



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 Self-Efficacy Scale

The following questions ask about how sure you are in dealing day-to-day with sickle cell disease. There are no right or wrong answers; we just want to know what you think. So for each question, tell us how sure you are by circling the response that best tells how you feel. Please answer every question.

1. How sure are you that you can do something to cut down on most of the pain?

1 Not Sure at All

2 Not Sure

3 Neither

4 Sure

5 Very Sure

2. How sure are you that you can keep doing most of the things you do day-to-day?

1 Not Sure at All

2 Not Sure

3 Neither

4 Sure

5 Very Sure

3. How sure are you that you can keep sickle cell disease pain from interfering with your sleep?

1 Not Sure at All

2 Not Sure

3 Neither

4 Sure

5 Very Sure

4. How sure are you that you can reduce your sickle cell disease pain by using methods other than taking medications?

1 Not Sure at All

2 Not Sure

3 Neither

4 Sure

5 Very Sure

5. How sure are you that you can control how often or when you get tired?

1 Not Sure at All

2 Not Sure

3 Neither

4 Sure

5 Very Sure

6. How sure are you that you can do something to help yourself feel better if you are feeling sad or blue?

1 Not Sure at All

2 Not Sure

3 Neither

4 Sure

5 Very Sure

7. As compared with other people with sickle cell disease, how sure are you that you can manage your life from day-to-day?

1 Not Sure at All

2 Not Sure

3 Neither

4 Sure

5 Very Sure

8. How sure are you that you can manage your sickle cell disease symptoms so that you can do the things you enjoy doing?

1 Not Sure at All

2 Not Sure

3 Neither

4 Sure

5 Very Sure

9. How sure are you that you can deal with the frustration of having sickle cell disease?

1 Not Sure at All

2 Not Sure

3 Neither

4 Sure

5 Very Sure

Scoring:

Responses from individual items are summed to give an overall score, with higher scores indicating greater self-efficacy.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/820401>