



Name _____ Date _____

Weekdays: Typical bedtime _____ Typical wake up time _____

Weekends: Typical bedtime _____ Typical wake up time _____

You are being asked questions about symptoms of a possible sleep problem. Think about your last week while you were in school when choosing your answers.

Check "Often" if the symptom happens 3 times or more per week. Check "Sometimes" if the symptoms happens 1-3 times per week Check "Never" if you do not have the symptom.

Check "DNK" for do not know if you are not sure if you have the symptom.

	Often (3) (> 3/week)	Sometimes (2) (1-3/week)	Never (1) (Never noted)	DNK (0) (Do not know)
1. I fall asleep in class	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I miss things in class because I am sleepy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. My friends tell me I fall asleep easily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I fall asleep in the bus/car after school	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I ask to go to the nurse's office or somewhere quiet to sleep during the school day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I feel weak in the knees when I laugh with my friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. My voice slurs when I laugh hard	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My body feels weak briefly when I get excited or laugh	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I dream when I sleep at night	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. My dreams seem very real	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. When I wake up, I can't move for a few minutes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I write silly things when taking notes in class because I am sleepy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. It takes me a long time to do my homework because I am so tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Doing homework makes me tired	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Instructions

Add up total points in each column:

Often = 3 points

Sometimes = 2 points

Never = 1 point

Do not Know = Ask your provider to explain symptom if you are unsure how to respond.

Total Score (1–14): _____

Sleepiness Subscale Score (1–5, 12): _____

Interpretation

This screening questionnaire is not a substitute for medical advice and should not be used to diagnose or treat a health condition.

Total score >24 suggests high risk for narcolepsy or idiopathic hypersomnia. Please take this form to your health care provider or sleep medicine specialist to discuss your sleep related concerns.

Sleepiness Subscale Score >8 suggests severe daytime sleepiness. Please take this form to your health care provider to discuss your sleep related concerns.

Maski KP, Worhach J, Steinhart E, Boduch M, Morse AM, Strunc M, Scammell TE, Owens J, Jesteadt L, Crisp C, Williams D, Sideridis G. Development and Validation of the Pediatric Hypersomnolence Survey (PHS). *Neurology*. Accepted January 26, 2022.



Boston Children's Hospital

Where the world comes for answers



Sleep Center

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Dear Colleague:

Thank you for your interest in the Pediatric Hypersomnolence Survey (PHS). This survey was designed by a group of researchers led by Dr. Kiran Maski at Boston Children's Hospital for children and adolescents ages 8-18 years, to improve early identification of narcolepsy (type 1 and type 2) and idiopathic hypersomnia (IH). The PHS is a screening tool that can be used by clinical health providers, school professionals, and concerned family to help identify children and adolescents in need of further evaluation and testing for pediatric IH and narcolepsy. Of note, insufficient sleep for age and delays in bedtime/wake time (suggesting delayed circadian sleep phase) are more common causes of daytime sleepiness in children/adolescents and ideally should be corrected before screening.

Reliability and validity data has been collected on a sample of 331 participants. Included in the sample are patients with narcolepsy, IH, other sleep disorders, and healthy controls. The manuscript detailing the psychometric properties, validity, and reliability of the PHS will be published in the journal *Neurology* in May 2022.

Scoring: The PHS is a 14 item self-reported questionnaire with 4 domains (sleepiness, fatigue, REM related symptoms, and cataplexy). The PHS response options are "Often" =3 points, "Sometimes" =2 points, "Never" =1 point, and "Do Not Know" =0. If the response is "Do Not Know" the provider is encouraged to review symptoms in more detail with the patient for clarification. The sum of questions 1-5 and question 12 comprise a **Sleepiness Subscale Score**. The **Total PHS Score** is the sum of all items 1-14.

Analysis:

Total PHS Score: An ROC curve analysis identified a Total PHS cut-off score of 24 to identify CNS disorders of hypersomnolence (narcolepsy and IH) vs. healthy controls and other sleep disorders. At this cutoff score, the Total PHS score had a sensitivity of 81.3% (95% CI: 73.7-87.5) and specificity of 81.2% (95% CI: 75.10-86.4) for these CNS disorders of hypersomnolence. Because the PHS total score includes questions about cataplexy, the PHS total score may be best for identifying patients with narcolepsy type 1.

PHS Sleepiness Subscale Score: We encourage users to also calculate the PHS Sleepiness Subscale Score for evaluation of IH and narcolepsy type 2. A cut off score of 8 on the PHS Sleepiness Subscale Score has a sensitivity of 88.9% (95% CI 73.9-96.1) and specificity of 70.6% (95% CI 63.7-76.8) for IH. The sensitivity and specificity for narcolepsy type 2 specifically was not tested due to low sample size.

We would appreciate receiving feedback from you if you utilize the PHS in your clinical practice and research. You are also welcome to translate the instrument into other languages. It would be most helpful if you could forward a copy of any translations, so we can make these available to other researchers. You can contact us at NeuroSleepResearch-dl@childrens.harvard.edu.

Sincerely,

Kiran Maski, MD, MPH
Assistant Professor of Neurology, Harvard Medical School
Boston Children's Hospital