

Pediatric Core Frequently Asked Questions:

What questionnaires should studies use if their samples cut across both early childhood and the adolescent population (e.g., 8-16 years)?

Because study context is an important consideration, we encourage investigators with samples across early childhood and adolescence to please contact the HEAL CDE program managers for assistance (heal_cde@hsc.utah.edu).

How should I report age in younger children/infants, where the number of months is developmentally significant?

For the pediatric demographics case report form, we ask studies to report age in months for children younger than 3 years old (i.e. 36 months). Otherwise, for children 3 years and older, record age in years.

I would like to ask more detailed information about race/ethnicity on the demographics form.

Researchers may expand the categories of the race/ethnicity question, as long as they follow guidance from the Office of Management and Budget for detailed responses and map their data back to the race/ethnicity CDE on the HEAL CDE Demographics form. Please see <https://spd15revision.gov/content/spd15revision/en/2024-spd15question-format.html> for the specified allowable responses for the expanded race/ethnicity categories.

If a CDE asks about pain duration, how do I record a participant's pain duration for answers less than one month?

As of late 2024, this is a multiple-choice question, therefore choose the appropriate answer (0 months, 1 week, 2 weeks, 3 weeks, 4 weeks or more). If selecting the 4 weeks or more response, please also input the numerical value of months for pain duration.

I would like to calculate Morphine Milligram Equivalent (MME) values in MME/KG/Day instead of MME/day for our study can capture the child's weight in the measurement.

It is fine to include weight in the MME calculation. Please review the MME CDE in order to submit this information to the data ecosystem. Please note that the online MME calculator tool (<https://research-mme.wakehealth.edu/login>) does not capture weight as a variable when calculating MME, so studies using this approach will need to calculate this data through their own collection tools.

How should I measure Pain Interference in an acute hospital setting?

For studies conducted in pediatric populations focused on assessment of acute pain and recovery within a hospital setting, pain interference can be measured using the "Youth Acute Pain Functional Ability Questionnaire". This assessment can be completed via self-report or proxy report and can be used from ages 8 to 18.

Which domains should be measured by child self-report, and which domains should be measured by parent/caregiver report?

The age and developmental status of the child should guide decisions on survey administration. In general, most self-report measurement tools are validated for children at a minimum age of 6 (for pain intensity) or age of 8 (most other domains). Children under age 6 should not be asked to complete any self-report measures. Children who are 8 and above, who have the

ability to complete self-reports, are recommended to do so. Substance use and pain catastrophizing should only be measured by self-report and at a minimum age of 11 years. Special considerations are needed for children who have cognitive or developmental limitations, or when contextual factors limit the ability to self-report (e.g., intubation). We encourage investigators with questions about special considerations to contact the HEAL CDE program managers for assistance (heal_cde@hsc.utah.edu).

Parent proxy measures are available for many domains for children who are too young or not developmentally able to complete a self-report. In these cases, studies should use parent proxy reporting when a proxy reporting tool is available (see table below for details).

Child/Adolescent Domain	Ages	Respondent
Pain Severity	Access in ages: 0-17 years	Parent Proxy: 0-6 years Self- Report 6 to 17 years
Pain Interference	Do not access: 0 to 7 years Access in ages: 8 to 17 years	Parent Proxy: 8 to 17 years Self- Report 8 to 17 years
Physical Functioning/ QOL	Do not access: 0 to 1 years Access in ages: 1 to 17 years	Parent Proxy: 1 to 7 years Self-Report: 5 to 17 years
Sleep	Do not access: 0 to 1 years Access in ages: 1 to 17 years	Parent Proxy: 1 to 7 years Self-Report: 8 to 17 years
Depression	Do not access: 0 to 1 years Access in ages: 1 to 17 years	Parent Proxy: 1 to 7 years Self-Report: 8 to 17 years
Anxiety	Do not access: 0 to 1 years Access in ages: 1 to 17 years	Parent Proxy: 1 to 7 years Self-Report: 8 to 17 years
Pain Catastrophizing	Do not access: 0 to 11 years Access in ages: 12 to 17 years	Self-Report: 12 to 17 years
Substance Use	Do not access: 0 to 11 years Access in ages: 12 to 17 years	Self-Report: 12 to 17 years
Morphine Milligram Equivalents	Access in ages: 0-17 years	Parent or Study Staff: 0 to 17 years
Demographics	Access in ages: 0-17 years	Parent Proxy: 0 to 17 years

Lastly, there are parent domains including Pain Catastrophizing, Anxiety, Depression, and Quality of Life, that are intended to assess the parent, guardian or caregiver regarding their own psychological health and well-being, recognizing the importance of parental health in childhood pain. These measures are not proxy reporting tools. These domains are in addition to any proxy reporting that the parent completes on the child domains (see table below for details).

Parent/Guardian/Caretaker Domain	Respondent
Pain Catastrophizing	Parent/guardian/caretaker self-report across all ages
Depression	
Anxiety	
Quality of Life	

For parent proxy reporting, what should studies do if there are both child self-report and parent proxy questionnaires available for the age ranges specified?

Self-report should always be prioritized when validated questionnaires are available for the age range. If the child is unable to respond for developmental or contextual reasons, then the parent proxy questionnaire could be considered for use in the study. The exception to this is that for some ages, some domains should not be measured (see question above). In these instances, parent proxy reporting nor child self-report are needed.

For parent proxy reporting and parent self-report (for domains where this is required), what should studies do for children that do not have a parent?

In general, the consenting adult (guardian or caregiver) should complete these measurements.

Some of the pediatric core CDEs were updated in 2025, so what should HEAL studies do that were funded before 2025?

Studies funded prior to Fiscal Year (FY) 2025 can continue to use the core CDEs that were required when they first began collecting data. Studies that are funded FY25 onwards should use the updated core CDEs (see requirements/tables listed above). If requirements change, the HEAL CDE team will communicate with researchers.

For the early childhood population, what questionnaire do studies use if there are multiple questionnaires under one domain?

Studies have the discretion to select the early childhood and/or adolescent core questionnaires to ensure flexibility across span of study. Therefore, they may use one to ensure consistency and/or several to ensure validity of the questionnaire across the age ranges.

What are the recall periods of each questionnaire?

Recall Period for Questionnaires in the HEAL CDE Pediatric Core	
Questionnaire	Recall Period
BPI Pain Severity	Past 24 hours or past 7 days
BPI Pain Interference	Past 24 hours or past 7 days
Peds-QL Inventory -23	Ages 2-4: Past one month Ages 5-7 (Parent-Proxy): Past one month

	Ages 5-7 (Self-Report): Past few weeks Ages 8-12: Past 7 days Ages 13-17: Past 7 days
AWS + Sleep Duration Items	N/A
PCS-C, PCS-P	N/A
PHQ-2, PHQ-8, PHQ-9	Past 2 weeks
GAD-2, GAD-7	Past 2 weeks
PGIC, PGIS	N/A
Demographics	N/A
Factors of MME and total MME	N/A
NIDA Modified-ASSIST Tool (Ages 11-17)	Past 2 weeks
NRS-11	Current Pain
FLACC	N/A
CALI-9	Past 24 hours or past 4 weeks
Youth Acute Pain Functional Ability Questionnaire (Only for acute pain, in hospital settings)	Past day
PROMIS Early Childhood Global Health 8a	N/A
PROMIS Pediatric Sleep Disturbance 8a	Past 7 days
PROMIS Early Childhood Sleep Problems 4a/ 8a	Past 7 days
PROMIS Pediatric Depressive Symptoms 6a/ 8a	Past 7 days
PROMIS Early Childhood Depressive Symptoms 4a	Past 7 days
PROMIS Pediatric Anxiety 8a	Past 7 days
PROMIS Parent Proxy Pediatric Anxiety 8a	Past 7 days
PROMIS Pediatric Anxiety Early Childhood	Past 7 days

For any other questions or support, please email the HEAL CDE team at HEAL_CDE@hsc.utah.edu.

Early Childhood (~ages 0-11 years)

Pain Severity		Pain Interference		Physical Functioning and Quality of Life		Sleep		Depression		Anxiety		Global Satisfaction with treatment		MME		Demographics	
Age/ Respondent	Measure	Age/ Respondent	Measure	Age/ Respondent	Measure	Age/ Respondent	Measure	Age/ Respondent	Measure	Age/ Respondent	Measure	Age/ Respondent	Measure	Age/ Respondent	Measure	Age/ Respondent	Measure
0 to 6 years Parent Proxy	FLACC (Copyrighted)	0 to 7 years	N/A (do not measure for these ages)	1 to 5 years Parent Proxy	PROMIS Early Childhood Global Health 8a	1 to 7 years Parent Proxy	PROMIS Early Childhood Pediatric Sleep Problems 4a or 8a* + Sleep Duration	1 to 5 years Parent Proxy	PROMIS Early Childhood Depressive Symptoms 4a	1 to 5 years Parent Proxy	PROMIS Early Childhood Anxiety 8a	0 to 17 years Parent Proxy & Self-Report	PGIC or PGIS **	0 to 17 years Parent or Study staff	Individual factors of MME + Total MME	0 to 17 years Parent Proxy	Child Demographics
6 to 17 years Self-Report	NRS - 11	8 to 17 years Parent Proxy & Self-Report	CALI - 9	2 to 17 years Parent Proxy & Self-Report	PedsQL - 23	8 to 17 years Self-Report & Parent Proxy	PROMIS Pediatric Sleep Disturbance 8a + Sleep Duration	6 to 7 years Parent Proxy	PROMIS Pediatric Depressive Symptoms 6a	6 to 7 years Parent Proxy	PROMIS Parent Proxy Anxiety 8a						
								8 to 17 years Self-Report	PROMIS Pediatric Depressive Symptoms 8a	8 to 17 years Self-Report	PROMIS Pediatric Anxiety 8a						

Adolescents (~ages 12-17 years)

Pain Severity	Pain Interference	Physical Functioning and Quality of Life	Sleep	Pain Catastrophizing	Depression	Anxiety	Global Satisfaction with treatment	Substance Use Screener	MME	Demographics
BPI Pain Severity	BPI Pain Interference (Copyrighted)	PedsQL-23 (Copyrighted)	ASWS + Sleep Duration	PCS for Children	PHQ-2 or PHQ-8* or PHQ-9*	GAD-2 or GAD-7*	PGIC or PGIS	NIDA Modified Assist Tool	Individual Factors of MME + Total MME	Child Demographics

Parent/Guardian/Caregiver (Ages 0 to 17 years)

Pain Catastrophizing	Depression	Anxiety	Quality of Life
PCS for Parents	PHQ-2 or PHQ-8* or PHQ-9*	GAD-2 or GAD-7*	WHOQOL - 2