



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.

Modified version of the Sickle Cell Disease Pain Burden Interview-Youth (SCPBI-Y)

I want you to think about your sickle cell pain experienced 7 days before or during your last menstrual period:

1. How many days have you had any sickle cell pain during this menstrual period?
 1 None
 2 A Few
 3 Some
 4 Many
 5 Every

2. How many nights have you slept poorly (trouble falling asleep or waking up during sleep) because of sickle cell pain during this menstrual period?
 1 None
 2 A Few
 3 Some
 4 Many
 5 Every

3. How many days have you had trouble taking care of yourself (dressing, going to the bathroom, showering) because of sickle cell pain during this menstrual period?
 1 None
 2 A Few
 3 Some
 4 Many
 5 Every

4. How many days have you missed from school/work because of sickle cell pain during this menstrual period?
 1 None
 2 A Few
 3 Some
 4 Many
 5 Every

5. How many days have you left school/work early because of sickle cell pain during this menstrual period?

- 1 None
- 2 A Few
- 3 Some
- 4 Many
- 5 Every

6. How many days have you been unable to do things you enjoy because of sickle cell pain during this menstrual period?

- 1 None
- 2 A Few
- 3 Some
- 4 Many
- 5 Every

7. How many days have you felt sad, mad, or upset because of sickle cell pain during this menstrual period?

- 1 None
- 2 A Few
- 3 Some
- 4 Many
- 5 Every

Scoring:

“None” = 0, “A Few” = 1, “Some” = 2, “Many” = 3, and “Every” = 4.

Scores range from 0 to 28; that is, no pain burden to severe pain burden.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/881101>