



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.

ID: _____

Date: _____

RESPONSES TO STRESS - [SC] (SR-C)

This is a list of things about having sickle cell disease that children and teenagers sometimes find stressful or a problem to deal with. Please circle the number indicating how stressful the following things have been for you in the past 6 months.

	Not at all	A Little	Somewhat	Very
a. Not being able to do the things that other kids can do or are allowed to do	1	2	3	4
b. Having to go to the hospital or clinic so often	1	2	3	4
c. Missing school days or falling behind in school work	1	2	3	4
d. Concerns about my family and friends	1	2	3	4
e. Feeling confused about what sickle cell disease is and why I got it	1	2	3	4
f. Not understanding what doctors tell me about sickle cell disease	1	2	3	4
g. Having Sickle Cell Pain crises	1	2	3	4
h. Concerns about the future	1	2	3	4
i. Other: _____	1	2	3	4
j.	1	2	3	4
k.	1	2	3	4
l.	1	2	3	4

Circle the number that shows how much control you generally think you have over these problems.

1	2	3	4
None	A little	Some	A lot

Below is a list of things that children and teenagers sometimes do, think, or feel when they are dealing with sickle cell disease. Everyone deals with problems in their own way - some people do a lot of the things on this list or have a bunch of feelings, other people just do or think a few of these things.

Think of all the stressful parts of having sickle cell disease that you indicated above. For each item below, circle **one** number from 1 (not at all) to 4 (a lot) that shows **how much** you do or feel these things when you have the problems with sickle cell like the ones you indicated above. Please let us know about everything you do, think, and feel, even if you don't think it helps make things better.

		How much do you do this?			
		Not at all	A Little	Some	A lot
	WHEN DEALING WITH THE STRESS OF SICKLE CELL DISEASE:				
1.	I try not to feel anything.	1	2	3	4
2.	When dealing with the stress of having sickle cell disease, I feel sick to my stomach or get headaches.	1	2	3	4
3.	I try to think of different ways to change or fix the situation. Write one plan you thought of: _____	1	2	3	4
4.	When faced with the stress of having sickle cell disease, I don't feel anything at all, it's like I have no feelings.	1	2	3	4
5.	I wish that I were stronger and less sensitive so that things would be different.	1	2	3	4
6.	I keep remembering what happened with sickle cell disease or can't stop thinking about what might happen.	1	2	3	4
7.	I let someone or something know how I feel. (remember to circle a number.) ----> Check all you talked to: [] Parent [] Friend [] Brother/Sister [] Pet [] Clergy Member [] Teacher [] God [] Stuffed Animal [] Other family member [] None of these	1	2	3	4
8.	I decide I'm okay the way I am, even though I'm not perfect.	1	2	3	4
9.	When I'm around other people I act like I do not have sickle cell disease.	1	2	3	4
10.	I just have to get away from everything when I am dealing with the stress of having sickle cell disease.	1	2	3	4
11.	I deal with the stress of having sickle cell disease by wishing it would	1	2	3	4

	just go away, that everything would work itself out.				
12.	I get really jumpy when I am dealing with the stress of having sickle cell disease.	1	2	3	4
13.	I realize that I just have to live with things the way they are.	1	2	3	4
14.	When I am dealing with the stress of having sickle cell disease, I just can't be near anything that reminds me of sickle cell.	1	2	3	4
15.	I try not to think about it, to forget all about it.	1	2	3	4
16.	When I am dealing with the stress of having sickle cell disease, I really don't know what I feel.	1	2	3	4
17.	I ask other people of things for help or for ideas about how to make things better (remember to circle a number.) ----> Check all you talked to: <input type="checkbox"/> Parent <input type="checkbox"/> Friend <input type="checkbox"/> Brother/Sister <input type="checkbox"/> Pet <input type="checkbox"/> Clergy Member <input type="checkbox"/> Teacher <input type="checkbox"/> God <input type="checkbox"/> Stuffed Animal <input type="checkbox"/> Other family member <input type="checkbox"/> None of these	1	2	3	4
18.	When I am trying to sleep, I can't stop thinking about the stressful aspects of having sickle cell disease or I have bad dreams about having sickle cell disease.	1	2	3	4
19.	I tell myself that I can get through this, or that I will be okay.	1	2	3	4
20.	I let my feelings out. (remember to circle a number.) I do this by: (Check all that you did.) <input type="checkbox"/> Writing in my journal/diary <input type="checkbox"/> Drawing/painting <input type="checkbox"/> Complaining to let off steam <input type="checkbox"/> Being sarcastic/making fun <input type="checkbox"/> Listening to music <input type="checkbox"/> Punching a pillow <input type="checkbox"/> Exercising <input type="checkbox"/> Yelling <input type="checkbox"/> Crying <input type="checkbox"/> None of these	1	2	3	4
21.	I get help from other people or things when I'm trying to figure out how to deal with my feelings. (remember to circle a number.) ----> Check all you went to: <input type="checkbox"/> Parent <input type="checkbox"/> Friend <input type="checkbox"/> Brother/Sister <input type="checkbox"/> Pet <input type="checkbox"/> Clergy Member <input type="checkbox"/> Teacher <input type="checkbox"/> God <input type="checkbox"/> Stuffed Animal <input type="checkbox"/> Other family member <input type="checkbox"/> None of these	1	2	3	4
22.	I just can't get myself to face the stress of having sickle cell disease.	1	2	3	4
23.	I wish that someone would just come and take away the stressful aspects of having sickle cell disease.	1	2	3	4

You're half done. Before you keep working, look back at the first page so you remember the aspects of having sickle cell disease that have been stressful for you lately. Remember to answer the questions below thinking about these things.

		How much do you do this?			
WHEN DEALING WITH THE STRESS OF SICKLE CELL DISEASE:		Not at all	A Little	Some	A lot
24.	I do something to try to fix the stressful parts of having sickle cell disease. Write one thing you did: _____	1	2	3	4
25.	Thoughts about having sickle cell disease just pop into my head.	1	2	3	4
26.	When I am dealing with the stress of having sickle cell disease, I feel it in my body. (remember to circle a number.) ----> Check all that happen: [] My heart races [] My breathing speeds up [] I feel hot or sweaty [] My muscles get tight [] None of these	1	2	3	4
27.	I try to stay away from people and things that make me feel upset or remind me of the stressful aspects of having sickle cell disease.	1	2	3	4
28.	I don't feel like myself when I am dealing with the stress of having sickle cell disease, it's like I am far away from everything.	1	2	3	4
29.	I just take things as they are; I go with the flow.	1	2	3	4
30.	I think about happy things to take my mind off the stressful parts of having sickle cell disease or how I'm feeling .	1	2	3	4
31.	When something stressful happens related to having sickle cell disease, I can't stop thinking about how I am feeling.	1	2	3	4
32.	I get sympathy, understanding, or support from someone. (remember to circle a number.) ----> Check all you went to: [] Parent [] Friend [] Brother/Sister [] Pet [] Clergy Member [] Teacher [] God [] Stuffed Animal [] Other family member [] None of these	1	2	3	4
33.	When something stressful happens related to having sickle cell disease, I can't always control what I do. (remember to circle a number.) ----> Check all that happen: [] I can't stop eating [] I can't stop talking [] I do dangerous things [] I have to keep fixing/checking things	1	2	3	4

	<input type="checkbox"/> Listen to music <input type="checkbox"/> Take a break <input type="checkbox"/> Meditate <input type="checkbox"/> None of these				
46.	I just freeze when I am dealing with stressful parts of having sickle cell disease, I can't do anything.	1	2	3	4
47.	When stressful things happen related to having sickle cell disease I sometimes act without thinking.	1	2	3	4
48.	I keep my feelings under control when I have to, then let them out when they won't make things worse.	1	2	3	4
49.	When something stressful happens related to having sickle cell disease, I can't seem to get around to doing things I'm supposed to do.	1	2	3	4
50.	I tell myself that everything will be all right.	1	2	3	4
51.	When something stressful happens related to having sickle cell disease, I can't stop thinking about why this is happening.	1	2	3	4
52.	I think of ways to laugh about it so that it won't seem so bad.	1	2	3	4
53.	My thoughts start racing when I am faced with the stressful parts of having sickle cell disease.	1	2	3	4
54.	I imagine something really fun or exciting happening in my life.	1	2	3	4
55.	When something stressful happens related to having sickle cell disease, I can get so upset that I can't remember what happened or what I did.	1	2	3	4
56.	I try to believe that it never happened.	1	2	3	4
57.	When I am dealing with the stress of having sickle cell disease, sometimes I can't control what I do or say.	1	2	3	4

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