



Toolbox background

Chronic pain assessment toolbox
for children with disabilities
Section 1.0 , 2018, Version 2





Holland Bloorview

Kids Rehabilitation Hospital Foundation

Section 1.0: Toolbox Background

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Conflict of Interest Declaration

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

Acknowledgements

Evidence to Care would like to acknowledge Shawna Wade, Holland Bloorview Senior Director of Inpatient Rehabilitation and Complex Continuing Care, and Dr. Darcy Fehlings, Holland Bloorview Physician Director of Medicine and Academic Affairs, for their contribution to the identification of this evidence to practice gap and development of this project. We thank the Evidence to Care Steering Committee for their oversight throughout the course of this body of work, as well as the Teaching and Learning Institute and the Bloorview Research Institute for the continued support as corporate sponsors. Evidence to Care also acknowledges the following individuals who contributed their expertise and perspectives: Carole-Anne Chiasson, Crystal Chin, Bruno Geremia, Kelly Hanlon, Michelle Halsey, Dr. Golda Milo-Manson, Aline Nizigama, Laura Thompson and Pui-Ying Wong. Finally, we thank all of the outpatient clinical staff who have supported the implementation and evaluation of the Toolbox.

Funding

Funding for this work was provided by the Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) Foundation and the Ontario Ministry of Health and Long-Term Care. Evidence to Care would also like to thank the Holland Bloorview Teaching and Learning Institute, Bloorview Research Institute, and the Holland Bloorview Centre for Leadership in Childhood Development for their continuing support of this project.



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How to Cite This Document

Orava, T., Townley, A., Provvidenza, C., Adler, E., Ami, N., Gresley-Jones, T., Mankad, D., Fay, L., Slonim, N., Hoffman, A., Joachimides, N., Hung, R., Fehlings, D. & Kingsnorth, S. (2014). *Chronic pain assessment toolbox for children with disabilities: Section 1.0: Toolbox background*. Toronto, Ontario: Holland Bloorview Kids Rehabilitation Hospital. Retrieved from: <http://hollandbloorview.ca/toolbox>

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Chronic Pain Toolbox for Children with Disabilities



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1.0 Toolbox Background

This document is comprised of three key sections:

1. An evidence-informed overview of the [experience of chronic pain](#), its impact on the lives of children with disabilities and the need to inform clinical practice to ensure every child receives a chronic pain assessment.
2. [The assembly of the chronic pain toolbox](#) describes the process by which the Toolbox was formed, including a structured review of clinical practice guidelines, practice point development, a systematic review of the pediatric chronic pain assessment tool literature and expert consensus activities.
3. Comprehensive summaries of the [pediatric chronic pain assessment tools](#) are discussed. Specific details pertaining to each tool can be found in Section 3.0 Pediatric Chronic Pain Assessment Tools at www.hollandbloorview.ca/toolbox. For more information on how to tailor the Toolbox to your local context, please refer to Section 4.0 Implementation Supports Manual.





The Pain Experience

Pain knows no bounds. Every year, millions of people are affected by pain regardless of their gender, race, ethnicity, age or geographical location.¹ Defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage,”² (pg. 249) this common, yet, multifaceted experience is mediated by beliefs, emotions, attitudes, physiological, and sensory stimuli.³

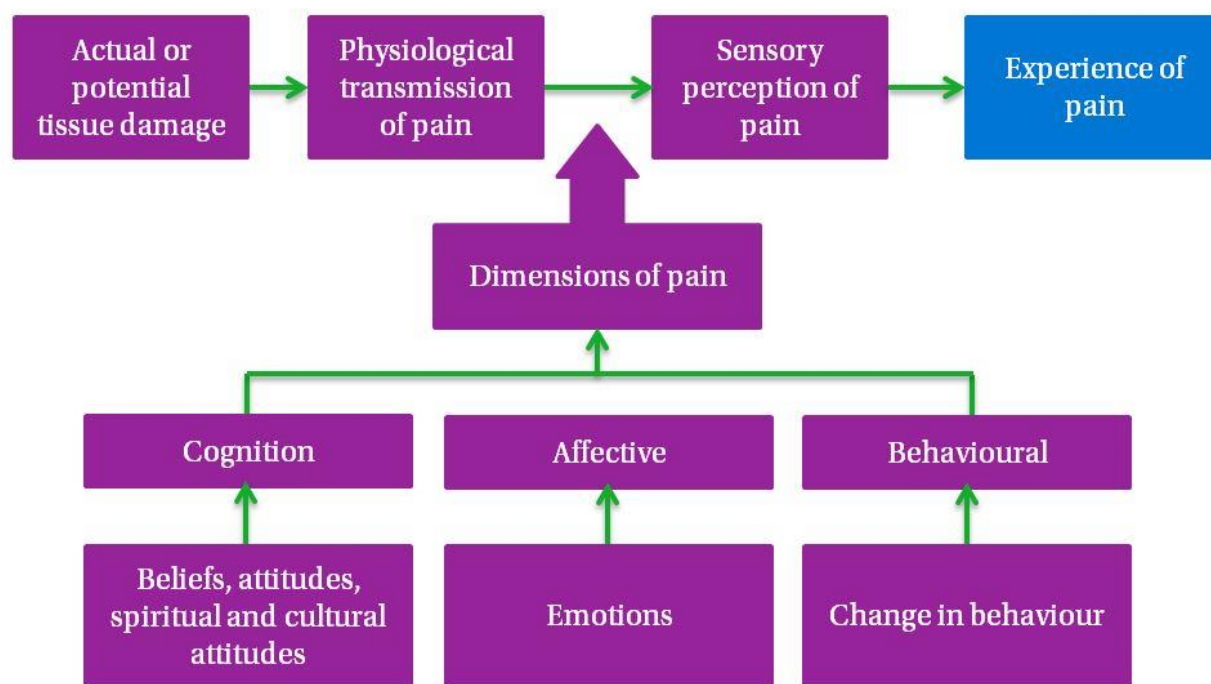


Figure 1: The Multiple Dimensions of Pain (World Health Organization, 2012)³

As outlined in Figure 1, the World Health Organization (WHO) demonstrates how the experience of pain is unique to each person.³ The figure draws attention to the complexity of pain and sheds light on the difficulties clinicians may encounter when attempting to conduct a pain assessment with a child who may not be able to acknowledge, understand or express his or her pain.

It is important to address the cognitive, affective, and behavioural dimensions of the pain experience when conducting a pain assessment with children with disabilities. Special attention should be paid to the areas for which a child may experience challenges in accurately capturing the source, intensity and frequency of pain.



To conduct such an assessment, one must first be knowledgeable about the pain experience and, in particular, how children with disabilities experience pain.

The Experience of Pain

The following sections provide a brief description of the classifications of pain: type (nociceptive or neuropathic) and duration (acute or chronic).⁴

Type of Pain

Nociceptive pain is caused by the activation of a sensory receptor (nociceptor) that detects potential or actual tissue damage throughout the body.⁴ Dependent on the location of the stimulated nociceptor, nociceptive pain can be somatic, in which surface or deep tissues are affected, or visceral, in which the internal organs are impacted.³ Neuropathic pain, on the other hand, derives from a lesion or disease causing harm to the somatosensory system.⁴ Subject to the location of the lesion or disease, neuropathic pain can affect the central nervous system, causing central neuropathic pain or the peripheral somatosensory system causing peripheral neuropathic pain.^{3,4} In some cases, individuals may experience nociceptive coinciding with neuropathic pain as a result of traumatic injury or disease.³

Pain Duration

Pain is classified as acute or chronic based upon its duration. The WHO (2012) recognizes the definition of acute pain as “of sudden onset, is felt immediately following injury, is severe in intensity, but is usually short-lasting” (pg. 20).⁵ Acute pain generally lasts less than 30 days and can be caused by medical procedures, illnesses and most frequently, trauma.⁶ The International Association for the Study of Pain (1986) has classified chronic pain as pain “which persists past the normal time of healing” with three months as the most appropriate cut-off for non-malignant pain.^{7,8} Chronic pain, also known as persistent pain, may be a result of disease, trauma or repeated noxious stimuli or injury.⁷

The Presence of Chronic Pain

Over the past few decades, chronic pain has become an increasingly common concern in pediatric care.⁹ The most frequent etiologies include headache, abdominal, musculoskeletal, and multi-site pain.^{9,10} The exact prevalence of chronic pain remains unknown; however, King and colleagues (2011) have estimated that chronic pain is more prevalent in females compared to males and pain tends to increase with age.⁹ Chronic pain is more likely to affect children with disabilities compared to typically developing children.¹¹⁻¹⁴ Children with cognitive impairments, including cerebral palsy, congenital or chromosomal syndromes, autism spectrum disorder, seizure disorders, neurodegenerative diseases and



encephalopathy experience pain so frequently that researchers, clinicians, and families begin to accept pain as part of the child.^{13, 15, 16} Although chronic pain is universal, cerebral palsy is considered to be a high priority population.¹⁷⁻²⁰

Cerebral palsy (CP) describes a group of non-progressive, permanent disorders that affect the development of movement and posture leading to limitations with daily activities.²¹ Cerebral palsy is attributed to non-progressive disturbances that occur in the development of the fetal or infant brain.²¹ Recent estimates suggest 60,000 Canadians live with CP and one out of every 500 babies born will have CP.²² The motor disorders of CP are often accompanied by disruptions to sensation, perception, cognition, communication, and behaviour.²¹ The complex co-morbidities associated with CP, such as epilepsy and gastroesophageal reflux disease, as well as secondary musculoskeletal problems (e.g. hip dislocations, hypertonia), can create multiple sites for persistent pain.



The Impact of Chronic Pain

Chronic pain can have a significant impact on daily functioning, emotion, interpersonal relationships, social skills, and physical abilities.^{11, 14, 16, 20, 23-29} Families of children with chronic pain can experience poor family functioning, conflict, depression and in turn, increased pain occurrence.¹⁶ As demonstrated in the pain cycle below, chronic pain may lead to cyclical ramifications on health.³⁰

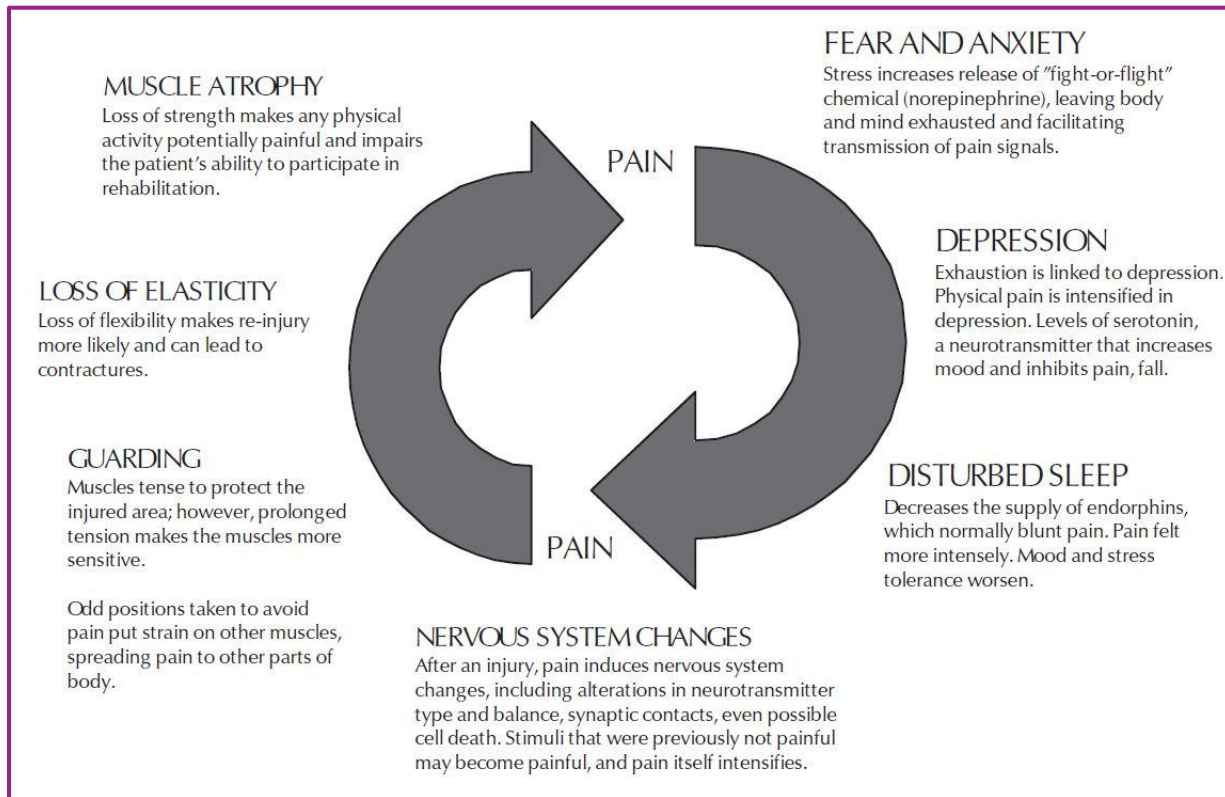


Figure 2: Vicious Pain Cycle (Whitten, Donovan, and Crisbbal, 2005)³⁰

Children may avoid regular daily activities because of fear of injury or amplification of pain.^{31, 32} The removal of oneself from daily activities, alongside the physical intensification of persistent pain can lead to depression, sleep disturbances and guarding against further injury to the sites of pain. As outlined in Figure 2, as this vicious cycle of pain continues to negatively impact a child's beliefs, attitudes or outlook towards particular movements, the child is likely to experience further pain associated with loss of tissue elasticity and muscle atrophy.³⁰



This cycle has particular negative implications when considering children with CP including:

- lower levels of participation in daily tasks;^{27, 33, 34}
- lower overall rating of quality of life;^{11, 23, 26, 28}
- higher absentee rate from school;^{35, 36}
- greater chance of sleep disturbances;^{14, 37} and
- decreased overall physical functioning.^{14, 29, 37}

Children with CP cannot fully participate in daily living activities if chronic pain is not effectively managed; however, in order for chronic pain to be managed, it must first be accurately assessed.³⁸ Reasons for not assessing chronic pain include a lack of knowledge about chronic pain practice, lack of valid and reliable pain measurement tools to meet the variable needs of clients, and a lack of time to conduct a formal assessment during an appointment addressing competing priorities.^{38, 39} As Chambliss and colleagues (2004, pg. 738) highlight, although an abundance of research has demonstrated that chronic pain is a valid and important concern for children with CP, **“pain continues to be poorly recognized and undertreated.”**



Measurement of Chronic Pain in Children with Disabilities

Pain is a subjective experience and is best described through self-report measures, which are considered the gold standard for assessing pain intensity and frequency.^{40, 41} Examples include one-on-one interviews, questionnaires, pain diaries, and pain rating scales completed by the child with pain.^{6, 31} The identification of chronic pain in children with disabilities, though, is met with several challenges. Difficulties associated with comprehension and communication allots challenges to the completion of traditional self-report assessment tools.^{39, 40, 42} When self-report measures are not feasible, family members and caregivers are encouraged to assist in the identification of the pain source, location, and intensity.⁴³ Parents and caregivers are well aware of the complex needs of their child and can report changes to behaviours, pain cues, and knowing intuitively when pain is present based upon their child's demeanor.^{40, 44, 45} Discrepancies can exist between how pain is self-reported, how different individuals rate pain (e.g. physicians, nurse, family member) within different types of settings (e.g. clinic, home, school), with the potential for family members to over or underestimate pain intensity.⁵⁹ Therefore, when treating a child with physical disabilities, the clinician must be cognizant of the ways in which pain is experienced through the perspectives of the child as well as the family members and caregivers.

Opportunity to Inform Care

A wide range of assessment tools are readily available to record the experience of chronic pain from the perspectives of children, family members, caregivers, and clinicians. These tools are psychometrically sound and can be used to identify or track chronic pain with several age groups from around the world. What is often absent from the literature are efforts to develop and validate tools for children who have cognitive and/or physical disabilities. As previously stated, following the gold standard of self-report measurement is not always a possibility for children with disabilities in which comprehension, communication or expression may be impaired. This is not to say that children with cognitive or physical impairments are not able to receive accurate chronic pain assessments, but there is a need to identify existing tools that have potential to be used with children with disabilities.



Evidence to Care (EtC) at Holland Bloorview Kids Rehabilitation Hospital is a specialized team of knowledge translation experts supporting the hospital in its commitment to transform care through evidence, knowledge generation, and translation. Through collaborative efforts, EtC strives to make research evidence accessible in promoting evidence-based care in the field of childhood disability.

EtC undertook this project to develop an evidence-based Toolbox to assist clinicians in their efforts to accurately assess chronic pain in children with disabilities. The benefits of this Toolbox include:

- ✓ Provide clinicians with psychometrically sound chronic pain assessment tools that have applicability for use with children with disabilities;
- ✓ Create a one-stop-shop for clinicians to select a tool that is appropriate for children with a broad spectrum of communicative and cognitive abilities;
- ✓ Inform chronic pain assessment protocols based upon high quality scientific research and clinical practice guidelines;
- ✓ Share knowledge translation strategies with other organizations so they may adapt the Toolbox to their own clinical settings; and
- ✓ Encourage conversations about pain with children and their families.

Why Chronic Pain?

Clinicians at [Holland Bloorview Kids Rehabilitation Hospital](#) (Toronto, Ontario) were asked to draw upon their knowledge and experiences working with children with disabilities to identify an area for which new knowledge was required in order to strengthen standard practice. Clinicians responded to this call for ideas with the recognition that chronic pain in children with CP was under-recognized and thereby under-treated. Within the Hospital's outpatient clinics, clinicians did not have access to tools or protocols for identifying or addressing chronic pain. As previously discussed, the livelihood of children with disabilities can be negatively affected if chronic pain is not accurately identified or assessed. Through its affiliation as a Registered Nurses' Association of Ontario [Best Practice Spotlight Organization](#) (BPSO) and using an integrated knowledge translation (iKT) approach, [Evidence to Care](#) worked alongside health researchers, clinical staff, decision makers, and clients and their families to address this evidence-to-practice gap.



The Assembly of the Chronic Pain Toolbox

The following section summarizes the key processes by which the Toolbox was crafted alongside the outcomes of each development phase. Figure 3 outlines how the clinical practice guideline recommendations, clinical practice points, and 15 chronic pain assessment tools were identified, critiqued, and selected for inclusion in the Toolbox.



Figure 3: Overview of the Assembly of the Toolbox



Establishment of the Systematic Review Working Group

An integrated knowledge translation (iKT) strategy is intended to facilitate an equal partnership collaboration between knowledge producers and knowledge users to develop, conduct, and evaluate meaningful health research.⁴⁶ Two inter-professional working groups were established at Holland Bloorview to develop and conduct the systematic review (Systematic Review Working Group) and to implement and evaluate the Toolbox products (Implementation Team).

The Systematic Review Working Group was made up of representatives from various disciplines within Holland Bloorview including medicine, occupational therapy, physiotherapy, psychology, nursing, research, knowledge translation, patient safety, health sciences, and clients/families. A broad range of stakeholders were also involved with the implementation and included the aforementioned stakeholders alongside client and family representation. Following an iKT approach, the working groups met in-person on a regular basis to define the systematic search strategy, share information on implementation procedures, and discuss expectations for the final product. More information regarding iKT and collaborative approaches to knowledge translation can be found on the [Canadian Institutes for Health Research website](#).

Clinical Practice Guidelines

Clinical practice guidelines (CPGs) are a series of topic-specific recommendations based upon high quality scientific evidence used to inform the clinical practice of health care professionals. Sourcing the best available scientific evidence is imperative to all hospitals in Ontario based on the [Excellent Care for All Act](#), ratified in 2010.⁴⁷ “Recommendations to health care organizations and other entities on standards of care in the health system will have to be made based on and respecting clinical practice guidelines and protocols” (2010, para. 7).⁴⁷ As such, EtC endeavored to source a rigorously developed clinical practice guideline to frame overall pain assessment within the Toolbox.

Clinical Practice Guideline Search Strategy

A structured review was conducted in order to identify existing pediatric clinical practice guidelines (CPG) for pain assessment. The search strategy was developed with the assistance of a health sciences librarian and contained a broad range of subject heading and key words related to pain, chronic pain and pediatric populations. An example of key search terms can be found in Figure 4.



Exp Chronic Pain/ and Child* or Adoles* or Teen*
or Youth* or Infant* or Young adj3 adult* or
Young adult* and exp Pain measurement/ or
Guideline or Assessment or Assess* or Measure* or

Figure 4: Example of Key Words and Descriptors Used to Search the Medline Database

The search was limited to guidelines: (1) printed in the English language; (2) focused on children between the ages of 1 to 18 years; and (3) published between 2001 and July 2013 in major, relevant databases (Medline, CINAHL, Embase) or guideline clearing houses such as:

- [American Pain Society](#)
- [Essential Evidence Medical Guidelines](#)
- [Joanna Briggs Institute](#)
- [Medical Journal of Australia](#)
- [National Clinical Guideline Centre](#)
- [National Guideline Clearinghouse](#)
- [Registered Nurses' Association of Ontario](#)
- [Royal Children's Hospital](#)
- [Royal College of Nursing](#)
- [Royal College of Physicians](#)
- [University of Queensland – Clinical Practice Guidelines](#)

Articles and guidelines were excluded if any of the three inclusion criteria were missing.

Broad internet searches using Google and Google Scholar portals were also conducted based upon key search terms. A manual hand search of the citation lists of relevant research articles gleaned seminal and commonly used works within pain, chronic pain, and pediatric health research.



Clinical Practice Guidelines Selection Process

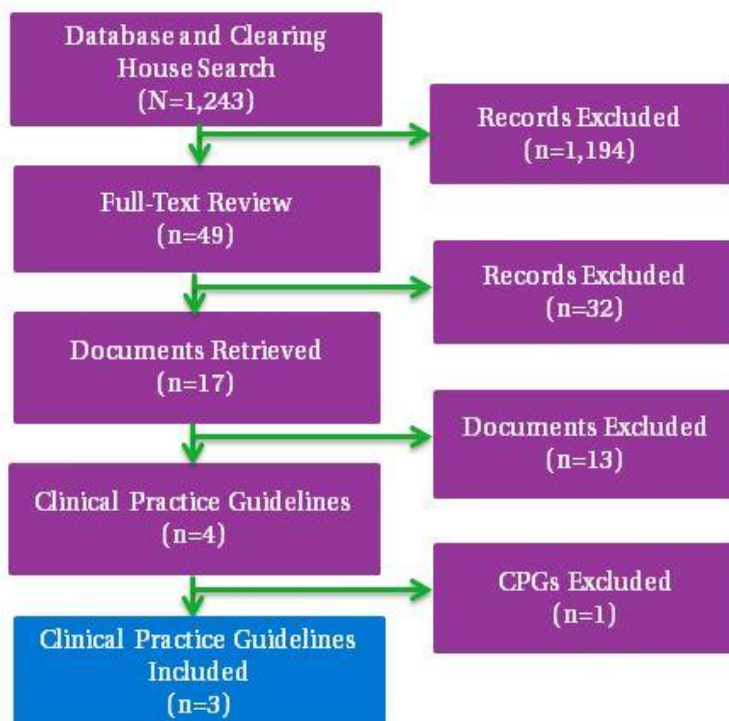


Figure 5: Search Strategy for Clinical Practice Guidelines

As outlined in Figure 5, a total of 1,243 titles were initially retrieved following the comprehensive search strategy. A title and abstract screening led by a single reviewer reduced this group to 49 full text documents relevant to the guideline topic. Of the 49 full text articles reviewed, 17 moved forward and four clinical practice guidelines were identified from:

1. Japanese Society of Psychosomatic Pediatrics Task Force;⁴⁸
2. Registered Nurses Association of Ontario;⁴⁹
3. Royal College of Nursing;⁵⁰ and
4. Winnipeg Regional Health Authority.⁵¹

Upon review, the Japanese Society of Psychosomatic Pediatrics Task Force guideline was removed because it was only available in Japanese and efforts to retrieve it by a health



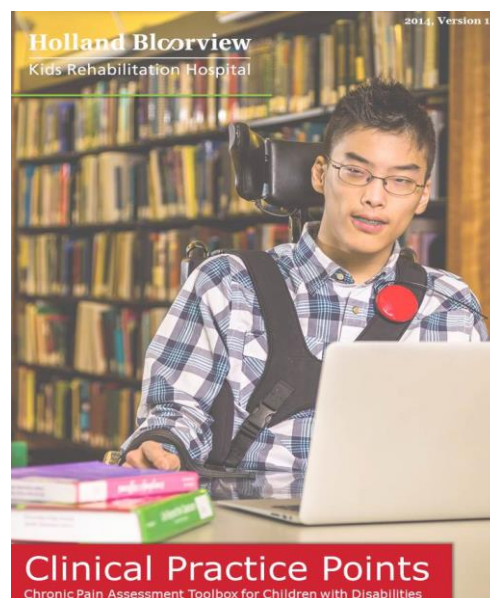
sciences librarian for translation were unsuccessful. The remaining three CPGs underwent further critique.

To assess the quality, methodology, and rigor to which the guidelines were developed, two reviewers assessed the eligible guidelines using the Appraisal of Guidelines for Research and Evaluation (AGREE II) instrument.⁵² This freely available instrument guides reviewers through six domains of appraisals including: the scope and purpose, stakeholder involvement, rigor of development, clarity of presentation, applicability, and editorial independence.⁵² Full results of the AGREE II can be found in the [Index](#). As a result of this process, the [RNAO 2007 Best Practice Guideline \(BPG\) for the Assessment and Management of Pain](#)⁴⁹ was determined as the highest quality resource. Further, this guideline was revised and re-released in December 2013 with an improved focus on interdisciplinary work, education, and assessment of all types of pain, including chronic pain.⁵³

A subcommittee of the Systematic Review Working Group met four times and was comprised of the EtC knowledge translation specialist and knowledge broker along with two physicians and one nurse practitioner. The RNAO BPG has a total of 20 recommendations, from which the expert committee selected nine as relevant to local context. The recommendations found in the Clinical Practice Points are verbatim reproductions of those selected from the RNAO BPG and can be applied to multiple populations with or without disabilities. In order to put the recommendations into practice, the group of experts was tasked with developing clinical practice points to assist in the accurate identification and assessment of chronic pain.

Formation of Clinical Practice Points

The selected RNAO BPG recommendations acted as a base from which the Clinical Practice Points were developed. The three excluded CPGs from the structured review alongside the 13 additional documents (position statements, practice guidelines and journal articles) identified therein were synthesized for items that addressed chronic pain assessment, pain re-assessment, self-reporting of pain, documentation, use of validated tools, items specific to chronic pain, and sociocultural factors affecting pain assessment and reporting. A second search of





literature on CP and chronic pain was also conducted to identify key practice considerations.

The key information from these two searches were collated and reviewed by the same subcommittee of the Systematic Review Working Group listed above to revise and deliver expert consensus, experience, and practice point refinement. These practice points were then presented to the larger Systematic Review Working Group and included within the Toolbox.

Systematic Review of Pediatric Chronic Pain Assessment Tools

Following guidelines offered by Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)⁵⁴ and Assessing the Methodological Quality of Systematic Reviews (AMSTAR),⁵⁵ a systematic review of three high quality scientific databases was conducted to identify pediatric chronic pain assessment tools. The search strategy was developed in consultation with a health sciences librarian and the screening took place with the assistance of the Systematic Review Working Group.

The search was conducted in the scientific databases Medline, CINAHL (Cumulative Index to Nursing and Allied Health) and Embase between January 2012 and July 2014. A manual hand search for relevant references within research article citation lists was also conducted. As disability research is an emerging field, the search strategy contained a broad series of subject headings and keywords related to pediatric chronic pain and assessment. Cerebral palsy shares many symptoms and comorbidities with other pediatric health conditions and so a range of pediatric health conditions were considered with no restrictions applied based on communication, mobility, and/or cognition.

Table 1: Inclusion and Exclusion Criteria for the Systematic Review

Inclusion Criteria
✓ Focused on a pediatric population (1-18 years of age)
✓ Assessed chronic pain as pain lasting more than three months or longer than the expected time to heal
✓ Described the validity and reliability of a chronic pain assessment tool
✓ Written in the English language
✓ Published between 1980 and 2014
Exclusion Criteria
× Focused on age group outside of pediatrics (<12 months, >18 years)
× Assessed pain that was not recognized as chronic pain
× Single-item measurement tool that did not screen for or track the presence of chronic pain



×	Pediatric population with diseases or disorders that were unlike CP including mental health concerns, HIV/AIDS, gynecological/prostate pain
×	The chronic pain assessment tool had not been validated
×	The chronic pain assessment tool was not available in the English language
×	The chronic pain assessment tool was only available electronically



As demonstrated in Figure 6, the comprehensive search strategy retrieved a total of 2,652 unique full-text articles, from which the Systematic Review Working Group reviewed 2,133 titles, 1,443 abstracts and 240 articles to identify chronic pain assessment tools. From the included articles, 308 assessment tools were identified and underwent further screening.

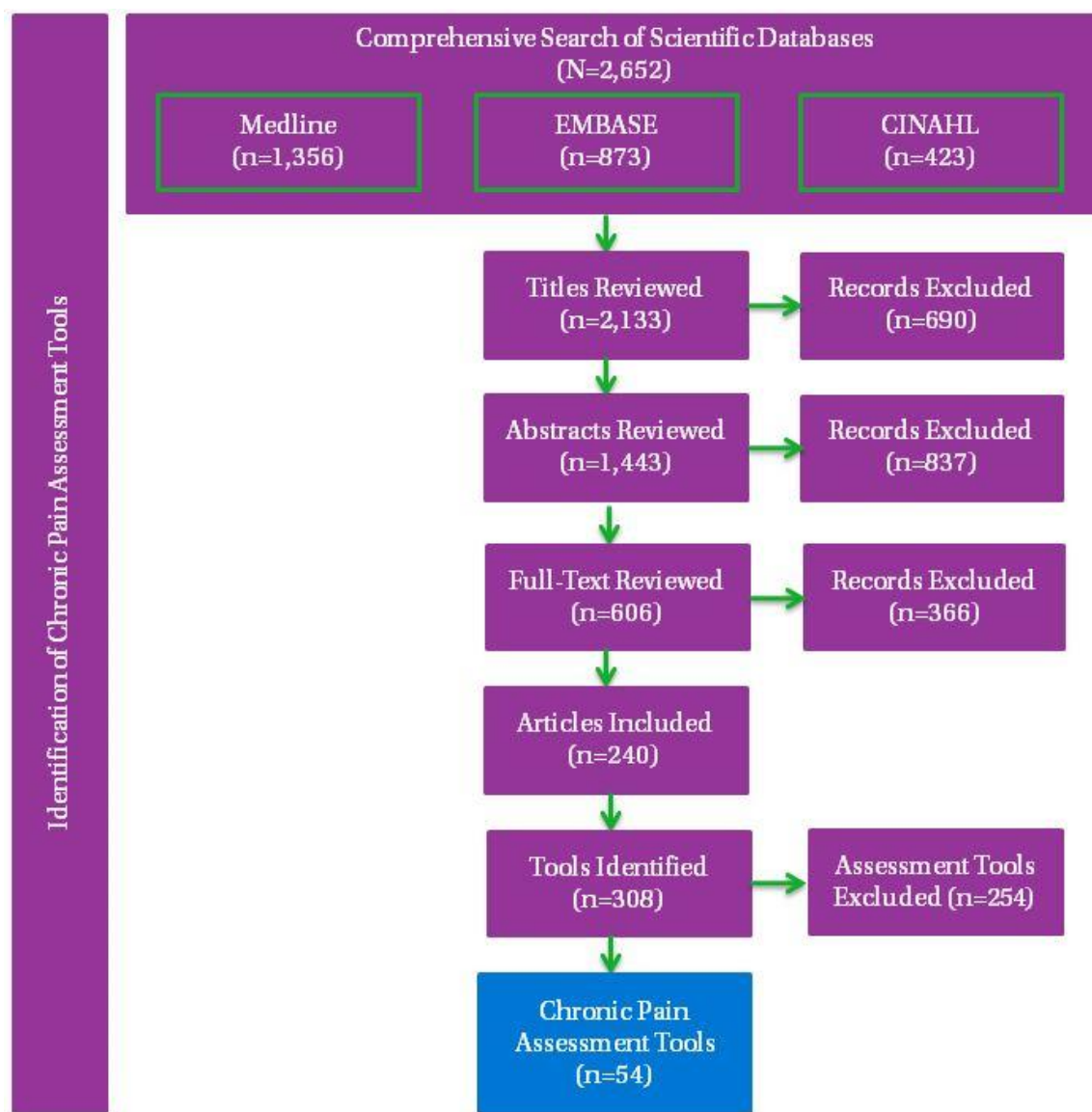


Figure 6: Identification of Chronic Pain Assessment Tools



Critique of Chronic Pain Assessment Tools

As demonstrated in Figure 7, 54 assessment tools met eligibility criteria and underwent a formal critique of: (a) the strength of psychometric properties; (b) the clinical utility within a tertiary pediatric rehabilitation setting; and (c) an expert review consensus activity to select the best available tools for inclusion within the Toolbox.

		Self-Report (n=24)	Observational (n=13)	Combination (n=17)
Psychometric Property Rating	Promising	7 (29%)	5 (38%)	4 (24%)
	Approaching Well-Established	14 (58%)	4 (31%)	7 (41%)
	Well-Established	3 (13%)	4 (31%)	6 (35%)
	Tools Excluded	0	0	0
Clinical Utility Rating	Weak	16 (67%)	4 (31%)	13 (76%)
	Moderate	2 (8%)	7 (54%)	4 (24%)
	Strong	3 (13%)	2 (15%)	0
	Tools Excluded	3 (13%)	0	0
Expert Consensus	Do Not Recommend	12 (50%)	11 (85%)	7 (41%)
	Recommend	6 (25%)	2 (15%)	8 (47%)
	Tools Excluded	6 (25%)	0	2 (12%)
Toolbox	Excluded	1 (17%)	0	0
	Included	5 (83%)	2 (100%)	8 (100%)

Figure 7: Series of Critiques of the Chronic Pain Assessment Tools

Chronic Pain Assessment Toolbox for Children with Disabilities



Ratings of Psychometric Properties

The Systematic Review Working Group members were assigned a series of assessment tools to review. The original validation articles for each of the 54 retrieved tools were critiqued by at least two experts, using a rating system developed by Cohen and colleagues (2008).⁵⁶ Three hierarchical categories (*promising*, *approaching well-established*, and *well-established*) were used to appraise the psychometric properties of each tool.⁵⁶ The criteria for each category were based upon validity and reliability, study design, and overall methodological rigor.⁵⁶ Further details on the Cohen's rating system can be found [here](#). In total, 16 tools (30%) were found to be *promising*, 25 tools (46%) categorized as *approaching well-established*, and 13 tools (24%) were categorized as *well-established*.

Ratings of Clinical Utility

The rating of clinical utility was of utmost importance as it addressed an existing gap in the assessment of chronic pain in children with disabilities. There are several high quality, psychometrically rigorous tools currently available to assess chronic pain in children and adolescents; however, there are very few tools which address chronic pain in conjunction with existing disability. The clinical utility of each tool was thus analyzed following an adapted version of the Clinical Utility Attributes Questionnaire (CUAQ) and incorporated questions regarding the inclusion of mobility and weight bearing activities.⁵⁷⁻⁶⁰ As some children with CP have restrictions to mobility, it was important to consider how tools intended to measure chronic pain with typically developing children could be applied to children of varied Gross Motor Function Classification System (GMFCS) levels.⁶¹ Mobility was defined within several progressions, similar to that of the GMFCS:

Level 1: Walk short and long distances without trouble and without help.⁶¹

Level 2: Walk short distances but have some trouble walking long distances and balancing.⁶¹

Level 3: Walk using a cane or walker for short distances, but a wheelchair for long distances.⁶¹

Level 4: Get around in a manual or power wheelchair or scooter on his/her own.⁶¹

Level 5: Get around in a manual wheelchair that someone else pushes.⁶¹

Table 2 outlines the questions which guided the clinical utility rating completed by at least two reviewers of the Systematic Review Working Group.



Table 2: Adapted CUAQ for the Assessment of Clinical Utility

Criterion	The Tool...	Scoring		
		Green (2 points - the tool is effective in this situation)	Yellow (1 point - the tool can be used with children with CP, but with caution)	Red (0 points - the tool is not effective in this situation)
Usability	1. Has questions that are easy to understand.			
	2. Is easy to score and interpret.			
	3. Is not too time consuming.			
	4. Is appropriate for use with children and adolescents with cerebral palsy.			
Comprehensiveness	5. Gives me useful information about how pain affects function or quality of life.			
	6. Tells me if the client does or does not have pain.			
	7. Can be used with a client of any Gross Motor Function Classification System (GMFCS)			
	8. Assess chronic pain/pain behaviour over	≥14 days	1-13 days	≤ 1 day
Other considerations	9. Measures outcomes other than pain (i.e. depression, anxiety).	Yes/No If yes, what does it measure?		
	10. A child with CP with verbal skills would be able to self-report pain using this tool.	Yes/No		

Each indicator statement (questions 1 through 10) was rated and assigned a numerical value, which coincided with the final clinical utility scores:

- **Weak tool (0-5 points);**
- **Moderate tool (6-11 points); and**
- **Strong tool (12-16 points).**

Of the 54 retrieved tools, 33 tools (61%) were categorized as *weak*, 13 tools (24%) as *moderate*, and 5 tools (9%) chronic pain assessment tools were labelled to have *strong* clinical utility for use with a pediatric CP population. Note 3 tools (6%) were excluded from the assessment of clinical utility as the reviewers were not able to retrieve a copy of the full assessment tool from the author.



Selection of Tools through Expert Consensus

Members of the Systematic Review Working Group reviewed psychometric ratings, clinical utility, and a full copy of the tool to make a yes/no recommendations for inclusion. The tools that were unanimously agreed upon by the Systematic Review Working Group were accepted for final inclusion in the Toolbox. When disagreements arose, the ratings were reviewed by the entire Working Group and put to vote with respect to inclusion. As outlined in Figure 7, 15 tools (28%) were recommended for inclusion within the Toolbox, 30 tools (55%) were not recommended for inclusion, and 9 tools (17%) were excluded from the consensus activity. Examples of reasons for why reviewers did not recommend a tool for inclusion were:

- Tool focused solely on one type of pain (e.g. abdominal, headache);
- Tool had a broad range of health-related questions with only a few focused on pain assessment;
- Tool did not have applicability to a clinical/rehabilitation setting;
- Tool had been used with typically developing children and had little transferability to children with disabilities; and
- Tool had low psychometric properties or the reporting requirements were too complicated to fit neatly into clinical practice.

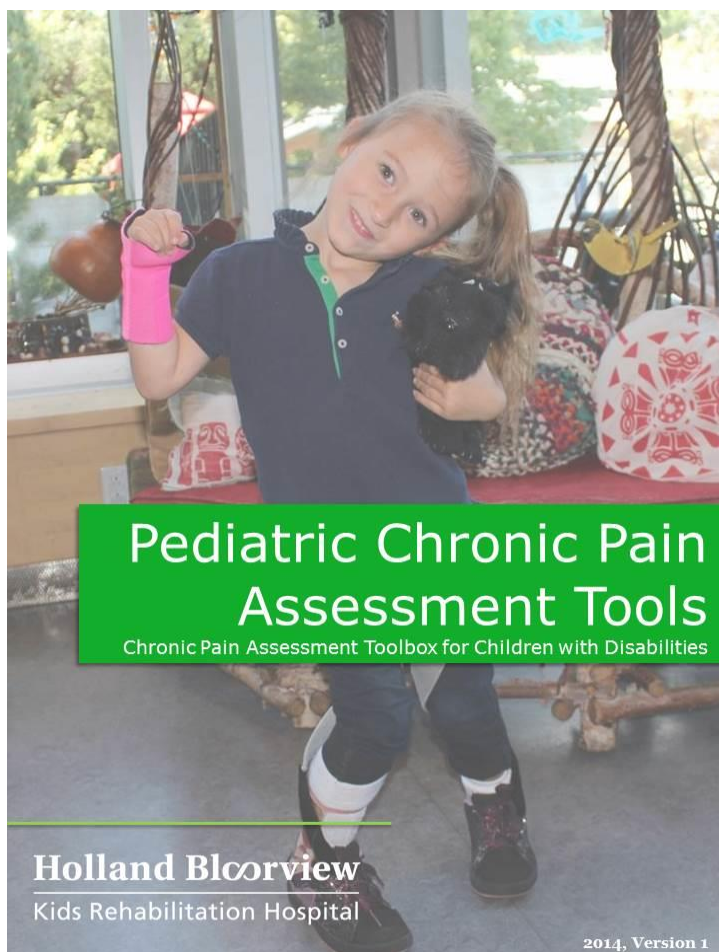
The fifteen tools selected for inclusion within the Toolbox are:

- ✓ Bath Adolescent Pain Questionnaire (BAPQ)
- ✓ Body Diagram
- ✓ Child Activity Limitations Interview (CALI)
- ✓ Children's Self-Efficacy Scale - Parent and Child (CSES)
- ✓ Chronic Pain Acceptance Questionnaire – Parent/Child (CPAQ)
- ✓ Graded Chronic Pain Scale (GCP)
- ✓ Non-Communicating Children's Pain Checklist-Revised (NCCPC-R)
- ✓ Pain Anxiety Symptom Scale (PASS-20)

Chronic Pain Assessment Toolbox for Children with Disabilities



- ✓ Pain Coping Questionnaire (PCQ)
- ✓ Pain Stages of Change Questionnaire for Adolescents (PSOCQ-A) and for Parents (PSOCQ-P)
- ✓ Pediatric Pain Interference Scale (PPIS)
- ✓ Paediatric Pain Profile (PPP)
- ✓ Psychological Inflexibility in Pain Scale (PIPS)
- ✓ Varni/Thompson Pediatric Pain Questionnaire (PPQ)
- ✓ Waldron/Varni Pediatric Pain Coping Inventory (PPCI) Child and Adolescent Form



Descriptions of each tool, along with information on how to access a full-text copy, can be found in **2.0 Pediatric Chronic Pain Assessment Tools** available to download at www.hollandbloorview.ca/toolbo



Chronic Pain Assessment Tools for Children with Disabilities

The following section provides an in-depth review of the pediatric chronic pain assessment tools included within the Toolbox, with a quick review of the tools available in Tables 3 and 4. The characteristics of each tool are described in detail in the pages that follow: the tool classification (screening versus outcome measures), reporting style (self-report, observational or combination), psychometric property, and clinical utility ratings, domains of chronic pain covered within tools and the inclusion of mobility and weight bearing content.

Chronic Pain Assessment Tool Classification

Tools were subdivided into two main categories: pain interference and pain coping. Pain interference refers to pain which impacts or impedes a child's daily physical, social, emotional or cognitive routines,⁶² while pain coping is defined as "purposeful cognitive or behavioural efforts to manage or minimize the negative impact of pain"⁵⁹ (pg. 18). Within each category, tools were further subdivided into screening or outcome measures. Through the Systematic Review Working Group consensus activities, screening tools were identified as measures that captured the presence of pain while outcome tools were identified as measures that evaluated the level of pain interference or pain coping. Within the body of literature reviewed, this distinction was not always clear as tools were frequently used with a wider scope than intended by the developers or developers may not have had the opportunity to generate new data in ways originally conceived at the time of publication. As outlined in Tables 3, of the seven pain interference tools selected, three were considered as screening (Body Diagram, NCCP-R, PPQ) and three were outcome measures (BAPQ, CALI, PPIS, PPP). Table 4 outlines the eight pain coping tools categorized as screening (CPAQ, GCP Scale, PPCI, PIPS) and outcome measures (CSES, PASS-20, PCQ, PSOCQ). Regardless, if a tool was intended for pain interference or pain coping, all assessments were classified as observational, self-report or possessing the capacity to be delivered in combination.

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Table 3: Pain Interference Assessment Tool Characteristics

Type of Assessment	Tool	Tool Objective	Age of Clients Validated with And Used With (Years)	Reporting Style		Psychometric Rating	Clinical Utility	Domain of Chronic Pain	Mobility and Weight Bearing Content	
				Self-Report	Observational				Independence / Some Assistance	Full Assistance
Screening Tools	Body Diagram	Assesses a child's perception of pain intensity and location.	- Validated: 8 - 17 - Used with: 8 - 18	√		AWE	S	Symptoms and adverse effects	—	—
	Non-Communicating Children's Pain Checklist - Revised (NCCPC-R)*	Assesses pain for children who are unable to self-report because of cognitive (mental/intellectual) impairments or disabilities.	- Validated: 3 – 18 - Used with: 3 – 18	—	√	WE	S	- Symptoms and adverse effects - Physical functioning - Emotional functioning - Role functioning - Sleep	—	—
	Pediatric Pain Interference Scale (PPIS)	Assesses the impact of chronic and recurrent pain on a child's behaviour.	- Validated: 18-65+ - Used with: 8 - 17	√	√	AWE	M	- Symptoms and adverse effects - Physical functioning - Emotional functioning - Role functioning	√	—
	Varni/Thompson Pediatric Pain Questionnaire (PPQ)	Assesses the multiple domains of pain: location, intensity, sensory, affective and evaluative properties.	- Validated: 4 – 16 - Used with: 4 - 21	√	√	WE	M	- Symptoms and adverse effects - Physical functioning	√	—
Outcome Tools	BATH Adolescent Pain Questionnaire for Parents and Self Report (BAPO)	Assesses the concordance and discordance in adolescent's self-report and parent's proxy report of chronic pain related functioning.	- Validated: 11 - 18 - Used with: 10 - 19	√	√	WE	W	- Symptoms and adverse effects - Physical functioning - Emotional functioning - Role functioning - Sleep	√	---
	Child Activity Limitations Interview (CALI)	Assesses the impact of recurrent pain on a child's activity/functional impairment.	- Validated: 8 - 16 - Used with: 8 - 18	√	√	WE	M	Role functioning	√	√
	Paediatric Pain Profile (PPP)*	Assesses and monitors pain in children with severe to profound neurological impairments.	Validated: 1 - 18	---	√	WE	M	- Symptoms and adverse effects - Emotional functioning	---	---

* Used with children with Cerebral Palsy or other physical disabilities.

Psychometric Rating of Assessment Tool: *WE* – Well-Established; *AWE* – Approaching Well-Established; *P* – Promising

Clinical Utility Rating: *S* – Strong Tool (12-16 points); *M* – Moderate Tool (6-11); *W* – Weak Tool (0-5)

Mobility Definition: Walk short and long distances without trouble and without help; walk short distances but have some trouble walking long distances and balancing; walk using a cane or walker for short distances, but a wheelchair for long distances; get around in a manual or power wheelchair or scooter on his/her own; get around in a manual wheelchair that someone else pushes

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Table 4: Pain Coping Assessment Tool Characteristics

Type of Assessment	Tool	Tool Objective	Age of Clients Validated with And Used With (Years)	Reporting Style		Psychometric Rating	Clinical Utility	Domain of Chronic Pain	Mobility and Weight Bearing Content	
				Self-Report	Observational				Independence/Some Assistance	Full Assistance
Screening Tools	Chronic Pain Acceptance Questionnaire – Parents and Child (CPAQ)	Assesses chronic pain acceptance in relation to measures of disability and distress.	- Validated: 10-18 - Used with: 8 – 17	√	√	AWE	W	- Symptoms and adverse effects - Emotional functioning - Role functioning	—	—
	Graded Chronic Pain Scale (GCP)	Assesses chronic pain intensity and interference with normal daily activities.	- Validated: 18 – 75 - Used with: 12 – 19	√	—	WE	S	- Symptoms and adverse effects - Role functioning	—	—
	Psychological Inflexibility in Pain Scale (PIPS)	Assesses the willingness to experience pain (psychological inflexibility) in children with chronic pain.	- Validated: 19 – 70 - Used with: 8 – 84	√	—	AWE	W	- Emotional functioning - Role functioning	—	—
	Waldron/Varni Pediatric Pain Coping Inventory (PPCI)	Assesses children's pain coping strategies.	Validated: 5 – 16	√	√	P	W	- Symptoms and adverse effects - Emotional functioning	—	—
Outcome Tools	Child's Self Efficacy Scale (CSES)	Assesses a child's self-efficacy with regard to normal functioning when in pain.	- Validated: 8 – 18 - Used with: 10 -19	√	√	P	W	- Physical functioning - Emotional functioning - Role functioning	—	—
	Pain Anxiety Symptom Scale – 20 (PASS-20)	Assesses fear and anxiety responses specific to pain.	- Validated: 18+ - Used with: 8 – 17	√	—	AWE	M	- Symptoms and adverse effects - Emotional functioning	—	—
	Pain Coping Questionnaire (PCQ)	Assesses pain coping strategies in children and adolescents.	- Validated: 8 – 18 - Used with: 5 – 20	√	√	AWE	W	Emotional functioning	—	—
	Pain Stages of Change Questionnaire for Adolescents (PSOCQ – P)	Assesses a child's readiness to adopt a self-management approach to their chronic pain condition.	- Validated: 18 -85 - Used with: 12 -18	√	—	AWE	W	Role functioning	—	—



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* Used with children with Cerebral Palsy and other physical disabilities.

Psychometric Rating of Assessment Tool: *WE* - Well-Established; *AWE* - Approaching Well-Established; *P* - Promising

Clinical Utility Rating: *S* – Strong Tool (12-16 points); *M* – Moderate Tool (6-11); *W* – Weak Tool (0-5)

Mobility Definition: Walk short and long distances without trouble and without help; walk short distances but have some trouble walking long distances and balancing; walk using a cane or walker for short distances, but a wheelchair for long distances; get around in a manual or power wheelchair or scooter on his/her own; get around in a manual wheelchair that someone else pushes



Reporting Style

Three reporting styles emerged from the systematic review of retrieved chronic pain assessment tools: self-report, observational, and combination measures in which tools contain both a self-report and observational reporting component.

Self-Reporting of Chronic Pain

Self-report measures are considered the gold-standard and primary source of assessment for verbal individuals in the absence of cognitive impairments.^{49, 63} As outlined in Tables 3 and 4, 13 of the chronic pain assessment tools contain a self-reporting component. None of the chronic pain interference tools rely solely on self-reporting; however, three chronic pain coping tools (CGP, PASS-20, PIPS) are exclusively self-report measures.

Observational Reporting of Pain

Although self-reporting measures are considered the gold standard, the difficulties associated with clearly expressing pain can make pain assessment challenging for young children and individuals with cognitive impairments.^{64, 65} Health care professionals look to parents, caregivers, and families who are familiar with the child, for interpretation of the child's behaviour in relation to pain.⁶⁶ This Toolbox hosts 11 tools, which incorporate an observational reporting style into pain assessment (BAPQ, CALI, NCCPC-R, PPIS, PPP, PPQ, CSES, CPAQ, PCQ, PSOCQ, PPCI). Two of the chronic pain interference tools (NCCPC-R, PPP) are uniquely observational tools intended to be used with children with cognitive impairments or limited communicative abilities. Observational components of these tools are often the same questions that would be asked within a self-report but are answered from the perspective of a parent, caregiver or clinician.

Combination Reporting

When necessary, self-report and observational assessment tools can be used in combination to limit the amount of bias within self-report and triangulate findings from a single measurement.^{49, 67} Nine assessment tools included in the Toolbox can be used as observation and self-report in combination to assess chronic pain in children with disabilities (BAPQ, CALI, PPIS, PPQ, CSES, CPAQ, PCQ, PSOCQ, PPCI).

Psychometric Properties and Clinical Utility Ratings

A formal critique of the psychometric properties of the chronic pain assessment tools revealed the majority of pain interference tools were *well-established* (BAPQ, CALI, NCCPC-R, PPP, PPQ), with two tools rated as *approaching well-established* (Body Diagram, PPIS).



As for the pain coping tools, the majority of tools were identified as *approaching well-established* (CPAQ, PASS-20, PCQ, PSOCQ, PIPS), two tools were *promising* (CSES, PPCI) and one tool was *well-established* (GCP).

The inter-professional working group classified the chronic pain interference tools as having *strong* (Body Diagram, NCCPC-R), *moderate* (CALI, PPIS, PPP, PPQ) and *weak* (BAPQ) clinical utility. The majority of chronic pain coping tools were reported to have *weak* clinical utility (CSES, CPAQ, PCQ, PSOCQ, PIPS, PPCI), with one tool rated as having *moderate* (PASS-20) and one tool as having *strong* (GCP) clinical utility.

Mobility Considerations for Pain Interference

Considering the Toolbox was designed for use within outpatient clinics for children with CP, the Implementation Team opted to deliver their interpretations on the capacity of the pain interference tools to be used with children with limited weight bearing and mobility in the Holland Bloorview context. As outlined in Table 3, the chronic pain interference tools that the Implementation Team identified for use with children that have independence or requiring some assistance included the PPIS, PPQ, BAPQ, and CALI. The Body Diagram, NCCPC-R and PPP were the only pain interference tools identified with the capacity to be used with children requiring full assistance.

Domains of Chronic Pain

As previously discussed the subjectivity of the pain experience can lead to a number of ways in which a child is affected by pain. The PedIMMPACT (Pediatric Initiative on Methods, Measurement and Pain Assessment in Clinical Trials) presents a series of evidence-informed domains of chronic pain to be included in the assessment of chronic pain.⁶⁸ In total, eight domains of chronic pain are recommended for use when assessing pediatric chronic pain:⁶⁸ pain intensity, global judgment of satisfaction with treatment, symptoms and adverse effects, physical functioning, emotional functioning, role functioning, sleep, and economic factors. Table 3 and 4 identify the domains of chronic pain identified in each of the chronic pain interference and chronic pain coping tools, note pain intensity, global judgment of satisfaction with treatment, and economic factors were not identified in retrieved tools. The most common domains include:

- Symptoms and adverse effects (BAPQ, Body Diagram, CPAQ, GCP, NCCPC-R, PASS-20, PPIS, PPP, PPQ, PCI);
- Emotional functioning (BAPQ, CSES, CPAQ, NCCPC-R, PASS-20, PCQ, PPIS, PPP, PIPS, PPCI);



- Role functioning (BAPQ, CALI, CSES, CPAQ, GCP, NCCPC-R, PSOCQ-P, PPIS, PIPS);
- Physical functioning (BAPQ, CSES, NCCPC-R, PPIS, PPQ); and
- Sleep (BAPQ, NCCPC-R).

**For a detailed overview of each tool please download
Section 3.0 Pediatric Chronic Pain Tools document.**

2018 Tool Update

In November 2017, a search was conducted to update the [Pain Interference Tools and Tools to Watch](#). A focused search was conducted to identify articles published between July 2013 – October 2017 to identify new publications meeting our eligibility criteria. Publications were reviewed for relevance to clinical populations that may use the Toolbox (e.g. cerebral palsy or related disability populations). The search strategy was implemented in MEDLINE using the name of the tool as a keyword search term and the ‘Find citing articles’ function for the original validation paper. New information, such as updated populations, validation information and citations have been added to [Section 3](#) of the Toolbox.



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AGREE II Tool Tables

Guideline (Author Organization, Guideline Title)	Year of Publication	Country	Language	Population & Pain Focus	AGREE Score (conducted by two reviewers)
Registered Nurses Association of Ontario: Pain Assessment and Management	2007	Canada	English	General population Acute & Procedural Pain	Reviewer 1: 6 Reviewer 2: 7
Royal College of Nursing: Recognition and Assessment of Acute Pain in Children	2009	United Kingdom	English	Pediatric Acute Pain	Reviewer 1: 6 Reviewer 2: 6
Winnipeg Regional Health Authority: Pain Assessment and Management	2012	Canada	English	General population Acute & Procedural Pain (Adapted from the RNAO 2007 Pain Assessment and Management Guideline)	Reviewer 1: 4 Reviewer 2: 5



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