



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.

Sickle Cell Disease Health-Related Stigma Scale Short Form (SCD-HRSS-SF)

Public and Physician/Doctor (P2) Subscale

Please select the number that best reflects your agreement with each statement below.

5 = Strongly Agree

4 = Somewhat Agree

3 = Neutral

2 = Somewhat Disagree

1 = Strongly Disagree

In the first 6 statements below, the word "people" refers to people in general, not members of your family. In the last 2 statements below, the word "doctor" refers to all of the doctors you have seen for sickle cell pain.

1.	People believe that it is mostly the patient's fault when his/her pain does not get better.	5	4	3	2	1
2.	People believe that sickle cell is used as an excuse to get pain medication.	5	4	3	2	1
3.	People think less of someone who is unable to work because of sickle cell.	5	4	3	2	1
4.	People believe that having sickle cell pain is a sign of weakness.	5	4	3	2	1

5.	People think that someone taking prescription pain medication on a regular basis is a "drug addict".	5	4	3	2	1
6.	When people hear that someone has sickle cell pain, they think that person is also likely to have mental or emotional problems.	5	4	3	2	1
7.	Many doctors think that people with sickle cell pain want more pain medication than is necessary for their physical pain.	5	4	3	2	1
8.	Doctors think that sickle cell pain is mostly a mental or emotional problem.	5	4	3	2	1

Family Subscale

In the following 7 statements, the word "family" refers to the people who are most important and significant to you.

5 = Strongly Agree

4 = Somewhat Agree

3 = Neutral

2 = Somewhat Disagree

1 = Strongly Disagree

1.	My family thinks I need less pain medication than I take.	5	4	3	2	1
2.	My family feels that I exaggerate how much I hurt in order to get out of doing things that I don't want to do.	5	4	3	2	1
3.	My family thinks that I could be more physically active if I wanted.	5	4	3	2	1
4.	My family thinks that by taking pain medication on a regular basis, I have become a "drug addict".	5	4	3	2	1
5.	I feel that my family has less respect for me since I have sickle cell.	5	4	3	2	1

6.	My family thinks that sickle cell pain is more of a mental or emotional problem than a physical problem.	5	4	3	2	1
7.	My family feels embarrassed to tell people that I have sickle cell.	5	4	3	2	1

Nurse Subscale

In the following 6 statements, the word "nurse" refers to all of the nurses you have seen for sickle cell pain.

5 = Strongly Agree

4 = Somewhat Agree

3 = Neutral

2 = Somewhat Disagree

1 = Strongly Disagree

1.	Nurses think that people with sickle cell exaggerate their pain.	5	4	3	2	1
2.	Many nurses think that people with sickle cell pain want more pain medication than is necessary for their physical pain.	5	4	3	2	1
3.	Nurses think that sickle cell pain is mostly a mental or emotional problem.	5	4	3	2	1
4.	Many nurses believe that people with sickle cell could be more physically active if they wanted.	5	4	3	2	1
5.	Many nurses think that people with sickle cell pain are "drug addicts".	5	4	3	2	1
6.	Most nurses would prefer not to care for people with sickle cell disease.	5	4	3	2	1

Scoring Instructions

Each subscale score is the sum of the items in the subscale scale (P2 Range= 8-40; Family Range= 7-35; Nurse Range= 6-30).The total score is the sum of all 3 subscale scores (Range: 21-105).

Protocol source: <https://www.phenxtoolkit.org/protocols/view/870202>