

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 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