

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 Hemophilia Joint Health Score (HJHS) 2.1

The Hemophilia Joint Health Score (HJHS) 2.1 is a physiotherapist-administered assessment that takes approximately 45-60 minutes to complete. The HJHS measures the impact of recurrent bleeding on the elbows, knees, and ankles across 11 symptoms: swelling, duration of swelling, muscle atrophy, axial alignment, crepitus on motion, flexion loss, instability, joint pain, strength, and gait. Each of the 11 symptoms is rated on a Likert-style scale ranging from 0-1 to 0-4, with higher numbers indicating greater severity of symptoms. Scores from the individual items are added together to give a joint score, gait score, and a total score, with higher scores indicating greater joint damage.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/911701>