



# Enroll-HD Data Dictionary

## Periodic and Specified Datasets

[includes variables from all data sources represented in PDS  
releases: Enroll-HD, REGISTRY, Ad Hoc]

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Enroll-HD

A worldwide observational study for Huntington's  
disease families

A CHDI Foundation Project

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# 1 Overview

This Data Dictionary is designed to accompany all Enroll-HD dataset releases, including periodic datasets (PDS) and specified datasets (SPS). Note that Enroll-HD dataset releases encompass data on Enroll-HD participants from several sources: Enroll-HD, REGISTRY study, and clinical data collected in adhoc visits outside of the aforementioned studies.

This document denotes each variable, including availability of the data in different types of datasets. A brief overview of constituent data sources, dataset structure, variable structure, and representation of special values is also provided.

We strongly encourage data users to thoroughly read the accompanying data support documentation for detailed descriptions of dataset structure, data quality control procedures and participant identification risk management, coding system descriptions, and data interpretation. Complete description of these important topics is out of scope of the current document.

## 2 Structure of the Dataset

### 2.1 Data Sources and Representation within the Dataset

Enroll-HD dataset releases encompass data on Enroll-HD participants collected from several sources, including: Enroll-HD, the European REGISTRY study, and clinical data collected in adhoc visits outside of the aforementioned studies. A brief overview of these data sources is described below.

**Enroll-HD (ENR)** is an observational cohort study and global clinical research platform designed to facilitate Huntington's disease (HD) clinical research. It includes participants from North America, Europe, Australasia, and Latin America. The study started in 2012 and is ongoing and actively recruiting.

**REGISTRY** is an observational cohort study of HD conducted mostly in Europe. The study started in 2004 and concluded in 2017. As Enroll-HD began, REGISTRY sites and participants transitioned into Enroll-HD. Enroll-HD dataset releases include a subset of individuals who initially participated in REGISTRY then consequently enrolled in Enroll-HD and consented to the migration of their REGISTRY data into the Enroll-HD dataset. The REGISTRY data included in this dataset were either obtained under the REGISTRY Protocol versions 1 and 2 (**R2**) or REGISTRY Protocol version 3 (**R3**). Specific forms and associated variables differ depending on which protocol was used at the time of data capture. Fields have been annotated with R2 or R3 as appropriate.

**Ad Hoc (RET)** data is available for a subset of Enroll-HD participants. These data were collected at routine clinical visits outside of the Enroll-HD and REGISTRY studies, and comprise HD assessment data (e.g., UHDRS Motor). The date of collection of these data typically pre-date a participant's enrolment into REGISTRY or Enroll-HD, hence the acronym RET for retrospective.

Data files are associated with one or several studies. The studies have been collected by different sponsors.

**Table 1.** Data sources within Enroll-HD dataset releases.

Study Name	Acronym	Chronological order
<i>Enroll-HD</i>	ENR	Enroll-HD is the most recent study a participant will have enrolled in. Participation in this study is mandatory for inclusion in the PDS
<i>REGISTRY V3</i>	R3	Participation in Registry v3 is optional. Participation in this study precedes Enroll-HD
<i>REGISTRY V2</i>	R2	Participation in Registry v2 is optional. Participation in this study precedes Enroll-HD, and Registry 3 (if available)
<i>Ad Hoc</i>	RET	Ad Hoc data are optional. These data are drawn from a variety of different sources, principally comprise UHDRS data, and are typically gathered prior to a participant's enrollment into Enroll-HD. Data are not collected under a specific study protocol.

## 2.2 Data Files within the Dataset

Enroll-HD PDS releases are comprised of 11 data files, each of which fall into one of three categories:

**Participant-based:** *profile, pharmacotx, nonpharmacotx, nutsuppl, comorbid*

These contain general study-independent information about the participant. This information is applicable to all studies.

**Study-based:** *participation, events*

These contain study specific information about a participant within a study. Note the data file *events* is a special data file for Enroll-HD which contains all the reportable events of a participant.

**Visit-based:** *enroll, registry, adhoc, assessment*

These contain all visit-dependent information for the study, combined into one data file.

Each PDS data file is described in Table 2.

**Table 2.** Enroll-HD dataset release data file descriptions.

Data file	Type	Studies	Description
<i>profile</i>	participant	ENR, R3, R2, RET	General participant related data, some of which may be annually updated. This includes: Demographics, HDCC (HD clinical characteristics), CAG, Mortality
<i>pharmacotx</i>	participant	ENR, R3, R2, RET	Information about pharmacological therapies
<i>nutssuppl</i>	participant	ENR, R3, R2, RET	Information about nutritional supplements
<i>nonpharmacotx</i>	participant	ENR, R3, R2, RET	Information about nonpharmacological therapies
<i>comorbid</i>	participant	ENR, R3, R2, RET	Information about comorbid conditions and surgeries
<i>participation</i>	study	ENR, R3, R2, RET	Provides study specific information about study participation. Includes participant identifier, participant status, study start day, study end day (in event of participant withdrawal or death). Note: If a participant is enrolled in several studies, one line per study is provided.
<i>event</i>	study	ENR	Enroll-HD study reportable event information
<i>assessment</i>	visit	ENR, R3, R2, RET	Visit-specific information about which assessments were performed at each visit (per study)
<i>enroll</i>	visit	ENR	Data from the Enroll-HD study
<i>registry</i>	visit	R3, R2	Data from both the REGISTRY3 and REGISTRY2 studies
<i>adhoc</i>	visit	RET	Ad Hoc data including: Variable, Motor, Function, TFC, MMSE, Cognitive assessment data



## 2.3 Entity Relation Diagram

The Enroll-HD dataset data file **entity relation diagram** is presented in Figure 1. This illustrates the **relationship** between each of the component data files, along with their **key variables** (primary keys [PK] and foreign keys [FK]) which are required to **combine** the data files.

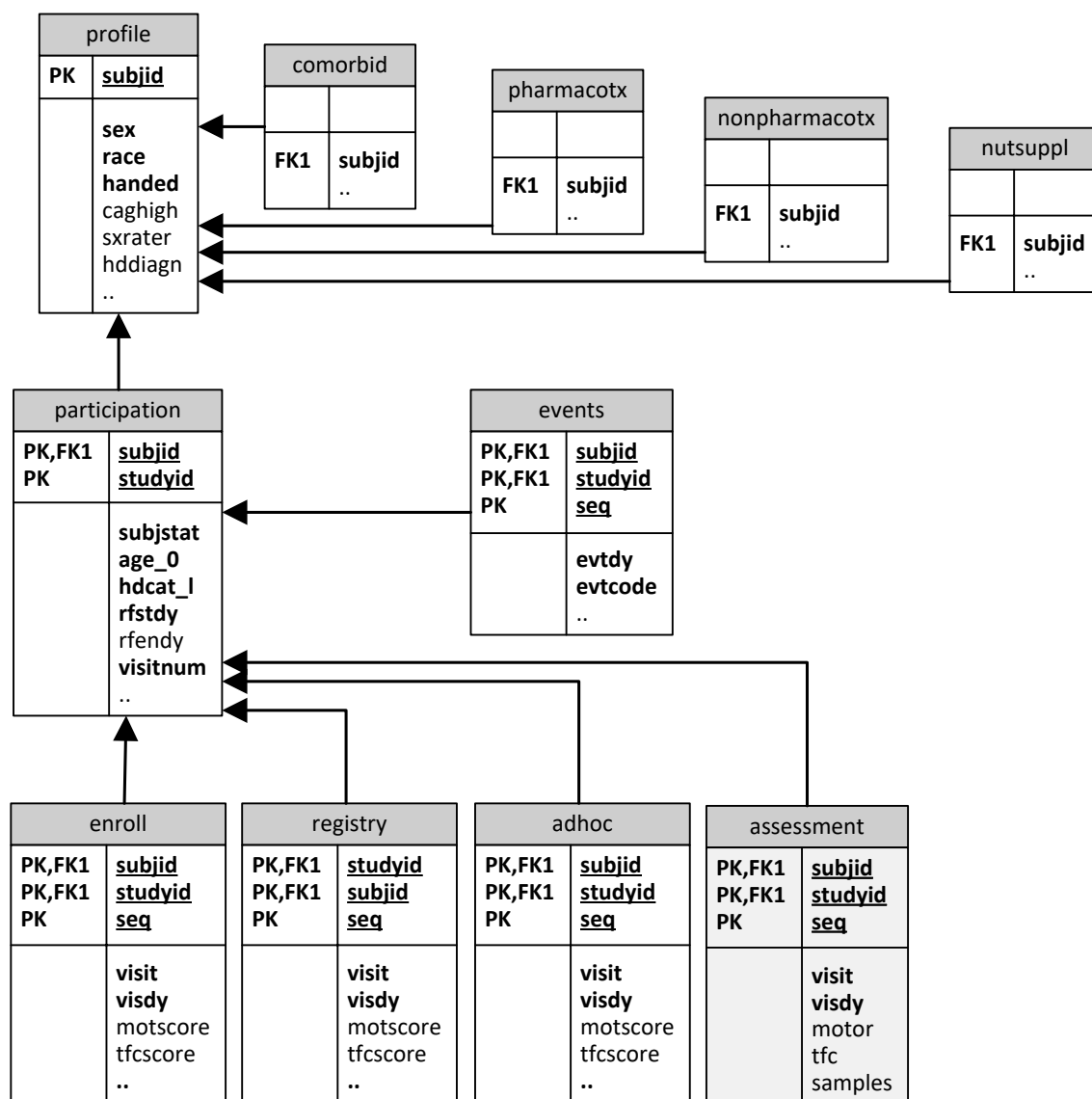


Figure 1: Entity Relationship Diagram.

## 2.4 Structure of Variables

Each Enroll-HD dataset file contains variables. This Data Dictionary lists all variables by form with the appropriate attributes. A list of the attribute types are provided in Table 3.

**Table 3.** Data dictionary column fields.

Attribute	Description
Label	Variable label (CDISC SDTM compliant)
Domain	Assigned CDISC SDTM Domain
Category	Assigned CDISC SDTM Category (optional)
Variable	Internal variable name. Variable is defined in CDISC SDTM compliant naming convention or as close as possible.
Data Type	<p><i>Boolean</i>: Represents the values 1 (yes) and 0 (no).</p> <p><i>Number</i>: Represents integer or floating-point data values.</p> <p><i>Text</i>: Represents alphanumeric string data values.</p> <p><i>Date</i>: The date type is represented as the number of days relative to the date of the participant's Enroll-HD baseline visit date. Note that dates that have been specified in the original data as "incomplete" (e.g. without entry of a day ) have been automatically completed by the following rule: use "15" as day if day is missing and use "1" as day and "7" as month if day and month is missing. After the date modification is complete, the number of days relating to the enrollment date is calculated and provided in the dataset. The information about whether a date has been automatically completed is not included in the PDS but can be obtained via SPS request.</p> <p><i>Single choice</i>: Variable with assigned list of options where one item can be selected. The value provided in the dataset is taken from the available options list. The list of options is defined as parameters in the data dictionary tables.</p>
Parameter	Parameter value of coded variables (optional).
Coding	Internal parameter value of coded variables (optional).
Unit	Unit of input field (optional).
Transformation	One important objective of the periodic dataset is to de-identify the Enroll-HD data in order to minimize the possibility to identify a participant. Therefore, many variables are transformed, recoded or outliers removed/cut. These transformations are described on a variable by variable basis.
Availability	All variables in the Enroll-HD dataset are listed in the Data Dictionary. This availability column allows the researcher to identify which variables are available in the PDS ("PDS"), which are available via special request ("available upon SRC approval"), and which are restricted ("not available").

## 2.5 Representation of Special Values

### Date Values

#### *Transformation of date values*

To minimize participant identification risk, the Enroll-HD PDS does not contain date values.

Date values referring to visit dates are transformed to a **numeric value**, reflective of the number of days between the Enroll-HD **baseline visit date** and the date of interest. Date values that refer to date of birth or symptom onset are transformed into age values.

Note that date values are **negative** if the date refers to a point in time before Enroll-HD enrollment. This is typical for start dates of medications and comorbid conditions, and visit dates in other studies (e.g., Registry).

For example, date values for a participant with a baseline enrollment date of 2020-11-01 (YYYY-MM-DD) would read as follows:

Entered date for e.g. a medication	Representation in dataset
2020-11-01	0
2020-11-30	29
2020-10-31	-1

#### *Imputation of date values/Autocompletion*

Incomplete date values were **imputed** according to the following rules:

Day is missing: YYYY-MM-**DD**(missing): YYYY-MM-15

Month and day are missing: YYYY-**MM**(missing)-**DD**(missing): YYYY-07-01

For example, date values for a participant with a **baseline enrollment date** of 2020-11-01 (YYYY-MM-DD) would read as follows:

Entered date	Imputed date	Representation in dataset
2020-11-01	N/A	0
2020-11	2020-11-15	14
2020	2020-07-01	-123

Note that because of these imputation rules, events with clear temporal definition sometimes appear **out of sequence** or have the **same date** values. For example, end dates may appear prior to, or on the same day as, start dates for comorbidities and pharmacotherapies. For example:

Entered start date	Imputed start date	Entered end date	Imputed end date	Date differential (days)
2020-11-01	N/A	2020-11	2020-11-15	14
2020-11	2020-11-15	2020-11	2020-11-15	0
2020	2020-07-01	2020-06-15	N/A	-16

## Missing Values

There are two overarching categories of missing data in the dataset: **system-defined** missing data (indicated by blank variable 'entries'), and **user-defined** missing data (indicated by specific codes, which indicate reason for missingness).

**System defined** missing data occurs where the electronic data capture (EDC) system dictates a missing variable field. These missing data values are indicated by **blank entries** in the dataset.

**User defined** missing data occur where a mandatory variable field, as determined by the EDC system, is **not completed**, or where the value entered into the EDC is **incorrect**. In these instances, data entry users are prompted to indicate why the value is missing, or why the value entered is not correct. These user-defined labels - 'exceptional values' – are listed below. Each is represented in the dataset by a **specific code**:

- **Unknown** (entered by the site, only available for specific fields): 9999 (numeric); UNKNOWN (text)

Refers to mandatory values which are **occasionally unknown**. This exceptional value code may be selected as a response to the question, "Is/was your Mother affected by HD? (response: yes/no/unknown)", where a participant did not know their mother.

- **Missing** (value expected, but not entered): 9998 (numeric); MISSING (text); 9998-09-09 (date)

Refers to mandatory values which could not be completed because **data collection was not performed**. This code may be used if a participant refuses to provide a response, if the collection of data was accidentally omitted, or if a value could not be obtained because required instrumentation was not available.

- **Not applicable** (value expected, but not entered): 9997 (numeric); NOTAPPL (text); 9997-09-09 (date)

Refers to mandatory values which could not be completed because they **do not apply to the participant due to certain circumstances or characteristics**. For example, the question “Age at onset of symptoms in mother” for the mother who is still premanifest and does not have symptoms yet shall be answered as not applicable. The variable value is **purposefully** not entered. **Note the distinction between this value and system-defined missing values is that the *user*, as opposed to the EDC *system*, marks them as non-applicable.**

- **Wrong** (value was entered, but declared as wrong by the site. Entered value excluded from dataset): 9996 (numeric); WRONG (text); 9996-09-09 (date)

Refers to mandatory values which are entered into the EDC and then identified **to be wrong or highly questionable**. This may be because data were collected by the wrong person (e.g., assessment performed by untrained site member), faulty instrumentation (e.g., uncalibrated weighing scales), etc. Although these data are not technically missing, they are recoded as wrong using the codes indicated above for PDS releases.

## Artificial Values for Aggregated Data

To minimize participant identification risk, **data aggregation techniques** are applied to specific variables for PDS releases. These variables, and the criteria/thresholds used for aggregation in PDS5, are described in the table below.

Note that aggregation **thresholds differ between PDS releases**. Changes in the Enroll-HD cohort size and profile allow for such aggregation threshold adjustments while maintaining low identification risk thresholds.

***Table:** Aggregated variables and aggregation thresholds.*

Data file	Variable	Variable label	Criteria for aggregation
<i>participation</i>	<i>age_0</i>	Age at enrollment	<18
<i>enroll, registry, adhoc</i>	<i>age</i>	Age at visit	<18
<i>profile</i>	<i>caghigh</i>	Research larger CAG allele determined from DNA	>70
<i>profile</i>	<i>caglow</i>	Research smaller CAG allele determined from DNA	>28
<i>profile</i>	<i>race</i>	Ethnicity	Fewer than 100 cases per category

Where values fall outside of aggregation thresholds, these values are represented by one artificial value.

The ***Understand and Interpret the Data*** document provides additional detail on handling aggregated values.

## 2.6 Data availability

This Data Dictionary details *all* variables collected in Enroll-HD.

**Periodic datasets (PDS)**, prepared from the Enroll-HD electronic data capture (EDC) database every 1-2 years, include the *majority of variables* collected. Variables included in the PDS are highlighted in green. Each Enroll-HD PDS goes through stringent quality control and de-identification procedures prior to release. To this end, certain variables are transformed, aggregated, or suppressed (excluded) in each PDS to minimize participant identification.

Access to non-transformed, deaggregated, or suppressed data may be obtained via **specified dataset (SPS)** request, pursuant to review and approval by the Enroll-HD Scientific Review Committee (SRC). These variables are highlighted in orange.

Finally, certain variables are restricted, typically due to their highly identifying nature. These variables, highlighted in red, and not available via PDS or SPS request, but are included here for completeness.

The variable column 'Availability' indicates these three classes of variables using the color-coding shown below.

Availability	Meaning
PDS	Included in the PDS
Available upon SRC approval	Not included in the PDS but available via SPS request contingent on SRC approval
Not available	Restricted variables which are not available in the PDS or via SPS request

### 3 Participant-Based Data Files

Participant-based data files are directly related to a participant independent of a study, i.e. the data is not assessed during a specific study visit. The data is either captured only once or in a periodically (e.g. annually) updated manner.

There are the following participant-based data files:

- profile
- pharmacotx
- nonpharmacotx
- nutsuppl
- comorbid

In general, these data files may contain one, more than one or no entry per participant. Different entries are characterized by an index (variable “seq”).



### 3.1 Data File “profile” (Participant Profile)

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR	---	Subjid	text				one-way transformation from HDID to HDID (recoded).	PDS
Region (latest)	---	ENR	---	region	text	- Europe - Latin America - Northern America - Australasia				PDS

#### 3.1.1 Form “Demographics (Demog)”

This form is part of the General visit.

##### Section Demographics (invariable)

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Gender	DM	ENR		sex	single choice	- female - male	- f - m			PDS
Ethnicity	DM	ENR		race	single choice	- American Indian/ Native American/ Amerindian	- 8			Available upon SRC approval

						- Alaska Native/Inuit	- 5			
						- African - North	- 12			
						- African - South	- 11			
						- American – Black	- 2			
						- Asian - West	- 13			
						- Asian – East	- 14			
						- Caucasian	- 1			
						- Native Hawaiian or Other Pacific Islander	- 4			
						- Hispanic or Latino Origin	- 3			
						- Mixed	- 15			
						- Other	- 6			
Ethnicity	DM	ENR		race	single choice	- Caucasian	- 1		Original values from eCRF are aggregated for de-identification reasons.	PDS
						- American Black	- 2			
						- Hispanic or Latino Origin	- 3			
						- American Indian/ Native American/ Amerindian	- 8			
						- Mixed	- 15			
						- Asian	- 16			
						- Other	- 6			
Handedness	SC	ENR		handed		- right	- 1			PDS

					single choice	- left - mixed	- 2 - 3			
Previous suicidal ideation or attempts?	MH	ENR		hxsid	boolean	- yes - no - unknown	- 1 - 0 - 9999			PDS

### 3.1.2 Form “Mortality”

This form is part of the General visit.

#### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	DS	ENR	Mortality	dsdte	date					Not available
Assessment day	DS	ENR	Mortality	dsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval

#### Section Death Report Form

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date of death	SUPPDS	ENR	Mortality	dssdte	number					Not available

Year of death	SUPPMH	ENR	FHx	deathy	number			Year		Not available
Age of death	SUPPDS	ENR	Mortality	dssage	number			Years	Age at death, e.g. "75" Calculated from date of birth and date of death	PDS
Place of death	SUPPDS	ENR	Mortality	dsplace	single choice	- home - hospital - nursing home - hospice care	- 1 - 2 - 3 - 4			PDS
Cause of death	SUPPDS	ENR	Mortality	dsend	single choice	- pneumonia - other infection - cancer - stroke - trauma - suicide - other	- 1 - 2 - 3 - 4 - 5 - 6 - 7			PDS
Please specify	SUPPDS	ENR	Mortality	dsendoth	text					Not available
Was an autopsy performed?	SUPPDS	ENR	Mortality	dsautop	single choice	- no - yes	- 0 - 1			Available upon SRC approval
Result of autopsy	SUPPDS	ENR	Mortality	dsautopr	text					Not available
	SUPPDS	ENR	Mortality	dsinfo		- spouse/family	- 1			

Information obtained primarily from					single choice	- friend - physician/nurse - patient's medical record - obituary in newspaper - death certificate - other	- 2 - 3 - 4 - 5 - 6 - 7			Available upon SRC approval
Please specify	SUPPDS	ENR	Mortality	infooth	text					Not available
Comments?	SUPPDS	ENR	Mortality	dscom	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Comment	CO	ENR	Mortality	coval	text					Not available

### 3.1.3 Form “CAG Report (CAG)”

This form is part of the General visit.

#### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date of report	LB	ENR	Local CAG	lbdtc	date					Not available

Day of report	LB	ENR	Local CAG	lbdy	number			Days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
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### Section CAG Analysis

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Specimen type	LB	ENR		lbspec	single choice	- blood - brain (postmortem)	- 1 - 2			Available upon SRC approval
Source of information	LB	ENR		lbsrc	single choice	- laboratory report - medical records/ correspondence - participant/ companion self-report	- 1 - 2 - 3			Available upon SRC approval
Group CAG analysis results (number of CAG repeats)										
Were the exact repeat lengths given?	SUPPLB	ENR		lbrpt	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Allele 2 (larger allele)										
CAG repeat length	LB	ENR		allele2l	number				Local CAG result	Not available
Tolerance	LB	ENR		allele2t	single choice	- 0 - 1 - 2 - 3	- 0 - 1 - 2 - 3			Not available

						- 4 - 5 - 6 - 7 - 8 - 9	- 4 - 5 - 6 - 7 - 8 - 9			
Group Allele 1 (smaller allele)										
CAG repeat length	LB	ENR		allele1l	number				Local CAG result	Not available
Tolerance	LB	ENR		allele1t	single choice	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9			Not available
HD Classification (larger allele)	LB	ENR		lbrng	single choice	- normal - <27 - 27-35 - 36-39 - >35 - >36 - >37	- 1 - b27 - 27_35 - 36_39 - a35 - a36 - a37			Not available

						- >38 - >39 - >40	- a38 - a39 - a40			
Analyzing laboratory	LB	ENR		lbnam	text					Not available
Comments	LB	ENR		cmt	boolean	- yes - no	- 1 - 0			Not available
Enter comment	LB	ENR		coval	text					Not available

### 3.1.4 Research Genotyping

This information is not part of the Enroll-HD EDC

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Larger research CAG allele determined from DNA as determined at central lab	SC	ENR		caghigh	text				Aggregation: Values greater than 70 are represented as ">70" .	PDS
Smaller research CAG allele determined from DNA as determined at central lab		ENR		caglow	text				Aggregation: Values greater than 28 are represented as ">28", others as numbers.	PDS



### 3.1.5 Form “HD Clinical Characteristics (HD CC)”

This form is part of the General visit.

#### Section Family History

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Mother affected	MH	ENR		momhd	single choice	- yes - no - unknown	- 1 - 0 - 9999			PDS
Age at onset of symptoms in mother	MH	ENR		momagesx	number			years		PDS
Father affected	MH	ENR		dadhd	single choice	- yes - no - unknown	- 1 - 0 - 9999			PDS
Age at onset of symptoms in father	MH	ENR		dadagesx	number			years		PDS
Enter comment	MH	ENR		fhxcmnt	text					Not available
Availability of family History pedigree diagram	SC	ENR		fhx	boolean	- yes - no	- 1 - 0			PDS

### Section History of Motor Symptoms

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Have motor symptoms compatible with HD ever been a part of the participant's medical history?	MH	ENR		ccmtr	boolean	- yes - no	- 1 - 0			PDS
Group At what age did the participant's motor symptoms begin?										
age (years)	SUPPMH	ENR		ccmtrage	number					PDS
year of onset	MH	ENR		ccmtryr	number					Not available

### Section HD History – Participant and Family

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Symptoms first noted by participant	MH	ENR		sxsubj	number				Convert to age, e.g. "41"	PDS
Initial major symptom	MH	ENR		sxsubjm	single choice	- motor - cognitive - psychiatric	- 1 - 2 - 3			PDS

noted by participant						- oculomotor - other - mixed	- 4 - 5 - 6			
Group Mixed symptoms										
Motor	MH	ENR		sxs_m	boolean	- yes	- 1			PDS
Cognitive	MH	ENR		sxs_c	boolean	- yes	- 1			PDS
Psychiatric	MH	ENR		sxs_p	boolean	- yes	- 1			PDS
Oculomotor	MH	ENR		sxs_o	boolean	- yes	- 1			PDS
Symptoms first noted by family	MH	ENR		sxfam	number				Convert to age, e.g. "41"	PDS
Initial major symptom noted by family	MH	ENR		sxfamm	single choice	- motor - cognitive - psychiatric - oculomotor - other - mixed	- 1 - 2 - 3 - 4 - 5 - 6			PDS
Group Mixed symptoms										
Motor	MH	ENR		sxf_m	boolean	- yes	- 1			PDS
Cognitive	MH	ENR		sxf_c	boolean	- yes	- 1			PDS
Psychiatric	MH	ENR		sxf_p	boolean	- yes	- 1			PDS
Oculomotor	MH	ENR		sxf_o	boolean	- yes	- 1			PDS

### Section HD History - Rater

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
-------	--------	-------	-----	----------	------	-----------	--------	------	----------------	--------------

Date of clinical HD diagnosis	MH	ENR		hddiagn	number				Convert to age, e.g. "41"	PDS
Can you, as a rater, estimate the time of symptom onset	MH	ENR		sxest	boolean	- yes - no	- 1 - 0			PDS
Rater's estimate of symptom onset	MH	ENR		sxrater	number				Convert to age, e.g. "41"	PDS
Confidence with which this estimation is made	MH	ENR		sxestcfd	single choice	- high - low	- 1 - 2			PDS
Please specify why you, as a rater, can not estimate symptom onset (without additional external information) at the moment	MH	ENR		sxreas	single choice	- participant can not provide information (mute, or cognitively too impaired) - information provided deemed unreliable	- 1  - 2			PDS

What is your best guess of how many years ago symptom onset took place	MH	ENR		sxgs	single choice	- < 5 - < 10 - < 15 - < 20 - > 20	- 1 - 2 - 3 - 4 - 5			PDS
Date of data entry	MH	ENR		sxgsdte	date					Not available
Day of data entry	MH	ENR		sxgsdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Group What are these symptoms?										
Rater's judgement of initial major symptom	MH	ENR		sxraterm	single choice	- motor - cognitive - psychiatric - oculomotor - other - mixed	- 1 - 2 - 3 - 4 - 5 - 6			PDS
Group Mixed symptoms										
Motor	MH	ENR		sxr_m	boolean	- yes	- 1			PDS
Cognitive	MH	ENR		sxr_c	boolean	- yes	- 1			PDS
Psychiatric	MH	ENR		sxr_p	boolean	- yes	- 1			PDS
Oculomotor	MH	ENR		sxr_o	boolean	- yes	- 1			PDS

## Section HD Clinical Characteristics and Age-of-Onset

Each estimate of symptom onset should be based on ALL available sources of information including reports of participant, companions, case notes and clinical rating scales.

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Has depression (includes treatment with antidepressants with or without a formally-stated diagnosis of depression) ever been a part of the participant's medical history?	MH	ENR		ccdep	boolean	- yes - no	- 1 - 0			PDS
Group At what age did the depression begin?										
age (years)	SUPPMH	ENR		ccdepage	number					PDS
years of onset	SUPPMH	ENR		ccdepyr	number					Not available
Has irritability ever been a part of the participant's	MH	ENR		ccirb	boolean	- yes - no	- 1 - 0			PDS

medical history?										
Group At what age did the irritability begin?										
age (years)	SUPPMH	ENR		ccirbage	number					PDS
years of onset	SUPPMH	ENR		ccirbyr	number					Not available
Has violent or aggressive behaviour ever been a part of the participant's medical history?	MH	ENR		ccvab	boolean	- yes - no	- 1 - 0			PDS
Group At what age did violent or aggressive behaviour begin?										
age (years)	SUPPMH	ENR		ccvabage	number					PDS
years of onset	SUPPMH	ENR		ccvabyr	number					Not available
Has apathy ever been a part of the participant's medical history?	MH	ENR		ccapt	boolean	- yes - no	- 1 - 0			PDS
Group At what age did apathy begin?										
age (years)	SUPPMH	ENR		ccaptage	number					PDS
years of onset	MH	ENR		ccaptyr	number					Not available
	MH	ENR		ccpob	boolean	- yes	- 1			PDS

Has perseverative obsessive behaviours ever been a part of the participant's medical history						- no	- 0			
Group At what age did perseverative obsessive behaviour begin?										
age (years)	SUPPMH	ENR		ccpobage	number					PDS
years of onset	MH	ENR		ccpoby	number					Not available
Has psychosis (hallucinations or delusions) ever been a part of the participant's medical history	MH	ENR		ccpsy	boolean	- yes - no	- 1 - 0			PDS
Group At what age did psychosis (hallucinations or delusions) begin?										
age (years)	SUPPMH	ENR		ccpsyage	number					PDS
years of onset	MH	ENR		ccpsy	number					Not available
Does the participant have a family	MH	ENR		ccpsyfh	boolean	- yes - no	- 1 - 0			PDS



history of a psychotic illness in a first degree relative										
Has significant cognitive impairment (severe enough to impact on work or activities of daily living) or dementia ever been a part of the participant's medical history	MH	ENR		cccog	boolean	- yes - no	- 1 - 0			PDS
Group At what age did cognitive impairment first start to have an impact on daily life?										
age (years)	SUPPMH	ENR		cccogage	number					PDS
years of onset	MH	ENR		cccogyr	number					Not available

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Additional GWAS data available		ENR		xgwas	boolean	- yes - no	- 1 - 0			PDS

Additional biosamples available		ENR		xbsp	boolean	- yes - no	- 1 - 0			PDS
Additional phenotypic data available		ENR		xpheno	boolean	- yes - no	- 1 - 0			PDS
Additional morphometric data available		ENR		xmorpho	boolean	- yes - no	- 1 - 0			PDS
Raw images available		ENR		ximage	boolean	- yes - no	- 1 - 0			PDS

### 3.2 Data File “pharmacotx (Pharmacotherapy)”

Label	Domain	Study	Category	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR		subjid	text				One-way transformation from HDID to HDID (recoded).	PDS
Drug name – Entered Term	CM	ENR		cmtrt__term	text					Not available

Drug name – Modified Term	CM	ENR		cmtrt__modify	text				Drug name	PDS
Drug name - Code	CM	ENR		cmtrt__decode	text				Enroll-HD specific drug code	PDS
Ingredient – Modified Term	CM	ENR		cmtrt__ingredient	text				comma “,” separated list	PDS
Drug ATC Code (coded by ATC)	CM	ENR		cmtrt__atc	text				comma “,” separated list	PDS
Drug name – Certainty	CM	ENR		cmtrt__certainty	text					Not available
Indication - Term	CM	ENR		cmindc__term	text					Not available
Indication – Modified Term	CM	ENR		cmindc__modify	text				Modified term in English.	PDS
Indication - Code	CM	ENR		cmindc__decode	text					PDS
Indication - Certainty	CM	ENR		cmindc__certainty	text					Not available
Dose / Unit (dose of one intake)	CM	ENR		cmdose__commandtext	text					Available upon SRC approval
Total daily dose	CM	ENR		cmdostot	number				Transformed value,	PDS

									calculated from dose and daily intake.	
Unit (unit of one intake)	CM	ENR		cmdose__cmdosu	text					PDS
Daily intake	SUPPCM	ENR		cmfrq	number array	- in the morning - at noon - in the evening - at night		- 1 - 2 - 3 - 4		Available upon SRC approval
Frequency	CM	ENR		cmdosfrq	single choice	- daily - every 2nd day - every 3rd day - weekly - every 2nd week - monthly - every 2nd month - every 3rd month - annually - as needed		- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10		PDS
Route	CM	ENR		cmroute	single choice	- p.o. - p.r. - s.c. - i.m. - i.v. - nasal - td		- 1 - 2 - 3 - 4 - 5 - 6 - 7		PDS

						- sl - inh - other		- 8 - 9 - 10		
Start date	CM	ENR		cmstdtc	date					Not available
Start day	CM	ENR		cmstdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Ongoing	CM	ENR		cmenrf	boolean	- yes - no		- 1 - 0		PDS
Stop date	CM	ENR		cmendtc	date					Not available
End day	CM	ENR		cmendy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS

### 3.3 Data File “nonpharmacotx (Non-Pharmacologic Therapies)”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR		subjid	text				One-way transformation from HDID to HDID (recoded).	PDS

Therapy	CM	ENR		cmtrt	single choice	- Physical therapy - Occupational therapy - Psychotherapy - Counseling - Speech Language therapy - Swallowing therapy - Music therapy - Relaxation therapy (meditation, massage, yoga, etc.) - Acupuncture	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9			PDS
Number of times	SUPPCM	ENR		cmfrq	number					PDS
Frequency	CM	ENR		cmdosfrq	single choice	- daily - weekly - monthly - as needed	-1 -2 -3 -4			PDS
Start date	CM	ENR		cmstdtc	date					Not available
Start day	CM	ENR		cmstdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Ongoing	CM	ENR		cmenrf	boolean	- yes	- 1			PDS

						- no	- 0			
Stop date	CM	ENR		cmendtc	date					Not available
End day	CM	ENR		cmendy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS

### 3.4 Data File “nutsuppl (Nutritional Supplements)”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR		subjid	text				One-way transformation from HDID to HDID (recoded).	PDS
Type	CM	ENR		cmcat	single choice	- vitamin & supplements - herbs (extracts) - herbs (teas) - other natural remedies - aromatherapies - homeopathic remedies - high calorie diet	- 1 - 2 - 3 - 4 - 5 - 6 - 7			PDS

NutSuppl Supplement – Modified Term	CM	ENR		cmtrt__modify	text					PDS
NutSuppl Supplement – Code	CM	ENR		cmtrt__decod	text					PDS
NutSuppl Supplement - ATC Code(s)	CM	ENR		cmtrt__atc	text					PDS
NutSuppl Supplement - ingredient(s)	CM	ENR		cmtrt__ing	text					PDS
Dose	CM	ENR		cmdostxt	number					Available upon SRC approval
Total daily dose	CM	ENR		cmdostot	number					PDS
Unit	CM	ENR		cmdosunit	single choice	- g - mg - IU - spoons - tablets - drops - capsule - other	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8			PDS
Daily intake	SUPPCM	ENR		cmfrq		- in the morning	- 1			



					number array	- at noon - in the evening - at night	- 2 - 3 - 4			Available upon SRC approval
Frequency	CM	ENR		cmdosfrq	single choice	- daily - every other day - every third day - weekly - every other week - monthly - every other month - every quarter - annually - as needed	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			PDS
Start date	CM	ENR		cmstdtc	date					Not available
Start day	CM	ENR		cmstdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Ongoing	CM	ENR		cmenrf	boolean	- yes - no	- 1 - 0			PDS
Stop date	CM	ENR		cmendtc	date					Not available

End day	CM	ENR		cmendy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
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### 3.5 Data File “comorbid (Comorbid Conditions)”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR		subjid	Text				One-way transformation from HDID to HDID (recoded).	PDS
Condition – Term (coded with ICD10 or MedDRA)	MH	ENR	mhx	mhterm	text array	- Term - Modified Term - Code - Certainty	- term - modify - decod - certainty			Not available
Condition – Modified Term (coded with ICD10 or Internal condition code)	MH	ENR	mhx	mhterm__modify	text				Comorbid conditions coded with ICD-10, surgeries and procedures coded with Internal condition code	PDS

									Modified term provided in English.	
Condition – Code (coded with ICD10 or Internal condition code)	MH	ENR	mhx	mhterm__decode	text					PDS
Condition – Code (coded with MedDRA or ICD-10)	MH	ENR	mhx	mhterm__decode	text				MedDRA codes are made available upon proof of license.	Available upon SRC approval
Condition – Certainty (coded with ICD10)	MH	ENR	mhx	mhterm__certainty	text					Not available
Body system code	MH	ENR	mhx	mhbodsys	single choice	<ul style="list-style-type: none"> <li>- cardiovascular</li> <li>- pulmonary</li> <li>- neurologic</li> <li>- ENT</li> <li>- gynecologic urologic</li> <li>- reproductive</li> <li>- gastrointestinal</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> <li>- 6</li> <li>- 7</li> </ul>			PDS

						- metabolic endocrine	- 8			
						- hemato lymphatic	- 9			
						- dermatological	- 10			
						- psychiatric	- 11			
						- musculoskelatal	- 12			
						- allergy immunologic	- 13			
						- ophthalmological	- 14			
						- hepatobiliary	- 15			
						- renal	- 16			
						- other	- 17			
Start date	MH	ENR	mhx	mhstdtc	date					Not available
Start day	MH	ENR	mhx	mhstdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Ongoing	MH	ENR	mhx	mhenrf	boolean	- yes - no	- 1 - 0			PDS
End date	MH	ENR	mhx	mhendtc	date					Not available
End day	MH	ENR	mhx	Mhendy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS

## 4 Study-Based Status, Participation, Assessment and Events Files

### 4.1 Participants' Status

A participant that is enrolled in the Enroll-HD study has a well-defined status at a certain point in time. A participant's status describes the progress of the participant in the study:

Participant Status	Description
<b>enrolled</b>	Participant is currently participating in the study.
<b>completed</b>	Completion of the study. Currently, the only possible completion <b>in the Enroll-HD study</b> is the death of the participant.
<b>excluded</b>	Screen failure, i.e. violation of an in- or exclusion criteria. Currently there are no inclusion criterias and only one exclusion criteria for "community controls".
<b>withdrawn</b>	Premature end of study (dependent on specific termination reasons given within the <i>End</i> form [data file <i>Premature End</i> or <i>Phone Contact</i> ]).
<b>violation</b>	Premature end of study (dependent on specific termination reasons given within the <i>End</i> form [data file <i>Premature End</i> or <i>Phone Contact</i> ]).

## 4.2 Data File “participation”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR		subjid	Text				One-way transformation from HDID to HDID (recoded).	PDS
Study ID	---	ENR R2 R3 RET	---	studyid	text	- ENR - R3 - R2 - RET				PDS
Study	---	ENR R2 R3 RET	---	study	text	- Enroll-HD - REGISTRY2 - REGISTRY3 - Ad Hoc				PDS
Subject state		ENR		sjstate	text	- screening - excluded - enrolled - violator - withdrawn - completed			Participant’s subject state. The state “screening” means created but Enrollment form not successfully completed. The state “enrolled” means that the participant passed enrollment, is still alive and still actively participates in the study. The state	Not available

									<p>“completed” means that participant has ended the study normally. Currently, the only reason for a normal termination is if the participant died. The states “withdrawn” and “violate” means that the participant has prematurely ended the study (see End form for detailed reason).</p>	
Participant status (latest)	SUPPSC	ENR	---	subjstat	text	<ul style="list-style-type: none"> <li>- enrolled</li> <li>- completed</li> <li>- excluded</li> <li>- withdrawn</li> <li>- violator</li> </ul>			See chapter 4.1 for details.	PDS
Participant category (at enrollment)	SUPPSC	ENR	---	hdcats_0	single choice	<ul style="list-style-type: none"> <li>- pre-manifest/pre-motor-manifest HD</li> <li>- manifest/motor-manifest HD</li> <li>- genotype negative</li> <li>- family control</li> </ul>	<ul style="list-style-type: none"> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> </ul>		Community controls are not included, genotype unknown participants are automatically mapped to another category, based on available data.	PDS

Participant category (latest)	SUPPSC	ENR	---	hdcatt_l	single choice	- pre-manifest/pre-motor-manifest HD - manifest/motor-manifest HD - genotype negative - family control	- 2 - 3 - 4 - 5		Community controls are not included, genotype unknown are automatically mapped to another category.	PDS
HD status	SUPPMH	ENR	FHx	hdstat	single choice	- manifest carrier - pre-manifest carrier - not a carrier	- 1 - 2 - 3			Available upon SRC approval
Degree of certainty	SUPPMH	ENR	FHx	hdstatc	single choice	- 0 - 1 - 2 - 3 - 4 - 5	- 0 - 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Availability of DNA samples	SUPPMH	ENR	FHx	dna	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Date of birth	DM	ENR	---	brthdtc	date					Not available
Age at enrollment	DM	ENR	---	age_0	number				Birth date is transformed into age in years at time of enrollment.	PDS



Date of enrollment	DM	ENR	---	rfstdtc	date					Not available
Study reference start day (baseline)	DM	ENR	---	rfstdy	number				Number of days before/since enrollment for Enroll-HD.	PDS
Date of informed consent	DM	ENR	---	rfstdtc	date					Not available
Day of informed consent	DM	ENR	---	rficdy	number				Number of days of informed consent before/after enrollment/baseline for Enroll-HD. Not available for Adhoc study since substudy of Enroll.	PDS
Signed by	SC	ENR		sgntr	single choice	- participant - legal representative	- 1 - 2			Not available
Date of end of study	DM	ENR	---	rfendtc	date					Not available
Day of end of study	DM	ENR	---	rfendy	number				Contains date of death if participant died or date of withdrawal/violation if participant discontinued the study prematurely	PDS
Vital status	SUPPMH	ENR	FHx	vstat	single choice	- alive - dead	- 1 - 2			Available upon SRC approval

#### 4.2.1 Form “Premature End of Study (End)”

This form is part of the Premature End and Phone Contact visit.

##### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	DS	ENR		dsdtc	date					Not available
Assessment day	DS	ENR		dsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval

##### Section End of Study

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Specify primary reason for participant's premature discontinuation from study (lost to follow up hint: failure of participant to return to follow-up visit and failure	DS	ENR R3		dsterm	single choice	- event or intercurrent illness of a nature requiring withdrawal - request of primary care physician, site investigator - participant's request (includes carer/spouse/authorized representative's request) - lost to follow up	- 1 - 2 - 3 - 4			PDS

to be located by investigator)						- institutionalized (will not be followed further) - Other	- 5 - 6			
Please specify	SUPPDS	ENR R3		termoth	text					Not available
Please specify the reason for the participant's request	SUPPDS	ENR R3		dsreas	single choice	- unable to travel - participant unwilling to continue - participant moved away from the study site	- 1 - 2 - 3			Available upon SRC approval

#### System calculated variables and Key variables of participant file

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Number of events	SV	ENR	---	evtnum	number				Number how many event forms are entered.	PDS
Number of visits	SV	ENR	---	visitnum	number					PDS
Visit type		R2		visit1, visit2,	text	- Baseline - Follow Up				PDS
Visit type		R3		visit1, visit2, ...	text	- Baseline - Follow Up - Unscheduled				PDS
Visit type	SV	ENR		visit1, visit2, ... visit21	text	- BL (Baseline) - FUP (Follow Up) - PC (Phone Contact) - U (Unscheduled)	- BL - FUP - PC - U			PDS

						- R (Ad Hoc)	- R			
Visit type	SV	ENR	---	visit1, visit2, ... visit21	text	- Baseline - Follow Up - Phone Contact - Unscheduled - Ad Hoc - Premature End	- BL - FUP - PC - U - R - E		Sequence of visits ordered by visit date	Available upon SRC approval
Date of visit	SV	ENR			date					Not available
Day of visit	SV	ENR	---	vis1dy, vis2dy, ..., vis21dy,	number				Ordered sequence of visit days (in dependency to Enroll-HD Baseline)	PDS

### 4.3 Data File “assessment”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR R2 R3 RET	---	subjid	text				one-way transformation from HDID to recoded HDID .	PDS
Study ID	---	ENR R2 R3 RET	---	studyid	text	- ENR - R3 - R2 - RET				PDS

Visit Index	---	ENR R2 R3 RET	---	seq	number				Unique row number to identify several entries.	PDS
Visit name	SV	ENR R2 R3 RET	----	visit	text	- Baseline - Follow-Up - Phone Contact - Unscheduled - Retro Visit				PDS
Visit day	SV	ENR R2 R3 RET	----	visdy	date			Days	Transformed into days relative to baseline date of Enroll-HD.	PDS
Enrollment	SUPPSV	ENR	---	enrollmen t	text	- 1 (available)  [empty cell indicates not available]				PDS
Variable	SUPPSV	ENR	---	variable		- 1 (available)  [empty cell indicates not available]				PDS
Medical History	SUPPSV	ENR	---	mhx		- 1 (available)  [empty cell indicates not available]				PDS

Samples	SUPPSV	ENR	---	samples		- 1 (available)  [empty cell indicates not available]				PDS
UHDRS Motor/Diagnostic Confidence	SUPPSV	ENR	---	motor		- 1 (available)  [empty cell indicates not available]				PDS
UHDRS Total Functional Capacity	SUPPSV	ENR	---	tfc		- 1 (available)  [empty cell indicates not available]				PDS
UHDRS Function Assessment/Independence Scale	SUPPSV	ENR	---	function		- 1 (available)  [empty cell indicates not available]				PDS
Cognitive Assessments	SUPPSV	ENR	---	cognitive		- 1 (available)  [empty cell indicates not available]				PDS
Mini Mental State Examination	SUPPSV	ENR	---	mmse		- 1 (available)  [empty cell indicates not available]				PDS
Physiotherapy Outcome Measures	SUPPSV	ENR	---	physio		- 1 (available)				PDS

						[empty cell indicates not available]				
Problem Behaviours Assessment - Short	SUPPSV	ENR	---	pbas		- 1 (available)  [empty cell indicates not available]				PDS
Client Service Receipt Inventory	SUPPSV	ENR	---	csri		- 1 (available)  [empty cell indicates not available]				PDS
Caregivers Quality of Life Questionnaire	SUPPSV	ENR	---	careqol		- 1 (available)  [empty cell indicates not available]				PDS
Short Form Health Survey – 12v2	SUPPSV	ENR	---	sf12		- 1 (available)  [empty cell indicates not available]				PDS
Hospital Anxiety and Depression Scale - Snaith Irritability Scale	SUPPSV	ENR	---	hadssis		- 1 (available)  [empty cell indicates not available]				PDS
Columbia-Suicide Severity Rating Scale - Baseline	SUPPSV	ENR	---	cssrsbl		- 1 (available)  [empty cell indicates not available]				PDS

Columbia-Suicide Severity Rating Scale - Annual	SUPPSV	ENR	---	cssrsfup		- 1 (available)  [empty cell indicates not available]				PDS
WPAI-SHP	SUPPSV	ENR	---	wpaishp		- 1 (available)  [empty cell indicates not available]				PDS
Missed Visit	SUPPSV	ENR	---	missedvisit		- 1 (available)  [empty cell indicates not available]				PDS
Extended Neuropsychological Assessment	SUPPSV	ENR	---	cognitivel		- 1 (available)  [empty cell indicates not available]				PDS
UHDRS Behavioral Assessment	SUPPSV	ENR	---	behaviour		- 1 (available)  [empty cell indicates not available]				PDS
Summary	SUPPSV	ENR	---	summary		- 1 (available)  [empty cell indicates not available]				PDS
Global Clinical Impression Scale	SUPPSV	ENR	---	gci		- 1 (available)				PDS



						[empty cell indicates not available]				
Caregiver Questionnaire	SUPPSV	ENR	---	care		- 1 (available)  [empty cell indicates not available]				PDS
Problem Behaviours Assessment for HD	SUPPSV	ENR	---	pbahd		- 1 (available)  [empty cell indicates not available]				PDS
SF-36v2 Health Survey	SUPPSV	ENR	---	sf36v2		- 1 (available)  [empty cell indicates not available]				PDS
Becks Depression Scale	SUPPSV	ENR	---	bdi		- 1 (available)  [empty cell indicates not available]				PDS
Hamilton Rating Scale for Depression	SUPPSV	ENR	---	hamilton		- 1 (available)  [empty cell indicates not available]				PDS
SF-36v1 Health Survey	SUPPSV	ENR	---	sf36v1		- 1 (available)				PDS

## 4.4 Data File “event (Reportable Event Monitoring)”

This form is part of the General visit.

### Section Reportable Event

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR	---	subjid	Text				One-way transformation from HDID to recoded HDID.	PDS
Study ID	---	ENR	---	studyid	Text	- ENR				PDS
Index	---	ENR	---	seq	number				Unique row number to identify several entries.	PDS
Date of report	SUPPAE	ENR		evtdtc	Date					Not available
Day of report	SUPPAE	ENR		evtdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Reportable event codes	SUPPAE	ENR		evtcode	single choice	- suicide attempts - completed suicide - mental health event requiring hospitalization	- 1 - 2 - 3			PDS

						- death (other than suicide, any cause)	- 4			
Event term (coded with MedDRA)	SUPPAE	ENR		evtterm__term	Text					Not available
Event term – Modified Term (coded with Internal condition code)	SUPPAE	ENR		evtterm__modify	Text				Internal condition code provided in English. (only filled if event code (evtcode) is 2).	PDS
Event term – Code	SUPPAE	ENR		evtterm__decoded	Text				Internal condition Code provided. (only filled if event code (evtcode) is 2).	PDS
Event term – MedDRA Code	SUPPAE	ENR		evtterm__decoded	Text				MedDRA codes are made available upon proof of license	Available upon SRC approval
Event term – Certainty (coded with MedDRA)	SUPPAE	ENR		evtterm__certainty	Text					Not available

#### Section Details of Reportable Event

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Onset date	SUPPAE	ENR		evtstdtc	Date					Not available

Onset day	SUPPAE	ENR		evtstdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Date estimated	SUPPAE	ENR		stdtcest	Boolean	- yes - no	- 1 - 0			PDS
Describe briefly circumstances and nature of event	SUPPAE	ENR		evt	Text					Not available
List any relevant tests, laboratory data, history	SUPPAE	ENR		evttst	Text					Not available
Is the report	SUPPAE	ENR		evtpatt	single choice	- initial - follow-up - final	- 1 - 2 - 3			Not available

### Section Event Resolution

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Resolved	SUPPAE	ENR		evtongo	boolean	- yes - no	- 1 - 0		Only for event type 3.	PDS
End date	SUPPAE	ENR		evtendtc	date					Not available
End Day	SUPPAE	ENR		evtendy	number				Transformed into days relative to	PDS

									baseline date of Enroll-HD.	
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### Section Interventions

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Medication	SUPPAE	ENR		evtcm	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Describe	SUPPAE	ENR		evtcmsc	Text					Not available
Non-pharmacologic treatments	SUPPAE	ENR		evtbls	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Describe	SUPPAE	ENR		evtblssc	Text					Not available
Other	SUPPAE	ENR		evtoth	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Describe	SUPPAE	ENR		evtothsc	Text					Not available

### Section DSMC Review

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Status of DSMC review (visible by core team only; modified by Outcome only)	SUPPAE	ENR		evtdsmc	single choice	- pending review - ongoing review - closed/completed review	- 1 - 2 - 3			Not available

Status of DSMC review	SUPPAE	ENR		evtdsmc	single choice	- closed /completed review	- 3		Only closed events are included.	PDS
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## 5 Visit-Based Data Files

### 5.1 Study Visits

Form entities are organized in visits, i.e. Baseline, Follow Up, Unscheduled, and Premature End visits.

A visit can either be a regular visit (i.e. Baseline, Follow Up), occurring within predefined time frames, or a non-regular visit (i.e. Unscheduled, Phone Contact, Premature End), occurring outside the scheduled visit frames.

The study visits are:

Visit	Studies	Description
Baseline	ENR R3 R2	The first scheduled regular visit during or after enrollment into the study.
Follow Up	ENR R3 R2	Annual visit scheduled <b>after</b> Baseline visit. Follow Up visits should be done annually.
Phone Contact	ENR	A visit that occurred at any time <b>after</b> the Baseline visit and <b>instead</b> of an annual Follow Up visit. It is created manually to document the reason for a missed Follow Up visit. It is handled as special visit by the system.
Unscheduled	ENR R3	An irregular visit <b>after</b> the Baseline visit occurs at any time outside the scheduled visit frames. It can be created manually whenever a visit takes place in-between regular visits. It is handled as a special visit by the system.
Ad Hoc	RET	A visit that has occurred <b>before</b> the Baseline visit of Enroll-HD and/or REGISTRY. Data are obtained from previous studies or clinical visits.

## 5.2 Study Visit Status

Data included in the dataset were monitored in accordance with the respective study monitoring plan. The progress of the visit in terms of completion is identified by its so-called *visit status*. Possible visit states are:

Visit Status	Study	Description
signed	RET	Visits that are marked as <i>signed</i> . All entered forms must be complete, without “errors” and be signed. Empty forms must have been deactivated.
completed	ENR R2 R3 RET	Visits that have undergone full monitoring review have the state completed or canceled. All queries raised by monitors must have been closed. Since monitoring is done not for 100% of the entered data, the visits might not have been reviewed in total or bypassed.



### 5.3 Form Schedules of Visits per Study

Form Name	Baseline	Follow Up	Unscheduled	Phone Contact	RET
MHx	Enroll-HD				
Variable (BL)	Enroll-HD Registry 3 Registry 2				RET
Variable (FU)		Enroll-HD Registry 3 Registry 2	Enroll-HD Registry 3		
Motor	Enroll-HD Registry 3 Registry 2	Enroll-HD Registry 3 Registry 2	Enroll-HD Registry 3		RET
TFC	Enroll-HD Registry 3 Registry 2	Enroll-HD Registry 3 Registry 2	Enroll-HD Registry 3		RET
Function	Enroll-HD Registry 3 Registry 2	Enroll-HD Registry 3 Registry 2	Enroll-HD Registry 3		RET
Cognitive	Enroll-HD Registry 3 Registry 2	Enroll-HD Registry 3 Registry 2	Enroll-HD Registry 3		RET
MMSE	Enroll-HD	Enroll-HD	Enroll-HD		RET
Physiotherapy	Enroll-HD	Enroll-HD			
PBA-s	Enroll-HD Registry 3	Enroll-HD Registry 3	Enroll-HD Registry 3		
SF-12	Enroll-HD	Enroll-HD	Enroll-HD		
SF-36v2	Registry 3	Registry 3	Registry 3		
SF-36v1	Registry 2	Registry 2			
HADS-SIS	Enroll-HD Registry 3	Enroll-HD Registry 3	Enroll-HD Registry 3		
WPAI-SHP	Enroll-HD	Enroll-HD	Enroll-HD		
C-SSRS BL	Enroll-HD Registry 3	Enroll-HD	Enroll-HD		
C-SSRS FUP	Enroll-HD	Enroll-HD Registry 3	Enroll-HD Registry 3		
Missed Visit				Enroll-HD	
Behaviour	Registry 3 Registry 2	Registry 3 Registry 2	Registry 3		
GCI	Registry 3 Registry 2	Registry 3 Registry 2	Registry 3		
BDI	Registry 2	Registry 2			
Hamilton	Registry 2	Registry 2			

## 6 Key Variables for all studies

Label	Domain	Study	Cat	Variable	Type	Parameter	Description	Transformation	Availability
HDID (recoded)		ENR R2 R3 RET		subjid	text			One-way transformation from HDID to HDID (recoded).	PDS
Study ID		ENR R2 R3 RET		studyid		- ENR - R2 - R3 - Ad Hoc			PDS
Creation Date				ctime	date		Date when the participant's eCRF was created.		Not available
Study Site Name		ENR		site	text	Text	Name of study site abbreviation.		Available upon SRC approval
Country name		ENR		country	text				Available upon SRC approval
Region		ENR		region	text	- Europe - Latin America - Northern America - Australasia			PDS
Subject State				sjstate	text	- screening	Participant's subject state. The state "screening" means created but		Not available

						<ul style="list-style-type: none"> <li>- excluded</li> <li>- enrolled</li> <li>- violator</li> <li>- withdrawn</li> <li>- completed</li> </ul>	Enrollment form not successfully completed. The state “enrolled” means that the participant passed enrollment, is still alive and still actively participates in the study. The state “completed” means that participant has normally ended the study. Currently, the only reason for a normal termination is if the participant died. The states “withdrawn” and “violator” means that the participant has prematurely ended the study (see End form for detailed reason).		
Subject State		ENR		substat	text	<ul style="list-style-type: none"> <li>- enrolled</li> <li>- completed</li> <li>- excluded</li> <li>- withdrawn</li> <li>- violator</li> </ul>			PDS
Visit index		ENR R2 R3 RET		seq					PDS
Visit name		ENR		vname	text	<ul style="list-style-type: none"> <li>- General</li> <li>- Baseline</li> <li>- Follow Up</li> </ul>		See also section 6.1.	Available upon SRC approval

						- Phone Contact - Unscheduled - Premature End			
Visit name	SV	ENR R2 R3 RET		visit	text	- Baseline - Follow Up - Phone Contact - Unscheduled - Retro Visit		See also section 6.1.	PDS
Visit date				vtime	date				Not available
Visit day	SV	ENR R2 R3 RET		visdy	number			Transformed into days relative to baseline date of Enroll-HD.	PDS
Visit status	SV	ENR R2 R3		visstat	text	- complete		See also section 6.2.	PDS
Visit status	SV	RET		visstat	text	- complete - signed		See also section 6.2.	PDS
Visit ID		ENR		vinst	number		Internal ID of study visit.		Not available

Form Index		ENR		nr	number		Represents the index of a form within the study visit. Usually this is “1” except if multiple forms within a study visit are possible, e.g. “Event Reporting” form. Then the forms are consecutively numbered.		Not available
Input Field Index		ENR		enr	number		Represents the index of an input field within a form. Usually this is “1” except if multiple input fields of the same type are possible per form, e.g. “PharmacoTx”. The multiple input fields are consecutively numbered, e.g. a new number for each row.		Not available
Age at visit	DM	ENR RET		age	number				PDS

## 7 Visit items

### 7.1 Form “Enrollment”

This form is part of the Baseline visit.

#### Section Enrollment

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Participant category	SC	ENR		hdcat	single choice	<ul style="list-style-type: none"> <li>- genotype unknown</li> <li>- pre-manifest/pre-motor-manifest HD</li> <li>- manifest/motor-manifest HD</li> <li>- genotype negative</li> <li>- family control</li> <li>- community control</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> <li>- 6</li> </ul>			Available upon SRC approval
Participant category	SC	ENR		hdcat	single choice	<ul style="list-style-type: none"> <li>- pre-manifest/pre-motor-manifest HD</li> <li>- manifest/motor-manifest HD</li> <li>- genotype negative</li> <li>- family control</li> </ul>	<ul style="list-style-type: none"> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> </ul>		Community controls are not included, genotype unknown participants are automatically mapped to another category, based on available data.	PDS
Group Inclusion criteria (community control)										

No history of or no concurrent major central nervous system disorder (e.g. Stroke, Parkinson's disease, Multiple Sclerosis, etc.)	SC	ENR		ec2	Boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components										
Biosamples for use in research	SC	ENR		bsp	Boolean	- yes - no	- 1 - 0			Available upon SRC approval
Linking clinical information from previous studies	SC	ENR		rtrspctv	Boolean	- yes - no	- 1 - 0			Available upon SRC approval
Participation in sub-studies	SC	ENR		nvl	Boolean	- yes - no	- 1 - 0			Available upon SRC approval
Contact between visits	SC	ENR		cntct	Boolean	- yes - no	- 1 - 0			Available upon SRC approval
Contact regarding other	SC	ENR		cntctst	boolean	- yes - no	- 1 - 0			Available upon SRC approval

research studies										
Contact regarding post-mortem tissue collection	SC	ENR		cntctpmt	Boolean	- yes - no	- 1 - 0			Available upon SRC approval

## 7.2 Form “Medical History (MHx)”

This form is part of the Baseline visit.

### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	MH	ENR		mhdte	date					Not available
Assessment day	MH	ENR		mhdye	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval



## Section Past Medical History

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Has the participant had alcohol problems in the past	MH	ENR		hxalcab	boolean	- yes - no - unknown	- 1 - 0 - 9999			PDS
Has the participant ever smoked	MH	ENR		hxtobab	boolean	- yes - no - unknown	- 1 - 0 - 9999			PDS
Cigarettes per day	MH	ENR		hxtobcpd	number					PDS
Years of smoking	MH	ENR		hxtobyos	number					PDS
Packyears	MH	ENR		hxpacky	number					PDS
Has the participant ever abused drugs	MH	ENR		hxdrugab	boolean	- yes - no - unknown	- 1 - 0 - 9999			PDS

## Group Drug use for non-medical reasons

Group Marijuana										
Abuse	SUPPSU	ENR		hxmar	Boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR		hxmarfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Heroin										
Abuse	SUPPSU	ENR		hxher	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR		hxherfrq		- seldom	- 1			PDS

					single choice	- occasionally - frequently	- 2 - 3			
Group Cocaine										
Abuse	SUPPSU	ENR		hxcoc	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR		hxcocfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Club drugs (Ecstasy, GHB, Roofies)										
Abuse	SUPPSU	ENR		hxclb	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR		hxclbfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Amphetamines										
Abuse	SUPPSU	ENR		hxamp	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR		hxampfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Ritalin										
Abuse	SUPPSU	ENR		hxrit	boolean	- yes - no	- 1 - 0			PDS
Frequency	SC	ENR		hxritfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Hallucinogens										
Abuse	SUPPSU	ENR		hxhal	boolean	- yes	- 1			PDS

						- no	- 0			
Frequency	SU	ENR		hxhalfreq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Inhalants										
Abuse	SUPPSU	ENR		hxinh	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR		hxinhfreq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Opium										
Abuse	SUPPSU	ENR		hxopi	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR		hxopifreq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Painkillers										
Abuse	SUPPSU	ENR		hxpak	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR		hxpakfreq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Barbiturates/sedatives										
Abuse	SUPPSU	ENR		hxbar	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR		hxbarfreq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS

Group Tranquilizers										
Abuse	SUPPSU	ENR		hxtrq	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR		hxtrqfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Other										
Abuse	SUPPSU	ENR		hxoth	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Frequency	SU	ENR		hxothfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			Available upon SRC approval

### 7.3 Form “Variable Items (Baseline Visit)”

This form is part of the Baseline visit.

#### Section General Variable Items I

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Vital Signs										
Height (cm)	VS	ENR R2 R3 RET		height	number				No cut-off values (due to data overdispersion)	PDS

Height (inches)	VS	ENR R2 R3 RET		height_2	number					Available upon SRC approval
Weight (kg)	VS	ENR R2 R3 RET		weight	number					PDS
Weight (lbs)	VS	ENR R2 R3 RET		weight_2	number					Available upon SRC approval
BMI	VS	ENR R2 R3 RET		bmi	number				Auto-calculated from height and weight values.	PDS
Does the participant currently drink alcohol?	MH	ENR R3	mhx	alcab	boolean	- yes - no	- 1 - 0			PDS
Units per week	SU	ENR R3	mhx	alcunits	number					PDS
Does the participant currently smoke?	MH	ENR R3	mhx	tobab	boolean	- yes - no	- 1 - 0			PDS
Cigarettes per day	SU	ENR	mhx	tobcpd	number					PDS
Years of smoking	SUPPSU	ENR	mhx	tobyos	number					PDS

Packyears	MH	ENR R3	mhx	packy	number				(tobcpd/20) * tobyos [rounded to one decimal place]	PDS
Current caffeine use?	MH	ENR	mhx	cafab	boolean	- yes - no	- 1 - 0			PDS
Do you drink more than 3 cups of coffee, tea and cola drinks combined per day?	SU	ENR	mhx	cafpd	boolean	- yes - no	- 1 - 0			PDS
Does the participant currently use drugs?	MH	ENR R3	mhx	drugab	boolean	- yes - no	- 1 - 0			PDS
Group Drug use for non-medical reasons?										
Group Marijuana										
Abuse	SUPPSU	ENR R3	mhx	mar	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	marfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Heroin										
Abuse	SUPPSU	ENR R3	mhx	her	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	herfrq	single choice	- seldom - occasionally	- 1 - 2			PDS

						- frequently	- 3			
Group Cocaine										
Abuse	SUPPSU	ENR R3	mhx	coc	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	cocfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Club drugs (Ecstasy, GHB, Roofies)										
Abuse	SUPPSU	ENR R3	mhx	clb	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	clbfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Amphetamines										
Abuse	SUPPSU	ENR R3	mhx	amp	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	ampfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Ritalin										
Abuse	SUPPSU	ENR R3	mhx	rit	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	ritfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Hallucinogens										
Abuse	SUPPSU		mhx	hal	boolean	- yes	- 1			PDS

		ENR R3				- no	- 0			
Frequency	SU	ENR R3	mhx	halfreq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Inhalants										
Abuse	SUPPSU	ENR R3	mhx	inh	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	inhfreq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Opium										
Abuse	SUPPSU	ENR R3	mhx	opi	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	opifreq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Painkillers										
Abuse	SUPPSU	ENR R3	mhx	pak	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	pakfreq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Barbiturates/sedatives										
Abuse	SUPPSU	ENR R3	mhx	bar	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	barfreq	single choice	- seldom - occasionally	- 1 - 2			PDS



						- frequently	- 3			
Group Tranquilizers										
Abuse	SUPPSU	ENR R3	mhx	trq	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	trqfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Other										
Abuse	SUPPSU	ENR R3	mhx	oth	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Frequency	SU	ENR R3	mhx	othfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			Available upon SRC approval

## Section General Variable Items II

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Marital status	SC	ENR R2 R3		maristat	single choice	- single - partnership - married - divorced - widowed - legally separated	- 1 - 2 - 3 - 4 - 5 - 6		Coding 5 and 6 are not available for studies R2 and R3.	PDS
Residence	SC	ENR R2 R3		res	single choice	- rural - village - town	- 1 - 2 - 3			PDS

						- city	- 4			
ISCED education level (US version)	SC	ENR R3		isced	single choice	- ISCED 0 - ISCED 1 - ISCED 2 - ISCED 3 - ISCED 4 - ISCED 5 - ISCED 6	- 0 - 1 - 2 - 3 - 4 - 5 - 6		Details about the ISCED education level can be found in the supporting documents for the ISCED [4]	PDS
Years of education	SC	ENR		eduyrs	number			years		Available upon SRC approval
Occupation (coded by Snomed)	SC	ENR		empjob	text array	- Term - Modified Term - Code - Certainty	- term - modify - decod - certainty			Available upon SRC approval
Employment	SC	ENR		jobclas	single choice	- full-time employed - part-time employed - self employed - not employed	- 1 - 2 - 3 - 4			PDS
Status (if employed)	SC	ENR		jobpaid	single choice	- paid - unpaid	- 1 - 2			PDS
Have you had to stop or reduce work due to your health?	SC	ENR		rdcwk	boolean	- yes - no	- 1 - 0			PDS

How many days in the last 6 months have you been off work because of HD?	SC	ENR		rdcwkd	number			days		PDS
How many fewer hours per week have you worked because of HD?	SC	ENR		rdcwkhw	number			hours/week		PDS
Reason (if not employed)	SC	ENR		emplnrsn	single choice	- sick leave - retirement - working in the home (e.g. caring for children) - unemployed - training/college	- 1 - 2 - 3 - 4 - 5			PDS
Retired due to (if retired)	SC	ENR		emplnrd	single choice	- ill health - age	- 1 - 2			PDS
Group If retired or unemployed										
Do you receive social security or disability benefit?	SC	ENR		ssdb	boolean	- yes - no	- 1 - 0			PDS
	SC	ENR		rtrnw	boolean	- yes	- 1			PDS

Do you intend to return to work?						- no	- 0			
Since when have you been unemployed/retired?	SC	ENR		rtrddur	number			Years	Age at retirement	PDS

## 7.4 Form “Variable Items (Follow-Up Visit)”

This form is part of the Follow Up and Unscheduled visit.

### Section General Variable Items I

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Vital Signs										
Height (cm)	VS	ENR R2 R3 RET		height	number				No cut-off values (due to data overdispersion)	PDS
Height (inches)	VS	ENR R2 R3 RET		height_2	number					Available upon SRC approval
Weight (kg)	VS	ENR R2 R3 RET		weight	number					PDS

Weight (lbs)	VS	ENR R2 R3 RET		weight_2	number					Available upon SRC approval
BMI	VS	ENR R2 R3 RET		bmi	number					PDS
Does the participant currently drink alcohol?	MH	ENR R3	mhx	alcab	boolean	- yes - no	- 1 - 0			PDS
Units per week	SU	ENR R3	Mhx	alcunits	number					PDS
Does the participant currently smoke?	MH	ENR R3	Mhx	tobab	boolean	- yes - no	- 1 - 0			PDS
Cigarettes per day	SU	ENR	Mhx	tobcpd	number					PDS
Years of smoking	SUPPSU	ENR	Mhx	tobyos	number					PDS
Packyears	MH	ENR R2 R3	Mhx	packy	number				(tobcpd/20) * tobyos [rounded to 1 decimal place]	PDS
Current caffeine use?	MH	ENR	Mhx	cafab	boolean	- yes - no	- 1 - 0			PDS
Do you drink more than 3 cups of coffee, tea and cola drinks combined per day?	SU	ENR	Mhx	cafpd	boolean	- yes - no	- 1 - 0			PDS
	MH		mhx	drugab	boolean	- yes	- 1			PDS

Does the participant currently use drugs?		ENR R3				- no	- 0			
Group Drug use for non-medical reasons?										
Group Marijuana										
Abuse	SUPPSU	ENR R3	mhx	mar	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	marfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Heroin										
Abuse	SUPPSU	ENR R3	mhx	her	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	Herfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Cocaine										
Abuse	SUPPSU	ENR R3	mhx	Coc	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	Cocfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Club drugs (Ecstasy, GHB, Roofies)										
Abuse	SUPPSU	ENR R3	mhx	Clb	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	clbfrq	single choice	- seldom - occasionally	- 1 - 2			PDS

						- frequently	- 3			
Group Amphetamines										
Abuse	SUPPSU	ENR R3	mhx	amp	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	ampfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Ritalin										
Abuse	SUPPSU	ENR R3	mhx	rit	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	ritfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Hallucinogens										
Abuse	SUPPSU	ENR R3	mhx	hal	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	halfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Inhalants										
Abuse	SUPPSU	ENR R3	mhx	inh	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	inhfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Opium										

Abuse	SUPPSU	ENR R3	mhx	opi	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	opifrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Painkillers										
Abuse	SUPPSU	ENR R3	mhx	pak	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	pakfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Barbiturates/sedatives										
Abuse	SUPPSU	ENR R3	mhx	bar	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	barfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Tranquilizers										
Abuse	SUPPSU	ENR R3	mhx	trq	boolean	- yes - no	- 1 - 0			PDS
Frequency	SU	ENR R3	mhx	trqfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Group Other										
Abuse	SUPPSU		mhx	oth	boolean	- yes	- 1			



		ENR R3				- no	- 0			Available upon SRC approval
Frequency	SU	ENR R3	mhx	othfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			Available upon SRC approval

## Section General Variable Items II

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Any changes to the following General Variable Items	MH	ENR R3		updsc	boolean	- yes - no	- 1 - 0			PDS
Marital status	SC	ENR R3 R2		maristat	single choice	- single - married - partnership - divorced - widowed - legally separated	- 1 - 3 - 2 - 4 - 5 - 6		Coding 6 is not available for study R3.	PDS
Residence	SC	ENR R3 R2		Res	single choice	- rural - village - town - city	- 1 - 2 - 3 - 4			PDS
ISCED education	SC	ENR R3		iscd	single choice	- ISCED 0 - ISCED 1 - ISCED 2	- 0 - 1 - 2			PDS

level (US version)						- ISCED 3 - ISCED 4 - ISCED 5 - ISCED 6	- 3 - 4 - 5 - 6			
Years of education	SC	ENR		eduyrs	number			years		Available upon SRC approval
Occupation (coded by Snomed)	SC	ENR		empjob	text array	- Term - Modified Term - Code - Certainty	- term - modify - decod - certainty			Available upon SRC approval
Employment	SC	ENR		jobclas	single choice	- full-time employed - part-time employed - self employed - not employed	- 1 - 2 - 3 - 4			PDS
Status (if employed)	SC	ENR		jobpaid	single choice	- paid - unpaid	- 1 - 2			PDS
Have you had to stop or reduce work due to your health?	SC	ENR		rdcwkw	boolean	- yes - no	- 1 - 0			PDS
How many days in the last 6 months have you been off work	SC	ENR		rdcwkd	number			days		PDS

because of HD?										
How many fewer hours per week have you worked because of HD?	SC	ENR		rdcwkhw	number			hours /week		PDS
Reason (if not employed)	SC	ENR		emplnrsn	single choice	- sick leave - retirement - working in the home (e.g. caring for children) - unemployed - training/college	- 1 - 2 - 3 - 4 - 5			PDS
Retired due to (if retired)	SC	ENR		emplnrd	single choice	- ill health - age	- 1 - 2			PDS
Do you receive social security or disability benefit?	SC	ENR		ssdb	boolean	- yes - no	- 1 - 0			PDS
Do you intend to return to work?	SC	ENR		rtrnwkw	boolean	- yes - no	- 1 - 0			PDS
Since when have you been	SC	ENR		rtrddur	number			Years	Age at retirement	PDS

unemployed/ retired?										
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**Section Since the last visit have there been:**

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Any changes to participant's medication?	SV	ENR R3		updmed	boolean	- yes - no	- 1 - 0			PDS
Any changes to participant's comorbid conditions?	SV	ENR R3		updmh	boolean	- yes - no	- 1 - 0			PDS
Any updates to the clinical characteristics and/or onset of HD?	SV	ENR R3		updhdh	boolean	- yes - no	- 1 - 0			PDS
Any updates to family history?	SV	ENR R3		updfh	boolean	- yes - no	- 1 - 0			PDS
Any changes to the optional components?	SV	ENR		updopt	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components										
Biosamples for use in research	SC	ENR		bsp	boolean	- yes - no	- 1 - 0			Available upon SRC approval
	SC	ENR		rtrspectv	boolean	- yes	- 1			

Linking clinical information from previous studies						- no	- 0			Available upon SRC approval
Participation in sub-studies	SC	ENR		nvl	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Contact between visits	SC	ENR		cntct	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Contact regarding other research studies	SC	ENR		cntctst	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Contact regarding post-mortem tissue collection	SC	ENR		cntctpmt	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Has the participant had a brain MRI?	SV	ENR		updmri	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Date of MRI	SV	ENR		mridtc	date					Not available
Day of MRI	SV	ENR		mridy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval

## 8 Clinical scales

### 8.1 Form “UHDRS Motor/Diagnostic Confidence (Motor)”

This form is part of the Baseline, Follow Up and Unscheduled visit.

#### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	Motor	qsdtc	date					Not available
Assessment day	QS	ENR	Motor	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Rater code	QS	ENR	Motor	raterid	number					Not available
Motor score (TMS)	QS	ENR R3 R2 RET	Motor	motscore	number				Score is calculated when every item on the TMS has been scored.	PDS
Motor score (TMS) incomplete	QS	ENR R3 R2 RET	Motor	miscore	number				The Motor score (incomplete) is calculated when there is at least one item on the TMS that has not been score (e.g. unable to assess left hand	PDS

									fingertapping due to amputation).	
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## Section Motor Assessment

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Ocular pursuit										
Horizontal	QS	ENR R3 R2 RET	Motor	ocularh	single choice	- complete (normal) - jerky movement - interrupted pursuits/full range - incomplete range - cannot pursue	- 0 - 1 - 2 - 3 - 4			PDS
Vertical	QS	ENR R3 R2 RET	Motor	ocular	single choice	- complete (normal) - jerky movement - interrupted pursuits/full range - incomplete range - cannot pursue	- 0 - 1 - 2 - 3 - 4			PDS
Group Saccade initiation										
Horizontal	QS	ENR R3 R2 RET	Motor	sacinith	single choice	- normal - increased latency only - suppressible blinks or head movements to initiate - unsuppressible head movements	- 0 - 1 - 2 - 3			PDS

						- cannot initiate saccades	- 4			
Vertical	QS	ENR R3 R2 RET	Motor	sacinitv	single choice	- normal - increased latency only - suppressible blinks or head movements to initiate - unsuppressible head movements - cannot initiate saccades	- 0 - 1 - 2 - 3 - 4			PDS
Group Saccade velocity										
Horizontal	QS	ENR R3 R2 RET	Motor	sacvelh	single choice	- normal - mild slowing - moderate slowing - severely slow, full range - incomplete range	- 0 - 1 - 2 - 3 - 4			PDS
Vertical	QS	ENR R3 R2 RET	Motor	sacvelv	single choice	- normal - mild slowing - moderate slowing - severely slow, full range - incomplete range	- 0 - 1 - 2 - 3 - 4			PDS
Dysarthria	QS	ENR R3 R2 RET	Motor	dysarth	single choice	- normal - unclear, no need to repeat - must repeat to be understood - mostly incomprehensible - anarthria	- 0 - 1 - 2 - 3 - 4			PDS
Tongue protrusion	QS	ENR R3	Motor	tongue	single choice	- can hold tongue fully protruded for 10 sec	- 0			PDS



		R2 RET				- cannot keep fully protruded for 10 sec - cannot keep fully protruded for 5 sec - cannot fully protrude tongue - cannot protrude tongue beyond lips	- 1 - 2 - 3 - 4			
Group Finger taps										
Right	QS	ENR R3 R2 RET	Motor	fingtapr	single choice	- normal ( $\geq 15/5$ sec.) - mild slowing, reduction in amplitude (11-14/5 sec.) - moderately impaired (7-10/5 sec.) - severely impaired (3-6/5 sec.) - can barely perform task (0-2/5 sec.)	- 0 - 1 - 2 - 3 - 4			PDS
Left	QS	ENR R3 R2 RET	Motor	fingtapl	single choice	- normal ( $\geq 15/5$ sec.) - mild slowing, reduction in amplitude (11-14/5 sec.) - moderately impaired (7-10/5 sec.) - severely impaired (3-6/5 sec.) - can barely perform task (0-2/5 sec.)	- 0 - 1 - 2 - 3 - 4			PDS
Group Pronate/supinate-hands										
Right	QS		Motor	prosupr		- normal	- 0			PDS

		ENR R3 R2 RET			single choice	- mild slowing and/or irregular - moderate slowing and irregular - severe slowing and irregular - cannot perform	- 1 - 2 - 3 - 4			
Left	QS	ENR R3 R2 RET	Motor	prosopl	single choice	- normal - mild slowing and/or irregular - moderate slowing and irregular - severe slowing and irregular - cannot perform	- 0 - 1 - 2 - 3 - 4			PDS
Luria	QS	ENR R3 R2 RET	Motor	luria	single choice	- ≥4 in 10 sec, no cue - <4 in 10 sec, no cue - ≥4 in 10 sec with cues - <4 in 10 sec with cues - cannot perform	- 0 - 1 - 2 - 3 - 4			PDS
Group Rigidity-arms										
Right	QS	ENR R3 R2 RET	Motor	rigarmr	single choice	- absent - slight or present only with activation - mild to moderate - severe, full range of motion - severe with limited range	- 0 - 1 - 2 - 3 - 4			PDS
Left	QS		Motor	rigarml		- absent	- 0			PDS

		ENR R3 R2 RET			single choice	- slight or present only with activation - mild to moderate - severe, full range of motion - severe with limited range	- 1 - 2 - 3 - 4			
Bradykinesia-body	QS	ENR R3 R2 RET	Motor	brady	single choice	- normal - minimally slow (?normal) - mildly but clearly slow - moderately slow, some hesitation - markedly slow, long delays in initiation	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal dystonia										
Trunk	QS	ENR R3 R2 RET	Motor	dysttrnk	single choice	- absent - slight/intermittent - mild/common or moderate/ intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
RUE	QS	ENR R3 R2 RET	Motor	dysttrue	single choice	- absent - slight/intermittent - mild/common or moderate/ intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
LUE	QS	ENR R3	Motor	dystlue	single choice	- absent - slight/intermittent	- 0 - 1			PDS

		R2 RET				- mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 2 - 3 - 4			
RLE	QS	ENR R3 R2 RET	Motor	dystrie	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
LLE	QS	ENR R3 R2 RET	Motor	dystlle	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal chorea										
Face	QS	ENR R3 R2 RET	Motor	chorface	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
BOL	QS	ENR R3 R2 RET	Motor	chorbol	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common	- 0 - 1 - 2 - 3			PDS

						- marked/prolonged	- 4			
Trunk	QS	ENR R3 R2 RET	Motor	chortrnk	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
RUE	QS	ENR R3 R2 RET	Motor	chorrue	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
LUE	QS	ENR R3 R2 RET	Motor	chorlue	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
RLE	QS	ENR R3 R2 RET	Motor	chorrle	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
LLE	QS	ENR R3	Motor	chorlle	single choice	- absent - slight/intermittent	- 0 - 1			PDS

		R2 RET				- mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 2 - 3 - 4			
Gait	QS	ENR R3 R2 RET	Motor	gait	single choice	- normal gait, narrow base - wide base and/or slow - wide base and walks with difficulty - walks only with assistance - cannot attempt	- 0 - 1 - 2 - 3 - 4			PDS
Tandem walking	QS	ENR R3 R2 RET	Motor	tandem	single choice	- normal for 10 steps - 1 to 3 deviations from straight line - >3 deviations - cannot complete - cannot attempt	- 0 - 1 - 2 - 3 - 4			PDS
Retropulsion pull test	QS	ENR R3 R2 RET	Motor	retropls	single choice	- normal - recovers spontaneously - would fall if not caught - tends to fall spontaneously - cannot stand	- 0 - 1 - 2 - 3 - 4			PDS

### Section Diagnostic Confidence

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
	QS	ENR R3	Motor	diagconf	single choice	- normal (no abnormalities)	- 0			PDS

Diagnostic confidence level (DCL)		R2 RET				<ul style="list-style-type: none"> <li>- non-specific motor abnormalities (less than 50 % confidence)</li> <li>- motor abnormalities that may be signs of HD (50 - 89 % confidence)</li> <li>- motor abnormalities that are likely signs of HD (90 - 98 % confidence)</li> <li>- motor abnormalities that are unequivocal signs of HD (<math>\geq 99</math> % confidence)</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>				
Reason for discrepancy between DCL/Total Motor Score	QS	ENR	Motor	dclrfi	text						Not available

## 8.2 Form “UHDRS Total Functional Capacity (TFC)”

This form is part of the Baseline, Follow Up and Unscheduled visit.

### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	TFC	qsdtc	date					Not available

Assessment day	QS	ENR	TFC	qsdv	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Rater code	QS	ENR	TFC	raterid	number					Not available
Functional score	QS	ENR R3 R2 RET	TFC	tfcscore	number					PDS

### Section Functional Capacity

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Occupation	QS	ENR R3 R2 RET	TFC	occupatn	single choice	- unable - marginal work only - reduced capacity for usual job - normal	- 0 - 1 - 2 - 3			PDS
Finances	QS	ENR R3 R2 RET	TFC	finances	single choice	- unable - major assistance - slight assistance - normal	- 0 - 1 - 2 - 3			PDS
Domestic chores	QS	ENR R3 R2 RET	TFC	chores	single choice	- unable - impaired - normal	- 0 - 1 - 2			PDS
ADL	QS	ENR R3	TFC	adl	single choice	- total care - gross tasks only	- 0 - 1			PDS



		R2 RET				- minimal impairment - normal	- 2 - 3			
Care level	QS	ENR R3 R2 RET	TFC	carelevl	single choice	- full time skilled nursing - home or chronic care - home	- 0 - 1 - 2			PDS
Was the information obtained from	QS	ENR	TFC	tfcsrc	single choice	- participant only - participant and family/companion	- 1 - 2			Available upon SRC approval

### 8.3 Form “UHDRS Functional Assessment/Independence Scale (Function)”

This form is part of the Baseline, Follow Up and Unscheduled visit.

#### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	Function	qsdtc	date					Not available
Assessment day	QS	ENR	Function	qsdyl	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Rater code	QS	ENR	Function	raterid	number					Not available

Functional assessment score	QS	ENR R3 R2 RET	Function	fascore	number				Calculated if all items are available.	PDS
Functional score incomplete	QS	ENR R3 R2 RET	Function	fiscore	number				Calculated, if at least one of the items is not available.	PDS
Independence scale in %	QS	ENR	Function	indpsclp	number					Available upon SRC approval

### Section Functional Assessment

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Could subject engage in gainful employment in his/her accustomed work?	QS	ENR R3 R2 RET	Function	emplusl	boolean	- yes - no	- 1 - 0			PDS
Could subject engage in any kind of gainful employment?	QS	ENR R3 R2 RET	Function	emplany	boolean	- yes - no	- 1 - 0			PDS
Could subject engage in any kind of volunteer or	QS	ENR R3 R2 RET	Function	volunt	boolean	- yes - no	- 1 - 0			PDS

non-gainful work?										
Could subject manage his/her finances (monthly) without any help?	QS	ENR R3 R2 RET	Function	fafinan	boolean	- yes - no	- 1 - 0			PDS
Could subject shop for groceries without help?	QS	ENR R3 R2 RET	Function	grocery	boolean	- yes - no	- 1 - 0			PDS
Could subject handle money as a purchaser in a simple cash (shop) transaction?	QS	ENR R3 R2 RET	Function	cash	boolean	- yes - no	- 1 - 0			PDS
Could subject supervise children without help?	QS	ENR R3 R2 RET	Function	supchild	boolean	- yes - no	- 1 - 0			PDS
Could subject operate an automobile safely and independently?	QS	ENR R3 R2 RET	Function	drive	boolean	- yes - no	- 1 - 0			PDS
Could subject do his/her own housework without help?	QS	ENR R3 R2 RET	Function	housewrk	boolean	- yes - no	- 1 - 0			PDS
Could subject do his/her own	QS	ENR R3	Function	laundry	boolean	- yes - no	- 1 - 0			PDS

laundry (wash/dry) without help?		R2 RET								
Could participant prepare his/her own meals without help?	QS	ENR R3 R2 RET	Function	prepmeal	boolean	- yes - no	- 1 - 0			PDS
Could subject use the telephone without help?	QS	ENR R3 R2 RET	Function	telephone	boolean	- yes - no	- 1 - 0			PDS
Could subject take his/her own medications without help?	QS	ENR R3 R2 RET	Function	ownmeds	boolean	- yes - no	- 1 - 0			PDS
Could subject feed himself/herself without help?	QS	ENR R3 R2 RET	Function	feedself	boolean	- yes - no	- 1 - 0			PDS
Could subject dress himself/herself without help?	QS	ENR R3 R2 RET	Function	dress	boolean	- yes - no	- 1 - 0			PDS
Could subject bathe himself/herself without help?	QS	ENR R3 R2 RET	Function	bathe	boolean	- yes - no	- 1 - 0			PDS
Could subject use public transportation	QS	ENR R3 R2 RET	Function	pubtrans	boolean	- yes - no	- 1 - 0			PDS

to get places without help?										
Could subject walk to places in his/her neighbourhood without help?	QS	ENR R3 R2 RET	Function	walknbr	boolean	- yes - no	- 1 - 0			PDS
Could subject walk without falling?	QS	ENR R3 R2 RET	Function	walkfall	boolean	- yes - no	- 1 - 0			PDS
Could subject walk without help?	QS	ENR R3 R2 RET	Function	walkhelp	boolean	- yes - no	- 1 - 0			PDS
Could subject comb hair without help?	QS	ENR R3 R2 RET	Function	comb	boolean	- yes - no	- 1 - 0			PDS
Could subject transfer between chairs without help?	QS	ENR R3 R2 RET	Function	trnchair	boolean	- yes - no	- 1 - 0			PDS
Could subject get in and out of bed without help?	QS	ENR R3 R2 RET	Function	bed	boolean	- yes - no	- 1 - 0			PDS
Could subject use toilet/commode without help?	QS	ENR R3 R2 RET	Function	toilet	boolean	- yes - no	- 1 - 0			PDS
	QS		Function	carehome	boolean	- yes	- 1			PDS

Could subject's care still be provided at home?		ENR R3 R2 RET				- no	- 0			
Was the functional assessment information obtained from	QS	ENR	Function	fasrc	single choice	- subject only - subject and family/companion	- 1 - 2			Available upon SRC approval
Subject's independence in %	QS	ENR R3 R2 RET	Independence	indepscl	single choice	- no special care needed - - no physical care needed if difficult tasks are avoided - - pre-disease level of employment changes or ends; cannot perform household chores to pre-disease level, may need help with finances -	- 100 - 95 - 90  - 85 - 80  - 75			PDS

					- self-care maintained for bathing, limited household duties, e.g. cooking and use of knives, driving terminates; unable to manage finances	- 70			
					-	- 65			
					- needs minor assistance in dressing, toileting, bathing; food must be cut for subject	- 60			
					-	- 55			
					- 24-hour supervision appropriate; assistance required for bathing, eating, toileting	- 50			
					-	- 45			
					- chronic care facility needed; limited self feeding, liquified diet	- 40			
					-	- 35			

						- subject provides minimal assistance in own feeding, bathing, toileting	- 30			
						-	- 25			
						- no speech, must be fed	- 20			
						-	- 15			
						- tube fed, total bed care	- 10			
						-	- 5			

## 8.4 Form “Core and Extended Cognitive Assessment (Cognitive)”

This form is part of the Baseline, Follow Up and Unscheduled visit.

### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	Cognitive Assessment	qsdtc	Date					Not available
Assessment day	QS	ENR	Cognitive Assessment	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
	QS	ENR		langpbf		- U.S. English	- 1			



Language of paper form (PBF)			Cognitive Assessment		single choice	- Brazilian Portuguese - Spanish (LA) - Canadian French - French - Czech - Danish - German - Spanish - Italian - Dutch - Norwegian - Polish - Portuguese - Russian - Finnish - Swedish	- 2 - 3 - 6 - 7 - 8 - 9 - 10 - 11 - 12 - 13 - 14 - 15 - 16 - 17 - 18 - 19			Available upon SRC approval
Rater code	QS	ENR	Cognitive Assessment	raterid	Number					Not available

### Section Specifics

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Did the participant complete the assessment in	SUPPQS	ENR R3 RET	Cognitive Assessment	gen1	boolean	- yes - no	- 1 - 0			PDS

their native language and with normal or corrected-to-normal vision and hearing?										
Did the participant complete the assessment in their native language?	SUPPQS	ENR R3 RET	Cognitive Assessment	gen2	Boolean	- yes - no	- 1 - 0			PDS
At what age did the participant learn the language used?	SUPPQS	ENR R3 RET	Cognitive Assessment	gen3	Number			years		PDS
Did the participant have normal/corrected-to-normal hearing and vision?	SUPPQS	ENR R3 RET	Cognitive Assessment	gen4	Boolean	- yes - no	- 1 - 0			PDS
Was vision uncorrected (e.g. no glasses during visit)?	SUPPQS	ENR R3 RET	Cognitive Assessment	gen5	Boolean	- yes - no	- 1 - 0			PDS
Was hearing uncorrected (e.g. no hearing aid worn)?	SUPPQS	ENR R3 RET	Cognitive Assessment	gen6	Boolean	- yes - no	- 1 - 0			PDS

## Section Core Cognitive Assessment

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Symbol Digit Modality Test completed	QS	ENR R3 RET	SDMT	sdmt	Boolean	- yes - no	- 1 - 0			PDS
Total correct	QS	ENR R2 R3 RET	SDMT	sdmt1	Number					PDS
Total errors	QS	ENR R3 RET	SDMT	sdmt2	Number					PDS
Reason	QS	ENR	SDMT	sdmtnd	single choice	- cognitive impairment - motor impairment - mental state - physical health - visual impairment - language barrier - refusal - study conflict - scheduling issue - site error	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			PDS

						- not administered because of participation in another study	- 11			
Verbal Fluency Test (Category) completed	QS	ENR R3 RET	Categorical Verbal Fluency	verfct	Boolean	- yes - no	- 1 - 0			PDS
Category	QS	ENR R3 RET	Categorical Verbal Fluency	verfctd	single choice	- animals - other	- 1 - 2			PDS
Please specify	SUPPQS	ENR	Categorical Verbal Fluency	verfctds	Text					Not available
Total correct 0-15 seconds	QS	ENR	Categorical Verbal Fluency	verfct1	Number					Available upon SRC approval
Total correct 16-30 seconds	QS	ENR	Categorical Verbal Fluency	verfct2	Number					Available upon SRC approval
Total correct 31-45 seconds	QS	ENR	Categorical Verbal Fluency	verfct3	Number					Available upon SRC approval
Total correct 46-60 seconds	QS	ENR	Categorical Verbal Fluency	verfct4	Number					Available upon SRC approval
Total correct (1 min)	QS	ENR R3 RET	Categorical Verbal Fluency	verfct5	Number					PDS

Total intrusion errors	QS	ENR R3 RET	Categorical Verbal Fluency	verfct6	Number					PDS
Total perseverative errors	QS	ENR R3 RET	Categorical Verbal Fluency	verfct7	Number					PDS
Reason	QS	ENR	Categorical Verbal Fluency	verfctnd	single choice	<ul style="list-style-type: none"> <li>- cognitive impairment</li> <li>- motor impairment</li> <li>- mental state</li> <li>- physical health</li> <li>- visual impairment</li> <li>- language barrier</li> <li>- refusal</li> <li>- study conflict</li> <li>- scheduling issue</li> <li>- site error</li> <li>- not administered because of participation in another study</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> <li>- 6</li> <li>- 7</li> <li>- 8</li> <li>- 9</li> <li>- 10</li> <li>- 11</li> </ul>			PDS
	QS			scnt	Boolean	- yes	- 1			PDS

Stroop Colour Naming Test completed		ENR R3 RET	Stroop Color Naming			- no	- 0			
Total correct	QS	ENR R2 R3 RET	Stroop Color Naming	scnt1	Number					PDS
Total errors	QS	ENR R3 RET	Stroop Color Naming	scnt2	Number					PDS
Total self-corrected errors	QS	ENR R3 RET	Stroop Color Naming	scnt3	Number					PDS
Reason	QS	ENR	Stroop Color Naming	scntnd	single choice	- cognitive impairment - motor impairment - mental state - physical health - visual impairment - language barrier - refusal - study conflict - scheduling issue - site error	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			PDS

						- not administered because of participation in another study	- 11			
Stroop Word Reading Test completed	QS	ENR R3 RET	Stroop Word Reading	swrt	Boolean	- yes - no	- 1 - 0			PDS
Total correct	QS	ENR R2 R3 RET	Stroop Word Reading	swrt1	Number					PDS
Total errors	QS	ENR R3 RET	Stroop Word Reading	swrt2	Number					PDS
Total self-corrected errors	QS	ENR R3 RET	Stroop Word Reading	swrt3	Number					PDS
Reason	QS	ENR	Stroop Word Reading	swrtnd	single choice	- cognitive impairment - motor impairment - mental state - physical health - visual impairment - language barrier	- 1 - 2 - 3 - 4 - 5 - 6			PDS

						- refusal - study conflict - scheduling issue - site error - not administered because of participation in another study	- 7 - 8 - 9 - 10 - 11			
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### Section Extended Cognitive Assessments

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Stroop Interference Test completed	QS	ENR R3 RET	Stroop Interference	sit	boolean	- yes - no	- 1 - 0			PDS
Totalcorrect	QS	ENR R2 R3 RET	Stroop Interference	sit1	number					PDS
Totalerrors	QS	ENR R3 RET	Stroop Interference	sit2	number					PDS
Totalself-corrected errors	QS	ENR R3 RET	Stroop Interference	sit3	number					PDS



Trailmaking Test completed	QS	ENR R3 R2	Trail Making A&B	trl	boolean	- yes - no	- 1 - 0			PDS
Part A: time to complete	QS	ENR R3 R2	Trail Making A&B	trla1	number			sec		PDS
Part A: total correct	QS	ENR R3 R2	Trail Making A&B	trla2	number					PDS
Part A: total errors	QS	ENR R3 R2	Trail Making A&B	trla3	Number					PDS
Part B: time to complete	QS	ENR R3 R2	Trail Making A&B	trlb1	Number			sec		PDS
Part B: total correct	QS	ENR R3 R2	Trail Making A&B	trlb2	Number					PDS
Part B: total errors	QS	ENR R3 R2	Trail Making A&B	trlb3	Number					PDS
Verbal Fluency Test (Letters) completed	QS	ENR R3 RET	Letter Verbal Fluency	verflt	Boolean	- yes - no	- 1 - 0			PDS
Total correct 0-15 seconds	QS	ENR	Letter Verbal Fluency	verflt11	number					Available upon SRC approval

Total correct 16-30 seconds	QS	ENR	Letter Verbal Fluency	verflt12	Number					Available upon SRC approval
Total correct 31-45 seconds	QS	ENR	Letter Verbal Fluency	verflt13	Number					Available upon SRC approval
Total correct 46-60 seconds	QS	ENR	Letter Verbal Fluency	verflt14	Number					Available upon SRC approval
Total correct 0-60 seconds	QS	ENR	Letter Verbal Fluency	verflt15	Number					Available upon SRC approval
Total correct 0-15 seconds	QS	ENR	Letter Verbal Fluency	verflt21	Number					Available upon SRC approval
Total correct 16-30 seconds	QS	ENR	Letter Verbal Fluency	verflt22	Number					Available upon SRC approval
Total correct 31-45 seconds	QS	ENR	Letter Verbal Fluency	verflt23	Number					Available upon SRC approval
Total correct 46-60 seconds	QS	ENR	Letter Verbal Fluency	verflt24	Number					Available upon SRC approval
Total correct 0-60 seconds	QS	ENR	Letter Verbal Fluency	verflt25	number					Available upon SRC approval

Total correct 0-15 seconds	QS	ENR	Letter Verbal Fluency	verflt31	Number					Available upon SRC approval
Total correct 16-30 seconds	QS	ENR	Letter Verbal Fluency	verflt32	Number					Available upon SRC approval
Total correct 31-45 seconds	QS	ENR	Letter Verbal Fluency	verflt33	Number					Available upon SRC approval
Total correct 46-60 seconds	QS	ENR	Letter Verbal Fluency	verflt34	Number					Available upon SRC approval
Total correct 0-60 seconds	QS	ENR	Letter Verbal Fluency	verflt35	Number					Available upon SRC approval
Total correct 0-15 seconds	QS	ENR	Letter Verbal Fluency	verflt01	Number					Available upon SRC approval
Total correct 16-30 seconds	QS	ENR	Letter Verbal Fluency	verflt02	Number					Available upon SRC approval
Total correct 31-45 seconds	QS	ENR	Letter Verbal Fluency	verflt03	number					Available upon SRC approval
Total correct 46-60 seconds	QS	ENR	Letter Verbal Fluency	verflt04	Number					Available upon SRC approval
Total correct (3 min)	QS	ENR R2 R3 RET	Letter Verbal Fluency	verflt05	Number					PDS

Total intrusion errors	QS	ENR R3 RET	Letter Verbal Fluency	verflt06	Number					PDS
Total perseverative errors	QS	ENR R3 RET	Letter Verbal Fluency	verflt07	Number					PDS

## 8.5 Form “Mini Mental State Examination (MMSE)” (US version)

This form is part of the Baseline and Follow Up visit.

### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	MMSE	qsdtc	date					Not available
Assessment day	QS	ENR	MMSE	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Language of paper form (PBF)	QS	ENR	MMSE	langpbf	single choice	<ul style="list-style-type: none"> <li>- U.S. English</li> <li>- Spanish (LA)</li> <li>- Brazilian Portuguese</li> <li>- Canadian French</li> <li>- French</li> <li>- Czech</li> <li>- Danish</li> <li>- German</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 6</li> <li>- 7</li> <li>- 8</li> <li>- 9</li> <li>- 10</li> </ul>			Available upon SRC approval

						- Spanish - Italian - Dutch - Norwegian - Polish - Portuguese - Russian - Finnish - Swedish	- 11 - 12 - 13 - 14 - 15 - 16 - 17 - 18 - 19			
Rater code	QS	ENR	MMSE	raterid	number					Not available
MMSE score	QS	ENR RET	MMSE	mmsetotal	number					PDS

### Section Mini Mental State Exam

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Orientation to time										
Year?	QS	ENR	MMSE	mmse011	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Season?	QS	ENR	MMSE	mmse012	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Month of the year?	QS	ENR	MMSE	mmse013	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Day of the week?	QS	ENR	MMSE	mmse014	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval

Date?	QS	ENR	MMSE	mmse015	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Orientation to place										
State (province)?	QS	ENR	MMSE	mmse021	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
County (or city/town)?	QS	ENR	MMSE	mmse022	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
City/town (or part of city/neighborhood)?	QS	ENR	MMSE	mmse023	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Building (name or type)?	QS	ENR	MMSE	mmse024	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Floor of the building (room number or address)?	QS	ENR	MMSE	mmse025	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Registration										
Word 1	QS	ENR	MMSE	mmse031	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Word 2	QS	ENR	MMSE	mmse032	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Word 3	QS	ENR	MMSE	mmse033	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Attention and calculation (Serial 7s)										

[Step 1]	QS	ENR	MMSE	mmse041	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
[Step 2]	QS	ENR	MMSE	mmse042	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
[Step 3]	QS	ENR	MMSE	mmse043	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
[Step 4]	QS	ENR	MMSE	mmse044	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
[Step 5]	QS	ENR	MMSE	mmse045	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Recall										
Word 1	QS	ENR	MMSE	mmse051	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Word 2	QS	ENR	MMSE	mmse052	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Word 3	QS	ENR	MMSE	mmse053	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Naming										
1 [Pencil or pen]	QS	ENR	MMSE	mmse061	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
2 [Watch]	QS	ENR	MMSE	mmse062	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval

Group Repetition										
No ifs, ands or buts	QS	ENR	MMSE	mmse07	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Comprehension										
Take in right hand	QS	ENR	MMSE	mmse081	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Fold in half	QS	ENR	MMSE	mmse082	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Put on floor (or table)	QS	ENR	MMSE	mmse083	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Reading										
Close your eyes	QS	ENR	MMSE	mmse09	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Writing										
Sentence	QS	ENR	MMSE	mmse10	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Drawing										
Figure	QS	ENR	MMSE	mmse11	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval



## 8.6 Form “Physiotherapy Outcomes Measures (Physiotherapy)”

This form is part of the Baseline and Follow Up visit.

### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	Physiotherapy	qsdtc	date					Not available
Assessment day	QS	ENR	Physiotherapy	qsdyc	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval

### Section Timed Up and Go Test

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Timed "Up and Go" performed	QS	ENR	TUG	tug	boolean	- yes - no	- 1 - 0			PDS
Total time	QS	ENR	TUG	tug1	number			sec		PDS

### Section 30 Second Chair Stand Test

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
30 second chair stand	QS	ENR	30sec Chair Stand	scst	boolean	- yes - no	- 1 - 0			PDS

test performed										
Number of times the participant stands in 30 seconds	QS	ENR	30sec Chair Stand	scst1	number					PDS

## 8.7 Form “Problem Behaviours Assessment – Short (PBA-s)”

This form is part of the Baseline, Follow Up and Unscheduled visit.

### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	PBA-s	qsdtc	date					Not available
Assessment day	QS	ENR	PBA-s	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Language of paper form (PBF)	QS	ENR	PBA-s	langpbf	single choice	<ul style="list-style-type: none"> <li>- U.S. English</li> <li>- Brazilian Portuguese</li> <li>- Spanish (LA)</li> <li>- Canadian French</li> <li>- French</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 6</li> <li>- 7</li> </ul>			Available upon SRC approval

						- Czech	- 8			
						- Danish	- 9			
						- German	- 10			
						- Spanish	- 11			
						- Italian	- 12			
						- Dutch	- 13			
						- Norwegian	- 14			
						- Polish	- 15			
						- Portuguese	- 16			
						- Russian	- 17			
						- Finnish	- 18			
						- Swedish	- 19			
Rater code	QS	ENR	PBA-s	raterid	number					Not available
Group Domain scores										
Depression	QS	ENR R3	PBA-s	depscore	number					PDS
Irritability/aggression	QS	ENR R3	PBA-s	irascore	number					PDS
Psychosis	QS	ENR R3	PBA-s	psyscore	number					PDS
Apathy	QS	ENR R3	PBA-s	aptscore	number					PDS
Executive function	QS	ENR R3	PBA-s	exfscore	number					PDS

## Section Problem Behaviours Assessment for HD

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Depressed mood										
Severity	QS	ENR R3	PBA-s	pbas1sv	single choice	- absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 0 - 1 - 2 - 3 - 4			PDS
Frequency	QS	ENR R3	PBA-s	pbas1fr	single choice	- never/almost never - seldom (less than once/week) - sometimes (up to four times a week) - frequently (most days/5, 6 or 7 times a week) - daily/almost daily for most (or all) of day	- 0 - 1 - 2 - 3 - 4			PDS
Worst	QS		PBA-s	pbas1wo		- absent	- 0			PDS

		ENR R3			single choice	<ul style="list-style-type: none"> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> <li>- moderate (symptom causing problem)</li> <li>- severe (almost intolerable for carer)</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			
Group Suicidal ideation										
Severity	QS	ENR R3	PBA-s	pbas2sv	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> <li>- moderate (symptom causing problem)</li> <li>- severe (almost intolerable for carer)</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			PDS
Frequency	QS	ENR R3	PBA-s	pbas2fr	single choice	<ul style="list-style-type: none"> <li>- never/almost never</li> <li>- seldom (less than once/week)</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> </ul>			PDS

						<ul style="list-style-type: none"> <li>- sometimes (up to 4 times a week)</li> <li>- frequently (most days/5, 6 or 7 times a week)</li> <li>- daily/almost daily for most (or all) of day</li> </ul>	<ul style="list-style-type: none"> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			
Worst	QS	ENR R3	PBA-s	pbas2wo	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> <li>- moderate (symptom causing problem)</li> <li>- severe (almost intolerable for carer)</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			PDS
Group Anxiety										
Severity	QS	ENR R3	PBA-s	pbas3sv	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> </ul>			PDS

						<ul style="list-style-type: none"> <li>- moderate (symptom causing problem)</li> <li>- severe (almost intolerable for carer)</li> </ul>	<ul style="list-style-type: none"> <li>- 3</li> <li>- 4</li> </ul>			
Frequency	QS	ENR R3	PBA-s	pbas3fr	single choice	<ul style="list-style-type: none"> <li>- never/almost never</li> <li>- seldom (less than once/week)</li> <li>- sometimes (up to 4 times a week)</li> <li>- frequently (most days/5, 6 or 7 times a week)</li> <li>- daily/almost daily for most (or all) of day</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			PDS
Worst	QS	ENR R3	PBA-s	pbas3wo	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> <li>- moderate (symptom causing problem)</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> </ul>			PDS

						- severe (almost intolerable for carer)	- 4			
Group Irritability										
Severity	QS	ENR R3	PBA-s	pbas4sv	single choice	- absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 0 - 1 - 2 - 3 - 4			PDS
Frequency	QS	ENR R3	PBA-s	pbas4fr	single choice	- never/almost never - seldom (less than once/week) - sometimes (up to 4 times a week) - frequently (most days/5, 6 or 7 times a week)	- 0 - 1 - 2 - 3			PDS



						- daily/almost daily for most (or all) of day	- 4			
Worst	QS	ENR R3	PBA-s	pbas4wo	single choice	- absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 0 - 1 - 2 - 3 - 4			PDS
Group Angry or aggressive behavior										
Severity	QS	ENR R3	PBA-s	pbas5sv	single choice	- absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 0 - 1 - 2 - 3 - 4			PDS

Frequency	QS	ENR R3	PBA-s	pbas5fr	single choice	- never/almost never - seldom (less than once/week) - sometimes (up to 4 times a week) - frequently (most days/5, 6 or 7 times a week) - daily/almost daily for most (or all) of day	- 0 - 1 - 2 - 3 - 4			PDS
Worst	QS	ENR R3	PBA-s	pbas5wo	single choice	- absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 0 - 1 - 2 - 3 - 4			PDS
Group Lack of initiative (apathy)										
Severity	QS		PBA-s	pbas6sv		- absent	- 0			PDS

		ENR R3			single choice	<ul style="list-style-type: none"> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> <li>- moderate (symptom causing problem)</li> <li>- severe (almost intolerable for carer)</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			
Frequency	QS	ENR R3	PBA-s	pbas6fr	single choice	<ul style="list-style-type: none"> <li>- never/almost never</li> <li>- seldom (less than once/week)</li> <li>- sometimes (up to 4 times a week)</li> <li>- frequently (most days/5, 6 or 7 times a week)</li> <li>- daily/almost daily for most (or all) of day</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			PDS
Worst	QS	ENR R3	PBA-s	pbas6wo	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- slight, questionable</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> </ul>			PDS

						- mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 2  - 3  - 4			
Group Perseverative thinking or behavior										
Severity	QS	ENR R3	PBA-s	pbas7sv	single choice	- absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 0 - 1 - 2 - 3 - 4			PDS
Frequency	QS	ENR R3	PBA-s	pbas7fr	single choice	- never/almost never - seldom (less than once/week)	- 0 - 1			PDS

						<ul style="list-style-type: none"> <li>- sometimes (up to 4 times a week)</li> <li>- frequently (most days/5, 6 or 7 times a week)</li> <li>- daily/almost daily for most (or all) of day</li> </ul>	<ul style="list-style-type: none"> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			
Worst	QS	ENR R3	PBA-s	pbas7wo	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> <li>- moderate (symptom causing problem)</li> <li>- severe (almost intolerable for carer)</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			PDS
Group Obsessive-Compulsive Behaviours										
Severity	QS	ENR R3	PBA-s	pbas8sv	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> </ul>			PDS

						<ul style="list-style-type: none"> <li>- moderate (symptom causing problem)</li> <li>- severe (almost intolerable for carer)</li> </ul>	<ul style="list-style-type: none"> <li>- 3</li> <li>- 4</li> </ul>			
Frequency	QS	ENR R3	PBA-s	pbas8fr	single choice	<ul style="list-style-type: none"> <li>- never/almost never</li> <li>- seldom (less than once/week)</li> <li>- sometimes (up to 4 times a week)</li> <li>- frequently (most days/5, 6 or 7 times a week)</li> <li>- daily/almost daily for most (or all) of day</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			PDS
Worst	QS	ENR R3	PBA-s	pbas8wo	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> <li>- moderate (symptom causing problem)</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> </ul>			PDS

						- severe (almost intolerable for carer)	- 4			
Group Delusions / paranoid thinking										
Severity	QS	ENR R3	PBA-s	pbas9sv	single choice	- absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 0 - 1 - 2 - 3 - 4			PDS
Frequency	QS	ENR R3	PBA-s	pbas9fr	single choice	- never/almost never - seldom (less than once/week) - sometimes (up to 4 times a week) - frequently (most days/5, 6 or 7 times a week)	- 0 - 1 - 2 - 3			PDS

						- daily/almost daily for most (or all) of day	- 4			
Worst	QS	ENR R3	PBA-s	pbas9wo	single choice	- absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 0 - 1 - 2 - 3 - 4			PDS
Group Hallucinations										
Severity	QS	ENR R3	PBA-s	pbas10sv	single choice	- absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 0 - 1 - 2 - 3 - 4			PDS



Group Please specify										
Modality of hallucinations	QS	ENR R3	PBA-s	pbas10sm	multiple choice	<ul style="list-style-type: none"> <li>- auditory</li> <li>- visual</li> <li>- tactile</li> <li>- olfactory</li> <li>- gustatory</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> </ul>			PDS
Frequency	QS	ENR R3	PBA-s	pbas10fr	single choice	<ul style="list-style-type: none"> <li>- never/almost never</li> <li>- seldom (less than once/week)</li> <li>- sometimes (up to 4 times a week)</li> <li>- frequently (most days/5, 6 or 7 times a week)</li> <li>- daily/almost daily for most (or all) of day</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			PDS
Worst	QS	ENR R3	PBA-s	pbas10wo	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> <li>- moderate (symptom causing problem)</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> </ul>			PDS

						- severe (almost intolerable for carer)	- 4			
Group Please specify										
Modality of hallucinations	QS	ENR	PBA-s	pbas10wm	multiple choice	- auditory - visual - tactile - olfactory - gustatory	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Group Disoriented Behaviour										
Severity	QS	ENR R3	PBA-s	pbas11sv	single choice	- absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer)	- 0 - 1 - 2 - 3 - 4			PDS
Frequency	QS	ENR R3	PBA-s	pbas11fr	single choice	- never/almost never - seldom (less than once/week)	- 0 - 1			PDS

						<ul style="list-style-type: none"> <li>- sometimes (up to 4 times a week)</li> <li>- frequently (most days/5, 6 or 7 times a week)</li> <li>- daily/almost daily for most (or all) of day</li> </ul>	<ul style="list-style-type: none"> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			
Worst	QS	ENR R3	PBA-s	pbas11wo	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- slight, questionable</li> <li>- mild (present, not a problem)</li> <li>- moderate (symptom causing problem)</li> <li>- severe (almost intolerable for carer)</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			PDS

#### Section Information

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
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Is informant a relative?	QS	ENR R3	PBA	pbainfo	single choice	<ul style="list-style-type: none"> <li>- spouse or partner</li> <li>- parent</li> <li>- sibling</li> <li>- child</li> <li>- other relative</li> <li>- friend or neighbor</li> <li>- professional care worker</li> <li>- other</li> <li>- no informant - participant came alone</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> <li>- 6</li> <li>- 7</li> <li>- 8</li> <li>- 9</li> </ul>			PDS
Is informant a household member?	QS	ENR R3	PBA	pbahshd	single choice	<ul style="list-style-type: none"> <li>- household member (i.e. relative or friend who lives with participant)</li> <li>- not a household member but has frequent contact with participant (most days)</li> <li>- not a household member and sees participant less than three or four times a week</li> <li>- staff of residential care home or hospital</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			PDS
	CO	ENR	PBA	coval	text					

General comments									Not available
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## 8.8 Form “Short Form Health Survey– 12v2 (SF-12)”

This form is part of the Baseline, Follow Up and Unscheduled visit.

### Section General

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	SF-12	qsdtc	date					Not available
Assessment day	QS	ENR	SF-12	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Language of paper form (PBF)	QS	ENR	SF-12	Langpbf	single choice	<ul style="list-style-type: none"> <li>- U.S. English</li> <li>- Brazilian Portuguese</li> <li>- Spanish (LA North)</li> <li>- Spanish (LA South)</li> <li>- Canadian French</li> <li>- French</li> <li>- Czech</li> <li>- Danish</li> <li>- German</li> <li>- Spanish</li> <li>- Italian</li> <li>- Dutch</li> <li>- Norwegian</li> <li>- Polish</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> <li>- 6</li> <li>- 7</li> <li>- 8</li> <li>- 9</li> <li>- 10</li> <li>- 11</li> <li>- 12</li> <li>- 13</li> <li>- 14</li> <li>- 15</li> </ul>			Available upon SRC approval

						- Portuguese	- 16			
						- Russian	- 17			
						- Finnish	- 18			
						- Swedish	- 19			

## Section Scoring

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Online scoring	QS	ENR		scoring	single choice	- pending - succeeded - failed (once) - failed (twice) - error	- 0 - 1 - 2 - 3 - 4			PDS
Group Norm-based scores										
Physical Functioning (PF)	QS	ENR		pf	number					PDS
Role-Physical (RP)	QS	ENR		rp	number					PDS
Bodily Pain (BP)	QS	ENR		bp	number					PDS
General Health (GH)	QS	ENR		gh	number					PDS
Group Norm-based scores										
Vitality (VT)	QS	ENR		vt	number					PDS
Social Functioning (SF)	QS	ENR		sf	number					PDS

Role-Emotional (RE)	QS	ENR		re	number					PDS
Mental Health (MH)	QS	ENR		mh	number					PDS
Physical Component (PCS)	QS	ENR		pcs	number					PDS
Mental Component (PCS)	QS	ENR		mcs	number					PDS

### Section Your Health and Well-Being

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
1. In general, would you say your health is?	QS	ENR	SF-12	sf12_1	single choice	- Excellent - Very good - Good - Fair - Poor	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?										
a) Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	QS	ENR	SF-12	sf12_2	single choice	- Yes, limited a lot - Yes, limited a little - No, not limited at all	- 1 - 2 - 3			Available upon SRC approval

b) Climbing several flights of stairs	QS	ENR	SF-12	sf12_3	single choice	- Yes, limited a lot - Yes, limited a little - No, not limited at all	- 1 - 2 - 3			Available upon SRC approval
3. During the past week, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?										
a) Accomplished less than you would like	QS	ENR	SF-12	sf12_4	single choice	- All of the time - Most of the time - Some of the time - A little of the time - None of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
b) Were limited in the kind of work or other activities	QS	ENR	SF-12	sf12_5	single choice	- All of the time - Most of the time - Some of the time - A little of the time - None of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
4. During the past week, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?										
a) Accomplished less than you would like	QS	ENR	SF-12	sf12_6	single choice	- All of the time - Most of the time - Some of the time - A little of the time - None of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
b) Did work or other activities less carefully than usual	QS	ENR	SF-12	sf12_7	single choice	- All of the time - Most of the time - Some of the time - A little of the time - None of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
	QS	ENR	SF-12	sf12_8		- Not at all	- 1			



5. During the past week, how much did pain interfere with your normal work (including both work outside the home and housework)?					single choice	- A little bit - Moderately - Quite a bit - Extremely	- 2 - 3 - 4 - 5			Available upon SRC approval
6. These questions are about how you feel and how things have been with you during the past week. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past week ...										
a) Have you felt calm and peaceful?	QS	ENR	SF-12	sf12_9	single choice	- All of the time - Most of the time - Some of the time - A little of the time - None of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
b) Did you have a lot of energy?	QS	ENR	SF-12	sf12_10	single choice	- All of the time - Most of the time - Some of the time - A little of the time - None of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
c) Have you felt downhearted and depressed?	QS	ENR	SF-12	sf12_11	single choice	- All of the time - Most of the time - Some of the time - A little of the time - None of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
7. During the past week, how much of the	QS	ENR	SF-12	sf12_12	single choice	- All of the time - Most of the time - Some of the time	- 1 - 2 - 3			Available upon SRC approval

time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?						- A little of the time - None of the time	- 4 - 5			
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## 8.9 Form “Hospital Anxiety and Depression Scale/Snaith Irritability Scale (HADS-SIS)”

This form is part of the Baseline, Follow Up and Unscheduled visit.

### Section General

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	HADS-SIS	qsdtc	date					Not available
Assessment day	QS	ENR	HADS-SIS	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Language of paper form (PBF)	QS	ENR	HADS-SIS	langpbf	single choice	- U.S. English - Brazilian Portuguese - Spanish (LA North) - Spanish (LA South)	- 1 - 3 - 4 - 5			Available upon SRC approval

						- Canadian French	- 6			
						- French	- 7			
						- Czech	- 8			
						- Danish	- 9			
						- German	- 10			
						- Spanish	- 11			
						- Italian	- 12			
						- Dutch	- 13			
						- Norwegian	- 14			
						- Polish	- 15			
						- Portuguese	- 16			
						- Russian	- 17			
						- Finnish	- 18			
						- Swedish	- 19			
Anxiety subscore	QS	ENR R3	HADS-SIS	anxscore	number					PDS
Depression subscore	QS	ENR R3	HADS-SIS	hads_depscore	number					PDS
Irritability subscore	QS	ENR R3	HADS-SIS	irrscore	number					PDS
Outward irritability subscore	QS	ENR R3	HADS-SIS	outscore	number					PDS
Inward irritability subscore	QS	ENR R3	HADS-SIS	inwscore	number					PDS

## Section HADS-SIS

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
I feel tense or 'wound up'	QS	ENR	HADS	hads1a	single choice	- most of the time - a lot of the time - from time to time, occasionally - not at all	- 3 - 2 - 1 - 0			Available upon SRC approval
I still enjoy the things I used to enjoy	QS	ENR	HADS	hads1d	single choice	- definitely as much - not quite so much - only a little - hardly at all	- 0 - 1 - 2 - 3			Available upon SRC approval
I get a sort of frightened feeling as if something awful is about to happen	QS	ENR	HADS	hads2a	single choice	- very definitely and quite badly - yes, but not too badly - a little, but it doesn't worry me - not at all	- 3 - 2 - 1 - 0			Available upon SRC approval
I lose my temper and shout or snap at others	QS	ENR	SIS	sis1	single choice	- yes, definitely - yes, sometimes - no, not much - no, not at all	- 3 - 2 - 1 - 0			Available upon SRC approval
I can laugh and see the funny side of things	QS	ENR	HADS	hads2d	single choice	- as much as I always could - not quite so much now - definitely not so much now - not at all	- 0 - 1 - 2 - 3			Available upon SRC approval
	QS	ENR	SIS	sis2		- all of the time	- 0			

I am patient with other people					single choice	- most of the time - some of the time - hardly ever	- 1 - 2 - 3			Available upon SRC approval
I feel cheerful	QS	ENR	HADS	hads3d	single choice	- never - not often - sometimes - most of the time	- 3 - 2 - 1 - 0			Available upon SRC approval
I get angry with myself and call myself names	QS	ENR	SIS	sis3	single choice	- yes, definitely - sometimes - not often - no, not at all	- 3 - 2 - 1 - 0			Available upon SRC approval
I can sit at ease and feel relaxed	QS	ENR	HADS	hads3a	single choice	- definitely - usually - not often - not at all	- 0 - 1 - 2 - 3			Available upon SRC approval
I feel as if I am slowed down	QS	ENR	HADS	hads4d	single choice	- nearly all the time - very often - sometimes - not at all	- 3 - 2 - 1 - 0			Available upon SRC approval
I feel like harming myself	QS	ENR	SIS	sis4	single choice	- yes, definitely - yes, sometimes - no, not much - no, not at all	- 3 - 2 - 1 - 0			Available upon SRC approval
Worrying thoughts go through my mind	QS	ENR	HADS	hads4a	single choice	- a great deal of the time - a lot of the time - not too often - very little	- 3 - 2 - 1 - 0			Available upon SRC approval
I have lost interest in my appearance	QS	ENR	HADS	hads5d	single choice	- definitely - I don't take as much care as I should	- 3 - 2			Available upon SRC approval

						- I may not take quite as much care - I take just as much care as ever	- 1 - 0			
The thought of hurting myself occurs to me	QS	ENR	SIS	sis5	single choice	- sometimes - not very often - hardly ever - not at all	- 3 - 2 - 1 - 0			Available upon SRC approval
I feel restless as if I have to be on the move	QS	ENR	HADS	hads5a	single choice	- very much indeed - quite a lot - not very much - not at all	- 3 - 2 - 1 - 0			Available upon SRC approval
I look forward with enjoyment to things	QS	ENR	HADS	hads6d	single choice	- as much as I ever did - rather less than I used to - definitely less than I used to - hardly at all	- 0 - 1 - 2 - 3			Available upon SRC approval
I feel I might lose control and hit or hurt someone	QS	ENR	SIS	sis6	single choice	- sometimes - occasionally - rarely - never	- 3 - 2 - 1 - 0			Available upon SRC approval
I get a sort of frightened feeling like 'butterflies' in the stomach	QS	ENR	HADS	hads6a	single choice	- not at all - occasionally - quite often - very often	- 0 - 1 - 2 - 3			Available upon SRC approval
People upset me so that I feel like slamming doors or banging about	QS	ENR	SIS	sis7	single choice	- yes, often - yes, sometimes - only occasionally - not at all	- 3 - 2 - 1 - 0			Available upon SRC approval

I get sudden feelings of panic	QS	ENR	HADS	hads7a	single choice	- very often indeed - quite often - not very often - not at all	- 3 - 2 - 1 - 0			Available upon SRC approval
I can enjoy a good book or radio or television programme	QS	ENR	HADS	hads7d	single choice	- often - sometimes - not often - very seldom	- 0 - 1 - 2 - 3			Available upon SRC approval
Lately I have been getting annoyed with myself	QS	ENR	SIS	sis8	single choice	- very much so - rather a lot - not much - not at all	- 3 - 2 - 1 - 0			Available upon SRC approval

## 8.10 Form “Work Productivity and Activity Impairment-Specific Health Problem Questionnaire (WPAI-SHP)”

This form is part of the Baseline and Follow Up visit.

### Section General

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	WPAI-SHP	qsdtc	date					Not available
Assessment day	QS	ENR	WPAI-SHP	qsdyc	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Language of paper form (PBF)	QS	ENR	WPAI-SHP	langpbf	single choice	- U.S. English - Brazilian Portuguese	- 1 - 2			Available upon SRC approval

						- Spanish (LA)	- 3			
						- Canadian French	- 6			
						- French	- 7			
						- Czech	- 8			
						- Danish	- 9			
						- German	- 10			
						- Spanish	- 11			
						- Italian	- 12			
						- Dutch	- 13			
						- Norwegian	- 14			
						- Polish	- 15			
						- Portuguese	- 16			
						- Russian	- 17			
						- Finnish	- 18			
						- Swedish	- 19			
Work time missed due to HD	QS	ENR	WPAI-SHP	wpaiscr1	number			%		PDS
Impairment while working due to HD	QS	ENR	WPAI-SHP	wpaiscr2	number			%		PDS
Overall work impairment due to HD	QS	ENR	WPAI-SHP	wpaiscr3	number			%		PDS
Activity impairment due to HD	QS	ENR	WPAI-SHP	wpaiscr4	number			%		PDS



# Section Work Productivity and Activity Impairment Questionnaire: Specific Health Problem (WPAI-SHP)

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Are you currently employed (working for pay)?	QS	ENR	WPAI-SHP	wpai01	boolean	- yes - no	- 1 - 0			Available upon SRC approval
During the past seven days, how many hours did you miss from work because of problems associated with Huntington's disease?	QS	ENR	WPAI-SHP	wpai02	number			hours		Available upon SRC approval
During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study?	QS	ENR	WPAI-SHP	wpai03	number			hours		Available upon SRC approval
During the past seven days, how many hours did you actually work?	QS	ENR	WPAI-SHP	wpai04	number			hours		Available upon SRC approval

During the past seven days, how much did Huntington's disease affect your productivity while you were working?	QS	ENR	WPAI-SHP	wpai05	single choice	- 0 = HD had no effect on my work - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 = HD completely prevented my from working	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
During the past seven days, how much did Huntington's disease affect your ability to do your regular daily activities, other than work at a job?	QS	ENR	WPAI-SHP	wpai06	single choice	- 0 = HD had no effect on my daily activities - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 = HD completely	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval

					prevented me from doing my daily activities				
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## 8.11 Form “Columbia-Suicide Severity Rating Scale – Baseline Version (C-SSRS)”

This form is part of the Baseline, Follow Up and Unscheduled visit.

### Section General

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	C-SSRS	qsdtc	date					Not available
Assessment day	QS	ENR	C-SSRS	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Rater code	QS	ENR	C-SSRS	raterid	number					Not available

### Section Suicidal Ideation - For Lifetime, rate the period when the participant felt the most suicidal.

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group 1. Wish to be dead										
Have you wished you were dead or wished you could go to sleep and not wake up?	QS	ENR R3	C-SSRS	sid1	boolean	- yes - no	- 1 - 0			PDS

Please describe	SUPPQS	ENR	C-SSRS	sid1sc	text					Not available
Group 2. Non-Specific Active Suicidal Thoughts										
Have you actually had any thoughts of killing yourself?	QS	ENR R3	C-SSRS	sid2	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	sid2sc	text					Not available

### Section Suicidal Ideation (continued)

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group 3. Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act										
Have you been thinking about how you might do this?	QS	ENR R3	C-SSRS	sid3	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	sid3sc	text					Not available
Group 4. Active Suicidal Ideation with Some Intent to Act, without Specific Plan										
Have you had these thoughts and had some intention of acting on them?	QS	ENR R3	C-SSRS	sid4	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	sid4sc	text					Not available
Group 5. Active Suicidal Ideation with Specific Plan and Intent										
Have you started to work out or worked out the details of how to kill yourself? Do you intend to	QS	ENR R3	C-SSRS	sid5	boolean	- yes - no	- 1 - 0			PDS

carry out this plan?										
Please describe	SUPPQS	ENR	C-SSRS	sid5sc	text					Not available

### Section Intensity of Ideation - Most Severe

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Most Severe Ideation										
Type # (1-5)	QS	ENR R3	C-SSRS	int1	single choice	- Wish to be dead - Non-Specific Active Suicidal Thoughts - Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act - Active Suicidal Ideation with Some Intent to Act, without Specific Plan - Active Suicidal Ideation with Specific Plan and Intent	- 1 - 2 - 3 - 4 - 5			PDS
Description of Ideation	SUPPQS	ENR	C-SSRS	int1sc	text					Not available
Group Frequency										

How many times have you had these thoughts?	QS	ENR R3	C-SSRS	int2	single choice	<ul style="list-style-type: none"> <li>- Less than once a week</li> <li>- Once a week</li> <li>- 2-5 times a week</li> <li>- Daily or almost daily</li> <li>- Many times each day</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> </ul>			PDS
Group Duration										
When you have the thoughts, how long do they last?	QS	ENR R3	C-SSRS	int3	single choice	<ul style="list-style-type: none"> <li>- Fleeting – few seconds or minutes</li> <li>- Less than 1 hour/some of the time</li> <li>- 1-4 hours/ a lot of time</li> <li>- 4-8 hours/most of day</li> <li>- Many times each day</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> </ul>			PDS
Group Controllability										
Could/can you stop thinking about killing yourself or wanting to die if you want to?	QS	ENR R3	C-SSRS	int4	single choice	<ul style="list-style-type: none"> <li>- Easily able to control thoughts</li> <li>- Can control thoughts with little difficulty</li> <li>- Can control thoughts with some difficulty</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> </ul>			PDS

						<ul style="list-style-type: none"> <li>- Can control thoughts with a lot of difficulty</li> <li>- Unable to control thoughts</li> <li>- Does not attempt to control thoughts</li> </ul>	<ul style="list-style-type: none"> <li>- 4</li> <li>- 5</li> <li>- 0</li> </ul>			
Group Deterrents										
Are there things - anyone or anything (e.g. family, religion, pain of death) - that stopped you from wanting to die or acting on thoughts of committing suicide?	QS	ENR R3	C-SSRS	int5	single choice	<ul style="list-style-type: none"> <li>- Deterrents definitely stopped you</li> <li>- Deterrents probably stopped you</li> <li>- Uncertain that deterrents stopped you</li> <li>- Deterrents most likely did not stop you from attempting suicide</li> <li>- Deterrents definitely did not stop you</li> <li>- Does not apply; wish to die only</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> <li>- 0</li> </ul>			PDS
Group Reasons for Ideation										
What sort of reasons did you have for thinking	QS	ENR R3	C-SSRS	int6	single choice	<ul style="list-style-type: none"> <li>- Completely to get attention, revenge or a</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> </ul>			PDS

about wanting to die or killing yourself?						reaction from others				
						- Mostly to get attention, revenge or a reaction from others	- 2			
						- Equally to get attention, revenge or a reaction from others	- 3			
						- Mostly to end or stop the pain (you couldn't go on living with the pain or hwo you were feeling)	- 4			
						- Completely to end or stop the pain (you couldn't go on living with the pain or hwo you were feeling)	- 5			
						- Does not apply	- 0			

## Section Suicidal Behavior

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
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Group Actual Attempt										
Actual attempt	QS	ENR R3	C-SSRS	sbh1	boolean	- yes - no	- 1 - 0			PDS
Total # of attempts	QS	ENR R3	C-SSRS	sbh1n	number					PDS
Please describe	SUPPQS	ENR	C-SSRS	sbh1sc	text					Not available
Has subject engaged in Non-Suicidal Self-Injurious Behavior?	QS	ENR R3	C-SSRS	sbh2	boolean	- yes - no	- 1 - 0			PDS
Group Interrupted Attempt										
Has there been a time when you started to do something to end your life but someone or something stopped you before you actually did anything?	QS	ENR R3	C-SSRS	sbh3	boolean	- yes - no	- 1 - 0			PDS
Total # of interrupted	QS	ENR R3	C-SSRS	sbh3n	number					PDS
Please describe	SUPPQS	ENR	C-SSRS	sbh3sc	text					Not available
Group Aborted Attempt										
Has there been a time when you started to do something to try	QS	ENR R3	C-SSRS	sbh4	boolean	- yes - no	- 1 - 0			PDS

to end your life but you stopped yourself before you actually did anything?										
Total# of aborted	QS	ENR R3	C-SSRS	sbh4n	number					PDS
Please describe	SUPPQS	ENR	C-SSRS	sbh4sc	text					Not available
Group Preparatory Acts or Behavior										
Have you taken any steps towards making a suicide attempt or preparing to kill yourself (such as collecting pills, getting a gun, giving valuables away or writing a suicide note)?	QS	ENR R3	C-SSRS	sbh5	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	sbh5sc	text					Not available
Group Suicidal Behavior										
Suicidal behavior was present during the assessment period?	QS	ENR R3	C-SSRS	sbh6	boolean	- yes - no	- 1 - 0			PDS
Completed Suicide was present during the assessment period	QS	ENR R3	C-SSRS	sbh7	boolean	- yes - no	- 1 - 0			PDS

### Section Answer for Actual Attempts Only

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Most recent attempt										
Date	QS	ENR	C-SSRS	attmpt1	date					Not available
Day	QS	ENR	C-SSRS	attmpt1dy	number			days	Transformed into days relative to baseline date of Enroll-HD.	PDS
Actual Lethality/Medical Damage	QS	ENR R3	C-SSRS	attmpt11	single choice	<ul style="list-style-type: none"> <li>- No physical damage</li> <li>- Minor physical damage</li> <li>- Moderate physical damage</li> <li>- Moderately severe physical damage</li> <li>- Severe physical damage</li> <li>- Death</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> </ul>			PDS
Potential Lethality	QS	ENR R3	C-SSRS	attmpt12	single choice	<ul style="list-style-type: none"> <li>- not likely to result in injury</li> <li>- likely to result in injury</li> <li>- likely to result in death</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> </ul>			PDS
Group Most lethal attempt										
Date	QS	ENR	C-SSRS	attmpt2	date					Not available

Day	QS	ENR	C-SSRS	attmpt2dy	number			Days	Transformed into days relative to baseline date of Enroll-HD.	PDS
Actual Lethality/Medical Damage	QS	ENR R3	C-SSRS	attmpt21	single choice	<ul style="list-style-type: none"> <li>- No physical damage</li> <li>- Minor physical damage</li> <li>- Moderate physical damage</li> <li>- Moderately severe physical damage</li> <li>- Severe physical damage</li> <li>- Death</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> </ul>			PDS
Potential Lethality	QS	ENR R3	C-SSRS	attmpt22	single choice	<ul style="list-style-type: none"> <li>- not likely to result in injury</li> <li>- likely to result in injury</li> <li>- likely to result in death</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> </ul>			PDS
Group Initial/First attempt										
Date	QS	ENR	C-SSRS	attmpt3	date					Not available
Day	QS	ENR	C-SSRS	attmpt3dy	number			days	Transformed into days relative to baseline date of Enroll-HD.	PDS
	QS	ENR R3	C-SSRS	attmpt31	single choice	<ul style="list-style-type: none"> <li>- No physical damage</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> </ul>			PDS

Actual Lethality/Medical Damage						<ul style="list-style-type: none"> <li>- Minor physical damage - 1</li> <li>- Moderate physical damage - 2</li> <li>- Moderately severe physical damage - 3</li> <li>- Severe physical damage - 4</li> <li>- Death - 5</li> </ul>				
Potential Lethality	QS	ENR R3	C-SSRS	attmpt32	single choice	<ul style="list-style-type: none"> <li>- not likely to result in injury - 0</li> <li>- likely to result in injury - 1</li> <li>- likely to result in death - 2</li> </ul>				PDS

## 8.12 Form “Columbia-Suicide Severity Rating Scale – Followup Version (C-SSRS)”

This form is part of the Baseline (sometimes), Follow Up and Unscheduled visit.

### Section General

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	C-SSRS	qsdtc	date					Not available
Assessment day	QS	ENR	C-SSRS	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Rater code	QS	ENR	C-SSRS	raterid	number					Not available

### Section Suicidal Ideation - Since last visit, rate the period when the participant felt the most suicidal

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group 1. Wish to be dead										
Have you wished you were dead or wished you could go to sleep and not wake up?	QS	ENR R3	C-SSRS	sid1	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	sid1sc	text					Not available
Group 2. Non-Specific Active Suicidal Thoughts										
Have you actually had any thoughts of killing yourself?	QS	ENR R3	C-SSRS	sid2	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	sid2sc	text					Not available

### Section Suicidal Ideation (continued)

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group 3. Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act										
Have you been thinking about how you might do this?	QS	ENR R3	C-SSRS	sid3	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	sid3sc	text					Not available
Group 4. Active Suicidal Ideation with Some Intent to Act, without Specific Plan										

Have you had these thoughts and had some intention of acting on them?	QS	ENR R3	C-SSRS	sid4	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	sid4sc	text					Not available
Group 5. Active Suicidal Ideation with Specific Plan and Intent										
Have you started to work out or worked out the details of how to kill yourself? Do you intend to carry out this plan?	QS	ENR R3	C-SSRS	sid5	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	sid5sc	text					Not available

### Section Intensity of Ideation - Most Severe

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Most Severe Ideation										
Type # (1-5)	QS	ENR R3	C-SSRS	int1	single choice	- Wish to be dead - Non-Specific Active Suicidal Thoughts - Active Suicidal Ideation with Any Methods (not Plan)	- 1 - 2 - 3			PDS

						without Intent to Act - Active Suicidal Ideation with Some Intent to Act, without Specific Plan - Active Suicidal Ideation with Specific Plan and Intent	- 4  - 5			
Description of Ideation	SUPPQS	ENR	C-SSRS	int1sc	text					Not available
Group Frequency										
How many times have you had these thoughts?	QS	ENR R3	C-SSRS	int2	single choice	- Less than once a week - Once a week - 2-5 times a week - Daily or almost daily - Many times each day	- 1 - 2 - 3 - 4 - 5			PDS
Group Duration										
When you have the thoughts, how long do they last?	QS	ENR R3	C-SSRS	int3	single choice	- Fleeting – few seconds or minutes - Less than 1 hour/some of the time - 1-4 hours/ a lot of time	- 1 - 2 - 3			PDS



						- 4-8 hours/most of day - Many times each day	- 4 - 5			
Group Controllability										
Could/can you stop thinking about killing yourself or wanting to die if you want to?	QS	ENR R3	C-SSRS	int4	single choice	- Easily able to control thoughts - Can control thoughts with little difficulty - Can control thoughts with some difficulty - Can control thoughts with a lot of difficulty - Unable to control thoughts - Does not attempt to control thoughts	- 1 - 2 - 3 - 4 - 5 - 0			PDS
Group Deterrents										
Are there things - anyone or anything (e.g. family, religion, pain of death) - that stopped	QS	ENR R3	C-SSRS	int5	single choice	- Deterrents definitely stopped you - Deterrents probably stopped you	- 1 - 2			PDS

you from wanting to die or acting on thoughts of committing suicide?						<ul style="list-style-type: none"> <li>- Uncertain that deterrents stopped you</li> <li>- Deterrents most likely did not stop you from attempting suicide</li> <li>- Deterrents definitely did not stop you</li> <li>- Does not apply; wish to die only</li> </ul>	- 3 - 4 - 5 - 0			
Group Reasons for Ideation										
What sort of reasons did you have for thinking about wanting to die or killing yourself?	QS	ENR R3	C-SSRS	int6	single choice	<ul style="list-style-type: none"> <li>- Completely to get attention, revenge or a reaction from others</li> <li>- Mostly to get attention, revenge or a reaction from others</li> <li>- Equally to get attention, revenge or a reaction from others</li> <li>- Mostly to end or stop the pain (you couldn't go</li> </ul>	- 1 - 2 - 3 - 4			PDS

						on living with the pain or how you were feeling)				
						- Completely to end or stop the pain (you couldn't go on living with the pain or how you were feeling)	- 5			
						- Does not apply	- 0			

### Section Suicidal Behavior

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Actual Attempt										
Actual attempt	QS	ENR R3	C-SSRS	sbh1	boolean	- yes - no	- 1 - 0			PDS
Total # of attempts	QS	ENR R3	C-SSRS	sbh1n	number					PDS
Please describe	SUPPQS	ENR	C-SSRS	sbh1sc	text					Not available
Has subject engaged in Non-Suicidal Self-Injurious Behavior?	QS	ENR R3	C-SSRS	sbh2	boolean	- yes - no	- 1 - 0			PDS
Group Interrupted Attempt										
Has there been a time when	QS	ENR R3	C-SSRS	sbh3	boolean	- yes - no	- 1 - 0			PDS

you started to do something to end your life but someone or something stopped you before you actually did anything?										
Total # of interrupted	QS	ENR R3	C-SSRS	sbh3n	number					PDS
Please describe	SUPPQS	ENR	C-SSRS	sbh3sc	text					Not available
Group Aborted Attempt										
Has there been a time when you started to do something to try to end your life but you stopped yourself before you actually did anything?	QS	ENR R3	C-SSRS	sbh4	boolean	- yes - no	- 1 - 0			PDS
Total # of aborted	QS	ENR R3	C-SSRS	sbh4n	number					PDS
Please describe	SUPPQS	ENR	C-SSRS	sbh4sc	text					Not available
Group Preparatory Acts or Behavior										
Have you taken any steps towards making a suicide attempt or	QS	ENR R3	C-SSRS	sbh5	boolean	- yes - no	- 1 - 0			PDS

preparing to kill yourself (such as collecting pills, getting a gun, giving valuables away or writing a suicide note)?										
Please describe	SUPPQS	ENR	C-SSRS	sbh5sc	text					Not available
Group Suicidal Behavior										
Suicidal behavior was present during the assessment period?	QS	ENR R3	C-SSRS	sbh6	boolean	- yes - no	- 1 - 0			PDS
Completed Suicide was present during the assessment period	QS	ENR R3	C-SSRS	Sbh7	boolean	- yes - no	- 1 - 0			PDS

#### Section Answer for Actual Attempts Only

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date	QS	ENR	C-SSRS	attmpt1	date					Not available
Day	QS	ENR	C-SSRS	attmpt1dy	number			days	Transformed into days relative to	PDS

									baseline date of Enroll-HD.	
Actual Lethality/Medical Damage	QS	ENR	C-SSRS	attmpt11	single choice	- No physical damage - Minor physical damage - Moderate physical damage - Moderately severe physical damage - Severe physical damage - Death	- 0 - 1 - 2 - 3 - 4 - 5			PDS
Potential Lethality	QS	ENR	C-SSRS	attmpt12	single choice	- not likely to result in injury - likely to result in injury - likely to result in death	- 0 - 1 - 2			PDS
Group Most lethal attempt										
Date	QS	ENR	C-SSRS	attmpt2	date					Not available
Day	QS	ENR	C-SSRS	attmpt2dy	number			Days	Transformed into days relative to baseline date of Enroll-HD.	PDS
Actual Lethality/Medical Damage	QS	ENR R3	C-SSRS	attmpt21	single choice	- No physical damage - Minor physical damage	- 0 - 1			PDS

						<ul style="list-style-type: none"> <li>- Moderate physical damage</li> <li>- Moderately severe physical damage</li> <li>- Severe physical damage</li> <li>- Death</li> </ul>	<ul style="list-style-type: none"> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> </ul>			
Potential Lethality	QS	ENR R3	C-SSRS	attmpt22	single choice	<ul style="list-style-type: none"> <li>- not likely to result in injury</li> <li>- likely to result in injury</li> <li>- likely to result in death</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> </ul>			PDS
Group Initial/First attempt										
Date	QS	ENR	C-SSRS	attmpt3	date					Not available
Day	QS	ENR	C-SSRS	attmpt3dy	number					PDS
Actual Lethality/Medical Damage	QS	ENR R3	C-SSRS	attmpt31	single choice	<ul style="list-style-type: none"> <li>- No physical damage</li> <li>- Minor physical damage</li> <li>- Moderate physical damage</li> <li>- Moderately severe physical damage</li> <li>- Severe physical damage</li> <li>- Death</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> </ul>			PDS

Potential Lethality	QS	ENR R3	C-SSRS	attmpt32	single choice	- not likely to result in injury - likely to result in injury - likely to result in death	- 0 - 1 - 2			PDS
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### 8.13 Form “Missed Visit”

This form is part of the Phone Contact visit.

#### Section Documentation of Missed Follow-Up

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date info obtained		ENR		mvdtc	date					Not available
Day info obtained		ENR		mvdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Source of information		ENR		mvsrsc	single choice	- participant - spouse/partner - next of kin (family or friends) - physician - nurse - other (e.g. hearsay, obituary in newspaper, death certificate)	- 1 - 2 - 3 - 4 - 5 - 6			PDS



Reason for missed follow-up visit		ENR		mvrnsn	single choice	<ul style="list-style-type: none"> <li>- missed visit due to participation in other studies</li> <li>- participant alive, unable to attend FUP, open to future FUPs</li> <li>- participant alive, objects to further FUP visits, open to further phone contacts</li> <li>- participant alive, objects to further FUP visits and to further phone contacts</li> <li>- participant alive, lost to FUP</li> <li>- participant dead</li> <li>- status unclear</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> <li>- 6</li> </ul>			PDS
Group If participant is alive										
Level of care required		ENR		crlvl	single choice	<ul style="list-style-type: none"> <li>- The participant does not require any help or help for basic activities of daily living (un/dressing, washing/bathing, getting up/going to bed).</li> <li>- The participant requires some help to manage basic activities of daily living (typically &lt; 4 h support per day), but no full-time supervision.</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> </ul>			PDS

						- The participant requires extensive help to manage basic activities of daily living (typically $\geq 4$ h support per day), and full-time supervision with additional help as required.	- 2			
Date since full-time dependency		ENR		dpdte	date					Not available
Days since full-time dependency		ENR		dpdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	PDS

## 9 Data specific for “Registry”

### 9.1 Form “Hopkins Verbal Learning Test-R”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Hopkins Verbal Learning TestR completed (optional)	QS	R2 R3	HVLT	hvl	boolean	- yes - no	- 1 - 0			PDS
Used form	QS	R2 R3	HVLT	hvltd	single choice	- form 1 - form 2 - form 3	- 1 - 2 - 3			PDS
Trial 1: correct	QS	R2 R3	HVLT	hvltt11	number					PDS
Trial 1: repetition (FR)	QS	R2 R3	HVLT	hvltt12	number					Available upon SRC approval
Trial 1: intrusion (FR)	QS	R2 R3	HVLT	hvltt13	number					Available upon SRC approval
Trial 2: correct	QS	R2 R3	HVLT	hvltt21	number					PDS
Trial 2: repetition (FR)	QS	R2 R3	HVLT	hvltt22	number					Available upon SRC approval
Trial 2: intrusion (FR)	QS	R2 R3	HVLT	hvltt23	number					Available upon SRC approval
Trial 3: correct	QS	R2 R3	HVLT	hvltt31	number					PDS

Trial 3: repetition (FR)	QS	R2 R3	HVLT	hvltt32	number					Available upon SRC approval
Trial 3: intrusion (FR)	QS	R2 R3	HVLT	hvltt33	number					Available upon SRC approval
Delayed recall correct	QS	R2 R3	HVLT	hvl1	number					PDS
Total repetitions (trials 13 & delayed)	QS	R2 R3	HVLT	hvl2	number					PDS
Total intrusions (trials 13 & delayed)	QS	R2 R3	HVLT	hvl3	number					PDS
Recognition: true positives	QS	R2 R3	HVLT	hvl4	number					PDS
Recognition: false positives	QS	R2 R3	HVLT	hvl5	number					PDS
Delayed recall: repetition (FR)	QS	R2 R3	HVLT	hvl6	number					Available upon SRC approval
Delayed recall: intrusion (FR)	QS	R2 R3	HVLT	hvl7	number					Available upon SRC approval

## 9.2 Form “Dementia Rating Scale 2”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Dementia Rating Scale2 completed (optional)	QS	R2 R3	Mattis DRS	mdrs	boolean	- Yes - No	1 0			PDS

Attention	QS	R2 R3	Mattis DRS	mdrs1	number					PDS
Initiation / perseveration	QS	R2 R3	Mattis DRS	mdrs2	number					PDS
Construction	QS	R2 R3	Mattis DRS	mdrs3	number					PDS
Conceptualization	QS	R2 R3	Mattis DRS	mdrs4	number					PDS
Memory	QS	R2 R3	Mattis DRS	mdrs5	number					PDS
Total Score	QS	R2 R3	Mattis DRS	mdrs6	number					Available upon SRC approval

### 9.3 Form “Short Form Health Survey – 36v1 (R2)”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
SF36 score	QS	R2		sfscore_v1	number					PDS
In general, would you say your health is	QS	R2		sf1	single choice	- excellent - very good - good - fair - poor	- 5 - 4.4 - 3.4 - 2 - 1			Available upon SRC approval
Compared to one year ago, how	QS	R2		sf2	single choice	- much better - somewhat better - about the same	- 5 - 4 - 3			Available upon SRC approval

would you rate your health in general now						- somewhat worse - much worse	- 2 - 1			
During the past 4 weeks to what extent has your physical health or emotional problems interfered with family, friends, neighbours or groups	QS	R2		sf3	single choice	- not at all - slightly - moderately - quite a bit - extremely	- 5 - 4 - 3 - 2 - 1			Available upon SRC approval
During the past 4 weeks how much bodily pain have you had	QS	R2		sf4	single choice	- none - very mild - mild - moderate - severe - very severe	- 6 - 5 - 4 - 3 - 2 - 1			Available upon SRC approval
During the past 4 weeks how much did pain interfere with your normal work	QS	R2		sf5	single choice	- not at all - a little bit - moderately - quite a bit - extremely	- 5 - 4 - 3 - 2 - 1			Available upon SRC approval
During the past 4 weeks how	QS	R2		sf6	single choice	- all of the time - most of the time	- 1 - 2			Available upon SRC approval

much of the time has your physical health or emotional problems interfered with your social activities like visiting friends, relatives, etc						- sometimes - a little of the time - none of the time	- 3 - 4 - 5			
Group "Does your health now limit you in these activities"										
Vigorous activities, such as running, lifting heavy object, participating in strenuous sports	QS	R2		sf7	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf	QS	R2		sf8	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Lifting and carrying groceries	QS	R2		sf9	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
	QS	R2		sf10		- yes, a lot	- 1			

Climbing several flights of stairs					single choice	- yes, a little - not at all	- 2 - 3			Available upon SRC approval
Climbing one flight of stairs	QS	R2		sf11	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Bending, kneeling or stooping	QS	R2		sf12	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Walking more than a mile	QS	R2		sf13	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Walking several blocks	QS	R2		sf14	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Walking one block	QS	R2		sf15	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Bathing or dressing yourself	QS	R2		sf16	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Group "During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of your physical health"										
Cut down on the amount of time you spent on work or other activities	QS	R2		sf17	boolean	- yes - no	- 0  - 1			Available upon SRC approval
	QS	R2		sf18	boolean	- yes	- 0			



Accomplished less than you would like						- no	- 1			Available upon SRC approval
Were limited in the kind of work or other activities	QS	R2		sf19	boolean	- yes - no	- 0 - 1			Available upon SRC approval
Had difficulty performing the work or other activities	QS	R2		sf20	boolean	- yes - no	- 0 - 1			Available upon SRC approval
Group "During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems"										
Cut down on the amount of time you spent on work or other activities	QS	R2		sf21	boolean	- yes - no	- 0 - 1			Available upon SRC approval
Accomplished less than you would like	QS	R2		sf22	boolean	- yes - no	- 0 - 1			Available upon SRC approval
Didn't do work or other activities as carefully as usual	QS	R2		sf23	boolean	- yes - no	- 0 - 1			Available upon SRC approval
Group "How did you feel during the past 4 weeks"										
Did you feel full of life?	QS	R2		sf24	single choice	- all of the time - most of the time	- 6 - 5			Available upon SRC approval

						- a good bit of the time - some of the time - a little of the time - none of the time	- 4 - 3 - 2 - 1			
Have you been a very nervous person?	QS	R2		sf25	single choice	- all of the time - most of the time - a good bit of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5 - 6			Available upon SRC approval
Have you felt so down in the dumps that nothing could cheer you up?	QS	R2		sf26	single choice	- all of the time - most of the time - a good bit of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5 - 6			Available upon SRC approval
	QS	R2		sf27		- all of the time	- 6			

Have you felt calm and peaceful?					single choice	- most of the time - a good bit of the time - some of the time - a little of the time - none of the time	- 5 - 4 - 3 - 2 - 1			Available upon SRC approval
Did you have a lot of energy?	QS	R2		sf28	single choice	- all of the time - most of the time - a good bit of the time - some of the time - a little of the time - none of the time	- 6 - 5 - 4 - 3 - 2 - 1			Available upon SRC approval
Have you felt downhearted and low?	QS	R2		sf29	single choice	- all of the time - most of the time - a good bit of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5 - 6			Available upon SRC approval

Did you feel worn out?	QS	R2		sf30	single choice	<ul style="list-style-type: none"> <li>- all of the time</li> <li>- most of the time</li> <li>- a good bit of the time</li> <li>- some of the time</li> <li>- a little of the time</li> <li>- none of the time</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> <li>- 6</li> </ul>			Available upon SRC approval
Have you been a happy person?	QS	R2		sf31	single choice	<ul style="list-style-type: none"> <li>- all of the time</li> <li>- most of the time</li> <li>- a good bit of the time</li> <li>- some of the time</li> <li>- a little of the time</li> <li>- none of the time</li> </ul>	<ul style="list-style-type: none"> <li>- 6</li> <li>- 5</li> <li>- 4</li> <li>- 3</li> <li>- 2</li> <li>- 1</li> </ul>			Available upon SRC approval
Did you feel tired?	QS	R2		sf32	single choice	<ul style="list-style-type: none"> <li>- all of the time</li> <li>- most of the time</li> <li>- a good bit of the time</li> <li>- some of the time</li> <li>- a little of the time</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> <li>- 5</li> </ul>			Available upon SRC approval

						- none of the time	- 6			
Group “How true or false is each of the following statements for you?”										
I seem to get sick a little more than other people	QS	R2		sf33	single choice	- definitely true - mostly true - don't know - mostly false - definitely false	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
I am as healthy as anybody I know	QS	R2		sf34	single choice	- definitely true - mostly true - don't know - mostly false - definitely false	- 5 - 4 - 3 - 2 - 1			Available upon SRC approval
I expect my health to get worse	QS	R2		sf35	single choice	- definitely true - mostly true - don't know - mostly false - definitely false	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
My health is excellent	QS	R2		sf36	single choice	- definitely true - mostly true - don't know - mostly false - definitely false	- 5 - 4 - 3 - 2 - 1			Available upon SRC approval

## 9.4 Form “Short Form Health Survey – 36v2 (R3)”

### Section Your Health and Well-Being

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
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1. In general, would you say your health is?	QS	R3		gh01	single choice	- excellent - very good - good - fair - poor	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
2. Compared to one year ago, how would you rate your health in general now?	QS	R3		ht	single choice	- much better now than one year ago - somewhat better now than one year ago - about the same as one year ago - somewhat worse now than one year ago - much worse now than one year ago	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Group 3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?										
Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	QS	R3		pf01	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			Available upon SRC approval
Moderate activities, such	QS	R3		pf02	single choice	- yes, limited a lot	- 1			

as moving a table, pushing a vacuum cleaner, bowling, or playing golf						- yes, limited a little - no, not limited at all	- 2 - 3			Available upon SRC approval
Lifting or carrying groceries	QS	R3		pf03	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			Available upon SRC approval
Climbing several flights of stairs	QS	R3		pf04	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			Available upon SRC approval
Climbing one flight of stairs	QS	R3		pf05	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			Available upon SRC approval
Bending, kneeling or stooping	QS	R3		pf06	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			Available upon SRC approval
Walking more than a mile (approx. 1.5 kilometres)	QS	R3		pf07	single choice	- yes, limited a lot - yes, limited a little	- 1 - 2			Available upon SRC approval

						- no, not limited at all	- 3			
Walking several hundred yards (metres)	QS	R3		pf08	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			Available upon SRC approval
Walking one hundred yards (metres)	QS	R3		pf09	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			Available upon SRC approval
Bathing or dressing yourself	QS	R3		pf10	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			Available upon SRC approval
Group 4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?										
Cut down on the amount of time you spent on work or other activities	QS	R3		rp01	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
	QS	R3		rp02		- all of the time	- 1			



Accomplished less than you would like					single choice	- most of the time - some of the time - a little of the time - none of the time	- 2 - 3 - 4 - 5			Available upon SRC approval
Were limited in the kind of work or other activities	QS	R3		rp03	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Had difficulty performing the work or other activities (for example, it took extra effort)	QS	R3		rp04	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Group 5. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?										
Cut down on the amount of time you spent on	QS	R3		re01	single choice	- all of the time - most of the time	- 1 - 2			Available upon SRC approval

work or other activities						- some of the time - a little of the time - none of the time	- 3 - 4 - 5			
Accomplished less than you would like	QS	R3		re02	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Did work or other activities less carefully than usual	QS	R3		re03	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal	QS	R3		sf01	single choice	- not at all - slightly - moderately - quite a bit - extremely	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval

social activities with family, friends, neighbours or groups?										
7. How much bodily pain have you had during the past 4 weeks?	QS	R3		bp01	single choice	- none - very mild - mild - moderate - severe - very severe	- 1 - 2 - 3 - 4 - 5 - 6			Available upon SRC approval
8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?	QS	R3		bp02	single choice	- not at all - a little bit - moderately - quite a bit - extremely	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Group 9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks										
Did you feel full of life?	QS	R3		vt01	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval

Have you been very nervous?	QS	R3		mh01	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Have you felt so down in the dumps that nothing could cheer you up?	QS	R3		mh02	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Have you felt calm and peaceful?	QS	R3		mh03	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Did you have a lot of energy?	QS	R3		vt02	single choice	- all of the time - most of the time - some of the time	- 1 - 2 - 3			Available upon SRC approval

						- a little of the time - none of the time	- 4 - 5			
Have you felt downhearted and low?	QS	R3		mh04	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Did you feel worn out?	QS	R3		vt03	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Have you been happy?	QS	R3		mh05	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval

Did you feel tired?	QS	R3		vt04	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?	QS	R3		sf02	single choice	- all of the time - most of the time - some of the time - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Group 11. How TRUE or FALSE is each of the following statements for you?										
I seem to get ill more easily than other people	QS	R3		gh02	single choice	- definitely true - mostly true - don't know - mostly false - definitely false	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
	QS	R3		gh03	single choice	- definitely true - mostly true	- 1 - 2			

I am as healthy as anybody I know						- don't know - mostly false - definitely false	- 3 - 4 - 5			Available upon SRC approval
I expect my health to get worse	QS	R3		gh04	single choice	- definitely true - mostly true - don't know - mostly false - definitely false	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
My health is excellent	QS	R3		gh05	single choice	- definitely true - mostly true - don't know - mostly false - definitely false	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval

### Section Your Health and Well-Being

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Physical Functioning (PF)	QS	R3		pf	number					Available upon SRC approval
RolePhysical (RP)	QS	R3		rp	number					Available upon SRC approval
Bodily Pain (BP)	QS	R3		bp	number					Available upon SRC approval
General Health (GH)	QS	R3		gh	number					Available upon SRC approval
Vitality (VT)	QS	R3		vt	number					Available upon SRC approval

Social Functioning (SF)	QS	R3		sf	number					Available upon SRC approval
RoleEmotional (RE)	QS	R3		re	number					Available upon SRC approval
Mental Health (MH)	QS	R3		mh	number					Available upon SRC approval
Group Normbased scores										
Physical Functioning (PF)	QS	R3		pf_nbs	number					Not available
RolePhysical (RP)	QS	R3		rp_nbs	number					Not available
Bodily Pain (BP)	QS	R3		bp_nbs	number					Not available
General Health (GH)	QS	R3		gh_nbs	number					Not available
Vitality (VT)	QS	R3		vt_nbs	number					Not available
Social Functioning (SF)	QS	R3		sf_nbs	number					Not available
RoleEmotional (RE)	QS	R3		re_nbs	number					Not available
Mental Health (MH)	QS	R3		mh_nbs	number					Not available
Physical Component Summary (PCS)	QS	R3		pcs	number					Available upon SRC approval
Mental Component Summary (MCS)	QS	R3		mcs	number					Available upon SRC approval
SF36 v.2 score	QS	R3		sfscore_v2	number					PDS



## 9.5 Form “Behaviour”

### Section General

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Behavioural score	QS	R2 R3		behscore	number					PDS
Behavioural score incomplete	QS	R2 R3		biscore	number					PDS
Group Subscores										
Depression	QS	R3		behaviour_depscore	number					PDS
Drive/executive function	QS	R3		defscore	number					PDS
Irritability/aggression	QS	R3		behaviour_irascore	number					PDS
Psychosis	QS	R3		behaviour_psyscore	number					PDS

### Section Behavioural Assessment

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Depressed mood										
Frequency	QS	R2 R3		deprfr	single choice	- never or almost never - seldom, less than once a week - sometimes, at least once a week - frequently, several times a week	- 0 - 1 - 2 - 3			PDS

						- very frequently, most of the time	- 4			
Severity	QS	R2 R3		deprsv	single choice	- no mood disturbance - questionable or equivocal - mild, responds to redirection and reassurance - moderately depressed, express distress - severe, significant suffering and loss of functioning	- 0 - 1 - 2 - 3 - 4			PDS
Group Low selfesteem/guilt										
Frequency	QS	R2 R3		guiltfr	single choice	- never or almost never - seldom, less than once a week - sometimes, at least once a week - frequently, several times a week - very frequently, most of the time	- 0 - 1 - 2 - 3 - 4			PDS
Severity	QS	R2 R3		guiltsv	single choice	- no evidence - questionable or equivocal - mild, definitely present - moderate, some distress	- 0 - 1 - 2 - 3			PDS

						- severe	- 4			
Group Anxiety										
Frequency	QS	R2 R3		anxifr	single choice	- never or almost never - seldom, less than once a week - sometimes, at least once a week - frequently, several times a week - very frequently, most of the time	- 0 - 1 - 2 - 3 - 4			PDS
Severity	QS	R2 R3		anxisv	single choice	- no evidence - questionable or equivocal - mild, responds to reassurance - moderate, impacts on everyday life - severe, causing a profound restriction of activities	- 0 - 1 - 2 - 3 - 4			PDS
Group Suicidal Thoughts										
Frequency	QS	R2 R3		suicfr	single choice	- not thinking about suicide or selfharm - seldom thinking about suicide less than once a month - sometimes thinking about suicide at least once a month	- 0 - 1 - 2			PDS

						- frequently thinking about suicide at least once a week	- 3			
						- often thinks about suicide sometimes for days or weeks on end	- 4			
Severity	QS	R2 R3		suicsv	single choice	- no suicidal thoughts - no thoughts at current time, but person talks about suicide as a potential option - fleeting thoughts about it - seriously considered suicide but as no plan - has a plan and is actively preparing	- 0 - 1  - 2 - 3 - 4			PDS
Group Disruptive or aggressive behaviour										
Frequency	QS	R2 R3		aggrfr	single choice	- never or almost never - seldom, less than once a month - sometimes, at least once a month - frequently, at least once a week - very frequently, everyday	- 0 - 1 - 2 - 3 - 4			PDS
Severity	QS	R2 R3		aggrsv	single choice	- behaviour wellcontrolled	- 0			PDS

						<ul style="list-style-type: none"> <li>- verbal threats or intimidating behaviour</li> <li>- mild physically or verbally threatening behaviour</li> <li>- clear physical threat (moderately aggressive), bumping, shoving, verbal outburst</li> <li>- clear physical threat (physical aggression), striking/hitting, or definite intention to cause injury</li> </ul>	- 1 - 2 - 3 - 4			
Group Irritable behaviour										
Frequency	QS	R2 R3		irritfr	single choice	<ul style="list-style-type: none"> <li>- never or almost never</li> <li>- seldom, less than once a week</li> <li>- sometimes, at least once a week</li> <li>- frequently, several times a week</li> <li>- very frequently, most of the time</li> </ul>	- 0 - 1 - 2 - 3 - 4			PDS
Severity	QS	R2 R3		irritsv	single choice	<ul style="list-style-type: none"> <li>- behaviour wellcontrolled</li> <li>- questionable or equivocal</li> <li>- definite, but mild</li> </ul>	- 0 - 1 - 2			PDS

						- moderate, others change their behaviour to avoid irritating subject - severe irritability	- 3 - 4			
Group Perseverative/Obsessional thinking										
Frequency	QS	R2 R3		obsessfr	single choice	- never or almost never - seldom, less than once a week - sometimes, at least once a week - frequently, several times a week - very frequently, most of the time	- 0 - 1 - 2 - 3 - 4			PDS
Severity	QS	R2 R3		obsesssv	single choice	- thinking is always flexible - questionable or equivocal - gets stuck on certain ideas but can be easily redirected - moderate gets stuck on certain ideas, difficult to redirect - severe gets stuck on certain ideas, and does not respond to redirection	- 0 - 1 - 2 - 3 - 4			PDS
Group Compulsive behaviour										

Frequency	QS	R2 R3		compulfr	single choice	- never or almost never - seldom, less than once a week - sometimes, at least once a week - frequently, several times a week - very frequently, most of the time	- 0 - 1 - 2 - 3 - 4			PDS
Severity	QS	R2 R3		compulsv	single choice	- behaviour always wellcontrolled - equivocal has a mild impulse not sufficient to act on - mild has impulse, acts on impulse, but can stop - moderate has impulse, acts on it and cannot stop - severe has impulse, acts on it and cannot stop	- 0 - 1 - 2 - 3 - 4			PDS
Group Delusions										
Frequency	QS	R2 R3		delusfr	single choice	- no evidence - seldom, less than once a month - sometimes, at least once a month	- 0 - 1 - 2			PDS

						- frequently, at least once a week	- 3			
						- very frequently, sometimes for days on end	- 4			
Severity	QS	R2 R3		delussv	single choice	- no evidence - has delusional idea(s), not sure it is true - convinced of idea(s), but allows that the idea is not true - utterly convinced of the idea(s) - utterly convinced of the idea(s), behaviour is determined by the delusion(s)	- 0 - 1 - 2 - 3 - 4			PDS
Group Hallucinations										
Frequency	QS	R2 R3		hallucfr	single choice	- no evidence of hallucinations - seldom, less than once a month - sometimes, at least once a month - frequently, at least once a week - often, sometimes for days on end	- 0 - 1 - 2 - 3 - 4			PDS
Severity	QS			hallucsv		- no evidence	- 0			PDS



		R2 R3			single choice	<ul style="list-style-type: none"> <li>- has hallucinations, but doubts they are real</li> <li>- convinced of the reality of the hallucinations, but allows that it is possible that they are not real</li> <li>- utterly convinced of the hallucinations being real, but not acting on them.</li> <li>- severe has allucinations that are vivid, subject is utterly convinced they are real and the hallucinations severely disrupt behaviour.</li> </ul>	- 1  - 2  - 3  - 4			
Group Apathy										
Frequency	QS	R2 R3		apathfr	single choice	<ul style="list-style-type: none"> <li>- never</li> <li>- seldom apathetic, less than once a week</li> <li>- sometimes, at least once a week</li> <li>- frequently, several times a week</li> <li>- very frequently, most of the time</li> </ul>	- 0 - 1 - 2 - 3 - 4			PDS
Severity	QS	R2 R3		apathsv	single choice	<ul style="list-style-type: none"> <li>- no evidence</li> <li>- equivocal</li> </ul>	- 0 - 1			PDS

						<ul style="list-style-type: none"> <li>- mild apathy subject not initiating conversation or activity but is responsive</li> <li>- moderate apathy sometimes responds to efforts to get involved in conversation/activities</li> <li>- several apathy generally unresponsive to attempts to involve subject in activities or conversation</li> </ul>	- 2   - 3   - 4			
Group Behavioural Milestones										
Does the examiner believes the participant is confused?	QS	R2 R3		confus	boolean	- yes - no	- 1 - 0			PDS
Does the examiner believes the participant is demented?	QS	R2 R3		dement	boolean	- yes - no	- 1 - 0			PDS
Does the examiner believe the participant is depressed?	QS	R2 R3		deprexam	boolean	- yes - no	- 1 - 0			PDS
Does the participant require pharmacotherapy for depression?	QS	R2 R3		deprfr	boolean	- yes - no	- 1 - 0			PDS

Does the participant require pharmacotherapy for irritability?	QS	R2 R3		irritrfr	boolean	- yes - no	- 1 - 0			PDS
Group Information Sources										
Was the behavioural assessment information obtained from:	QS	R2 R3		isobt	single choice	- participant only - participant and family/companion	- 1 - 2			PDS

## 9.6 Form “Becks Depression Scale (BDI)”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date data obtained	QS	R2		qsdtc	date					Not available
Date data obtained	QS	R2		qsdy	number					Available upon SRC approval
Becks score	QS	R2		bdiscore	number					PDS
A	QS	R2		bdi1	single choice	- I do not feel sad - I feel sad - I am sad all the time and cannot snap out of it - I am sad or unhappy that I cannot stand it	- 0 - 1 - 2 - 3			Available upon SRC approval
B	QS	R2		bdi2	single choice	- I am not particularly discouraged about the future - I feel discouraged about the future	- 0 - 1			Available upon SRC approval

						-I feel I have nothing to look forward to -I feel that the future is hopeless and that things cannot improve	- 2 - 3			
C	QS	R2		bdi3	single choice	-I do not feel like a failure -I feel I have failed more than the average person -As I look back on my life, all I can see is a lot of failure -I feel I am a complete failure as a person; I do not feel sad.	- 0 - 1 - 2 - 3			Available upon SRC approval
D	QS	R2		bdi4	single choice	- I get as much satisfaction out of things as I used to -I do not enjoy things the way I used to -I do not get real satisfaction out of anything anymore -I am dissatisfied or bored with everything	- 0 - 1 - 2 - 3			Available upon SRC approval
E	QS	R2		bdi5	single choice	-I do not feel particularly guilty -I feel guilty a good part of the time - I feel quite guilty most of the time	- 0 - 1 - 2			Available upon SRC approval

						- I feel guilty all of the time	- 3			
F	QS	R2		bdi6	single choice	-I do not feel I am being punished -I feel I may be punished -I expect to be punished -I feel I am being punished	- 0 - 1 - 2 - 3			Available upon SRC approval
G	QS	R2		bdi7	single choice	- I do not feel disappointed in myself - I am disappointed in myself - I am disgusted with myself - I hate myself	- 0 - 1 - 2 - 3			Available upon SRC approval
H	QS	R2		bdi8	single choice	-I do not feel I am worse than anybody else - I am critical of myself for my weaknesses or mistakes -I blame myself all the time for my faults - I blame myself for everything bad that happens	- 0 - 1 - 2 - 3			Available upon SRC approval
I	QS	R2		bdi9	single choice	-I do not have any thoughts of killing myself	- 0			Available upon SRC approval

						- I have thoughts of killing myself, but I would not carry them out - I would like to kill myself - I would kill myself if I had the chance	- 1 - 2 - 3			
J	QS	R2		bdi10	single choice	- I do not cry any more than usual - I cry more than I used to - I cry all the time now - I used to be able to cry, but now I cannot cry even though I want	- 0 - 1 - 2 - 3			Available upon SRC approval
K	QS	R2		bdi11	single choice	- I am no more irritated by things than I ever am - I am slightly more irritated now than usual - I am quite annoyed or irritated a good deal of the time - I feel irritated all the time now	- 0 - 1 - 2 - 3			Available upon SRC approval
L	QS	R2		bdi12	single choice	- I have not lost interest in other people	- 0			Available upon SRC approval

						<ul style="list-style-type: none"> <li>- I am less interested in other people than I used to be</li> <li>- I have lost most of my interest in other people</li> <li>- I have lost all of my interest in other people</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> </ul>			
M	QS	R2		bdi13	single choice	<ul style="list-style-type: none"> <li>- I make decisions about as well as I ever could</li> <li>- I put off making decisions more than I used to</li> <li>- I have greater difficulty in making decisions than before</li> <li>- I can not make decisions at all anymore</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> </ul>			Available upon SRC approval
N	QS	R2		bdi14	single choice	<ul style="list-style-type: none"> <li>- I do not feel that I look any worse than I used to</li> <li>- I am worried that I am looking old or unattractive</li> <li>- I feel that there are permanent changes in my appearance that make me look unattractive</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> </ul>			Available upon SRC approval

						- I believe that I look ugly	- 3			
O	QS	R2		bdi15	single choice	- I can work about as well as before - it takes an extra effort to get started at doing something - I have to push myself very hard to do anything - I cannot do any work at all	- 0 - 1 - 2 - 3			Available upon SRC approval
P	QS	R2		bdi16	single choice	- I can sleep as well as usual - I do not sleep as well as I used to - I wake up 12 hours earlier than usual and find it hard to get back to sleep - I wake up several hours earlier than I used to and cannot get back to sleep	- 0 - 1 - 2 - 3			Available upon SRC approval
Q	QS	R2		bdi17	single choice	- I do not get tired more than usual - I get tired more easily than I used to - I get tired from doing almost anything - I am too tired to do anything	- 0 - 1 - 2 - 3			Available upon SRC approval



R	QS	R2		bdi18	single choice	-my appetite is no worse than usual -my appetite is not as good as it used to be -my appetite is much worse now -I have no appetite at all anymore	- 0 - 1 - 2 - 3			Available upon SRC approval
S	QS	R2		bdi19	single choice	- I have not lost much weight, if any, lately -I have lost more than five pounds - I have lost more than ten pounds -I have lost more than fifteen pounds	- 0 - 1 - 2 - 3			Available upon SRC approval
T	QS	R2		bdi20	single choice	- I am no more worried about my health than usual -I am worried about physical problems such as aches or pains, or upset stomach or constipation -I am very worried about physical problems and it is hard to think of much else - I am so worried about my physical problems that I	- 0 - 1 - 2 - 3			Available upon SRC approval

						cannot think about anything else				
U	QS	R2		bdi21	single choice	- I have not noticed any recent change in my interest in sex - I am less interested in sex than I used to be - I am much less interested in sex now - I have lost interest in sex completely	- 0 - 1 - 2 - 3			Available upon SRC approval

## 9.7 Form “Hamilton”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Hamilton Score	QS	R2		hamscore	number					PDS
Depressed mood	QS	R2		ham1	single choice	- absent - these feeling states indicated only on questioning - these feeling states spontaneously reported verbally - communicates feeling states nonverbally, i.e., through facial expression, posture, voice, and tendency to weep - participant reports VIRTUALLY ONLY these	- 0 - 1 - 2 - 3 - 4			Available upon SRC approval

						feeling states in his spontaneous verbal and non/verbal communication				
Feelings of guilt	QS	R2		ham2	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- self reproach, feels he has let people down</li> <li>- ideas of guilt or rumination over past errors or sinful deeds</li> <li>- present illness is a punishment. Delusions of guilt</li> <li>- hears accusatory or denunciatory voices and/or experiences threatening visual hallucinations</li> </ul>	- 0 - 1 - 2 - 3 - 4			Available upon SRC approval
Suicide	QS	R2		ham3	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- feels life is not worth living</li> <li>- wishes he were dead or any thoughts of possible death to self</li> <li>- suicidal ideas or gesture</li> <li>- attempts at suicide (any serious attempt rates 4)</li> </ul>	- 0 - 1 - 2 - 3 - 4			Available upon SRC approval
Insomnia early	QS	R2		ham4	single choice	<ul style="list-style-type: none"> <li>- no difficulty falling asleep</li> </ul>	- 0			

						<ul style="list-style-type: none"> <li>- complains of occasional difficulty falling asleep, i.e., more than 1/2 hour</li> <li>- complains of nightly difficulty falling asleep</li> </ul>	- 1 - 2			Available upon SRC approval
Insomnia middle	QS	R2		ham5	single choice	<ul style="list-style-type: none"> <li>- no difficulty</li> <li>- participant complains of being restless and disturbed during the night</li> <li>- waking during the night any getting out of bed rates 2 (except for purposes of voiding)</li> </ul>	- 0 - 1 - 2			Available upon SRC approval
Insomnia late	QS	R2		ham6	single choice	<ul style="list-style-type: none"> <li>- no difficulty</li> <li>- waking in early hours of the morning but goes back to sleep</li> <li>- unable to fall asleep again if he gets out of bed</li> </ul>	- 0 - 1 - 2			Available upon SRC approval
Work and activities	QS	R2		ham7	single choice	<ul style="list-style-type: none"> <li>- no difficulty</li> <li>- thoughts and feelings of incapacity, fatigue or weakness related to activities; work or hobbies</li> <li>- loss of interest in activity; hobbies or work either directly reported by</li> </ul>	- 0 - 1 - 2			Available upon SRC approval

						<ul style="list-style-type: none"> <li>participant, or indirect in listlessness, indecision and vacillation (feels he has to push self to work or activities)</li> <li>- decrease in actual time spent in activities or decrease in productivity</li> <li>- stopped working because of present illness</li> </ul>	<ul style="list-style-type: none"> <li>- 3</li> <li>- 4</li> </ul>			
Retardation: Psychomotor	QS	R2		ham8	single choice	<ul style="list-style-type: none"> <li>- normal speech and thought</li> <li>- slight retardation at interview</li> <li>- obvious retardation at interview</li> <li>- interview difficult</li> <li>- complete stupor</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			Available upon SRC approval
Agitation	QS	R2		ham9	single choice	<ul style="list-style-type: none"> <li>- none</li> <li>- fidgetiness</li> <li>- playing with hands, hair, etc.</li> <li>- moving about, can't sit still</li> <li>- hand wringing, nail biting, hairpulling, biting of lips</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 4</li> </ul>			Available upon SRC approval
Anxiety	QS	R2		ham10	single choice	<ul style="list-style-type: none"> <li>- no difficulty</li> <li>- subjective tension and irritability</li> </ul>	<ul style="list-style-type: none"> <li>- 0</li> <li>- 1</li> </ul>			Available upon SRC approval

						<ul style="list-style-type: none"> <li>- worrying about minor matters</li> <li>- apprehensive attitude apparent in face or speech</li> <li>- fears expressed without questioning</li> </ul>	- 2 - 3 - 4			
Anxiety somatic	QS	R2		ham11	single choice	<ul style="list-style-type: none"> <li>- absent</li> <li>- mild</li> <li>- moderate</li> <li>- severe</li> <li>- incapacitating</li> </ul>	- 0 - 1 - 2 - 3 - 4			Available upon SRC approval
Somatic symptoms	QS	R2		ham12	single choice	<ul style="list-style-type: none"> <li>- none</li> <li>- loss of appetite but eating without encouragement from others. Food intake about normal</li> <li>- difficulty eating without urging from others. Marked reduction of appetite and food intake</li> </ul>	- 0 - 1 - 2			Available upon SRC approval
Somatic symptoms general	QS	R2		ham13	single choice	<ul style="list-style-type: none"> <li>- none</li> <li>- heaviness in limbs, back or head. Backaches, headache, muscle aches. Loss of energy and fatigability</li> <li>- any clearcut symptom rates 2</li> </ul>	- 0 - 1 - 2			Available upon SRC approval
Genital Symptoms	QS	R2		ham14		<ul style="list-style-type: none"> <li>- absent</li> </ul>	- 0			

					single choice	- mild - severe	- 1 - 2			Available upon SRC approval
Hypochondriasis	QS	R2		ham15	single choice	- not present - selfabsorption (bodily) - preoccupation with health - frequent complaints, requests for help, etc. - hypochondriacal delusions	- 0 - 1 - 2 - 3 - 4			Available upon SRC approval
Loss of weight	QS	R2		ham16	single choice	- no weight loss - probably weight loss associated with present illness - definite (according to participant) weight loss - not assessed	- 0 - 1 - 2 - 3			Available upon SRC approval
Insight	QS	R2		ham17	single choice	- acknowledges being depressed and ill - acknowledges illness but attributes cause to bad food, climate, overwork, virus, need for rest, etc. - denies being ill at all	- 0 - 1 - 2			Available upon SRC approval
Group Diurnal variation										
Time of variation	QS	R2		ham18	single choice	- no variation - worse in A.M.	- 0 - 1			

						- worse in P.M.	- 2			Available upon SRC approval
Severity of variation	QS	R2		ham18a	single choice	- none - mild - severe	- 0 - 1 - 2			Available upon SRC approval
Depersonalization and derealization	QS	R2		ham19	single choice	- absent - mild - moderate - severe - incapacitating	- 0 - 1 - 2 - 3 - 4			Available upon SRC approval
Paranoid symptoms	QS	R2		ham20	single choice	- none - suspicious - ideas of reference - delusions of reference and persecution	- 0 - 1 - 2 - 3			Available upon SRC approval
Obsessional and compulsive symptoms	QS	R2		ham21	single choice	- absent - mild - severe	- 0 - 1 - 2			Available upon SRC approval

## 9.8 Form “Global Clinical Impression”

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Based upon my review of the information, I feel	QS	R2 R3	Global Clinical Impression	svrtyll	single choice	- normal, not at all ill - borderline ill - mildly ill - moderately ill	- 1 - 2 - 3 - 4			PDS



the severity of illness is						- markedly ill	- 5			
						- severely ill	- 6			
						- among the most extremely ill patients	- 7			
						- not assessed	- 0			

## 10 Additional assessments (not provided in regular PDS)

### 10.1 Form “Clinical Trials”

This form is part of the General visit.

#### Section Clinical Trials

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Clinical trial name		ENR		ctnm	text array	- Term - Modified Term - Code - Certainty	- term - modify - decod - certainty			Available upon SRC approval
Participant ID in trial		ENR		sbjid	text					Not available
Date of enrollment		ENR		rfstdtc	date					Not available
Days of enrollment		ENR		rfstdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
What is ppt current clinical trial status?		ENR		ctstts	single choice	- active - completed - discontinued prematurely	- 1 - 2 - 3			Available upon SRC approval
End date of participation		ENR		rfendtc	date					Not available

End day of participation		ENR		rfendy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
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## 10.2 Form “Caregivers Quality of Life Questionnaire (CareQoL)”

This form is part of the Baseline, Follow Up and Unscheduled visit.

### Section General

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	CqoL	qsdtc	date					Not available
Assessment day	QS	ENR	CqoL	qsdyc	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Language of paper form (PBF)	QS	ENR	cQoL	langpbf	single choice	<ul style="list-style-type: none"> <li>- U.S. English</li> <li>- Spanish (LA)</li> <li>- Brazilian Portuguese</li> <li>- Canadian French</li> <li>- French</li> <li>- Czech</li> <li>- Danish</li> </ul>	<ul style="list-style-type: none"> <li>- 1</li> <li>- 2</li> <li>- 3</li> <li>- 6</li> <li>- 7</li> <li>- 8</li> <li>- 9</li> </ul>			Available upon SRC approval

					- German	- 10			
					- Spanish	- 11			
					- Italian	- 12			
					- Dutch	- 13			
					- Norwegian	- 14			
					- Polish	- 15			
					- Portuguese	- 16			
					- Russian	- 17			
					- Finnish	- 18			
					- Swedish	- 19			

### Section Information About Yourself

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
ID of caregiver	QS	ENR	CqoL	cqoli1	string					Not available
Does the caregiver have a unique HD identifier (HDID)?	QS	ENR	CQoL	cqoli2	boolean					Available upon SRC approval
Caregiver's HDID	QS	ENR	CQoL	cqoli2a	text					Available upon SRC approval
What is your year of birth?	QS	ENR	CQoL	cqoli3	number					Available upon SRC approval
What is your gender?	QS	ENR	CQoL	cqoli4		- male	- m			

					single choice	- female	- f			Available upon SRC approval
Country of residence	QS	ENR	CQoL	cqoli5	single choice	use ISO 3166 in EN and FR	use country codes			Available upon SRC approval
How many years of formal education did you have?	QS	ENR	CQoL	cqoli6	number	[0..13]				Available upon SRC approval
Do you have a job	QS	ENR	CQoL	cqoli7	single choice	- yes, full time - yes, part time - no	- 2 - 1 - 0			Available upon SRC approval
What is your marital status	QS	ENR	CQoL	cqoli8	single choice	- single - married - partnership - divorced - widowed - legally separated	- 1 - 3 - 2 - 4 - 5 - 6			Available upon SRC approval
How long have you known about Huntington's Disease in the family of the affected person(s)?	QS	ENR	CQoL	cqoli9	number			years		Available upon SRC approval
How long have you been caring for any Huntington's Disease affected person(s)?	QS	ENR	CQoL	cqoli10	number			years		Available upon SRC approval
Are you the main carer for the HD affected person(s)?	QS	ENR	CQoL	cqoli11	boolean	- yes - no	- 1 - 0			Available upon SRC approval

The HD affected person(s) is/are my	QS	ENR	CQoL	cqoli12	multiple choice	- sibling - spouse/partner - parent - child - other	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Please specify	SUPPQS	ENR	CQoL	cqoli12a	text					Not available
Have you previously cared for any other person(s) with Huntington's Disease?	QS	ENR	CQoL	cqoli13	boolean	- yes - no	- 1 - 0			Available upon SRC approval
The affected person is/was my	QS	ENR	CQoL	cqoli13a	text					Not available
Do you have children who are at risk/carrier/symptomatic?	QS	ENR	CQoL	cqoli14	boolean	- yes - no	- 1 - 0			Available upon SRC approval
How many persons live in your household?	QS	ENR	CQoL	cqoli15	number					Available upon SRC approval
Do you live in the same household as the HD person(s)?	QS	ENR	CQoL	cqoli16	boolean	- yes - no	- 1 - 0			Available upon SRC approval

### Section Quality of Life

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
How satisfied are you with your physical health?	QS	ENR	CQoL	cqol1	single choice	- 0 - dissatisfied - 1 - 2 - 3	- 0 - 1 - 2 - 3			Available upon SRC approval

						- 4 - 5 - 6 - 7 - 8 - 9 - 10 - satisfied	- 4 - 5 - 6 - 7 - 8 - 9 - 10			
How satisfied are you with your psychological health?	QS	ENR	CQoL	cqol2	single choice	- 0 - dissatisfied - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - satisfied	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
How satisfied are you with what you have achieved in life?	QS	ENR	CQoL	cqol3	single choice	- 0 - dissatisfied - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9			Available upon SRC approval

						- 10 - satisfied	- 10			
How satisfied are you with family relationships?	QS	ENR	CQoL	cqol4	single choice	- 0 - dissatisfied - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - satisfied	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
How satisfied are you with your relationships with your friends?	QS	ENR	CQoL	cqol5	single choice	- 0 - dissatisfied - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - satisfied	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
How satisfied are you with feeling a part of your social environment?	QS	ENR	CQoL	cqol6	single choice	- 0 - dissatisfied - 1 - 2 - 3 - 4	- 0 - 1 - 2 - 3 - 4			Available upon SRC approval



						- 5 - 6 - 7 - 8 - 9 - 10 - satisfied	- 5 - 6 - 7 - 8 - 9 - 10			
How satisfied are you with the medical treatment that your HD relative(s) receive(s)?	QS	ENR	CQoL	cqol7	single choice	- 0 - dissatisfied - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - satisfied	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
How satisfied are you with the way other people behave towards the HD person?	QS	ENR	CQoL	cqol8	single choice	- 0 - dissatisfied - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - satisfied	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval

How satisfied are you with the professional support you receive?	QS	ENR	CQoL	cqol9	single choice	- 0 - dissatisfied - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - satisfied	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
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### Section Life Aspects

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
I feel a sense of loss	QS	ENR	CQoL	cqol10	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel a sense of grieving	QS	ENR	CQoL	cqol11	single choice	- 0 - never - 1	- 0 - 1			

						- 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel happy	QS	ENR	CQoL	cqol12	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel a sense of anguish	QS	ENR	CQoL	cqol13	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7			Available upon SRC approval

						- 8 - 9 - 10 - always	- 8 - 9 - 10			
I feel full of fear	QS	ENR	CQoL	cqol14	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel safe	QS	ENR	CQoL	cqol15	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel guilty	QS	ENR	CQoL	cqol16	single choice	- 0 - never - 1 - 2	- 0 - 1 - 2			Available upon SRC approval

						- 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			
I feel financially disadvantaged	QS	ENR	CQoL	cqol17	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel isolated	QS	ENR	CQoL	cqol18	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8			Available upon SRC approval

						- 9 - 10 - always	- 9 - 10			
I feel there is hope for the future	QS	ENR	CQoL	cqol19	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel exhausted	QS	ENR	CQoL	cqol20	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel supported	QS	ENR	CQoL	cqol21	single choice	- 0 - never - 1 - 2 - 3	- 0 - 1 - 2 - 3			Available upon SRC approval

						- 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 4 - 5 - 6 - 7 - 8 - 9 - 10			
I feel depressed	QS	ENR	CQoL	cqol22	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel sad	QS	ENR	CQoL	cqol23	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9			Available upon SRC approval

						- 10 - always	- 10			
I feel stressed	QS	ENR	CQoL	cqol24	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel worried about the genetic consequences of Huntington's Disease	QS	ENR	CQoL	cqol25	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel that my own needs are important to others	QS	ENR	CQoL	cqol26	single choice	- 0 - never - 1 - 2 - 3 - 4	- 0 - 1 - 2 - 3 - 4			Available upon SRC approval



						- 5 - 6 - 7 - 8 - 9 - 10 - always	- 5 - 6 - 7 - 8 - 9 - 10			
I feel lonely	QS	ENR	CQoL	cqol27	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel that Huntington's Disease brought something positive to my life	QS	ENR	CQoL	cqol28	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval

I feel comforted by my beliefs (religious, philosophical or spiritual)	QS	ENR	CQoL	cqol29	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel that I can cope	QS	ENR	CQoL	cqol30	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel that Huntington's Disease has made me a stronger person	QS	ENR	CQoL	cqol31	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5	- 0 - 1 - 2 - 3 - 4 - 5			Available upon SRC approval

						- 6 - 7 - 8 - 9 - 10 - always	- 6 - 7 - 8 - 9 - 10			
I feel that I have had a duty of care forced on me	QS	ENR	CQoL	cqol32	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel like I don't know who I am anymore	QS	ENR	CQoL	cqol33	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
	QS	ENR	CQoL	cqol34		- 0 - never	- 0			

I feel that my role as a carer is rewarding					single choice	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel restricted by a regimented daily routine	QS	ENR	CQoL	cqol35	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel restricted by having to provide continuous care	QS	ENR	CQoL	cqol36	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6	- 0 - 1 - 2 - 3 - 4 - 5 - 6			Available upon SRC approval

						- 7 - 8 - 9 - 10 - always	- 7 - 8 - 9 - 10			
I feel resentful	QS	ENR	CQoL	cqol37	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel embarrassed by the behaviour of my HD relative(s)	QS	ENR	CQoL	cqol38	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel ashamed of the	QS	ENR	CQoL	cqol39	single choice	- 0 - never - 1	- 0 - 1			

behaviour of my HD relative(s)						- 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel frustrated by the misconceptions of others towards my HD relative(s)	QS	ENR	CQoL	cqol40	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel threatend	QS	ENR	CQoL	cqol41	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7			Available upon SRC approval

						- 8 - 9 - 10 - always	- 8 - 9 - 10			
I feel frustrated by the discrimination of others toward my HD	QS	ENR	CQoL	cqol42	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel restricted by the need to maintain secrecy about Huntington's Disease in the family	QS	ENR	CQoL	cqol43	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel I have enough time for myself	QS	ENR	CQoL	cqol44	single choice	- 0 - never - 1 - 2	- 0 - 1 - 2			Available upon SRC approval

						- 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			
I feel I get enough sleep	QS	ENR	CQoL	cqol45	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
I feel I have somebody to turn to for assistance if I am overwhelmed	QS	ENR	CQoL	cqol46	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8			Available upon SRC approval



						- 9 - 10 - always	- 9 - 10			
I feel satisfied with my overall quality of life	QS	ENR	CQoL	cqol47	single choice	- 0 - never - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - always	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval

### Section Improvements

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Is there anything else related to your caring role that you feel hasn't been covered in this questionnaire?	QS	ENR	CQoL	cqoli17	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Could you please describe what it is?	SUPPQS	ENR	CQoL	cqoli17a	text					Not available

As a carer of someone with HD, is there anything that affects you most?	QS	ENR	CQoL	cqol18	boolean	- yes - no	- 1 - 0			Available upon SRC approval
positive	SUPPQS	ENR	CQoL	cqoli18a	text					Not available
negative	SUPPQS	ENR	CQoL	cqoli18b	text					Not available
Can you think of anything that would most improve your quality of life as a carer?	QS	ENR	CQoL	cqol19	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Could you please describe what it is?	SUPPQS	ENR	CQoL	cqoli19a	text					Not available
Have you taken any action to achieve this?	QS	ENR	CQoL	cqoli20	boolean	- yes - no	- 1 - 0			Available upon SRC approval
What action have you taken?	SUPPQS	ENR	CQoL	cqoli20a	text					Not available

### 10.3 Form “Client Service Receipt Inventory (CSRI)” (US)

This form is part of the Baseline and Follow Up visit.

#### Section General

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	CSRI	qsdtc	date					Not available
Assessment day	QS	ENR	CSRI	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval

#### Section Hospital and Residential Services in the last 6 months

Label	Domain	Studies	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Neurology outpatient visit	QS	ENR	CSRI	csri1	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri1a	number			visits		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri1b	number			visits		Available upon SRC approval
	QS	ENR	CSRI	csri2	boolean	- yes	- 1			

Other hospital outpatient visit						- no	- 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri2a	number			visits		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri2b	number			visits		Available upon SRC approval
Ambulatory or same day surgery	QS	ENR	CSRI	csri3	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri3a	number			visits		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri3b	number			visits		Available upon SRC approval
Nursing or residential home	QS	ENR	CSRI	csri4	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri4a	number			days		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri4b	number			days		Available upon SRC approval
	QS	ENR	CSRI	csri61	boolean	- yes	- 1			

Hospital emergency room visits?						- no	- 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri61a	number			days		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri61b	number			days		Available upon SRC approval
Inpatient hospital stay	QS	ENR	CSRI	csri5	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri5a	number			days		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri5b	number			days		Available upon SRC approval
Inpatient hospital stay - Intensive care unit (ICU)	QS	ENR	CSRI	csri6	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri6a	number			days		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri6b	number			days		Available upon SRC approval
	QS	ENR	CSRI	csri7	boolean	- yes	- 1			

Other inpatient hospital stay						- no	- 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri7a	number			days		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri7b	number			days		Available upon SRC approval
General practitioner (GP) or internist/family doctor	QS	ENR	CSRI	csri8	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri8a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri8b	number			contacts		Available upon SRC approval
Physical Therapist (PT)	QS	ENR	CSRI	csri9	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri9a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri9b	number			contacts		Available upon SRC approval

Psychiatrist	QS	ENR	CSRI	csri10	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri10a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri10b	number			contacts		Available upon SRC approval
Psychologist/p psychotherapist	QS	ENR	CSRI	csri11	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri11a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri11b	number			contacts		Available upon SRC approval
Counsellor	QS	ENR	CSRI	csri12	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri12a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri12b	number			contacts		Available upon SRC approval
Family therapist/marriage guidance	QS	ENR	CSRI	csri13	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Use in the last 6 months because of your HD	QS	ENR	CSRI	csri13a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri13b	number			contacts		Available upon SRC approval
Dietician/nutritionist	QS	ENR	CSRI	csri14	boolean	- yes	- 1			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri14a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri14b	number			contacts		Available upon SRC approval
Clinical geneticist	QS	ENR	CSRI	csri15	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri15a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri15b	number			contacts		Available upon SRC approval
Social worker	QS	ENR	CSRI	csri16	boolean	- yes - no	- 1 - 0			Available upon SRC approval



Use in the last 6 months because of your HD	QS	ENR	CSRI	csri16a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri16b	number			contacts		Available upon SRC approval
Practice nurse (nurse practitioner or physician assistant)	QS	ENR	CSRI	csri17	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri17a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri17b	number			contacts		Available upon SRC approval
Home healthcare nurse	QS	ENR	CSRI	csri18	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri18a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri18b	number			contacts		Available upon SRC approval
Speech therapist	QS	ENR	CSRI	csri19	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Use in the last 6 months because of your HD	QS	ENR	CSRI	csri19a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri19b	number			contacts		Available upon SRC approval
Home help/home care worker	QS	ENR	CSRI	csri20	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri20a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri20b	number			contacts		Available upon SRC approval
Acupuncturist	QS	ENR	CSRI	csri21	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri21a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri21b	number			contacts		Available upon SRC approval
Homeopath	QS	ENR	CSRI	csri22	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months	QS	ENR	CSRI	csri22a	number			contacts		Available upon SRC approval

because of your HD										
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri22b	number			contacts		Available upon SRC approval
Herbalist	QS	ENR	CSRI	csri23	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri23a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri23b	number			contacts		Available upon SRC approval
Aromatherapy	QS	ENR	CSRI	csri24	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	csri24a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri24b	number			contacts		Available upon SRC approval
Reflexologist	QS	ENR	CSRI	csri25	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Use in the last 6 months because of your HD	QS	ENR	CSRI	csri25a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	csri25b	number			contacts		Available upon SRC approval
Other service	QS	ENR	CSRI	csri26	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Genetic test	QS	ENR	CSRI	csri27	boolean	- yes - no	- 1 - 0			Available upon SRC approval
No. in the last 6 months	QS	ENR	CSRI	csri27a	number					Available upon SRC approval
Why did you have this test/investigation?	QS	ENR	CSRI	csri27sc	text					Not available
Magnetic Resonance Image (MRI)	QS	ENR	CSRI	csri28	boolean	- yes - no	- 1 - 0			Available upon SRC approval
No. in the last 6 months	QS	ENR	CSRI	csri28a	number					Available upon SRC approval

Why did you have this test/investigation?	SUPPQS	ENR	CSRI	csri28sc	text					Not available
CT/CAT scan	QS	ENR	CSRI	csri29	boolean	- yes - no	- 1 - 0			Available upon SRC approval
No. in the last 6 months	QS	ENR	CSRI	csri29a	number					Available upon SRC approval
Why did you have this test/investigation?	SUPPQS	ENR	CSRI	csri29sc	text					Not available
Electroencephalogram (EEG)	QS	ENR	CSRI	csri30	boolean	- yes - no	- 1 - 0			Available upon SRC approval
No. in the last 6 months	QS	ENR	CSRI	csri30a	number					Available upon SRC approval
Why did you have this test/investigation?	SUPPQS	ENR	CSRI	csri30sc	text					Not available
Blood test	QS	ENR	CSRI	csri31	boolean	- yes - no	- 1 - 0			Available upon SRC approval
No. in the last 6 months	QS	ENR	CSRI	csri31a	number					Available upon SRC approval

Why did you have this test/investigation?	SUPPQS	ENR	CSRI	csri31sc	text					Not available
Personal care (e.g. bathing, dressing)	QS	ENR	CSRI	csri32	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Average no. of hours per week	QS	ENR	CSRI	csri32a	number			hours		Available upon SRC approval
Any other information?	SUPPQS	ENR	CSRI	csri32sc	text					Not available
Help inside the home (e.g. cooking, cleaning)	QS	ENR	CSRI	csri33	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Average no. of hours per week	QS	ENR	CSRI	csri33a	number			hours		Available upon SRC approval
Any other information?	SUPPQS	ENR	CSRI	csri33sc	text					Not available
Help outside the home (e.g. shopping)	QS	ENR	CSRI	csri34	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Average no. of hours per week	QS	ENR	CSRI	csri34a	number			hours		Available upon SRC approval
Any other information?	SUPPQS	ENR	CSRI	csri34sc	text					Not available
Other	QS	ENR	CSRI	csri35	boolean	- yes	- 1			

						- no	- 0			Available upon SRC approval
Average no. of hours per week	QS	ENR	CSRI	csri35a	number			hours		Available upon SRC approval
Any other information?	SUPPQS	ENR	CSRI	csri35sc	text					Not available
Stair lift	QS	ENR	CSRI	csri36	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	csri36a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Handrails	QS	ENR	CSRI	csri37	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	csri37a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Ramps	QS	ENR	CSRI	csri38	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	csri38a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Shower/bath relocation	QS	ENR	CSRI	csri39	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	csri39a	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Toilet relocation	QS	ENR	CSRI	csri40	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	csri40a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Redesign kitchen	QS	ENR	CSRI	csri41	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	csri41a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Chair raises/special chair	QS	ENR	CSRI	csri42	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last six months?	QS	ENR	CSRI	csri42a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Bed moved downstairs	QS	ENR	CSRI	csri43	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	csri43a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Hospital bed	QS	ENR	CSRI	csri44	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	csri44a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Other	QS	ENR	CSRI	csri45	boolean	- yes - no	- 1 - 0			Available upon SRC approval



Was this in the last 6 months?	QS	ENR	CSRI	csri45a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Wheelchair	QS	ENR	CSRI	csri46	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	csri46a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Crutches/sticks	QS	ENR	CSRI	csri47	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	csri47a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Zimmer frame	QS	ENR	CSRI	csri48	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	csri48a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Commode	QS	ENR	CSRI	csri49	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	csri49a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Bath board	QS	ENR	CSRI	csri50	boolean	- yes	- 1			

						- no	- 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	csri50a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Pressure relieving cushions/mattress	QS	ENR	CSRI	csri51	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	csri51a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Adapted eating utensils	QS	ENR	CSRI	csri52	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	csri52a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Other	QS	ENR	CSRI	csri53	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	csri53a	boolean	- yes - no	- 1 - 0			Available upon SRC approval

## 10.4 Form “Bio Specimens for Bio Banking (Samples)”

This form is part of the Baseline and Follow Up visit.

### Section Enroll-HD Biosamples Collection

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
LAB-ID	LB	ENR		labid	text					Not available
Collection of ACD blood required	LB	ENR		acd	boolean	- yes - no	- 1 - 0			Available upon SRC approval

### Section Blood Collection: ACD Tubes (yellow cap)

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date and time of collection	LB	ENR		lbdtc	datetime					Not available
Day and time of collection	LB	ENR		lbdtc	datetime				Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Number of ACD tubes collected	LB	ENR		qty	Number					Available upon SRC approval
0-∞ TIMES:										
Bar code	LB	ENR		barcode	Text					Not available

State	LB	ENR		state	single choice	- arrived - lost - damaged - at site - shipped	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Withdrawal number	LB	ENR		wthdrwl	Number					Available upon SRC approval

### Section Room Temperature Shipment

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Courier	LB			courier	single choice	- DHL - FedEx - World Courier - Marken	- 1 - 2 - 13 - 16			Available upon SRC approval
Airway bill no (DHL)	LB	ENR		dhlnum	Number					Not available
Date of shipment	LB	ENR		shipdte	Date					Not available
Day of shipment	LB	ENR			Number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Date of notification	LB	ENR		ntfydte	Date					Not available

Day of notification	LB	ENR			Number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Date of receipt	LB	ENR		rcptdtc	Date					Not available
Day of receipt	LB	ENR			Number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Total shipping time	LB	ENR		shiptime	number array	- -	- h - min			Available upon SRC approval
Resubmit notification to BioRep	LB	ENR		resubmit	Boolean	- yes - no	- 1 - 0			Available upon SRC approval

### Section Laboratory Results/Evaluation of Specimen/Biobank

Label	Domain	Study	Cat	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
0-∞ TIMES:										
SampleID	LB	ENR		id	Text					Not available
Type	LB	ENR		type	single choice	- Whole Blood - DNA - Cell Line - Buffy coat	- 1 - 2 - 3 - 4			Available upon SRC approval

						- SQC	- 5			
Sample	LB	ENR		id	text					Available upon SRC approval
Source	LB	ENR		sourceid	text					Available upon SRC approval
Qty	LB	ENR		qty	number					Available upon SRC approval
Collection	LB	ENR		lbdtc	datetime					Not available
Collection Day	LB	ENR		lbdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Wthdrwl.	LB	ENR		wthdrwl	number					Available upon SRC approval
Receipt state	LB	ENR		substate	single choice	- culture prep. - culture prep. (r) - duplicated - split (buffy c.) - split (culture) - test only - buffy coat prep.	- 1 - 2 - 3 - 4 - 5 - 9 - 10			Available upon SRC approval

					- submitted	- 11			
					- stored safely	- 12			
					- archived	- 13			
					- RNA prep.	- 14			
					- buffy coat (r)	- 15			
					- biopsy freeze	- 16			
					- frozen	- 17			
					(culture)				
					- frozen	- 18			
					(culture, r)				
					- requires	- 19			
					quality c.				
					- test only	- 20			
					(frozen)				
					- damaged	- 21			
					- self-	- 22			
					processed				
					- virtual culture	- 23			
					- DNA prep.	- 24			
					- work order	- 25			
					init.				
					- plasma prep.	- 26			
					- plasma prep.	- 27			
					(r)				
					- redraw	- 49			
					problems				
					- package lost	- 0			
					- stored safely	- 28			
					(r)				
					- virus stocks.	- 29			

						- split (dna) - split (buffy c., r) - split (culture, r) - derived	- 31 - 50 - 51 - 100			
Outcome	LB	ENR		outcome	single choice	- pass - failed	- 1 - 2			Available upon SRC approval
Date Completed	LB	ENR		compldtc	date					Not available
Day Completed	LB	ENR			number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval



## Revision History

Document	Summary of Changes
ENROLL-HD Data Dictionary (for PDS and SPS) 2020-12-16	Initial version.