

VALIDATED QUESTIONNAIRES AND SCALES FOR MEASURING OUTCOMES IN CHILDREN WITH CEREBRAL PALSY

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Determining a baseline of function in children with cerebral palsy is essential for setting goals, planning treatment and assessing progress following intervention. One strategy for obtaining baseline function is to use parent and child questionnaires which have the added advantage of immediately involving the child and family in the goal setting process and can lead to helpful reflection on what the child can do and what they might be able to do next. These can also prove a helpful adjunct to clinic-based tests. Many of these are available as free downloads or free online tests meaning they are widely available in any country.

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Information follows about each of these scales and questionnaires, and sources. For some of these translations in other languages also exist. For more information on development of the measures, reliability and validity please see references.

1. MOBILITY QUESTIONNAIRE 47 AND 28 (MOBQUEST)^{1,2}

These are evaluations for children with cerebral palsy of 47 and 28 daily indoor and outdoor mobility activities. These are rated on a 5-point Likert scale from 'Not difficult at all' to 'Impossible without help'. Examples of easier activities include sitting down on a bed or chair, standing still, walking in and outdoors. The most difficult items include walking downstairs holding an object, standing while taking a shower to running on grass or sand when outdoors. Any aids typically used by the child are also recorded. It was originally tested on children aged 2 to 13 years, GMFCS I-IV. The questionnaire and scoring instructions can be downloaded free from the Amsterdam University Hospital: [Amsterdam Universitair, Medische Centra UMC](#) - search for [MobQuest \(MoVra – dutch\) and English translation](#).

There are also German, Korean, and Turkish translations in development.

2. [LOCOMOTION ABILITY MEASURE \(ABIL-LOCO KIDS\)](#)³

This is a 10-item scale of mobility activities for children with cerebral palsy aged 6-15 years. Items are rated on a 3-point Likert scale from impossible to easy. Items range from walking less than 5 metres holding furniture to going up an escalator alone. It was developed using the Rasch model so the raw scores can be entered online to be converted into scores arranged on a linear scale.

[French and English translations](#) were developed at Louvain University and can be found at Rehab-Scales. Research articles can be located documenting translation work into Turkish, Gujarati, Arabic and Japanese.

3. MEASURE OF MANUAL ABILITY FOR CHILDREN WITH UPPER LIMB IMPAIRMENT (ABIL-HANDS KIDS)^{4,5}

The Abil-Hands Kids is a measure of manual ability for children with upper limb impairments aged 6-15 years. Items are rated on a 3-point Likert scale from impossible to easy. Items range from putting on a hat and taking off a T-shirt to unscrewing a bottle top and sharpening a pencil. It was developed using the Rasch model so the raw scores can be entered online to be converted into scores arranged on a linear scale. This is available in French and English at [Rehab-Scales](#). Research articles can be located documenting translation work into Iranian, Arabic, Ukrainian and Turkish.

4. CHILD HAND USE AND EXPERIENCE QUESTIONNAIRE (MINI CHEQ AND CHEQ 2)⁶

These are online questionnaires assessing experience of hand use when bimanual activities are executed in children 3-8 years and 6-18 years with unilateral hand impairment (Obstetric Brachial Plexus Palsy, hemiplegia, Upper limb deficiency). The questionnaire can be completed by the child, the parent & child together or the parent (if child under 13 years). There are 27 items in the CHEQ and 21 items in the Mini CHEQ. Examples include putting money in a purse or wallet, eating out of a small container of yoghurt, pulling up track suit trousers and removing the wrapping from an ice cream. Items are rated on 4-point Likert scales for perceived efficacy of grasp (ineffective to effective); time taken to perform activity (considerably to equally long); and degree of feeling bothered (much bothered to not bothered). Scoring uses Rasch methodology, so scores can indicate the level of item difficulty achieved and detect discrepancies between overall test score and observed scores for each item. Scores can be downloaded in the form of a report showing the profile of the individual child.

This [questionnaire](#) is available in English, Swedish, Norwegian, Russian, Portuguese, Spanish, German, French, Italian, Turkish, Hebrew, Arabic and Japanese.

5. PEDIATRIC QUALITY OF LIFE MEASUREMENT MODEL PEDSQL⁷

This measures health-related quality of life (HRQOL) in healthy children and adolescents and those with acute and chronic health conditions. It contains 23 items so is brief making it a feasible measure taking less than 4 minutes to complete. It is a generic questionnaire but there are also disease specific modules: for cerebral palsy asthma, rheumatology, diabetes, cancer, cardiac and other conditions. Items are scored on a five-point scale from never a problem to always a problem. Examples of items from the generic scale are:

School Functioning, e.g.
Paying attention in class
Keeping up with schoolwork
Missing school to go to the doctor or hospital

Physical functioning, e.g.
Walking a block
Participating in sports
Low energy level
Having hurts or aches

There are parent Proxy-Reports for ages 2-4, 5-7, 8-12, 13-18 and Child Self-Reports for ages 5-7, 8-12, 13-18. It is multidimensional including physical, emotional, social and school functioning. The PedsQL has been demonstrated to show responsiveness to clinical change over time, and good reliability (Total Scale Score: 0.88 Child Self-Report; 0.90 Parent Proxy-Report). It is valid, distinguishing between healthy children and children with acute and chronic health conditions; and distinguishes disease severity within a chronic health condition.

This [measure](#) has been translated into multiple languages (see website for information).

6. CEREBRAL PALSY QUALITY OF LIFE QUESTIONNAIRE CPQOL - CHILD⁸

The Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child) and Cerebral Palsy Quality of Life Questionnaire for Adolescents (CP QOL-Teen) assess the quality of life of children with cerebral palsy aged 4-12 years and adolescents aged 13-18 years. There are child and youth report questionnaires and caregiver questionnaires with between 53 and 66 items each. Items are rated on 9-point Likert scales, e.g. from 1 (very unhappy) to 9 (very happy) or from 1 (not at all bothered) to 9 (very bothered).

Examples of themes within the different sections are:

- Social wellbeing & acceptance e.g. going on trips with family
- Participation and physical health e.g. ability to participate in sports
- Functioning e.g. sleep, ability to dress yourself
- Emotional wellbeing e.g. how you feel about yourself, how you look, how you get on with parents
- Pain and impact of disability e.g. how much pain do you have?
- Access to services e.g. therapy, respite care, equipment
- Family health e.g. are you bothered by hospital visits?

This [questionnaire](#) has been or is in the process of being translated from English into the following languages. Arabic, Bahasa Indonesian, Bahasa Malaysian, Dutch, Farsi, French, German, Greek, Hebrew, Italian, Korean, Mandarin, Myanmar, Polish, Portuguese, Serbian, Spanish, Tamil, Thai and Turkish.

7. CAREGIVERS PRIORITIES AND CHILD HEALTH INDEX CPCHILD⁹ (CHANGING NAME TO PSCORE)

A questionnaire for the caregivers of children with severe cerebral palsy GMFCS IV & V or severe traumatic brain injury. It measures functional and health status, caregiver burden and health related quality of life in children. It was designed for measuring change before and after interventions such as orthopaedic surgery and has been used pre and post baclofen pump.

There are six domains:

- Personal care / Activities of daily living, *e.g. eating or being fed*
- Positioning, Transferring & Mobility *e.g. getting in and out bed*
- Comfort & Emotions *e.g. frequency of discomfort when dressed/undressed*
- Communication & Social interaction *e.g. difficulty of child playing alone*
- Health *e.g. number of visits to hospital*
- Overall quality of life including the importance of items to the child's quality of life.

Parents/carers are asked to consider how each of the activities is usually performed by/for their child. Then they are asked to rate how difficult each activity was in the past 2 weeks on a 7 point Likert scale from Impossible to no problem at all, and choose the level of assistance that was required to help their child perform the activities

on a four point Likert scale from Total assistance to independent. Examples of items are putting on and wearing footwear (shoes, socks, splints),

The [manual](#) can be downloaded and it is available in a wide variety of languages:

8. ASSISTANCE TO PARTICIPATE SCALE APS¹⁰

This measures the assistance that a school-aged child with a disability requires to participate in 8 play/leisure activities at home or in community from the primary caregiver's perspective E.g. watch TV, play with friend at a playground, attend a club. Items are rated on 5-point Likert scale:

- Unable to participate
- Participates with my assistance at all stages of the activity
- Participates after I have set him/her up and help at times during activity
- Participates with my supervision only
- Participates independently.

The APS can be used to evaluate changes in the level of assistance after interventions designed to increase participation.

The [scale](#) is available as a free download from the CanChild website.

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