

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.

PAINFUL EVENTS - Number of visits should include visits to BOTH your hospital AND outside hospitals.

1. In the last 6 months, how many times did you visit an emergency room because of a sickle cell painful event?

Number of times (_)

DATE OF VISIT NAME OF HOSPITAL, CITY, STATE

2. In the last 12 mo of a sickle cell pain	nths, how many times were you admitted to a hospital because ful event?
Number of times ()
DATE OF HOSPITALIZATION	NAME OF HOSPITAL, CITY, STATE

3. In the last 6 months, have you had a painful episode severe enough to keep you from doing the usual daily activities, but without being seen by a doctor?

[] No

[] Yes

- a. How many episodes
- [] <4
- []>=4
- b. How many days were missed?
- [] <= a week
- [] > a week

Protocol source: https://www.phenxtoolkit.org/protocols/view/830101