



## 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.

### Hemoglobin Characterization

#### Blood Draw

Blood should be drawn into an appropriate EDTA tube.

#### Laboratory Assay for Hemoglobin Characterization

The Sickle Cell Disease Scientific and Research Panel (SRSP) notes that there are numerous different assays and instruments (e.g., hemoglobin electrophoresis, isoelectric focusing, high performance liquid chromatography, capillary zone electrophoresis, DNA sequencing analysis) that are appropriate to characterize hemoglobin variants. Once an assay is chosen for a particular study, the SRSP recommends that the same protocol be used over the course of the study. To aid comparability, the SRSP recommends that the investigator record the make and manufacturer of equipment used and the repeatability and coefficients of variation for the assay.

The SRSP notes that investigators should record the assay results for the following hemoglobins (the exact list of hemoglobins that can be distinguished will depend on the assay being used). The hemoglobins are listed in order of the amount present with the most prevalent coming first.

- A
- F
- S
- C
- A2
- E
- D
- G
- O

Protocol source: <https://www.phenxtoolkit.org/protocols/view/830302>