.gov/pubmed/22818900
Description	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.
No of items / questions	3
Target	use of arm / use of hand / appearance of arm & hand
Questionnaire (direct link)	https://www.vll.se/VLL/Filer/BPOM%20Manual%20v.%202.0%20e-version.pdf
Validated or used for BPBI	Hosbay 2018 - https://www.ncbi.nlm.nih.gov/pubmed/29395601
Availability	free
Ages	
Languages	english
Classification (Isoquol)	Functional Status PRO-children
ICF domains	ICF - Participation
	ICF - Personal Factors
PDF available	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)

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

DASH - Free text comments from the previous round

- Generally not applicable with children
- Not useful
- Too wide and unspecific about the side to be 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)

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

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

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

Measure (abb)	PedsQL
Measure (full)	Pediatric Quality of Life Inventory
Reference	http://www.pedsqol.org/
Description	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.
No of items / questions	23 (child) 23 (teen) 23 (parent)
Target	QoL
Questionnaire (direct link)	
Validated or used for BPBI	Butler 2017 - https://www.ncbi.nlm.nih.gov/pubmed/28719549
Availability	licence
Ages	8 - 12 (child) 13 - 18 (teen) 8 - 12 (parent)
Languages	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)
Classification (Isoquol)	HRQOL PRO - children
ICF domains	ICF - Body functions & structures
	ICF - Activities
	ICF - Participation
	ICF - Personal Factors
	ICF - Environmental Factors
PDF available	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)

Measure (abb)	EQ5D-Y
Measure (full)	EuroQol five Dimensional scale - Youth edition
Reference	https://euroqol.org/eq-5d-instruments/eq-5d-y-about/
Description	<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>
No of items / questions	6
Target	QoL
Questionnaire (direct link)	https://euroqol.org/support/how-to-obtain-eq-5d/
Validated or used for BPBI	nil found
Availability	licence
Ages	"children and youth"
Languages	40 languages
Classification (Isoquol)	HRQOL PRO - children
ICF domains	ICF - Body functions & structures
	ICF - Activities
	ICF - Participation
	ICF - Personal Factors
PDF available	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)

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

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

Measure (abb)	FPS
Measure (full)	Faces Pain Scale - Revised
Reference	
Description	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.
No of items / questions	
Target	
Questionnaire (direct link)	https://s3.amazonaws.com/rdcms-iasp/files/production/public/Content/ContentFolders/Resources2/FPSR/facepainscale_english_eng-au-ca.pdf
Validated or used for BPBI	Ho 2015 - https://www.ncbi.nlm.nih.gov/pubmed/25817754 Ho 2018 - https://www.ncbi.nlm.nih.gov/pubmed/30042027
Availability	
Ages	
Languages	
Classification (Isoquol)	Symptom PRO (Pain)
ICF domains	ICF - Body functions & structures
PDF available	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)

Measure (abb)	APPT
Measure (full)	Adolescent Pediatric Pain Tool
Reference	https://www.ncbi.nlm.nih.gov/pubmed/24950413
Description	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.
No of items / questions	3
Target	multidimensional pain assessment
Questionnaire (direct link)	http://www.allcare.org/CancerPain-and-SymptomManagement/comfort/cfm3/appt.pdf
Validated or used for BPBI	Ho 2015 - https://www.ncbi.nlm.nih.gov/pubmed/25817754
Availability	free
Ages	8-17
Languages	English
Classification (Isoquol)	Symptom PRO (Pain)
ICF domains	ICF - Body functions & structures
	ICF - Personal Factors
PDF available	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)

Measure (abb)	BPI
Measure (full)	Brief Pain Inventory
Reference	https://www.journalofphysiotherapy.com/article/S1836-9553(15)00075-2/pdf
Description	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).
No of items / questions	9
Target	Pain
Questionnaire (direct link)	https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0015/212910/Brief_Pain_Inventory_Final.pdf
Validated or used for BPBI	no
Availability	free
Ages	has been used from age 6+ in CP
Languages	translated into 12 languages
Classification (Isoquo)	Symptom PRO (Pain)
ICF domains	ICF - Body functions & structures
	ICF - Activities
	ICF - Participation
	ICF - Personal Factors
	ICF - Environmental Factors
PDF available	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)

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