

## 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.

### Sleep Disturbances Scale for Children

**INSTRUCTIONS:** This questionnaire will allow your doctor to have a better understanding of the sleep-wake rhythm of your child and of any problems in his/her sleep behaviour. Try to answer every question; in answering, consider each question as pertaining to the past 6 months of the child's life. Please answer the questions by circling or striking the number 1 to 6. Thank you very much for your help.

1. How many hours of sleep does your child get on most nights?	(1)	(2)	(3)	(4)	(5)
	9-11 hours	8-9 hours	7-8 hours	5-7 hours	Less than 5 hours
2. How long after going to bed does your child usually fall asleep?	(1)	(2)	(3)	(4)	(5)
	Less than 15'	15-30'	30-45'	45-60'	More than 60'
	(1) Never	(2) Occasionally (once or twice per month)	(3) Sometimes (once or twice per week)	(4) Often (3 or 5 times per week)	(5) Always (daily)
3. The child goes to bed reluctantly.	(1)	(2)	(3)	(4)	(5)

4. The child has difficulty getting to sleep at night.	(1)	(2)	(3)	(4)	(5)
5. The child feels anxious or afraid when falling asleep.	(1)	(2)	(3)	(4)	(5)
6. The child startles or jerks parts of the body while falling asleep.	(1)	(2)	(3)	(4)	(5)
7. The child shows repetitive actions such as rocking or head banging while falling asleep.	(1)	(2)	(3)	(4)	(5)
8. The child experiences vivid dream-like scenes while falling asleep.	(1)	(2)	(3)	(4)	(5)
9. The child sweats excessively while falling asleep.	(1)	(2)	(3)	(4)	(5)
10. The child wakes up more than twice per night.	(1)	(2)	(3)	(4)	(5)
11. After waking up in the night, the child has difficulty to fall asleep again.	(1)	(2)	(3)	(4)	(5)
12. The child has frequent twitching or jerking of legs while asleep or often changes position during the	(1)	(2)	(3)	(4)	(5)

night or kicks the covers off the bed.					
13. The child has difficulty breathing during the night.	(1)	(2)	(3)	(4)	(5)
14. The child gasps for breath or is unable to breathe during sleep.	(1)	(2)	(3)	(4)	(5)
15. The child snores.	(1)	(2)	(3)	(4)	(5)
16. The child sweats excessively during the night.	(1)	(2)	(3)	(4)	(5)
17. You have observed the child sleepwalking.	(1)	(2)	(3)	(4)	(5)
18. You have observed the child talking in his/her sleep.	(1)	(2)	(3)	(4)	(5)
19. The child grinds teeth during sleep.	(1)	(2)	(3)	(4)	(5)
20. The child wakes from sleep screaming or confused so that you cannot seem to get through to him/her, but has no memory of these events the next morning.	(1)	(2)	(3)	(4)	(5)
21. The child has nightmares which he/she	(1)	(2)	(3)	(4)	(5)

doesn't remember the next day.					
22. The child is unusually difficult to wake up in the morning.	(1)	(2)	(3)	(4)	(5)
23. The child awakes in the morning feeling tired.	(1)	(2)	(3)	(4)	(5)
24. The child feels unable to move when waking up in the morning.	(1)	(2)	(3)	(4)	(5)
25. The child experiences daytime somnolence.	(1)	(2)	(3)	(4)	(5)
26. The child falls asleep suddenly in inappropriate situations.	(1)	(2)	(3)	(4)	(5)

**Scoring:**

- Disorders of initiating and maintaining sleep (sum the score of the items 1, 2, 3, 4, 5, 10, 11)
- Sleep Breathing Disorders (sum the score of the items 13, 14, 15)
- Disorders of arousal (sum the score of the items 17, 20, 21)
- Sleep-Wake Transition Disorders (sum the score of the items 6, 7, 8, 12, 18, 19)
- Disorders of excessive somnolence (sum the score of the items 22, 23, 24, 25, 26)
- Sleep Hyperhidrosis (sum the score of the items 9, 16)

Total score (sum 6 factors' scores)

Protocol source: <https://www.phenxtoolkit.org/protocols/view/121002>