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.

ID: _____

Date: _____

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

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 your child 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 his/her family and friends	1	2	3	4
e. Feeling confused about what sickle cell disease is and why he/she got it	1	2	3	4
f. Not understanding what doctors tell him/her 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 he/she generally thinks he/she has 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 aspects of having sickle cell disease that have been stressful for your child lately that you checked off above. For each item below, circle **one** number from 1 (not at all) to 4 (a lot) that shows **how much** he/she does or feels these things when he/she has the problems with sickle cell like the ones you indicated above. Please let us know about everything he/she does, thinks, and feels, even if you don't think it helps make things better.

		How much does he/she do this?			
	WHEN DEALING WITH THE STRESS OF SICKLE CELL DISEASE:	Not at all	A Little	Some	A lot
1.	He/she **tries** not to feel anything.	1	2	3	4
2.	When dealing with the stress of having sickle cell disease, he/she feels sick to his/her stomach or get headaches.	1	2	3	4
3.	He/she tries to think of different ways to change or fix the situation. **Write one plan he/she thought of:** _____	1	2	3	4
4.	When faced with the stress of having sickle cell disease, he/she doesn't feel anything at all, it's like he/she has no feelings.	1	2	3	4
5.	He/she wishes that he/she were stronger and less sensitive so that things would be different.	1	2	3	4
6.	He/she **keeps remembering** what happened with sickle cell disease or **can't stop thinking about** what might happen.	1	2	3	4
7.	He/she lets someone or something know how he/she feels. (remember to circle a number.) ----> **Check all he/she talked to:** [ ] Parent [ ] Friend [ ] Brother/Sister [ ] Pet [ ] Clergy Member [ ] Teacher [ ] God [ ] Stuffed Animal [ ] Other family member [ ] None of these	1	2	3	4
8.	He/she decides he/she is okay the way he/she is, even though he/she's not perfect.	1	2	3	4
9.	When he/she is around other people he/she acts like having sickle cell disease never happened.	1	2	3	4
10.	He/she just has to get away from everything when he/she is dealing with the stress of having sickle cell disease.	1	2	3	4
11.	He/she deals with the stress of having sickle cell disease by wishing it	1	2	3	4

	would just go away, that everything would work itself out.				
12.	He/she gets really jumpy when he/she is dealing with the stress of having sickle cell disease.	1	2	3	4
13.	He/she realizes that he/she just has to live with things the way they are.	1	2	3	4
14.	When he/she is dealing with the stress of having sickle cell disease, he/she just **can't** be near anything that reminds him/her of what is happening.	1	2	3	4
15.	He/she tries not to think about it, to forget all about it.	1	2	3	4
16.	When he/she is dealing with the stress of having sickle cell disease, he/she really doesn't know what he/she feels.	1	2	3	4
17.	He/she asks other people of things for help or for ideas about how to make things better (remember to circle a number.) ---> **Check all he/she talked to:** [ ] Parent [ ] Friend [ ] Brother/Sister [ ] Pet [ ] Clergy Member [ ] Teacher [ ] God [ ] Stuffed Animal [ ] Other family member [ ] None of these	1	2	3	4
18.	When he/she is trying to sleep, he/she **can't stop** thinking about the stressful aspects of having sickle cell disease or he/she has bad dreams about having sickle cell disease.	1	2	3	4
19.	He/she tells himself/herself that he/she can get through this, or that he/she will be okay.	1	2	3	4
20.	He/she lets his/her feelings out. (remember to circle a number.) **He/she does this by: (Check all that he/she did.)** [ ] Writing in his/her journal/diary [ ] Drawing/painting [ ] Complaining to let off steam [ ] Being sarcastic/making fun [ ] Listening to music [ ] Punching a pillow [ ] Exercising [ ] Yelling [ ] Crying [ ] None of these	1	2	3	4
21.	He/she gets help from other people or things when he/she is trying to figure out how to deal with his/her feelings. (remember to circle a number.) ----> **Check all that he/she went to:** [ ] Parent [ ] Friend [ ] Brother/Sister [ ] Pet [ ] Clergy Member [ ] Teacher [ ] God [ ] Stuffed Animal [ ] Other family member [ ] None of these	1	2	3	4
22.	**He/she just can't** get himself/herself to face the stress of having sickle cell disease.	1	2	3	4
23.	He/she wishes 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 does he/she do this?			
	WHEN DEALING WITH THE STRESS OF SICKLE CELL DISEASE:	**Not at all**	**A Little**	**Some**	**A lot**
24.	He/she does something to try to fix the stressful parts of having sickle cell disease. **Write one thing he/she did:**_____	1	2	3	4
25.	Thoughts about having sickle cell disease just pop into his/her head.	1	2	3	4
26.	When he/she is dealing with the stress of having sickle cell disease, he/she feels it in his/her body. (remember to circle a number.) ----> **Check all that happen:** [ ] His/her heart races [ ] His/her breathing speeds up [ ] He/she feels hot or sweaty [ ] His/her muscles get tight [ ] None of these	1	2	3	4
27.	He/she **tries** to stay away from people and things that make him/her feel upset or remind him/her of the stressful aspects of having sickle cell disease.	1	2	3	4
28.	He/she doesn't feel like himself/herself when he/she is dealing with the stress of having sickle cell disease, it's like he/she is far away from everything.	1	2	3	4
29.	He/she just takes things as they are; he/she goes with the flow.	1	2	3	4
30.	He/she thinks about happy things to take his/her mind off the stressful parts of having sickle cell disease or how he/she is **feeling**.	1	2	3	4
31.	When something stressful happens related to having sickle cell disease, he/she **can't stop** thinking about how he/she is feeling.	1	2	3	4
32.	He/she gets sympathy, understanding, or support from someone. (remember to circle a number.) ----> **Check all he/she 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, he/she **can't** always control what he/she does. (remember to circle a number.) ----> **Check all that happen:** [ ] He/she can't stop eating [ ] He/she can't stop talking [ ] He/she does dangerous things [ ] He/she had to keep fixing/checking things [ ] None of these	1	2	3	4
34.	He/she tells himself/herself that things could be worse.	1	2	3	4

35.	His/her mind just goes blank when something stressful happens related to having sickle cell disease, he/she can't think at all.	1	2	3	4
36.	He/she tells himself/herself that it doesn't matter, that it isn't a big deal.	1	2	3	4
37.	When he/she is faced with the stressful parts of sickle cell disease, right away he/she feels really: (remember to circle a number.) ----> **Check all that he/she feels:** [ ] Angry [ ] Sad [ ] None of these [ ] Worried/anxious [ ] Scared	1	2	3	4
38.	It's really hard for him/her to concentrate or pay attention when something stressful happens related to having sickle cell disease.	1	2	3	4
39.	He/she thinks about the things he/she is learning from having sickle cell disease, or something good that will come from it.	1	2	3	4

		How much does he/she do this?			
	WHEN DEALING WITH THE STRESS OF SICKLE CELL DISEASE:	Not at all	A Little	Some	A lot
40.	After something stressful happens related to having sickle cell disease, he/she **can't stop** thinking about what he/she did or said.	1	2	3	4
41.	When stressful parts of sickle cell disease happen, he/she says to himself/herself, "This isn't real."	1	2	3	4
42.	When he/she is dealing with the stressful parts of sickle cell disease, he/she ends up just lying around or sleeping a lot.	1	2	3	4
43.	He/she keeps his/her mind off stressful parts of having sickle cell disease by: (remember to circle a number.) ----> **Check all that he/she does:** [ ] Exercising [ ] Seeing friends [ ] Watching TV [ ] Playing video games [ ] Doing a hobby [ ] Listening to music [ ] None of these	1	2	3	4
44.	When something stressful happens related to having sickle cell disease, he/she gets upset by things that don't usually bother him/her.	1	2	3	4
45.	He/she does something to calm himself/herself down when he/she is dealing with the stress of having sickle cell disease. (remember to circle a number.) ----> **Check all that he/she does:** [ ] Take deep breaths [ ] Pray [ ] Walk [ ] Listen to music [ ] Take a break [ ] Meditate [ ] None of these	1	2	3	4
46.	He/she just freezes when he/she is dealing with stressful parts of sickle cell disease, he/she **can't** do anything.	1	2	3	4
47.	When stressful things happen related to having sickle cell disease he/she sometimes act without thinking.	1	2	3	4

48.	He/she keeps his/her feelings under control when he/she has to, then lets them out when they won't make things worse.	1	2	3	4
49.	When something stressful happens related to having sickle cell disease, he/she can't seem to get around to doing things he/she is supposed to do.	1	2	3	4
50.	He/she tells himself/herself that everything will be all right.	1	2	3	4
51.	When something stressful happens related to having sickle cell disease, he/she **can't stop** thinking about **why** this is happening.	1	2	3	4
52.	He/she thinks of ways to laugh about it so that it won't seem so bad.	1	2	3	4
53.	His/her thoughts start racing when he/she is faced with the stressful parts of having sickle cell disease.	1	2	3	4
54.	He/she imagines something really fun or exciting happening in his/her life.	1	2	3	4
55.	When something stressful happens related to having sickle cell disease, he/she can get so upset that he/she can't remember what happened or what he/she did.	1	2	3	4
56.	He/she tries to believe that it never happened.	1	2	3	4
57.	When he/she is dealing with the stress of having sickle cell disease, sometimes he/she **can't** control what he/she does or says.	1	2	3	4

Protocol source: https://www.phenxtoolkit.org/protocols/view/870702