



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 Teens

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

1	2	3	4	5
No, I do not do this.	No, but I am learning how to do this.	Yes, I have started doing this when I am reminded.	Yes, I always do this when I am reminded.	Yes, I always do this when I need to.

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

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

1	2	3
No, I don't know.	No, but I am learning.	Yes, I know.

1	Do you know what type of sickle cell disease you have?	1	2	3
2	Do you know about complications related to sickle cell disease (like stroke retinopathy, and bone infection)?	1	2	3
3	Do you know how to manage mild to moderate pain episodes at home?	1	2	3
4	Do you know how to prevent a pain crisis?	1	2	3

5	Do you know when to go to the hospital if you can't manage your symptoms at home?	1	2	3
6	Do you know how often you need to come to your clinic appointments?	1	2	3
7	Do you know which insurance plan you have?	1	2	3
8	Do you know how to find a doctor (not at St. Jude) who is covered by your insurance plan?	1	2	3
9	Do you know how to protect yourself from unplanned pregnancy and sexually transmitted diseases (STDs)?	1	2	3
10	Do you know the effects of tobacco, street drugs, and alcohol on your body?	1	2	3

On a scale of 0 to 10, please circle one number that best describes how confident you feel about managing your illness on your own.

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/870801>