



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.

The EQ-5D-Y is the ED-5D youth version of the self-reported questionnaire. The questionnaire includes a descriptive system of youth health-related quality-of-life states consisting of five dimensions. The descriptive system comprises five dimensions:

- Mobility
- Looking after myself
- Doing usual activities
- Having pain or discomfort
- Feeling worried, sad, or unhappy

Each dimension has three levels:

- No (problems)
- Some
- A lot of

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Protocol source: <https://www.phenxtoolkit.org/protocols/view/560402>