



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.

Summary of the PedsQL™

The PedsQL™ Sickle Cell Disease Module includes 43 items from 9 subscales: Pain and Hurt (9 items); Pain Impact (10 items); Pain Management and Control (2 items); Worry (5 items); Worry II (2 items); Emotions (2 items); Treatment (7 items); Communication I (3 items); and Communication II (3 items). For all ages, each item asks how much of a problem there has been in the past month. There are self- or parent-reported forms for ages 8 to 18, and responses are scored on a 5-point Likert-style scale (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem; 4 = almost always a problem). Forms for children ages 5 to 7 are interviewer administered, and responses include a 3-point Likert-style scale (0 = not at all a problem; 2 = sometimes a problem; 4 = a lot of a problem). Items are reversed-scored and converted to a 100-point scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0) with higher scores indicating better quality of life. Scores for individual subscales are the sum of items divided by the total number of items answered. The total score for the PedsQL™ Sickle Cell Disease Module is the sum of the items divided by the number of items answered.

The PedsQL™ Sickle Cell Disease Module is a proprietary instrument and administration requires permission and a license from the MAPI Research Trust.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/820202>