



## 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.

Name: \_\_\_\_\_ MRN: \_\_\_\_\_ Date: \_\_\_\_\_

### Self-Management Skills Checklist for Caregivers

Directions: Below is a list of skills that teens use to manage their sickle cell disease. Please circle the number that best describes your child for each question.

1	2	3	4	5
No, my child does not do this.	No, but my child is learning how to do this.	Yes, my child has started doing this when reminded.	Yes, my child always does this when reminded.	Yes, my child always does this when needed.

  

1.	Can your child name all of his medicines?	1	2	3	4	5
2.	Can your child find information about sickle cell disease if needed (like at the doctor's office, on the internet, or in the community)?	1	2	3	4	5
3.	Can your child find information about educational options if needed?	1	2	3	4	5
4.	Does your child ask the doctor or medical team questions during clinical appointments?	1	2	3	4	5
5.	Does your child use strategies other than pain medicines to manage pain (like deep breathing, distraction, imagery)?	1	2	3	4	5

6.	Does your child take medicines on the correct schedule?	1	2	3	4	5
7.	Does your child refill pain medicines on his own?	1	2	3	4	5
8.	Can your child complete a medical history form?	1	2	3	4	5
9.	Does your child take part in activities to stay healthy like exercising and eating healthy foods?	1	2	3	4	5
10.	Does your child find someone to talk to when feeling sad, down, anxious, or angry?	1	2	3	4	5
11.	Does your child talk to the school or medical team about education and the future?	1	2	3	4	5

1	2	3
No, my child does not know.	No, but my child is learning.	Yes, my child knows.

1	Does your child know the type of sickle cell disease he has?	1	2	3
2	Does your child know about complications related to sickle cell disease (like stroke retinopathy, and bone infection)?	1	2	3
3	Does your child know how to manage mild to moderate pain episodes at home?	1	2	3
4	Does your child know how to prevent a pain crisis?	1	2	3
5	Does your child know when to go to the hospital if symptoms become too much to manage at home?	1	2	3

6	Does your child know how often to come to clinic appointments?	1	2	3
7	Does your child know which insurance plan he has?	1	2	3
8	Does your child know how to find a doctor (not at St. Jude) who is covered by that insurance plan?	1	2	3
9	Does your child know how to protect against unplanned pregnancy and sexually transmitted diseases (STDs)?	1	2	3
10	Does your child know the effects of tobacco, street drugs, and alcohol on the body of a person with sickle cell disease?	1	2	3

On a scale of 0 to 10, please circle one number that best describes how confident you feel about your child's ability to manage his own illness.

0	1	2	3	4	5	6	7	8	9	10
Not Confident										Very Confident

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Protocol source: <https://www.phenxtoolkit.org/protocols/view/870802>