

NINDS CDE Notice of Copyright
Problem Behaviours Assessment for HD Short Version (PBA-S)

Availability:	Please email the author for information about obtaining the instrument: david.craufurd@man.ac.uk
Classification:	Core: Huntington's Disease (HD) Supplemental: Mitochondrial Disease (Mito)
Short Description of Instrument:	<p>Summary/ Overview of Instrument: Brief semi-structured interview covering the most common behavioural and psychiatric manifestations of HD.</p> <p>Construct measured: The interview is not restricted to a single construct, but rather covers several broad symptom domains (affect, irritability, loss of motivation, perseverative phenomena and psychotic symptoms) relevant to HD.</p> <p>Intended use of instrument/ purpose of tool: Cross-sectional or longitudinal studies. The interview is focused on symptoms rather than diagnoses and does not make assumptions about the diagnostic significance of these symptoms in the presence of organic brain disease (i.e. HD).</p> <p>Means of administration: Face to face semi-structured interview. The suggested approach is to complete the Problem Behaviours Assessment for HD Short Version (PBA-S) with the companion and participant together. After completing the scale the interviewer should speak with the companion without the participant present.</p> <p>Location of administration: Clinic or home.</p> <p>Intended respondent: Patient and knowledgeable informant (e.g. spouse or caregiver) together; the informant should be briefly re-interviewed afterwards to elicit any additional information which could not be discussed openly in presence of the patient.</p> <p># of items: 11 items (low mood, suicidal ideation, anxiety, irritability, anger/aggressive behaviour, loss of motivation, perseverative thinking or behaviour, obsessive-compulsive behaviours, paranoid thinking, hallucinations, behaviour suggestive of disorientation).</p> <p># of subscales and names of sub-scales: The PBA-S has not been formally divided up into subscales; however, principal components analysis of data obtained with the original 40-item Problem Behaviours Assessment for HD (PBA-HD) in both English (Craufurd <i>et al.</i>, 2001) and Dutch (Kingma <i>et al.</i>, 2007) translations identified three main factors corresponding to affective symptoms, irritability and apathy respectively. It would therefore be reasonable to add the scores for low mood, suicidal ideation and anxiety to create a single 'affect' score, and to add the scores for irritability and anger to create a composite 'irritability and aggression' score, as was done in the TRACK-HD study (Tabrizi <i>et al.</i>, 2009).</p> <p>Strengths: Obvious face validity (semi-structured interview covering the same core behavioural symptoms as the UHDRS behavioural section); demonstrated excellent inter-rater reliability in TRACK-HD study; suitable for use by all professionals familiar with HD (physician, psychologist, study nurse, etc.).</p> <p>Weaknesses: Investment of staff time for 25-minute interview; some training required.</p> <p>Administration Time: 20-25 minutes.</p> <p>Translations available: Available in English, Dutch, French, German, Norwegian and Spanish versions. Translation into other European languages in progress.</p>

NINDS CDE Notice of Copyright
Problem Behaviours Assessment for HD Short Version (PBA-S)

<p>Scoring:</p>	<p>Each symptom is rated for severity on a 5-point scale according to detailed scoring criteria which roughly correspond to the following: 0 = "not at all"; 1 = trivial; 2 = mild; 3 = moderate (disrupting everyday activities) and 4 = severe or intolerable. Each symptom is also scored for frequency on a 5-point scale as follows: 0 = symptom absent; 1 = less than once weekly; 2 = at least once a week; 3 = most days (up to and including some part of every day); and 4 = all day, every day. Severity and frequency scores are multiplied to produce an overall 'PBA score' for each symptom. Although it would be possible to sum the individual PBA symptom scores to derive an overall total score, it is unlikely that this is very meaningful. Standardization of scores to a reference population (z scores, T scores, etc): Not applicable.</p>
<p>Psychometric Properties:</p>	<p>Test-retest or intra-interview (within rater) reliability (as applicable): N/A.</p> <p>Inter-interview (between-rater) reliability (as applicable): inter-rater reliability was measured in the TRACK-HD study by video-recording interviews and re-scoring of a random sample by an expert rater. Overall unweighted kappa scores for the severity ratings were 0.70 and for the frequency ratings, 0.77. Kappa scores in the range 0.61 – 0.80 are usually considered to represent 'substantial agreement'.</p> <p>Internal consistency: N/A.</p> <p>Statistical methods used to assess reliability: Cohen's kappa.</p> <p>Validity: Difficult to assess because of the lack of an alternative 'gold standard' measure. The selection of symptoms for inclusion in the measure, and the development of the detailed scoring criteria used, were carried out by a group of experts from the EHDN Behavioural Phenotype Working Group. The range of symptoms covered by the measure is very similar to the behavioural section of the UHDRS, and the PBA-S is probably best thought of as the latest elaboration of the UHDRS behavioural interview.</p> <p>Sensitivity to Change/ Ability to Detect Change (over time or in response to an intervention): The longitudinal rate of change in PBA-S apathy scores over 24 months' follow-up was significantly greater in manifest HD subjects than in controls (Tabrizi et al., manuscript under review). Analysis of the TRACK-HD 36-month longitudinal data is in progress.</p> <p>Known Relationships to Other Variables: A paper describing relationships between PBA-S scores and those obtained using other symptom-specific measures in the TRACK-HD study is in preparation.</p> <p>Diagnostic Sensitivity and Specificity, if applicable (in general population, HD population- premanifest/ manifest, other disease groups): Developed for use with manifest HD population.</p>

NINDS CDE Notice of Copyright
Problem Behaviours Assessment for HD Short Version (PBA-S)

References:	<p>Key Reference: A paper describing the reliability of the PBA-S (in English, Dutch and French) based on data from the TRACK-HD study is in preparation and will be submitted shortly.</p> <p>Other References: Craufurd D, Thompson J, Snowden JS. Behavioural changes in Huntington's disease: the Problem Behaviours Assessment. <i>Neuropsychiatry, Neuropsychology and Behavioural Neurology</i> 2001; 14 (4): 219-226.</p> <p>Kingma EM, van Duijn E, Timman R, van der Mast RC, Roos RAC. Behavioural problems in Huntington's disease using the Problem Behaviours Assessment. <i>General Hospital Psychiatry</i> 2008; 30: 155-161.</p> <p>Tabrizi SJ, Langbehn DR, Leavitt BR, Roos RAC, Durr A, Craufurd D, Kennard C, Hicks SL, Fox NC, Scahill RI, Borowsky B, Tobin A, Rosas HD, Johnson H, Reilmann R, Landwehrmeyer GB, Stout JC and the TRACK-HD Investigators. Biological and clinical manifestations of Huntington's disease before and after diagnosis – the TRACK-HD study. <i>Lancet Neurology</i> 2009; 8 (9): 791-801. epub 2009 July 29.</p>
--------------------	--