

Welcome to the fifth round of iPluto.

Introduction

Although this introduction may seem long, it is essential that you read its content. In this set of rounds the participants' preference of Patient Reported Outcome (PROs) measures for use with children who have a Brachial Plexus Birth Injury (BPBI) will be assessed.

In order to be clear, it is important that we distinguish PROs from *observer-reported* outcome measures. Examples of observer-reported functional scales include the Brachial Plexus Outcome Measure (BPOM), Assisting Hand Assessment (AHA), Mallet Scale, Gilbert Shoulder Scale and Raimondi Hand Score etc. These are defined as systems that evaluate function as tested by an observer. Observer-reported outcome measures were the subject of the previous iPluto rounds (See <https://onlinelibrary.wiley.com/doi/10.1002/jor.23901>), and are NOT considered in this round of iPluto.

Patient Reported Outcome (PRO) measures are defined as indexes, scales or questionnaires completed by patients and/or their parents/guardians. They measure (from the patient's perspective) the effect of the disease as well as the consequences of treatment on their health and functioning. (www.isoqol.org)

The aspects which will be evaluated in this iPluto round are:

- Functional Status (children)
- Functional Status (teens and adults)
- Health Related Quality of Life (children)
- Health Related Quality of Life (teens and adults)
- Symptom – pain (children, teens, adults)

In Addition, the related domains according to the ICF-framework (International Classification of Functioning, Disability and Health) for the included PROs, will be provided. These ICF domains are: Body Functions & Structures, Activity, Participation, Environmental Factors and Personal Factors.

Some questionnaires cover multiple ICF domains.

Examples of PROs in the Body Functions domain are:

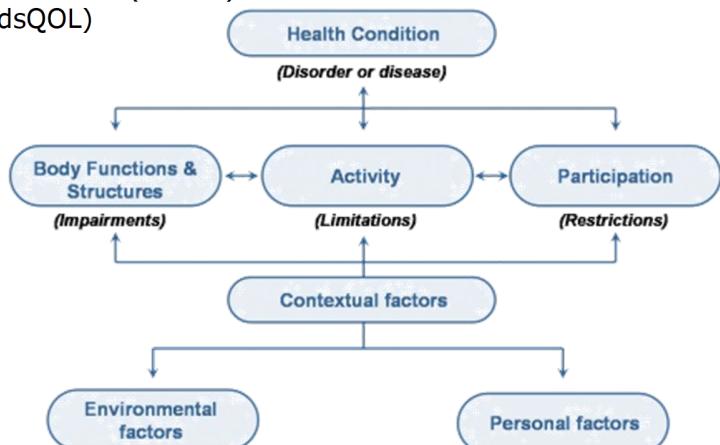
- Adolescent Pediatric Pain Tool (APPT)
- Faces pain scale
- ...

Examples of PROs in the Activity domain are:

- Pediatric Evaluation of Disability Inventory (PEDI)
- PROMIS Upper Extremity Scale
- Pediatric Outcomes Data Collection Instrument (PODCI)
- ...

Examples of PROs in the Participation domain are:

- Pediatric Outcomes Data Collection Instrument (PODCI)
- Pediatric Quality of Life Inventory (PedsQOL)
- PROMIS Global Health Scale
- Child Health Questionnaire
- ...



OPTIONAL READING

On this page, the available literature will be summarised and is provided as background knowledge to optimise your rating of different PROs.

Review-articles for suggested reading.

Ho (2015) summarizes which methods are encountered in literature to evaluate both motor and sensory function in children with nerve lesions, and describes merits and drawbacks of different methods.

Hao (2014) conducted a Delphi survey to establish expert consensus on utility, satisfaction and importance of functional outcome measures in children with upper extremity musculoskeletal conditions. Consensus on relative importance, but low satisfaction in the Activity domain suggests a need for better outcomes in this domain.

Two systematic reviews established that many different outcome measures have been used. (Chang 2013, Sarac 2015) The conclusion in both papers was that not all domains of the ICF were taken into account in most papers describing outcome of BPBI.

Duff and DeMatteo (2015) provide a narrative review that describes evaluation methods that can be useful in the evaluation of children with a BPBI. These authors suggest that evaluation focus may shift during the life of an infant with BPBI. In the infant age, the assessment focus should be on impairment, which gradually shifts to activity at school age and to participation during adolescence. In the first iPluto rounds the standard ages for evaluation of outcome were determined at 1-3-5-7 years of age. The age of 15 was almost agreed upon, so it was added in these rounds to represent adolescent ages, as was adult age.

In a systematic review by Bialocerkowski (2013) the psychometric properties (reliability, validity, and responsiveness) of BPBI outcome measures are discussed. Reliability is the extent to which a measurement is free from error. Validity is the extent to which an outcome measure evaluates a variable of interest. Responsiveness refers to the ability of an outcome measure to detect clinically meaningful changes over time. In this systematic review, the outcome measures which showed to have the most robust psychometric properties include the Active Movement Scale, the Assisting Hand Assessment, the PEDI, and the PODCI. Psychometric properties of outcome measures are important, but a specific test should not be discarded when the psychometric properties were not formally tested in the target population. Clinical utility – such as the administration, scoring, interpretation, and feasibility of using an outcome measure – are equally important when selecting an outcome measure for use in clinical and research settings.

Link to the mentioned papers:

<https://www.ncbi.nlm.nih.gov/pubmed/25449719,25449718,23930602,26410060,25840493,23808952?report=abstract>

Please provide your comments. (facultative)

| | |
|---|---|
| [|] |
| [|] |
| [|] |
| [|] |

Question 1.

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

Please indicate your opinion...

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

On the following pages, a list of PRO measures which were generated from iPluto participants and the moderator panel are presented. Please rate each PRO measure using the 9-point Likert scale provided. Scores 1-9 will be used for calculation, if you score 0 (zero) this will be interpreted as 'no 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.**

The goal of these sequential questionnaires is to allow participants to reach consensus on which items will serve as a preferred dataset of PROs. After each questionnaire, the group response is fed back to all participants, including (anonymously made) comments or feedback that you may type as free text. In this way you are able to express your personal opinion on specific items; which may serve as argument for other participants to revise their judgement in the light of the group feedback. Hopefully, in this way opinion of participants will converge in one direction, after several rounds. The consensus percentage is set as 75%, or the percentage after 2-3 Delphi rounds.

Only participants who complete a survey will be invited for the subsequent round. We encourage participants to complete **all** the rounds of the survey **within the set timeframe**, as the results will mainly be generated in the last round.

It is very important that you discuss the different iPluto study items with your team. It may be necessary to recruit team members who have the most knowledge and are familiar with PRO measures. In this context, please choose one person from your center to serve as contact. Send a direct email if you wish to change the contact person from your center. If you feel that after this introduction your knowledge of the subject may fall short, or that you are unable to answer the question in its full depth, please don't feel obliged to continue.

| Functional Status PRO-children * | | |
|--|------------------------------|---|
| 6 | CHEQ | Children's Hand-use Experience Questionnaire |
| 10 | PODCI | Pediatric Outcomes Data Collection Instrument |
| 14 | HUH | Hand Use at Home questionnaire |
| 18 | PROMIS - Upper Extremity | Patient-Reported Outcomes Measurement Information System - Pediatric upper extremity |
| 22 | BPOM | Brachial Plexus Outcome Measurement - self evaluation scales |
| 26 | ABILHAND-Kids | Manual ABILity |
| 30 | PEM-CY | Participation and Environment Measure - Children and Youth |
| Functional Status PRO- teens and adults * | | |
| 34 | DASH | Disability of the Arm, Shoulder, and Hand |
| 38 | MHQ | Michigan Hand Outcomes Questionnaire |
| | ABILHAND | Manual ABILity |
| 42 | WOSI | Western Ontario Shoulder Instability Index |
| HRQOL PRO - children | | |
| 48 | PROMIS - Global Health Scale | Patient-Reported Outcomes Measurement Information System Global Health Scale |
| 52 | PROMIS - Peer Relationships | Patient-Reported Outcomes Measurement Information System - Peer relationships |
| 56 | PedsQL (3) | Pediatric Quality of Life Inventory |
| 60 | EQ5D-Y | EuroQol five Dimensional scale - Youth edition |
| 64 | CHQ | child health questionnaire |
| Symptom PRO (Pain) | | |
| 70 | VAS for pain | Visual Analogue Scale |
| 74 | NRS for pain | Numerical Rating Scale |
| 78 | FPS | Faces Pain Scale - Revised |
| 82 | APPT | Adolescent Pediatric Pain Tool |
| 86 | PROMIS - pain intensity | Patient-Reported Outcomes Measurement Information System - Pain Intensity |
| 90 | PROMIS - pain interference | Patient-Reported Outcomes Measurement Information System - Pediatric Pain Interference |
| 94 | PROMIS - pain quality | Patient-Reported Outcomes Measurement Information System - Pediatric Pain Quality - Sensory |
| 98 | BPI | Brief Pain Inventory |

* some scales have an overlap in ages

Table of PRO measures in this iPluto 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 |

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)

[
[
[
[

**Open a plastic box with a lid (for example an ice-cream box)**

Do you usually use one hand, both hands together or get help?

One hand
 Both hands
 Get help

How do you think your hand works?

1 Bad 2 3 4 Good

How much time do you need to do the whole task, compared to peers?

1 Considerably longer 2 3 4 Equally long

Does your hand function bother you in this activity / situation?

1 It bothers me a lot 2 3 4 It does not bother me at all

[Previous question](#)[Next question](#)



Report

Children's Hand-use Experience Questionnaire

Name: Test Sample

Age: 13 years

Sex: Boy

Reduced hand-/armfunction on right side caused by obstetric brachial plexus palsy.

Answered by: Myself

Report created 9/28/2018

| | Two hands | Use hand * | Time required ** | Feeling *** |
|---|-----------|------------|------------------|-------------|
| Pull up track suit trousers | Yes | 3 | 3 | 3 |
| Remove a straw from the front of a juice box and insert it. (Refers to the whole process, including taking off the wrapping of the straw) | Yes | 2 | 1 | 2 |
| Put on socks | Help | 2 | 3 | 3 |
| Eat out of a small container of yoghurt | Yes | 2 | 2 | 3 |
| Spread out glue on paper using a glue stick | Yes | 2 | 2 | 3 |
| Cut out a picture using scissors | Help | 1 | 3 | 3 |
| Butter a slice of soft bread | Yes | 2 | 3 | 3 |
| Open a small box (for example a box of mints) | Yes | 1 | 2 | 3 |
| Put toothpaste on a toothbrush | One hand | 1 | 2 | 2 |
| Cut up a pancake (or other food easy to cut up) on the plate | Help | 3 | 3 | 2 |
| Remove the wrapping from a piece of candy | Help | 2 | 1 | 2 |
| Open the zipper on a small bag (e.g. pencil case or purse) | Yes | 2 | 3 | 3 |
| Handle playing-cards (Refers to the whole process; holding, selecting and placing cards in the hand while playing) | Yes | 2 | 2 | 2 |
| Pick money out of a purse or wallet | Yes | 2 | 2 | 3 |
| Carry a tray (for example in the canteen) | Yes | 3 | 3 | 3 |
| Pull up the zipper of a jacket | Yes | 2 | 3 | 3 |
| Button up the trousers | Help | 1 | 1 | 2 |
| Open a plastic box with a lid (for example an ice-cream box) | Yes | 3 | 4 | 2 |
| Screw off the cap of a small, unopened softdrink bottle. | One hand | 1 | 2 | 3 |
| Remove the wrapping from an ice-cream | Yes | 2 | 2 | 3 |
| Cut on a chopping board (for example fruit, vegetables, bread) | Yes | 2 | 3 | 2 |
| Peel an orange | Help | 1 | 2 | 2 |
| Open a bag (for example a bag of crisps) | Yes | 2 | 2 | 2 |
| Take off the protective plastic backing of a Elastoplast | Help | 2 | 3 | 3 |
| Cut meat (or other food hard to cut up) on a plate | Help | 1 | 2 | 1 |
| Open up a box of milk or juice | Yes | 3 | 3 | 3 |
| Tie shoelaces | Help | 3 | 3 | 4 |

* How do you think your hand works? Bad, 1-----2-----3-----4, Good

** How much time do you need to do the whole task, compared to peers? Considerably longer, 1-----2-----3-----4, Equally long

*** Does your hand function bother you in this activity / situation? It bothers me a lot, 1-----2-----3-----4, It does not bother me at all

| | |
|------------------------------------|---|
| 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 |

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)

[
[
[
[

Pediatric Health Assessment (parent-reported)

Some kind of problems can make it hard to do many activities, such as eating, bathing, school work, and playing with friends. We would like to find out how your child is doing. (Circle one response on each line.)

During the last week was it easy or hard for your child to:

| | Easy | A little hard | Very hard | Can't do at all | Too young for this activity |
|--|------|---------------|-----------|-----------------|-----------------------------|
| 1. Lift heavy books? | 1 | 2 | 3 | 4 | 5 |
| 2. Pour a half gallon of milk? | 1 | 2 | 3 | 4 | 5 |
| 3. Open a jar that has been opened before? | 1 | 2 | 3 | 4 | 5 |
| 4. Use a fork and spoon? | 1 | 2 | 3 | 4 | 5 |
| 5. Comb his/her hair? | 1 | 2 | 3 | 4 | 5 |
| 6. Button buttons? | 1 | 2 | 3 | 4 | 5 |
| 7. Put on his/her coat? | 1 | 2 | 3 | 4 | 5 |
| 8. Write with a pencil? | 1 | 2 | 3 | 4 | 5 |

9. On average, over the last 12 months, how often did your child miss school (preschool, day care, camp, etc.) because of his/her health?

1. Rarely
2. Once a month
3. Two or three times a month
4. Once a week
5. More than once a week
6. Does not attend school, etc.

During the last week how happy has your child been with: (Circle one response on each line.)

| | Very happy | Somewhat happy | Not sure | Somewhat unhappy | Very unhappy | Child is too young |
|---|------------|----------------|----------|------------------|--------------|--------------------|
| 10. How he/she looks? | 1 | 2 | 3 | 4 | 5 | 6 |
| 11. His/her body? | 1 | 2 | 3 | 4 | 5 | 6 |
| 12. What clothes or shoes he/she can wear? | 1 | 2 | 3 | 4 | 5 | 6 |
| 13. His/her ability to do the same things his/her friends do? | 1 | 2 | 3 | 4 | 5 | 6 |
| 14. His/her health in general? | 1 | 2 | 3 | 4 | 5 | 6 |

Pediatric Health Assessment (parent-reported)

During the **last week**, how much of the time:
(Circle one response on each line.)

| | | Most of the time | Some of the time | A little of the time | None of the time |
|-----|--|------------------|------------------|----------------------|------------------|
| 15. | Did your child feel sick and tired? | 1 | 2 | 3 | 4 |
| 16. | Were your child full of pep and energy? | 1 | 2 | 3 | 4 |
| 17. | Did pain or discomfort interfere with your child's activities? | 1 | 2 | 3 | 4 |

During the **last week**, has it been easy or hard for your child to:
(Circle one response on each line.)

| | | Easy | A little hard | Very hard | Can't do at all | Too young for this activity |
|-----|--------------------------------|------|---------------|-----------|-----------------|-----------------------------|
| 18. | Run short distances? | 1 | 2 | 3 | 4 | 5 |
| 19. | Bicycle or tricycle? | 1 | 2 | 3 | 4 | 5 |
| 20. | Climb three flights of stairs? | 1 | 2 | 3 | 4 | 5 |
| 21. | Climb one flight of stairs? | 1 | 2 | 3 | 4 | 5 |
| 22. | Walk more than a mile? | 1 | 2 | 3 | 4 | 5 |
| 23. | Walk three blocks? | 1 | 2 | 3 | 4 | 5 |
| 24. | Walk one block? | 1 | 2 | 3 | 4 | 5 |
| 25. | Get on and off a bus? | 1 | 2 | 3 | 4 | 5 |

26. How often does your child need help from another person for walking and climbing? (Circle one response.)

1 Never 2 Sometimes 3 About half the time 4 Often 5 All the time

27. How often does your child use assistive devices (such as braces, crutches, or wheelchair) for walking and climbing? (Circle one response.)

1 Never 2 Sometimes 3 About half the time 4 Often 5 All the time

During the **last week**, has it been easy or hard for your child to:
(Circle one response on each line.)

| | | Easy | A little hard | Very hard | Can't do at all | Too young for this activity |
|-----|---|------|---------------|-----------|-----------------|-----------------------------|
| 28. | Stand while washing his/her hands and face at a sink? | 1 | 2 | 3 | 4 | 5 |
| 29. | Sit in a regular chair without holding on? | 1 | 2 | 3 | 4 | 5 |
| 30. | Get on and off a toilet or chair? | 1 | 2 | 3 | 4 | 5 |
| 31. | Get in and out of bed? | 1 | 2 | 3 | 4 | 5 |
| 32. | Turn door knobs? | 1 | 2 | 3 | 4 | 5 |
| 33. | Bend over from a standing position and pick up something off the floor? | 1 | 2 | 3 | 4 | 5 |

| | |
|------------------------------------|--|
| 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 |

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)

[
[
[
[

Start Questionnaire

Please keep in mind that we want to know how often your child chooses **to spontaneously use** the affected hand while performing these activities (so without prompting).

You can only mark 1 option.

1 How often does your child use the affected hand putting **toothpaste on the toothbrush?**

- Never
- Sometimes
- Regularly
- Often
- Always

2 How often does your child use the affected hand to **hold a toy while **playing on the floor**?**

- Never
- Sometimes
- Regularly
- Often
- Always

3 How often does your child use the affected hand to assist **undressing the upper body? (remove their singlet, shirt, sweater)**

- Never
- Sometimes
- Regularly
- Often
- Always

4 How often does your child use the affected hand to **move a chair?**

- Never
- Sometimes
- Regularly
- Often
- Always

5 How often does your child use the affected hand to **pull off socks?**

- Never
- Sometimes
- Regularly
- Often
- Always



6 *How often does your child use the affected hand to **play with construction toys** (Lego/Duplo/etc.)?*

- Never
- Sometimes
- Regularly
- Often
- Always

7 *How often does your child use the affected hand to assist with **buttering bread**?*

- Never
- Sometimes
- Regularly
- Often
- Always
- Not applicable due to the age of my child

8 *How often does your child **hold a toy** in the affected hand while **walking**?*

- Never
- Sometimes
- Regularly
- Often
- Always

9 *How often does your child use the affected hand to **hold a booklet** while **reading or looking at pictures**?*

- Never
- Sometimes
- Regularly
- Often
- Always

10 *How often does your child use the affected hand to assist with **tearing off and folding toilet paper** when using the toilet?*

- Never
- Sometimes
- Regularly
- Often
- Always

| | |
|------------------------------------|---|
| 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 | The ability to perform 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 |

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)

[
[
[
[

Pediatric Upper Extremity

Please respond to each question or statement by marking one box per row.

| In the past 7 days... | | With no trouble | With a little trouble | With some trouble | With a lot of trouble | Not able to do |
|-----------------------|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 3880R2r | I could button my shirt or pants | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| 2671R1r | I could open a jar by myself..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 4143R1r | I could open the rings in school binders.... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 4112R1r | I could pour a drink from a full pitcher..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 3881R1r | I could pull a shirt on over my head by myself | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| 4130R1r | I could pull open heavy doors | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 2657bR1r | I could put on my shoes by myself..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 4109R1r | I could use a key to unlock a door..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 2645R2r | I could move my hands or fingers | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| 2657aR1r | I could put on my socks by myself..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 2659R1r | I could tie shoelaces by myself | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |

| In the past 7 days... | | With no trouble | With a little trouble | With some trouble | With a lot of trouble | Not able to do |
|-----------------------|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 2663R1r | I could put on my clothes by myself | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| 2727R1r | I could write with a pen or pencil..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 3334aR1r | I could put toothpaste on my toothbrush by myself..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 3334bR1r | I could brush my teeth by myself | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 3796R1r | I could turn door handles by myself..... | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| 3891R2r | I could use a mouse or touch pad for the computer..... | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| 3907aR1r | I could hold a full cup..... | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| 3907bR1r | I could hold an empty cup | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 | <input type="checkbox"/> 1 |
| 3908R2r | I could lift a cup to drink | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 4097bR2r | I could zip up my clothes | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 4098R1r | I could pull on and fasten my seatbelt..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 4107R2r | I could open my clothing drawers | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |

| | |
|------------------------------------|---|
| 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 |

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)

[
[
[
[

BRACHIAL PLEXUS OUTCOME MEASURE

| ACTIVITY SCALE | | Functional Movement Score |
|--|--|---------------------------|
| SHOULDER | | |
| Combs Back of Head - Uses affected hand to reach the back of head to comb hair | | |
| Places Container Above Head - Uses both hands to reach forward to place a container directly above their head | | |
| Undo Button at Midline - Undo button or snap at navel level with both hands | | |
| Hand to Back Pant Pocket - Puts affected fingers into ipsilateral back pant pocket | | |
| ELBOW AND FOREARM | | |
| Pretends to Eat Candy - Hold plate with unaffected hand, pick up bead with affected hand from plate and bring it up to mouth | | |
| Uses Computer Mouse - Uses affected hand with isolated finger flexion to click on mouse | | |
| Plays Drums - Hits drumsticks on container with both hands | | |
| Holds Plate with Palm Up - Holds plate with affected hand palm up | | |
| WRIST, FINGER, AND THUMB | | |
| Opens Large Container - Uses both hands to open 5" diameter container with snap on lid; abducts thumb with affected hand | | |
| Pulls Apart Theraputty - Uses power grasp to pull apart theraputty with active wrist extension with both hands | | |
| Strings Bead - Uses both hands to string bead; uses precision grasp (pinch) with affected hand | | |

FUNCTIONAL MOVEMENT SCALE

1. Cannot complete task
2. Completes task using only unaffected arm
3. Completes task
Absent active movement in primary mover(s). May use passive range of motion to complete movement pattern
4. Completes task
Initiates all movement actively or position of primary mover(s) is sufficient for function. Compensatory techniques used to complete movement pattern
5. Completes task with normal movement pattern

SELF-EVALUATION SCALE

My arm works . . .



Very POORLY



Very WELL

My hand works . . .



Very POORLY



Very WELL

My arm and hand looks . . .



Very BAD



Very GOOD

| | |
|------------------------------------|--|
| Measure (abb) | ABILHAND-Kids / ABILHAND |
| Measure (full) | |
| Reference | https://www.ncbi.nlm.nih.gov/pubmed/15452296 |
| Description | ABILHAND-Kids is a PRO measure completed by parents that evaluates their children's (6 - 15 years) manual ability in performing daily activities that require the use of the upper limbs. The child's ease or difficulty in performing each of the 21-items on this questionnaire is rated on a 3-level response scale (impossible, difficult, easy). |
| No of items / questions | 21 |
| Target | manual ability |
| Questionnaire (direct link) | http://www.rehab-scales.org/abilhand-kids.html |
| Validated or used for BPBI | Spaargaren 2011 - https://www.ncbi.nlm.nih.gov/pubmed/21511503 |
| Availability | free |
| Ages | 6-15 |
| Languages | English - French - Dutch - Swedish - Polish |
| Classification (Isoquol) | Functional Status PRO-children Functional Status PRO- teens and adults |
| ICF domains | ICF - Activities |
| PDF available | yes |

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)

[
[
[
[



INSTRUCTIONS FOR THE ABILHAND-NMD QUESTIONNAIRE

The ABILHAND-NMD questionnaire

The ABILHAND-NMD questionnaire was developed as a measure of manual ability in children and adults with **neuromuscular disorders** (Vandervelde et al, JNNP, 2010). Manual ability is defined as difficulties a patient may have in executing manual activities of daily living. The questionnaire includes 22 items that are daily activities. Among these 22 items, 4 are specifically designed for child evaluation, 4 for adult evaluation, and the remaining 14 items are common to all patients. ABILHAND-NMD was built either on the perception of the parents of the affected children or on the perception of the adult patients themselves. This perception concerns the difficulty in performing each activity of the questionnaire. The 22 items of ABILHAND-NMD defined a valid, reliable and reproducible scale. ABILHAND-NMD was originally developed using the Rasch measurement model. It allows to convert ordinal scores into linear measures located on a unidimensional scale.

Evaluation

For a child evaluation (between 6 and 15 years-old):

The **parents** fill in the questionnaire by estimating their child's difficulty or ease in performing each activity.

For an adult evaluation (more than 16 years-old):

The **patient** fills in himself the questionnaire by estimating their own difficulty or ease in performing each activity.

The activities should be done:

- **Without technical or human help** (even if the patient actually uses help in daily life)
- Irrespective the limb(s) actually used to achieve the activity
- Whatever the strategy used (any compensation is allowed)

Three responses are presented. These assess the perception of the difficulty/ease depending on whether the activity is “impossible”, “difficult” or “easy”. Activities not attempted in the last 3 months are not scored and entered as missing responses (to tick the question mark).

So, for any activity, the four potential answers are:

- **Impossible:** The patient is unable to perform the activity without using any other help.
- **Difficult:** The patient is able to perform the activity without any help but experiences some difficulty.
- **Easy:** The patient is able to perform the activity without any help and experiences no difficulty.
- **Question mark:** The patient cannot estimate the difficulty of the activity because he has never done the activity.

Watch out!! If the activity was never attempted because it is impossible, then it must be scored “impossible” rather than “question mark”.

ABILHAND-NMD - Manual ability measure

English version

Name: _____

Date: _____

| How difficult are the following activities? | Impossible | Difficult | Easy | ? |
|---|------------|-----------|------|---|
|---|------------|-----------|------|---|

| | | | | | |
|----|--|--|--|--|--|
| 1 | Wiping one's hands | | | | |
| 2 | Spreading butter on a slice of bread | | | | |
| 3 | Turning a key in a keyhole | | | | |
| 4 | Fastening a snap (jacket, bag,...) | | | | |
| 5 | Squeezing toothpaste onto a toothbrush | | | | |
| 6 | Filling a glass with water | | | | |
| 7 | Opening a bread box | | | | |
| 8 | Turning on a tap | | | | |
| 9 | Washing one's hands | | | | |
| 10 | Opening a toothpaste tube | | | | |
| 11 | Opening a pack of biscuits | | | | |
| 12 | Buttoning up a shirt | | | | |
| 13 | Turning off a tap | | | | |
| 14 | Fastening the zipper of a jacket | | | | |

To evaluate an adult patient (age 16-80), please answer the following questions

To evaluate a child patient (age 6-15), please mark the following questions with the "?"

| | | | | | | |
|----|------------------------------|---|--|--|--|--|
| 15 | Taking the cap off a bottle | A | | | | |
| 16 | Cutting one's nails | A | | | | |
| 17 | Inserting a key in a keyhole | A | | | | |
| 18 | Counting banknotes | A | | | | |

To evaluate a child patient (age 6-15), please answer the following questions

To evaluate an adult patient (age 16-80), please mark the following questions with the "?"

| | | | | | | |
|----|----------------------------|---|--|--|--|--|
| 19 | Opening a pack of chips | C | | | | |
| 20 | Sharpening a pencil | C | | | | |
| 21 | Dealing cards | C | | | | |
| 22 | Unwrapping a chocolate bar | C | | | | |

Order
1

| | |
|------------------------------------|--|
| Measure (abb) | PEM-CY |
| Measure (full) | Participation and Environment Measure - Children and Youth |
| Reference | https://onlinelibrary.wiley.com/doi/full/10.1111/j.1469-8749.2011.04094.x |
| Description | The Participation and Environment Measure for Children and Youth, or the PEM-CY, is a measurement tool designed to help parents, service providers and researchers better understand the participation of children and youth, ages 5 to 17. The PEM-CY is a parent-report measure that asks about participation in the home, school and community , along with environmental factors within each of these settings. |
| No of items / questions | 25 |
| Target | Activities, Participation and Environmental factors affecting ability to participate |
| Questionnaire (direct link) | https://www.canchild.ca/en/resources/248-participation-and-environment-measure-for-children-and-youth-pem-cy |
| Validated or used for BPBI | no |
| Availability | licence or online - they hold the results and data |
| Ages | 5-17 |
| Languages | 14 languages Arabic - Dutch - French - German - Hebrew - Icelandic - Italian - Korean - Portuguese - Serbian - Spanish - Turkish - Traditional Chinese - English adaptation for Singapore. Several others in process |
| Classification (Isoquol) | Functional Status PRO-children |
| ICF domains | ICF - Activities |
| | ICF - Participation |
| | ICF - Environmental Factors |
| PDF available | |

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)

[
[
[
[

| HOME Participation | | | | | | | | | |
|--|--|--|--|--|--|--|--|--|--|
| <p>A) Typically, <u>how often</u> does your child participate in <u>1 or more activities</u> of this type?</p> <p>CHECK ONE RESPONSE <input checked="" type="checkbox"/></p> <p>Daily Few times a week Once a week Few times a month Once a month Few times in last four months Once in last four months Never (<i>skip to Question C</i>)</p> <p>B) Think about <u>1 or 2 activities</u> of this type that your child participates in most often. Typically, <u>how involved</u> is your child when doing these activities?</p> <p>CHECK ONE RESPONSE <input checked="" type="checkbox"/></p> <p>5 Very Involved 4 3 Somewhat Involved 2 1 Minimally Involved</p> <p>C) Would you like your child's participation <u>to change</u> in this type of activity?</p> <p>IF YES, CHECK ALL THAT APPLY <input checked="" type="checkbox"/></p> <p>No change desired Yes, do more often Yes, do less often Yes, be more involved Yes, be less involved Yes, be involved in a broader variety of activities</p> | | | | | | | | | |
| 1) Computer and video games (e.g., playing video games, playing computer games) | | | | | | | | | |
| 2) Indoor play and games (e.g., playing with toys, puzzles, or board games, playing kitchen or dress-up) | | | | | | | | | |
| 3) Arts, crafts, music, and hobbies (e.g., doing arts and crafts, listening to music, playing an instrument, collecting, reading for leisure, cooking for fun) | | | | | | | | | |
| 4) Watching TV, videos, and DVDs | | | | | | | | | |
| 5) Getting together with other people (e.g., interacting with peers, family, other houseguests) | | | | | | | | | |
| 6) Socializing using technology (e.g., telephone, computer) | | | | | | | | | |
| 7) Household chores (e.g., unloading/loading the dishwasher, cleaning room or other areas of the house, cooking, taking out the garbage, setting the table, caring for household pet) | | | | | | | | | |
| 8) Personal care management (e.g., getting dressed, choosing clothing, brushing hair or teeth, applying makeup) | | | | | | | | | |
| 9) School preparation (not homework) (e.g., gathering materials, packing school bag, packing lunch, reviewing schedule) | | | | | | | | | |
| 10) Homework (e.g., daily reading, homework assignments, school projects) | | | | | | | | | |

| | |
|------------------------------------|---|
| 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 |

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)

[
[
[
[

The Disabilities of the Arm, Shoulder and Hand (DASH) Score

Clinician's name (or ref) _____

Patient's name (or ref) _____

INSTRUCTIONS: This questionnaire asks about your symptoms as well as your ability to perform certain activities. Please answer *every question*, based on your condition in the **last week**. If you did not have the opportunity to perform an activity in the past week, please make your *best estimate* on which response would be the most accurate. It doesn't matter which hand or arm you use to perform the activity; please answer based on your ability regardless of how you perform the task.

Please rate your ability to do the following activities in the last week.

| | | | | | |
|---|-------------------------------------|---------------------------------------|---|---|------------------------------|
| 1. Open a tight or new jar | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 2. Write | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 3. Turn a key | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 4. Prepare a meal | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 5. Push open a heavy door | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 6. Place an object on a shelf above your head | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 7. Do heavy household chores (eg wash walls, wash floors) | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 8. Garden or do yard work | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 9. Make a bed | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 10. Carry a shopping bag or briefcase | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 11. Carry a heavy object (over 10 lbs) | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 12. Change a lightbulb overhead | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 13. Wash or blow dry your hair | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 14. Wash your back | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 15. Put on a pullover sweater | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| 16. Use a knife to cut food | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| Recreational activities which require little effort (eg cardplaying, knitting, etc) | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| Recreational activities in which you take some force or impact through your arm, shoulder or hand (eg golf, hammering, tennis, etc) | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| Recreational activities in which you move your arm freely (eg playing frisbee, badminton, etc) | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |

| | | | | | |
|---|--|--|--|---|---|
| 20. Manage transportation needs (getting from one place to another) | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | iPluto |
| 21. Sexual activities | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> Unable |
| <p>During the past week, <i>to what extent</i> has your arm, shoulder or hand problem interfered with your normal social activities with family, friends, neighbours or groups?</p> | | | | | |
| 22. hand problem interfered with your normal social activities with family, friends, neighbours or groups? | <input type="radio"/> Not at all | <input type="radio"/> Slightly | <input type="radio"/> Moderately | <input type="radio"/> Quite a bit | <input type="radio"/> Extremely |
| <p>During the past week, were you limited in your work or other regular daily activities as a result of your arm, shoulder or hand problem?</p> | | | | | |
| 23. | <input type="radio"/> Not limited at all | <input type="radio"/> Slightly limited | <input type="radio"/> Moderately limited | <input type="radio"/> Very limited | <input type="radio"/> Unable |
| <p>Please rate the severity of the following symptoms in the last week</p> | | | | | |
| 24. Arm, shoulder or hand pain | <input type="radio"/> None | <input type="radio"/> Mild | <input type="radio"/> Moderate | <input type="radio"/> Severe | <input type="radio"/> Extreme |
| 25. Arm, shoulder or hand pain when you performed any specific activity | <input type="radio"/> None | <input type="radio"/> Mild | <input type="radio"/> Moderate | <input type="radio"/> Severe | <input type="radio"/> Extreme |
| 26. Tingling (pins and needles) in your arm, shoulder or hand | <input type="radio"/> None | <input type="radio"/> Mild | <input type="radio"/> Moderate | <input type="radio"/> Severe | <input type="radio"/> Extreme |
| 27. Weakness in your arm, shoulder or hand | <input type="radio"/> None | <input type="radio"/> Mild | <input type="radio"/> Moderate | <input type="radio"/> Severe | <input type="radio"/> Extreme |
| 28. Stiffness in your arm, shoulder or hand | <input type="radio"/> None | <input type="radio"/> Mild | <input type="radio"/> Moderate | <input type="radio"/> Severe | <input type="radio"/> Extreme |
| <p>During the past week, how much difficulty have you had sleeping because of the pain in your arm, shoulder or hand?</p> | | | | | |
| 29. | <input type="radio"/> No difficulty | <input type="radio"/> Mild difficulty | <input type="radio"/> Moderate difficulty | <input type="radio"/> Severe difficulty | <input type="radio"/> So much I can't sleep |
| <p>I feel less capable, less confident or less useful because of my arm, shoulder or hand problem</p> | | | | | |
| 30. | <input type="radio"/> Strongly disagree | <input type="radio"/> Disagree | <input type="radio"/> Neither agree nor disagree | <input type="radio"/> Agree | <input type="radio"/> Strongly agree |

Thank you very much for completing all the questions in this questionnaire.

The Disabilities of the Arm, Shoulder and Hand (DASH) Score is 0

(**NB.** A DASH score may not be calculated if there are greater than 3 missing items.)

There are two further small sections to this score. They are both optional. Just click below to select

WORK MODULE

SPORTS/PERFORMING ARTS MODULE

Reference for Score: Hudak PL, Amadio PC, Bombardier C. Development of an upper extremity outcome measure: the DASH (disabilities of the arm, shoulder and hand) [corrected]. The Upper Extremity Collaborative Group (UECG) Am J Ind Med. 1996 Jun;29(6):602-8. Erratum in: Am J Ind Med 1996 Sep;30(3):372. The Institute for Work & Health are the copyright owners of the DASH and QuickDASH Outcome Measures (<http://www.dash.iwh.on.ca/>)

| | |
|------------------------------------|--|
| Measure (abb) | MHQ |
| Measure (full) | Michigan Hand Outcomes Questionnaire |
| Reference | https://www.ncbi.nlm.nih.gov/pubmed/9708370 |
| Description | The MHQ is a hand-specific outcomes instrument that measures outcomes of patients with conditions of, or injury to, the hand or wrist. Six distinct scales: overall hand function, activities of daily living (ADLs), pain, work performance, aesthetics, patient satisfaction with hand function. Rated on a likert type scale with reference to the last 7 days. |
| No of items / questions | 37 core questions however some duplicated for each hand |
| Target | Hand function and QoL |
| Questionnaire (direct link) | http://mhq.lab.medicine.umich.edu/mhq |
| Validated or used for BPBI | |
| Availability | Licence - online free |
| Ages | 6 - 17 |
| Languages | 12 languages |
| Classification (Isoquol) | Functional Status PRO- teens and adults |
| ICF domains | ICF - Body functions & structures |
| | ICF - Activities |
| | ICF - Participation |
| PDF available | yes |

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)

[
[
[
[

Instructions: This survey asks for your views about your hands and your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer **EVERY** question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

I. The following questions refer to the function of your hand(s)/wrist(s) ***during the past week***. (Please circle one answer for each question). Please answer **EVERY** question, even if you do not experience any problems with the hand and/or wrist.

A. The following questions refer to your ***right*** hand/wrist.

| | Very Good | Good | Fair | Poor | Very Poor |
|--|-----------|------|------|------|-----------|
| 1. Overall, how well did your <i>right</i> hand work? | 1 | 2 | 3 | 4 | 5 |
| 2. How well did your <i>right</i> fingers move? | 1 | 2 | 3 | 4 | 5 |
| 3. How well did your <i>right</i> wrist move? | 1 | 2 | 3 | 4 | 5 |
| 4. How was the strength in your <i>right</i> hand? | 1 | 2 | 3 | 4 | 5 |
| 5. How was the sensation (feeling) in your <i>right</i> hand? | 1 | 2 | 3 | 4 | 5 |

B. The following questions refer to your ***left*** hand/wrist.

| | Very Good | Good | Fair | Poor | Very Poor |
|---|-----------|------|------|------|-----------|
| 1. Overall, how well did your <i>left</i> hand work? | 1 | 2 | 3 | 4 | 5 |
| 2. How well did your <i>left</i> fingers move? | 1 | 2 | 3 | 4 | 5 |
| 3. How well did your <i>left</i> wrist move? | 1 | 2 | 3 | 4 | 5 |
| 4. How was the strength in your <i>left</i> hand? | 1 | 2 | 3 | 4 | 5 |
| 5. How was the sensation (feeling) in your <i>left</i> hand? | 1 | 2 | 3 | 4 | 5 |

II. The following questions refer to the ability of your hand(s) to do certain tasks *during the past week*. (Please circle one answer for each question). If you do not do a certain task, please estimate the difficulty with which you would have in performing it.

A. How difficult was it for you to perform the following activities using your **right hand**?

| | Not at All Difficult | A Little Difficult | Somewhat Difficult | Moderately Difficult | Very Difficult |
|--------------------------|-------------------------|-----------------------|-----------------------|-------------------------|-------------------|
| 1. Turn a door knob | 1 | 2 | 3 | 4 | 5 |
| 2. Pick up a coin | 1 | 2 | 3 | 4 | 5 |
| 3. Hold a glass of water | 1 | 2 | 3 | 4 | 5 |
| 4. Turn a key in a lock | 1 | 2 | 3 | 4 | 5 |
| 5. Hold a frying pan | 1 | 2 | 3 | 4 | 5 |

B. How difficult was it for you to perform the following activities using your **left hand**?

| | Not at All Difficult | A Little Difficult | Somewhat Difficult | Moderately Difficult | Very Difficult |
|--------------------------|-------------------------|-----------------------|-----------------------|-------------------------|-------------------|
| 1. Turn a door knob | 1 | 2 | 3 | 4 | 5 |
| 2. Pick up a coin | 1 | 2 | 3 | 4 | 5 |
| 3. Hold a glass of water | 1 | 2 | 3 | 4 | 5 |
| 4. Turn a key in a lock | 1 | 2 | 3 | 4 | 5 |
| 5. Hold a frying pan | 1 | 2 | 3 | 4 | 5 |

| | |
|------------------------------------|---|
| Measure (abb) | WOSI |
| Measure (full) | Western Ontario Shoulder Instability Index |
| Reference | http://journals.sagepub.com/doi/abs/10.1177/03635465980260060501 |
| Description | WOSI has 21-items that assess shoulder related quality of life in patients with symptomatic shoulder instability. |
| No of items / questions | 21 |
| Target | QoL relating to shoulder instability |
| Questionnaire (direct link) | https://www.aaos.org/uploadedFiles/WOSI.pdf |
| Validated or used for BPBI | no |
| Availability | free |
| Ages | 10+ |
| Languages | English - French |
| Classification (Isoquol) | HRQOL PRO - children |
| ICF domains | ICF - Body functions & structures ICF - Activities ICF - Participation |
| PDF available | yes |

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)

[
[
[
[

The Western Ontario Shoulder Instability Index (WOSI)

Clinician's name (or ref) _____

Patient's name (or ref) _____

The following questions concern the symptoms you have experienced due to your shoulder problem. In all cases, please enter the amount of the symptom you have experienced in the last week. (please move the slider on the horizontal line.)

| | | | | |
|---|---|---|--|--|
| 1. How much pain do you experience in your shoulder with overhead activities? | 12. How much has your shoulder affected your ability to perform the specific skills required for your sport or work? (If your shoulder affects both sports and work, consider the area that is most affected.) | | | |
|  No pain |  Extreme pain |  Not affected |  Extremely affected | |
| 2. How much aching or throbbing do you experience in your shoulder? | 13. How much do you feel the need to protect your arm during activities? | | | |
|  No aching/throbbing |  Extreme aching/throbbing |  Not at all |  Extreme | |
| 3. How much weakness or lack of strength do you experience in your shoulder? | 14. How much difficulty do you experience lifting heavy objects below shoulder level? | | | |
|  No weakness |  Extreme weakness |  No difficulty |  Extreme difficulty | |
| 4. How much fatigue or lack of stamina do you experience in your shoulder? | 15. How much fear do you have of falling on your shoulder? | | | |
|  No fatigue |  Extreme fatigue |  No fear |  Extreme fear | |
| 5. How much clicking, cracking or snapping do you experience in your shoulder? | 16. How much difficulty do you experience maintaining your desired level of fitness? | | | |
|  No clicking |  Extreme clicking |  No difficulty |  Extreme difficulty | |
| 6. How much stiffness do you experience in your shoulder? | 17. How much difficulty do you have "roughhousing" or "horsing around" with family or friends? | | | |
|  No stiffness |  Extreme stiffness |  No difficulty |  Extreme difficulty | |

7. How much discomfort do you experience in your neck muscles as a result of your shoulder?

No discomfort Extreme discomfort

8. How much feeling of instability or looseness do you experience in your shoulder?

No instability Extreme instability

9. How much do you compensate for your shoulder with other muscles?

No at all Extreme

10. How much loss of range of motion do you have in your shoulder?

No loss Extreme loss

11. How much has your shoulder limited the amount you can participate in sports or recreational activities?

No limited Extremely limited

18. How much difficulty do you have sleeping because of your shoulder?

No difficulty Extreme difficulty

19. How conscious are you of your shoulder

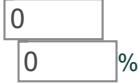
Not conscious Extremely conscious

20. How concerned are you about your shoulder becoming worse

No concern Extremely concerned

21. How much frustration do you feel because of your shoulder

No frustration Extremely frustrated

Physical symptoms Score is:  0 %

Sports/recreation/work Score is:  0 %

Lifestyle Score is:  0 %

Emotion Score is:  0 %

The WOSI Score is:  0 %

Link for Reference:

The Development and Evaluation of a Disease-Specific Quality of Life Measurement Tool for Shoulder Instability
The Western Ontario Shoulder Instability Index (WOSI) Am J Sports Med November 1998 vol. 26 no. 6 764-772
Alexandra Kirkley, MD, FRCSC*, Sharon Griffin, CSS, Heidi McLintock, BSc, PT, MSc and, Linda Ng, BSc, PT, <http://ajs.sagepub.com/content/26/6/764.abstract>

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
- () PROMIS - Upper Extremity
- () BPOM - Brachial Plexus Outcome Measurement - self evaluation scales
- () ABILHAND-Kids - Manual ABILity
- () PEM-CY - Participation and Environment Measure - Children and Youth
- () DASH - Disability of the Arm, Shoulder, and Hand
- () MHQ - Michigan Hand Outcomes Questionnaire
- () WOSI - Western Ontario Shoulder Instability Index

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.

- () CHEQ - Children's Hand-use Experience Questionnaire
- () PODCI -Pediatric Outcomes Data Collection Instrument
- () HUH - Hand Use at Home questionnaire
- () PROMIS - Upper Extremity
- () BPOM - Brachial Plexus Outcome Measurement - self evaluation scales
- () ABILHAND - Manual ABILITY
- () PEM-CY - Participation and Environment Measure - Children and Youth
- () DASH - Disability of the Arm, Shoulder, and Hand
- () MHQ - Michigan Hand Outcomes Questionnaire
- () WOSI - Western Ontario Shoulder Instability Index

| | |
|------------------------------------|---|
| 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 |

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)

[
[
[
[

Pediatric Global Health 7

Please respond to each question or statement by marking one box per row.

| | | Excellent | Very Good | Good | Fair | Poor |
|--------------|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Global01R1 | In general, would you say your health is:..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| Global02R1 | In general, would you say your quality of life is:..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| Global03R1 | In general, how would you rate your physical health? | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| Global04R1 | In general, how would you rate your mental health, including your mood and your ability to think? | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| PedGlobal2R1 | How often do you feel really sad? | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| PedGlobal5R1 | How often do you have fun with friends? | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| PedGlobal6R1 | How often do your parents listen to your ideas? | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |

| | |
|------------------------------------|---|
| Measure (abb) | PROMIS - Peer Relationships |
| Measure (full) | Patient-Reported Outcomes Measurement Information System - Peer relationships |
| Reference | http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-pediatric-measures |
| Description | Quality of relationships with friends and other acquaintances. |
| No of items / questions | 8 (patients) 15 (parents) |
| Target | QoL |
| 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 - Participation |
| | ICF - Personal Factors |
| | ICF - Environmental Factors |
| PDF available | yes |

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)

[
[
[
[

Pediatric Peer Relationships

Please respond to each question or statement by marking one box per row.

In the past 7 days...

| | | Never 1 | Almost Never 2 | Sometimes 3 | Often 4 | Almost Always 5 |
|---------|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 5018R1r | I felt accepted by other kids my age..... | <input type="checkbox"/> |
| 5058R1r | I was able to count on my friends | <input type="checkbox"/> |
| 5056R1r | I was able to talk about everything with my friends..... | <input type="checkbox"/> |
| 1147R1r | I was good at making friends | <input type="checkbox"/> |
| 5055R1r | My friends and I helped each other out..... | <input type="checkbox"/> |
| 233R2r | Other kids wanted to be my friend..... | <input type="checkbox"/> |
| 210R1r | Other kids wanted to be with me..... | <input type="checkbox"/> |
| 9020R1r | Other kids wanted to talk to me | <input type="checkbox"/> |
| 726aR2r | I felt good about my friendships | <input type="checkbox"/> |
| 9019r | I liked being around other kids my age..... | <input type="checkbox"/> |

In the past 7 days...

| | Never | Almost Never | Sometimes | Often | Almost Always |
|--|--------------|-------------------------|------------------|--------------|--------------------------|
|--|--------------|-------------------------|------------------|--------------|--------------------------|

| | | | | | | |
|---------|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 5152R1r | I played alone and kept to myself..... | <input type="checkbox"/> 5 | <input type="checkbox"/> 4 | <input type="checkbox"/> 3 | <input type="checkbox"/> 2 | <input type="checkbox"/> 1 |
| 5150R1r | I shared with other kids (food, games, pens, etc.)..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 5052R1r | I spent time with my friends..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 733R1r | I was a good friend | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 2964R1r | I was able to have fun with my friends | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

| | |
|------------------------------------|---|
| Measure (abb) | PedsQL |
| Measure (full) | Pediatric Quality of Life Inventory |
| Reference | http://www.pedsql.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 |

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)

[
[
[
[

ID# _____

Date: _____

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

PARENT REPORT for CHILDREN (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0** if it is **never** a problem
- 1** if it is **almost never** a problem
- 2** if it is **sometimes** a problem
- 3** if it is **often** a problem
- 4** if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has your child had with ...*

| PHYSICAL FUNCTIONING (problems with...) | Never | Almost Never | Sometimes | Often | Almost Always |
|---|-------|-----------------|-----------|-------|------------------|
| 1. Walking more than one block | 0 | 1 | 2 | 3 | 4 |
| 2. Running | 0 | 1 | 2 | 3 | 4 |
| 3. Participating in sports activity or exercise | 0 | 1 | 2 | 3 | 4 |
| 4. Lifting something heavy | 0 | 1 | 2 | 3 | 4 |
| 5. Taking a bath or shower by him or herself | 0 | 1 | 2 | 3 | 4 |
| 6. Doing chores around the house | 0 | 1 | 2 | 3 | 4 |
| 7. Having hurts or aches | 0 | 1 | 2 | 3 | 4 |
| 8. Low energy level | 0 | 1 | 2 | 3 | 4 |

| EMOTIONAL FUNCTIONING (problems with...) | Never | Almost Never | Sometimes | Often | Almost Always |
|--|-------|-----------------|-----------|-------|------------------|
| 1. Feeling afraid or scared | 0 | 1 | 2 | 3 | 4 |
| 2. Feeling sad or blue | 0 | 1 | 2 | 3 | 4 |
| 3. Feeling angry | 0 | 1 | 2 | 3 | 4 |
| 4. Trouble sleeping | 0 | 1 | 2 | 3 | 4 |
| 5. Worrying about what will happen to him or her | 0 | 1 | 2 | 3 | 4 |

| SOCIAL FUNCTIONING (problems with...) | Never | Almost Never | Sometimes | Often | Almost Always |
|--|-------|-----------------|-----------|-------|------------------|
| 1. Getting along with other children | 0 | 1 | 2 | 3 | 4 |
| 2. Other kids not wanting to be his or her friend | 0 | 1 | 2 | 3 | 4 |
| 3. Getting teased by other children | 0 | 1 | 2 | 3 | 4 |
| 4. Not able to do things that other children his or her age can do | 0 | 1 | 2 | 3 | 4 |
| 5. Keeping up when playing with other children | 0 | 1 | 2 | 3 | 4 |

| SCHOOL FUNCTIONING (problems with...) | Never | Almost Never | Sometimes | Often | Almost Always |
|---|-------|-----------------|-----------|-------|------------------|
| 1. Paying attention in class | 0 | 1 | 2 | 3 | 4 |
| 2. Forgetting things | 0 | 1 | 2 | 3 | 4 |
| 3. Keeping up with schoolwork | 0 | 1 | 2 | 3 | 4 |
| 4. Missing school because of not feeling well | 0 | 1 | 2 | 3 | 4 |
| 5. Missing school to go to the doctor or hospital | 0 | 1 | 2 | 3 | 4 |

| | |
|------------------------------------|--|
| 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 |

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)

[
[
[
[

Describing your health TODAY

Under each heading, please tick the ONE box that best describes your health TODAY.

Mobility (walking about)

I have no problems walking about

I have some problems walking about

I have a lot of problems walking about

Looking after myself

I have no problems washing or dressing myself

I have some problems washing or dressing myself

I have a lot of problems washing or dressing myself

Doing usual activities (for example, going to school, hobbies, sports, playing, doing things with family or friends)

I have no problems doing my usual activities

I have some problems doing my usual activities

I have a lot of problems doing my usual activities

Having pain or discomfort

I have no pain or discomfort

I have some pain or discomfort

I have a lot of pain or discomfort

Feeling worried, sad or unhappy

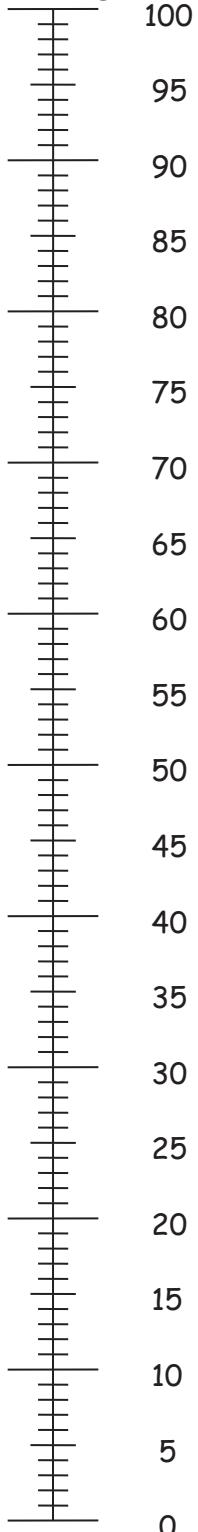
I am not worried, sad or unhappy

I am a bit worried, sad or unhappy

I am very worried, sad or unhappy

How good is your health TODAY

The best health
you can imagine



- We would like to know how good or bad your health is TODAY.
- This line is numbered from 0 to 100.
- 100 means the best health you can imagine.
0 means the worst health you can imagine.
- Please mark an X on the line that shows how good or bad your health is TODAY.

| | |
|------------------------------------|---|
| Measure (abb) | CHQ |
| Measure (full) | Child Health Questionnaire |
| Reference | https://www.healthactchq.com/survey/chq |
| Description | The Child Health Questionnaire (CHQ) is a PRO measure completed by children/parents that evaluates health-related quality of life in children 5-to-18 years of age. It is available in 2 lengths: 50 items (CHQ-PF50) or 28 items (CHQ-PF28) that have response scale options which vary from 4-6 levels. |
| No of items / questions | 28 or 50 |
| Target | |
| Questionnaire (direct link) | |
| Validated or used for BPBI | Akel 2013 - https://www.ncbi.nlm.nih.gov/pubmed/23423758 Squitieri 2013 - https://www.ncbi.nlm.nih.gov/pubmed/24416766 |
| Availability | license |
| Ages | 5-18 |
| Languages | https://www.healthactchq.com/translation/chq |
| Classification (Isoquol) | HRQOL PRO - children |
| ICF domains | ICF - Participation |
| | ICF - Personal Factors |
| | ICF - Environmental Factors |
| PDF available | yes |

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)

[
[
[
[

Recall Time Frames

CHQ response options vary - for example some scales ask about the past 4 weeks, the global health items asks about health "in general" and the global change items asks as compared to one year ago. Response options also vary from 4-6 levels for the scales.

FOLLOWING IS THE ITEM CONTENT FOR THE CHQ FAMILY OF MEASURES:

Child Health Questionnaire Parent Form 50 Questions (CHQ-PF50)

- In general, how would you rate your child's health?
- Has your child been limited in any of the following activities due to health problems - doing things that take a lot of energy, such as playing soccer or running; doing things that take some energy such as riding a bike or skating; ability (physically) to get around the neighborhood, playground, or school; walking one block or climbing one flight of stairs; bending, lifting,/stooping; taking care of him/herself?
- Has your child's school work or activities with friends been limited in any of the following ways due to emotional difficulties or problems with his/her behavior - limited in the kind of schoolwork or activities with friends he/she could do; limited in the amount of time he/she could spend on schoolwork or activities with friends; limited in performing schoolwork or activities with friends?
- Has your child's school work or activities with friends been limited in any of the following ways due to problems with his/her physical health - limited in the kind of schoolwork or activities with friends he/she could do; limited in the amount of time he/she could spend on schoolwork or activities with friends?
- How much bodily pain or discomfort has your child had?
- How often has your child had bodily pain or discomfort?
- How often did each of the following statements describe your child - argued a lot; had difficulty concentrating or paying attention; lied/cheated; stole things; had tantrums?
- Compared to other children your child's age, in general how would you rate his/her behavior?
- How much of the time do you think your child: felt like crying; felt lonely; acted nervous; bothered or upset; cheerful?
- How satisfied do you think your child has felt about: his/her school ability; athletic ability; friendships; looks/appearance; family relationships; life overall?
- My child seems to be less healthy than other children I know; My child has never been seriously ill; When there is something going around my child usually catches it; I expect my child will have a very healthy life; I worry more about my child's health than other people.
- Compared to one year ago, how would you rate your child's health now?
- How much emotional worry or concern did each of the following cause you - your child's physical health; emotional well-being or behavior; attention or learning abilities?
- Were you limited in the amount of time you had for your own needs because of your child's - physical health; emotional well-being or behavior; attention or learning abilities?
- How often has your child's health or behavior - limited the types of activities you could do as a family; interrupted various everyday family activities; limited your ability as a family to "pick up and go"; caused tension or conflict; been a source of disagreements or arguments in your family; caused you to cancel or change plans (personal or work) at the last minute?
- In general, how would you rate your family's ability to get along with one another?

Child Health Questionnaire Parent Form 28 Questions (CHQ-PF28)

- In general, how would you rate your child's health?
- Has your child been limited in any of the following activities due to health problems - doing things that take a lot of energy, such as playing soccer or running; doing things that take some energy such as riding a bike or skating; bending, lifting, or stooping
- Has your child's been limited in the amount of time he/she could spend on schoolwork or activities with friends due to emotional difficulties or problems with his/her behavior?
- Has your child been limited in the kind of schoolwork or activities he/she could do with friends due to problems with his/her physical health?

- How often has your child had bodily pain or discomfort?
- How often did each of the following statements describe your child - argued a lot; had difficulty concentrating or paying attention; lied/cheated?
- Compared to other children your child's age, in general how would you rate his/her behavior?
- How much of the time do you think your child: felt lonely; acted nervous; bothered or upset?
- How satisfied do you think your child has felt about: his/her school ability; friendships; life overall?
- My child seems to be less healthy than other children I know; My child has never been seriously ill; I worry more about my child's health than other people.
- Compared to one year ago, how would you rate your child's health now?
- How much emotional worry or concern did each of the following cause you - your child's physical health; emotional well-being or behavior?
- Were you limited in the amount of time you had for your own needs because of your child's - physical health; emotional well-being or behavior?
- How often has your child's health or behavior - limited the types of activities you could do as a family; interrupted various everyday family activities (eating meals, watching tv)?
- In general, how would you rate your family's ability to get along with one another?

Child Health Questionnaire Child Form 87 Questions (CHQ-CF87)

- In general, how would you say your health is?
- Has it been difficult for you to do the following activities due to health problems - doing things that take a lot of energy, such as playing soccer or running; doing things that take some energy such as riding a bike or skating; walk several blocks or climb several flights of stairs; ability (physically) to get around the neighborhood, playground, or school; walk one block or climbing one flight of stairs; do your tasks around the house; bend, lift or stoop; eat, dress, bathe or go to the toilet by yourself; get in/out of bed?
- Has it been difficult to do certain kinds of schoolwork or activities with friends because of problems like feeling sad or worried; spend the usual amount of time on schoolwork or activities with friends; get schoolwork done at all or do any activities with friends?
- Has it been difficult to do certain kinds of schoolwork or activities with friends because of problems with your behavior; spend the usual amount of time on schoolwork or activities with friends; get schoolwork done at all or do any activities with friends?
- Has it been difficult to do certain kinds of schoolwork or activities with friends because of problems with your physical health; spend the usual amount of time on schoolwork or activities with friends; get schoolwork done at all or do any activities with friends?
- How much bodily pain or discomfort have you had? How often have you had bodily pain or discomfort?
- How often did each of the following statements describe you; acted too young for your age; argued; had a hard time paying attention; did not do what your teacher or parent asked you to do; wanted to be alone; lied/cheated; had a hard time getting others to like you; felt clumsy; ran away from home; had speech problems; stole things at home or outside the home; acted mean or moody if you did not get what you wanted; got really mad when you did not get what you wanted; found it hard to be with others; had a hard time getting along with others.
- Compared to other children your age, in general how would you rate your behavior?
- How much of the time do you: feel sad; feel like crying; feel afraid or scared; worry about things; feel lonely; feel unhappy; feel nervous; feel bothered or upset; feel happy; feel cheerful; enjoy the things you do; have fun; feel jittery or restless; have trouble sleeping; have headaches; like yourself?
- How good or bad have you felt about: yourself; your school work; your ability to play sports; your friendships; the things you can do; the way you get along with others; your body and your looks; the way you seem to feel most of the time; the way you get along with your family; the way life seems to be for you; your ability to be a friend to others; the way others seem to feel about you; your ability to talk with others; your health in general?
- My health is excellent; I was so sick once I thought I might die; I do not seem to get very sick; I seem to be less healthy than other kids I know; I have never been very, very sick; I always seem to get sick; I think I will be less healthy when I get older; I think I will be very healthy when I get older; I never worry about my health; I think I am healthy now; I think I worry more about my health than other kids my age.
- Compared to one year ago, how would you rate your health now?
- How often has your health or behavior - limited the types of activities you could do as a family; interrupted various everyday family activities; limited your ability as a family to "pick up and go"; caused tension or conflict; been a source of disagreements or arguments in your family; caused your family to cancel or change plans at the last minute?

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.

- () PROMIS - Global Health Scale
- () PROMIS - Peer Relationships
- () PedsQL (3) - Pediatric Quality of Life Inventory
- () EQ5D-Y - EuroQol five Dimensional scale - Youth edition
- () CHQ - child health questionnaire

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.

- PROMIS - Global Health Scale
- PROMIS - Peer Relationships
- PedsQL (3) - Pediatric Quality of Life Inventory
- EQ5D-Y - EuroQol five Dimensional scale - Youth edition
- CHQ - child health questionnaire

| | |
|------------------------------------|--|
| 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 |

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)

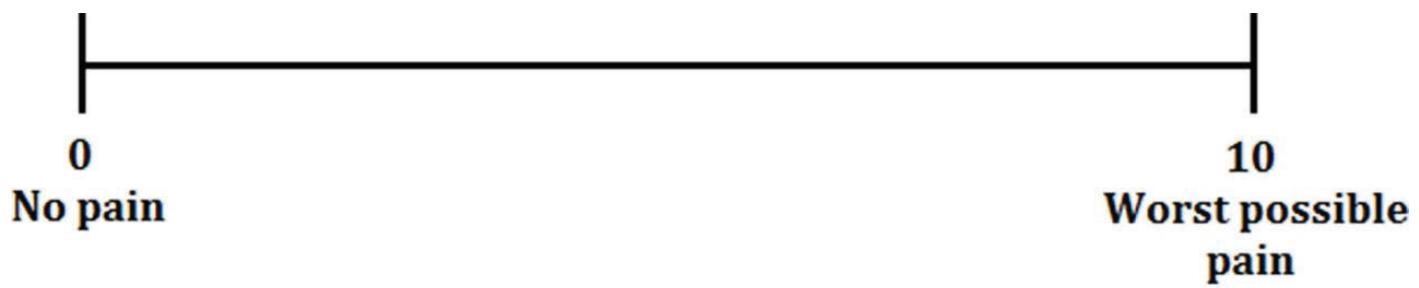
| | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | |
|---------------------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|---------------|
| not specific at all | () | () | () | () | () | () | () | () | () | () | most specific |

"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)

[
[
[
[



NOTE: A mark is placed on the line at the point that represents the level of pain observed. This is measured in millimeter from the left anchor 'no pain' to generate a pain score.
The word 'distress' replaces 'pain' to create a distress scale

| | |
|------------------------------------|--|
| Measure (abb) | NRS for pain |
| Measure (full) | Numerical Rating Scale |
| Reference | |
| Description | Numeric Rating Scale (NRS) is a PRO measures completed by children >7 years that measures pain intensity. This scale ranks the child's severity of pain on a 0-10 scale, where 0 represents "no pain" and 10 represents "worse possible 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 |

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 |

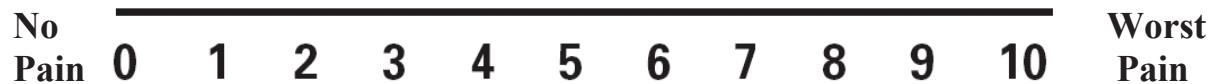
"This PRO measure should be employed at..." (multiple answers possible)

- () 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)

[
[
[
[

Pain Assessment Tool Guidelines for use: Numeric Pain Scale



Instructions for use:

The numerical rating scale (NRS) is perhaps the most common pain assessment tool used. It is important to recognize this is an 11-point scale (0-10 not 1-10). Ask the patient whether or not they are experiencing discomfort right now. If so, ask them to describe the discomfort.

- To ascertain their understanding of the scale, ask if they would recognize:
 - a state of no pain (“0”) (or specific discomfort they describe)
 - and the worst pain (or specific discomfort) imaginable (“10”).
- Have the patient rate the intensity of their pain/discomfort “right now” verbally with a number or by pointing to the number that represents their pain intensity
- This process can be repeated with similar questions about emotional distress

Scoring instructions:

Record the corresponding numerical value based on the patient’s response.

| | |
|------------------------------------|---|
| 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 |

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)

[
[
[
[

Faces Pain Scale – Revised (FPS-R)

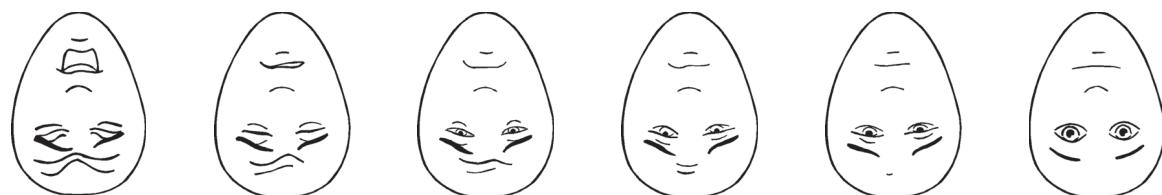
In the following instructions, say "hurt" or "pain", whichever seems right for a particular child.

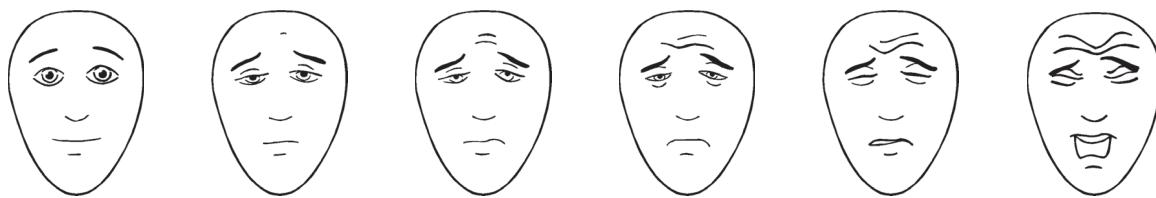
"These faces show how much something can hurt. This face [point to face on far left] shows no pain. The faces show more and more pain [point to each from left to right] up to this one [point to face on far right] - it shows very much pain. Point to the face that shows how much you hurt [right now]."

*Score the chosen face **0, 2, 4, 6, 8, or 10**, counting left to right, so "0" = "no pain" and "10" = "very much pain". Do not use words like "happy" or "sad". This scale is intended to measure how children feel inside, not how their face looks.*

Permission for Use. Copyright of the FPS-R is held by the International Association for the Study of Pain (IASP) ©2001. This material may be photocopied for **non-commercial clinical, educational and research** use. For reproduction of the FPS-R in a journal, book or web page, or for any commercial use of the scale, request permission from IASP online at www.iasp-pain.org/FPS-R.

Sources. Hicks CL, von Baeyer CL, Spafford P, van Korlaar I, Goodenough B. The Faces Pain Scale – Revised: Toward a common metric in pediatric pain measurement. Pain 2001;93:173-183. Bieri D, Reeve R, Champion GD, Addicoat L, Ziegler J. The Faces Pain Scale for the self-assessment of the severity of pain experienced by children: Development, initial validation and preliminary investigation for ratio scale properties. Pain 1990;41:139-150.





10 8 6 4 2 0

(Fold along dotted line)

Reeve R, Champlain GD, Addicott L, Ziegler J. The Faces Pain Scale for the self-assessment of the severity of pain experienced by children: Development, initial validation and preliminary investigation for ratio scale properties. *Pain* 1990;41:139-150.

Sources: Hicks CL, von Baeyer CL, Sparto P, van Karlaar L, Goedertier B. The Faces Pain Scale - Revised: Toward a common metric in pediatric pain measurement. *Pain* 2001;93:173-183. Bieri D, Reeve R, Champlain GD, Addicott L, Ziegler J, Goedertier B. The Faces Pain Scale - Revised: Toward a common metric in pediatric pain measurement. *Pain* 1990;41:139-150.

Permit for use. For reproduction of the FPS-R is held by the International Association for the Study of Pain (IASP) ©2001. This material may be photocopied for non-commercial clinical educational and research use. For any commercial use of the scale, request permission from IASP online at www.iasp-pain.org/FPS-R.

Score the chosen face **0, 2, 4, 6, 8 or 10**, counting left to right, so "0" = "no pain" and "10" = "very much pain". Do not use words like "happy" or "sad". This scale is intended to measure how children feel inside, not how their face looks.

"These faces show how much something can hurt. This face [point to face on far left] shows no pain. The faces show more and more pain [point to each from left to right] up to this one [point to face on far right] - it shows very much pain. Point to the face that shows how much you hurt [right now]."

In the following instructions, say "hurt" or "pain", whichever seems right for a particular child.

Faces Pain Scale - Revised (FPS-R)

EPS-R - Australia/English - Version of 30 Jan 14 - Map1. ID7858 / FPS-R-AU2.0_english-AU1.doc

| | |
|------------------------------------|--|
| 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 |

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)

[
[
[
[

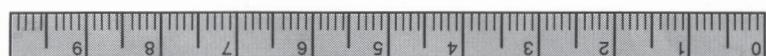
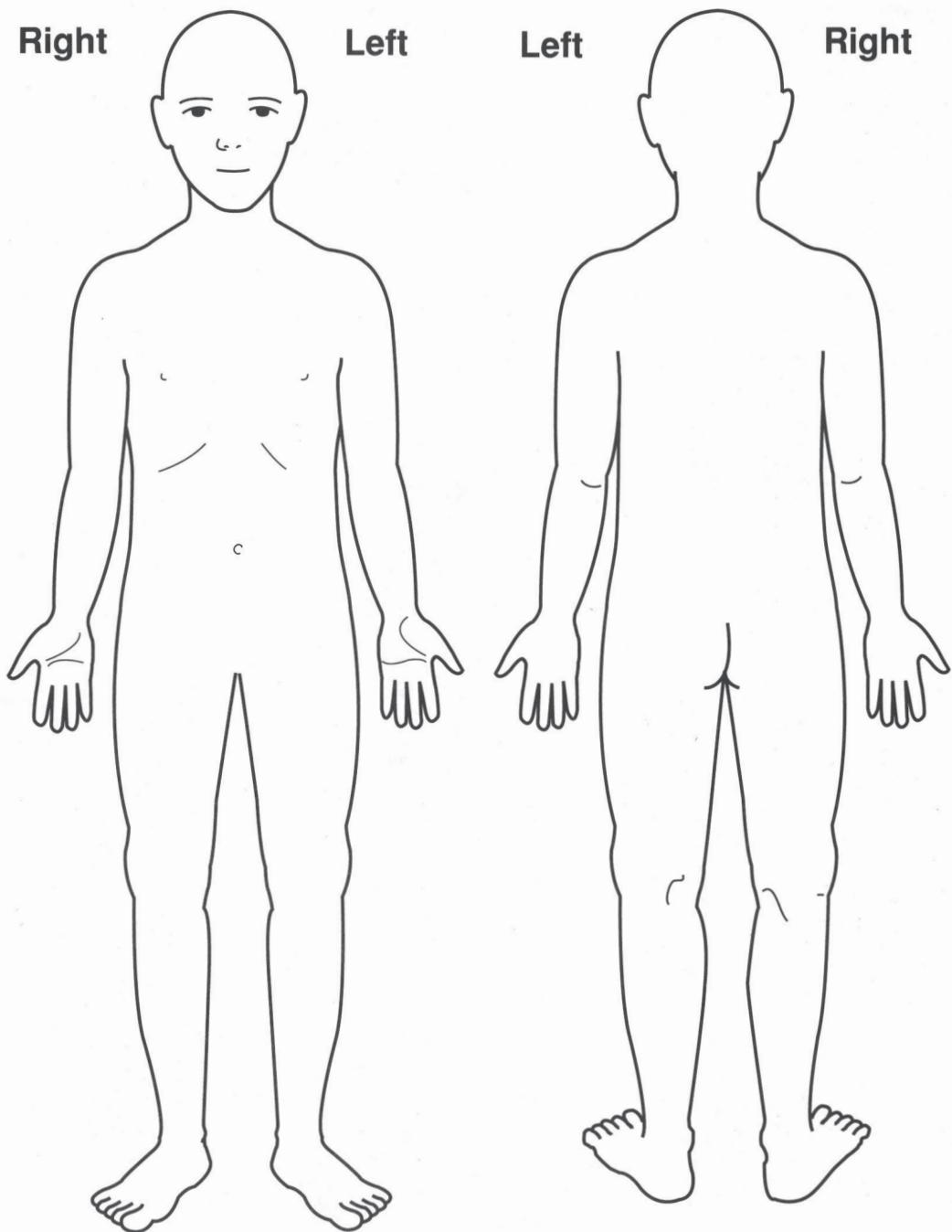
CODE _____

DATE _____

ADOLESCENT PEDIATRIC PAIN TOOL (APPT)

INSTRUCTIONS:

1. Color in the areas on these drawings to show where you have pain. Make the marks as big or small as the place where the pain is.



2. Place a straight, up and down mark on this line to show how much pain you have.



3. Point to or circle as many of these words that describe your pain.

1
annoying
bad
horrible
miserable
terrible
uncomfortable

2
aching
hurting
like an ache
like a hurt
sore

3
beating
hitting
pounding
punching
throbbing

4
biting
cutting
like a pin
like a sharp knife
pin like
sharp
stabbing

5
blistering
burning
hot
6
cramping
crushing
like a pinch
pinching
pressure

7
itching
like a scratch
like a sting
scratching
stinging

8
shocking
shooting
splitting

9
numb
stiff
swollen
tight

10
awful
deadly
dying
killing
11
crying
frightening
screaming
terrifying

12
dizzy
sickening
suffocating

13
never goes away
uncontrollable

14
always
comes and goes
comes on all of
a sudden
constant
continuous
forever

15
off and on
once in a while
sneaks up
sometimes
steady

If you like,
you may add
other words:

For office use only.

| |
|---|
| BSA: _____ |
| IS: _____ |
| #S ⁽²⁻⁹⁾ _____ /37 = _____ % |
| #A ⁽¹⁰⁻¹²⁾ _____ /11 = _____ % |
| #E ^(1,13) _____ /8 = _____ % |
| #T ^(14,15) _____ /11 = _____ % |
| Total _____ /67 = _____ % |

| | |
|------------------------------------|---|
| Measure (abb) | PROMIS - pain intensity |
| Measure (full) | Patient-Reported Outcomes Measurement Information System - Pain Intensity |
| Reference | http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-pediatric-measures |
| Description | pain severity items that cover average pain, worst pain, and pain right now |
| No of items / questions | 1 |
| Target | pain severity |
| Questionnaire (direct link) | http://www.healthmeasures.net/search-view-measures |
| Validated or used for BPBI | |
| Availability | PDF free licence for electronic submissions |
| Ages | 8 - 17 |
| Languages | English - Spanish - others available via online request |
| Classification (Isoquol) | Symptom PRO (Pain) |
| ICF domains | ICF - Body functions & structures |
| PDF available | yes |

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)

[
[
[
[

Pain Intensity – 1a

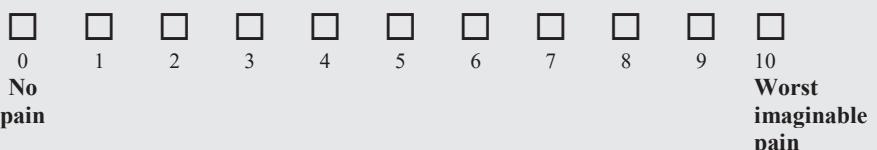
Please respond to the question by marking one box.

Pain Intensity

In the past 7 days...

Global07

How would you rate your pain on average?.....



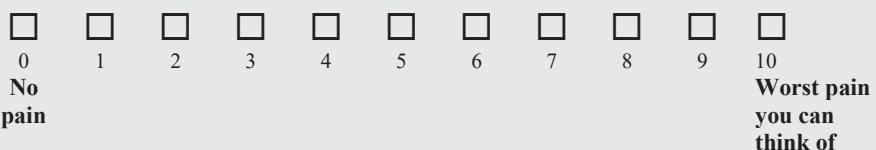
Pain Intensity – 1a

Please respond to the question by marking one box.

Pain Intensity

In the past 7 days...

How bad was your child's pain on average?.....



prx9033R1

| | |
|------------------------------------|---|
| Measure (abb) | PROMIS - pain interference |
| Measure (full) | Patient-Reported Outcomes Measurement Information System - Pediatric Pain Interference |
| Reference | http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-pediatric-measures |
| Description | Pain interference refers to the degree to which pain limits or interferes with an individual's physical, mental, and social activities. Patient reported and parent proxy evaluations available. |
| No of items / questions | 8 (patients) 13 (parents) |
| Target | pain and everyday life |
| 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) | Symptom PRO (Pain) |
| ICF domains | ICF - Body functions & structures |
| | ICF - Activities |
| | ICF - Participation |
| | ICF - Personal Factors |
| PDF available | yes |

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)

[
[
[
[

Parent Proxy Pain Interference

Please respond to each question or statement by marking one box per row.

In the past 7 days...

| | | Never | Almost Never | Sometimes | Often | Almost Always |
|-----------|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Pf3pain4r | It was hard for my child to have fun when he/she had pain | <input type="checkbox"/> |
| | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| Pf3pain2r | It was hard for my child to pay attention when he/she had pain | <input type="checkbox"/> |
| | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| Pf2pain2r | My child had trouble doing schoolwork when he/she had pain | <input type="checkbox"/> |
| | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| Pf4pain2r | It was hard for my child to remember things when he/she had pain..... | <input type="checkbox"/> |
| | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| Pf2pain5r | My child had trouble sleeping when he/she had pain | <input type="checkbox"/> |
| | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| Pf2pain4r | It was hard for my child to run when he/she had pain | <input type="checkbox"/> |
| | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| Pf4pain6r | It was hard for my child to stay standing when he/she had pain | <input type="checkbox"/> |
| | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| Pf4pain4r | It was hard for my child to get along with other people when he/she had pain | <input type="checkbox"/> |
| | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| Pf1pain4r | It was hard for my child to walk one block when he/she had pain | <input type="checkbox"/> |
| | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |
| Pf3pain7r | My child felt angry when he/she had pain | <input type="checkbox"/> |
| | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 | 1 2 3 4 5 |

In the past 7 days...

| | Never | Almost Never | Sometimes | Often | Almost Always |
|--|--------------|-------------------------|------------------|--------------|--------------------------|
|--|--------------|-------------------------|------------------|--------------|--------------------------|

| | | | | | | |
|-----------|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| Pf4pain1r | My child hurt a lot | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| Pf3pain6r | My child hurt all over his/her body | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| Pf4pain5r | My child missed school when he/she had pain | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

| | |
|------------------------------------|--|
| Measure (abb) | PROMIS - pain quality |
| Measure (full) | Patient-Reported Outcomes Measurement Information System - Pediatric Pain Quality - Sensory |
| Reference | http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-pediatric-measures |
| Description | Assesses pain quality through Likert-type response scales of differing descriptors of pain. The child reports frequency (never to always) and severity (none to very severe). The recall period for all pain quality items is the past 7 days. |
| No of items / questions | 8 |
| Target | Sensory descriptors of pain |
| Questionnaire (direct link) | http://www.healthmeasures.net/search-view-measures |
| Validated or used for BPBI | |
| Availability | PDF free licence for electronic submissions |
| Ages | 8 - 17 |
| Languages | English - Spanish - others available via online request |
| Classification (Isoquol) | Symptom PRO (Pain) |
| ICF domains | ICF - Body functions & structures |
| PDF available | yes |

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)

[
[
[
[

**In the past 7 days, did your pain
feel...**

| | | No | Yes |
|---------|----------------------|-------------------------------|-------------------------------|
| pqa21_p | sickening? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |
| pqa12_p | tiring? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |
| pqa13_p | uncomfortable? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |
| pqa14_p | unending? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |
| pqa22_p | stressful? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |
| pqa19_p | intolerable? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |
| pqa6_p | cruel? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |
| pqa17_p | torturing? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |
| pqa18_p | unbearable? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |
| pqa16_p | annoying? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |
| pqa15_p | nagging? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 |

In the past 7 days, did your pain feel....

| | | Not at all | A little bit | Somewhat | Quite a bit | Very much |
|------------|------------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| paqual15_p | throbbing?..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual20_p | stabbing?..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual28_p | spreading?..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual7_p | stinging? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual17_p | tearing (ripping)? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual13_p | pounding? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual16_p | splitting? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual3_p | sensitive? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual23_p | like pins and needles? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual25_p | deep?..... | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual32_p | constant? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| paqual10_p | pulling? | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |

| | |
|------------------------------------|---|
| 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 (Isoquol) | Symptom PRO (Pain) |
| ICF domains | ICF - Body functions & structures ICF - Activities ICF - Participation ICF - Personal Factors ICF - Environmental Factors |
| PDF available | yes |

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)

[
[
[
[

Brief Pain Inventory (Short Form)

iPluto

Study ID# _____ Hospital # _____
Do not write above this line.

Date: _____

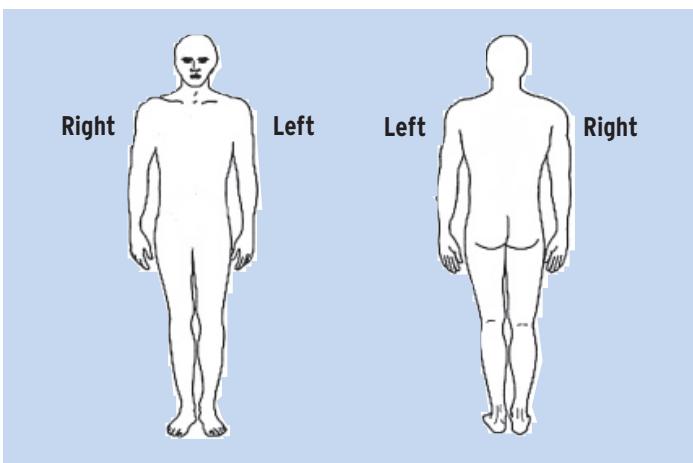
Time: _____

Name: _____ Last _____ First _____ Middle Initial _____

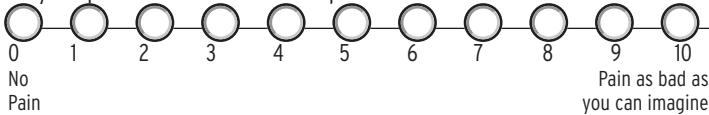
1) Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

1. yes 2. no

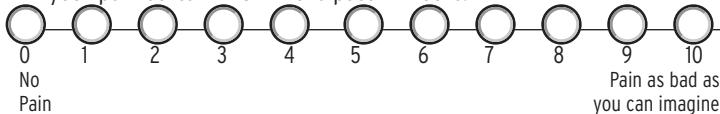
2) On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



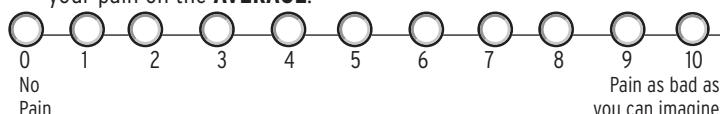
3) Please rate your pain by circling the one number that best describes your pain at its **WORST** in the past 24 hours.



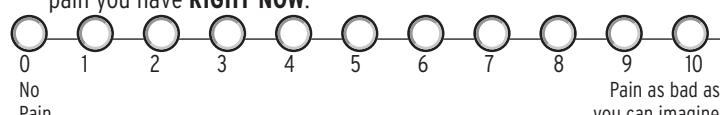
4) Please rate your pain by circling the one number that best describes your pain at its **LEAST** in the past 24 hours.



5) Please rate your pain by circling the one number that best describes your pain on the **AVERAGE**.

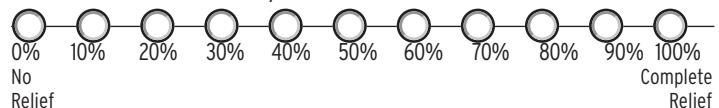


6) Please rate your pain by circling the one number that tell how much pain you have **RIGHT NOW**.



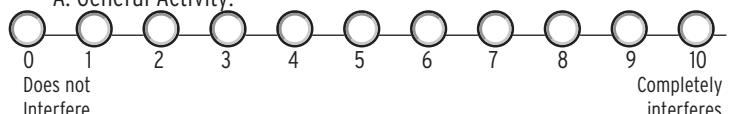
7) What treatments or medications are you receiving for your pain?

8) In the past 24 hours, how much **RELIEF** have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

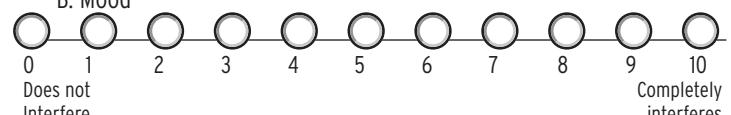


9) Circle the one number that describes how, during the past 24 hours, **PAIN HAS INTERFERED** with your:

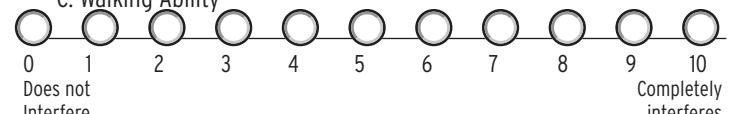
A. General Activity:



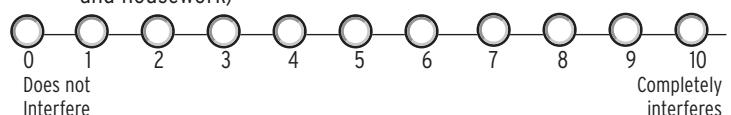
B. Mood



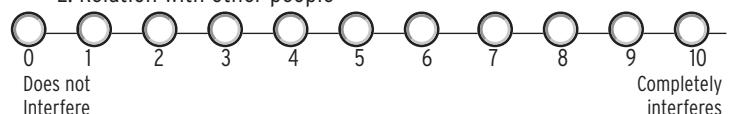
C. Walking Ability



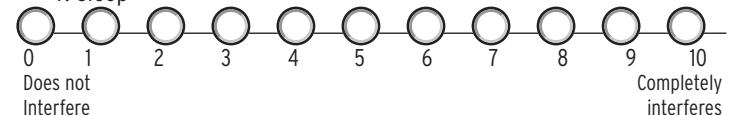
D. Normal work (Includes both work outside the home and housework)



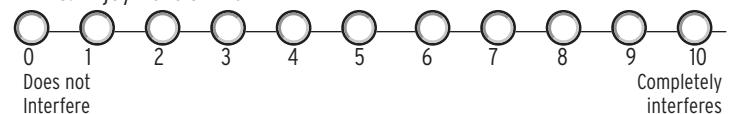
E. Relation with other people



F. Sleep



G. Enjoyment of life



Copyright © 1991 Charles S. Cleeland, PhD

Save

Print

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

- VAS for pain - Visual Analogue Scale
- NRS for pain - Numerical Rating Scale
- FPS - Faces Pain Scale - Revised
- APPT - Adolescent Pediatric Pain Tool
- PROMIS - pain intensity
- PROMIS - pain interference
- PROMIS - pain quality
- BPI - Brief Pain Inventory

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.

- VAS for pain - Visual Analogue Scale
- NRS for pain - Numerical Rating Scale
- FPS - Faces Pain Scale - Revised
- APPT - Adolescent Pediatric Pain Tool
- PROMIS - pain intensity
- PROMIS - pain interference
- PROMIS - pain quality
- BPI - Brief Pain Inventory

This was the last question.

Thank you very much for your input.