

Data Collection Worksheet

Please Note: The Data Collection Worksheet (DCW) is a tool to aid investigators to integrate the collection of PhenX measures in your study. The PhenX measures that you selected and added to your Cart are presented in the DCW in alphabetical order. The DCW includes worksheets for data collection. Variables derived from the collected data are shown in the Data Dictionary (DD) with variable names and unique PhenX variable identifiers. The collection of DCWs produced by the Toolkit is not designed as a data collection instrument. Each investigator will decide how to integrate PhenX measures into data collection for their study.

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: [link[elearning.wfh.org/resource/pediatric-haemophilia-activities-list-pedhal-children-and-teenager-version/ | 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>