

## 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.

Some kind of problems can make it hard to do many activities, such as eating, bathing, school work, and playing with friends. We would like to find out how your child is doing. (Circle one response on each line.)

During the last week was it easy or hard for your child to:

		<b>Easy</b>	<b>A little hard</b>	<b>Very hard</b>	<b>Can't do at all</b>	<b>Too young for this activity</b>
		1	2	3	4	5
1.	Lift heavy books?					
2.	Pour a half gallon of milk?					
3.	Open a jar that has been opened before?					
4.	Use a fork and spoon?					
5.	Comb his/her hair?					
6.	Button buttons?					
7.	Put on his/her coat?					
8.	Write with a pencil?					

9. On average, over the last 12 months, how often did your child miss school (preschool, day care, camp, etc.) because of his/her health?

- 1 [ ]. Rarely
- 2 [ ]. Once a month
- 3 [ ]. Two or three times a month
- 4 [ ]. Once a week
- 5 [ ]. More than once a week
- 6 [ ]. Does not attend school, etc.

During the last week how happy has your child been with: (Circle one response on each line.)

		Very happy	Somewhat happy	Not sure	Somewhat unhappy	Very unhappy	Child is too young
10.	How he/she looks?	1	2	3	4	5	6
11.	His/her body?	1	2	3	4	5	6
12.	What clothes or shoes he/she can wear?	1	2	3	4	5	6
13.	His/her ability to do the same things his/her friends do?	1	2	3	4	5	6
14.	His/her health in general?	1	2	3	4	5	6

During the last week, how much of the time:

(Circle one response on each line.)

		Most of the time	Some of the time	A little of the time	None of the time
15.	Did your child feel sick and tired?	1	2	3	4
16.	Were your child full of pep and energy?	1	2	3	4
17.	Did pain or discomfort interfere with your child's activities?	1	2	3	4

During the last week, has it been easy or hard for your child to:

(Circle one response on each line.)

		Easy	A little hard	Very hard	Can't do at all	Too young for this activity
18.	Run short distances?	1	2	3	4	5
19.	Bicycle or tricycle?	1	2	3	4	5
20.	Climb three flights of stairs?	1	2	3	4	5
21.	Climb one flight of stairs?	1	2	3	4	5
22.	Walk more than a mile?	1	2	3	4	5

23.	Walk three blocks?	1	2	3	4	5
24.	Walk one block?	1	2	3	4	5
25.	Get on and off a bus?	1	2	3	4	5

26. How often does your child need help from another person for walking and climbing? (Circle one response.)

- 1  Never
- 2  Sometimes
- 3  About half the time
- 4  Often
- 5  All the time

27. How often does your child use assistive devices (such as braces, crutches, or wheelchair) for walking and climbing? (Circle one response.)

- 1  Never
- 2  Sometimes
- 3  About half the time
- 4  Often
- 5  All the time

During the **last week**, has it been easy or hard for your child to:

(Circle one response on each line.)

		Easy	A little hard	Very hard	Can't do at all	Too young for this activity
28.	Stand while washing his/her hands and face at a sink?	1	2	3	4	5

29.	Sit in a regular chair without holding on?	1	2	3	4	5
30.	Get on and off a toilet or chair?	1	2	3	4	5
31.	Get in and out of bed?	1	2	3	4	5
32.	Turn door knobs?	1	2	3	4	5
33.	Bend over from a standing position and pick up something off the floor?	1	2	3	4	5

34. How often does your child need help from another person for sitting and standing? (Circle one response.)

- 1  Never
- 2  Sometimes
- 3  About half the time
- 4  Often
- 5  All the time

35. How often does your child use assistive devices (such as braces, crutches, or wheelchair) for sitting and standing? (Circle one response.)

- 1  Never
- 2  Sometimes
- 3  About half the time
- 4  Often
- 5  All the time

36. Can your child participate in recreational outdoor activities with other children the same age? (For example: bicycling, tricycling, skating, hiking, jogging)

(Circle one response.)

- 1  Yes, easily
- 2  Yes, but a little hard
- 3  Yes, but very hard
- 4  No

**If you answered "no" to Question 36 above, was your child's activity limited by:**  
(Circle yes to all that apply)

		Yes
37.	Pain?	1
38.	General Health?	1
39.	Doctor or parent instructions?	1
40.	Fear the other kids won't like him/her?	1
41.	Dislike of recreational outdoor activities?	1
42.	Too young?	1
43.	Activity not in season?	1

**44. Can your child participate in pickup games or sports with other children the same age? (For example: tag, dodge ball, basketball, soccer, catch, jump rope, touch football, hop scotch)**

(Circle one response.)

- 1  Yes, easily
- 2  Yes, but a little hard
- 3  Yes, but very hard

4 [ ] No

If you answered "no" to Question 44 above, was your child's activity limited by:  
(Circle yes to all that apply)

		Yes
45.	Pain?	1
46.	General Health?	1
47.	Doctor or parent instructions?	1
48.	Fear the other kids won't like him/her?	1
49.	Dislike of pickup games or sports?	1
50.	Too young?	1
51.	Activity not in season?	1

52. Can your child participate in **competitive level sports** with other children the same age? (For example: hockey, basketball, soccer, football, baseball, swimming, running [track or cross country], gymnastics, or dance) (Circle one response.)

1 [ ] Yes, easily

2 [ ] Yes, but a little hard

3 [ ] Yes, but very hard

4 [ ] No

If you answered "no" to Question 52 above, was your child's activity limited by:  
(Circle yes to all that apply)

		Yes

53.	Pain?	1
54.	General Health?	1
55.	Doctor or parent instructions?	1
56.	Fear the other kids won't like him/her?	1
57.	Dislike of pickup games or sports?	1
58.	Too young?	1
59.	Activity not in season?	1

60. How often in the **last week** did your child get together and do things with friends? (Circle one response.)

1  Often

2  Sometimes

3  Never or rarely

If you answered "sometimes" or "never or rarely" to Question 60 above, was your child's activity limited by: (Circle yes to all that apply)

		Yes
61.	Pain?	1
62.	General Health?	1
63.	Doctor or parent instructions?	1
64.	Fear the other kids won't like him/her?	1



65.	Friends not around?	1
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66. How often in the last week did your child participate in **gym/recess**? (Circle one response.)

- 1  Often
- 2  Sometimes
- 3  Never or rarely
- 4  No gym or recess

If you answered "sometimes" or "never or rarely" to Question 63 above, was your child's activity limited by: (Circle yes to all that apply)

		Yes
67.	Pain?	1
68.	General Health?	1
69.	Doctor or parent instructions?	1
70.	Fear the other kids won't like him/her?	1
71.	Dislike of gym/recess?	1
72.	School not in session?	1
73.	Does not attend school?	1

74. Is it easy or hard for your child to make friends with children his/her own age? (Circle one response.)

- 1  Usually easy
- 2  Sometimes easy

3 [ ] Sometimes hard

4 [ ] Usually hard

**75.** How much pain has your child had during the last week? (Circle one response.)

1 [ ] None

2 [ ] Very mild

3 [ ] Mild

4 [ ] Moderate

5 [ ] Severe

6 [ ] Very severe

**76.** During the last week, how much did pain interfere with your child's normal activities (including at home, outside of the home, and at school)? (Circle one response.)

1 [ ] Not at all

2 [ ] A little bit

3 [ ] Moderately

4 [ ] Quite a bit

5 [ ] Extremely

What expectations do you have for your child's treatment?

As a result of my child's treatment, I expect my child:

(Circle one response on each line.)

		Definitely yes	Probably yes	Not sure	Probably not	Definitely not
77.	To have pain relief.	1	2	3	4	5
78.	To look better.	1	2	3	4	5
79.	To feel better about himself/herself.	1	2	3	4	5

80.	To sleep more comfortably.	1	2	3	4	5
81.	To be able to do activities at home.	1	2	3	4	5
82.	To be able to do more at school.	1	2	3	4	5
83.	To be able to do more play or recreational activities (biking, walking, doing things with friends).	1	2	3	4	5
84.	To be able to do more sports.	1	2	3	4	5
85.	To be free from pain or disability as an adult.	1	2	3	4	5

86. If your child had to spend the rest of his/her life with his/her bone and muscle condition as it is right now, how would you feel about it? (Circle one response.)

- 1 [ ] Very satisfied
- 2 [ ] Somewhat satisfied
- 3 [ ] Neutral
- 4 [ ] Somewhat dissatisfied
- 5 [ ] Very dissatisfied

Protocol source: <https://www.phenxtoolkit.org/protocols/view/221501>