PhenX Toolkit

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.

Pediatric Quality of Life Enjoyment and Satisfaction Questionnaire (PQ-LES-Q)

INSTRUCTIONS: This survey asks for your views about your general health, well-being, and feelings about your life. Please answer EVERY question by circling the number for your response. If you are not sure about how to answer a question, please give the best answer you can. Remember, there are no right or wrong answers.

Over the past week, how have things been with ...	Very Poor	Poor	Fair	Good	Very Good
1) … your health?	1	2	3	4	5
2) … your mood or feelings?	1	2	3	4	5
3) … school or learning?	1	2	3	4	5
4) … helping out at home?	1	2	3	4	5
5) … getting along with friends?	1	2	3	4	5
6) … getting along with your family?	1	2	3	4	5
7) … play or free time?	1	2	3	4	5

8) … getting things done?	1	2	3	4	5
9) … your love or affection?	1	2	3	4	5
10) … getting or buying things?	1	2	3	4	5
11) … the place where you live?	1	2	3	4	5
12) … paying attention?	1	2	3	4	5
13) … your energy level?	1	2	3	4	5
14) … feelings about yourself?	1	2	3	4	5
15) … Overall, how has your life been?	1	2	3	4	5

Scoring:

The Pediatric Quality of Life Enjoyment and Satisfaction Questionnaire (PQ-LES-Q) has 15 items. The first 14 are used to form a Total Score (see below). The fifteenth item is used as a "stand alone" measure.

The first 14 items are summed to form a total score. It can be reported as a Raw Total Score (range 14-84) or as a Percentage Maximum Possible Total Score. The %MAX Total Score is most frequently used.

%MAX= raw total score minus minimum score/maximum score minus minimum score

If items are left blank, the minimum and maximum score must be modified to reflect the number of items scored.

The 1/3 rule is usually used for excluding subjects who have no score for 1/3 or more of the items. Some investigators use different rules for excluding subjects.

Protocol source: https://www.phenxtoolkit.org/protocols/view/180303