



## 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 Pediatric Haemophilia Activities List (PedHAL)

The Pediatric Haemophilia Activities List (PedHAL) is a self- or proxy-administered questionnaire that includes 53 multiple-choice items across seven domains: sitting/kneeling/standing (10 items), functions of the legs (11 items), functions of the arms (6 items), use of transportation (3 items), self-care (9 items), household tasks (3 items), leisure activities and sports (11 items). Each item is rated on a 6-point scale from 1 (impossible) to 6 (never) describing difficulty due to hemophilia in the past month. Scores from individual items can be summed to give a total score or component scores for upper extremity, basic lower extremity, and complex lower extremity activities. Higher scores indicate greater functional status. The questionnaire also includes 4 multiple-choice items assessing the use of adaptive and assistive devices. There is a parent report version for children ages 4-9 and a self-report version for children and adolescents ages 8-18.

The Pediatric Haemophilia Activities List (PedHAL) may be obtained via the World Federation of Hemophilia (WFH) Network website: <https://elearning.wfh.org/resource/pediatric-haemophilia-activities-list-pedhal-children-and-teenager-version>. The scoring manual is available with the Haemophilia Activities List (HAL) questionnaire.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/910801>