



Pediatric chronic pain assessment tools

Chronic pain assessment toolbox
for children with disabilities
Section 3.0, 2018, Version 2





Holland Bloorview

Kids Rehabilitation Hospital Foundation

Section 3.0: Chronic Pain Assessment Tools

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Conflict of Interest Declaration

The contributing committee members have no conflict of interest to declare.

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Chronic Pain Toolbox for Children with Disabilities



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3.0 Pediatric Chronic Pain Assessment Tools

The following section provides a detailed description of the pediatric chronic pain assessment tools selected for inclusion within the Toolbox. As outlined in Section 1.0 Toolbox Background, the psychometric properties and clinical utility of each tool were rated by the inter-professional, Systematic Review Working Group. The psychometric properties were rated based upon criteria as set by the Society of Pediatric Psychology Assessment Task Force, which is summarized in Table A below.

Table A: Rating of Psychometric Properties

Rating of Psychometric Properties	Description of Rating
Well-established	<ul style="list-style-type: none">• The tool has been published in at least two peer-reviewed articles by different research groups.• Sufficient detail is available regarding tool development.• Testing for validity and reliability is well-detailed.¹
Approaching well-established	<ul style="list-style-type: none">• The tool has been published in at least two peer-reviewed articles, of the same or different research groups.• Sufficient detail is available regarding tool development.• Testing for validity and reliability is vague.¹
Promising	<ul style="list-style-type: none">• The tool has been published in at least one peer-reviewed article.• Sufficient detail is available regarding tool development.• Testing for validity and reliability is vague.¹

Adapted from Cohen and colleagues (2008)¹

The clinical utility of each tool was deciphered by the Systematic Review Working Group following an adapted Clinical Utility Attributes Questionnaire.² An outline of this scoring system is available in Section 1.0 Toolbox background and demonstrates how tools were rated as weak, moderate or having strong clinical utility based upon usability, comprehensiveness and other considerations.



Chronic Pain Interference Tools

Chronic Pain Interference Screening Tools

Body Diagram

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain interference	Screening	Self-Report

Original Source: Savedra, M.C., Tesler, M.D., Holzemer, W.L., Wilkie, D.J., and Ward, J.A. (1989). Pain location: Validity and reliability of body outline markings by hospitalized children and adolescents. *Research in Nursing & Health*, 12, 307-314.

Summary: The Body Diagram is a screening tool used to identify the location of pain, with an option to assess pain intensity. It is an age appropriate diagram, showing an anterior and posterior view of the body, developed with children ages 8 – 17 years³ and used with children ages 8 – 18 years old.^{4,11} It has been used to identify pain related to Duchene (DMD) and Becker (BMD) muscular dystrophy along with a range of other pediatric health conditions.^{4,11}

Psychometric Properties and Clinical Utility: The Body Diagram was tested for content and concurrent validity and alternate forms reliability.³ As assessed by the Systematic Review Working Group, this tool is rated as *approaching well-established* according to the evidence based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *strong*.

Mobility and Weight Bearing Content: There is no mobility or weight bearing content in this tool. The Body Diagram has potential for use with children with a broad range of mobility needs, from independence to full assistance.

Scoring: The Body Diagram does not have a scoring system. It is primarily used to assess for the presence and location of pain. For pain intensity, the child can choose different colours which they feel best represents the intensity of pain. The child should select the colour and be allowed to explain their choices. The Body Diagram can be a standalone instrument or used as part of an interview or intake exam.

Cut Off: There is no cut-off score indicated for this tool.



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Non-Communicating Children’s Pain Checklist – Revised (NCCPC – R)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain interference	Screening	Observational

Original Source(s): Breau, L., McGrath, P.J., Camfield, C., Rosmus, C., and Finley, G.A. (2000). Preliminary validation of an observational pain checklist for persons with cognitive impairments and inability to communicate verbally. *Developmental Medicine & Child Neurology*, 42(8) 609-616.

Breau, L. M., McGrath, P.J., Camfield, C.S., and Finley, G.A. (2002). Psychometric properties of the non-communicating children’s pain checklist-revised. *Pain*, 99(9) 349-357.

Summary: The Non-Communicating Children’s Pain Checklist – Revised (NCCPC- R) is a screening tool designed to measure pain in children with severe cognitive impairments.¹² The tool has been developed and used with children ages 3 - 18 years¹² and used with adults 17 – 76 years old.¹³ Caregivers of children with cerebral palsy and severe cognitive impairment were part of the development cohort¹⁴ and the tool has since been used with children with profound intellectual disability in combination with profound or severe motor disabilities.^{13, 15, 16} The NCCPC-R is a 30-item tool that takes two hours to complete, retrospectively by a caregiver who has known the child for at least six months.

Psychometric Properties and Clinical Utility: The NCCPC-R was tested for internal reliability, concurrent validity, inter-episode consistency and discriminant validity for everyday pain.^{12, 14} As assessed by the Systematic Review Working Group, this tool is rated as *well-established* according to the evidenced-based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *strong*.

Mobility and Weight Bearing Content: The tool does not contain any weight bearing or mobility related content.

Scoring: This tool is an ordinal scale with seven subscales (Vocal, Eating/sleeping, Social, Facial, Activity, Body/limb, Physiological signs) and is scored based on a total score. A



response of ‘not at all’ is given a score of ‘0’ to a response of ‘very often,’ which is given a score of ‘3.’ Children receive a total score between 0–90.

Cut-off: A total NCCPC-R score of 7/90 signifies clinically significant pain and indicates a decision to treat the child for pain.

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Patient Reporting Outcomes Measurement Information System (PROMIS) Pediatric Pain Interference Scale (PPIS)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain interference	Screening	Combination*

*Self-report and Observational

Original Source: Revicki, D.A., Chen, W.H., Harnam, N., Cook, K.F., Amtmann, D., Callahan, L.F., Jensen, P.M., and Keefe, F.J. (2009). Development and psychometric analysis of the PROMIS pain behavior item bank. *Pain*, 146(1-2), 158-169.

Varni, J.W., Stucky, B.D., Thissen, D., Dewitt, E.M., Irwin, D.E., Lai, J.S., Yeatts, K., and Dewalt, D.A. (2010). PROMIS Pediatric Pain Interference Scale: An item response theory analysis of the pediatric pain item bank. *Journal of Pain*, 11(11), 1109-1119.

Summary: The Patient Reported Outcome Measurement Information System (PROMIS) developed the Pediatric Pain Interference Scale (PPIS) as a screening tool for chronic pain.¹⁷ The PPIS was developed with an adult general population, ages 18 – 65 years¹⁷ and a tailored pediatric pain item bank was later developed and used with children ages 8 – 17 years old.¹⁸ The PPIS has shown to be valid for children with cerebral palsy (ages 8-18 years) across Gross Motor Function Classification System (GMFCS) levels.¹⁹ The original tool has been reduced from a 39-item bank to an 8-item short form for children and parents to be applied across pediatric chronic and recurrent pain conditions. The PPIS assesses pain on daily activities during the previous seven days (interference on physical, psychological and social functioning).¹⁷

Psychometric Properties and Clinical Utility: The PPIS was tested for item-total correlations, internal consistency reliability and differential item functioning.¹⁷ As assessed by the Systematic Review Working Group, the PPIS has been rated as an *approaching well-established* assessment according to the evidence-based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *moderate*.

Mobility and Weight Bearing Content: The PPIS contains mobility and weight bearing content. Therefore, caution should be taken when using this tool with children who require mobility or weight bearing assistance.



Scoring: The PPIS tool is scored on a 5-point Likert response scale, ranging from ‘0’ (‘never’) to ‘4’ (‘almost always’). The recall period for the pain behaviour items is the previous seven days. The tool can be scored for subscales and for total score.

Cut off: There is no cut-off score indicated for this tool.

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Varni/Thompson Pediatric Pain Questionnaire (PPQ)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain interference	Screening	Combination*

*Self-report and Observational

Original Source: Varni, J.W., Thompson, K.L., and Hanson, V. (1987). The Varni/Thompson Pediatric Pain Questionnaire: Chronic musculoskeletal pain in juvenile rheumatoid arthritis. *Pain*, 28(1), 27-38.

Summary: The Varni/Thompson Pediatric Pain Questionnaire (PPQ) is a parent and child screening tool that assesses the intensity of pain, the sensory, affective, and evaluative qualities of pain and the location of pain in children. The tool was developed with children ages 4 – 16 years²⁰ and used with children ages 4 – 18 years.²¹ The PPQ provides an assessment of pain experience for children and adolescents at the appropriate cognitive-developmental stage and is broken down into three forms: children, adolescents, and adults. This pain interference tool was developed with children with rheumatoid arthritis and spina bifida and used with a range of musculoskeletal pain.^{22, 23} The PPQ includes a VAS (visual analog scale), colour coded body diagram and open-ended questions.²⁰ There is a two-week response timeframe.

Psychometric Properties and Clinical Utility: The PPQ was tested for construct validity and reliability.²⁰ As assessed by the Systematic Review Working Group, this tool is rated as *well-established* according to the evidence-based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *moderate*.

Mobility and Weight Bearing Content: The adolescent and parent versions contain mobility and weight bearing content. Therefore, caution should be taken when using this tool with children who require mobility or weight bearing assistance.

Scoring: Pain intensity is scored by measuring the VAS with a ruler. This tool includes a 10 cm horizontal line that ranges from ‘0’ (with a smiling cartoon face and ‘no hurt at all’ or by ‘no pain, not hurting, no discomfort’) to ‘10’ (with a sad cartoon face and ‘hurting a whole lot’ or by ‘severe pain, hurting a whole lot, very uncomfortable’). The body diagram is used to score the locations with current pain. For intensity, the child would choose

3.0 Pediatric Chronic Pain Assessment Tools



different colours to represent their pain from 'none' to 'severe' and colour in the pain location on the diagram. A list of descriptive words is provided and the child is asked to circle the most relevant words to express his or her pain. The adult version contains additional questions regarding socio-environmental and family factors and child background information.

Cut Off: There is no cut-off score indicated for this tool.

Benefits: This tool has been translated into other languages, including: Danish, Norwegian, Portuguese, Spanish, Swedish and French, and can be accessed at www.pedsql.org.

Copyright information: There are different conditions for use for academic and commercial users. Please visit the website and review the options for using this tool: [www.proqolid.org/instruments/pediatric quality of life inventory pedsql](http://www.proqolid.org/instruments/pediatric_quality_of_life_inventory_pedsql)



Chronic Pain Interference Outcome Tools

Bath Adolescent Pain Questionnaire (BAPQ and BAPQ – P)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain interference	Outcome	Combination*

*Self-report and Observational

Original Source: Eccleston, C., Jordan, A., McCracken, L.M., Sled, M., Connell, H., and Clinch, J. (2005). The Bath Adolescent Pain Questionnaire (BAPQ): Development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents. *Pain*, 118(1-2), 263-270.

Eccleston, C., McCracken, L.M., Jordan, A., and Sled, M. (2007). Development and preliminary psychometric evaluation of the parent report version of the Bath Adolescent Pain Questionnaire (BAPQ-P): A multidimensional parent report instrument to assess the impact of chronic pain on adolescents. *Pain*, 131(1-2), 48-56.

Summary: The BAPQ (adolescent version)²⁴ and BAPQ - P (parent version)²⁵ are outcome tools for adolescents and parents to assess chronic pain. The BAPQ was developed with adolescents ages 11 – 18 years and used with children ages 10 – 19 years²⁶ that experienced a variety of chronic pain conditions, including chronic musculoskeletal pain.²⁷ Adolescents with cognitive impairments were excluded from the development.²⁴ BAPQ and BAPQ – P each consist of 61 items across seven domains of functioning affected by pain in a two-week retrospective timeframe.^{24, 25}

Psychometric Properties and Clinical Utility: The BAPQ and BAPQ – P were tested for internal consistency of the subscales, temporal stability and construct validity of the subscales.^{24, 25} As assessed by the Systematic Review Working Group, this tool is rated as *well-established* according to the evidence-based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *weak*.

Mobility and Weight Bearing Content: Both versions of this tool contain mobility and weight bearing content. Therefore, caution should be taken when using this tool with children who require mobility or weight bearing assistance.



Scoring: This is a multidimensional ordinal scale consisting of 61 items and seven subscales: Social functioning, physical functioning, depression, general anxiety, pain specific anxiety, family functioning, and development.²⁴ Each subscale is scored separately by summing all items within the subscale.²⁴ Most of the subscales use a frequency dimension from ‘never’ to ‘always,’ except for the development scale, which asks for a comparison with other people the same age, from ‘very behind’ to ‘very ahead.’²⁴ Higher scores on each subscale indicate greater impact of pain or greater distress.^{24, 25}

Cut Off: Higher scores on each subscale indicate greater impact of pain or greater distress, however, no specific cut off scores are indicated.^{24, 25}

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Child Activity Limitations Interview (CALI)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain interference	Outcome	Combination*

*Self-report and Observational

Original Source: Palermo, T.M., Witherspoon, D., Valenzuela, D., and Drotar, D. (2004). Development and validation of the Child Activity Limitations Interview: A measure of pain-related functional impairment in school-age children and adolescents. *Pain*, 109, 461-470.

Summary: The Child Activity Limitations Interview (CALI) is a parent and child outcome tool that assesses functional impairment due to recurrent and chronic pain in children and adolescents.⁶ There are two similar versions of this tool, the CALI and CALI-21. The original CALI, as referenced above, is the version used in this Toolbox. The tool was developed with children ages 8 – 16 years⁶ and used with children ages 8 – 18 years.²⁸ The CALI was not developed for children with developmental disabilities; however it has been used with children with Duchene’s Muscular Dystrophy (DMD) and Becker’s Muscular Dystrophy (BMD).⁴ This tool lists 21 activities by which the respondents retrospectively choose eight activities that are the most difficult or troublesome to them (or their child) due to recurrent pain. There is also the option for children/parents to identify their own activities. For each selected activity, the child/parent indicates a pain score and then ranks the activities in terms of importance to the child/parent.⁶

Psychometric Properties and Clinical Utility: The CALI was tested for internal consistency, reliability, and concurrent, face and content validity.⁶ As assessed by the Systematic Review Working Group, this tool is rated as *well-established* according to the evidence-based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *moderate*.

Mobility and Weight Bearing Content: This tool contains mobility and weight bearing content. Therefore, caution should be taken when using this tool with children who require mobility or weight bearing assistance.

Scoring: The score for the CALI is derived from the difficulty ratings, which are obtained on a 5-point ordinal scale, ‘0’ (‘not difficult’) to ‘4’ (‘extremely difficult’). Difficulty scores



for the eight chosen items are summed to tabulate a total difficulty score ranging from 0 – 32, with higher scores indicating greater levels of activity limitations.⁶ Respondents are encouraged to generate additional items if no important or relevant activities in their lives are identified by the item list.

Cut off: Higher scores indicate greater levels of difficulty, but no absolute cut off score has been identified.

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Paediatric Pain Profile (PPP)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain interference	Outcome	Observational

Original Source: Hunt, A., Goldman, A., Seers, K., Crichton, N., Mastroyannopoulou, K., Moffat, V., Oulton, K., and Brady, M. (2004). Clinical validation of the Paediatric Pain Profile. *Developmental Medicine & Child Neurology*, 46, 10.

Summary: The Paediatric Pain Profile (PPP) is an outcome tool designed to provide ongoing assessment and monitoring of pain in children with severe neurological disability.²⁹ The PPP has been used within an outpatient settings and assesses sensitivity to change in pain.^{29, 61, 62, 63, 64, 65} This tool was developed with children ages 1 – 18 years, who were unable to communicate through speech or augmentative communication²⁹ and has been used with adults up to 76 years of age.^{13, 61, 62, 63, 64, 65} Children with cerebral palsy made up a significant proportion of the development cohort.²⁹ The PPP is a 20-item behaviour rating scale with an ‘open window’ response timeframe.²⁹ Of note, the person administering the tool does not need to know the routine behaviours, expressions or pain responses of the child.

Psychometric Properties and Clinical Utility: The PPP was tested for face and concurrent validity, internal consistency, inter-rater reliability and sensitivity of the measure.²⁹ As assessed by the Systematic Review Working Group, this tool is rated as *well-established* according to the evidence-based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *moderate*.

Mobility and Weight Bearing Content: This tool does not contain any mobility or weight bearing content.

Scoring: The PPP is a 20-item single, ordinal scale tool. Each question is scored from ‘0’ (‘not at all’) to ‘3’ (‘a great deal’), except the first two questions in which the scoring is reversed. All responses are summed to give a total score between 0 – 60.

Cut-Off: A cut-off score of 14/60 indicates clinically significant pain and can be subsequently grouped into various levels of severity: mild (10 – 19), moderate (20 – 29), severe (30 – 39), and very severe (40+).²⁹



Benefits: The PPP is available in Portuguese. ⁶⁶

Copyright information: The PPP is free to photocopy and use in the care of children with severe neurological and learning impairments. Go to the website and fill out a short form to receive the tool. www.ppprofile.org.uk/ppptooldownload.php?s=209

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Chronic Pain Coping Tools

Chronic Pain Coping Screening Tools

Chronic Pain Acceptance Questionnaire – Parents (CPAQ - P) and Adolescent (CPAQ - A)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain coping	Screening	Combination*

*Self-report and Observational

Original Source: McCracken, L. M., Gauntlett-Gilbert, J., and Eccleston, C. (2010). Acceptance of pain in adolescents with chronic pain: Validation of an adapted assessment instrument and preliminary correlation analyses. *European Journal of Pain*, 14(3), 316-320.

Simons, L. E., Sieberg, C. B., and Kaczynski, K. J. (2011). Measuring parent beliefs about child acceptance of pain: A preliminary validation of the Chronic Pain Acceptance Questionnaire, parent report. *Pain*, 152(10), 6.

Summary: The Chronic Pain Acceptance Questionnaire (CPAQ) is a parent³⁰ and adolescent (CPAQ - A) screening tool²⁶ designed to assess chronic pain acceptance. It was developed with children ages 10 – 18 years²⁶ and used with children ages 8 – 17 years.³¹ No children with developmental disabilities were used in the validation but it has been used across varied types of pain, such as generalized idiopathic pain syndromes and complex regional pain syndromes.^{26,31} The CPAQ is a 20-item measure that includes two components of acceptance of chronic pain: activity engagement and pain willingness. The first of these reflects the degree of participation in regular daily activities in the presence of pain. The second component reflects relative absence of attempts to avoid or control pain. Each item on the CPAQ - A is rated on a scale from zero to four using age appropriate language. The parent version differs slightly with an expanded scale from zero to six and higher level language.

Psychometric Properties and Clinical Utility: The CPAQ - P and CPAQ - A were tested for internal consistency and validity.²⁶ As assessed by the Systematic Review Working Group, this tool is rated as *approaching well-established* according to the evidence based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *weak*.



Mobility and Weight Bearing Content: This tool does not contain any mobility or weight bearing content. The CPAQ has potential for use with children with a broad range of mobility needs, from independence to full assistance.

Scoring: The child questionnaire is scored on a five point ordinal scale from 0 – 4, with verbal labels ‘never true’, ‘rarely true’, ‘sometimes true’, ‘often true’ and ‘always true’. The parent version is scored on a scale from 0 – 6, with verbal labels ‘never true’, ‘very rarely true’, ‘seldom true’, ‘sometimes true’, ‘often true’, ‘almost always true’ and ‘always true.’ Higher scores on each subscale indicate greater impact of pain or greater distress. The subscales can be scored independently for activity engagement or pain willingness and derive a total overall score.

Cut-off: There is no cut-off score indicated for this tool.

Copyright information: The tool can be requested directly from the author at:

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Graded Chronic Pain (GCP) Scale

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain coping	Screening	Self-report

Original Source: Von Korff, M., Ormel, J., Keefe, F. J., and Dworkin, S. F. (1992). Grading the severity of chronic pain. *Pain*, 50(2), 133-149.

Summary: The Graded Chronic Pain (GCP) Scale is a screening tool intended to quantify the severity of chronic pain.³² A seven item ordinal scale measures pain intensity, disability, persistence and regency of onset of chronic pain to grade the severity. The GCP was developed for adult’s ages 18 – 75 years³² and used with adolescent’s ages 12 – 19 years.³³ It has been used with a range of pain issues including headaches, back pain, and temporomandibular joint dysfunction.³³⁻³⁵

Psychometric Properties and Clinical Utility: The graded Chronic Pain Scale was tested for reliability and validity.³² As assessed by the Systematic Review Working Group, this tool is rated as *well-established* according to the evidenced-based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *strong*.

Mobility and weight bearing content: This tool does not contain any mobility or weight bearing content. The GCP has potential for use with children with a broad range of mobility needs, from independence to full assistance.

Scoring: The Graded Chronic Pain Scale is a seven question ordinal scale where ‘Grade one’ is the lowest and ‘Grade five’ the highest, indicating severely limiting pain. The tool has two subscales, with a hierarchical relationship between pain intensity and disability.

Cut Off: There is no cut-off score indicated for this tool.

Copyright information: This tool can be found in the original validation paper.

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3.0 Pediatric Chronic Pain Assessment Tools



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Psychological Inflexibility in Pain Scale (PIPS)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain coping	Screening	Self-Report

Original Source: Wicksell, R. K., Renofalt, J., Olsson, G.L., bond, and F.W., Melin, L. (2008). Avoidance and cognitive fusion – central components in pain related disability? Development and preliminary validation of the Psychological Inflexibility in Pain Scale (PIPS). *European Journal of Pain*, 12, 491 - 501.

Summary: Psychological Inflexibility in Pain Scale (PIPS) is a screening tool used to measure pain willingness and activities engagement of individuals living with chronic pain.³⁶ It emphasizes the willingness to experience pain rather than trying to control or reduce pain symptoms. The PIPS was developed with people experiencing persistent pain conditions such as fibromyalgia, migraines and low back pain.³⁶ The tool was developed for adults ages 19 -70³⁶ and has been used with children and adults ages 8 – 84 years.^{37, 38} PIPS is a 16-item tool that consists of two subscales, avoidance and cognitive function.

Psychometric Properties and Clinical Utility: The PIPS was tested for internal consistency, reliability, and validity.³⁶ As assessed by the Systematic Review Working Group, this tool is rated as *approaching well-established* according to the evidence-based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *weak*.

Mobility and Weight Bearing Content: This tool does not contain any mobility or weight bearing content. The PIPS has potential for use with children with a broad range of mobility needs, from independence to full assistance.

Scoring: Clients rate how true the statements are on a 7-point Likert scale ranging from ‘never true’ to ‘always true’. Items consist of different statements that are considered to be related to chronic pain, psychological inflexibility, suffering, and disability with higher scores indicating more psychological inflexibility.

Cut off: There is no cut-off score indicated for this tool, however, higher scores indicate more psychological inflexibility.



Copyright information: This tool can be found in the original validation paper.

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Pediatric Pain Coping Inventory (PPCI)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain coping	Screening	Combination*

*Self-report and Observational

Original Source: Varni, J. W., Waldron, S.A., Gragg, R.A., Rapoff, M.A., Bernstein, B.H., Lindsley, C.B., and Newcomb, M.D. (1996). Development of the Waldron/Varni Pediatric Pain Coping Inventory. *Pain*, 67, 10.

Summary: The Pediatric Pain Coping Inventory (PPCI) is a parent and child screening tool to assess pediatric pain coping strategies.³⁹ It was developed with children ages 5 -16 years.³⁹ This 41-item questionnaire consists of five subscales and four open-ended questions. This tool is designed to provide a standardized assessment of the child’s and the parent’s perception of the mechanisms that the child utilizes to cope with pain.

Psychometric Properties and Clinical Utility: The PPCI was tested for internal consistency reliability and conceptual validity.³⁹ As assessed by the Systematic Review Working Group, this tool is rated as *promising* according to the evidenced based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *weak*.

Mobility and Weight Bearing Content: This tool does not contain any mobility or weight bearing content. The PPCI has potential for use with children with a broad range of mobility needs, from independence to full assistance.

Scoring: This tool contains four open-ended questions and 41 items on an ordinal scale scored from 0 – 3. There are five subscales broken down into cognitive self-instruction, problem solving, distraction, seeks social support, catastrophizing/helplessness. Each subscale is scored separately by summing all of the items over the number of items answered in the subscale. Higher scores on this tool indicate better health related quality of life.

Cut-off: There is no cut-off indicated for this tool.

Copyright information: There are different conditions for use for academic and commercial users. Please visit the website and review the options for using this tool:

www.proqolid.org/instruments/pediatric_quality_of_life_inventory_pedsql



Chronic Pain Coping Outcome Tools

Child Self Efficacy Scale (CSES)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain coping	Outcome	Combination*

*Self-report and Observational

Original Source: Bursch, B., Tsao, J.C.I., Meldrum, and M., Zeltzer, L.K. (2006). Preliminary validation of a self-efficacy scale for child functioning despite chronic pain (child and parent versions). *Pain*, 125(1-2), 35-42.

Summary: The Child Self Efficacy Scale (CSES) is a parent and child outcome tool designed to assess self-efficacy related to functioning when in pain.⁴⁰ It has been developed with children ages 8 – 18 years⁴⁰ and used with children ages 10 – 19 years.³¹ It was developed and used with children who experience chronic pain. This survey consists of seven items and is scored on a single scale.

Psychometric Properties and Clinical Utility: The CSES was tested for internal consistency reliability and construct validity.⁴⁰ As assessed by the Systematic Review Working Group, this tool is rated as a *promising* assessment according to the evidence based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *weak*.

Mobility and Weight Bearing Content: This tool does not contain any mobility or weight bearing content. The CSES has potential for use with children with a broad range of mobility needs, from independence to full assistance.

Scoring: The CSES is a 7-item Likert scale, and all items are close-ended with a response from '1' ('very sure') to '5' ('very unsure') measuring confidence in the ability to function normally when in pain. Higher scores indicate lower self-efficacy.

Cut-off: There is no cut-off indicated for this tool.

Copyright: This tool can be found in the validation paper.



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Pain Anxiety Symptom Scale (PASS – 20)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain coping	Outcome	Self-report

Original Source(s): McCracken, L. M., Zayfert, C., and Gross, R.T. (1992). The Pain Anxiety Symptoms Scale: Development and validation of a scale to measure fear of pain. *Pain*, 50, 67 - 74.

McCracken, L. M., and Dhingra, L. (2002). A short version of the pain anxiety symptoms scale (PASS-20): Preliminary development and validity. *Pain Research & Management: The Journal of the Canadian Pain Society*, 7(1), 45 - 51.

Summary: The Pain Anxiety Scale (Pass – 20) is an outcome tool used to measure fear and anxiety responses specific to pain.⁴¹ It was developed with adults ages 18 years^{42, 43} and over and has since been used with children ages 8 – 17 years.⁴⁴ The PASS - 20 has 20 items and is a shortened version of the 40-item original tool that is best used when time constraints outweigh a lengthier in-depth tool.⁴³ It contains four subscales (cognitive, escape/avoidance, fear, and physiological anxiety).

Psychometric Properties and Clinical Utility: The PASS - 20 was tested for internal consistency and predictive and construct validity.⁴¹ As assessed by the Systematic Review Working Group, this tool is rated as *approaching well-established* according to the evidenced based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *moderate*.

Mobility and Weight Bearing Content: This tool does not contain any mobility or weight bearing content. The PASS - 20 has potential for use with children with a broad range of mobility needs, from independence to full assistance.

Scoring: This tool can be scored using subscale scores between 0 – 25 or the total score between 0 – 100. The subscales include: cognitive, escape and avoidance, fear, and physiological anxiety. All items are rated on a frequency scale from ‘0’ (‘never’) to ‘5’ (‘always’).



Cut off: There is no cut-off score indicated for this tool, however higher scores indicate greater pain anxiety.

Copyright information: The tool can be requested directly from the author at:

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Pain Coping Questionnaire (PCQ)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain coping	Outcome	Combination*

*Self-report and Observational

Original Source: Reid, G. J., Gilbert, C. A., and McGrath, P. J. (1998). The Pain Coping Questionnaire: Preliminary validation. *Pain*, 76(1-2), 83-96.

Summary: The Pain Coping Questionnaire (PCQ) is parent and child screening tool designed to assess coping strategies for children in pain.⁴⁵ It was developed with children ages 8 – 18 years⁴⁵ and used with individuals ages 5 – 20 years.⁴⁶ This tool consists of 39 items, eight subscales and three higher-order scales. Different patterns of coping are linked to different experiences of pain. This tool was developed with children with arthritis⁴⁵ and has been used with children with a range of chronic pain conditions such as migraines, back pain, fibromyalgia, and non-cancer related pain.⁴⁵⁻⁵⁰

Psychometric Properties and Clinical Utility: The PCQ was tested for internal consistency reliability and validity.⁴⁵ As assessed by the Systematic Review Working Group, this tool is rated as *approaching well-established* according to the evidenced based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *weak*.

Mobility and Weight Bearing Content: This tool does not contain any mobility or weight bearing content. The PCQ has potential for use with children with a broad range of mobility needs, from independence to full assistance.

Scoring: This tool is a Likert scale consisting of eight pain coping strategies including information seeking, problem solving, seeking social support, positive self-statements, behavioural distraction, cognitive distraction, externalizing, and internalizing/ catastrophizing. Subscales are scored from 1 – 5 and are based on the average rating of the items in that scale.

These eight subscales can be divided into three higher-order scales: approach, problem-focused avoidance, and emotion-focused avoidance. The mean pain coping efficacy score is



calculated by averaging the rating of the three efficacy items. Higher scores indicate greater use of that coping strategy.

At the end of the tool there are three items measuring the child's perception of their ability to cope with and manage pain. These items are rated using the same 1– 5 Likert scale and are averaged to create a coping efficacy mean score.

Cut-off: There is no cut-off indicated for this tool, however higher scores indicate greater use of that coping strategy.

Benefits: This tool has been translated into Danish.

Copyright information: Please contact the tool developer directly to receive this tool:

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Pain Stages of Change Questionnaire for Adolescents (PSOCQ – A)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain coping	Outcome	Self-report

Original Source: Kerns, R. D., Rosenberg, R., Jamison, R. N., Caudill, M. A., and Haythornthwaite, J. (1997). Readiness to adopt a self-management approach to chronic pain: the Pain Stages of Change Questionnaire (PSOCQ). *Pain*, 72(1-2), 227-234.

Guite, J. W., Logan, D. E., Simons, L. E., Blood, E. A., and Kerns, R. D. (2011). Readiness to change in pediatric chronic pain: Initial validation of adolescent and parent versions of the Pain Stages of Change Questionnaire. *Pain*, 152(10), 2301-2311.

Summary: The Pain Stages of Change Questionnaire (PSOCQ) is a 30 item outcome questionnaire designed to assess an individual’s readiness to adopt a self-management approach to their chronic pain condition.⁵¹ This tool was originally developed with adult’s ages 18 – 85 years⁵¹ and then validated with adolescents 12 –18 years as an adolescent and parent report.⁵² However, the Systematic Review Working Group decided to keep this tool in the self-report category because the parent version assesses the parent’s feelings about the child’s pain problem and not their observation of the child’s pain experience. The PSOCQ - A assesses four factors: pre-contemplation, contemplation, action, and maintenance. A parent version was developed as an accompaniment to the pediatric version.

Psychometric Properties and Clinical Utility: The PSOCQ - A was tested for internal consistency, reliability, stability, as well as discriminant and criterion - related validity.⁵³ As assessed by the Systematic Review Working Group, this tool is rated as *approaching well-establish* according to the evidenced based psychometric properties assessment criteria set out at the beginning of this document. The Working Group classified the clinical utility of this tool as *weak*.

Mobility and Weight Bearing Content: This tool does not contain any mobility or weight bearing content. The PSOCQ - A has potential for use with children with a broad range of mobility needs, from independence to full assistance.

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Scoring: This tool includes a 5-point ordinal scale with four subscales. The subscales are scored individually, either by hand or using Statistical Package for the Social Sciences (SPSS). The highest subscale score indicates which stage of change the patient is in. When two subscale score values are equal, the patient is categorized in the stage of change that is more progressive towards self-management. For example, if the pre-contemplation and contemplation subscale scores are equal, the patient is categorized into the contemplation stage.

Cut off: There is no cut-off indicated for this tool.

Copyright information: This tool can be requested directly from the author at:
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Tools to Watch

This *Tools to Watch* section provides readers with an overview of emerging trends in chronic pain assessment tools for children with disabilities. The following tools did not meet the inclusion criteria during initial expert review; however, since this time, additional research evidence has been published to strengthen the case for tool inclusion within the Toolbox. You may wish to seek out these tools if they meet the needs of your population and chronic pain domains of interest. As part of the sustainability plan to keep this Toolbox up-to-date, these tools will undergo a formal critique of psychometric properties and clinical utility with an inter-professional group at Holland Bloorview Kids Rehabilitation Hospital in 2015. New additions to the Toolbox will be posted on the website www.hollandbloorview.ca/toolbox

Pain Behaviour Checklist

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain interference	Screening	Observational

Original Source: Terstegen, C., Koot, H.M., De Boer, J.B., and Tibboel, D. (2003). Measuring pain in children with cognitive impairment: Pain response to surgical procedures. *Pain*, 103,187-198.

Summary: The Pain Behaviour Checklist was originally developed and validated with children (ages 3-19 years) with profound cognitive impairments to assess post-surgical pain.⁵⁴ This screening tool has since been used with children (3-17 years) and adults (18-76 years) with profound intellectual and severe or profound motor disabilities including congenital/metabolic anomalies, cognitive impairments during and after birth, visual disabilities, epilepsy, and gastroesophageal reflux disease.¹³ The list of 10 questions focuses on changes to non-verbal reactions (e.g. grimacing, squeezing eyes, tears) and is completed by a parent, caregiver or clinician. The Checklist is often accompanied by a VAS (visual analogue scale), which rates that presence of pain on a 10 cm line with 9 being no pain and 10 being extreme pain.⁵⁵ In previously studies, the Checklist in combination with the VAS is completed during or following daily living activities using video recording.



Scoring/Cut-off: A positive score is assigned in the presence of Checklist pain behaviour lasting two seconds or longer for a maximum score of 10.⁵⁵ In combination with the VAS score:

PBC score ≥ 5 or <5 and VAS ≥ 4 = pain is likely present

PBC score ≥ 5 and VAS ≤ 3 = restlessness with absence of pain

PBC score ≤ 3 and VAS ≤ 3 = unlikely that pain is present

The Pain Behaviour Checklist items can also be scored independently without the VAS. In this case, a higher score indicates that the child is more likely to experience pain. The developers have assigned a probability of pain to specific scores:

A score of 3 = 35% probability

A score of 4 = 57% probability

A score of 5 = 77% probability

A score of 10 = 99% probability.⁵⁶



Pain Catastrophizing Scale – Children

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain coping	Outcome	Self-report

Original Source: Crombez, G., Bijttebier, P., Eccleston, C., Mascagni, T., Mertens, G., Goubert, L., and Verstraeten, K. (2003). The child version of the pain catastrophizing scale (PCS-C): a preliminary validation. *Pain*, 104(3), 639-46.

Summary: The Pain Catastrophizing Scale for Children (PCS-C) is a self-report chronic pain coping tool primarily developed for an adult audience and later validated for Flemish-speaking children (ages 9-16 years).⁵⁷ The purpose of this evaluative tool is to assess catastrophic thoughts and feelings when experiencing chronic pain.⁵⁷ The tool has been validated with English-speaking children and adolescents (ages 8-18 years) in Canada.⁵⁸ During its English validation, the PCS-C underwent a factorial analysis of a three-factor model reduced the 13 items to 11 items covering the topics of: rumination, magnification, and helplessness.⁵⁸ This revised PCS-C subscales reported good internal consistency and invariance amongst pain catastrophizing dimensions across age and sex.⁵⁸ The Flemish PCS-C was also validated in English-speaking children and adolescents (ages 8-20 years) in the United States and focused on catastrophizing in children with cerebral palsy, neuromuscular diseases, and spina bifida.⁵⁹ In this research study, the PCS-C was deduced to 12-items, which showed good internal consistency and internal reliability.⁵⁹

Scoring: Scoring will vary dependent on the 11, 12 or preliminary 13-item PSC-C. Children and adolescents are asked to choose the most relevant response to each statement using a 5-point response scale (not at all, mildly, moderately, severely, and extremely). Scores are summed to equal a minimum of 0 to a maximum of 52.⁵⁷ A lower score indicates less catastrophizing when in pain.⁵⁸



Pain Evaluation Scale for Clients with Cerebral Palsy (PES-CP)

<i>Chronic Pain Focus:</i>	<i>Type of Assessment:</i>	<i>Reporting Style:</i>
Chronic pain interference	Screening	Observational

Original Source: Collignon, P., and Giusiano, B. (2001). Validation of a pain evaluation scale for clients with severe cerebral palsy. *European Journal of Pain*, 5, 433-442.

Summary: The Pain Evaluation Scale for Clients with Cerebral Palsy (PES-CP) is an observational tool designed to screen for the presence of pain and determine whether current treatment is necessary or if prescribed treatment is effective. The PES-CP has been validated and used with individuals between the ages of 6-33 years.⁶⁰ All individuals involved in the development and validation have been described as being 'polyhandicapped', which is defined by the severe impairments to communication (verbal and non-verbal expression) and neuromotor function (severe spasticity, dystonia or mixed deficiencies such as tetraplegia, triplegia, hemiplegia or diplegia).⁶⁰ The 10-items of the PES – CP were tested for construct validity, internal scale coherence, and between-expert consensus on the decision to treat for pain. The tool has been used with children with cognitive impairment, cerebral palsy, scoliosis and spasticity.^{67, 68} The Systematic Review Working Group was unable to assess the full extent of the tool's psychometric properties and clinical utility as it is only available in French.

Scoring: Assessment of pain-related behaviours is quite difficult for individuals with severe cognitive, communicative or motor disabilities. Assessment of pain sources is based on modifications to the usual behaviour of the individual client, referred to a personal 'basic chart'. This basic chart describes the usual state of the client in different conditions: caregiving, washing, meal, sleep, spontaneous state, and scored during a period of observation. Each item includes a definition of a specific behaviour and the description of its increasing severity in five stages:

0: no modification

1: doubtful modification

2: modification is present



3: major modification

4: extreme modification

Scoring can be done by caregivers who are unfamiliar with the clients' routine behaviours and who have less experience with the client's condition.⁶⁰

Cut-off: If the score is greater than or equal to two, the client may suffer and requires particular attention; if the score is greater than or equal to six, pain is highly presumed and analgesic treatment is required.⁶⁰



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