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Published in:
Journal of Orthopaedic and Sports Physical Therapy

DOI:
[10.2519/jospt.2017.7469](https://doi.org/10.2519/jospt.2017.7469)

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Recommended citation(APA):
Michaleff, Z. A., Kamper, S. J., Stinson, J. N., Hestbaek, L., Williams, C. M., Campbell, P., & Dunn, K. M. (2017). Measuring musculoskeletal pain in infants, children, and adolescents. *Journal of Orthopaedic and Sports Physical Therapy*, 47(10), 712-730. <https://doi.org/10.2519/jospt.2017.7469>

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Measuring musculoskeletal pain in infants, children and adolescents

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Funding statement:

The funding bodies played no role in the design or conduct of the study; the collection, management, analysis, or interpretation of the data; or preparation, review, or approval of the manuscript. SJK and CMW receive research funding from the National Health and Medical research Council and industry, paid directly to their respective institutions.

Acknowledgements: Nil.

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Anonymous title page

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6. Financial Disclosure and Conflict of Interest. I affirm that I have no financial affiliation (including research funding) or involvement with any commercial organization that has a direct financial interest in any matter included in this manuscript, except as disclosed in an attachment and cited in the manuscript.

1 **ABSTRACT:**

2 Accurate, reliable and timely assessment of pain is critical for effective management of
3 musculoskeletal pain conditions. The assessment of pain in infants, children and
4 adolescents with and without cognitive impairment can be particularly challenging for
5 healthcare clinicians for a number of reasons including factors related to the consultation
6 (e.g. heterogeneous patient population, time constraints), the healthcare clinician (e.g.
7 awareness / knowledge of available pain scales), standardised assessment scales (e.g.
8 availability, psychometric properties and application of each scale) the patient (e.g.
9 developmental stage, ability to communicate) and the context in which the interaction takes
10 place (e.g. familiarity with the setting, physiological and psychological state). As a result,
11 pain is frequently not assessed or measured during the consultation, and in many instances,
12 is underestimated and undertreated in this population. The purpose of this paper is to
13 provide healthcare clinicians with an overview of scales that can be used to measure pain in
14 infants, children and adolescents. Specifically, the paper reviews the various approaches to
15 measure pain intensity, identifies factors that can influence the pain experience, expression
16 and assessment in infants, children and adolescents, provides age appropriate suggestions
17 for measuring pain intensity in patients with and without cognitive impairment, and identifies
18 ways to assess the impact of pain using multidimensional pain scales.

19 INTRODUCTION

20 Musculoskeletal (MSK) pain is a common experience for children and adolescents. As many
21 as half of all children and adolescents will report experiencing MSK pain at least once a
22 month and as many as a third will report persistent or recurrent MSK pain.^{67, 72}

23 Musculoskeletal pain is known to have a substantial impact on the everyday life of children
24 and adolescents, for example, in those who report MSK pain; ~40% report interference with
25 daily activities and sports participation, 20% report missing school / work, 20-30% take
26 medication, and over half seek healthcare which is associated with significant healthcare
27 costs especially for those who experience persistent pain.^{50, 55, 99, 108, 109} Critical to the
28 effective management of MSK pain by healthcare clinicians is the accurate, reliable and
29 timely assessment of pain and the routine implementation of age appropriate, valid and
30 reliable measurement of pain is a pivotal component of evidence-based medicine.

31 Specifically, the valid and reliable measurement of pain is helpful in understanding a
32 person's pain experience, can help identify appropriate treatment options, and assist in
33 monitoring change in a person's pain condition, minimising potential adverse physiological
34 and psychological consequences of unrelieved or inadequately managed pain.^{4, 18, 90, 97, 106,}

35 110, 145

36

37 Fundamental differences exist between infants, children, adolescents and adult's pain
38 experience and expression which highlight the need to assess and interpret pain in a way
39 that is specific to each age group. For example, while the definition of pain is universal "*a*
40 *distressing experience associated with actual or potential tissue damage with sensory,*
41 *emotional, cognitive and social components*",¹⁵⁸ the way in which these components interact
42 with environmental, developmental, sociocultural and contextual factors means that the
43 conceptualisation, understanding and communication of pain is distinctly different for infants,
44 children and adolescents and adults.^{4, 33, 54, 67} For example, pain vocabulary emerges from 18

45 months (e.g. 'ouch', 'ow', 'hurt'.) and continues to develop until it can reliably be used from
46 around 5 years of age. Similarly, it is from this time that a child begins to develop an
47 understanding of the causes and consequence of pain and the ability to control the
48 expression of pain.^{54, 127, 161} In the absence of intellectual or cognitive deficit, a child's age
49 serves as a reasonable and easily measured proxy for development, and should be used to
50 guide the way in which pain is measured in children and adolescents.^{54, 127, 150}

51

52 The assessment and measurement of pain in infants, children and adolescents can be a
53 challenge for healthcare clinicians.^{53, 139} Reasons for this include factors related to the
54 consultation (e.g. heterogeneous patient population, time constraints), the healthcare
55 clinician (e.g. awareness / knowledge of available pain scales), standardised assessment
56 scales (e.g. availability, psychometric properties and application of each scale) the patient
57 (e.g. developmental stage, ability to communicate) and the context in which the interaction
58 takes place (e.g. familiarity with the setting, physiological and psychological state). As a
59 result pain is frequently not formally assessed or measured during the consultation with
60 more informal questioning used e.g. questions such as 'are you ok?' or 'feeling better?' and
61 the presence of pain validated through observation of behavioural cues such as crying or
62 grimacing.^{102, 128, 145} Even in populations who are at a higher risk of experiencing MSK pain
63 e.g. children with cerebral palsy there is data to suggest that pain is assessed using
64 validated tools in less than 10% of encounters.⁹⁸ The inconsistent assessment,
65 measurement and documentation of pain means that in many instances pain is
66 underestimated and undertreated in this population.¹⁴⁵ Reports of hospital audit data
67 suggests that a third of children experience moderate to severe pain during their hospital
68 admission and documentation of pain assessment is varied (occurring between 12-100% of
69 the time) across hospital settings and between clinicians but all too frequently the
70 assessment, measurement and documentation of pain does not meet hospital or
71 professional guidelines.^{98, 102, 110} Encouragingly, clinical practice has been found to be

72 responsive to knowledge translation and implementation strategies aimed at improving the
73 assessment, measurement and documentation of pain in children and adolescents.^{51, 73}
74 Further work is needed to understand the frequency at which the assessment and
75 measurement of pain occurs in other healthcare settings such as primary care and
76 community facilities.

77

78 Pain is recognised as a core outcome domain by a number of national and international
79 initiatives such as the Pediatric Initiative on Methods, Measurement and Pain Assessment in
80 Clinical Trials Consensus Group (PedIMMPACT) and the Society of Pediatric Pain
81 Assessment Task Force and NIH Tool Box.^{31, 90, 96} These initiatives promote the use of
82 evidence based measures of pain intensity and impact in clinical practice and research.
83 Recommendations are the results of formal, collaborative processes and methodologies that
84 combine empirical evidence, expert opinion and clinical utility. The purpose of this paper is to
85 provide healthcare clinicians with an overview of scales that can be used to measure
86 musculoskeletal pain in infants, children and adolescents in a way that is quick, accurate and
87 reliable. However, few pain scales have specifically been evaluated for this purpose and
88 suggestions are based on scales that have been evaluated to measure procedural (e.g.
89 immunisation pain) and non-specific pain (e.g. MSK pain) with the emphasis being on clinical
90 utility of scales. Using the social communication model of pain as a framework the paper
91 specifically considers factors that influence the pain experience and expression, reviews the
92 various approaches that can be used to assess and measure pain; provides age appropriate
93 suggestions for measuring pain intensity in patients with and without cognitive impairment,
94 and identifies ways to assess the impact of pain using multidimensional pain scales. This
95 paper incorporates and extends the work of the previous collaborations outlined above by
96 identifying and integrating evidence from more recent publications into the measurement of
97 pain in infants, children and adolescents. Scales designed for use in the intensive care
98 setting (e.g. to assess pain in the intubated patient) or those that have *only* been evaluated

99 to assess post-operative pain are not reported in this paper unless specifically stated. We
100 also acknowledge that there are aspects of pain beyond pain intensity, such as affective and
101 evaluative dimensions but we do not address them comprehensively in this article.

102

103 **The social communication model of pain**

104 It is often helpful to use a theoretical model as a framework for understanding the many
105 aspects and processes involved in the experience of pain. This review has chosen the social
106 communication model of pain (see Figure 1) as a framework from which to examine,
107 understand and approach the assessment and management of pain in individuals of all ages
108 and for those with cognitive impairments.^{33, 53} This comprehensive model highlights that at
109 each stage there are a number of factors (biological, psychological and social factors)
110 related to the individual in pain and clinician that influence how pain is experienced,
111 expressed and interpreted and the effectiveness of this communication. The model also
112 considers the social context (interpersonal context) in which the communication of pain
113 occurs, and importantly recognises that the communication of pain may differ whether it is
114 self-initiated by the person in pain or elicited by an observer's question (or repeat
115 questioning e.g. after treatment when a socially desirable response may be provided). This
116 model places assessment and measurement at the heart of understanding a person's pain
117 experience and highlights the importance of how that information is obtained. The remainder
118 of this paper will consider the measurement and assessment of pain in children and
119 adolescents with a particular focus on the social communication model as a guide.

120

121 As outlined in the above social communication model, a number of factors related to the
122 individual in pain, clinician and context can influence each stage. In Figure 2 below we have
123 outlined some of the key factors within these stages that are relevant to the assessment and
124 measurement of pain in children, for example the cognitive ability of the child to understand
125 concepts such as pain severity or intensity, the burden that a child may feel when

126 questioned by a clinician, the potential influences of parents who are present within the
127 consultation.

128

129 **Approaches to measuring pain intensity**

130 There are three main approaches to measuring pain intensity: *physiological* (how the body
131 *reacts*), *observations of behaviour* (how the child reacts) and *self-report* (what the child
132 says). It is important to note that the choice of approach will depend on the age and abilities
133 of the child and that the different approaches are not interchangeable and typically only
134 correlate poor to moderately.^{47, 156} Ideally, information from each approach is used
135 simultaneously to provide a detailed understanding of the pain experience with consideration
136 of both automatic processing and higher cognitive function (see Figure 1).^{33, 47, 53, 156}

137 *Physiological indicators* (e.g. increased heart rate, blood pressure, sweating) are associated
138 with generalised (non-specific) stress reaction and are more strongly associated with
139 distress and anxiety than self-report pain measures.²² For this reason, physiological
140 indicators should not be used in isolation to estimate presence, quality or intensity of pain.
141 Further, these indicators habituate over time and are therefore are not appropriate for use in
142 acute pain that is continuous or in those with chronic pain.⁵⁹

143 *Observational measures* involve observing an individual's non-verbal behaviour (e.g. crying,
144 facial expression, torso and limb movements) and interactions (e.g. social, appetite). The
145 behavioural response to pain is recognised to be more of an automatic and reflexive
146 response to actual or potential tissue damage. Parents and carers can often provide specific
147 and helpful information about typical and idiosyncratic pain-related behaviours that reflect
148 different quality or intensity of pain in their child, this information can then be used inform the
149 selection of appropriate pain management or prevention strategies.^{33, 53, 153} As cognitive skills
150 and function increase with age as does one's ability control (e.g. suppress, exaggerate or
151 feign) behaviour and where possible observational measures should be used to complement

152 self-report measures of pain (see Figure 1). Observational measures are particularly useful
153 for assessing pain in:

- 154 • Children aged less than 4 years who do not have the language skills necessary to
155 communicate pain, or lack the comprehension necessary for self-report measures.
- 156 • Patients with cognitive or communication impairments e.g. cerebral palsy.
- 157 • Situations where valid self-report is not possible (e.g. extreme distress) or the
158 credibility of the self-report is in doubt.⁵³

159

160 *Self-report* is the most direct and reliable approach for measuring pain in those who can self-
161 report.^{129, 139} The ability of a child to understand and report the presence and intensity of pain
162 requires cognitive skills including receptive language and understanding, knowledge and
163 memory of pain, executive function (e.g. cognitive flexibility, working memory), and the ability
164 to understand and estimate magnitudes and symbolic processing.^{63, 150, 151, 161} These skills
165 begin to emerge as early as 3 years of age and gradually develop to enable the accurate
166 and reliable self-reporting of pain intensity by children aged 5 years (on average) or older.
167 While screening tasks (e.g. counting, comprehension and seriation task) are available these
168 are time consuming and do not predict a child's ability to accurately and reliably self-report
169 pain beyond age alone.^{154, 161} The association between a child's age and cognitive skills
170 highlights the need to measure pain using different pain scales in children of different ages
171 e.g. using a more simplified scale (with fewer response options) for younger children.^{151, 161}

172 *Proxy-report*; while input from parents / guardians has a place in the assessment of pain in
173 children, clinicians should be mindful of over-reliance on this information. Numerous studies
174 have shown discrepancies between parental and child report of pain. Typically, studies in the
175 general population of healthy children show that parents under-report pain in their children.^{29,}
176 ^{66, 76} In contrast, studies in children with painful health conditions typically report better

177 concordance, although with a tendency for parents to over-estimate pain severity, compared
178 to the child's report.^{32, 148}

179

180 **AGE APPROPRIATE SCALES TO MEASURE PAIN INTENSITY**

181 Single-item scales of pain intensity are most commonly used to measure pain as they are
182 quick, simple to administer and closely correlated with the impact of pain on the individual
183 (e.g. activity limitations, health care seeking, medication use).¹⁴⁰ Tables 2-4 outline available
184 scales of pain intensity including a general description of the scale, age range, psychometric
185 properties, and practical considerations for use. These tables synthesise evidence from
186 several systematic reviews,^{23, 31, 34, 36, 40, 59, 74, 80, 129, 141, 153} practice guidelines¹¹⁰ and peer-
187 reviewed articles. The evidence outlined in Tables 2-4 was used to identify an appropriate
188 pain intensity scale for each age-group, the suggested scales are summarised in Table 5.
189 The scales that have been suggested for use are based on authors' judgements along with
190 consideration of the psychometric properties of the scale, type of pain (e.g. procedural
191 versus non-specific pain), population, and context in which the scale has been evaluated.

192

193 **Infant (3 years or younger)**

194 Observations of behaviour are most commonly used in this age-group, most typically: crying,
195 facial expression, verbalisation, torso and leg movements. It is important to note that *no*
196 scale has been comprehensively evaluated to assess pain in children aged 3 years or
197 younger in primary care settings, or for children with chronic or persistent pain.^{34, 153} The
198 majority of observational scales have been developed to measure post-operative pain in the
199 hospital setting, but a number of these scales have since been used to assess brief pain
200 associated with medical procedures e.g. venepuncture, immunisations. In the absence of
201 more robust evidence, the scales that have been validated to assess procedural pain are

202 reported in Table 2.³⁵ Scales that *only* evaluate post-operative pain or incorporate
203 physiological measures (e.g. blood pressure, oxygen levels), have not been included as this
204 information is not readily available or feasible for use by many healthcare clinicians.

205 *Suggested scale:* The Face, Legs, Activity, Cry and Consolability (FLACC) Scale.

206 The FLACC scale was originally designed and validated for use in infants and children aged
207 2 months to 7 years to measure post-operative pain.⁹¹ Since original development, the scale
208 has been used to measure acute and procedural pain in emergency departments,
209 immunisation centres, and various clinical settings (e.g. radiology, ambulatory, dental) and in
210 research.³⁴ The FLACC scale is suggested to measure pain in infants aged 3 years or
211 younger on the basis that it has been validated to measure acute procedural pain in a
212 variety of settings (e.g. outpatient paediatric clinic, emergency department, immunization
213 clinic), and in the absence of a scale that has been more comprehensively evaluated.

214

215 *Description:* A score of 0, 1 or 2 is given for each of the five items. Descriptions of typical
216 behaviours are provided for each item, e.g. Legs: “Normal or relaxed position” (score 0);
217 “Uneasy, restless, tense” (score 1); “Kicking, or leg drawn up” (score 2). Item scores are
218 summed to provide a total score from 0-10. Table 2 contains additional details about the
219 FLACC, and other observational scales to measure of pain intensity in children who are
220 unable to self-report.

221

222 **Preschool child (3-5 years)**

223 Age is the strongest predictor of a child’s ability to understand and use self-report pain
224 scales.^{127, 154} It is noted however, that rate of development is varied. While preschool aged
225 children (3-5 years) are *generally less likely* to be able to understand self-reported pain
226 scales than older children, some will be able to. Experience of pain and prior use of a scale
227 appears to influence a child’s ability to use a pain scale reliably, emphasising the need to

228 measure pain consistently. It is suggested that pain intensity is captured through self-report in
229 children of this age (if deemed appropriate), supplemented by information from parents /
230 guardians of the child, and observation of behaviour (FLACC scale).

231

232 *Suggested scale:* Pieces of hurt tool (as able), supplemented by parent / guardian report and
233 observation.

234 The pieces of hurt tool was designed and validated for use in children aged 4 to 6 years to
235 measure procedural pain at immunisation clinics.⁵⁷ The scale has since been used to
236 measure acute (e.g. post-operative), procedural, chronic and recurrent pain in hospitalised
237 children as young as 3 years. The Pieces of hurt tool is the suggested pain scale for infants
238 aged 3 to 5 years.

239

240 *Description:* The child is asked 'Does it hurt?', if the child says 'no' then zero is recorded. If
241 the child responds 'yes' the child is presented with 4 tokens (e.g. poker chips) and it is
242 explained that each token represents a 'piece of hurt' (one token is a little bit of hurt, two is a
243 bit more, to four tokens the most hurt you could ever have). The child is then asked 'how
244 many pieces of hurt they have right now?' The number of tokens is then recorded; additional
245 details are reported in Table 3.

246

247 **Child (6-11 years)**

248 Face scales are consistently preferred by children over numerical, analogue, or word
249 descriptor scales.¹⁴¹ Several versions are available that use either line drawings or
250 photographs (e.g. Faces pain scale – Revised, Wong-Baker, Oucher). While the scales
251 perform similarly they are not interchangeable due to the different anchors used by each of
252 the scales, highlighting the importance of using the same scale consistently. The main
253 limitation of face scales is that pain intensity, a sensory component of pain, is being

254 measured using faces that express the effective / emotional dimension of pain. The type of
255 face anchors used by scales (e.g. smiling vs. neutral) has been found to influence children's
256 responses.^{26, 31, 141}

257 *Suggested scale:* Faces Pain Scale-Revised (FPS-R) scale.

258 The FPS-R was adapted from the original Faces Pain Scale¹¹ and validated in children 4 to
259 12 years undergoing a painful procedure (ear piercing), and in an inpatient clinical
260 population.⁵⁸ The FPS-R is the suggested pain scale for children aged 6 to 11 years based
261 on considerable evidence in support of its reliability and validity in this age-group. The
262 primary strength of the FPS-R compared to other face scales are the gender neutral face
263 anchors that do not convey the emotional / affective dimension of pain (e.g. smiling,
264 crying).²⁶

265

266 *Description:* Faces Pain Scale-Revised (FPS-R) is a set of 6 line-drawn faces with depictions
267 of increasing levels of pain from left to right. Children are asked to specify which face best
268 illustrates the amount of pain they are experiencing at that time. Each face is assigned an
269 increasing score from left to right, either 0-5, or 0-10 (increments of 2). Electronic versions of
270 the FPS-R have also been developed and validated e.g. the Sydney Animated Facial
271 Expressions (SAFE) scale⁵⁸ and *Painometer App*,^{114, 115} additional details are reported in
272 Table 3.

273

274 **Adolescent (12-18 years)**

275 *Suggested scale:* Verbal Numerical Rating Scale (NRS)-11.

276 The NRS-11 is one of the most commonly used scales to measure pain intensity in both
277 clinical and research settings, despite only recently undergoing appropriate psychometric

278 evaluation in children and adolescents. The scale has been validated to measure acute,
279 procedural pain, as well as chronic pain in a wide range of settings including school children
280 receiving immunisations¹⁵², outpatient pain clinics¹¹³, emergency departments⁶. The NRS-11
281 is suggested to measure acute pain in children aged 12 to 18 years due to its simplicity,
282 validity, reliability, and brevity as a pain assessment tool.

283

284 *Description:* The child is asked “On a scale of 0 to 10, where 0 is no pain and 10 is the worst
285 possible pain, tell me what number best represents your pain?” The individual responds with
286 a number that reflects their pain. The NRS-11 has also been adapted and validated for use
287 to capture pain intensity for both acute and chronic conditions by SMS and online,^{3, 134}
288 additional details are reported in Table 3.

289

290 **Children and adolescents with cognitive impairment**

291 Children and adolescents with cognitive impairments (e.g. cerebral palsy) experience more
292 significant and frequent pain than children without cognitive impairment, and are less likely to
293 receive adequate pain management, indicating the need for specific and appropriate pain
294 assessment measures.^{12, 86, 126} Pain behaviours displayed by children with cognitive
295 impairment are not always comparable to those of children without cognitive impairment,
296 although pain expression has been found to be consistent, observable and reflective of the
297 presence and severity of pain.^{12, 110} Thus pain measurement tools should be adaptable to
298 reflect individual pain related behaviours, but ideally also contain standardised items that
299 enable its use in any setting.³⁶ Very few scales are available to assess pain in children with
300 cognitive impairment and as seen in Table 4, these have only been tested in post-operative,
301 residential care, or school settings. No scale has been tested to measure brief procedural,
302 chronic, or recurrent pain in children and adolescents with cognitive impairment.

303 *Suggested scale:* Revised-Face, Legs, Activity, Cry and Consolability (r-FLACC) Scale

304 The r-FLACC was adapted from the FLACC scale⁹¹ for use in children and adolescents with
305 cognitive impairment.⁸⁵ The r-FLACC is suggested for children and adolescents with
306 cognitive impairment, based on evidence demonstrating valid and reliable measurement of
307 post-operative pain in a hospital setting, the ability of the scale to be individualised, and
308 evidence of its clinical utility. This suggestion is made in the absence of any other more
309 comprehensively evaluated scale.

310 *Description:* The r-FLACC is essentially the same as the FLACC scale but also enables
311 behaviours that are unique to the individual to be described for each of the five behaviours
312 (face, movement of the body and legs, cry and consolability). Identifying pain behaviours that
313 are unique to the individual requires input from a family member or carer.

314

315 **Assessing the broader impact of pain using multidimensional pain scales**

316 While this paper has focused predominantly on the measurement of pain intensity it is
317 acknowledged that pain experience is complex and contains other dimensions including
318 affective (e.g. unpleasantness) and evaluative dimensions (e.g. appraisal of pain) as well as
319 the impact pain has on everyday life including an individual's physical, social, emotional
320 functioning and ability to fulfil their 'role'. The social communication model presented at the
321 start of this paper can still be used to conceptualise the communication of these other
322 dimensions of pain albeit using broader, multidimensional pain scales. Multidimensional pain
323 scales are particularly useful for assessing recurrent and chronic pain as they can capture
324 various dimensions of the pain experience (including pain duration, frequency, location,
325 nature of pain, aggravating and easing factors) and how pain impacts everyday life e.g.
326 interference with daily activity, or participation in school and sport. This fills a well-accepted
327 need to differentiate between low intensity, transient pain and more persistent pain that has
328 substantial impact on life.⁹⁹ Multidimensional scales differ with respect to the factors

329 assessed e.g. psychosocial factors, situational factors, nature of disability and period of time.
330 Some of the most commonly-used multidimensional pain scales for use in children and
331 adolescents with chronic or recurring pain are outlined in Table 5. No specific scale has
332 been suggested, as the choice will depend on the purpose of measurement and the health
333 condition being measured e.g. region- or condition-specific scales. Common to many of the
334 scales is identification of impact on school absenteeism, interference with sports
335 participation, interference with activities of daily living, medication use, and healthcare
336 utilisation. These being acknowledged important indicators of pain impact in paediatric
337 populations.⁹⁹

338

339 Another important dimension of pain assessment is fluctuation over time. In addition to the
340 scales outlined in Table 5, pain diaries are often used to capture information about pain (e.g.
341 pain intensity, frequency and location), and its effect on behaviour over time. The information
342 collected in a pain diary may provide a more accurate and reliable measure of pain if
343 completed on a regular basis, by minimising recall bias. Recent advances in information and
344 communication technology (e.g. Internet, smartphones) have permitted the development of
345 electronic methods such as e-diaries. Advantages of this electronic approach over traditional
346 paper-based techniques include: minimizing errors in data transfer and transcription, ability
347 to capture time-stamped data, ease of data sharing, increased compliance, and heightened
348 patient satisfaction⁷⁸. Recently, Stinson and colleagues have validated a number of web-
349 based and smart-phone-based multidimensional electronic pain assessment tools (e-Ouch,
350 Standardized Universal Pain Evaluation for Rheumatology providers (SUPER-KIDZ) and
351 Pain-QuILT™ (freely available).^{77, 78, 132} These tools can be used in a variety of clinical
352 settings to monitor MSK in children in real time.^{77, 78}

353

354 **GOOD PRACTICE POINTS**

355 Pain in children has been inadequately assessed, underestimated, and undertreated for
356 many years.¹⁴⁵ This situation can only be rectified through the improved communication of
357 pain between the individual in pain and the observer at every relevant clinical contact, until
358 this becomes a part of routine care.¹¹⁰ Central to the social communication model of pain
359 framework are the various intra- and interpersonal factors that may influence the expression,
360 assessment and management of pain. Consideration of these factors and the context in
361 which the communication occurs is vital for effective, accurate and reliable communication of
362 pain, early detection of pain and timely management (including reassurance and advice).
363 Most importantly the improved communication of pain has been found to improve patient
364 outcomes (e.g. reduction in mean pain scores, improved satisfaction) and reduce in health
365 care costs (e.g. reduction in length of stay).^{73, 119}

366

367 An individual's pain experience and expression is determined by a range of biopsychosocial
368 factors that are specific to their developmental stage. The clarity of the pain expression can
369 be optimised through the consistent use of valid and reliable pain scales that are age
370 appropriate and meet the cognitive and communication capabilities of the individual, where
371 available. For infants this means using observational scales of behaviour, for children
372 integrating both observational and self-report scales until later childhood and teenage years
373 where self-report can primarily be used. In all cases, patient self-report of pain should be
374 considered and interpreted alongside knowledge of the context, and supplemented with
375 information gained from observation of their behavior and input from parents / guardians and
376 carers, when appropriate. A child's ability to use a pain scale accurately and reliably
377 increases with their familiarity of the scale, highlighting the need to introduce and educate
378 children on the use of pain scales early in their life course. By providing children with the
379 vocabulary and skills necessary to express their pain the clarity of the pain expression can
380 be improved and potentially reduce errors in the interpretation by the observer.

381

382 Effective pain assessment and management by clinicians can be enhanced through the
383 consistent use of standardised pain scales within and across health care settings and the
384 accurate and timely documentation of assessment findings.⁵⁸ Advantages of this approach
385 include improved continuity of care for the individual and the ability to generate consistent
386 data for longitudinal comparison of pain overtime. Evidence from studies on global perceived
387 effect scales show that patient reported outcomes taken overtime provide a more accurate
388 understanding of changes in a person's health status compared to recall of improvement /
389 deterioration.⁶⁸ The minimally clinically important change has been determined for a number
390 of scales (reported in Table 3 where available) which can assist clinician's determine the
391 effectiveness of an intervention and provide insight into the meaningfulness of the change
392 for the individual. Areas in need of further development however is the assessment and
393 measurement of pain that is the result of other mechanisms e.g. neuropathic and central
394 pain, for which there are currently no scales that have been validated for use by children and
395 adolescents. Undoubtedly preferable to the timely assessment and management of pain are
396 practices that can help minimise or prevent the experience of pain. In many instances pain
397 can be anticipated (e.g. procedural, vaccinations, post-operative pain), and proactively
398 managed by clinicians and parents / carers using both pharmacological (e.g. topical
399 analgesics) and non-pharmacological interventions (e.g. distraction). Initiatives such as the
400 'It doesn't have to hurt' online video is one such example of providing clinicians, parents /
401 guardians with effective, evidence based information that can positively influence a child's
402 experience of painful situations.²⁵

403

404 **DISCUSSION**

405 To date little research has been done to evaluate the use of measures designed for
406 assessment of pain in infants, children and adolescents outside the hospital setting. This

407 constitutes an important evidence gap given that primary care, community outpatient and
408 rehabilitation clinics have frequent contact with infants, children and adolescents with pain.
409 While further work is needed, this paper provides clinicians with a pragmatic, evidence-
410 based overview of scales that can be used to measure pain intensity in infants, children, and
411 adolescents, with and without cognitive impairment, and assess the impact of pain using
412 multi-dimensional pain scales.

Table 1: Operational definitions

| Term | Operational definition |
|--|--|
| Reliability | The reproducibility of a measure over different occasions and is concerned with minimizing sources of random error so that measures are reproducible. In general, acceptable reliability coefficients for research and clinical purposes are ≥ 0.7 and ≥ 0.9 respectively ¹³³ . |
| Test-retest | The agreement between observations with the same individuals on at least two occasions ¹³³ . |
| Inter-rater reliability | The agreement between different raters / observers of an observational measure of pain ¹³³ . |
| Validity | Used to assess whether that the scale is measuring what it is intending to measure ¹³³ |
| Face validity | Whether the pain scale includes appropriate items that appear to measure what it is proposing to measure ¹³³ . |
| Content validity | The assessment of whether the items in the pain measure include the appropriate information and content ¹³³ . |
| Criterion | Includes concurrent validity and predictive validity. In concurrent validity, a new pain measure is correlated with a gold standard measure which is administered at the same time. In general, correlations between the new measure and the gold standard should be at least $r \geq 0.3-0.5$. The magnitude of the coefficients are hypothesis dependent but should not be too high as to make the new measure redundant. In predictive validity, the correlation of the measure to the criterion variable is determined later ¹³³ . |
| Construct | Determines the validity of abstract variables that cannot be directly observed, such as pain. These constructs are assessed by their relationships with other variables ¹³³ . |
| Convergent validity | Evaluates how well items on a pain scale correlate with other measures of the same construct or related variables. In general, correlations between the measure and another measure of the same construct should be $r \geq 0.3-0.5$; however, the magnitude of the coefficients are hypothesis dependent ¹³³ . |
| Discriminant validity | Evaluates how items on a pain scale correlate with other measures that are unrelated. In general, correlations between the measure and another unrelated measure should be $r < .3$; however, the magnitude of the coefficients are hypothesis dependent ¹³³ . |
| Responsiveness | Measures whether the measure is able to identify changes in pain over time where change is expected (e.g. after analgesia). (COSMIN taxonomy) |
| Interpretability | The meaningfulness of the scores obtained from a pain measure. |
| Feasibility | How easily a pain measure can be scored and interpreted. |
| Minimally clinically important change | The smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate, in the absence of troublesome side effects and excessive cost, a change in the patient's management. ⁶⁵ |

Table 2: Observational scales used to measure pain in infants and children 3 years or younger

| Pain scales | Description | Age range | Reliability | | Validity | | | | Responsiveness | Practical considerations | | | | Strengths | Limitations |
|---|---|--|-------------|-------------|------------|--------------|---------|-----------|----------------|--------------------------|------------------|----------|-----------------|--|--|
| | | | Intra-rater | Inter-rater | Convergent | Discriminant | Content | Criterion | | Feasibility | Interpretability | Training | User preference | | |
| Face, Arms, Legs, Activity Cry and Consolability Scale (FLACC) ^{5, 34, 46, 90, 91, 135} | 5 item scale measures facial expression, leg movements, activity, cry and consolability. Each item is scored 0-2, range 0-10 Originally validated for post-operative pain in children 2months to 7years. | I: 2mnths-7years S: 2months-16yrs | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | - | - | ✓ | - Validated for acute procedural pain e.g. immunisations and post-operative pain - Scored on a commonly understood 0-10 scale - Translated into Swedish - Recommended by PedIMMPACT ⁹⁰ - Adapted for children with cognitive impairment (Table 4) | - Observation time not specified originally. Subsequent studies have used 15 sec and 30 sec for acute procedural pain. - to date only tested in post-operative and procedural pain, additional studies needed to evaluate generalisability. - Ambiguity around amount and timing of some items e.g. 'jaw clench', consolability. |
| Child facial coding system (CFCS) ^{17, 31, 52} | Frequency and intensity of 13 facial actions; scored 0 (no action) to 2 (distinct action). E.g. squinting, brow lowering, nostril flare, mouth stretching | I: 2-5 years S: 3-7 years | - | ✓ | - | - | - | ✓ | - | - | - | - | - | - Validated for children with Cerebral Palsy, used in children with autism ⁹⁵ - Developed from the <i>Neonatal facial coding system</i> | - Facial actions scored second by second. |
| Children's Hospital Of Eastern Ontario Pain Scale (CHEOPS) ^{34, 35, 39} | Six item scale (cry, facial expression, verbalisation, touching, torso and leg movement) rated on a four point scale. Range 4-13. | I: 6months-6 years S: 6m – 12 years | - | - | ✓ | - | - | - | - | - | - | - | - | - Well evaluated for post-operative pain - Score based on observable behaviour only (i.e. does not include items such as consolability) | - Length and scoring system makes it impractical - Not validated for acute procedural pain but has been used for this in intervention studies ³⁵ |
| Modified behaviour pain scale (MBPS) ^{135, 136} | 3 item scale measures facial expression, cry and movements. Facial expression and | I: 4-6 months | ✓ | ✓ | ✓ | - | - | ✓ | ✓ | ✓ | - | - | ✓ | - Validated to assess acute procedural pain e.g. immunisations | - Evaluated for infants only - Little evaluation done, but used in numerous intervention studies |

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| | movement scored on a 0-3 scale and cry 0-4 scale, range 0-10 | | | | | | | | | | | | | | - Scored on a commonly understood 0-10 scale | |
| Neonatal Infant Pain Scale (NIPS) <small>39, 81, 135</small> | 6 item scale (facial expression, breathing patterns, cry, arm movement, arousal, leg movement). All items 0 (absent/relaxed) to 1 (change from normal) except cry; 0 to 2. | I: 0-2 months | | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | - Validated for acute procedural pain e.g. immunisations - Multidimensional scale taking into consideration factors such as arousal | - Evaluated for infants only, limited applicability - No reports on clinical utility / feasibility | |

✓Evidence available; – no supporting evidence
I: intended age range; S: studied age range.

Table 3: Self report scales used to measure pain intensity in children and adolescents

| Pain scale | Description | Age range | Reliability | | Validity | | | Responsiveness | Practical considerations | | | | | | | |
|---|---|--------------------------------|-------------|-------------|------------|--------------|---------|----------------|--------------------------|-------------|------------------|----------|-----------------|------------------------|--|---|
| | | | Intra-rater | Inter-rater | Convergent | Discriminant | Content | | Criterion | Feasibility | Interpretability | Training | User preference | Acceptable to patients | Strengths | Limitations |
| Pieces of hurt tool (Hester's Poker Chip Tool) ^{45, 48, 57, 125, 138} | The child is asked "Did it hurt?"; if the child responds yes they are given four chips -'pieces of hurt'. The child is told; "These are pieces of hurt- one chip is a little bit of hurt, and four chips are the most hurt you could ever have. Do you have one, two, three or four pieces of hurt?" The number of chips is recorded. | I: 4-7 years S: 3-18 years | ✓ | ✓ | ✓ | ✓ | - | - | ✓ | - | - | - | - | ✓ | - Tangible quantity of pain is easier for younger children to understand - Developmentally appropriate, yes/no followed by limited response options - Developed in English. Validated in Jordanian and Thai - Validated recurrent or persistent pain - Can use any items ¹³⁸ | - Little testing in younger children - Potential bias toward higher pain scores especially in younger children - Requires the ability to count and estimate quantities using numbers - Infection risk, storage, and availability of tokens |
| Faces pain scale - revised (FPS-R) ^{11, 24, 58, 92, 93, 105, 114-116, 129, 141-144} | 6 line drawn faces aligned horizontally from an expression of "no pain" (left) to "most pain possible" (right). The child points to point to the face that shows their pain. Standardised instructions are used. The original Faces Pain Scale had 7 faces scored on 0-6 scale. Revised to make compatible with other 0-10 scales. | I: 4-12 years S: 3-18 years | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - | - | ✓ | - Scored on a commonly understood 0-10 scale - Gender neutral drawings of faces - Developed in English. Translations: > 35 languages, validated in French, Thai and Catalan. - Minimally clinically important change: 2/10 (1 face), or 25% - Electronic version available ^{114, 115} | - Reduced accuracy with decreasing age - Response bias in those under 5 years of age - skewed pain intensity ratings towards 'no pain', may underestimate pain intensity |
| Verbal Numerical rating Scale-11 ^{6.} | The child is asked "On a scale of 0 to 10, where 0 is no pain and 10 is the worst possible pain, tell me what | I: 8-18 years | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | - | ✓ | - Scored on a commonly understood 0-10 scale | - Requires the ability to count, estimate quantities using numbers, recall pain |

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| 23, 24, 37, 92, 113-116, 152 | number best represents your pain?" The individual responds with a number that reflects their pain. | S: 6-18 years | | | | | | | | | | | | | | <ul style="list-style-type: none"> - Adaptable e.g. usual, strongest, lowest pain, at rest / activity - Developed in English. Translations: Spanish, French - suitable for 8-20 years, physical disabilities (e.g. cerebral palsy, neuromuscular disease), chronic pain - electronic version available^{114, 115} - Minimally clinically important change 1/10 | <ul style="list-style-type: none"> - Variability in the time period (e.g. past week, current pain) and anchors used (e.g. worst possible pain, strongest pain) - Further testing required in younger children (6-8 years). |
| Coloured analogue scale (CAS) 20, 21, 24, 88, 89, 113-116, 142-144 | Visual analogue scale with a mechanical device with a plastic slider over a 143 mm long tetragon varying from narrow (10 mm) and white labelled 'no pain', to wide (30 mm) and dark red at the end labelled 'most pain'. Range 0-10. | I: 5-17 years S: 3-18 years | ✓ | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | <ul style="list-style-type: none"> - Minimally clinically important change: 1/10, or 15% - May be easier to administer and score than VAS⁸⁹ - Developed in English. Validated in Spain and India - Electronic version available^{114, 115} | <ul style="list-style-type: none"> - Requires users to have the CAS device available - Infection risk | |
| OUCHER (NRS and photographic) 9, 10, 84, 141 | 0-10 numerical rating scale aligned vertically next to 6 photographs ranging from "no hurt at all" (at the bottom - 0) to the "biggest hurt you could ever have" (at the top - 10). (Prior to 2009 scoring was 0-100) Boucher manual | I: 3-7 years S: 3-18 years | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | | ✓ | - | - | ✓ | <ul style="list-style-type: none"> - Various versions (Caucasian, Hispanic, Asian, boy/girl) - Child can choose photographic or VAS - photographic scale (other face scales are line drawings) - Scored on a commonly understood 0-10 scale - Evaluated in specific populations e.g. sickle cell | <ul style="list-style-type: none"> - Little testing in younger children - Printed OUCHER scale required - infection risk - Photographs resemble acute pain only - The NRS left of the photographs may be confusing for young children (3-7 years)⁸⁴. | |
| Visual Analogue Scale (VAS) ^{6, 8, 24,} | 10cm vertical/horizontal line with anchors (e.g. 'No pain', 'Worst possible pain'). The child marks along the line to | I: 2-17 years S: 3-18 years | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - | ✓ | - | - | ✓ | <ul style="list-style-type: none"> - Evaluated in several populations e.g. sickle cell, juvenile chronic arthritis | <ul style="list-style-type: none"> - Variability in line length, demarcations, orientation (and anchors (e.g. worst pain, strongest pain) | |

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| 84, 115, 116, 120, 121, 159 | indicate the intensity of their pain. | | | | | | | | | | | | | | | | <ul style="list-style-type: none"> - Minimum clinically significant change 10 mm (95% CI 7 to 12) - Electronic version available ^{114, 115} - Recommended for use by PedIMMPACT⁹⁰ | <ul style="list-style-type: none"> - Photocopying the scale may alter the length of the line - Marking on the VAS scale needs to be measured and recorded (potential source of error) - less reliable in children <8 yrs - one of the least preferred scale |
| Wong-Baker Faces Pain Scale ^{26, 31, 45, 71, 84, 129, 141, 159} | 6 line drawn faces aligned horizontally from a smiling “no hurt” face (left) to crying “hurts worst” face (right), range 0-5 (or 0-10 if each face is 2 points). | I: 3-18 years S: 9 months – 18 years | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | | | <ul style="list-style-type: none"> - Developed in English. Translations ≥ 10 languages, but not all validated - Preferred face scale - Scored on a commonly understood 0-10 scale - suitable for 8-20 years, with physical disabilities, specific conditions e.g. sickle cell | <ul style="list-style-type: none"> - Younger children tend to use the extremes²⁷ - may provide higher pain intensity rating than other face scales^{26, 141} - unclear if it has interval properties |
| Word descriptor scales / Word Graphic Scale ^{45, 71, 137, 159} | 5-6 words to describe pain from ‘no pain’ to ‘worst pain’. A word is selected to best describe their pain Each word has a number for scoring. Range from 0 (no pain) to 5 (worst pain). | I: 8-17 years S: 3-18 years | ✓ | - | ✓ | ✓ | - | ✓ | - | | | - | - | - | ✓ | | <ul style="list-style-type: none"> - Developed in English. Validated for use in Jordanian - Incorporated into multidimensional scales e.g. Adolescent Pediatric Pain Tool. | <ul style="list-style-type: none"> - Requires ability to comprehend pain intensity terms - one of the least preferred scale^{45, 71} - May not perform as a continuous scale; pain ratings cluster around words which reduces sensitivity ¹³⁷ |

I: intended age range; S: studied age range. ✓ Evidence available; – no supporting evidence

Table 4: Scales used to measure pain in children and adolescents with a cognitive impairment

| Pain scale | Description | Age range | Reliability | | Validity | | | | Responsiveness | Practical considerations | | | | | Strengths | Limitations |
|--|--|-------------------------------------|-------------|-------------|------------|--------------|---------|-----------|----------------|--------------------------|------------------|----------|-----------------|---|--|-------------|
| | | | Intra-rater | Inter-rater | Convergent | Discriminant | Content | Criterion | | Feasibility | Interpretability | Training | User preference | Acceptable to carers | | |
| Revised Face, Arms, Legs, Activity Cry and Consolability Scale (rFLACC) 28, 36, 43, 85, 103-105, 149 | 5 item scale measures facial expression, leg movements, activity, cry and consolability. Each item is scored 0-2, total range 0-10. Needs input from parent/guardian to identify 'baseline' behaviours. Includes open-ended descriptor for individual pain behaviours | I: 4-19 years S: 3- 18 years | ✓ | ✓ | ✓ | ✓ | | ✓ | ✓ | ✓ | - | ✓ | ✓ | - simple to use, score and interpret - Scored on a commonly understood 0-10 scale - Individualised by parent/carer - Developed in English. Validated in Danish | - evaluated in post-operative settings only - underlying motor impairments e.g. spasticity may affect assessment - Observation time not established; 5 min used in previous testing. - Ambiguity around amount and timing of some items e.g. 'jaw clench', consolability. | |
| Individualised numerical rating scale (INRS) ^{36, 105, 123, 124} | Carers provide word descriptors to be used as anchors for their child's pain behaviours from 0 (no pain) to 10 (worst possible pain). | I: 6 – 18 years | - | ✓ | ✓ | - | - | - | ✓ | - | - | - | ✓ | - Uniquely created for each individual according using information from carer - 1 minute observation time | - Minimal psychometric evaluation, not assessed in procedures e.g. injections. - Requires parent-nurse collaboration | |
| Non-communicating children pain checklist –revised (NCCPC-R) ^{13-16, 36, 87} | 30 items (6 sub-scales: vocal, social, facial, activity, body and limb, physiological). Frequency of each behaviour; 0=not at all to 3=very. Range 0-90. Post-operative version (NCCPC-PV - 27-items, total range 0-81), does not include eat/sleeping items. | I: 3- 18 years | ✓ | - | - | - | - | ✓ | ✓ | - | ✓ | - | - | - Intended for use by parents but can be used by anyone involved in child's care. - Has been used in observational studies | - Psychometric properties not assessed in procedures e.g. injections. - 10 minute observation time before scoring - Validation study used 2 hour observation period. | |
| Pediatric Pain Profile (PPP) 28, 36, 43, 60-62, 104, 105 | 20 items rated on 4 point Likert scales (0=not at all to 3=a great deal). Used by an observer familiar with the | I: 1- 18 years | ✓ | ✓ | ✓ | - | - | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - Developed for use in residential (during normal morning routine in a home, residential care, residential | - Psychometric properties not assessed in procedures e.g. injections. | |

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| | child. Observer completes the scale to establish baseline on a 'good day' which is then used as a benchmark for on-going ratings | | | | | | | | | | | | | | | school) and hospital care (post-operative) settings. - Parents rated nurse assessment of PPP as accurate than r-FLACC | - Five-minute observation period - Clinical utility may be low due to time required to complete the scale, and training ³⁶ |
|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|--|

** All of these scales are observational scales which have been evaluated to assess post-operative pain. None of the above scales have been evaluated to assess procedural type pain.

I: intended age range; S: studied age range. ✓Evidence available; – no supporting evidence

Table 5: Multidimensional pain scales that measure the impact of pain in infants, children and adolescents

| Pain scale | Description | Age range | Reliability | | Validity | | | | Responsiveness | Practical considerations | | | | | Strengths | Limitations |
|---|--|--------------------------------------|-------------|-------------|------------|--------------|---------|-----------|----------------|--------------------------|------------------|----------|------|---------------|--|---|
| | | | Intra-rater | Inter-rater | Convergent | Discriminant | Content | Criterion | | Feasibility | Interpretability | Training | User | Acceptable to | | |
| Adolescent pediatric pain tool (APPT) ^{44, 64, 117, 118} | Pain intensity measured on 0-100mm VAS, body chart and 67-word descriptors to express sensory (37 words), evaluative (8), affective (11) and temporal (11) qualities 5 pain subscale scores: number of pain sites (from body chart), pain intensity score, number of temporal descriptors (%), total pain quality and temporal descriptors. | I: 8-18 years S: 8-18 years | - | - | - | - | - | - | ✓ | - | - | - | - | - | - Self-report - Standardised instructions on the scale - 3-6mins to complete - Used in a variety of pain conditions e.g. post-operative, sickle cell, traumatic injury, cancer and minor procedures e.g. allergy testing - Developed in English. Translation: Spanish | - Evaluated as single components (e.g. body chart and word graphic scale has been evaluated in school, medical and surgical pain setting), but not entire scale - evaluation required in complex, recurrent, chronic pain states - few descriptors represent neuropathic pain - Requires equipment and overlay to score - Children must read or understand English. Some children required assistance |
| Bath Adolescent Pain Questionnaire (BAPQ) ^{41, 42, 155} | 61 items in 7 domains: social functioning, physical functioning, physical functioning, depression, general anxiety, pain specific anxiety, family functioning and development. Each item rated on 5 point scale (never=0 to always=4) except the development subscale rated from 0 ("very behind") to 4 ("very ahead"). Range 0-244 | I: 11-18 years S: 10-18 years | ✓ | - | ✓ | ✓ | - | ✓ | - | - | ✓ | - | - | - | - Initially developed and tested in outpatient Rheumatology and multidisciplinary pain clinic. - Used to assess chronic pain from perspective of adolescent or parent - Validated in secondary care e.g. Rheumatology / pain management clinics. | - Questionnaire length - Complicated scoring with reverse scoring for some items - Total sum score not clinically useful |
| Childhood Health Assessment Questionnaire (CHAQ) ^{75, 94, 111, 122} | Includes: Disability and Discomfort, in the last week. Disability incl. 30 items, eight subscales: dressing, grooming, arising, eating, walking, reaching, grip, activities. Each item scored 0=no difficulty to 3=unable to do it (or 'not applicable' if beyond | I: 1-19 years | ✓ | ✓ | ✓ | ✓ | - | ✓ | ✓ | - | ✓ | - | - | - | - evaluated in Juvenile Idiopathic Arthritis (JIA), cerebral palsy, inflammatory myopathies. - core outcome measure for clinical trials in JIA - Self-report and parent proxy versions | - relatively insensitive to important short term changes in children with JIA - evidence of a floor effect |

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| | development level). Disability score is the unweighted average of the 8 subscale scores. Discomfort; 10cm VAS. | | | | | | | | | | | | | | | | - 10 mins to complete - Validated in 32 countries. | |
| Child Activity Limitations Interview (CALI / CALI-21) ^{100, 101} | 8 activities selected from list of 21 options found difficult or bothersome due to pain. Importance and difficulty over the last 4 weeks is rated on 5-point scale from 0=not important/ difficult to 4=extremely important. Ratings are summed; total score 0-32. <u>CALI-21</u> : participants report on limitations for all 21 activities. Ratings summed; total score 0-84 | I: 8 – 18 years | - | ✓ | ✓ | | - | ✓ | ✓ | - | - | - | - | ✓ | | | - Developed in healthy children and validated in chronic or recurrent pain e.g. headache, JIA, sickle cell. - Available as an interview and self-report questionnaire - Child and parent versions - Assesses both active (e.g. sports) and routine (e.g. going to school) domains - Evaluated in e-diary format | - Tested in specific populations. Requires further evaluation. |
| E-ouch electronic pain diary ^{83, 129-131} | Electronic diary with real-time data: pain intensity, unpleasantness and interference (with activity, mood, walking, stiffness, enjoyment of life, sleep, schoolwork, tiredness, relationships, and control over pain) using a sliding 0-100 VAS. Number of painful joints and pain words also selected. Pain ratings captured 3x/day (on waking, after school and before bed). | I: 9-18 years | - | - | ✓ | ✓ | - | - | ✓ | - | - | - | - | ✓ | | | - Developed and tested in JIA - Self-reported scale, in real time. - Scored by the program and missing data is summarised. - Completing all three daily pain ratings takes <9 mins - Low administrative burden due to electronic capture - Adolescents found 'easy to use' and 'learn', 'quick to complete' and were 'very satisfied'. | - Requires further evaluation - Analysis of real time data collection is complex potentially limiting its clinical implementation - E-ouch recorded on a personal handheld device as opposed to an app or online - Pre-specified reporting times used in testing |
| Functional disability Inventory (FDI) ^{30, 70, 157} | 15 items assessing everyday activities in the past 2 week e.g. walking up stairs. Each item scored 0= no trouble to 4= Impossible. Scores summed; total score 0-60 | I: 8 – 17 years | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | - | - | - | | | - Evaluated in a variety of conditions e.g. abdominal pain, acute minor illnesses, back pain - Recommended by PedIMPACT ⁹⁰ - Interview or self-report | - Largely evaluated in clinical populations |
| Pain experience Questionnaire (PEQ) ⁵⁶ | 15-item questionnaire, four subscales: pain severity, pain-related interference, social support and affective distress. Each item scored on 7 point Likert scale from 'not at all' to 'very much'. | I: 7 – 18 years | - | ✓ | ✓ | ✓ | ✓ | - | - | - | - | - | - | - | | | - Developed and validated in mixed population with chronic pain e.g. fibromyalgia, rheumatoid arthritis, headache - Self report and parent scale - Validated in German. Based on Multidimensional Pain Inventory | - Requires further evaluation |

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| Pain-QuILT 77, 78 Previously the Iconic Pain Assessment Tool Version 2 (IPAT2) | Web-based tool for tracking pain (quality, intensity, location) using time-stamped records. Pain quality involves choosing from a validated library of pain icons, e.g. a matchstick for 'burning pain'. Pain intensity; 0-10 NRS from 'no pain' to 'worst pain imaginable'. Pain location by dragging-and-dropping " pain icons onto a virtual body-map. | I: 12 – 18 years | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | <ul style="list-style-type: none"> - Ability to self-report complex sensations associated with chronic pain e.g. 'burning' - Real time data entry - Users able to record information faster than other electronic pain assessment tools (median completion 1.4 min) - Available at: www.painquilt.mcmaster.ca | <ul style="list-style-type: none"> - Requires further evaluation - Developed and tested in an adult population and utility tested in adolescent populations |
| Pediatric pain assessment tool (PPAT) 1, 2, 83 | 32 word descriptors, 10 cm VAS; present and worst pain, pain coping strategies, and influence of pain on daily activities. Modelled on McGill Pain questionnaire, Pediatric Pain Questionnaire. | I: 5 – 17 years | - | - | ✓ | ✓ | ✓ | - | ✓ | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | <ul style="list-style-type: none"> - Used JIA, cancer, surgery - child and parent versions - Children 7-16 years had no problems using scale - Developed in Dutch. Validated in Jordanian. Has been administered to Arab-American children. | <ul style="list-style-type: none"> - Younger children may require assistance - PPAT has been evaluated as single components, not the entire scale |
| Promis Pediatric Pain Interference Scale (PPIS) ^{38, 69, 146} | Pain interference bank contains 13 questions, (8 in the short form). All questions use 7 day recall scored on a 5 point Likert scale with anchors 0='never' to 4='almost always'. Raw score totals can be converted to a T-score using reference tables | I: 8 – 18 years | - | - | ✓ | | ✓ | ✓ | ✓ | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | <ul style="list-style-type: none"> - developed for wide range of conditions e.g. arthritis, rehabilitation, asthma. - developed using Item Response Theory, users can select appropriate items from a 'bank' of questions - Preliminary validation in chronic MSK pain receiving multidisciplinary treatment - Child (8-17 years) and parent proxy (children 5-17 years) versions. - Developed in English. Validated in German and Spanish | <ul style="list-style-type: none"> - Requires further evaluation - Most accurate way to score the scale is through the online assessment centre. - Scale can be scored manually however require reference tables to convert to a T-score. |
| Teen Nordic Musculoskeletal Screening Questionnaire (TNMQ-S) ⁸² | 27-item questionnaire, dichotomous responses. The presence of MSK symptoms, their impact on school attendance, and on sports and leisure activity participation over the past 6 months. | I: 6 – 18 years | ✓ | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | <ul style="list-style-type: none"> - Musculoskeletal symptom screening tool - Developed and tested in French. | <ul style="list-style-type: none"> - Requires further evaluation |
| Varni-Thompson | Assesses chronic pain intensity, location, sensory, evaluative and | I: 4 – 18 | ✓ | ✓ | ✓ | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | - | <ul style="list-style-type: none"> - Developed and tested JIA | <ul style="list-style-type: none"> - Administered by interview |

| | | | | | | | | | | | | | | | | |
|--|--|------------------------------|---|---|---|---|---|---|---|---|---|---|---|---|--|--|
| Pediatric Pain Questionnaire (PPQ) 7, 31, 49, 74, 83, 107, 147 | affective qualities. Pain intensity measured on 10 cm VAS, body chart (location and number of pain sites), 46 word descriptors to assess sensory, evaluative and affective qualities of pain. Modelled on the McGill Pain questionnaire. | years S: 6 – 16 years | | | | | | | | | | | | | <ul style="list-style-type: none"> - Assesses chronic pain from perspective of adolescent, parent or clinician - in various populations (juvenile rheumatoid arthritis, sickle-cell, fibromyalgia) - Adapted for children with cerebral palsy - Developed in English. Validated: Norwegian. Translations: Danish, Portuguese, Swedish, French. | <ul style="list-style-type: none"> - 10-15mins to complete. <5 mins to score. - younger children likely require assistance |
| Young spine questionnaire ⁷⁹ | For each region of the spine (cervical, thoracic, lumbar); pain presence, frequency and intensity (Revised Faces Pain Scale). Also includes function at school, recreation, treatment and family history of pain. No summary score. | I: 9-11 years | - | - | ✓ | - | - | - | - | - | - | - | - | - | <ul style="list-style-type: none"> - Iterative development with children aged 9-11 years. - Self report - Developed in Danish. Translated to English. | <ul style="list-style-type: none"> - Requires further evaluation - Validated in narrow age range - Developed and tested in a cross-sectional study not tested for longitudinal use. |

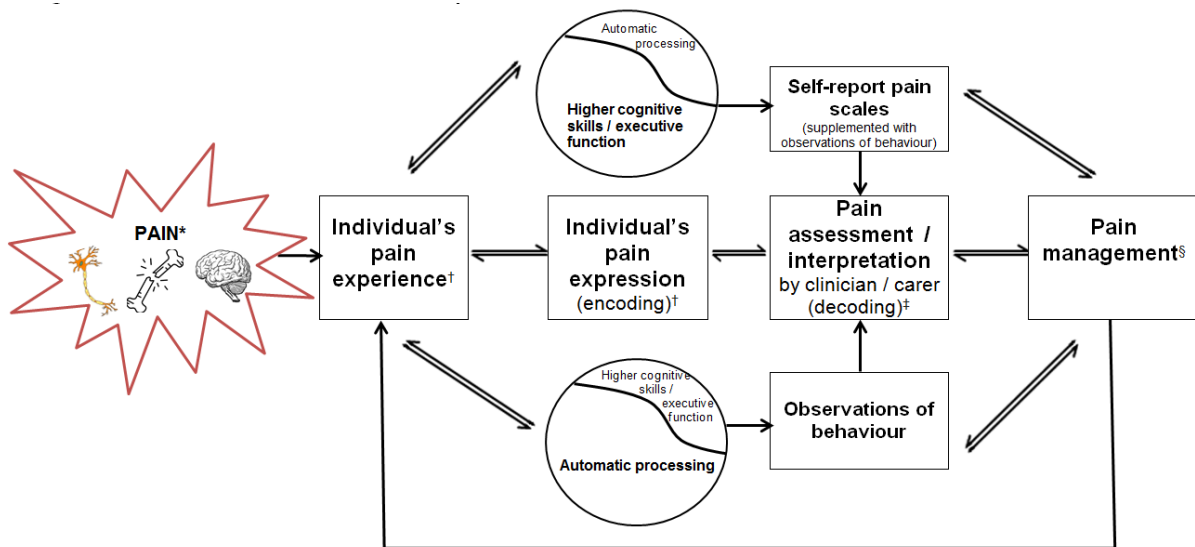
I: intended age range; S: studied age range. ✓ Evidence available; – no supporting evidence

Table 5: Summary of the scales that have been suggested to measure pain intensity for each age group

| Age range | Recommended scale | Type of scale | Psychometric properties | Strengths | Limitations |
|-------------------------------------|---|---------------|---|---|---|
| Infants (3 years or younger) | Face, Arms, Legs, Activity Cry and Consolability Scale (FLACC) ^{5, 34, 46, 90, 91, 135} | Observational | Reliability: Yes Validity: Yes Responsiveness: Yes User preference: Yes Patient preference: Yes | - Validated for acute procedural pain e.g. immunisations and post-operative pain - Scored on a commonly understood 0-10 scale - Recommended for use by PedIMMPACT ⁹⁰ | - Additional studies needed to evaluate generalisability. |
| Preschool child (3-5 years) | Pieces of hurt tool (Hester's Poker Chip Tool) ^{45, 48, 57, 125, 138} | Self-report | Reliability: Yes Validity: Yes Responsiveness: Yes Assessor preference: - Patient preference: Yes | - Developmentally appropriate scale i.e. yes/no followed by limited response options - Validated recurrent or persistent pain - Validated in Jordanian and Thai - Can use any items ¹³⁸ - Recommended for use by PedIMMPACT ⁹⁰ | - Little testing in younger children - Potential bias toward higher pain scores especially in younger children - Requires the ability to count and estimate quantities using numbers - Infection risk, storage, and availability of tokens |
| Child (6-11 years) | Faces pain scale - revised (FPS-R) ^{11, 24, 58, 92, 93, 105, 114-116, 129, 141-144} | Self-report | Reliability: Yes Validity: Yes Responsiveness: Yes User preference: - Patient preference: Yes | - Scored on a commonly understood 0-10 scale - Gender neutral drawings of faces - Translations: > 35 languages, validated in French, Thai and Catalan. - Minimally clinically important change: 2/10 (1 face), or 25% - Electronic version available; Sydney Animated Facial Expressions Scale (SAFE), <i>Painometer App</i> ^{114, 115} - Recommended for use by PedIMMPACT ⁹⁰ | - Reduced accuracy with decreasing age - Response bias in those under 5 years of age - skewed pain intensity ratings towards 'no pain', may underestimate pain intensity |
| Adolescent (12-18 years) | Verbal Numerical rating Scale-11 ^{6, 23, 24, 37, 92, 113-116, 152} | Self-report | Reliability: Yes Validity: Yes Responsiveness: Yes User preference: - Patient preference: Yes | - Scored on a commonly understood 0-10 scale - Adaptable e.g. usual, strongest, lowest pain, at rest / activity - Translations: Spanish, French - suitable for 8-20 yrs, physical disabilities (e.g. cerebral palsy, neuromuscular disease), chronic pain - electronic version available ^{114, 115} - Minimally clinically important change 1/10 | - Requires the ability to count, estimate quantities using numbers, recall pain - Variability in the time period (e.g. past week, current pain) and anchors used (e.g. worst possible pain, strongest pain) - Further testing required in younger children (6-8 years). |

| | | | | | |
|--|--|---------------|---|---|--|
| Cognitive Impairment (4-19 years) | Revised Face, Arms, Legs, Activity Cry and Consolability Scale (rFLACC) 28, 36, 43, 85, 103-105, 149 | Observational | Reliability: Yes Validity: Yes Responsiveness: Yes User preference: Yes Carer preference: Yes | - simple to use, score and interpret - Scored on a commonly understood 0-10 scale - Individualised by parent/carer - Validated in Danish | - evaluated in post-operative settings only - underlying motor impairments e.g. spasticity may affect assessment - Observation time not established; 5 min used in previous testing. - Ambiguity of some items e.g. 'jaw clench' and consolability (amount and timing). |
|--|--|---------------|---|---|--|

Figure 1: The social communication model of pain



* Pain: a distressing experience associated with actual or potential tissue damage with sensory, emotional, cognitive and social components (Williams, 2016).

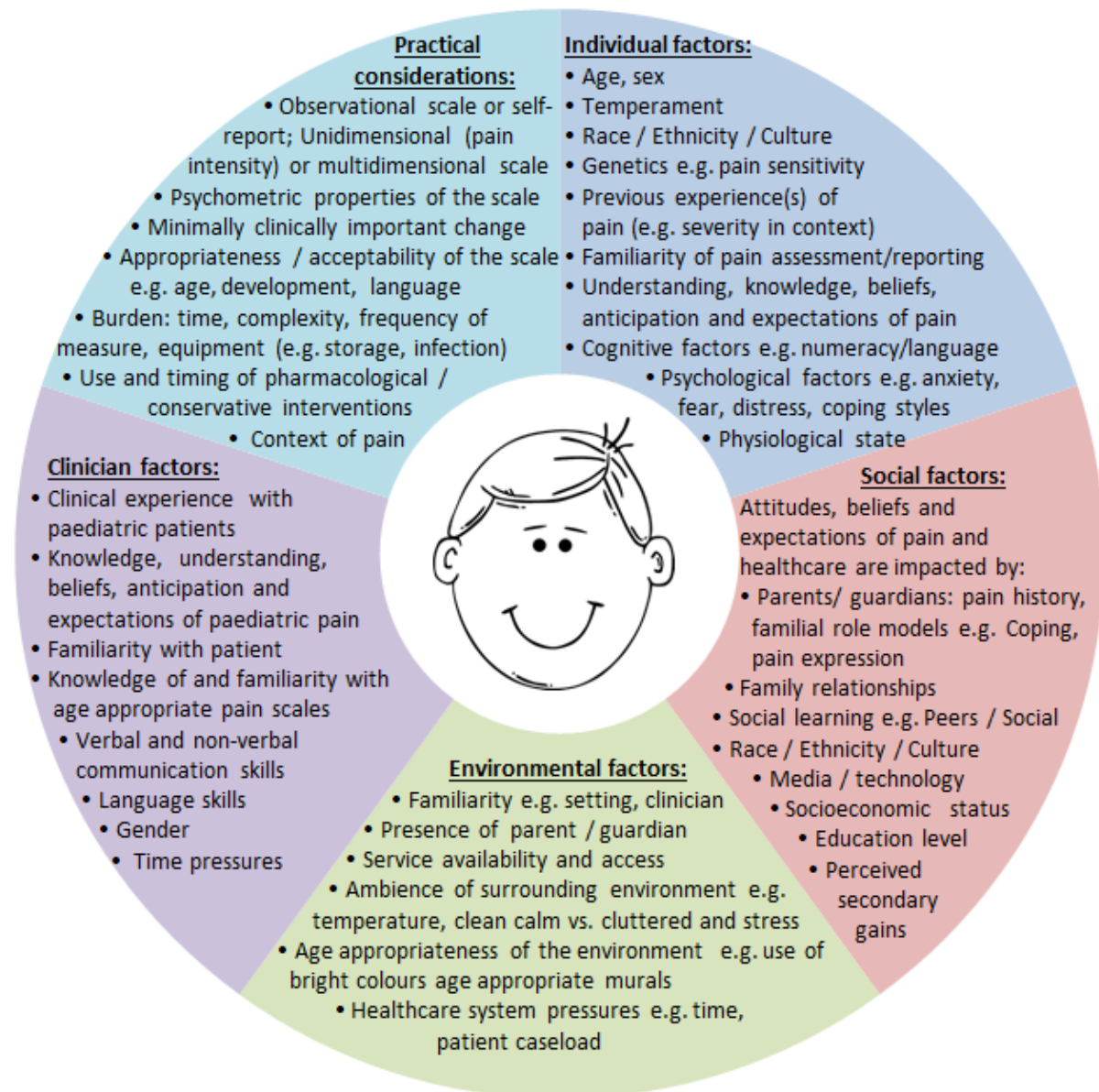
† Pain experience and expression can be influenced by a number of individual, social and environmental factors, examples of each of these factors are outlined in Figure 2. The expression of pain may verbal, self-reported or observation of behaviour and this may be self-initiated by the person in pain or elicited by an observer's question.

‡ Pain assessment can be influenced by a number of clinician factors and practical considerations, examples of these are outlined in Figure 2.

§ Pain management can include pharmacological, conservative (e.g. distraction, relaxation, exercise, education) and environmental interventions. Pain management can be influenced by a clinician / parent or carers appraisal of the situation, their own knowledge / understanding and beliefs and contextual factors e.g. setting.

Adapted from T Hadjistavropoulos and KD Craig, 2002, Fig 1, p 555 and KD Craig, 2009, Figure 1, p24.^{33, 53}

Figure 2: Factors (biological, psychological and social factors) related to the individual in pain, clinician and context that influence how pain is experienced, expressed and assessed. ^{58, 78, 112, 150, 153, 160}



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