We provide a review of a number of different concepts, including patient-reported outcome measures that assess health-related quality of life (HRQOL), other measures that are physician- or proxy-reported health-related quality of life, as well as more traditional measures that evaluate functional assessment (again including self report, proxy report, and physician report). Below, we include a brief definition of each of these constructs.

We define HRQOL as a multidimensional construct; it reflects the extent to which one’s usual or expected physical, emotional, and social well-being are affected by a medical condition or its treatment (Guyatt, 1993; Cella, 1995). While we define HRQOL as a multidimensional construct, this can be contrasted with quality of life (QOL), a less clearly defined unidimensional construct that evaluates general well-being or life satisfaction (Campbell, Converse, & Rodgers, 1976; Patrick & Erikson, 1988). Although, most researchers use HRQOL and QOL interchangeably, this distinction is important. We include measures that evaluate both constructs in this review.

We also include measures that assess functional activities, which is a broadly defined construct that includes an objective (performance-based) or subjective (self-report or physician report) assessment of an individual's mobility, transfer skills, and activities of daily living, including self-care, sphincter control, mobility, locomotion, and communication.

## CDE Recommendation Descriptions:

CDE recommendations were formulated using the three general descriptive levels of Core, Supplemental and Exploratory. Data elements described as Core are intended to encompass the minimal set of measures that are to be applied to all clinical and research studies concerning HD. Data elements described as Supplemental are measures that clinicians/researchers should consider when examining a particular construct (i.e., either functional assessment or quality of life). Finally, data elements described as Exploratory are either under development, or do not yet have validation data in HD. We describe these categories in more detail, below.

First, in order to be considered for inclusion as either a Core or Supplemental measure, a measure needed to have at least one peer-reviewed publication of its reliability and validity in an HD sample. A measure was identified as Core, only if there were multiple studies that supported the measure’s reliability and validity (as we are recommending that these measures be included in all HD studies). In this manner, only well-established measures were considered for the Core classification. Furthermore, a measure was identified as Supplemental only if it was fully developed and had published data in HD (as we are recommending that these measures be included in HD studies wishing to evaluate either functional assessment or HRQOL in greater depth/breadth or when examining more specialized subpopulations). Finally, a measure was identified as Exploratory if it was currently under development or is fully developed but not yet validated in HD (data elements described as Exploratory require development and validation, and may fill gaps in currently validated measures; these measures will need subsequent evaluation to determine if they will meet the criteria as a Core or Supplemental classification).

## CDE Recommendations:

Recommendations were made for the three aforementioned classifications (i.e., Core, Supplemental, and Exploratory) for two subdomains: Functional Assessment and Quality of Life Assessment. For Functional Assessment, we have elected to designate the following three measures from the Unified Huntington’s Disease Rating Scale (UHDRS) (Huntington Study Group, 1996) as Core: Total Functional Capacity (TFC), the Independence Scale and the Functional Assessment Scale. All three of these measures have extensive literature highlighting their utility (including strengths and weaknesses) in individuals’ with manifest HD. The group was unanimous with this recommendation. No designations were made for Supplemental measures for Functional Assessment. For Quality of Life, the group did not make any **Core** designations; there was general consensus that more work needs to be done before such recommendations can be made. We did elect to designate one measure as **Supplemental:** the Huntington’s Disease Quality of Life questionnaire (HDQoL; Hocaoglu, Gaffan & Ho AK, 2012). The HDQoL is a newly developed, HD-specific HRQOL measure.