

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 Haem-A-QoL

The Haem-A-QoL[©] is a 46-item self-administered questionnaire with 10 domains that measure physical health (5 items), feelings (4 items), view of self (5 items), sport and leisure (5 items), work and school (4 items), dealing with hemophilia (3 items), treatment (8 items), future (5 items), family planning (4 items), and relationship and sexuality (3 items).

Subscribe to PROQOLID to access full information: https://eprovide.mapi-trust.org/instruments/haemophilia-quality-of-life-questionnaire-for-adults#member_access_content

Protocol source: <https://www.phenxtoolkit.org/protocols/view/910701>