

Data Collection Worksheet

Please Note: The Data Collection Worksheet (DCW) is a tool to aid investigators to integrate the collection of PhenX measures in your study. The PhenX measures that you selected and added to your Cart are presented in the DCW in alphabetical order. The DCW includes worksheets for data collection. Variables derived from the collected data are shown in the Data Dictionary (DD) with variable names and unique PhenX variable identifiers. The collection of DCWs produced by the Toolkit is not designed as a data collection instrument. Each investigator will decide how to integrate PhenX measures into data collection for their study.

Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me)

Answer all the questions by checking the box to the left of your answer.

Emotional Impact

1. In the past 7 days, how often did you feel completely hopeless because of your health?

Never

Rarely

Sometimes

Often

Always

2. In the past 7 days, how lonely did you feel because of your health problems?

Not at all

A little

Somewhat

Quite

Very

3. In the past 7 days, how depressed were you about your health problems?

Not at all

A little

Somewhat

Quite

Very

4. In the past 7 days, how much did you worry about getting sick?

Not at all

A little bit

Somewhat

Quite a bit

Very much

5. In the past 7 days, how often were you very worried about needing to go to the hospital?

Never

Rarely

Sometimes

Often

Always

Social Functioning Impact

1. In the past 30 days, how much did you rely on others to take care of you because of your health?

Not at all

A little bit

Somewhat

Quite a bit

Very much

2. In the past 30 days, how often did your health slow you down?

Never

Rarely

Sometimes

Often

Always

3. In the past 30 days, how often did your health make it hard for you to do things?

Never

Rarely

Sometimes

Often

Always

4. In the past 30 days, how often did your health keep you from going out?

Never

Rarely

Sometimes

Often

Always

5. In the past 30 days, how much did your health make it hard for you to do things with your friends?

Not at all

A little bit

Somewhat

Quite a bit

Very much

Sleep Impact

1. In the past 7 days, how often did you stay up most of the night because you could not fall asleep?

Never

Rarely

Sometimes

Often

Always

2. In the past 7 days, how often was it very easy for you to fall asleep?

Never

Rarely

Sometimes

Often

Always

3. In the past 7 days, how often did you have a lot of trouble falling asleep?

Never

Rarely

Sometimes

Often

Always

4. In the past 7 days, how often did you stay up all night because you could not fall asleep?

- Never
- Rarely
- Sometimes
- Often
- Always

5. In the past 7 days, how often did you stay up half of the night because you could not fall asleep?

- Never
- Rarely
- Sometimes
- Often
- Always

Stiffness Impact

1. In the past 7 days, how often were your joints very stiff when you woke up?

- Never
- Rarely
- Sometimes
- Often
- Always

2. In the past 7 days, how often were your joints very stiff during the day?

- Never
- Rarely
- Sometimes
- Often

Always

3. In the past 7 days, how often were your joints so stiff during the day that you could not move?

Never

Rarely

Sometimes

Often

Always

4. In the past 7 days, how often did you wake up so stiff that you could not move?

Never

Rarely

Sometimes

Often

Always

5. In the past 7 days, how often did it take you a very long time to get out of bed because of stiffness?

Never

Rarely

Sometimes

Often

Always

Pain Impact

1. In the past 7 days, how often did you have pain so bad that you could not do anything for a whole day?

- Never
- Rarely
- Sometimes
- Often
- Always

2. In the past 7 days, how often did you have pain so bad that you could not get out of bed?

- Never
- Rarely
- Sometimes
- Often
- Always

3. In the past 7 days, how often did you have very severe pain?

- Never
- Rarely
- Sometimes
- Often
- Always

4. In the past 7 days, how often did you have pain so bad that you had to stop what you were doing?

- Never
- Rarely
- Sometimes
- Often
- Always

5. In the past 7 days, how often did you have pain so bad that it was hard to finish what you were doing?

- Never
- Rarely
- Sometimes
- Often
- Always

Pain Episodes

1. In the past 12 months, how many sickle cell pain attacks (crises) did you have?

- I did not have a pain attack (crisis) in the past 12 months
- 1
- 2
- 3
- 4 or more

2. When was your last pain attack (crisis)?

- I've never had a pain attack (crisis)
- More than 5 years ago
- 1-5 years ago
- 7-11 months ago
- 1-6 months ago
- 1-3 weeks ago
- Less than a week ago
- I have one right now

3. Using any number from 0 to 10, where 0 is no pain and 10 is the worst pain imaginable, how severe was your pain during your last pain attack (crisis)?

0 No pain

1

2

3

4

5

6

7

8

9

10 Worst pain imaginable

I've never had a pain attack (crisis)

4. How much did your last pain attack (crisis) interfere with your life?

I've never had a pain attack (crisis)

Not at all, I did everything I usually do

I had to cut down on some things I usually do

I could not do most things I usually do

I could not take care of myself and needed some help from family or friends

I could not take care of myself and needed constant care from family, friends, doctors, or nurses

5. About how long did your most recent pain attack (crisis) last?

I've never had a pain attack (crisis)

Less than 1 hour

1-12 hours

13-23 hours

1-3 days

4-6 days

1-2 weeks

More than 2 weeks

Scoring information is available from Keller S. D., Evensen, C., Yang, M., & Owens, T. (2011). *Adult Sickle Cell Quality of Life Measurement Information System user's manual and interpretation guide*. Bethesda, MD: U.S. Department of Health and Human Services, National Institutes of Health, National Heart, Lung and Blood Institute.

Protocol source: <https://www.phenxtoolkit.org/protocols/view/820201#Source>