Data Collection Worksheet

PhenX Measure: Quality of Life in Sickle Cell Disease (#820200)
PhenX Protocol: Adult Sickle Cell Quality of Life Measurement Information System (ASCQ-Me) (#820201)

Date of Interview/Examination/Bioassay (MM/DD/YYYY): ______________________

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
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?
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
