



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.

Questions Regarding SCD Pain Associated with Menstruation, excerpted from Demographic Survey from Table 1 in Sharma et al. (2019).

The Sickle Cell Disease Genitourinary Working Group notes the term “pain” in the questions below refers to specifically to “sickle cell pain.”

1. Have you been able to identify any triggers for your pain?
 1 Yes
 2 No

2. If you answered yes to question 1, what triggers your pain? (Circle all that apply)
 1 Cold weather
 2 Seasons changing
 3 Dehydration in the summer time
 4 Exercise
 5 Menstrual periods
 6 Stress
 7 Illness
 8 Other: _____
 9 Not applicable

3. Have you ever experienced “sickle cell pain” in the week before or during your period?
 1 Yes
 2 No

4. If you answered “Yes” to the question above (question 3), when you think of your last menstrual period, when did you start to have “Sickle cell pain”? If no, please skip this question.
 1 0-7 days before the start of your menstrual period
 2 During your menstrual period
 3 0-7 days after your menstrual period
 4 I did not have sickle cell pain associated with my menstrual period
 5 Not applicable

5. If you answer “Yes” to question 3 above, how often do you have your “sickle cell pain” during your periods?

If no, please skip this question.

- 1 Every now and then
- 2 Almost every period
- 3 With every period
- 4 Not applicable

Scoring Instructions:

Acute “sickle cell” pain associated with menstruation is defined as a “Yes” answer to all of the following:

Do your menstrual periods trigger your “sickle cell pain”

- Answers “Yes” to question 1 and
- Selects “Menstrual periods” in question 2.

Do you start to have “sickle cell pain” 0-7 days before or during your periods?

- Answers “Yes” to question 3 and
- Selects “0-7 days before the start of your menstrual period” or “During your menstrual period” in question 4.

Does your “sickle cell pain” occur with either every or almost every menstrual period?

- Selects “Almost every period” or “With every period” for question 5.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/881001>