

**NINDS CDE Notice of Copyright
Unified Huntington's Disease Rating Scale (UHDRS)**

Availability:	Please visit this website for more information about the instrument: Huntington Study Group website.
Classification:	Core: Huntington's Disease Note: The Functional Assessment Checklist, Independence Scale and Total Functional Capacity subtests are Supplemental – Highly Recommended Motor Function Assessments for diagnosed patients only
Short Description of Instrument:	The Unified Huntington's Disease Rating Scale (UHDRS) is a research tool which has been developed by the Huntington Study Group to provide a uniform assessment of the clinical features and course of HD. This Scale Consists of 6 Subtests: Motor Assessment. Cognitive Assessment. Behavioral Assessment. The Independence Scale. Functional Assessment. Total Functional Capacity. UHDRS 99: The UHDRS was updated in 1999 and represented improved effectiveness and applicability. *The Symbol Digit Modalities Test (SDMT) and The Stroop Test are also included in the UHDRS but must be acquired separately*.
Scoring	Each question is scored individually. For the Cognitive component, the following tests are scored: Verbal Fluency, Symbol Digit Modality, Stroop Interference Test. The modified motor score consists of the sum score of items 4-10 and 13-15 of the UHDRS motor assessments.
References:	Marder, K., et al., Rate of functional decline in Huntington's disease. Huntington Study Group. <i>Neurology</i> , 2000. 54(2): p. 452-8. Paulsen, J. S., Wang, C., Duff, K., Barker, R., Nance, M., Beglinger, L. et al. (2010). Challenges assessing clinical endpoints in early Huntington disease. <i>Mov Disord</i> , 25(15), 2595-2603. Beglinger, L. J., O'Rourke, J. J., Wang, C., Langbehn, D. R., Duff, K., Paulsen, J. S., et al. (2010). Earliest functional declines in Huntington disease. <i>Psychiatry Res</i> , 178(2), 414-418. Tabrizi SJ, Scahill RI, Durr A, et al. Biological and clinical changes in pre-manifest and early stage Huntington's disease in the TRACK-HD study: the 12-month longitudinal analysis. <i>Lancet Neurol</i> . Jan 2011;10 (1):31-42.

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Short Description of Instrument:	Total Functional Capacity (TFC)
Short Description of Instrument:	<p>The Total Functional Capacity (TFC) is a brief interview involving the participant and a close family member or friend familiar with the participant's functioning. The measure has 5 items and addresses basic activities of living: occupation, handling finances, domestic responsibilities, ADLs (eating, dressing, bathing), and Level of Care (home or facility).</p> <p>The TFC focuses on assessment of CAPACITY rather than actual performance. This places emphasis on the clinician's judgment and does not require rigorous documentation of performance. The TFC covers a wide range of basic aspects of daily living.</p> <p>The HDFCS is reported as the total TFC score. Higher scores on the function scales indicate better functioning than lower scores.</p>
Short Description of Instrument:	The Independence Scale
Short Description of Instrument:	<p>The Independence Scale is a useful clinical tool to follow disease progression in functional disability. It covers a wide range of functioning.</p> <p>The scale is rated from 100 (no special care needed) to 0 (tube-fed, total bed care); descriptors are provided to gauge function levels at every 10 points.</p>
Short Description of Instrument:	The Functional Assessment Checklist
Short Description of Instrument:	<p>This Checklist is a 25 question Assessment that screens for Capacity to complete the tasks mentioned in the Assessment alone. It is considered an extension of the Total Functional Capacity in that it is more detailed in certain tasks.</p> <p>It is a 5-10 minute interview and the questions are to be asked in the presence of a family or friend to get the clinician's best judgment based on both responses.</p> <p>The checklist is summed by giving a score of 1 to all "yes" replies. Higher scores on the function scales indicate better functioning than lower scores.</p>