Decision Tree for selecting chronic pain assessment tools for people with cerebral palsy

Smith N, Harvey A, Imms C, Thornton A and Gibson N.

Chronic pain, defined as pain that persists or recurs for longer than three months or longer than the expected time to heal[1], is the most common co-morbidity seen in young people with cerebral palsy (CP). Up to three out of four people with CP experience chronic pain at varying stages of their life, with reported prevalence between 14 and 76%[2]. Assessment using a biopsychosocial approach is best practice, as the development of chronic pain involves the interplay of multiple factors that are unique to each individual. Assessment should consider interference with daily living* and the impact on emotional functioning** at a minimum.

**Chronic pain interference with daily living is defined as how much pain interferes with engagement in social, physical, and recreational activities.*[3]

***Impact on emotional functioning is defined as impact of chronic pain on psychological and emotional well-being (such as experiencing anxiety or depression).*[3]

Attached are two decision trees to help guide assessment of chronic pain for people with CP. We recommend you start at Decision Tree 1 if you are unclear as to whether the young person has chronic pain.

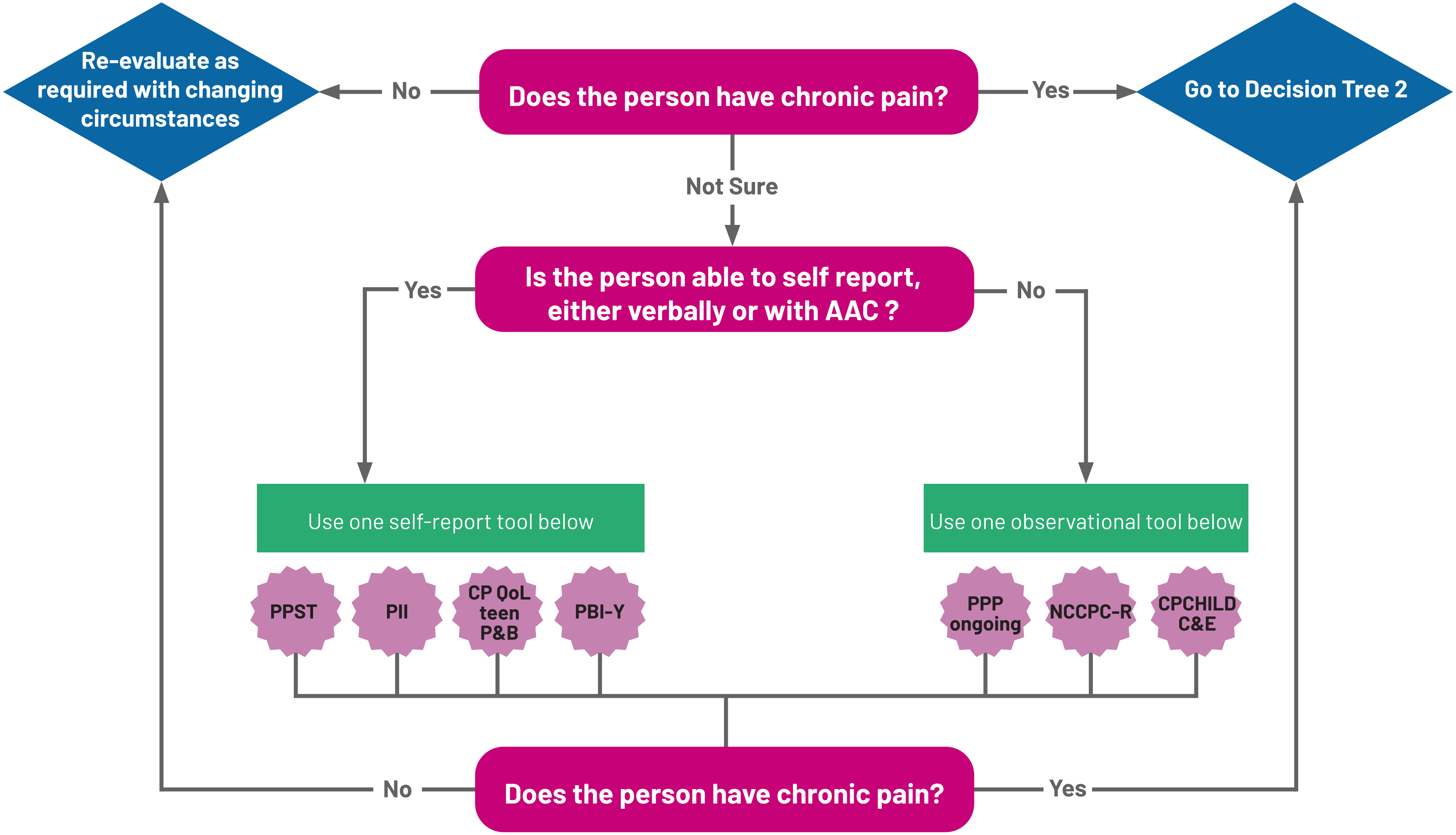
The decision trees help you to identify if a person with CP has chronic pain (if you are unsure) and to select the most appropriate chronic pain assessment to use for people with CP, based on their ability to self-report or need for proxy or observational assessment. Once you are guided through the process you will come to a selection of recommended tools to assess chronic pain in CP. You can then choose a tool for the domain of interest.

The recommended tools have undergone examination to ensure they are valid and reliable and can be used for the varying functional abilities of people with CP. People with the lived experience of CP (caregivers of young people with CP and young people with CP) and clinicians worked together to reach consensus on the tools that are the most meaningful and helpful to include in this decision tree[4].

This QR code will take you to a copy of the tools. Websites and further information are also available at the links under each assessment tool. All links to tools have been included with permission from authors.

Chronic Pain Assessment for People with Cerebral Palsy

Decision Tree 1: Identifying if chronic pain is present



Does the person have chronic pain?

No

Re-evaluate as required with changing circumstances

Yes

Go to Decision Tree 2

Not Sure

Is the person able to self report, either verbally or with AAC ?

Yes

Use one self-report tool below

PPST

PII

CP QoL teen P&B

PBI-Y

No

Use one observational tool below

PPP ongoing

NCCPC-R

CPCHILD C&E

Does the person have chronic pain?

No

Yes

CPCHILD C&E=Caregivers Priorities and Child Health Index of Life with Disabilities Questionnaire–Comfort and Emotions subscale; CP QoL-teen P&B=The Cerebral Palsy Quality of Life Questionnaire–teen version Pain and bother subscale; NCCPC-R=Non-Communicating Children's Pain Checklist-Revised; PBI-Y=Pain Burden Inventory-Youth; PII=Pain Interference Index; PPP=Paediatric Pain Profile; PPST=Pediatric Pain Screening Tool;

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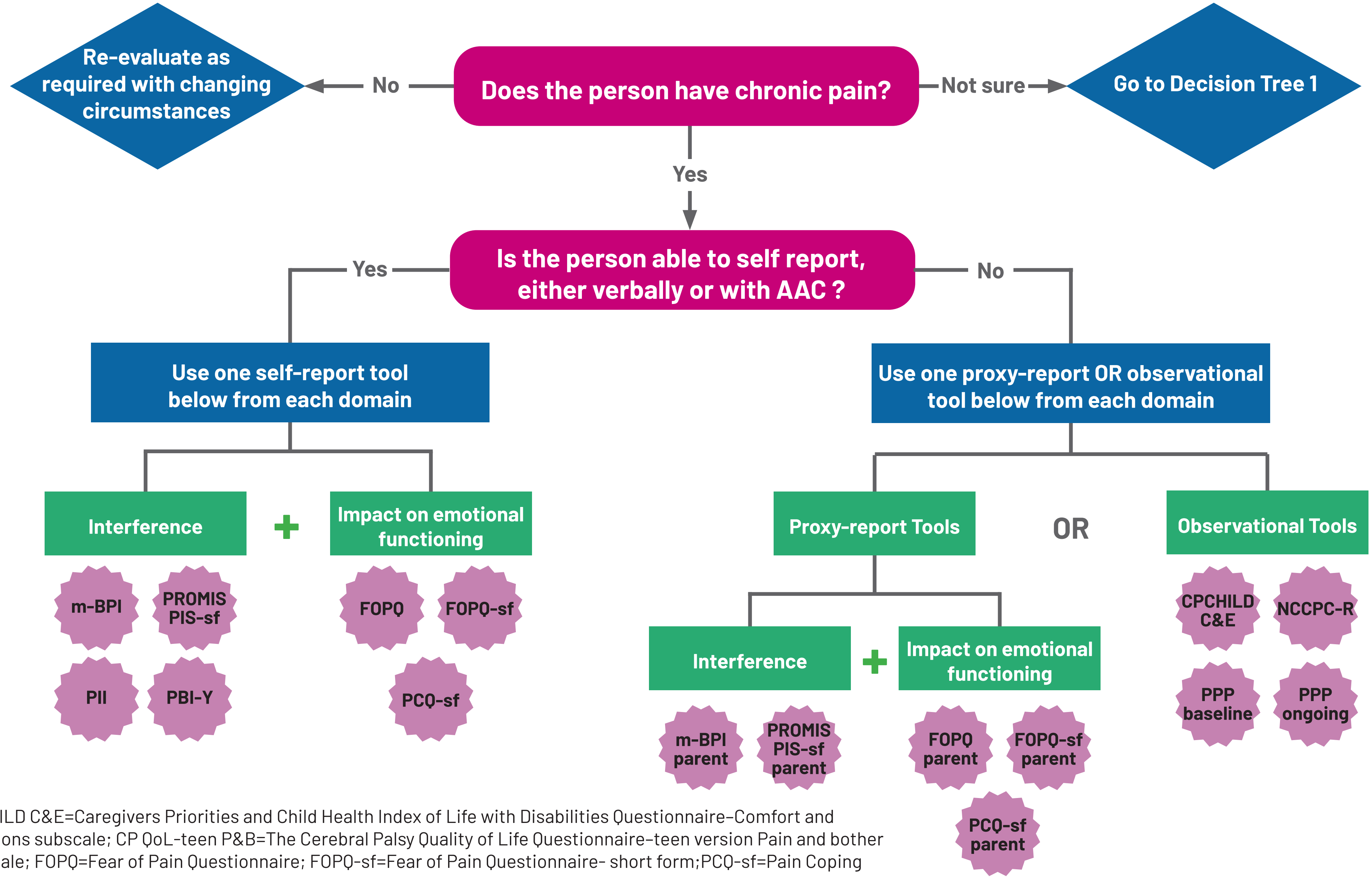
Decision Tree 2: Assessment of chronic pain for people with cerebral palsy



Does the person have chronic pain?

No → Re-evaluate as required with changing circumstances

Not sure → Go to Decision Tree 1

Yes ↓

Is the person able to self report, either verbally or with AAC ?

Yes → Use one self-report tool below from each domain

- Interference: m-BPI, PROMIS PIS-sf, PII, PBI-Y
- +
- Impact on emotional functioning: FOPQ, FOPQ-sf, PCQ-sf

No → Use one proxy-report OR observational tool below from each domain

- Proxy-report Tools
  - Interference: m-BPI parent, PROMIS PIS-sf parent
  - +
  - Impact on emotional functioning: FOPQ parent, FOPQ-sf parent, PCQ-sf parent
- OR
- Observational Tools: CPCHILD C&E, NCCPC-R, PPP baseline, PPP ongoing

CPCHILD C&E=Caregivers Priorities and Child Health Index of Life with Disabilities Questionnaire-Comfort and Emotions subscale; CP QoL-teen P&B=The Cerebral Palsy Quality of Life Questionnaire–teen version Pain and bother subscale; FOPQ=Fear of Pain Questionnaire; FOPQ-sf=Fear of Pain Questionnaire- short form;PCQ-sf=Pain Coping Questionnaire- short form; m-BPI=modified Brief Pain Inventory; NCCPC-R= Non-Communicating Children's Pain Checklist-Revised; PBI-Y=Pain Burden Inventory-Youth; PII=Pain Interference Index; PPP=Paediatric Pain Profile; PPST=Pediatric Pain Screening Tool; PROMIS PPI-sf=Patient Reported Outcomes Measurement Instrument System–Pediatric Pain interference short form

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Decision tree 1: Tools for identifying chronic pain

Tools that identify the presence of chronic pain

For people who can self-report

1. The Pain Burden Inventory-Youth[5]

The Pain Burden Inventory-Youth is a seven-item tool that measures impact of pain on a person's physical function, participation in social and community activities and some emotions.

Availability: In the article: Validation of the Sickle Cell Disease Pain Burden Interview-Youth - ScienceDirect

2. The Pediatric Pain Screening Tool[6]

The Pediatric Pain Screening Tool consists of nine items used to identify a person's risk status (high, medium, or low) of poor clinical outcomes because of chronic pain.

Availability: Measures – BPP (stanford.edu)

3. The Pain Interference Index[7]

The Pain Interference Index is a six-item tool to assess the degree to which pain has interfered with daily activities in the past two weeks.

Availability: Validation of the Sickle Cell Disease Pain Burden Interview-Youth - ScienceDirect

4. The CP QoL-teen (pain and bother subscale)[8]

The Pain and Bother subscale is one section from the Cerebral Palsy Quality of Life - teenager version. There is also a caregiver proxy report version.

Availability: The Cerebral Palsy Quality of Life Questionnaire - AusACPDM

Observational Tools

1. Paediatric Pain Profile - ongoing assessments[9]

The Paediatric Pain Profile ongoing assessment is one page. Parents/caregivers rate how the young person's pain is in general. This ongoing assessment helps monitor pain over longer periods of time. Comparing the ongoing assessment to the "pain on a good day" at baseline can help to monitor interventions and facilitate communication with the person's multidisciplinary team.

Availability: https://ppprofile.org.uk/

2. Non-Communicating Child's Pain Checklist-Revised[10]

The Non-Communicating Children's Pain Checklist Revised (NCCPC-R) is designed for pain assessment with cognitively impaired children and adolescents, who cannot express pain consciously and adequately, either verbally or non-verbally. It is recommended to observe the child's behaviours over the past two hours. It is not necessary to watch the child continuously for this period, however, it is recommended that the observer be in the child's presence for the majority of this time (e.g. be in the same room with the child).

Availability: Non-communicating Children's Pain Checklist – Revised (NCCPC-R) (community-networks.ca)

3. CPCHILD[11]

The CPCHILD© Questionnaire is a proxy measure of health-related quality of life of children with severe disabilities. It measures the caregiver's perspective about their child's health, comfort, wellbeing, functional abilities and ease of caregiving. There are 8 sections, *Section 3: Comfort and emotions* has questions that ask about pain and discomfort during activities of daily living such as eating, dressing and positioning (7 items).

Although technically not an observational tool, the CP CHILD is designed for use with people who have significant functional limitations.

Availability: PSCORE | CPCHILD (sickkids.ca)

Decision Tree 2: Tools for assessing chronic pain

Tools that assess pain interference

1. The Pain Burden Inventory-Youth[5]

The Pain Burden Inventory-Youth is a seven-item tool that measures impact of pain on a person's physical function, participation in social and community activities and some emotions.

Availability: In the article: Validation of the Sickle Cell Disease Pain Burden Interview–Youth - ScienceDirect

2. The Pain Interference Index[7]

The Pain Interference Index is a six-item tool to assess the degree to which pain has interfered with daily activities in the past two weeks.

Availability: Validation of the Sickle Cell Disease Pain Burden Interview–Youth - ScienceDirect

3. The modified-Brief Pain Inventory (self and proxy-report)[12]

The modified-Brief Pain Inventory is an eleven-item tool that assesses interference across multiple areas of a person's life. It does not contain items that require standing or walking, so can be used across all GMFCS levels. Recently this tool has been modified for use with children and young people with CP[13].

** Version adapted for CP available from Meredith.smith@adelaide.edu.au

4. PROMIS pain interference short-form (self and proxy report)[14]

The PROMIS pain interference (PROMIS-PIS) assesses the negative effects of pain on functioning in the range experienced by most people who have pain. There are self-report and parent proxy versions. The PROMIS-PIS contains items that require the ability to stand and walk and run, therefore it cannot be used with children classified within GMFCS levels III, IV or IV.

Availability: PROMIS (healthmeasures.net)

Tools that assess impact on emotional functioning

It is important to assess emotional functioning because ongoing negative thoughts about pain can make it harder to participate with friends and family, go to school or have fun. When pain is difficult to cope with, young people and their families may also have more mental health problems like anxiety and depression.

1. Fear of Pain Questionnaire-child (self and proxy-report)[15]

The Fear of Pain Questionnaire-child report (FOPQ-child) and Fear of Pain Questionnaire-parent proxy report (FOPQ-parent) assess how pain related fear can lead to emotional distress and pain-related disability among children and adolescents with chronic pain. Identification of patients with high levels of fear avoidance of pain with the FOPQ will inform how to proceed with psychological and physiotherapy interventions for chronic pain.

Availability: Measures – BPP (stanford.edu)- original version

2. Fear of Pain Questionnaire-short form (self ** and proxy-report)[16]

The Fear of Pain Questionnaire self-report and parent proxy short forms have a reduced number of items (10 items) which assess fear and avoidance related behaviours for children and adolescents with chronic pain. The FOPQ-short forms help to understand if it would be helpful to refer people with chronic pain for psychological and physiotherapy interventions for help. Recently this tool has been modified for use with children and young people with CP 13.

Availability: Measures – BPP (stanford.edu)- original version

** Version adapted for CP available from Meredith.smith@adelaide.edu.au

3. Pain Coping Questionnaire short-form (self and proxy-report)[17]

This is a 16-item short form of the original Pain Coping Questionnaire. It assesses the types of coping strategies people use when they are in chronic pain. It can help identify if the young person is using positive or negative coping strategies. It can help you decide if referral for therapies such as clinical psychology are needed.

Availability: In supplementary material of the original article

The Pain Coping Questionnaire short-form: preliminary reliability and validity - PMC (nih.gov)

Decision Tree 2: Tools for assessing chronic pain

Observational tools for young people unable to self-report

These tools have been designed to pick up the most important behaviours or non-verbal cues that indicate pain. They can be used to help caregivers communicate and monitor a child's pain if they are not able to tell us themselves.

1. Paediatric Pain Profile-baseline[9]

This is a 60-item behavioural assessment tool that can be used for young people who are unable to self-report. The baseline assessment asks for background information, and what the young person is like "on a good day" compared to when they are in pain. If the caregiver knows what is causing the pain, they can identify up to three sources of pain, e.g., pain from muscle spasm/dystonia, gastrointestinal pain or pain from equipment such as AFO's.

Availability: https://ppprofile.org.uk/

2. Paediatric Pain Profile-ongoing assessments[9]

The Paediatric Pain Profile ongoing assessment is one page. Parents/caregivers rate how the young person's pain is in general. This ongoing assessment helps monitor pain over longer periods of time. Comparing the ongoing assessment to the "pain on a good day" at baseline can help to monitor interventions and facilitate communication with the person's multidisciplinary team.

Availability: https://ppprofile.org.uk/

3. Non-Communicating Child's Pain Checklist-Revised[10]

The Non-Communicating Children's Pain Checklist Revised is designed for pain assessment with cognitively impaired children and adolescents, who cannot express pain consciously and adequately, either verbally or non-verbally. It is recommended to observe the child/young person's behaviours over two hours to complete this checklist. It is not necessary to watch the child continuously for this period, however, it is recommended that the observer be in the child's presence for the majority of this time.

Availability: Non-communicating Children's Pain Checklist – Revised (NCCPC-R) (community-networks.ca)

4. CPCHILD[11]

The CPCHILD© Questionnaire is a proxy measure of health-related quality of life of children with severe disabilities. It measures the caregiver's perspective about their child's health, comfort, wellbeing, functional abilities and ease of caregiving. There are 8 sections, Section 3: Comfort and emotions has questions that ask about pain and discomfort during activities of daily living such as eating, dressing and positioning (7 items).

Although technically not an observational tool, the CPCHILD is designed for use with people who have significant functional limitations.

Availability: PSCORE | CPCHILD (sickkids.ca)

Summary of Feasibility of Tools

TOOL	Time taken (minutes)	GMFCS levels	Age range (years)	Scoring minutes (scoring time for AAC)
TOOLS TO IDENTIFY THE PRESENCE OF CHRONIC PAIN				
PBI-Y | Pain Burden Inventory-Youth	5	I, II	Not specified	5
PPST | Pediatric Pain Screening Tool	5	I, II	8-18	5
PII | Pain Interference Index	5	I, II	Not specified	5
CP QoL teen (pain and bother) | Cerebral Palsy Quality of Life Questionnaire-teenager version	5-8	I, II	13-18	5-10
OBSERVATIONAL TOOLS (can also identify presence of pain)				
PPP baseline | Paediatric Pain Profile baseline	10-15	I-V	1-60	5
PPP ongoing | Paediatric Pain Profile ongoing version	5-10	I-V	1-60	5
NCCPC-R | Non-Communicating Children's Pain Checklist-revised	2 hrs	I-V	3-18	5-10
CPCHILD (comfort and emotions subscale) | Caregivers Priorities and Child Health Index of Life with Disabilities Questionnaire	10	IV, IV	5-19	10-15
CHRONIC PAIN INTERFERENCE				
PBI-Y | Pain Burden Inventory-Youth	as above			
PII | Pain Interference Index	as above			
m-BPI (adapted for CP) | modified-Brief Pain Inventory (adapted for CP)	5-10	I-V	5-30	7 (24)
PROMIS-PIS sf | Pediatric Reported Outcomes Measurement Information System Pain Interference Scale short-form	5	I, II	5-17	5-10
IMPACT ON EMOTIONAL FUNCTIONING				
FOPQ (adapted for CP) | Fear of Pain Questionnaire	5-10	I-V	5-30	5 (24)
FOPQ-SF | Fear of Pain Questionnaire short-form	5	I-V	8-17	5
PCQ-SF | Pain Coping Questionnaire short form	5-10	I-V	7-18	5

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