



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,

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