

## **Data Collection Worksheet**

other things.

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.

Please answer each of the following questions about your child or the person who is under your care by indicating a box that reflects your answer to the question most appropriately.

1. S/he prefers to do things with others rather than on her/his own.
[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
2. S/he prefers to do things the same way over and over again.
[ ] Definitely Agree
[] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
3. If $s$ /he tries to imagine something, $s$ /he finds it very easy to create a picture in her/his mind.
[ ] Definitely Agree
[] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
4. S/he frequently gets so strongly absorbed in one thing that s/he loses sight of

[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
5. S/he often notices small sounds when others do not.
[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
6. S/he usually notices car number plates or similar strings of information.
[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
7. Other people frequently tell her/him that what s/he has said is impolite, even though s/he thinks it is polite.
[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
8. When s/he is reading a story, s/he can easily imagine what the characters migh look like.
[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
9. S/he is fascinated by dates.

[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
10. In a social group, s/he can easily keep track of several different people's conversations.
[ ] Definitely Agree
[] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
11. S/he finds social situations easy.
[ ] Definitely Agree
[] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
12. S/he tends to notice details that others do not.
[ ] Definitely Agree
[] Slightly Agree
[] Slightly Disagree
[ ] Definitely Disagree
13. S/he would rather go to a library than a party.
[ ] Definitely Agree
[] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
14. S/he finds making up stories easy.
[ ] Definitely Agree

[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
15. S/he finds her/himself drawn more strongly to people than to things.
[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[] Definitely Disagree
16. S/he tends to have very strong interests, which s/he gets upset about if s/he can't pursue.
[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
17. S/he enjoys social chit-chat.
[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[] Definitely Disagree
18. When s/he talks, it isn't always easy for others to get a word in edgeways.
[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
19. S/he is fascinated by numbers.
[] Definitely Agree
[ ] Slightly Agree

[ ] Slightly Disagree	
[] Definitely Disagree	
20. When s/he is reading a story, s/he finds it difficult to work out the character intentions.	s'
[] Definitely Agree	
[ ] Slightly Agree	
[ ] Slightly Disagree	
[] Definitely Disagree	
21. S/he doesn't particularly enjoy reading fiction.	
[] Definitely Agree	
[] Slightly Agree	
[ ] Slightly Disagree	
[] Definitely Disagree	
22. S/he finds it hard to make new friends.	
[] Definitely Agree	
[] Slightly Agree	
[ ] Slightly Disagree	
[] Definitely Disagree	
23. S/he notices patterns in things all the time.	
[] Definitely Agree	
[] Slightly Agree	
[ ] Slightly Disagree	
[] Definitely Disagree	
24. S/he would rather go to the theatre than a museum.	
[] Definitely Agree	
[] Slightly Agree	
[ ] Slightly Disagree	

[ ] Definitely Disagree
25. It does not upset him/her if his/her daily routine is disturbed.
[ ] Definitely Agree
[] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
26. S/he frequently finds that s/he doesn't know how to keep a conversation going.
[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
27. S/he finds it easy to "read between the lines" when someone is talking to her/him.
[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[] Definitely Disagree
28. S/he usually concentrates more on the whole picture, rather than the small details.
[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
29. S/he is not very good at remembering phone numbers.
[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree

[ ] Definitely Disagree
30. S/he doesn't usually notice small changes in a situation, or a person's appearance.
[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
31. S/he knows how to tell if someone listening to him/her is getting bored.
[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
32. S/he finds it easy to do more than one thing at once.
[ ] Definitely Agree
[] Slightly Agree
[] Slightly Disagree
[] Definitely Disagree
33. When s/he talks on the phone, s/he is not sure when it's her/his turn to speak.
[ ] Definitely Agree
[] Slightly Agree
[] Slightly Disagree
[ ] Definitely Disagree
34. S/he enjoys doing things spontaneously.
[] Definitely Agree
[] Slightly Agree
[] Slightly Disagree
[ ] Definitely Disagree

35. S/he is often the last to understand the point of a joke.
[ ] Definitely Agree
[] Slightly Agree
[] Slightly Disagree
[ ] Definitely Disagree
36. S/he finds it easy to work out what someone is thinking or feeling just by looking at their face.
[ ] Definitely Agree
[] Slightly Agree
[] Slightly Disagree
[ ] Definitely Disagree
37. If there is an interruption, s/he can switch back to what s/he was doing verquickly.
[ ] Definitely Agree
[] Slightly Agree
[] Slightly Disagree
[ ] Definitely Disagree
38. S/he is good at social chit-chat.
[ ] Definitely Agree
[] Slightly Agree
[] Slightly Disagree
[ ] Definitely Disagree
39. People often tell her/him that s/he keeps going on and on about the same thing.
[ ] Definitely Agree
[] Slightly Agree
[] Slightly Disagree
[ ] Definitely Disagree

40. When s/he was younger, s/he used to enjoy playing games involving pretending with other children.
[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[] Definitely Disagree
41. S/he likes to collect information about categories of things (e.g., types of car, types of bird, types of train, types of plant, etc.).
[ ] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
42. S/he finds it difficult to imagine what it would be like to be someone else.
[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
43. S/he likes to plan any activities s/he participates in carefully.
[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree
44. S/he enjoys social occasions.
[] Definitely Agree
[ ] Slightly Agree
[ ] Slightly Disagree
[ ] Definitely Disagree

45.	S/he finds it difficult to work out people's intentions.
	[ ] Definitely Agree
	[ ] Slightly Agree
	[ ] Slightly Disagree
	[ ] Definitely Disagree
46.	New situations make him/her anxious.
	[ ] Definitely Agree
	[ ] Slightly Agree
	[ ] Slightly Disagree
	[ ] Definitely Disagree
47.	S/he enjoys meeting new people.
	[ ] Definitely Agree
	[ ] Slightly Agree
	[ ] Slightly Disagree
	[ ] Definitely Disagree
48.	S/he is a good diplomat.
	[] Definitely Agree
	[ ] Slightly Agree
	[ ] Slightly Disagree
	[ ] Definitely Disagree
49.	S/he is not very good at remembering people's date of birth.
	[ ] Definitely Agree
	[ ] Slightly Agree
	[ ] Slightly Disagree
	[ ] Definitely Disagree
50.	S/he finds it very easy to play games with children that involve pretending.

[] Definitely Agree
[] Slightly Agree
[] Slightly Disagree
[] Definitely Disagree

## **Scoring Instructions**

Responses that score 1 point are marked. Other responses score 0. For total score, sum all items. Minimum score possible is 0, Maximum score possible is 50. A score of 30 or above is highly predictive of Autism Spectrum disorders in adolescents.

	Definitely Agree		Slightly Disagree	Definit ely Disagr ee
1. S/he prefers to do things with others rather than on her/his own.			1	1
2. S/he prefers to do things the same way over and over again.	1	1		
3. If s/he tries to imagine something, s/he finds it very easy to create a picture in her/his mind.			1	1
4. S/he frequently gets so strongly absorbed in one thing that s/he loses sight of other things.	1	1		
5. S/he often notices small sounds when others do not.	1	1		
6. S/he usually notices car number plates or similar strings of information.	1	1		

7. Other people frequently tell her/him that what s/he has said is impolite, even though s/he thinks it is polite.	1	1		
8. When s/he is reading a story, s/he can easily imagine what the characters might look like.			1	1
9. S/he is fascinated by dates.	1	1		
10. In a social group, s/he can easily keep track of several different people's conversations.			1	1
11. S/he finds social situations easy.			1	1
12. S/he tends to notice details that others do not.	1	1		
13. S/he would rather go to a library than a party.	1	1		
14. S/he finds making up stories easy.			1	1
15. S/he finds her/himself drawn more strongly to people than to things.			1	1
16. S/he tends to have very strong interests, which s/he gets upset about if s/he can't pursue.	1	1		
17. S/he enjoys social chit-chat.			1	1

18. When s/he talks, it isn't always easy for others to get a word in edgeways.	1	1		
19. S/he is fascinated by numbers.	1	1		
20. When s/he is reading a story, s/he finds it difficult to work out the characters' intentions.	1	1		
21. S/he doesn't particularly enjoy reading fiction.	1	1		
22. S/he finds it hard to make new friends.	1	1		
23. S/he notices patterns in things all the time.	1	1		
24. S/he would rather go to the theatre than a museum.			1	1
25. It does not upset him/her if his/her daily routine is disturbed.			1	1
26. S/he frequently finds that s/he doesn't know how to keep a conversation going.	1	1		
27. S/he finds it easy to "read between the lines" when someone is talking to her/him.			1	1
28. S/he usually concentrates more on the whole picture, rather than			1	1

the small details.				
29. S/he is not very good at remembering phone numbers.			1	1
30. S/he doesn't usually notice small changes in a situation, or a person's appearance.			1	1
31. S/he knows how to tell if someone listening to him/her is getting bored.			1	1
32. S/he finds it easy to do more than one thing at once.			1	1
33. When s/he talks on the phone, s/he is not sure when it's her/his turn to speak.	1	1		
34. S/he enjoys doing things spontaneously.			1	1
35. S/he is often the last to understand the point of a joke.	1	1		
36. S/he finds it easy to work out what someone is thinking or feeling just by looking at their face.			1	1
37. If there is an interruption, s/he can switch back to what s/he was doing very quickly.			1	1
38. S/he is good at social chit-chat.			1	1

39. People often tell her/him that s/he keeps going on and on about the same thing.	1	1		
40. When s/he was younger, s/he used to enjoy playing games involving pretending with other children.			1	1
41. S/he likes to collect information about categories of things (e.g., types of car, types of bird, types of train, types of plant, etc.).	1	1		
42. S/he finds it difficult to imagine what it would be like to be someone else.		1		
43. S/he likes to plan any activities s/he participates in carefully.	1	1		
44. S/he enjoys social occasions.			1	1
45. S/he finds it difficult to work out people's intentions.	1	1		
46. New situations make him/her anxious.	1	1		
47. S/he enjoys meeting new people.			1	1
48. S/he is a good diplomat.			1	1
49. S/he is not very good at			1	1

remembering people's date of birth.			
50. S/he finds it very easy to play games with children that involve pretending.		1	1

Protocol source: https://www.phenxtoolkit.org/protocols/view/120902