PhenX Toolkit

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.

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.

♦ You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

[ ] Yes → **If Yes, Go to Question 1**

[ ] No

1. In the past 12 months, did you try to make an appointment to see a doctor or nurse?

[ ] Yes

[ ] No →**If No, Go to Question 4**

2. In the past 12 months, when you tried to make an appointment to see a doctor or nurse, how often were you able to get one as soon as you wanted?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

3. In the past 12 months, how often were you satisfied with the care you received during these scheduled appointments?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

4. Do you have a doctor or nurse who you usually see if you need a check-up, want advice about a health problem, or get sick or hurt?

[ ] Yes

[ ] No →**If No, Go to Question 13**

5. In the past 12 months, how many visits have you had with this doctor or nurse?

[ ] 0 visits →**If 0 visits, Go to Question 13**

[ ] 1 visit

[ ] 2 visits

[ ] 3 visits

[ ] 4 or more visits

6. In the past 12 months, how often did this doctor or nurse explain things in a way that is easy to understand?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

7. In the past 12 months, how often did this doctor or nurse listen carefully to you?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

8. In the past 12 months, how often did this doctor or nurse treat you with courtesy and respect?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

9. In the past 12 months, how often did this doctor or nurse spend enough time with you?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

10. In the past 12 months, how often were you satisfied with the care you received from this doctor or nurse?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

11. How much does this doctor or nurse know how sickle cell affects you personally?

[ ] Nothing

[ ] A little bit

[ ] Some

[ ] Quite a bit

[ ] Very much

12. Does this doctor or nurse treat a lot of patients with sickle cell disease?

[ ] Yes

[ ] No

13. In the past 12 months, did you go to an emergency room for any sickle cell care you needed right away?

[ ] Yes

[ ] No →**If No, Go to Question 19**

14. In the past 12 months, when you went to the emergency room for this care, how often did you get it as soon as you wanted?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

15. In the past 12 months, when you went to the emergency room for this care, how often did the <u>doctors</u> treating you seem to really care about you?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

16. In the past 12 months, when you went to the emergency room for this care, how often did the <u>nurses</u> treating you seem to really care about you?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

17. In the past 12 months, when you went to the emergency room for this care, how often did the clerks and receptionists treat you with courtesy and respect?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

18. In the past 12 months, when you went to the emergency room for this care, how often were you satisfied with the care you received?

[ ] Never

[ ] Sometimes

[ ] Usually

[ ] Always

19. In the past 12 months, how many times did you manage a pain attack (crisis) at home without going to a doctor, clinic, or hospital?

[ ] I did not have a pain attack (crisis) in the past 12 months →**If you did not have a pain attack in the last 12 months, Go to Question 27**

[ ] 0 times

[ ] 1 time

[ ] 2 times

[ ] 3 times

[ ] 4 or more times

20. In the past 12 months, did you ever delay or avoid going to an emergency room when you thought you needed care?

[ ] Yes, I did not always go for care when I needed it

[ ] No, I always went for care when I thought I needed it →**If No, Go to Question 23**

21. How important were bad experiences in the emergency room in your decision to avoid going for care?

[ ] Not at all

[ ] A little

[ ] Somewhat

[ ] Quite

[ ] Very

22. How important were health insurance issues in your decision to avoid going for care?

[ ] Not at all

[ ] A little

[ ] Somewhat

[ ] Quite

[ ] Very

23. In the past 12 months, how many times did you go to the emergency room because of a pain attack (crisis)?

[ ] 0 times →**If 0 times, Go to Question 27**

[ ] 1 time

[ ] 2 times

[ ] 3 times

[ ] 4 or more times

24. In the past 12 months, how much were the emergency room doctors and nurses able to help your pain?

[ ] Not at all

[ ] A little bit

[ ] Somewhat

[ ] Quite a bit

[ ] Very much

25. In the past 12 months, how much did the emergency room doctors and nurses believe that you had very bad sickle cell pain?

[ ] Not at all

[ ] A little bit

[ ] Somewhat

[ ] Quite a bit

[ ] Very much

26. In the past 12 months, what is the longest you had to wait in the emergency room before your sickle cell pain was treated?

[ ] Less than 5 minutes

[ ] 5 to 15 minutes

[ ] 16 minutes to 1 hour

[ ] More than 1 hour but less than 2 hours

[ ] 2 hours or more

27. Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate all of the care you received for your health in the last 12 months?

0 [ ] Worst care possible

1 [ ]

2 [ ]

3 [ ]

4 [ ]

5 [ ]

6 [ ]

7 [ ]

8 [ ]

9 [ ]

10 [ ] Best care possible

Thank you!