



## 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 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>