

Data Collection Worksheet

Please Note: The Data Collection Worksheet (DCW) is a tool to aid integration of a PhenX protocol into a study. The PhenX DCW is not designed to be a data collection instrument. Investigators will need to decide the best way to collect data for the PhenX protocol in their study. Variables captured in the DCW, along with variable names and unique PhenX variable identifiers, are included in the PhenX Data Dictionary (DD) files.

REVISED FLACC Scale

Categories	0	1	2
Face	No particular expression or smile.	Occasional grimace or frown; withdrawn or disinterested; appears sad or worried.	Consistent grimace or frown; frequent/constant quivering chin, clenched jaw; distressed-looking face; expression of fright or panic.
Legs	Normal position or relaxed; usual tone and motion to limbs.	Uneasy, restless, tense; occasional tremors.	Kicking, or legs drawn up; marked increase in spasticity, constant tremors or jerking.
Activity	Lying quietly, normal position, moves easily; regular, rhythmic respirations.	Squirming, shifting back and forth, tense or guarded movements; mildly agitated (e.g., head back and forth, aggression); shallow, splinting respirations, intermittent sighs	Arched, rigid or jerking; severe agitation; head banging; shivering (not rigors); breath holding, gasping, or sharp intake of breaths, severe splinting.
Cry	No cry/verbalization	Moans or whimpers; occasional complaint;	Crying steadily, screams or sobs, frequent complaints; repeated outbursts,

		occasional verbal outburst or grunt	constant grunting.
Consolability	Content and relaxed	Reassured by occasional touching, hugging, or being talked to. Distractible	Difficult to console or comfort; pushing away caregiver, resisting care or comfort measures.

Each of the five categories (F) Face; (L) Legs; (A) Activity; (C) Cry; (C) Consolability is scored from 0-2, which results in a total score between zero and ten. Revised FLACC scores coded as: mild (scores 0-3), moderate (4-6), and severe (7-10).

Protocol source: <https://www.phenxtoolkit.org/protocols/view/860403>