

**NINDS CDE Notice of Copyright  
Cambridge Brain Repair Centre (BRC) HD Sleep Questionnaire**

<b>Availability:</b>	<b>Please email the authors for information about obtaining the instrument:</b> <a href="mailto:anna.goodman@lshtm.ac.uk">anna.goodman@lshtm.ac.uk</a>
<b>Classification:</b>	Exploratory for Huntington's Disease (HD)
<b>Short Description of Instrument:</b>	<p><b>Summary/ Overview of Instrument:</b> A newly created instrument specifically designed for use with HD patients, this questionnaire was, in part, based on recent questionnaires used in Parkinson's disease. It contains 45 questions that focus on many aspects of sleep: duration, quality, quality of life, and abnormal sleep behaviors. The authors group the questions into four themed subcategories: quality of sleep, motor activity, abnormal nocturnal behavior and other aspects of disturbed sleep. The authors of this instrument have written comprehensive reviews of the literature in HD and have conducted prior studies of sleep in HD.</p> <p><b>Construct measured:</b> The total score is conceptualized as a measure of "sleep disturbance", but individual questions address a broad range of sleep problems.</p> <p><b>Generic vs. disease specific:</b> Developed specifically for Huntington's disease populations, though the questions do not specifically mention HD such that it could potentially be studied for possible use in other populations.</p> <p><b>Intended use of instrument/ purpose of tool:</b> To date the instrument has only been used in one cross-sectional study (primary reference) but the authors suggest that it might be useful in longitudinal studies. It is primarily proposed as a screen for sleep disturbance.</p> <p>Means of administration: Paper and pencil.</p> <p>Location of administration: Clinic or home.</p> <p>Intended respondent: Patient.</p> <p># of items: 45.</p> <p># of subscales and names of sub-scales: None.</p>
<b>Scoring:</b>	<p><b>Scoring:</b> A total sleep disturbance score is calculated using a number (but not all) of the questions in the questionnaire. The questions that count toward the total score were, in part, selected as they distinguished HD patients from controls in the primary reference study. A scoring sheet is appended to the original paper which identifies the items that count toward the total score as well as the points assigned to various options. Scores range from 0-19 and the authors recommend the following subgroup classifications: normal (0-3), mild (4-6) and significant sleep disturbance (7 and greater) with significant sleep disturbance being the classification that warrants further investigation and/or treatment when used as a screening measure in clinical settings.</p> <p><b>Standardization of scores to a reference population (z scores, T scores, etc):</b> Insufficient research.</p>

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<b>Psychometric Properties:</b>	<p><b>Reliability:</b> The primary reference study statistically tested for differences in individual questions and total scores between subject group (HD, caregivers and controls) but no analysis of the psychometric properties of this new instrument was reported to determine its reliability.</p> <p><b>Test-retest or intra-interview (within rater) reliability (as applicable):</b> Not available.</p> <p><b>Inter-interview (between-rater) reliability (as applicable):</b> Not available.</p> <p><b>Internal consistency:</b> Not available.</p> <p><b>Statistical methods used to assess reliability:</b> Not available.</p> <p><b>Validity:</b> While a number of questions effectively distinguished between an HD group and controls, no analyses of validity were reported in the primary reference study.</p> <p><b>Content validity:</b> Not available.</p> <p><b>Construct validity:</b> Not available.</p> <p><b>Sensitivity to Change/ Ability to Detect Change (over time or in response to an intervention):</b> Unknown.</p> <p><b>Known Relationships to Other Variables (e.g. gender, education, age, etc):</b> Unknown.</p> <p><b>Diagnostic Sensitivity and Specificity, if applicable (in general population, HD population- premanifest/ manifest, other disease groups):</b> Not intended for diagnosis of specific sleep disorders, but rather for clinical screening for sleep disturbance in Huntington’s disease.</p> <p><b>Strengths:</b> Specifically designed to screen for sleep disturbances in HD, simple to administer and brief.</p> <p><b>Weaknesses:</b> Psychometric properties (internal consistency, test-retest reliability, inter-interview reliability, construct validity) are unknown at present. Other than the primary reference study, no studies to date have used this instrument so that comparisons cannot be made with the literature of other populations. The sleep disturbance score, while based on items that distinguished HD patients and controls, may not be an effective measure for outcome studies as many items are dichotomous (yes/no) and do not allow for gradations of severity.</p>
	<p><b>Key Reference:</b> Goodman AO, Morton AJ, Barker RA. Identifying sleep disturbances in Huntington’s disease using a simple disease-focused questionnaire. PLoS Currents 2010; October 15. (Online access: <a href="http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2957697/">http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2957697/</a>)</p>