



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 RET 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, event*

These contain study specific information about a participant within a study. Note the data file *event* 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.

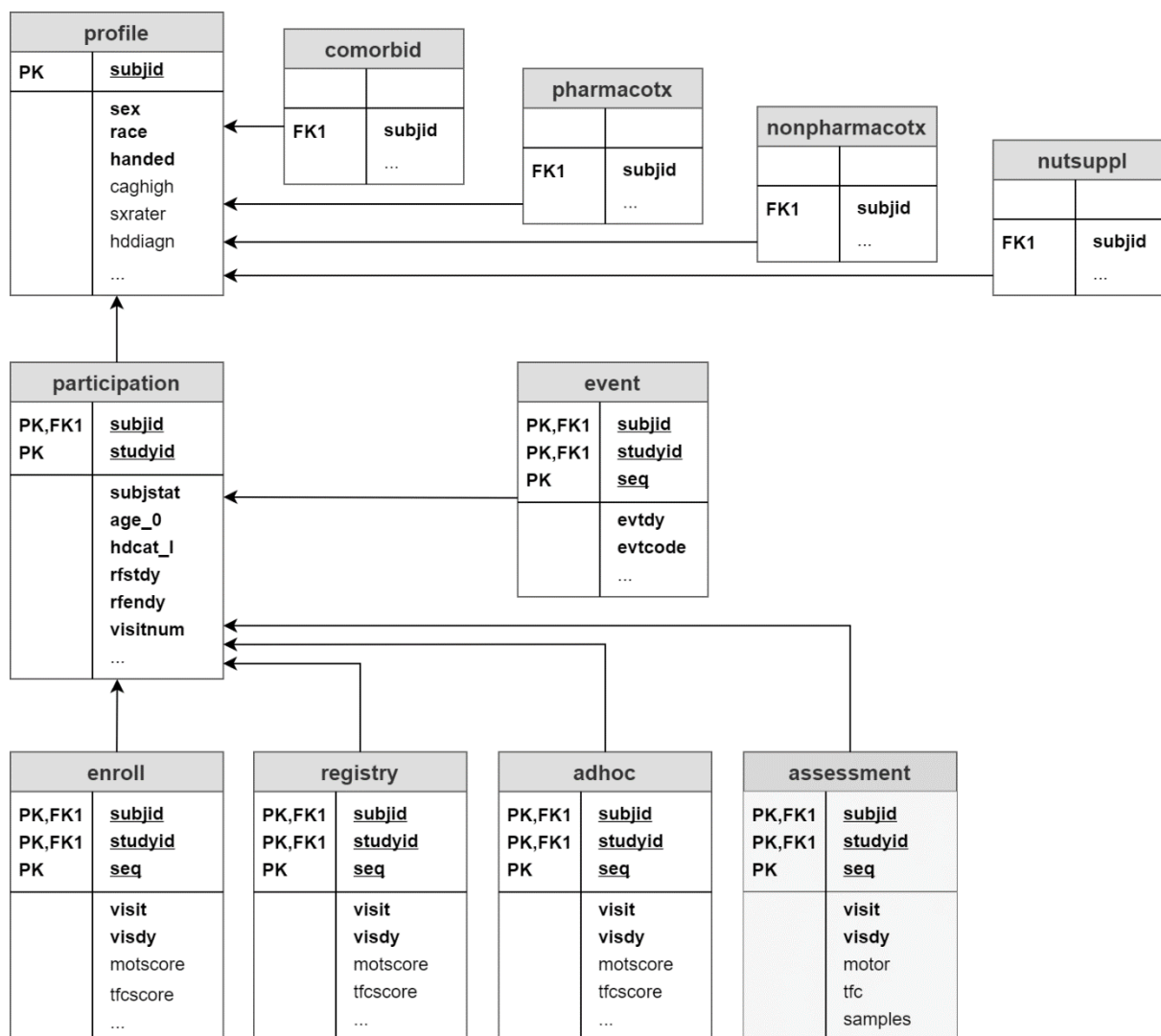


Figure 1: Entity Relationship Diagram.

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).
Form	Identifies the form where the information is collected during the visit.
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 the current PDS release, are described in the table below.

Note that aggregation **thresholds may 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, they are converted to a single string value (e.g., *caghigh* = '>70').

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.
Internal	Variables internal to the EDC that cannot be exported because they are not stored in the database.

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	Form	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	<ul style="list-style-type: none"> - 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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Gender	DM	ENR		Demog	sex	single choice	<ul style="list-style-type: none"> - female - male 	<ul style="list-style-type: none"> - f - m 			PDS
Ethnicity	DM	ENR		Demog	race	single choice	<ul style="list-style-type: none"> - American Indian/ Native American/ Amerindian - Alaska Native/Inuit - African - North - African - South - American – Black - Asian - West - Asian – East - Caucasian 	<ul style="list-style-type: none"> - 8 - 5 - 12 - 11 - 2 - 13 - 14 - 1 			Available upon SRC approval

							- Native Hawaiian or Other Pacific Islander - Hispanic or Latino Origin - Mixed - Other	- 4 - 3 - 15 - 6			
Ethnicity	DM	ENR		Demog	race	single choice	- Caucasian - American Black - Hispanic or Latino Origin - American Indian/ Native American/ Amerindian - Mixed - Asian - Other	- 1 - 2 - 3 - 8 - 15 - 16 - 6		Original values from eCRF are aggregated for de-identification reasons.	PDS
Handedness	SC	ENR		Demog	handed	single choice	- right - left - mixed	- 1 - 2 - 3			PDS

3.1.2 Form “Mortality”

This form is part of the General visit.

Section General

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	DS	ENR	Mortality	Mortality	dsdtc	date					Not available
Assessment day	DS	ENR	Mortality	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date of death	SUPPDS	ENR	Mortality	Mortality	dssdtc	number					Not available
Year of death	SUPPMH	ENR	FHx	Mortality	deathy	number			Year		Not available
Age of death	SUPPDS	ENR	Mortality	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	Mortality	dsplace	single choice	- home - hospital - nursing home - hospice care	- 1 - 2 - 3 - 4			PDS
Cause of death	SUPPDS	ENR	Mortality	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	Mortality	dsendoth	text					Not available
Was an autopsy performed?	SUPPDS	ENR	Mortality	Mortality	dsautop	single choice	- no - yes	- 0 - 1			Available upon SRC approval
Result of autopsy	SUPPDS	ENR	Mortality	Mortality	dsautopr	text					Not available
Information obtained	SUPPDS	ENR	Mortality	Mortality	dsinfo	single choice	- spouse/family - friend	- 1 - 2			

primarily from							- physician/nurse - patient's medical record - obituary in newspaper - death certificate - other	- 3 - 4 - 5 - 6 - 7			Available upon SRC approval
Please specify	SUPPDS	ENR	Mortality	Mortality	infooth	text					Not available
Comments?	SUPPDS	ENR	Mortality	Mortality	dscom	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Comment	CO	ENR	Mortality	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date of report	LB	ENR	Local CAG	CAG	lbdtc	date					Not available
Day of report	LB	ENR	Local CAG	CAG	lbdy	number			Days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval

Section CAG Analysis

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Specimen type	LB	ENR		CAG	lbspec	single choice	- blood - brain (postmortem)	- 1 - 2			Available upon SRC approval
Source of information	LB	ENR		CAG	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		CAG	lbrpt	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Allele 2 (larger allele) - CAG repeat length	LB	ENR		CAG	allele2l	number				Local CAG result	Not available
Group Allele 2 (larger allele) - Tolerance	LB	ENR		CAG	allele2t	single choice	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9			Not available
Group Allele 1 (smaller allele) - CAG repeat length	LB	ENR		CAG	allele1l	number				Local CAG result	Not available
Group Allele 1 (smaller allele) - Tolerance	LB	ENR		CAG	allele1t	single choice	- 0 - 1 - 2 - 3	- 0 - 1 - 2 - 3			Not available

							- 4 - 5 - 6 - 7 - 8 - 9	- 4 - 5 - 6 - 7 - 8 - 9			
HD Classification (larger allele)	LB	ENR		CAG	lbrng	single choice	- normal - <27 - 27-35 - 36-39 - >35 - >36 - >37 - >38 - >39 - >40	- 1 - b27 - 27_35 - 36_39 - a35 - a36 - a37 - a38 - a39 - a40			Not available
Analyzing laboratory	LB	ENR		CAG	lbnam	text					Not available
Comments	LB	ENR		CAG	cmt	boolean	- yes - no	- 1 - 0			Not available
Enter comment	LB	ENR		CAG	coval	text					Not available

3.1.4 Research Genotyping

This information is not part of the Enroll-HD EDC

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

Section History of Motor Symptoms

Label	Domain	Study	Cat	Form	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		HDCC	ccmtr	boolean	- yes - no	- 1 - 0			PDS
Group At what age did the participant's motor symptoms begin? - age (years)	SUPPMH	ENR		HDCC	ccmtrage	number					PDS
Group At what age did the participant's motor symptoms begin? - year of onset	MH	ENR		HDCC	ccmtryr	number					Not available

Section HD History – Participant and Family

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Symptoms first noted by participant	MH	ENR		HDCC	sxsubj	number				Convert to age, e.g. "41".	PDS
Initial major symptom noted by participant	MH	ENR		HDCC	sxsubj_m	single choice	- motor - cognitive - psychiatric - oculomotor - other - mixed	- 1 - 2 - 3 - 4 - 5 - 6			PDS
Group Mixed symptoms - Motor	MH	ENR		HDCC	sxs_m	boolean	- yes	- 1			PDS
Group Mixed symptoms - Cognitive	MH	ENR		HDCC	sxs_c	boolean	- yes	- 1			PDS
Group Mixed symptoms - Psychiatric	MH	ENR		HDCC	sxs_p	boolean	- yes	- 1			PDS

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

Section HD History - Rater

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date of clinical HD diagnosis	MH	ENR		HDCC	hddiagn	number				Convert to age, e.g. "41".	PDS
Can you, as a rater, estimate the time of symptom onset	MH	ENR		HDCC	sxest	boolean	- yes - no	- 1 - 0			PDS
Rater's estimate of symptom onset	MH	ENR		HDCC	sxrater	number				Convert to age, e.g. "41".	PDS
Confidence with which this estimation is made	MH	ENR		HDCC	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		HDCC	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		HDCC	sxgs	single choice	- < 5 - < 10 - < 15 - < 20 - > 20	- 1 - 2 - 3 - 4 - 5			PDS
Date of data entry	MH	ENR		HDCC	sxgsdtc	date					Not available
Day of data entry	MH	ENR		HDCC	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		HDCC	sxraterm	single choice	- motor - cognitive - psychiatric - oculomotor - other - mixed	- 1 - 2 - 3 - 4 - 5 - 6			PDS
Group Mixed symptoms - Motor	MH	ENR		HDCC	sxr_m	boolean	- yes	- 1			PDS
Group Mixed symptoms - Cognitive	MH	ENR		HDCC	sxr_c	boolean	- yes	- 1			PDS
Group Mixed symptoms - Psychiatric	MH	ENR		HDCC	sxr_p	boolean	- yes	- 1			PDS

Group Mixed symptoms - Oculomotor	MH	ENR		HDCC	sxr_o	boolean	- yes	- 1			PDS
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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	Form	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		HDCC	ccdep	boolean	- yes - no	- 1 - 0			PDS
Group At what age did the depression begin? - age (years)	SUPPMH	ENR		HDCC	ccdepage	number					PDS
Group At what age did the depression begin? - years of onset	SUPPMH	ENR		HDCC	ccdepyr	number					Not available
Has irritability ever been a part of the participant's medical history?	MH	ENR		HDCC	ccirb	boolean	- yes - no	- 1 - 0			PDS
Group At what age did the irritability begin? - age (years)	SUPPMH	ENR		HDCC	ccirbage	number					PDS
Group At what age did the irritability begin? - years of onset	SUPPMH	ENR		HDCC	ccirbyr	number					Not available
Has violent or aggressive behaviour ever been a part of the participant's medical history?	MH	ENR		HDCC	ccvab	boolean	- yes - no	- 1 - 0			PDS
Group At what age did violent or aggressive behaviour begin? - age (years)	SUPPMH	ENR		HDCC	ccvabage	number					PDS
Group At what age did violent or aggressive behaviour begin? - years of onset	SUPPMH	ENR		HDCC	ccvabyr	number					Not available
	MH	ENR		HDCC	ccapt	boolean	- yes	- 1			PDS

Has apathy ever been a part of the participant's medical history							- no	- 0			
Group At what age did apathy begin? - age (years)	SUPPMH	ENR		HDCC	ccaptage	number					PDS
Group At what age did apathy begin? - years of onset	MH	ENR		HDCC	ccaptyr	number					Not available
Has perseverative obsessive behaviours ever been a part of the participant's medical history	MH	ENR		HDCC	ccpob	boolean	- yes - no	- 1 - 0			PDS
Group At what age did perseverative obsessive behaviour begin? - age (years)	SUPPMH	ENR		HDCC	ccpobage	number					PDS
Group At what age did perseverative obsessive behaviour begin? - years of onset	MH	ENR		HDCC	ccpobyr	number					Not available
Has psychosis (hallucinations or delusions) ever been a part of the participant's medical history	MH	ENR		HDCC	ccpsy	boolean	- yes - no	- 1 - 0			PDS
Group At what age did psychosis (hallucinations or delusions) begin? - age (years)	SUPPMH	ENR		HDCC	ccpsyage	number					PDS
Group At what age did psychosis (hallucinations or delusions) begin? - years of onset	MH	ENR		HDCC	ccpsyrr	number					Not available
Does the participant have a family history of a psychotic illness in a first degree relative	MH	ENR		HDCC	ccpsyfh	boolean	- yes - no	- 1 - 0			PDS
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		HDCC	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		HDCC	cccogage	number					PDS

Group At what age did cognitive impairment first start to have an impact on daily life? - years of onset	MH	ENR		HDCC	cccogyr	number					Not available
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Data File “profile” (Participant Profile) additional values

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Additional GWAS data available (GWAS3 or GWAS4 or GWAS5 or GWAS-THD or GWAS6)		ENR			xgwas	boolean	- yes - no	- 1 - 0			PDS
Additional biosamples available (Cohort or Track-HD or Track-ON or HDClarity or HD-YAS or MTM)		ENR			xbsp	boolean	- yes - no	- 1 - 0			PDS
Additional phenotypic data available (Cohort or Predict or Track-HD or Track-ON or HDClarity or HD-YAS or RHLF or QoL or Lifestyle or MTM or Pearl or LongPDE10 or JHU1 (or MITO))		ENR			xpheno	boolean	- yes - no	- 1 - 0			PDS
Additional morphometric data available (Predict or Track-HD or Track-ON)		ENR			xmorpho	boolean	- yes - no	- 1 - 0			PDS
Raw images available (Predict or Track-HD or Track-ON or MTM)		ENR			ximage	boolean	- yes - no	- 1 - 0			PDS
Availability of family history pedigree diagram	SC	ENR		N/A	xfhx	boolean	- yes - no	- 1 - 0			PDS

Section Suicidal Behavior

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Previous suicidal ideation or attempts?	MH	ENR		Demog	hxsid	boolean	- yes - no - unknown	- 1 - 0 - 9999			PDS

Section Local genetic test

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Has an genetic test been done?				HDCC	hdtest	single choice	- no - yes - unknown	- 0 - 1 - 9999			Not available
Is there a comment?				HDCC	hxcmt	boolean	'- no - yes	- 0 - 1			Not available
Entered comment				HDCC	coval	Text					Not available

3.2 Data File “pharmacotx (Pharmacotherapy)”

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR		pharmacotx	subjid	text				One-way transformation from HDID to HDID (recoded).	PDS
Drug name – Entered Term	CM	ENR		pharmacotx	cmtrt	text					Not available
Drug name – Modified Term	CM	ENR		pharmacotx	cmtrt__modify	text				Drug name	PDS
Drug name – Code	CM	ENR		pharmacotx	cmtrt__decod	text				Enroll-HD specific drug code	PDS

Ingredient – Modified Term	CM	ENR		pharmacotx	cmtrt__ing	text				comma “,” separated list	PDS
Drug ATC Code (coded by ATC)	CM	ENR		pharmacotx	cmtrt__atc	text				comma “,” separated list	PDS
Drug name – Certainty	CM	ENR		pharmacotx	cmtrt__certainty	text					Not available
Indication – Entered term	CM	ENR		pharmacotx	cmindc	text					Not available
Indication – Modified Term	CM	ENR		pharmacotx	cmindc__modify	Text				Modified term in English.	PDS
Indication – Code (Internal Condition Code)	CM	ENR		pharmacotx	cmindc__decod	Text					PDS
Indication – Code (MedDRA code)	CM	ENR		pharmacotx	cmindc__decod	Text				MedDRA codes are made available upon proof of license.	Available upon SRC approval
Indication - Certainty	CM	ENR		pharmacotx	cmindc__certainty	Text					Not available
Dose / Unit (dose of one intake)	CM	ENR		pharmacotx	cmdose__cmdostxt	Text					Available upon SRC approval
Total daily dose	CM	ENR		pharmacotx	cmdostot	number				Transformed value, calculated from dose and daily intake.	PDS
Unit (unit of one intake)	CM	ENR		pharmacotx	cmdose__cmdosu	Text					PDS
Daily intake	SUPPCM	ENR		pharmacotx	cmfrq	number array	- in the morning - at noon		- 1 - 2		

							- in the evening		- 3		Available upon SRC approval
							- at night		- 4		
Frequency	CM	ENR		pharmacotx	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		Pharmacotx	cmroute	single choice	- p.o. - p.r. - s.c. - i.m. - i.v. - nasal - td - sl - inh - other		- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10		PDS
Start date	CM	ENR		pharmacotx	cmstdtc	date					Not available
Start day	CM	ENR		pharmacotx	cmstdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Ongoing	CM	ENR		pharmacotx	cmenrf	boolean	- yes - no		- 1 - 0		PDS

Stop date	CM	ENR		pharmacotx	cmendtc	date					Not available
End day	CM	ENR		pharmacotx	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR		nonpharmacotx	subjid	text				One-way transformation from HDID to HDID (recoded).	PDS
Therapy	CM	ENR		nonpharmacotx	cmtrt	single choice	<ul style="list-style-type: none"> - Physical therapy - Occupational therapy - Psychotherapy - Counseling - Speech Language therapy - Swallowing therapy - Music therapy - Relaxation therapy (meditation, massage, yoga, etc.) - Acupuncture 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 			PDS
Number of times	SUPPCM	ENR		nonpharmacotx	cmfrq	number					Available upon SRC approval
Frequency	CM	ENR		nonpharmacotx	cmdosfrq	single choice	<ul style="list-style-type: none"> - daily - weekly 	<ul style="list-style-type: none"> -1 -2 			PDS

							- monthly - as needed	-3 -4			
Start date	CM	ENR		nonpharmacotx	cmstdtc	date					Not available
Start day	CM	ENR		nonpharmacotx	cmstdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Ongoing	CM	ENR		nonpharmacotx	cmenrf	boolean	- yes - no	- 1 - 0			PDS
Stop date	CM	ENR		nonpharmacotx	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR		nutsuppl	subjid	text				One-way transformation from HDID to HDID (recoded).	PDS
Type	CM	ENR		nutsuppl	cmcat	single choice	- vitamin & supplements - herbs (extracts) - herbs (teas) - other natural remedies - aromatherapies	- 1 - 2 - 3 - 4 - 5			PDS

							- homeopathic remedies - high calorie diet	- 6 - 7			
NutSuppl Supplement – entered term	CM	ENR		nutssuppl	cmtrt	text					Not available
NutSuppl Supplement – Modified Term	CM	ENR		nutssuppl	cmtrt__modify	text					PDS
NutSuppl Supplement – Code	CM	ENR		nutssuppl	cmtrt__decod	text					PDS
NutSuppl Supplement - ATC Code(s)	CM	ENR		nutssuppl	cmtrt__atc	text					PDS
NutSuppl Supplement - ingredient(s)	CM	ENR		nutssuppl	cmtrt__ing	text					PDS
Dose	CM	ENR		nutssuppl	cmdostxt	number					Available upon SRC approval
Total daily dose	CM	ENR		nutssuppl	cmdostot	number					PDS
Unit	CM	ENR		nutssuppl	cmdosunit	single choice	- g - mg - IU - spoons - tablets - drops - capsule - other	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8			PDS
Daily intake	SUPPCM	ENR		nutssuppl	cmfrq	number array	- in the morning - at noon	- 1 - 2			

							- in the evening - at night	- 3 - 4			Available upon SRC approval
Frequency	CM	ENR		nutssuppl	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		nutssuppl	cmstdtc	date					Not available
Start day	CM	ENR		nutssuppl	cmstdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Ongoing	CM	ENR		nutssuppl	cmenrf	boolean	- yes - no	- 1 - 0			PDS
Stop date	CM	ENR		nutssuppl	cmendtc	date					Not available
End day	CM	ENR		nutssuppl	cmendy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS

3.5 Data File “comorbid (Comorbid Conditions)”

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
HDID (recoded)	---	ENR		comorbid	subjid	Text				One-way transformation from HDID to HDID (recoded).	PDS
Condition – Term (coded with ICD10 or MedDRA)	MH	ENR	mhx	comorbid	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	comorbid	mhterm__modify	text				Comorbid conditions coded with ICD-10, surgeries and procedures coded with Internal condition code Modified term provided in English.	PDS
Condition – Code (coded with ICD10 or Internal condition code)	MH	ENR	mhx	comorbid	mhterm__decod	text					PDS
Condition – Code (coded with MedDRA or ICD-10)	MH	ENR	mhx	comorbid	mhterm__decod	text				MedDRA codes are made available upon proof of license.	Available upon SRC approval

Condition – Certainty (coded with ICD10)	MH	ENR	mhx	comorbid	mhterm__certainty	text					Not available
Body system code	MH	ENR	mhx	comorbid	mhbodsys	single choice	- cardiovascular - pulmonary - neurologic - ENT - gynecologic urologic - reproductive - gastrointestinal - metabolic endocrine - hemato lymphatic - dermatological - psychiatric - musculoskeletal - allergy immunologic - ophthalmological - hepatobiliary - renal - other	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - 11 - 12 - 13 - 14 - 15 - 16 - 17			PDS
Start date	MH	ENR	mhx	comorbid	mhstdtc	date					Not available
Start day	MH	ENR	mhx	comorbid	mhstdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Ongoing	MH	ENR	mhx	comorbid	mhenrf	boolean	- yes	- 1			PDS

						- no	- 0			
End date	MH	ENR	mhx	comorbid	mhendtc	date				
End day	MH	ENR	mhx	comorbid	mhendy	number				Transformed into days relative to baseline date of Enroll-HD.

Not
available

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 identifies the progress of the participant in the study.

All possible participant states in the Enroll-HD EDC are displayed in the table below. Note that only participant states displayed in *white* rows are applicable to the PDS.

Label	Internal Value	Category	Description
screening	screening	active	Participant is in screening
screen failure	excluded	cancelled	Participant does not meet the in-/exclusion criteria and is excluded from the study
enrolled	enrolled	active	Participant meets the in-/exclusion criteria and is enrolled to the study
withdrawn	withdrawn	cancelled	Participant leaves the study prematurely and has withdrawn its signed consent
violation	violation	cancelled	Participant leaves the study prematurely (other reason than withdrawal)
completed	completed	complete	Participant has completed the study
quarantined	locked	isolated	Participant is locked, e.g. due to missing ICF
deleted	deleted	isolated	Participant is deleted

4.2 Data File “participation”

Label	Domain	Study	Cat	Form	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 “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 “violator” means that the participant has prematurely ended the study (see End form for detailed reason).	Not available
Participant status (latest)	SUPPSC	ENR	---		subjstat	text	- enrolled - completed - excluded - withdrawn - violator			See chapter 4.1 for details.	PDS

Participant category (at enrollment)	SUPPSC	ENR	---		hdcatt_0	single choice	- pre-manifest/pre-motor-manifest HD - manifest/ motor-manifest HD - genotype negative - family control	- 2 - 3 - 4 - 5		In the PDS 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_1	single choice	- pre-manifest/pre-motor-manifest HD - manifest/ motor-manifest HD - genotype negative - family control	- 2 - 3 - 4 - 5		In the PDS community controls are not included, genotype unknown are automatically mapped to another category.	PDS
Date of birth	DM	ENR	---	Demog	brthdtc	date					Not available
Age at enrollment	DM	ENR	---		age_0	number				Birth date is transformed into age in years at time of enrollment. Ages under 18 are represented as "<18"	PDS
Date of enrollment	DM	ENR	---	Enrollment	rfstdtc	date					Not available
Study reference start day (baseline)	DM	ENR	---	Enrollment	rfstdy	number				Number of days before/since enrollment into Enroll-HD, typically this is day 0 in the PDS.	PDS
Date of informed consent	DM	ENR	---	Enrollment	rficdtc	date					Not available
Day of informed consent	DM	ENR	---	Enrollment	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		Enrollment	sgntr		- participant	- 1			

						single choice	- legal representative	- 2			Not available
Date of end of study	DM	ENR	---	End	rfendtc	date					Not available
Day of end of study	DM	ENR	---	End	rfendy	number				Contains date of death if participant died or date of withdrawal/violation if participant discontinued the study prematurely	PDS

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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	DS	ENR		End	dsdte	date					Not available
Assessment day	DS	ENR		End	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	Form	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 to be located by investigator)	DS	ENR R3		End	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 - institutionalized (will not be followed further)	- 1 - 2 - 3 - 4 - 5			PDS

							- Other	- 6			
Please specify	SUPPDS	ENR R3		End	termoth	text					Not available
Please specify the reason for the participant's request	SUPPDS	ENR R3		End	dsreas	single choice	- unable to travel - participant unwilling to continue - participant moved away from the study site	- 1 - 2 - 3			Available upon SRC approval

4.2.2 Data File “participation” system calculated additional values and key variables

Label	Domain	Study	Cat	Form	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) - R (Ad Hoc)	- BL - FUP - PC - U - R			PDS
Visit type	SV	ENR	---		visit1, visit2, ... visit21	text	- Baseline - Follow Up - Phone Contact - Unscheduled - Ad Hoc	- BL - FUP - PC - U - R		Sequence of visits ordered by visit date	Available upon SRC approval

							- Premature End	- E			
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	Form	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	number			Days	Transformed into days relative to baseline date of Enroll-HD.	PDS
Enrollment	SUPPSV	ENR	---		enrollment	number	- available ¹	- 1			PDS
Variable	SUPPSV	ENR	---		variable	number	- available ¹	- 1			PDS
Medical History	SUPPSV	ENR	---		mhx	number	- available ¹	- 1			PDS
Samples	SUPPSV	ENR	---		samples	number	- available ¹	- 1			PDS
UHDRS Motor/Diagnostic Confidence	SUPPSV	ENR R2 R3	---		motor	number	- available ¹	- 1			PDS
UHDRS Total Functional Capacity	SUPPSV	ENR R2 R3	---		tfc	number	- available ¹	- 1			PDS
UHDRS Function Assessment/Independence Scale	SUPPSV	ENR R2 R3	---		function	number	- available ¹	- 1			PDS
Cognitive Assessments	SUPPSV	ENR R2 R3	---		cognitive	number	- available ¹	- 1			PDS
Mini Mental State Examination	SUPPSV	ENR	---		mmse	number	- available ¹	- 1			PDS
Physiotherapy Outcome Measures	SUPPSV	ENR	---		physio	number	- available ¹	- 1			PDS
Problem Behaviours Assessment - Short	SUPPSV	ENR R3	---		pbas	number	- available ¹	- 1			PDS
Client Service Receipt Inventory	SUPPSV	ENR R2 R3	---		csri	number	- available ¹	- 1			PDS

¹ empty cell indicates not available

Caregivers Quality of Life Questionnaire	SUPPSV	ENR	---		careqol	number	- available ¹	- 1			PDS
Short Form Health Survey – 12v2	SUPPSV	ENR	---		sf12	number	- available ¹	- 1			PDS
Hospital Anxiety and Depression Scale - Snaith Irritability Scale	SUPPSV	ENR R2 R3	---		hadssis	number	- available ¹	- 1			PDS
Columbia-Suicide Severity Rating Scale - Baseline	SUPPSV	ENR R3	---		cssrsbl	number	- available ¹	- 1			PDS
Columbia-Suicide Severity Rating Scale - Annual	SUPPSV	ENR R3	---		cssrsfup	number	- available ¹	- 1			PDS
WPAI-SHP	SUPPSV	ENR	---		wpaishp	number	- available ¹	- 1			PDS
Missed Visit	SUPPSV	ENR	---		missedvisit	number	- available ¹	- 1			PDS
Extended Neuropsychological Assessment	SUPPSV	R2 R3	---		cognitivel	number	- available ¹	- 1			PDS
UHDRS Behavioral Assessment	SUPPSV	R2 R3	---		behaviour	number	- available ¹	- 1			PDS
Summary	SUPPSV	R2 R3	---		summary	number	- available ¹	- 1			PDS
Global Clinical Impression Scale	SUPPSV	R2 R3	---		gci	number	- available ¹	- 1			PDS
Caregiver Questionnaire	SUPPSV	R2 R3	---		care	number	- available ¹	- 1			PDS
Problem Behaviours Assessment for HD	SUPPSV	R3	---		pbahd	number	- available ¹	- 1			PDS
SF-36v2 Health Survey	SUPPSV	R3	---		sf36v2	number	- available ¹	- 1			PDS
Becks Depression Scale	SUPPSV	R2 R3	---		bdi	number	- available ¹	- 1			PDS
Hamilton Rating Scale for Depression	SUPPSV	R2 R3	---		hamilton	number	- available ¹	- 1			PDS

SF-36v1 Health Survey	SUPPSV	R2	---		sf36v1	number	- available ¹	- 1			PDS
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4.4 Data File “event (Reportable Event Monitoring)”

This form is part of the General visit.

Section Reportable Event

Label	Domain	Study	Cat	Form	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		Event	evtdtc	Date					Not available
Day of report	SUPPAE	ENR		Event	evtdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Reportable event codes	SUPPAE	ENR		Event	evtcode	single choice	- suicide attempts - completed suicide - mental health event requiring hospitalization - death (other than suicide, any cause)	- 1 - 2 - 3 - 4			PDS
Event term – Entered term				Event	evtterm	text					Not available

Event term – Modified Term (coded with Internal condition code)	SUPPAE	ENR		Event	evtterm__modify	Text				Internal condition code provided in English. (only filled if event code (evtcode) is 3).	PDS
Event term – Code	SUPPAE	ENR		Event	evtterm__decod	Text				Internal condition Code provided. (only filled if event code (evtcode) is 3).	PDS
Event term – MedDRA Code	SUPPAE	ENR		Event	evtterm__decod	Text				MedDRA codes are made available upon proof of license	Available upon SRC approval
Event term – Certainty (coded with MedDRA)	SUPPAE	ENR		Event	evtterm__certainty	Text					Not available

Section Details of Reportable Event

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Onset date	SUPPAE	ENR		Event	evtstdtc	Date					Not available
Onset day	SUPPAE	ENR		Event	evtstdy	number				Transformed into days relative to baseline date of Enroll-HD.	PDS
Date estimated	SUPPAE	ENR		Event	stdtcest	Boolean	- yes - no	- 1 - 0			PDS
Describe briefly circumstances and nature of event	SUPPAE	ENR		Event	evt	Text					Not available
List any relevant tests, laboratory data, history	SUPPAE	ENR		Event	evttst	Text					Not available
Is the report	SUPPAE	ENR		Event	evtpatt		- initial	- 1			

						single choice	- follow-up - final	- 2 - 3			Not available
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Section Event Resolution

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

Section Interventions

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

Section DSMC Review

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

5 Visit-Based Data Files

5.1 Study Visit Types

Form entities are organized in visits (i.e. Baseline, Follow Up, Unscheduled, and Premature End visits) except for retrospective 'studies' which only have an Adhoc visit type.

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.

All study visit types are displayed in the table below. Note that the 'General' visit type is not applicable to the PDS – the data collected in this visit type are redistributed across other files (e.g., profile).

Visit	Studies	Description
RET	Adhoc	A visit that has occurred before the Baseline visit of Enroll-HD and/or REGISTRY. Data are obtained from previous studies or clinical visits.
General	ENR	<p>This is an ongoing visit or log where continuously updated information (e.g. medication, co-morbid conditions) and generally static information (e.g., sex) is stored.</p> <p>That means that data is shared among studies if the same information is part of another study (e.g. date of birth). Therefore, the data may be available after enrolment if a participant is already participating in a study where data was already entered.</p> <p>The visit is generated automatically at enrolment in the study, and the date of the general visit is automatically set to the date the participant was added to the database.</p> <p>Note that 'General' visit type is not applicable to the PDS – the data collected in this visit type are redistributed across other files (e.g., profile)</p>
Family History	ENR	<p>This is an optional ongoing visit or log where continuously updated information (i.e., family history) is stored.</p> <p>The data can be shared among participants.</p>

		The visit is generated automatically if consented to by the participant, and the date of the family history visit is automatically set to the date the participant's consent is entered.
Baseline	ENR, R3, R2	The first scheduled regular visit after enrolment into the study.
Follow Up	ENR, R3, R2	Annual visit scheduled after Baseline visit. A Follow Up visit is ready for data entry within the scheduled visit frame of 1 years -3/+3 months after the Baseline visit (i.e. first Follow Up visit is scheduled at "Baseline plus 1 year -3/+3 months", the second one is scheduled at "Baseline plus 2 years -3/+3 months").
Unscheduled	ENR, R3	An irregular visit after 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.
Phone Contact	ENR	A 'visit' that occurred at any time after the Baseline visit and instead 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.
Premature End	ENR	A 'visit' that is completed at any point in time after enrollment - either during or outside of a scheduled visit - when a participant leaves the study prematurely.

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*.

All possible visit states in the Enroll-HD EDC are displayed in the table below. Note that only visit states displayed in *white* rows are applicable to the PDS.

Visit status	Description
editing	Visits that are not marked as signed. Visits being in state editing still contain forms with flagged errors that need to be corrected or empty forms that have not been deactivated.
plausible	Visits that are completely entered but not marked as signed yet. Visits being in state plausible contain entered forms without any flagged errors or empty forms that have been deactivated.
signed	Visits that are marked as signed. All entered forms must be complete, without errors and be signed. Empty forms must have been deactivated.
reviewing	Visits that are ready for review or in the process of being reviewed by a monitor.
completed	Visits that have undergone full monitoring review have the state completed or cancelled. All queries raised by the monitor must have been completed. Since monitoring is done not for 100% of the entered, the reviews might have been incompletely reviewed or bypassed.

5.2 Visit assessment schedule by study

eCRF Form	General	Family History	Baseline	Follow Up	Unscheduled	Phone Contact	Premature End	RET
Demographic Data (Demog)	●							
HD Clinical Characteristics (HD CC)	●							
CAG Report (CAG)	(●)							
Pharmacotherapy (PharmacoTx)	●							
Nutritional Supplements (NutSuppl)	(●)							
Non-Pharmacologic Therapies (Non-PharmacoTx)	(●)							
Comorbid Conditions (Comorbid)	●							
Clinical Trials Form (Clinical Trials)	(●)							
Reportable Event (Event)	(●)							
Mortality	(●)							
Family History (FHx)		(●)						
Enrollment into Enroll-HD (Enrollment)			●					
Medical History (MHx)			●					
Variable Items Baseline (education, employment, BMI, alcohol, tobacco and drug use)			●(●)(●)					(●)
Variable Items Follow Up (Variable) (education, employment, BMI, alcohol, tobacco and drug use)				●(●)(●)	●(●)(●)			(●)
UHDRS® Motor/Diagnostic Confidence (Motor)			●(●)(●)	●(●)(●)	(●)(●)			(●)
UHDRS® Total Functional Capacity (TFC)			●(●)(●)	●(●)(●)	(●)(●)			(●)

UHDRS® Functional Assessment (Function)			●(●)(●)	●(●)(●)	(●)(●)			(●)
Problem Behaviours Assessment – Short (PBA-s)			●(●)	●(●)	(●)(●)			
Core and Extended Cognitive Assessment (Cognitive)			●(●)(●)	●(●)(●)	(●)(●)			(●)
Bio Specimens for Bio Banking (Samples)			(●)	(●)				
Hospital Anxiety and Depression Scale - Snaith Irritability Scale (HADS-SIS)			(●)(●)	(●)(●)	(●)(●)			
Columbia-Suicide Severity Rating Scale (C-SSRS) – Baseline			(●)(●)					
Columbia-Suicide Severity Rating Scale (C-SSRS) – Follow Up				(●)(●)	(●)(●)			
Mini Mental State Examination (MMSE)			(●)	(●)	(●)			(●)
Physiotherapy Outcome Measures (Physio)			(●)	(●)	(●)			
Short Form Health Survey – 12v2 (SF12)			(●)	(●)	(●)			
Caregivers Quality of Life Questionnaire (CareQoL)			(●)	(●)	(●)			
Client Service Receipt Inventory (CSRI)			(●)	(●)	(●)			
Work Productivity and Activity Impairment-Specific Health Problem (WPAI-SH)			(●)	(●)	(●)			
Follow-up on Missed Visit (Missed Visit)						●		
Premature End of Study (End)						●	●	

● = Enroll-HD; ● = Registry 3; ● = Registry 2; ● = RET

Brackets (●) indicate optional components.

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		ENR R2 R3		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 "completed" means that participant has normally ended the study. Currently, the only reason for a normal termination is if the participant died. The states		Not available

							"withdrawn" and "violation" means that the participant has prematurely ended the study (see End form for detailed reason).		
Subject State		ENR R2 R3		subjstat	text	- enrolled - completed - excluded - withdrawn - violator			PDS
Visit index		ENR R2 R3 RET		seq					PDS
Visit name		ENR		vname	text	- General - Baseline - Follow Up - Phone Contact - Unscheduled - Premature End		See also section 6.1.	Available upon SRC approval
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. “PharmacTx”. 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
CAP score ²		ENR R3		capscore	number		Age * (CAG – L)/K, where L=30 and K=6.49		PDS

² For further information on CAP score calculation, please see “Understand and Interpret the Data” document. CAP score formula reference: Warner, J. H., Long, J. D., Mills, J. A., Langbehn, D. R., Ware, J., Mohan, A., & Sampaio, C. (2022). Standardizing the CAP Score in Huntington's Disease by Predicting Age-at-Onset. Journal of Huntington's disease, 11(2), 153–171. <https://doi.org/10.3233/JHD-210475>.

		R2 RET							
Imputed HD-ISS stage ³		ENR		hdiss_stage_imp	number	- Stage 0 - Stage 1 - Stage 2 - Stage 3	- 0 - 1 - 2 - 3	Only computed for BL and FUP visits	PDS
Probability of classification as HD-ISS Stage 0		ENR		hdiss_stage0_prob	number				PDS
Probability of classification as HD-ISS Stage 1		ENR		hdiss_stage1_prob	number				PDS
Probability of classification as HD-ISS Stage 2		ENR		hdiss_stage2_prob	number				PDS
Probability of classification as HD-ISS Stage 3		ENR		hdiss_stage3_prob	number				PDS

³ For further information on HD-ISS variable generation, please see „Understand and Interpret the Data“ document. HD-ISS reference: Tabrizi SJ, Schobel S, Gantman EC, et al. A biological classification of Huntington’s disease: The integrated staging system. The Lancet Neurology 2022; 21: 632–644

7 Visit items

7.1 Form “Enrollment”

This form is part of the Baseline visit.

Section Enrollment

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Participant category	SC	ENR		Enrollment	hdcat	single choice	- genotype unknown - pre-manifest/pre-motor-manifest HD - manifest/motor-manifest HD - genotype negative - family control - community control	- 1 - 2 - 3 - 4 - 5 - 6			Available upon SRC approval
Participant category	SC	ENR R3		Enrollment	hdcat	single choice	- pre-manifest/pre-motor-manifest HD - manifest/motor-manifest HD - genotype negative - family control	- 2 - 3 - 4 - 5		In the PDS 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		Enrollment	ic1	Boolean	- yes - no	- 1 - 0			Not available
Group Optional Components: Family History	SC	ENR		Enrollment	fhx	Boolean	- yes - no	- 1 - 0			Available upon SRC approval

Group Optional Components: Biosamples for use in research	SC	ENR		Enrollment	bsp	Boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Linking clinical information from previous studies	SC	ENR		Enrollment	rtrspctv	Boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Participation in sub-studies	SC	ENR		Enrollment	nvl	Boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Contact between visits	SC	ENR		Enrollment	cntct	Boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Contact regarding other research studies	SC	ENR		Enrollment	cntctst	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Contact regarding post-mortem tissue collection	SC	ENR		Enrollment	cntctpmt	Boolean	- yes - no	- 1 - 0			Available upon SRC approval
IDs in other Studies: COHORT HDID	SC	ENR		Enrollment	ch_id	text					Not available
IDs in other Studies: PREDICT HDID	SC	ENR		Enrollment	pd_id	text					Not available

7.2 Form “Medical History (MHx)”

This form is part of the Baseline visit.

Section General

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	MH	ENR		MHx	mhdct	date					Not available

Assessment day	MH	ENR		MHx	mhdyy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
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Section Past Medical History

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Has the participant had alcohol problems in the past	MH	ENR		MHx	hxalcab	boolean	- yes - no - unknown	- 1 - 0 - 9999			PDS
Has the participant ever smoked	MH	ENR		MHx	hxtobab	boolean	- yes - no - unknown	- 1 - 0 - 9999			PDS
Cigarettes per day	MH	ENR		MHx	hxtobcpd	number					PDS
Years of smoking	MH	ENR		MHx	hxtobyos	number					PDS
Packyears	MH	ENR		MHx	hxpacky	number					PDS
Has the participant ever abused drugs	MH	ENR		MHx	hxdrugab	boolean	- yes - no - unknown	- 1 - 0 - 9999			PDS
Marijuana - Abuse	SUPPSU	ENR		MHx	hxmar	boolean	- yes - no	- 1 - 0			PDS
Marijuana - Frequency	SU	ENR		MHx	hxmarfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Heroin - Abuse	SUPPSU	ENR		MHx	hxher	boolean	- yes - no	- 1 - 0			PDS
Heroin - Frequency	SU	ENR		MHx	hxherfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Cocaine - Abuse	SUPPSU	ENR		MHx	hxcoc	boolean	- yes - no	- 1 - 0			PDS

Cocaine - Frequency	SU	ENR		MHx	hxcocfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Club drugs (Ecstasy, GHB, Roofies) - Abuse	SUPPSU	ENR		MHx	hxclb	boolean	- yes - no	- 1 - 0			PDS
Club drugs (Ecstasy, GHB, Roofies) - Frequency	SU	ENR		MHx	hxclbfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Amphetamines - Abuse	SUPPSU	ENR		MHx	hxamp	boolean	- yes - no	- 1 - 0			PDS
Amphetamines - Frequency	SU	ENR		MHx	hxampfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Ritalin - Abuse	SUPPSU	ENR		MHx	hxrit	boolean	- yes - no	- 1 - 0			PDS
Ritalin - Frequency	SC	ENR		MHx	hxritfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Hallucinogens - Abuse	SUPPSU	ENR		MHx	hxhal	boolean	- yes - no	- 1 - 0			PDS
Hallucinogens - Frequency	SU	ENR		MHx	hxhalfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Inhalants - Abuse	SUPPSU	ENR		MHx	hxinh	boolean	- yes - no	- 1 - 0			PDS
Inhalants - Frequency	SU	ENR		MHx	hxinhfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Opium - Abuse	SUPPSU	ENR		MHx	hxopi	boolean	- yes - no	- 1 - 0			PDS
Opium - Frequency	SU	ENR		MHx	hxopifrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Painkillers - Abuse	SUPPSU	ENR		MHx	hxpak	boolean	- yes - no	- 1 - 0			PDS

Painkillers - Frequency	SU	ENR		MHx	hxpakfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Barbiturates/sedatives - Abuse	SUPPSU	ENR		MHx	hxbar	boolean	- yes - no	- 1 - 0			PDS
Barbiturates/sedatives - Frequency	SU	ENR		MHx	hxbarfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Tranquilizers - Abuse	SUPPSU	ENR		MHx	hxtrq	boolean	- yes - no	- 1 - 0			PDS
Tranquilizers - Frequency	SU	ENR		MHx	hxtrqfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Other - Abuse	SUPPSU	ENR		MHx	hxoth	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Other - Frequency	SU	ENR		MHx	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

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	HDCC	ENR		Variable BL	svstdtc	date					Internal

Section General Variable Items I

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Is participant part of mobile clinic site				Variable BL	mclinic	boolean	- yes - no	- 1 - 0			Not available

Height (cm)	VS	ENR R2 R3 RET		Variable BL	height	number				No cut-off values (due to data overdispersion)	Available upon SRC approval
Height (inches)	VS	ENR R2 R3 RET		Variable BL	height_2	number					Available upon SRC approval
Weight (kg)	VS	ENR R2 R3 RET		Variable BL	weight	number					Available upon SRC approval
Weight (lbs)	VS	ENR R2 R3 RET		Variable BL	weight_2	number					Available upon SRC approval
BMI	VS	ENR R2 R3 RET		Variable BL	bmi	number				Auto-calculated from height and weight values.	Available upon SRC approval
BMI imputed	VS	ENR R2 R3 RET		N/A	bmi_imp	number				Based on observed weight at visit and height at Enroll-HD <i>baseline</i> visit; value is imputed for all visits except Enroll-HD <i>baseline</i> .	PDS
Does the participant currently drink alcohol?	MH	ENR R3	mhx	Variable BL	alcab	boolean	- yes - no	- 1 - 0			PDS
Units per week	SU	ENR R3	mhx	Variable BL	alcunits	number					PDS
	MH		mhx	Variable BL	tobab	boolean	- yes	- 1			PDS

Does the participant currently smoke?		ENR R3					- no	- 0			
Cigarettes per day	SU	ENR	mhx	Variable BL	tobcpd	number					PDS
Years of smoking	SUPPSU	ENR	mhx	Variable BL	tobyos	number					PDS
Packyears	MH	ENR R3	mhx	Variable BL	packy	number				(tobcpd/20) * tobyos [rounded to one decimal place]	PDS
Current caffeine use?	MH	ENR	mhx	Variable BL	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	Variable BL	cafpd	boolean	- yes - no	- 1 - 0			PDS
Does the participant currently use drugs?	MH	ENR R3	mhx	Variable BL	drugab	boolean	- yes - no	- 1 - 0			PDS
Marijuana - Abuse	SUPPSU	ENR R3	mhx	Variable BL	mar	boolean	- yes - no	- 1 - 0			PDS
Marijuana - Abuse	SU	ENR R3	mhx	Variable BL	marfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Heroin - Abuse	SUPPSU	ENR R3	mhx	Variable BL	her	boolean	- yes - no	- 1 - 0			PDS
Heroin - Abuse	SU	ENR R3	mhx	Variable BL	herfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Cocaine - Abuse	SUPPSU	ENR R3	mhx	Variable BL	coc	boolean	- yes - no	- 1 - 0			PDS
Cocaine - Abuse	SU	ENR R3	mhx	Variable BL	cocfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS

Club drugs (Ecstasy, GHB, Roofies) - Abuse	SUPPSU	ENR R3	mhx	Variable BL	clb	boolean	- yes - no	- 1 - 0			PDS
Club drugs (Ecstasy, GHB, Roofies) - Abuse	SU	ENR R3	mhx	Variable BL	clbfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Amphetamines - Abuse	SUPPSU	ENR R3	mhx	Variable BL	amp	boolean	- yes - no	- 1 - 0			PDS
Amphetamines - Abuse	SU	ENR R3	mhx	Variable BL	ampfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Ritalin - Abuse	SUPPSU	ENR R3	mhx	Variable BL	rit	boolean	- yes - no	- 1 - 0			PDS
Ritalin - Abuse	SU	ENR R3	mhx	Variable BL	ritfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Hallucinogens - Abuse	SUPPSU	ENR R3	mhx	Variable BL	hal	boolean	- yes - no	- 1 - 0			PDS
Hallucinogens - Abuse	SU	ENR R3	mhx	Variable BL	halfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Inhalants - Abuse	SUPPSU	ENR R3	mhx	Variable BL	inh	boolean	- yes - no	- 1 - 0			PDS
Inhalants - Abuse	SU	ENR R3	mhx	Variable BL	inhfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Opium - Abuse	SUPPSU	ENR R3	mhx	Variable BL	opi	boolean	- yes - no	- 1 - 0			PDS
Opium - Abuse	SU	ENR R3	mhx	Variable BL	opifrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS

Painkillers - Abuse	SUPPSU	ENR R3	mhx	Variable BL	pak	boolean	- yes - no	- 1 - 0			PDS
Painkillers - Abuse	SU	ENR R3	mhx	Variable BL	pakfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Barbiturates/sedatives - Abuse	SUPPSU	ENR R3	mhx	Variable BL	bar	boolean	- yes - no	- 1 - 0			PDS
Barbiturates/sedatives - Abuse	SU	ENR R3	mhx	Variable BL	barfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Tranquilizers - Abuse	SUPPSU	ENR R3	mhx	Variable BL	trq	boolean	- yes - no	- 1 - 0			PDS
Tranquilizers - Abuse	SU	ENR R3	mhx	Variable BL	trqfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Other – Abuse	SUPPSU	ENR R3	mhx	Variable BL	oth	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Other – Abuse	SU	ENR R3	mhx	Variable BL	othfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			Available upon SRC approval

Section General Variable Items II

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Marital status	SC	ENR R2 R3		Variable BL	maristat	single choice	- single - partnership - married - divorced - widowed	- 1 - 2 - 3 - 4 - 5		Coding 6 are not available for studies R2 and R3.	Available upon SRC approval

							- legally separated	- 6			
Residence	SC	ENR R2 R3		Variable BL	res	single choice	- rural - village - town - city	- 1 - 2 - 3 - 4			PDS
ISCED education level (US version)	SC	ENR R3		Variable BL	iscd	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		Variable BL	eduys	number			years		Available upon SRC approval
Occupation - Entered Term	SC	ENR		Variable BL	empjob	text					Available upon SRC approval
Occupation – Modified Term	SC	ENR		Variable BL	empjob_modify	text				Coded with SNOMED	Available upon SRC approval
Occupation - Code	SC	ENR		Variable BL	empjob_decod	text					Available upon SRC approval
Employment	SC	ENR		Variable BL	jobclas	single choice	- full-time employed - part-time employed - self employed - not employed	- 1 - 2 - 3 - 4			PDS
Status (if employed)	SC	ENR		Variable BL	jobpaid	single choice	- paid - unpaid	- 1 - 2			PDS

Have you had to stop or reduce work due to your health?	SC	ENR		Variable BL	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		Variable BL	rdcwkd	number			days		PDS
How many fewer hours per week have you worked because of HD?	SC	ENR		Variable BL	rdcwkhw	number			hours/week		PDS
Reason (if not employed)	SC	ENR		Variable BL	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		Variable BL	emplnrd	single choice	- ill health - age	- 1 - 2			PDS
Group If retired or unemployed - Do you receive social security or disability benefit?	SC	ENR		Variable BL	ssdb	boolean	- yes - no	- 1 - 0			PDS
Group If retired or unemployed - Do you intend to return to work?	SC	ENR		Variable BL	rtrnw	boolean	- yes - no	- 1 - 0			PDS

Group If retired or unemployed - Since when have you been unemployed/retired?	SC	ENR		Variable BL	rtrddur	number			Years	Age at retirement	PDS
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7.4 Form “Variable Items (Follow-Up Visit)”

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

Section General

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	HDCC	ENR		Variable FUP	svstdtc	date					Internal

Section General Variable Items I

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Is participant part of mobile clinic site				Variable FUP	mclinic	boolean	- yes - no	- 1 - 0			Not available
Height (cm)	VS	ENR R2 R3 RET		Variable FUP	height	number				No cut-off values (due to data overdispersion)	Available upon SRC approval
Height (inches)	VS	ENR R2 R3 RET		Variable FUP	height_2	number					Available upon SRC approval
Weight (kg)	VS	ENR R2 R3 RET		Variable FUP	weight	number					Available upon SRC approval

Weight (lbs)	VS	ENR R2 R3 RET		Variable FUP	weight_2	number					Available upon SRC approval
BMI	VS	ENR R2 R3 RET		Variable FUP	bmi	number					Available upon SRC approval
BMI imputed	VS	ENR R2 R3 RET		N/A	bmi_imp	number				Based on observed weight at visit and height at Enroll-HD <i>baseline</i> visit; imputed for all visits except Enroll-HD <i>baseline</i> .	PDS
Does the participant currently drink alcohol?	MH	ENR R3	mhx	Variable FUP	alcab	boolean	- yes - no	- 1 - 0			PDS
Units per week	SU	ENR R3	Mhx	Variable FUP	alcunits	number					PDS
Does the participant currently smoke?	MH	ENR R3	Mhx	Variable FUP	tobab	boolean	- yes - no	- 1 - 0			PDS
Cigarettes per day	SU	ENR	Mhx	Variable FUP	tobcpd	number					PDS
Years of smoking	SUPPSU	ENR	Mhx	Variable FUP	tobyos	number					PDS
Packyears	MH	ENR R2 R3	Mhx	Variable FUP	packy	number				(tobcpd/20) * tobyos [rounded to 1 decimal place]	PDS
Current caffeine use?	MH	ENR	Mhx	Variable FUP	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	Variable FUP	cafpd	boolean	- yes - no	- 1 - 0			PDS

Does the participant currently use drugs?	MH	ENR R3	mhx	Variable FUP	drugab	boolean	- yes - no	- 1 - 0			PDS
Marijuana - Abuse	SUPPSU	ENR R3	mhx	Variable FUP	mar	boolean	- yes - no	- 1 - 0			PDS
Marijuana - Abuse	SU	ENR R3	mhx	Variable FUP	marfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Heroin - Abuse	SUPPSU	ENR R3	mhx	Variable FUP	her	boolean	- yes - no	- 1 - 0			PDS
Heroin - Abuse	SU	ENR R3	mhx	Variable FUP	herfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Cocaine - Abuse	SUPPSU	ENR R3	mhx	Variable FUP	coc	boolean	- yes - no	- 1 - 0			PDS
Cocaine - Abuse	SU	ENR R3	mhx	Variable FUP	cocfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Club drugs (Ecstasy, GHB, Roofies) - Abuse	SUPPSU	ENR R3	mhx	Variable FUP	clb	boolean	- yes - no	- 1 - 0			PDS
Club drugs (Ecstasy, GHB, Roofies) - Abuse	SU	ENR R3	mhx	Variable FUP	clbfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Amphetamines - Abuse	SUPPSU	ENR R3	mhx	Variable FUP	amp	boolean	- yes - no	- 1 - 0			PDS
Amphetamines - Abuse	SU	ENR R3	mhx	Variable FUP	ampfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Ritalin - Abuse	SUPPSU		mhx		rit	boolean	- yes	- 1			PDS

		ENR R3		Variable FUP			- no	- 0			
Ritalin - Abuse	SU	ENR R3	mhx	Variable FUP	ritfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Hallucinogens - Abuse	SUPPSU	ENR R3	mhx	Variable FUP	hal	boolean	- yes - no	- 1 - 0			PDS
Hallucinogens - Abuse	SU	ENR R3	mhx	Variable FUP	halfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Inhalants - Abuse	SUPPSU	ENR R3	mhx	Variable FUP	inh	boolean	- yes - no	- 1 - 0			PDS
Inhalants - Abuse	SU	ENR R3	mhx	Variable FUP	inhfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Opium - Abuse	SUPPSU	ENR R3	mhx	Variable FUP	opi	boolean	- yes - no	- 1 - 0			PDS
Opium - Abuse	SU	ENR R3	mhx	Variable FUP	opifrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Painkillers - Abuse	SUPPSU	ENR R3	mhx	Variable FUP	pak	boolean	- yes - no	- 1 - 0			PDS
Painkillers - Abuse	SU	ENR R3	mhx	Variable FUP	pakfrq	single choice	- seldom - occasionally - frequently	- 1 - 2 - 3			PDS
Barbiturates/sedatives - Abuse	SUPPSU	ENR R3	mhx	Variable FUP	bar	boolean	- yes - no	- 1 - 0			PDS
Barbiturates/sedatives - Abuse	SU	ENR R3	Mhx	Variable FUP	barfrq	single choice	- seldom - occasionally	- 1 - 2			PDS

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

Section General Variable Items II

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Any changes to the following General Variable Items	MH	ENR R3		Variable FUP	updsc	boolean	- yes - no	- 1 - 0			PDS
Marital status	SC	ENR R3 R2		Variable FUP	maristat	single choice	- single - married - partnership - divorced - widowed - legally separated	- 1 - 3 - 2 - 4 - 5 - 6		Coding 6 are not available for studies R2 and R3.	Available upon SRC approval
Residence	SC	ENR R3 R2		Variable FUP	res	single choice	- rural - village - town - city	- 1 - 2 - 3 - 4			PDS
ISCED education level (US version)	SC	ENR R3		Variable FUP	Isced	single choice	- ISCED 0 - ISCED 1	- 0 - 1			PDS

							- ISCED 2 - ISCED 3 - ISCED 4 - ISCED 5 - ISCED 6	- 2 - 3 - 4 - 5 - 6			
Years of education	SC	ENR		Variable FUP	eduysr	number			years		Available upon SRC approval
Occupation – Entered Term	SC	ENR		Variable FUP	empjob	text					Available upon SRC approval
Occupation – Modified Term	SC	ENR		Variable FUP	empjob_modify	text				Coded with SNOMED	Available upon SRC approval
Occupation - Code	SC	ENR		Variable FUP	Empjob_d ecod	text					Available upon SRC approval
Employment	SC	ENR		Variable FUP	jobclas	single choice	- full-time employed - part-time employed - self employed - not employed	- 1 - 2 - 3 - 4			PDS
Status (if employed)	SC	ENR		Variable FUP	jobpaid	single choice	- paid - unpaid	- 1 - 2			PDS
Have you had to stop or reduce work due to your health?	SC	ENR		Variable FUP	rdcwkw	boolean	- yes - no	- 1 - 0			PDS
How many days in the last 6 months have you been off work because of HD?	SC	ENR		Variable FUP	rdcwkd	number			days		PDS
How many fewer hours per week have	SC	ENR		Variable FUP	rdcwkhw	number			hours /week		PDS

you worked because of HD?											
Reason (if not employed)	SC	ENR		Variable FUP	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		Variable FUP	emplnrd	single choice	- ill health - age	- 1 - 2			PDS
Do you receive social security or disability benefit?	SC	ENR		Variable FUP	ssdb	boolean	- yes - no	- 1 - 0			PDS
Do you intend to return to work?	SC	ENR		Variable FUP	rtrnwks	boolean	- yes - no	- 1 - 0			PDS
Since when have you been unemployed/retired?	SC	ENR		Variable FUP	rtrddur	number			Years	Age at retirement	PDS

Section Since the last visit have there been:

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Any changes to participant's medication?	SV	ENR R3		Variable FUP	updmed	boolean	- yes - no	- 1 - 0			PDS
Any changes to participant's comorbid conditions?	SV	ENR R3		Variable FUP	updmh	boolean	- yes - no	- 1 - 0			PDS
Any updates to the clinical characteristics and/or onset of HD?	SV	ENR R3		Variable FUP	updhhd	boolean	- yes - no	- 1 - 0			PDS
	SV	ENR			updfh	boolean	- yes	- 1			PDS

Any updates to family history?		R3		Variable FUP			- no	- 0			
Any changes to the optional components?	SV	ENR		Variable FUP	updopt	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Biosamples for use in research	SC	ENR		Variable FUP	bsp	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Linking clinical information from previous studies	SC	ENR		Variable FUP	rtrspctv	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Participation in sub-studies	SC	ENR		Variable FUP	nvl	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Contact between visits	SC	ENR		Variable FUP	cntct	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Contact regarding other research studies	SC	ENR		Variable FUP	cntctst	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Group Optional Components: Contact regarding post-mortem tissue collection	SC	ENR		Variable FUP	cntctpmt	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Has the participant had a brain MRI?	SV	ENR		Variable FUP	updmri	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Date of MRI	SV	ENR		Variable FUP	mrldtc	date					Not available
Day of MRI	SV	ENR		Variable FUP	mrldy	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	Motor	Motor	qsdtc	date					Not available
Assessment day	QS	ENR	Motor	Motor	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Rater code	QS	ENR	Motor	Motor	raterid	number					Not available
Motor score (TMS)	QS	ENR R3 R2 RET	Motor	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	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 fingertapping due to amputation).	PDS

Section Motor Assessment

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Ocular pursuit - Horizontal	QS	ENR R3	Motor	Motor	ocularh	single choice	- complete (normal) - jerky movement	- 0 - 1			PDS

		R2 RET					- interrupted pursuits/full range - incomplete range - cannot pursue	- 2 - 3 - 4			
Ocular pursuit - Vertical	QS	ENR R3 R2 RET	Motor	Motor	ocularv	single choice	- complete (normal) - jerky movement - interrupted pursuits/full range - incomplete range - cannot pursue	- 0 - 1 - 2 - 3 - 4			PDS
Saccade initiation - Horizontal	QS	ENR R3 R2 RET	Motor	Motor	sacinith	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
Saccade initiation - Vertical	QS	ENR R3 R2 RET	Motor	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
Saccade velocity - Horizontal	QS	ENR R3 R2 RET	Motor	Motor	sacvelh	single choice	- normal - mild slowing - moderate slowing - severely slow, full range - incomplete range	- 0 - 1 - 2 - 3 - 4			PDS
Saccade velocity - Vertical	QS	ENR R3 R2 RET	Motor	Motor	sacvelv	single choice	- normal - mild slowing - moderate slowing - severely slow, full range	- 0 - 1 - 2 - 3			PDS

							- incomplete range	- 4			
Saccade velocity - Dysarthria	QS	ENR R3 R2 RET	Motor	Motor	dysarth	single choice	- normal - unclear, no need to repeat - must repeat to be understood - mostly incomprehensible - anarthria	- 0 - 1 - 2 - 3 - 4			PDS
Saccade velocity - Tongue protrusion	QS	ENR R3 R2 RET	Motor	Motor	tongue	single choice	- can hold tongue fully protruded for 10 sec - cannot keep fully protruded for 10 sec - cannot keep fully protruded for 5 sec - cannot fully protrude tongue - cannot protrude tongue beyond lips	- 0 - 1 - 2 - 3 - 4			PDS
Group Finger taps – Right	QS	ENR R3 R2 RET	Motor	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
Group Finger taps - Left	QS	ENR R3 R2 RET	Motor	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

Pronate/supinate-hands - Right	QS	ENR R3 R2 RET	Motor	Motor	prosupr	single choice	- normal - mild slowing and/or irregular - moderate slowing and irregular - severe slowing and irregular - cannot perform	- 0 - 1 - 2 - 3 - 4			PDS
Pronate/supinate-hands – Left	QS	ENR R3 R2 RET	Motor	Motor	prosupl	single choice	- normal - mild slowing and/or irregular - moderate slowing and irregular - severe slowing and irregular - cannot perform	- 0 - 1 - 2 - 3 - 4			PDS
Pronate/supinate-hands – Luria	QS	ENR R3 R2 RET	Motor	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	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
Group Rigidity-arms: Left	QS	ENR R3 R2 RET	Motor	Motor	rigarml	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
Bradykinesia-body	QS	ENR R3	Motor	Motor	brady	single choice	- normal - minimally slow (?normal) - mildly but clearly slow	- 0 - 1 - 2			PDS

		R2 RET					- moderately slow, some hesitation - markedly slow, long delays in initiation	- 3 - 4			
Group Maximal dystonia: Trunk	QS	ENR R3 R2 RET	Motor	Motor	dysttrnk	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal dystonia: RUE	QS	ENR R3 R2 RET	Motor	Motor	dyst rue	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal dystonia: LUE	QS	ENR R3 R2 RET	Motor	Motor	dyst lue	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal dystonia: RLE	QS	ENR R3 R2 RET	Motor	Motor	dyst rle	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal dystonia: LLE	QS	ENR R3	Motor	Motor	dyst lle	single choice	- absent - slight/intermittent	- 0 - 1			PDS

		R2 RET					- mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 2 - 3 - 4			
Group Maximal chorea: Face	QS	ENR R3 R2 RET	Motor	Motor	chorface	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal chorea: BOL	QS	ENR R3 R2 RET	Motor	Motor	chorbol	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal chorea: Trunk	QS	ENR R3 R2 RET	Motor	Motor	chortrnk	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal chorea: RUE	QS	ENR R3 R2 RET	Motor	Motor	chorrue	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal chorea: LUE	QS	ENR R3	Motor	Motor	chorlue	single choice	- absent - slight/intermittent	- 0 - 1			PDS

		R2 RET					- mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 2 - 3 - 4			
Group Maximal chorea: RLE	QS	ENR R3 R2 RET	Motor	Motor	chorle	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Group Maximal chorea: LLE	QS	ENR R3 R2 RET	Motor	Motor	chorlle	single choice	- absent - slight/intermittent - mild/common or moderate/intermittent - moderate/common - marked/prolonged	- 0 - 1 - 2 - 3 - 4			PDS
Gait	QS	ENR R3 R2 RET	Motor	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	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	Motor	Motor	retropls	single choice	- normal - recovers spontaneously - would fall if not caught	- 0 - 1 - 2			PDS

		R2 RET				- tends to fall spontaneously - cannot stand	- 3 - 4			
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Section Diagnostic Confidence

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Diagnostic confidence level (DCL)	QS	ENR R3 R2 RET	Motor	Motor	diagconf	single choice	<ul style="list-style-type: none"> - normal (no abnormalities) - non-specific motor abnormalities (less than 50 % confidence) - motor abnormalities that may be signs of HD (50 - 89 % confidence) - motor abnormalities that are likely signs of HD (90 - 98 % confidence) - motor abnormalities that are unequivocal signs of HD (≥ 99 % confidence) 	- 0 - 1 - 2 - 3 - 4			PDS
Reason for discrepancy between DCL/Total Motor Score	QS	ENR	Motor	Motor	dclrfi	text					Not available

8.2 Form “UHDRS Total Funtional Capacity (TFC)”

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

Section General

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
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Assessment date	QS	ENR	TFC	TFC	qsdtc	date					Not available
Assessment day	QS	ENR	TFC	TFC	qsdyc	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Rater code	QS	ENR	TFC	TFC	raterid	number					Not available
Functional score	QS	ENR R3 R2 RET	TFC	TFC	tfcscore	number					PDS

Section Functional Capacity

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Occupation	QS	ENR R3 R2 RET	TFC	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	TFC	finances	single choice	- unable - major assistance - slight assistance - normal	- 0 - 1 - 2 - 3			PDS
Domestic chores	QS	ENR R3 R2 RET	TFC	TFC	chores	single choice	- unable - impaired - normal	- 0 - 1 - 2			PDS
ADL	QS	ENR R3 R2 RET	TFC	TFC	adl	single choice	- total care - gross tasks only - minimal impairment - normal	- 0 - 1 - 2 - 3			PDS
Care level	QS		TFC	TFC	carelevl		- full time skilled nursing	- 0			PDS

		ENR R3 R2 RET				single choice	- home or chronic care - home	- 1 - 2			
Was the information obtained from	QS	ENR	TFC	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	Function	Function	qsdtc	date					Not available
Assessment day	QS	ENR	Function	Function	qsdyc	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Rater code	QS	ENR	Function	Function	raterid	number					Not available
Functional assessment score	QS	ENR R3 R2 RET	Function	Function	fascore	number				Calculated if all items are available.	PDS
Functional score incomplete	QS	ENR R3 R2 RET	Function	Function	fiscore	number				Calculated, if at least one of the items is available.	PDS
Independence scale in %	QS	ENR	Function	Function	indpsclp	number					Internal

Section Functional Assessment

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Could subject engage in gainful employment in his/her accustomed work?	QS	ENR R3 R2 RET	Function	Function	emplusl	boolean	- yes - no	- 1 - 0			PDS
Could subject engage in any kind of gainful employment?	QS	ENR R3 R2 RET	Function	Function	emplany	boolean	- yes - no	- 1 - 0			PDS
Could subject engage in any kind of volunteer or non-gainful work?	QS	ENR R3 R2 RET	Function	Function	volunt	boolean	- yes - no	- 1 - 0			PDS
Could subject manage his/her finances (monthly) without any help?	QS	ENR R3 R2 RET	Function	Function	fafinan	boolean	- yes - no	- 1 - 0			PDS
Could subject shop for groceries without help?	QS	ENR R3 R2 RET	Function	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	Function	cash	boolean	- yes - no	- 1 - 0			PDS
Could subject supervise children without help?	QS	ENR R3 R2 RET	Function	Function	supchild	boolean	- yes - no	- 1 - 0			PDS
Could subject operate an automobile safely and independently?	QS	ENR R3 R2 RET	Function	Function	drive	boolean	- yes - no	- 1 - 0			PDS

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

Could subject walk to places in his/her neighbourhood without help?	QS	ENR R3 R2 RET	Function	Function	walknbr	boolean	- yes - no	- 1 - 0			PDS
Could subject walk without falling?	QS	ENR R3 R2 RET	Function	Function	walkfall	boolean	- yes - no	- 1 - 0			PDS
Could subject walk without help?	QS	ENR R3 R2 RET	Function	Function	walkhelp	boolean	- yes - no	- 1 - 0			PDS
Could subject comb hair without help?	QS	ENR R3 R2 RET	Function	Function	comb	boolean	- yes - no	- 1 - 0			PDS
Could subject transfer between chairs without help?	QS	ENR R3 R2 RET	Function	Function	trnchair	boolean	- yes - no	- 1 - 0			PDS
Could subject get in and out of bed without help?	QS	ENR R3 R2 RET	Function	Function	bed	boolean	- yes - no	- 1 - 0			PDS
Could subject use toilet/commode without help?	QS	ENR R3 R2 RET	Function	Function	toilet	boolean	- yes - no	- 1 - 0			PDS
Could subject's care still be provided at home?	QS	ENR R3 R2 RET	Function	Function	carehome	boolean	- yes - no	- 1 - 0			PDS
Was the functional assessment information obtained from	QS	ENR	Function	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	Function	indep scl	single choice	- no special care needed	- 100			PDS
							-	- 95			
							- no physical care needed if difficult tasks are avoided	- 90			
							-	- 85			
							- pre-disease level of employment changes or ends; cannot perform household chores to pre-disease level, may need help with finances	- 80			
							-	- 75			
							- 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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	Cognitive Assessment	Cognitive	qsdtc	Date					Not available
Assessment day	QS	ENR	Cognitive Assessment	Cognitive	qsdyc	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Language of paper form (PBF)	QS	ENR	Cognitive Assessment	Cognitive	langpbf	single choice	- U.S. English - Brazilian Portuguese - Spanish (LA) - Canadian French - French - Czech - Danish - German - Spanish - Italian - Dutch - Norwegian - Polish - Portuguese - Russian - Finnish - Swedish	- 1 - 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	Cognitive	raterid	Number					Not available

Section Specifics

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Did the participant complete the assessment in their native language and with normal or corrected-to-normal vision and hearing?	SUPPQS	ENR R3 RET	Cognitive Assessment	Cognitive	gen1	boolean	- yes - no	- 1 - 0			PDS
Did the participant complete the assessment in their native language?	SUPPQS	ENR R3 RET	Cognitive Assessment	Cognitive	gen2	Boolean	- yes - no	- 1 - 0			PDS
At what age did the participant learn the language used?	SUPPQS	ENR R3 RET	Cognitive Assessment	Cognitive	gen3	Number			years		PDS
Did the participant have normal/ corrected-to-normal hearing and vision?	SUPPQS	ENR R3 RET	Cognitive Assessment	Cognitive	gen4	Boolean	- yes - no	- 1 - 0			PDS
Was vision uncorrected (e.g. no glasses during visit)?	SUPPQS	ENR R3 RET	Cognitive Assessment	Cognitive	gen5	Boolean	- yes - no	- 1 - 0			PDS
Was hearing uncorrected (e.g. no hearing aid worn)?	SUPPQS	ENR R3 RET	Cognitive Assessment	Cognitive	gen6	Boolean	- yes - no	- 1 - 0			PDS

Section Core Cognitive Assessment

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Symbol Digit Modality Test completed	QS	ENR R3 RET	SDMT	Cognitive	sdmt	Boolean	- yes - no	- 1 - 0			PDS
Total correct	QS	ENR R2 R3 RET	SDMT	Cognitive	sdmt1	Number					PDS

Total errors	QS	ENR R3 RET	SDMT	Cognitive	sdmt2	Number					PDS
Reason	QS	ENR	SDMT	Cognitive	sdmtnd	single choice	- cognitive impairment - motor impairment - mental state - physical health - visual impairment - language barrier - refusal - study conflict - scheduling issue - site error - not administered because of participation in another study	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - 11			PDS
Verbal Fluency Test (Category) completed	QS	ENR R3 RET	Categorical Verbal Fluency	Cognitive	verfct	Boolean	- yes - no	- 1 - 0			PDS
Category	QS	ENR R3 RET	Categorical Verbal Fluency	Cognitive	verfctd	single choice	- animals - other	- 1 - 2			PDS
Please specify	SUPPQS	ENR	Categorical Verbal Fluency	Cognitive	verfctds	Text					Not available
Total correct 0- 15 seconds	QS	ENR	Categorical Verbal Fluency	Cognitive	verfct1	Number					Available upon SRC approval
Total correct 16-30 seconds	QS	ENR	Categorical Verbal Fluency	Cognitive	verfct2	Number					Available upon SRC approval

Total correct 31-45 seconds	QS	ENR	Categorical Verbal Fluency	Cognitive	verfct3	Number					Available upon SRC approval
Total correct 46-60 seconds	QS	ENR	Categorical Verbal Fluency	Cognitive	verfct4	Number					Available upon SRC approval
Total correct (1 min)	QS	ENR R3 RET	Categorical Verbal Fluency	Cognitive	verfct5	Number					PDS
Total intrusion errors	QS	ENR R3 RET	Categorical Verbal Fluency	Cognitive	verfct6	Number					PDS
Total perseverative errors	QS	ENR R3 RET	Categorical Verbal Fluency	Cognitive	verfct7	Number					PDS
Reason	QS	ENR	Categorical Verbal Fluency	Cognitive	verfctnd	single choice	- cognitive impairment - motor impairment - mental state - physical health - visual impairment - language barrier - refusal - study conflict - scheduling issue - site error - not administered because of participation in another study	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - 11			PDS
Stroop Colour Naming Test completed	QS	ENR R3 RET	Stroop Color Naming	Cognitive	scnt	Boolean	- yes - no	- 1 - 0			PDS

Total correct	QS	ENR R2 R3 RET	Stroop Color Naming	Cognitive	scnt1	Number					PDS
Total errors	QS	ENR R3 RET	Stroop Color Naming	Cognitive	scnt2	Number					PDS
Total self-corrected errors	QS	ENR R3 RET	Stroop Color Naming	Cognitive	scnt3	Number					PDS
Reason	QS	ENR	Stroop Color Naming	Cognitive	scntnd	single choice	- cognitive impairment - motor impairment - mental state - physical health - visual impairment - language barrier - refusal - study conflict - scheduling issue - site error - not administered because of participation in another study	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - 11			PDS
Stroop Word Reading Test completed	QS	ENR R3 RET	Stroop Word Reading	Cognitive	swrt	Boolean	- yes - no	- 1 - 0			PDS
Total correct	QS	ENR R2 R3 RET	Stroop Word Reading	Cognitive	swrt1	Number					PDS

Total errors	QS	ENR R3 RET	Stroop Word Reading	Cognitive	swrt2	Number					PDS
Total self-corrected errors	QS	ENR R3 RET	Stroop Word Reading	Cognitive	swrt3	Number					PDS
Reason	QS	ENR	Stroop Word Reading	Cognitive	swrtnd	single choice	- cognitive impairment - motor impairment - mental state - physical health - visual impairment - language barrier - refusal - study conflict - scheduling issue - site error - not administered because of participation in another study	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - 11			PDS

Section Extended Cognitive Assessments

Label	Domain	Study	Cat	Function	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Stroop Interference Test completed	QS	ENR R3 RET	Stroop Interference	Cognitive	sit	boolean	- yes - no	- 1 - 0			PDS
Total correct	QS	ENR R2 R3 RET	Stroop Interference	Cognitive	sit1	number					PDS

Total errors	QS	ENR R3 RET	Stroop Interference	Cognitive	sit2	number					PDS
Total self- corrected errors	QS	ENR R3 RET	Stroop Interference	Cognitive	sit3	number					PDS
Trailmaking Test completed	QS	ENR R3 R2	Trail Making A&B	Cognitive	trl	boolean	- yes - no	- 1 - 0			PDS
Part A: time to complete	QS	ENR R3 R2	Trail Making A&B	Cognitive	trla1	number			sec		PDS
Part A: total correct	QS	ENR R3 R2	Trail Making A&B	Cognitive	trla2	number					PDS
Part A: total errors	QS	ENR R3 R2	Trail Making A&B	Cognitive	trla3	Number					PDS
Part B: time to complete	QS	ENR R3 R2	Trail Making A&B	Cognitive	trlb1	Number			sec		PDS
Part B: total correct	QS	ENR R3 R2	Trail Making A&B	Cognitive	trlb2	Number					PDS
Part B: total errors	QS	ENR R3 R2	Trail Making A&B	Cognitive	trlb3	Number					PDS
Verbal Fluency Test (Letters) completed	QS	ENR R3 RET	Letter Verbal Fluency	Cognitive	verflt	Boolean	- yes - no	- 1 - 0			PDS

Total correct 0-15 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt11	number					Available upon SRC approval
Total correct 16-30 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt12	Number					Available upon SRC approval
Total correct 31-45 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt13	Number					Available upon SRC approval
Total correct 46-60 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt14	Number					Available upon SRC approval
Total correct 0-60 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt15	Number					Available upon SRC approval
Total correct 0-15 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt21	Number					Available upon SRC approval
Total correct 16-30 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt22	Number					Available upon SRC approval
Total correct 31-45 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt23	Number					Available upon SRC approval
Total correct 46-60 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt24	Number					Available upon SRC approval
Total correct 0-60 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt25	number					Available upon SRC approval

Total correct 0-15 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt31	Number					Available upon SRC approval
Total correct 16-30 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt32	Number					Available upon SRC approval
Total correct 31-45 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt33	Number					Available upon SRC approval
Total correct 46-60 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt34	Number					Available upon SRC approval
Total correct 0-60 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt35	Number					Available upon SRC approval
Total correct 0-15 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt01	Number					Available upon SRC approval
Total correct 16-30 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt02	Number					Available upon SRC approval
Total correct 31-45 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt03	number					Available upon SRC approval
Total correct 46-60 seconds	QS	ENR	Letter Verbal Fluency	Cognitive	verflt04	Number					Available upon SRC approval
Total correct (3 min)	QS	ENR R2 R3 RET	Letter Verbal Fluency	Cognitive	verflt05	Number					PDS
Total intrusion errors	QS	ENR R3 RET	Letter Verbal Fluency	Cognitive	verflt06	Number					PDS

Total perseverative errors	QS	ENR R3 RET	Letter Verbal Fluency	Cognitive	verflt07	Number					PDS
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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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	MMSE	MMSE	qsdtc	date					Not available
Assessment day	QS	ENR	MMSE	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	MMSE	langpbf	single choice	- U.S. English - Spanish (LA) - Brazilian Portuguese - Canadian French - French - Czech - Danish - German - Spanish - Italian - Dutch - Norwegian - Polish - Portuguese - Russian - Finnish	- 1 - 2 - 3 - 6 - 7 - 8 - 9 - 10 - 11 - 12 - 13 - 14 - 15 - 16 - 17 - 18			Available upon SRC approval

							- Swedish	- 19			
Rater code	QS	ENR	MMSE	MMSE	raterid	number					Not available
MMSE score	QS	ENR RET	MMSE	MMSE	mmsetotal	number					PDS

Section Mini Mental State Exam

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Orientation to time - Year?	QS	ENR	MMSE	MMSE	mmse011	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Orientation to time - Season?	QS	ENR	MMSE	MMSE	mmse012	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Orientation to time - Month of the year?	QS	ENR	MMSE	MMSE	mmse013	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Orientation to time - Day of the week?	QS	ENR	MMSE	MMSE	mmse014	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Orientation to time - Date?	QS	ENR	MMSE	MMSE	mmse015	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Orientation to place - State (province)?	QS	ENR	MMSE	MMSE	mmse021	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Orientation to place - County (or city/town)?	QS	ENR	MMSE	MMSE	mmse022	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Orientation to place - City/town (or part of city/neighborhood)?	QS	ENR	MMSE	MMSE	mmse023	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
	QS	ENR	MMSE	MMSE	mmse024		- incorrect	- 0			

Orientation to place - Building (name or type)?						single choice	- correct	- 1			Available upon SRC approval
Orientation to place - Floor of the building (room number or address)?	QS	ENR	MMSE	MMSE	mmse025	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Registration - Word 1	QS	ENR	MMSE	MMSE	mmse031	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Registration - Word 2	QS	ENR	MMSE	MMSE	mmse032	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Registration - Word 3	QS	ENR	MMSE	MMSE	mmse033	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Attention and calculation (Serial 7s) - [Step 1]	QS	ENR	MMSE	MMSE	mmse041	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Attention and calculation (Serial 7s) - [Step 2]	QS	ENR	MMSE	MMSE	mmse042	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Attention and calculation (Serial 7s) - [Step 3]	QS	ENR	MMSE	MMSE	mmse043	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Attention and calculation (Serial 7s) - [Step 4]	QS	ENR	MMSE	MMSE	mmse044	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Group Attention and calculation (Serial 7s) - [Step 5]	QS	ENR	MMSE	MMSE	mmse045	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Recall - Word 1	QS	ENR	MMSE	MMSE	mmse051	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Recall - Word 2	QS	ENR	MMSE	MMSE	mmse052		- incorrect	- 0			

						single choice	- correct	- 1			Available upon SRC approval
Recall - Word 3	QS	ENR	MMSE	MMSE	mmse053	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Naming 1 [Pencil or pen]	QS	ENR	MMSE	MMSE	mmse061	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Naming 2 [Watch]	QS	ENR	MMSE	MMSE	mmse062	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Repetition - No ifs, ands or buts	QS	ENR	MMSE	MMSE	mmse07	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Comprehension - Take in right hand	QS	ENR	MMSE	MMSE	mmse081	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Comprehension - Fold in half	QS	ENR	MMSE	MMSE	mmse082	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Comprehension - Put on floor (or table)	QS	ENR	MMSE	MMSE	mmse083	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Reading - Close your eyes	QS	ENR	MMSE	MMSE	mmse09	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Writing - Sentence	QS	ENR	MMSE	MMSE	mmse10	single choice	- incorrect - correct	- 0 - 1			Available upon SRC approval
Drawing - Figure	QS	ENR	MMSE	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	Physiotherapy	Physiotherapy	qsdtc	date					Not available
Assessment day	QS	ENR	Physiotherapy	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Timed "Up and Go" performed	QS	ENR	TUG	Physiotherapy	tug	boolean	- yes - no	- 1 - 0			PDS
Total time	QS	ENR	TUG	Physiotherapy	tug1	number			sec		PDS

Section 30 Second Chair Stand Test

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
30 second chair stand test performed	QS	ENR	30sec Chair Stand	Physiotherapy	scst	boolean	- yes - no	- 1 - 0			PDS
Number of times the participant stands in 30 seconds	QS	ENR	30sec Chair Stand	Physiotherapy	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	PBA-s	PBA-s	qsdtc	date					Not available
Assessment day	QS	ENR	PBA-s	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	PBA-s	langpbf	single choice	<ul style="list-style-type: none"> - U.S. English - Brazilian Portuguese - Spanish (LA) - Canadian French - French - Czech - Danish - German - Spanish - Italian - Dutch - Norwegian - Polish - Portuguese - Russian - Finnish - Swedish 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 6 - 7 - 8 - 9 - 10 - 11 - 12 - 13 - 14 - 15 - 16 - 17 - 18 - 19 			Available upon SRC approval
Rater code	QS	ENR	PBA-s	PBA-s	raterid	number					Not available

Domain scores - Depression	QS	ENR R3	PBA-s	PBA-s	depscore	number					PDS
Domain scores - Irritability/aggression	QS	ENR R3	PBA-s	PBA-s	irascore	number					PDS
Domain scores - Psychosis	QS	ENR R3	PBA-s	PBA-s	psyscore	number					PDS
Domain scores - Apathy	QS	ENR R3	PBA-s	PBA-s	aptscore	number					PDS
Domain scores - Executive function	QS	ENR R3	PBA-s	PBA-s	exfscore	number					PDS

Section Problem Behaviours Assessment for HD

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Depressed mood - Severity	QS	ENR R3	PBA-s	PBA-s	pbas1sv	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer) 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Depressed mood - Frequency	QS	ENR R3	PBA-s	PBA-s	pbas1fr	single choice	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Depressed mood - Worst	QS	ENR R3	PBA-s	PBA-s	pbas1wo	single choice	<ul style="list-style-type: none"> - absent - slight, questionable 	<ul style="list-style-type: none"> - 0 - 1 			PDS

							<ul style="list-style-type: none"> - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer) 	<ul style="list-style-type: none"> - 2 - 3 - 4 			
Suicidal ideation - Severity	QS	ENR R3	PBA-s	PBA-s	pbas2sv	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer) 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Suicidal ideation - Frequency	QS	ENR R3	PBA-s	PBA-s	pbas2fr	single choice	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Suicidal ideation - Worst	QS	ENR R3	PBA-s	PBA-s	pbas2wo	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer) 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Anxiety - Severity	QS	ENR R3	PBA-s	PBA-s	pbas3sv	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) 	<ul style="list-style-type: none"> - 0 - 1 - 2 			PDS

							- moderate (symptom causing problem) - severe (almost intolerable for carer)	- 3 - 4			
Anxiety - Frequency	QS	ENR R3	PBA-s	PBA-s	pbas3fr	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
Anxiety - Worst	QS	ENR R3	PBA-s	PBA-s	pbas3wo	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
Irritability - Severity	QS	ENR R3	PBA-s	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
Irritability - Frequency	QS	ENR R3	PBA-s	PBA-s	pbas4fr	single choice	- never/almost never - seldom (less than once/week) - sometimes (up to 4 times a week)	- 0 - 1 - 2			PDS

							<ul style="list-style-type: none"> - frequently (most days/5, 6 or 7 times a week) - daily/almost daily for most (or all) of day 	<ul style="list-style-type: none"> - 3 - 4 			
Irritability - Worst	QS	ENR R3	PBA-s	PBA-s	pbas4wo	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer) 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Angry or aggressive behavior - Severity	QS	ENR R3	PBA-s	PBA-s	pbas5sv	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer) 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Angry or aggressive behavior - Frequency	QS	ENR R3	PBA-s	PBA-s	pbas5fr	single choice	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Angry or aggressive behavior - Worst	QS	ENR R3	PBA-s	PBA-s	pbas5wo	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 			PDS

							- severe (almost intolerable for carer)	- 4			
Lack of initiative (apathy) – Severity	QS	ENR R3	PBA-s	PBA-s	pbas6sv	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
Lack of initiative (apathy) – Frequency	QS	ENR R3	PBA-s	PBA-s	pbas6fr	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
Lack of initiative (apathy) – Worst	QS	ENR R3	PBA-s	PBA-s	pbas6wo	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
Perseverative thinking or behavior - Severity	QS	ENR R3	PBA-s	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
	QS		PBA-s	PBA-s	pbas7fr		- never/almost never	- 0			PDS

Perseverative thinking or behavior - Frequency		ENR R3				single choice	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 			
Perseverative thinking or behavior - Worst	QS	ENR R3	PBA-s	PBA-s	pbas7wo	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer) 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Obsessive-Compulsive Behaviours - Severity	QS	ENR R3	PBA-s	PBA-s	pbas8sv	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer) 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Obsessive-Compulsive Behaviours - Frequency	QS	ENR R3	PBA-s	PBA-s	pbas8fr	single choice	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Obsessive-Compulsive	QS	ENR R3	PBA-s	PBA-s	pbas8wo	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) 	<ul style="list-style-type: none"> - 0 - 1 - 2 			PDS

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

							- severe (almost intolerable for carer)	- 4			
Please specify - Modality of hallucinations - auditory	QS	ENR R3	PBA-s	PBA-s	pbas10sm__1	boolean	- yes	- 1			PDS
Please specify - Modality of hallucinations - visual	QS	ENR R3	PBA-s	PBA-s	pbas10sm__2	boolean	- yes	- 1			PDS
Please specify - Modality of hallucinations - tactile	QS	ENR R3	PBA-s	PBA-s	pbas10sm__3	boolean	- yes	- 1			PDS
Please specify - Modality of hallucinations - olfactory	QS	ENR R3	PBA-s	PBA-s	pbas10sm__4	boolean	- yes	- 1			PDS
Please specify - Modality of hallucinations - gustatory	QS	ENR R3	PBA-s	PBA-s	pbas10sm__5	boolean	- yes	- 1			PDS
Please specify - Frequency	QS	ENR R3	PBA-s	PBA-s	pbas10fr	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
Please specify - Worst	QS	ENR R3	PBA-s	PBA-s	pbas10wo	single choice	- absent - slight, questionable	- 0 - 1			PDS

							<ul style="list-style-type: none"> - mild (present, not a problem) - moderate (symptom causing problem) - severe (almost intolerable for carer) 	<ul style="list-style-type: none"> - 2 - 3 - 4 			
Please specify - Modality of hallucinations - auditory	QS	ENR	PBA-s	PBA-s	pbas10wm__1	boolean	- yes	- 1			PDS
Please specify - Modality of hallucinations - visual	QS	ENR	PBA-s	PBA-s	pbas10wm__2	boolean	- yes	- 1			PDS
Please specify - Modality of hallucinations - tactile	QS	ENR	PBA-s	PBA-s	pbas10wm__3	boolean	- yes	- 1			PDS
Please specify - Modality of hallucinations - olfactory	QS	ENR	PBA-s	PBA-s	pbas10wm__4	boolean	- yes	- 1			PDS
Please specify - Modality of hallucinations - gustatory	QS	ENR	PBA-s	PBA-s	pbas10wm__5	boolean	- yes	- 1			PDS
Disoriented Behaviour - Severity	QS	ENR R3	PBA-s	PBA-s	pbas11sv	single choice	<ul style="list-style-type: none"> - absent - slight, questionable - mild (present, not a problem) - moderate (symptom causing problem) 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 			PDS

							- severe (almost intolerable for carer)	- 4			
Disoriented Behaviour - Frequency	QS	ENR R3	PBA-s	PBA-s	pbas11fr	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
Disoriented Behaviour - Worst	QS	ENR R3	PBA-s	PBA-s	pbas11wo	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

Section Information

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Is informant a relative?	QS	ENR R3	PBA	PBA-s	pbainfo	single choice	- spouse or partner - parent - sibling - child - other relative	- 1 - 2 - 3 - 4 - 5			PDS

							- friend or neighbor - professional care worker - other - no informant - participant came alone	- 6 - 7 - 8 - 9			
Is informant a household member?	QS	ENR R3	PBA	PBA-s	pbahshd	single choice	- household member (i.e. relative or friend who lives with participant) - not a household member but has frequent contact with participant (most days) - not a household member and sees participant less than three or four times a week - staff of residential care home or hospital	- 1 - 2 - 3 - 4			PDS
General comments	CO	ENR	PBA	PBA-s	coval	text					Not available

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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	SF-12	SF-12	qsdtc	date					Not available
Assessment day	QS	ENR	SF-12	SF-12	qsdyc	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	SF-12	langpbf	single choice	<ul style="list-style-type: none"> - U.S. English - Brazilian Portuguese - Spanish (LA North) - Spanish (LA South) - Canadian French - French - Czech - Danish - German - Spanish - Italian - Dutch - Norwegian - Polish - Portuguese - Russian - Finnish - Swedish 	<ul style="list-style-type: none"> - 1 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - 11 - 12 - 13 - 14 - 15 - 16 - 17 - 18 - 19 			Available upon SRC approval
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Section Scoring

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Online scoring	QS	ENR		SF-12	scoring	single choice	<ul style="list-style-type: none"> - pending - succeeded - failed (once) - failed (twice) - error 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			PDS
Physical Functioning (PF)	QS	ENR		SF-12	pf	number					PDS
Role-Physical (RP)	QS	ENR		SF-12	rp	number					PDS
Bodily Pain (BP)	QS	ENR		SF-12	bp	number					PDS
General Health (GH)	QS	ENR		SF-12	gh	number					PDS

Vitality (VT)	QS	ENR		SF-12	vt	number					PDS
Social Functioning (SF)	QS	ENR		SF-12	sf	number					PDS
Role-Emotional (RE)	QS	ENR		SF-12	re	number					PDS
Mental Health (MH)	QS	ENR		SF-12	mh	number					PDS
Physical Component (PCS)	QS	ENR		SF-12	pcs	number					PDS
Mental Component (PCS)	QS	ENR		SF-12	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
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? 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	QS	ENR	SF-12	sf12_4	single choice	- All of the time - Most of the time - Some of the time	- 1 - 2 - 3			Available upon SRC approval

other regular daily activities as a result of your physical health? a) Accomplished less than you would like						- A little of the time - None of the time	- 4 - 5			
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? 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
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)? 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
5. During the past week, how much did pain interfere with your normal work (including both work outside the home and housework)?	QS	ENR	SF-12	sf12_8	single choice	- Not at all - A little bit - Moderately - Quite a bit - Extremely	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
	QS	ENR	SF-12	sf12_9		- All of the time	- 1			

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?					single choice	<ul style="list-style-type: none"> - Most of the time - Some of the time - A little of the time - None of the time 	<ul style="list-style-type: none"> - 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 ... b) Did you have a lot of energy?	QS	ENR	SF-12	sf12_10	single choice	<ul style="list-style-type: none"> - All of the time - Most of the time - Some of the time - A little of the time - None of the time 	<ul style="list-style-type: none"> - 1 - 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 ... c) Have you felt downhearted and depressed?	QS	ENR	SF-12	sf12_11	single choice	<ul style="list-style-type: none"> - All of the time - Most of the time - Some of the time - A little of the time - None of the time 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 - 5 			Available upon SRC approval
7. During the past week, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?	QS	ENR	SF-12	sf12_12	single choice	<ul style="list-style-type: none"> - All of the time - Most of the time - Some of the time - A little of the time - None of the time 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 - 5 			Available upon SRC approval

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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	HADS-SIS	HADS-SIS	qsdtc	date					Not available
Assessment day	QS	ENR	HADS-SIS	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	HADS-SIS	langpbf	single choice	<ul style="list-style-type: none"> - U.S. English - Brazilian Portuguese - Spanish (LA North) - Spanish (LA South) - Canadian French - French - Czech - Danish - German - Spanish - Italian - Dutch - Norwegian - Polish - Portuguese - Russian - Finnish - Swedish 	<ul style="list-style-type: none"> - 1 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - 11 - 12 - 13 - 14 - 15 - 16 - 17 - 18 - 19 			Available upon SRC approval
Anxiety subscore	QS	ENR R3	HADS-SIS	HADS-SIS	anxscore	number					PDS
Depression subscore	QS	ENR R3	HADS-SIS	HADS-SIS	hads_depscore	number					PDS

Irritability subscore	QS	ENR R3	HADS-SIS	HADS-SIS	irrscore	number					PDS
Outward irritability subscore	QS	ENR R3	HADS-SIS	HADS-SIS	outscore	number					PDS
Inward irritability subscore	QS	ENR R3	HADS-SIS	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

I am patient with other people	QS	ENR	SIS	sis2	single choice	- all of the time - most of the time - some of the time - hardly ever	- 0 - 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 - I may not take quite as much care - I take just as much care as ever	- 3 - 2 - 1 - 0			Available upon SRC approval
	QS	ENR	SIS	sis5		- sometimes	- 3			

The thought of hurting myself occurs to me					single choice	- not very often - hardly ever - not at all	- 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	- 3 - 2 - 1			Available upon SRC approval

						- not at all	- 0			
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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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	WPAI-SHP	WPAI-SHP	qsdtc	date					Not available
Assessment day	QS	ENR	WPAI-SHP	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	WPAI-SHP	langpbf	single choice	- U.S. English - Brazilian Portuguese - Spanish (LA) - Canadian French - French - Czech - Danish - German - Spanish - Italian - Dutch - Norwegian - Polish - Portuguese - Russian - Finnish	- 1 - 2 - 3 - 6 - 7 - 8 - 9 - 10 - 11 - 12 - 13 - 14 - 15 - 16 - 17 - 18			Available upon SRC approval

							- Swedish	- 19			
Work time missed due to HD	QS	ENR	WPAI-SHP	WPAI-SHP	wpaiscr1	number			%		PDS
Impairment while working due to HD	QS	ENR	WPAI-SHP	WPAI-SHP	wpaiscr2	number			%		PDS
Overall work impairment due to HD	QS	ENR	WPAI-SHP	WPAI-SHP	wpaiscr3	number			%		PDS
Activity impairment due to HD	QS	ENR	WPAI-SHP	WPAI-SHP	wpaiscr4	number			%		PDS

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

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Are you currently employed (working for pay)?	QS	ENR	WPAI-SHP	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	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	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	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	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	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 prevented me from doing my	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval

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

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

Label	Domain	Studies	Cat	Group	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	C-SSRS BL	sid1	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	C-SSRS BL	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	C-SSRS BL	sid2	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	C-SSRS BL	sid2sc	text					Not available

Section Suicidal Ideation (continued)

Label	Domain	Studies	Cat	Form	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	C-SSRS BL	sid3	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	C-SSRS BL	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	C-SSRS BL	sid4	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	C-SSRS BL	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	C-SSRS BL	sid5	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	C-SSRS BL	sid5sc	text					Not available

Section Intensity of Ideation - Most Severe

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Most Severe Ideation - Type # (1-5)	QS	ENR R3	C-SSRS	C-SSRS BL	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	- 1 - 2 - 3 - 4			PDS

							- Active Suicidal Ideation with Specific Plan and Intent	- 5			
Description of Ideation	SUPPQS	ENR	C-SSRS	C-SSRS BL	int1sc	text					Not available
Group Frequency - How many times have you had these thoughts?	QS	ENR R3	C-SSRS	C-SSRS BL	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	C-SSRS BL	int3	single choice	- Fleeting – few seconds or minutes - Less than 1 hour/some of the time - 1-4 hours/ a lot of time - 4-8 hours/most of day - Many times each day	- 1 - 2 - 3 - 4 - 5			PDS
Group Controllability - Could/can you stop thinking about killing yourself or wanting to die if you want to?	QS	ENR R3	C-SSRS	C-SSRS BL	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	QS	ENR R3	C-SSRS	C-SSRS BL	int5	single choice	- Deterrents definitely stopped you - Deterrents probably stopped you	- 1 - 2			PDS

anything (e.g. family, religion, pain of death) - that stopped you from wanting to die or acting on thoughts of committing suicide?							<ul style="list-style-type: none"> - Uncertain that deterrents stopped you - Deterrents most likely did not stop you from attempting suicide - Deterrents definitely did not stop you - Does not apply; wish to die only 	<ul style="list-style-type: none"> - 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	C-SSRS BL	int6	single choice	<ul style="list-style-type: none"> - Completely to get attention, revenge or a reaction from others - Mostly to get attention, revenge or a reaction from others - Equally to get attention, revenge or a reaction from others - Mostly to end or stop the pain (you couldn't go 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) - Does not apply 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 - 5 - 0 			PDS

Section Suicidal Behavior

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Actual Attempt - Actual attempt	QS	ENR R3	C-SSRS	C-SSRS BL	sbh1	boolean	<ul style="list-style-type: none"> - yes - no 	<ul style="list-style-type: none"> - 1 - 0 			PDS

Group Actual Attempt - Total # of attempts	QS	ENR R3	C-SSRS		sbh1n	number					PDS
Group Actual Attempt - Please describe	SUPPQS	ENR	C-SSRS	C-SSRS BL	sbh1sc	text					Not available
Has subject engaged in Non-Suicidal Self-Injurious Behavior?	QS	ENR R3	C-SSRS	C-SSRS BL	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	C-SSRS BL	sbh3	boolean	- yes - no	- 1 - 0			PDS
Group Interrupted Attempt - Total # of interrupted	QS	ENR R3	C-SSRS	C-SSRS BL	sbh3n	number					PDS
Group Interrupted Attempt - Please describe	SUPPQS	ENR	C-SSRS	C-SSRS BL	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	C-SSRS BL	sbh4	boolean	- yes - no	- 1 - 0			PDS
Group Aborted Attempt - Total # of aborted	QS	ENR R3	C-SSRS	C-SSRS BL	sbh4n	number					PDS
Group Aborted Attempt - Please describe	SUPPQS	ENR	C-SSRS	C-SSRS BL	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	C-SSRS BL	sbh5	boolean	- yes - no	- 1 - 0			PDS
Group Preparatory Acts or Behavior - Please describe	SUPPQS	ENR	C-SSRS	C-SSRS BL	sbh5sc	text					Not available

Group Suicidal Behavior - Suicidal behavior was present during the assessment period?	QS	ENR R3	C-SSRS	C-SSRS BL	sbh6	boolean	- yes - no	- 1 - 0			PDS
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Section Answer for Actual Attempts Only

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Most recent attempt - Date	QS	ENR	C-SSRS	C-SSRS BL	attmpt1	date					Not available
Group Most recent attempt - Day	QS	ENR	C-SSRS	C-SSRS BL	attmpt1dy	number			days	Transformed into days relative to baseline date of Enroll-HD.	PDS
Group Most recent attempt - Actual Group Most recent attempt - Lethality/Medical Damage	QS	ENR R3	C-SSRS	C-SSRS BL	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
Group Most recent attempt - Potential Lethality	QS	ENR R3	C-SSRS	C-SSRS BL	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	C-SSRS BL	attmpt2	date					Not available
Group Most lethal attempt - Day	QS	ENR	C-SSRS	C-SSRS BL	attmpt2dy	number			Days	Transformed into days relative to baseline date of Enroll-HD.	PDS
	QS	ENR	C-SSRS	C-SSRS BL	attmpt21		- No physical damage	- 0			PDS

Group Most lethal attempt - Actual Lethality/Medical Damage		R3				single choice	<ul style="list-style-type: none"> - Minor physical damage - Moderate physical damage - Moderately severe physical damage - Severe physical damage - Death 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 - 5 			
Group Most lethal attempt - Potential Lethality	QS	ENR R3	C-SSRS		attmpt22	single choice	<ul style="list-style-type: none"> - not likely to result in injury - likely to result in injury - likely to result in death 	<ul style="list-style-type: none"> - 0 - 1 - 2 			PDS
Group Initial/First attempt - Date	QS	ENR	C-SSRS	C-SSRS BL	attmpt3	date					Not available
Group Initial/First attempt - Day	QS	ENR	C-SSRS	C-SSRS BL	attmpt3dy	number			days	Transformed into days relative to baseline date of Enroll-HD.	PDS
Group Initial/First attempt - Actual Lethality/Medical Damage	QS	ENR R3	C-SSRS	C-SSRS BL	attmpt31	single choice	<ul style="list-style-type: none"> - No physical damage - Minor physical damage - Moderate physical damage - Moderately severe physical damage - Severe physical damage - Death 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 - 5 			PDS
Group Initial/First attempt - Potential Lethality	QS	ENR R3	C-SSRS	C-SSRS BL	attmpt32	single choice	<ul style="list-style-type: none"> - not likely to result in injury - likely to result in injury - likely to result in death 	<ul style="list-style-type: none"> - 0 - 1 - 2 			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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	C-SSRS	C-SSRS FUP	qsdtc	date					Not available
Assessment day	QS	ENR	C-SSRS	C-SSRS FUP	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Rater code	QS	ENR	C-SSRS	C-SSRS FUP	raterid	number					Not available

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

Label	Domain	Studies	Cat	Form	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	C-SSRS FUP	sid1	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	C-SSRS FUP	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	C-SSRS FUP	sid2	boolean	- yes - no	- 1 - 0			PDS
Please describe	SUPPQS	ENR	C-SSRS	C-SSRS FUP	sid2sc	text					Not available

Section Suicidal Ideation (continued)

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
	QS	ENR	C-SSRS	C-SSRS FUP	sid3	boolean	- yes	- 1			PDS

Group 3. Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act - Have you been thinking about how you might do this?		R3					- no	- 0			
Group 3. Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act - Please describe	SUPPQS	ENR	C-SSRS	C-SSRS FUP	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	C-SSRS FUP	sid4	boolean	- yes - no	- 1 - 0			PDS
Group 4. Active Suicidal Ideation with Some Intent to Act, without Specific Plan. Please describe	SUPPQS	ENR	C-SSRS	C-SSRS FUP	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	C-SSRS FUP	sid5	boolean	- yes - no	- 1 - 0			PDS
Group 5. Active Suicidal Ideation with Specific Plan and Intent. Please describe	SUPPQS	ENR	C-SSRS	C-SSRS FUP	sid5sc	text					Not available

Section Intensity of Ideation - Most Severe

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Most Severe Ideation - Type # (1-5)	QS	ENR R3	C-SSRS	C-SSRS FUP	int1	single choice	- Wish to be dead - Non-Specific Active Suicidal Thoughts	- 1 - 2			PDS

							<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 3 - 4 - 5 			
Group Most Severe Ideation - Description of Ideation	SUPPQS	ENR	C-SSRS	C-SSRS FUP	int1sc	text					Not available
Group Frequency - How many times have you had these thoughts?	QS	ENR R3	C-SSRS	C-SSRS FUP	int2	single choice	<ul style="list-style-type: none"> - Less than once a week - Once a week - 2-5 times a week - Daily or almost daily - Many times each day 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 - 5 			PDS
Group Duration - When you have the thoughts, how long do they last?	QS	ENR R3	C-SSRS	C-SSRS FUP	int3	single choice	<ul style="list-style-type: none"> - Fleeting – few seconds or minutes - Less than 1 hour/some of the time - 1-4 hours/ a lot of time - 4-8 hours/most of day - Many times each day 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 - 5 			PDS
Group Controllability - Could/can you stop thinking about killing yourself or wanting to die if you want to?	QS	ENR R3	C-SSRS	C-SSRS FUP	int4	single choice	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 - 5 - 0 			PDS

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	C-SSRS FUP	int5	single choice	<ul style="list-style-type: none"> - Deterrents definitely stopped you - Deterrents probably stopped you - Uncertain that deterrents stopped you - Deterrents most likely did not stop you from attempting suicide - Deterrents definitely did not stop you - Does not apply; wish to die only 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 - 5 - 0 			PDS
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	C-SSRS FUP	int6	single choice	<ul style="list-style-type: none"> - Completely to get attention, revenge or a reaction from others - Mostly to get attention, revenge or a reaction from others - Equally to get attention, revenge or a reaction from others - Mostly to end or stop the pain (you couldn't go on living with the pain or hwo you were feeling) - Completely to end or stop the pain (you couldn't go on living with the pain or hwo you were feeling) - Does not apply 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 4 - 5 - 0 			PDS

Section Suicidal Behavior

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Actual Attempt - Actual attempt	QS	ENR R3	C-SSRS	C-SSRS FUP	sbh1	boolean	- yes - no	- 1 - 0			PDS
Actual Attempt - Total # of attempts	QS	ENR R3	C-SSRS	C-SSRS FUP	sbh1n	number					PDS
Actual Attempt - Please describe	SUPPQS	ENR	C-SSRS	C-SSRS FUP	sbh1sc	text					Not available
Has subject engaged in Non-Suicidal Self-Injurious Behavior?	QS	ENR R3	C-SSRS	C-SSRS FUP	sbh2	boolean	- yes - no	- 1 - 0			PDS
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	C-SSRS FUP	sbh3	boolean	- yes - no	- 1 - 0			PDS
Interrupted Attempt - Total # of interrupted	QS	ENR R3	C-SSRS	C-SSRS FUP	sbh3n	number					PDS
Interrupted Attempt - Please describe	SUPPQS	ENR	C-SSRS	C-SSRS FUP	sbh3sc	text					Not available
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	C-SSRS FUP	sbh4	boolean	- yes - no	- 1 - 0			PDS
Aborted Attempt - Total # of aborted	QS	ENR R3	C-SSRS	C-SSRS FUP	sbh4n	number					PDS
Aborted Attempt - Please describe	SUPPQS	ENR	C-SSRS	C-SSRS FUP	sbh4sc	text					Not available
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	QS	ENR	C-SSRS	C-SSRS FUP	sbh5	boolean	- yes	- 1			PDS
		R3					- no	- 0			

valuable away or writing a suicide note)?											
Preparatory Acts or Behavior - Please describe	SUPPQS	ENR	C-SSRS	C-SSRS FUP	sbh5sc	text					Not available
Group Suicidal Behavior - Suicidal behavior was present during the assessment period?	QS	ENR R3	C-SSRS	C-SSRS FUP	sbh6	boolean	- yes - no	- 1 - 0			PDS
Completed Suicide was present during the assessment period	QS	ENR R3	C-SSRS	C-SSRS FUP	sbh7	boolean	- yes - no	- 1 - 0			PDS

Section Answer for Actual Attempts Only

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Group Most recent attempt - Date	QS	ENR	C-SSRS	C-SSRS FUP	atmpt1	date					Not available
Group Most recent attempt - Day	QS	ENR	C-SSRS	C-SSRS FUP	atmpt1dy	number			days	Transformed into days relative to baseline date of Enroll-HD.	PDS
Group Most recent attempt - Actual Group Most recent attempt - Lethality/Medical Damage	QS	ENR	C-SSRS	C-SSRS FUP	atmpt11	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
Group Most recent attempt - Potential Lethality	QS	ENR	C-SSRS	C-SSRS FUP	atmpt12	single choice	- not likely to result in injury - likely to result in injury	- 0 - 1			PDS

							- likely to result in death	- 2			
Group Most lethal attempt - Date	QS	ENR	C-SSRS	C-SSRS FUP	atmpt2	date					Not available
Group Most lethal attempt - Day	QS	ENR	C-SSRS	C-SSRS FUP	atmpt2dy	number			Days	Transformed into days relative to baseline date of Enroll-HD.	PDS
Group Most lethal attempt - Actual Lethality/Medical Damage	QS	ENR R3	C-SSRS	C-SSRS FUP	atmpt21	single choice	<ul style="list-style-type: none"> - No physical damage - Minor physical damage - Moderate physical damage - Moderately severe physical damage - Severe physical damage - Death 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 - 5 			PDS
Group Most lethal attempt - Potential Lethality	QS	ENR R3	C-SSRS	C-SSRS FUP	atmpt22	single choice	<ul style="list-style-type: none"> - not likely to result in injury - likely to result in injury - likely to result in death 	<ul style="list-style-type: none"> - 0 - 1 - 2 			PDS
Group Initial/First attempt - Date	QS	ENR	C-SSRS	C-SSRS FUP	atmpt3	date					Not available
Group Initial/First attempt - Day	QS	ENR	C-SSRS	C-SSRS FUP	atmpt3dy	number					PDS
Group Initial/First attempt - Actual Lethality/Medical Damage	QS	ENR R3	C-SSRS	C-SSRS FUP	atmpt31	single choice	<ul style="list-style-type: none"> - No physical damage - Minor physical damage - Moderate physical damage 	<ul style="list-style-type: none"> - 0 - 1 - 2 			PDS

							- Moderately severe physical damage - Severe physical damage - Death	- 3 - 4 - 5			
Group Initial/First attempt - Potential Lethality	QS	ENR R3	C-SSRS	C-SSRS FUP	attmpt32	single choice	- not likely to result in injury - likely to result in injury - likely to result in death	- 0 - 1 - 2			PDS

8.13 Form “Missed Visit”

This form is part of the Phone Contact visit.

Section Documentation of Missed Follow-Up

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date info obtained		ENR		Missed visit	mvdtc	date					Not available
Day info obtained		ENR		Missed visit	mvdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Source of information		ENR		Missed visit	mvsrcc	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		Missed visit	mvrns	single choice	<ul style="list-style-type: none"> - missed visit due to participation in other studies - participant alive, unable to attend FUP, open to future FUPs - participant alive, objects to further FUP visits, open to further phone contacts - participant alive, objects to further FUP visits and to further phone contacts - participant alive, lost to FUP - participant dead - status unclear 	-0 - 1 - 2 - 3 - 4 - 5 - 6			PDS
Group If participant is alive - Level of care required		ENR		Missed visit	crvl	single choice	<ul style="list-style-type: none"> - The participant does not require any help or help for basic activities of daily living (un/dressing, washing/bathing, getting up/going to bed). - The participant requires some help to manage basic activities of daily living (typically < 4 h support per day), but no full-time supervision. - The participant requires extensive help to manage basic activities of daily living (typically ≥ 4 h support per day), and full-time supervision with additional help as required. 	- 0 - 1 - 2			PDS
Group If participant is alive - Date since full-time dependency		ENR		Missed visit	dpdte	date					Not available
Group If participant is alive - Days since full-		ENR		Missed visit	dpdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	PDS

time dependency											
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9 Data specific for “Registry”

9.1 Form “Hopkins Verbal Learning Test-R”

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Hopkins Verbal Learning TestR completed (optional)	QS	R2 R3	HVLT	HVLT	hvltd	boolean	- yes - no	- 1 - 0			PDS
Used form	QS	R2 R3	HVLT	HVLT	hvltd	single choice	- form 1 - form 2 - form 3	- 1 - 2 - 3			PDS
Trial 1: correct	QS	R2 R3	HVLT	HVLT	hvltd11	number					PDS
Trial 1: repetition (FR)	QS	R2 R3	HVLT	HVLT	hvltd12	number					Available upon SRC approval
Trial 1: intrusion (FR)	QS	R2 R3	HVLT	HVLT	hvltd13	number					Available upon SRC approval
Trial 2: correct	QS	R2 R3	HVLT	HVLT	hvltd21	number					PDS
Trial 2: repetition (FR)	QS	R2 R3	HVLT	HVLT	hvltd22	number					Available upon SRC approval
Trial 2: intrusion (FR)	QS	R2 R3	HVLT	HVLT	hvltd23	number					Available upon SRC approval
Trial 3: correct	QS	R2 R3	HVLT	HVLT	hvltd31	number					PDS
Trial 3: repetition (FR)	QS	R2 R3	HVLT	HVLT	hvltd32	number					Available upon SRC approval

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

9.2 Form “Dementia Rating Scale 2”

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Dementia Rating Scale2 completed (optional)	QS	R2 R3	Mattis DRS	Mattis DRS	mdrs	boolean	- Yes - No	1 0			PDS
Attention	QS	R2 R3	Mattis DRS	Mattis DRS	mdrs1	number					PDS
Initiation / perseveration	QS	R2 R3	Mattis DRS	Mattis DRS	mdrs2	number					PDS
Construction	QS	R2 R3	Mattis DRS	Mattis DRS	mdrs3	number					PDS

Conceptualization	QS	R2 R3	Mattis DRS	Mattis DRS	mdrs4	number					PDS
Memory	QS	R2 R3	Mattis DRS	Mattis DRS	mdrs5	number					PDS

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

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
SF36 score	QS	R2		36v1	sfscore_v1	number					PDS
In general, would you say your health is	QS	R2		36v1	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 would you rate your health in general now	QS	R2		36v1	sf2	single choice	- much better - somewhat better - about the same - somewhat worse - much worse	- 5 - 4 - 3 - 2 - 1			Available upon SRC approval
During the past 4 weeks to what extent has your physical health or emotional problems interfered with family, friends, neighbours or groups	QS	R2		36v1	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		36v1	sf4	single choice	- none - very mild - mild - moderate	- 6 - 5 - 4 - 3			Available upon SRC approval

							- severe - very severe	- 2 - 1			
During the past 4 weeks how much did pain interfere with your normal work	QS	R2		36v1	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 much of the time has your physical health or emotional problems interfered with your social activities like visiting friends, relatives, etc	QS	R2		36v1	sf6	single choice	- all of the time - most of the time - sometimes - a little of the time - none of the time	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Group “Does your health now limit you in these activities”: Vigorous activities, such as running, lifting heavy object, participating in strenuous sports	QS	R2		36v1	sf7	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Group “Does your health now limit you in these activities”: Moderate activities, such as moving a table, pushing a vacuum cleaner,	QS	R2		36v1	sf8	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval

bowling or playing golf											
Group “Does your health now limit you in these activities”: Lifting and carrying groceries	QS	R2		36v1	sf9	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Group “Does your health now limit you in these activities”: Climbing several flights of stairs	QS	R2		36v1	sf10	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Group “Does your health now limit you in these activities”: Climbing one flight of stairs	QS	R2		36v1	sf11	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Group “Does your health now limit you in these activities”: Bending, kneeling or stooping	QS	R2		36v1	sf12	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Group “Does your health now limit you in these activities”: Walking more than a mile	QS	R2		36v1	sf13	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Group “Does your health now limit you in these activities”: Walking several blocks	QS	R2		36v1	sf14	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval

Group “Does your health now limit you in these activities”: Walking one block	QS	R2		36v1	sf15	single choice	- yes, a lot - yes, a little - not at all	- 1 - 2 - 3			Available upon SRC approval
Group “Does your health now limit you in these activities”: Bathing or dressing yourself	QS	R2		36v1	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		36v1	sf17	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 your physical health”: Accomplished less than you would like	QS	R2		36v1	sf18	boolean	- yes - no	- 0 - 1			Available upon SRC approval
	QS	R2		36v1	sf19	boolean	- yes	- 0			

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”: Were limited in the kind of work or other activities							- no	- 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 your physical health”: Had difficulty performing the work or other activities	QS	R2		36v1	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	QS	R2		36v1	sf21	boolean	- yes - no	- 0 - 1			Available upon SRC approval

you spent on work or other activities											
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”: Accomplished less than you would like	QS	R2		36v1	sf22	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”: Didn't do work or other activities as carefully as usual	QS	R2		36v1	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		36v1	sf24	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

Group “How did you feel during the past 4 weeks”: Have you been a very nervous person?	QS	R2		36v1	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
Group “How did you feel during the past 4 weeks”: Have you felt so down in the dumps that nothing could cheer you up?	QS	R2		36v1	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
Group “How did you feel during the past 4 weeks”: Have you felt calm and peaceful?	QS	R2		36v1	sf27	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
Group “How did you feel during the past 4 weeks”: Did you have a lot of energy?	QS	R2		36v1	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
Group “How did you feel during the past 4 weeks”: Have you felt downhearted and low?	QS	R2		36v1	sf29	single choice	- all of the time - most of the time - a good bit of the time - some of the time	- 1 - 2 - 3 - 4			Available upon SRC approval

							- a little of the time - none of the time	- 5 - 6			
Group “How did you feel during the past 4 weeks”: Did you feel worn out?	QS	R2		36v1	sf30	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
Group “How did you feel during the past 4 weeks”: Have you been a happy person?	QS	R2		36v1	sf31	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
Group “How did you feel during the past 4 weeks”: Did you feel tired?	QS	R2		36v1	sf32	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
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		36v1	sf33	single choice	- definitely true - mostly true - don't know - mostly false - definitely false	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Group “How true or false is each of the following statements	QS	R2		36v1	sf34	single choice	- definitely true - mostly true - don't know	- 5 - 4 - 3			Available upon SRC approval

for you?": I am as healthy as anybody I know							- mostly false - definitely false	- 2 - 1			
Group "How true or false is each of the following statements for you?": I expect my health to get worse	QS	R2		36v1	sf35	single choice	- definitely true - mostly true - don't know - mostly false - definitely false	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Group "How true or false is each of the following statements for you?": My health is excellent	QS	R2		36v1	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
1. In general, would you say your health is?	QS	R3		36v2	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		36v2	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	- 1 - 2 - 3 - 4			Available upon SRC approval

							- much worse now than one year ago	- 5			
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		36v2	pf01	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			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? - Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	QS	R3		36v2	pf02	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			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? - Lifting or carrying groceries	QS	R3		36v2	pf03	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			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? - Climbing several flights of stairs	QS	R3		36v2	pf04	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			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? - Climbing one flight of stairs	QS	R3		36v2	pf05	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			Available upon SRC approval
Group 3. The following questions are about activities you might do during a typical day. Does your health now limit	QS	R3		36v2	pf06	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3			Available upon SRC approval

you in these activities? If so, how much? - Bending, kneeling or stooping										
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? - Walking more than a mile (approx. 1.5 kilometres)	QS	R3		36v2	pf07	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3		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? - Walking several hundred yards (metres)	QS	R3		36v2	pf08	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3		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? - Walking one hundred yards (metres)	QS	R3		36v2	pf09	single choice	- yes, limited a lot - yes, limited a little - no, not limited at all	- 1 - 2 - 3		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? - Bathing or dressing yourself	QS	R3		36v2	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		36v2	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
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	QS	R3		36v2	rp02	single choice	- all of the time - most of the time - some of the time - a little of the time	- 1 - 2 - 3 - 4		Available upon SRC approval

result of your physical health? - Accomplished less than you would like							- none of the time	- 5			
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? - Were limited in the kind of work or other activities	QS	R3		36v2	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
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? - Had difficulty performing the work or other activities (for example, it took extra effort)	QS	R3		36v2	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 work or other activities	QS	R3		36v2	re01	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)? - Accomplished less than you would like	QS	R3		36v2	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
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	QS	R3		36v2	re03	single choice	- all of the time - most of the time - some of the time - a little of the time	- 1 - 2 - 3 - 4			Available upon SRC approval

result of any emotional problems (such as feeling depressed or anxious)? - Did work or other activities less carefully than usual							- none of the time	- 5			
6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?	QS	R3		36v2	sf01	single choice	- not at all - slightly - moderately - quite a bit - extremely	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
7. How much bodily pain have you had during the past 4 weeks?	QS	R3		36v2	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		36v2	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		36v2	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
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	QS	R3		36v2	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

the time during the past 4 weeks - Have you been very nervous?											
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 - Have you felt so down in the dumps that nothing could cheer you up?	QS	R3		36v2	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
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 - Have you felt calm and peaceful?	QS	R3		36v2	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
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 have a lot of energy?	QS	R3		36v2	vt02	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 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 - Have you felt downhearted and low?	QS	R3		36v2	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
	QS	R3		36v2	vt03		- all of the time	- 1			

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 worn out?						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
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 - Have you been happy?	QS	R3		36v2	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
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 tired?	QS	R3		36v2	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		36v2	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		36v2	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		36v2	gh03		- definitely true	- 1			

Group 11. How TRUE or FALSE is each of the following statements for you? - I am as healthy as anybody I know						single choice	- mostly true - don't know - mostly false - definitely false	- 2 - 3 - 4 - 5			Available upon SRC approval
Group 11. How TRUE or FALSE is each of the following statements for you? - I expect my health to get worse	QS	R3		36v2	gh04	single choice	- definitely true - mostly true - don't know - mostly false - definitely false	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Group 11. How TRUE or FALSE is each of the following statements for you? - My health is excellent	QS	R3		36v2	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Physical Functioning (PF)	QS	R3		36v2	pf	number					Available upon SRC approval
RolePhysical (RP)	QS	R3		36v2	rp	number					Available upon SRC approval
Bodily Pain (BP)	QS	R3		36v2	bp	number					Available upon SRC approval
General Health (GH)	QS	R3		36v2	gh	number					Available upon SRC approval
Vitality (VT)	QS	R3		36v2	vt	number					Available upon SRC approval

Social Functioning (SF)	QS	R3		36v2	sf	number					Available upon SRC approval
RoleEmotional (RE)	QS	R3		36v2	re	number					Available upon SRC approval
Mental Health (MH)	QS	R3		36v2	mh	number					Available upon SRC approval
Physical Functioning (PF)	QS	R3		36v2	pf_nbs	number					Not available
RolePhysical (RP)	QS	R3		36v2	rp_nbs	number					Not available
Bodily Pain (BP)	QS	R3		36v2	bp_nbs	number					Not available
General Health (GH)	QS	R3		36v2	gh_nbs	number					Not available
Vitality (VT)	QS	R3		36v2	vt_nbs	number					Not available
Social Functioning (SF)	QS	R3		36v2	sf_nbs	number					Not available
RoleEmotional (RE)	QS	R3		36v2	re_nbs	number					Not available
Mental Health (MH)	QS	R3		36v2	mh_nbs	number					Not available
Physical Component Summary (PCS)	QS	R3		36v2	pcs	number					Available upon SRC approval
Mental Component Summary (MCS)	QS	R3		36v2	mcs	number					Available upon SRC approval
SF36 v.2 score	QS	R3		36v2	sfscore_v2	number					PDS

9.5 Form “Behaviour”

Section General

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

Section Behavioural Assessment

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Depressed mood - Frequency	QS	R2 R3		Behaviour	deprfr	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
Depressed mood - Severity	QS	R2 R3		Behaviour	deprsv	single choice	- no mood disturbance - questionable or equivocal - mild, responds to redirection and reassurance - moderately depressed, express distress	- 0 - 1 - 2 - 3			PDS

							- severe, significant suffering and loss of functioning	- 4			
Low selfesteem/guilt - Frequency	QS	R2 R3		Behaviour	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
Low selfesteem/guilt - Severity	QS	R2 R3		Behaviour	guiltsv	single choice	- no evidence - questionable or equivocal - mild, definitely present - moderate, some distress - severe	- 0 - 1 - 2 - 3 - 4			PDS
Low selfesteem/guilt - Frequency	QS	R2 R3		Behaviour	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
Low selfesteem/guilt - Severity	QS	R2 R3		Behaviour	anxisv	single choice	- no evidence - questionable or equivocal - mild, responds to reassurance - moderate, impacts on everyday life	- 0 - 1 - 2 - 3			PDS

							- severe, causing a profound restriction of activities	- 4			
Suicidal Thoughts - Frequency	QS	R2 R3		Behaviour	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 - frequently thinking about suicide at least once a week - often thinks about suicide sometimes for days or weeks on end	- 0 - 1 - 2 - 3 - 4			PDS
Suicidal Thoughts - Severity	QS	R2 R3		Behaviour	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
Disruptive or aggressive behaviour - Frequency	QS	R2 R3		Behaviour	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
	QS			Behaviour	aggrsv		- behaviour wellcontrolled	- 0			PDS

Disruptive or aggressive behaviour - Severity		R2 R3				single choice	- verbal threats or intimidating behaviour - mild physically or verbally threatening behaviour - clear physical threat (moderately aggressive), bumping, shoving, verbal outburst - clear physical threat (physical aggression), striking/hitting, or definite intention to cause injury	- 1 - 2 - 3 - 4			
Irritable behaviour - Frequency	QS	R2 R3		Behaviour	irritfr	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
Irritable behaviour - Severity	QS	R2 R3		Behaviour	irritsv	single choice	- behaviour wellcontrolled - questionable or equivocal - definite, but mild - moderate, others change their behaviour to avoid irritating subject - severe irritability	- 0 - 1 - 2 - 3 - 4			PDS
Perseverative/Obsessional thinking - Frequency	QS	R2 R3		Behaviour	obsessfr	single choice	- never or almost never - seldom, less than once a week - sometimes, at least once a week	- 0 - 1 - 2			PDS

							- frequently, several times a week - very frequently, most of the time	- 3 - 4			
Perseverative/Obsessional thinking - Severity	QS	R2 R3		Behaviour	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
Compulsive behaviour - Frequency	QS	R2 R3		Behaviour	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
Compulsive behaviour - Severity	QS	R2 R3		Behaviour	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	- 0 - 1 - 2 - 3			PDS

							- severe has impulse, acts on it and cannot stop	- 4			
Delusions - Frequency	QS	R2 R3		Behaviour	delusfr	single choice	- no evidence - seldom, less than once a month - sometimes, at least once a month - frequently, at least once a week - very frequently, sometimes for days on end	- 0 - 1 - 2 - 3 - 4			PDS
Delusions - Severity	QS	R2 R3		Behaviour	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
Hallucinations - Frequency	QS	R2 R3		Behaviour	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

Hallucinations - Severity	QS	R2 R3		Behaviour	hallucsv	single choice	- no evidence - has hallucinations, but doubts they are real - convinced of the reality of the hallucinations, but allows that it is possible that they are not real - utterly convinced of the hallucinations being real, but not acting on them. - severe has allucinations that are vivid, subject is utterly convinced they are real and the hallucinations severely disrupt behaviour.	- 0 - 1 - 2 - 3 - 4			PDS
Apathy - Frequency	QS	R2 R3		Behaviour	apathfr	single choice	- never - seldom apathetic, 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
Apathy - Severity	QS	R2 R3		Behaviour	apathsv	single choice	- no evidence - equivocal - mild apathy subject not initiating conversation or activity but is responsive	- 0 - 1 - 2			PDS

							- moderate apathy sometimes responds to efforts to get involved in conversation/activities - several apathy generally unresponsive to attempts to involve subject in activities or conversation	- 3 - 4			
Behavioural Milestones - Does the examiner believes the participant is confused?	QS	R2 R3		Behaviour	confus	boolean	- yes - no	- 1 - 0			PDS
Behavioural Milestones - Does the examiner believes the participant is demented?	QS	R2 R3		Behaviour	dement	boolean	- yes - no	- 1 - 0			PDS
Behavioural Milestones - Does the examiner believe the participant is depressed?	QS	R2 R3		Behaviour	deprexam	boolean	- yes - no	- 1 - 0			PDS
Behavioural Milestones - Does the participant require pharmacotherapy for depression?	QS	R2 R3		Behaviour	deprfr	boolean	- yes - no	- 1 - 0			PDS
Behavioural Milestones - Does the participant require pharmacotherapy for irritability?	QS	R2 R3		Behaviour	irritfr	boolean	- yes - no	- 1 - 0			PDS
Information Sources - Was the behavioural assessment information obtained from:	QS	R2 R3		Behaviour	isobt	single choice	- participant only - participant and family/companion	- 1 - 2			PDS

9.6 Form “Becks Depression Scale (BDI)”

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date data obtained	QS	R2		BDI	qsdtc	date					Not available
Date data obtained	QS	R2		BDI	qsdyc	number					Available upon SRC approval
Becks score	QS	R2		BDI	bdiscore	number					PDS
A	QS	R2		BDI	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		BDI	bdi2	single choice	- I am not particularly discouraged about the future - I feel discouraged about the future - I feel I have nothing to look forward to - I feel that the future is hopeless and that things cannot improve	- 0 - 1 - 2 - 3			Available upon SRC approval
C	QS	R2		BDI	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		BDI	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		BDI	bdi5		- I do not feel particularly guilty	- 0			

						single choice	- I feel guilty a good part of the time - I feel quite guilty most of the time - I feel guilty all of the time	- 1 - 2 - 3			Available upon SRC approval
F	QS	R2		BDI	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		BDI	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		BDI	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		BDI	bdi9	single choice	- I do not have any thoughts of killing myself - 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	- 0 - 1 - 2 - 3			Available upon SRC approval
J	QS	R2		BDI	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		BDI	bdi11	single choice	- I am no more irritated by things than I ever am - I am slightly more irritated now than usual	- 0 - 1			Available upon SRC approval

							- I am quite annoyed or irritated a good deal of the time - I feel irritated all the time now	- 2 - 3			
L	QS	R2		BDI	bdi12	single choice	- I have not lost interest in other people - I am less interested in other people than I used to be - I have lost most of my interest in other people - I have lost all of my interest in other people	- 0 - 1 - 2 - 3			Available upon SRC approval
M	QS	R2		BDI	bdi13	single choice	- I make decisions about as well as I ever could - I put off making decisions more than I used to - I have greater difficulty in making decisions than before - I can not make decisions at all anymore	- 0 - 1 - 2 - 3			Available upon SRC approval
N	QS	R2		BDI	bdi14	single choice	- I do not feel that I look any worse than I used to - I am worried that I am looking old or unattractive - I feel that there are permanent changes in my appearance that make me look unattractive - I believe that I look ugly	- 0 - 1 - 2 - 3			Available upon SRC approval
O	QS	R2		BDI	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		BDI	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	- 0 - 1 - 2			Available upon SRC approval

							- I wake up several hours earlier than I used to and cannot get back to sleep	- 3			
Q	QS	R2		BDI	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		BDI	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		BDI	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		BDI	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 cannot think about anything else	- 0 - 1 - 2 - 3			Available upon SRC approval
U	QS	R2		BDI	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Hamilton Score	QS	R2		Hamilton	hamscore	number					PDS
Depressed mood	QS	R2		Hamilton	ham1	single choice	<ul style="list-style-type: none"> - 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 feeling states in his spontaneous verbal and non/verbal communication 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			Available upon SRC approval
Feelings of guilt	QS	R2		Hamilton	ham2	single choice	<ul style="list-style-type: none"> - absent - self reproach, feels he has let people down - ideas of guilt or rumination over past errors or sinful deeds - present illness is a punishment. Delusions of guilt - hears accusatory or denunciatory voices and/or experiences threatening visual hallucinations 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			Available upon SRC approval
Suicide	QS	R2		Hamilton	ham3	single choice	<ul style="list-style-type: none"> - absent - feels life is not worth living - wishes he were dead or any thoughts of possible death to self - suicidal ideas or gesture - attempts at suicide (any serious attempt rates 4) 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			Available upon SRC approval

Insomnia early	QS	R2		Hamilton	ham4	single choice	<ul style="list-style-type: none"> - no difficulty falling asleep - complains of occasional difficulty falling asleep, i.e., more than 1/2 hour - complains of nightly difficulty falling asleep 	- 0 - 1 - 2			Available upon SRC approval
Insomnia middle	QS	R2		Hamilton	ham5	single choice	<ul style="list-style-type: none"> - no difficulty - participant complains of being restless and disturbed during the night - waking during the night any getting out of bed rates 2 (except for purposes of voiding) 	- 0 - 1 - 2			Available upon SRC approval
Insomnia late	QS	R2		Hamilton	ham6	single choice	<ul style="list-style-type: none"> - no difficulty - waking in early hours of the morning but goes back to sleep - unable to fall asleep again if he gets out of bed 	- 0 - 1 - 2			Available upon SRC approval
Work and activities	QS	R2		Hamilton	ham7	single choice	<ul style="list-style-type: none"> - no difficulty - thoughts and feelings of incapacity, fatigue or weakness related to activities; work or hobbies - loss of interest in activity; hobbies or work either directly reported by participant, or indirect in listlessness, indecision and vacillation (feels he has to push self to work or activities) - decrease in actual time spent in activities or decrease in productivity - stopped working because of present illness 	- 0 - 1 - 2 - 3 - 4			Available upon SRC approval
Retardation: Psychomotor	QS	R2		Hamilton	ham8	single choice	<ul style="list-style-type: none"> - normal speech and thought - slight retardation at interview 	- 0 - 1			

							<ul style="list-style-type: none"> - obvious retardation at interview - interview difficult - complete stupor 	<ul style="list-style-type: none"> - 2 - 3 - 4 			Available upon SRC approval
Agitation	QS	R2		Hamilton	ham9	single choice	<ul style="list-style-type: none"> - none - fidgetiness - playing with hands, hair, etc. - moving about, can't sit still - hand wringing, nail biting, hairpulling, biting of lips 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			Available upon SRC approval
Anxiety	QS	R2		Hamilton	ham10	single choice	<ul style="list-style-type: none"> - no difficulty - subjective tension and irritability - worrying about minor matters - apprehensive attitude apparent in face or speech - fears expressed without questioning 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			Available upon SRC approval
Anxiety somatic	QS	R2		Hamilton	ham11	single choice	<ul style="list-style-type: none"> - absent - mild - moderate - severe - incapacitating 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			Available upon SRC approval
Somatic symptoms	QS	R2		Hamilton	ham12	single choice	<ul style="list-style-type: none"> - none - loss of appetite but eating without encouragement from others. Food intake about normal - difficulty eating without urging from others. Marked reduction of appetite and food intake 	<ul style="list-style-type: none"> - 0 - 1 - 2 			Available upon SRC approval
Somatic symptoms general	QS	R2		Hamilton	ham13	single choice	<ul style="list-style-type: none"> - none - heaviness in limbs, back or head. Backaches, headache, muscle aches. Loss of energy and fatigability - any clearcut symptom rates 2 	<ul style="list-style-type: none"> - 0 - 1 - 2 			Available upon SRC approval

Genital Symptoms	QS	R2		Hamilton	ham14	single choice	<ul style="list-style-type: none"> - absent - mild - severe 	<ul style="list-style-type: none"> - 0 - 1 - 2 			Available upon SRC approval
Hypochondriasis	QS	R2		Hamilton	ham15	single choice	<ul style="list-style-type: none"> - not present - selfabsorption (bodily) - preoccupation with health - frequent complaints, requests for help, etc. - hypochondriacal delusions 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			Available upon SRC approval
Loss of weight	QS	R2		Hamilton	ham16	single choice	<ul style="list-style-type: none"> - no weight loss - probably weight loss associated with present illness - definite (according to participant) weight loss - not assessed 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 			Available upon SRC approval
Insight	QS	R2		Hamilton	ham17	single choice	<ul style="list-style-type: none"> - 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 	<ul style="list-style-type: none"> - 0 - 1 - 2 			Available upon SRC approval
Group Diurnal variation - Time of variation	QS	R2		Hamilton	ham18	single choice	<ul style="list-style-type: none"> - no variation - worse in A.M. - worse in P.M. 	<ul style="list-style-type: none"> - 0 - 1 - 2 			Available upon SRC approval
Group Diurnal variation - Severity of variation	QS	R2			ham18a	single choice	<ul style="list-style-type: none"> - none - mild - severe 	<ul style="list-style-type: none"> - 0 - 1 - 2 			Available upon SRC approval
Depersonalization and derealization	QS	R2		Hamilton	ham19	single choice	<ul style="list-style-type: none"> - absent - mild - moderate - severe - incapacitating 	<ul style="list-style-type: none"> - 0 - 1 - 2 - 3 - 4 			Available upon SRC approval
	QS	R2		Hamilton	ham20		<ul style="list-style-type: none"> - none 	<ul style="list-style-type: none"> - 0 			

Paranoid symptoms						single choice	- suspicious - ideas of reference - delusions of reference and persecution	- 1 - 2 - 3			Available upon SRC approval
Obsessional and compulsive symptoms	QS	R2		Hamilton	ham21	single choice	- absent - mild - severe	- 0 - 1 - 2			Available upon SRC approval

9.8 Form “Global Clinical Impression”

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Based upon my review of the information, I feel the severity of illness is	QS	R2 R3	Global Clinical Impression	GCI	svrtyll	single choice	- normal, not at all ill - borderline ill - mildly ill - moderately ill - markedly ill - severely ill - among the most extremely ill patients - not assessed	- 1 - 2 - 3 - 4 - 5 - 6 - 7 - 0			PDS

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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Clinical trial name – Entered Term		ENR		Clinical trials	ctnm	text					Available upon SRC approval
Clinical trial name – Modified Term		ENR		Clinical trials	ctnm__modify	text					Available upon SRC approval
Clinical trial name - Code		ENR		Clinical trials	ctnm_decod	text					Available upon SRC approval
Participant ID in trial		ENR		Clinical trials	subjid	text					Not available
Date of enrollment		ENR		Clinical trials	rfstdtc	date					Not available
Day of enrollment		ENR		Clinical trials	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		Clinical trials	ctstts	single choice	- active - completed - discontinued prematurely	- 1 - 2 - 3			Available upon SRC approval
End date of participation		ENR		Clinical trials	rfendtc	date					Not available

End day of participation		ENR		Clinical trials	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	CqoL	CareQoL	qsdtc	date					Not available
Assessment day	QS	ENR	CqoL	CareQoL	qsdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Language of paper form (PBF)	QS	ENR	cQoL	CareQoL	langpbf	single choice	<ul style="list-style-type: none"> - U.S. English - Spanish (LA) - Brazilian Portuguese - Canadian French - French - Czech - Danish - German - Spanish - Italian 	<ul style="list-style-type: none"> - 1 - 2 - 3 - 6 - 7 - 8 - 9 - 10 - 11 - 12 			Available upon SRC approval

						- Dutch - Norwegian - Polish - Portuguese - Russian - Finnish - Swedish	- 13 - 14 - 15 - 16 - 17 - 18 - 19			
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Section Information About Yourself

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
ID of caregiver	QS	ENR	CqoL	CareQoL	cqoli1	string					Not available
Does the caregiver have a unique HD identifier (HDID)?	QS	ENR	CQoL	CareQoL	cqoli2	boolean					Available upon SRC approval
Caregiver's HDID	QS	ENR	CQoL	CareQoL	cqoli2a	text					Available upon SRC approval
What is your year of birth?	QS	ENR	CQoL	CareQoL	cqoli3	date					Not available
What is your year of birth?	QS	ENR	CQoL	CareQoL	cqoli3	number				Converted to age.	Available upon SRC approval
What is your gender?	QS	ENR	CQoL	CareQoL	cqoli4	single choice	- male - female	- m - f			Available upon SRC approval
Country of residence	QS	ENR	CQoL	CareQoL	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	CareQoL	cqoli6	number	[0..13]				Available upon SRC approval
Do you have a job	QS	ENR	CQoL	CareQoL	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	CareQoL	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	CareQoL	cqoli9	number			years		Available upon SRC approval
How long have you been caring for any Huntington's Disease affected person(s)?	QS	ENR	CQoL	CareQoL	cqoli10	number			years		Available upon SRC approval
Are you the main carer for the HD affected person(s)?	QS	ENR	CQoL	CareQoL	cqoli11	boolean	- yes - no	- 1 - 0			Available upon SRC approval
The HD affected person(s) is/are my – sibling	QS	ENR	CQoL	CareQoL	cqoli12_1	boolean	- yes - no	- 1 - 0			Available upon SRC approval
The HD affected person(s) is/are my – spouse/partner	QS	ENR	CQoL	CareQoL	cqoli12_2	boolean	- yes - no	- 1 - 0			Available upon SRC approval

The HD affected person(s) is/are my – parent	QS	ENR	CQoL	CareQoL	cqoli12_3	boolean	- yes - no	- 1 - 0			Available upon SRC approval
The HD affected person(s) is/are my - child	QS	ENR	CQoL	CareQoL	cqoli12_4	boolean	- yes - no	- 1 - 0			Available upon SRC approval
The HD affected person(s) is/are my – other	QS	ENR	CQoL	CareQoL	cqoli12_5	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Please specify	SUPPQS	ENR	CQoL	CareQoL	cqoli12a	text					Not available
Have you previously cared for any other person(s) with Huntington's Disease?	QS	ENR	CQoL	CareQoL	cqoli13	boolean	- yes - no	- 1 - 0			Available upon SRC approval
The affected person is/was my	QS	ENR	CQoL	CareQoL	cqoli13a	text					Not available
Do you have children who are at risk/carrier/symptomatic?	QS	ENR	CQoL	CareQoL	cqoli14	boolean	- yes - no	- 1 - 0			Available upon SRC approval
How many persons live in your household?	QS	ENR	CQoL	CareQoL	cqoli15	number					Available upon SRC approval
Do you live in the same household as the HD person(s)?	QS	ENR	CQoL	CareQoL	cqoli16	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Section Quality of Life

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
How satisfied are you with your physical health?	QS	ENR	CQoL	CareQoL	cqol1	single choice	- 0 - dissatisfied - 1	- 0 - 1			

							- 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 - satisfied	- 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10			Available upon SRC approval
How satisfied are you with your psychological health?	QS	ENR	CQoL	CareQoL	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	CareQoL	cqol3	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 family relationships?	QS	ENR	CQoL	CareQoL	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	CareQoL	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	CareQoL	cqol6	single choice	- 0 - dissatisfied - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8	- 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8			Available upon SRC approval

							- 9 - 10 - satisfied	- 9 - 10			
How satisfied are you with the medical treatment that your HD relative(s) receive(s)?	QS	ENR	CQoL	CareQoL	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	CareQoL	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	CareQoL	cqol9	single choice	- 0 - dissatisfied - 1 - 2 - 3 - 4 - 5 - 6	- 0 - 1 - 2 - 3 - 4 - 5 - 6			Available upon SRC approval

							- 7 - 8 - 9 - 10 - satisfied	- 7 - 8 - 9 - 10			
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Section Life Aspects

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
I feel a sense of loss	QS	ENR	CQoL	CareQoL	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	CareQoL	cqol11	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 happy	QS	ENR	CQoL	CareQoL	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	CareQoL	cqol13	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 full of fear	QS	ENR	CQoL	CareQoL	cqol14	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 safe	QS	ENR	CQoL	CareQoL	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	CareQoL	cqol16	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 financially disadvantaged	QS	ENR	CQoL	CareQoL	cqol17	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 isolated	QS	ENR	CQoL	CareQoL	cqol18	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 there is hope for the future	QS	ENR	CQoL	CareQoL	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	CareQoL	cqol20	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 supported	QS	ENR	CQoL	CareQoL	cqol21	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 depressed	QS	ENR	CQoL	CareQoL	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	CareQoL	cqol23	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 stressed	QS	ENR	CQoL	CareQoL	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	CareQoL	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
	QS	ENR	CQoL	CareQoL	cqol26		- 0 - never	- 0			

I feel that my own needs are important to others						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 lonely	QS	ENR	CQoL	CareQoL	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	CareQoL	cqol28	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 comforted by my beliefs (religious, philosophical or spiritual)	QS	ENR	CQoL	CareQoL	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	CareQoL	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	CareQoL	cqol31	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 that I have had a duty of care forced on me	QS	ENR	CQoL	CareQoL	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	CareQoL	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
I feel that my role as a carer is rewarding	QS	ENR	CQoL	CareQoL	cqol34	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 restricted by a regimented daily routine	QS	ENR	CQoL	CareQoL	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	CareQoL	cqol36	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 resentful	QS	ENR	CQoL	CareQoL	cqol37	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 embarrassed by the behaviour of my HD relative(s)	QS	ENR	CQoL	CareQoL	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 behaviour of my HD relative(s)	QS	ENR	CQoL	CareQoL	cqol39	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 frustrated by the	QS	ENR	CQoL	CareQoL	cqol40	single choice	- 0 - never - 1	- 0 - 1			

misconceptions of others towards 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 threatend	QS	ENR	CQoL	CareQoL	cqol41	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 frustrated by the discrimination of others toward my HD	QS	ENR	CQoL	CareQoL	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	CareQoL	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	CareQoL	cqol44	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 get enough sleep	QS	ENR	CQoL	CareQoL	cqol45	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 I have somebody to turn to for assistance if I am overwhelmed	QS	ENR	CQoL	CareQoL	cqol46	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 satisfied with my overall quality of life	QS	ENR	CQoL	CareQoL	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Is there anything else related to your caring role that you feel hasn't been	QS	ENR	CQoL	CareQoL	cqoli17	boolean	- yes - no	- 1 - 0			Available upon SRC approval

covered in this questionnaire?											
Could you please describe what it is?	SUPPQS	ENR	CQoL	CareQoL	cqoli17a	text					Not available
As a carer of someone with HD, is there anything that affects you most?	QS	ENR	CQoL	CareQoL	cqol18	boolean	- yes - no	- 1 - 0			Available upon SRC approval
positive	SUPPQS	ENR	CQoL	CareQoL	cqoli18a	text					Not available
negative	SUPPQS	ENR	CQoL	CareQoL	cqoli18b	text					Not available
Can you think of anything that would most improve your quality of life as a carer?	QS	ENR	CQoL	CareQoL	cqol19	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Could you please describe what it is?	SUPPQS	ENR	CQoL	CareQoL	cqoli19a	text					Not available
Have you taken any action to achieve this?	QS	ENR	CQoL	CareQoL	cqoli20	boolean	- yes - no	- 1 - 0			Available upon SRC approval
What action have you taken?	SUPPQS	ENR	CQoL	CareQoL	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Assessment date	QS	ENR	CSRI	CSRI	qsdtc	date					Not available

Assessment day	QS	ENR	CSRI	CSRI	qsd	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
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Section Hospital and Residential Services in the last 6 months

Label	Domain	Studies	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Neurology outpatient visit	QS	ENR	CSRI	CSRI	csri1	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri1a	number			visits		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri1b	number			visits		Available upon SRC approval
Other hospital outpatient visit	QS	ENR	CSRI	CSRI	csri2	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri2a	number			visits		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri2b	number			visits		Available upon SRC approval
Ambulatory or same day surgery	QS	ENR	CSRI	CSRI	csri3	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri3a	number			visits		Available upon SRC approval

Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri3b	number			visits		Available upon SRC approval
Nursing or residential home	QS	ENR	CSRI	CSRI	csri4	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri4a	number			days		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri4b	number			days		Available upon SRC approval
Hospital emergency room visits?	QS	ENR	CSRI	CSRI	csri61	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri61a	number			days		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri61b	number			days		Available upon SRC approval
Inpatient hospital stay	QS	ENR	CSRI	CSRI	csri5	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri5a	number			days		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri5b	number			days		Available upon SRC approval
Inpatient hospital stay - Intensive care unit (ICU)	QS	ENR	CSRI	CSRI	csri6	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri6a	number			days		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri6b	number			days		Available upon SRC approval
Other inpatient hospital stay	QS	ENR	CSRI	CSRI	csri7	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri7a	number			days		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri7b	number			days		Available upon SRC approval
General practitioner (GP) or internist/family doctor	QS	ENR	CSRI	CSRI	csri8	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri8a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri8b	number			contacts		Available upon SRC approval
Physical Therapist (PT)	QS	ENR	CSRI	CSRI	csri9	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri9a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri9b	number			contacts		Available upon SRC approval
Psychiatrist	QS	ENR	CSRI	CSRI	csri10	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri10a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri10b	number			contacts		Available upon SRC approval
Psychologist/psychotherapist	QS	ENR	CSRI	CSRI	csri11	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri11a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri11b	number			contacts		Available upon SRC approval
Counsellor	QS	ENR	CSRI	CSRI	csri12	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri12a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri12b	number			contacts		Available upon SRC approval
Family therapist/marriage guidance	QS	ENR	CSRI	CSRI	csri13	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri13a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri13b	number			contacts		Available upon SRC approval
Dietician/nutritionist	QS	ENR	CSRI	CSRI	csri14	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri14a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri14b	number			contacts		Available upon SRC approval
Clinical geneticist	QS	ENR	CSRI	CSRI	csri15	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri15a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri15b	number			contacts		Available upon SRC approval
Social worker	QS	ENR	CSRI	CSRI	csri16	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri16a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri16b	number			contacts		Available upon SRC approval
Practice nurse (nurse practitioner or physician assistant)	QS	ENR	CSRI	CSRI	csri17	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri17a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri17b	number			contacts		Available upon SRC approval
Home healthcare nurse	QS	ENR	CSRI	CSRI	csri18	boolean	- yes	- 1			

							- no	- 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri18a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri18b	number			contacts		Available upon SRC approval
Speech therapist	QS	ENR	CSRI	CSRI	csri19	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri19a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri19b	number			contacts		Available upon SRC approval
Home help/home care worker	QS	ENR	CSRI	CSRI	csri20	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri20a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri20b	number			contacts		Available upon SRC approval
Acupuncturist	QS	ENR	CSRI	CSRI	csri21	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri21a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri21b	number			contacts		Available upon SRC approval

Homeopath	QS	ENR	CSRI	CSRI	csri22	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri22a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri22b	number			contacts		Available upon SRC approval
Herbalist	QS	ENR	CSRI	CSRI	csri23	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri23a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri23b	number			contacts		Available upon SRC approval
Aromatherapy	QS	ENR	CSRI	CSRI	csri24	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri24a	number			contacts		Available upon SRC approval
Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri24b	number			contacts		Available upon SRC approval
Reflexologist	QS	ENR	CSRI	CSRI	csri25	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Use in the last 6 months because of your HD	QS	ENR	CSRI	CSRI	csri25a	number			contacts		Available upon SRC approval

Use in the last 6 months for other reasons	QS	ENR	CSRI	CSRI	csri25b	number			contacts		Available upon SRC approval
Other service	QS	ENR	CSRI	CSRI	csri26	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Genetic test	QS	ENR	CSRI	CSRI	csri27	boolean	- yes - no	- 1 - 0			Available upon SRC approval
No. in the last 6 months	QS	ENR	CSRI	CSRI	csri27a	number					Available upon SRC approval
Why did you have this test/investigation?	QS	ENR	CSRI	CSRI	csri27sc	text					Not available
Magnetic Resonance Image (MRI)	QS	ENR	CSRI	CSRI	csri28	boolean	- yes - no	- 1 - 0			Available upon SRC approval
No. in the last 6 months	QS	ENR	CSRI	CSRI	csri28a	number					Available upon SRC approval
Why did you have this test/investigation?	SUPPQS	ENR	CSRI	CSRI	csri28sc	text					Not available
CT/CAT scan	QS	ENR	CSRI	CSRI	csri29	boolean	- yes - no	- 1 - 0			Available upon SRC approval
No. in the last 6 months	QS	ENR	CSRI	CSRI	csri29a	number					Available upon SRC approval
Why did you have this test/investigation?	SUPPQS	ENR	CSRI	CSRI	csri29sc	text					Not available

Electroencephalogram (EEG)	QS	ENR	CSRI	CSRI	csri30	boolean	- yes - no	- 1 - 0			Available upon SRC approval
No. in the last 6 months	QS	ENR	CSRI	CSRI	csri30a	number					Available upon SRC approval
Why did you have this test/investigation?	SUPPQS	ENR	CSRI	CSRI	csri30sc	text					Not available
Blood test	QS	ENR	CSRI	CSRI	csri31	boolean	- yes - no	- 1 - 0			Available upon SRC approval
No. in the last 6 months	QS	ENR	CSRI	CSRI	csri31a	number					Available upon SRC approval
Why did you have this test/investigation?	SUPPQS	ENR	CSRI	CSRI	csri31sc	text					Not available
Personal care (e.g. bathing, dressing)	QS	ENR	CSRI	CSRI	csri32	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Average no. of hours per week	QS	ENR	CSRI	CSRI	csri32a	number			hours		Available upon SRC approval
Any other information?	SUPPQS	ENR	CSRI	CSRI	csri32sc	text					Not available
Help inside the home (e.g. cooking, cleaning)	QS	ENR	CSRI	CSRI	csri33	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Average no. of hours per week	QS	ENR	CSRI	CSRI	csri33a	number			hours		Available upon SRC approval
Any other information?	SUPPQS	ENR	CSRI	CSRI	csri33sc	text					Not available
	QS	ENR	CSRI	CSRI	csri34	boolean	- yes	- 1			

Help outside the home (e.g. shopping)							- no	- 0			Available upon SRC approval
Average no. of hours per week	QS	ENR	CSRI	CSRI	csri34a	number			hours		Available upon SRC approval
Any other information?	SUPPQS	ENR	CSRI	CSRI	csri34sc	text					Not available
Other	QS	ENR	CSRI	CSRI	csri35	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Average no. of hours per week	QS	ENR	CSRI	CSRI	csri35a	number			hours		Available upon SRC approval
Any other information?	SUPPQS	ENR	CSRI	CSRI	csri35sc	text					Not available
Stair lift	QS	ENR	CSRI	CSRI	csri36	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	CSRI	csri36a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Handrails	QS	ENR	CSRI	CSRI	csri37	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	CSRI	csri37a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Ramps	QS	ENR	CSRI	CSRI	csri38	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	CSRI	csri38a	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Shower/bath relocation	QS	ENR	CSRI	CSRI	csri39	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	CSRI	csri39a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Toilet relocation	QS	ENR	CSRI	CSRI	csri40	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	CSRI	csri40a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Redesign kitchen	QS	ENR	CSRI	CSRI	csri41	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	CSRI	csri41a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Chair raises/special chair	QS	ENR	CSRI	CSRI	csri42	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last six months?	QS	ENR	CSRI	CSRI	csri42a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Bed moved downstairs	QS	ENR	CSRI	CSRI	csri43	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	CSRI	csri43a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Hospital bed	QS	ENR	CSRI	CSRI	csri44	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	CSRI	csri44a	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Other	QS	ENR	CSRI	CSRI	csri45	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Was this in the last 6 months?	QS	ENR	CSRI	CSRI	csri45a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Wheelchair	QS	ENR	CSRI	CSRI	csri46	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	CSRI	csri46a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Crutches/sticks	QS	ENR	CSRI	CSRI	csri47	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	CSRI	csri47a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Zimmer frame	QS	ENR	CSRI	CSRI	csri48	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	CSRI	csri48a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Commode	QS	ENR	CSRI	CSRI	csri49	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	CSRI	csri49a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Bath board	QS	ENR	CSRI	CSRI	csri50	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	CSRI	csri50a	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Pressure relieving cushions/mattress	QS	ENR	CSRI	CSRI	csri51	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	CSRI	csri51a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Adapted eating utensils	QS	ENR	CSRI	CSRI	csri52	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	CSRI	csri52a	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Other	QS	ENR	CSRI	CSRI	csri53	boolean	- yes - no	- 1 - 0			Available upon SRC approval
Did you receive it in the last 6 months?	QS	ENR	CSRI	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	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
LAB-ID	LB	ENR		Samples	labid	text					Not available
Collection of ACD blood required	LB	ENR		Samples	acd	boolean	- yes - no	- 1 - 0			Available upon SRC approval

Section Blood Collection: ACD Tubes (yellow cap)

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Date and time of collection	LB	ENR		Samples	lbdtc	datetime					Not available
Day and time of collection	LB	ENR		Samples	lbdy	datetime				Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Number of ACD tubes collected	LB	ENR		Samples	qty	Number					Available upon SRC approval
Bar code	LB	ENR		Samples	barcode	Text					Not available
State	LB	ENR		Samples	state	single choice	- arrived - lost - damaged - at site - shipped - deleted - destroyed	- 1 - 2 - 3 - 4 - 5 - 0 - -1			Not available
State	LB	ENR		Samples	state	single choice	- arrived - lost - damaged - at site - shipped	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Withdrawal number	LB	ENR		Samples	wthdrwl	Number					Available upon SRC approval

Section Room Temperature Shipment

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
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Courier	LB			Samples	courier	single choice	- DHL - FedEx - World Courier - Marken	- 1 - 2 - 13 - 16			Available upon SRC approval
Airway bill no (DHL)	LB	ENR		Samples	dhlnum	Number					Not available
Date of shipment	LB	ENR		Samples	shipdtc	Date					Not available
Day of shipment	LB	ENR		Samples	shipdy	Number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Date of notification	LB	ENR		Samples	ntfydtc	Date					Not available
Day of notification	LB	ENR		Samples	ntfydy	Number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Date of receipt	LB	ENR		Samples	rcptdtc	Date					Not available
Day of receipt	LB	ENR		Samples	rcptdy	Number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Total shipping time	LB	ENR		Samples	shiptime	number array	- -	- h - min			Available upon SRC approval
Resubmit notification to BioRep	LB	ENR		Samples	resubmit	Boolean	- yes - no	- 1 - 0			Available upon SRC approval

Section Laboratory Results/Evaluation of Specimen/Biobank

Label	Domain	Study	Cat	Samples	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
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Type	LB	ENR		Samples	type	single choice	- Whole Blood - DNA - Cell Line - Buffy coat - SQC	- 1 - 2 - 3 - 4 - 5			Available upon SRC approval
Sample	LB	ENR		Samples	id	text					Available upon SRC approval
Source	LB	ENR		Samples	sourceid	text					Available upon SRC approval
Qty	LB	ENR		Samples	qty	number					Available upon SRC approval
Collection	LB	ENR		Samples	lbdtc	datetime					Not available
Collection Day	LB	ENR		Samples	lbdy	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
Wthdrwl.	LB	ENR		Samples	wthdrwl	number					Available upon SRC approval
Receipt state	LB	ENR		Samples	substate	single choice	- culture prep. - culture prep. (r) - duplicated - split (buffy c.) - split (culture) - test only - buffy coat prep. - submitted - stored safely	- 1 - 2 - 3 - 4 - 5 - 9 - 10 - 11 - 12			Available upon SRC approval

							<ul style="list-style-type: none"> - archived - 13 - RNA prep. - 14 - buffy coat (r) - 15 - biopsy freeze - 16 - frozen (culture) - 17 - frozen (culture, r) - 18 - requires quality c. - 19 - test only (frozen) - 20 - damaged - 21 - self-processed - 22 - virtual culture - 23 - DNA prep. - 24 - work order init. - 25 - plasma prep. - 26 - plasma prep. (r) - 27 - redraw problems - 49 - package lost - 0 - stored safely (r) - 28 - virus stock s. - 29 - split (dna) - 31 - split (buffy c., r) - 50 - split (culture, r) - 51 - derived - 100 				
Outcome	LB	ENR		Samples	outcome	single choice	<ul style="list-style-type: none"> - pass - 1 - failed - 2 				Available upon SRC approval
Date Completed	LB	ENR		Samples	compldtc	date					Not available

Day Completed	LB	ENR		Samples	comply	number			days	Transformed into days relative to baseline date of Enroll-HD.	Available upon SRC approval
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10.5 Form “Family history (FHx)”

Section “members”

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Study ID	SUPPMH	ENR	FHx	FHx	studyid	text	- Enroll-HD	- ENR			Available upon SRC approval
Family ID	SUPPMH	ENR	FHx	FHx	fmlyid	number					Not available
Family ID (recoded)	SUPPMH	ENR	FHx	FHx	fmlyid	number					Available upon SRC approval
Node ID	SUPPMH	ENR	FHx	FHx	id	number					Available upon SRC approval
Unique subject identifier, i.e. HDID	SUPPMH	ENR	FHx	FHx	subjid	text					Available upon SRC approval
Parent ID 1	SUPPMH	ENR	FHx	FHx	pid1	number					Available upon SRC approval
Parent ID 2	SUPPMH	ENR	FHx	FHx	pid2	number					Available upon SRC approval
ID of spouse	SUPPMH	ENR	FHx	FHx	spid	number					Available upon SRC approval
Other family member ID	SUPPMH	ENR	FHx	FHx	othid	number					Available upon SRC approval
Special type of this node or type of relationship to other family member	SUPPMH	ENR	FHx	FHx	type	text	"infertile", "childless", "bitwin", "monotwin", or "donor"				Available upon SRC approval

Gender	SUPPMH	ENR	FHx	FHx	sex	single choice	- female - male	- f - m			Not available
Year of birth	SUPPMH	ENR	FHx	FHx	brthy	number					Not available
Vital status	SUPPMH	ENR	FHx	FHx	vstat	single choice	- alive - dead - unknown	- 1 - 2 - 9999			Available upon SRC approval
Year of death	SUPPMH	ENR	FHx	FHx	deathy	date					Not available
HD status	SUPPMH	ENR	FHx	FHx	hdstat	single choice	- manifest carrier - pre-manifest carrier, genetically confirmed - not a carrier, genetic test done - unknown, no genetic test done	- 1 - 2 - 3 - 9999			Not available
HD status	SUPPMH	ENR	FHx	FHx	hdstat	single choice	- manifest carrier - pre-manifest carrier, genetically confirmed - not a carrier, genetic test done - unknown, no genetic test done	- 1 - 2 - 3 - 9999			Available upon SRC approval
Degree of certainty	SUPPMH	ENR	FHx	FHx	hdstatc	single choice	- 0 - 1 - 2 - 3 - 4	- 0 - 1 - 2 - 3 - 4			Available upon SRC approval

							- 5	- 5			
Availability of DNA samples	SUPPMH	ENR	FHx	FHx	dna	boolean	- Yes - No	-1 - 0			Available upon SRC approval
Participant in Enroll-HD	SUPPMH	ENR	FHx	FHx	registry	single choice	- yes - no - unknown	- 1 - 2 - 9999			Available upon SRC approval
Pseudonym	SUPPMH	ENR	FHx	FHx	pseudo	text					Not available

Section “relations”

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Study ID	SUPPMH	ENR	FHx	FHx	studyid	Text	- Enroll-HD	- ENR			Available upon SRC approval
Family ID	SUPPMH	ENR	FHx	FHx	fmlyid	number					Not available
Family ID (recoded)	SUPPMH	ENR	FHx	FHx	fmlyid	number					Available upon SRC approval
Node ID	SUPPMH	ENR	FHx	FHx	id	number					Available upon SRC approval
Node ID2	SUPPMH	ENR	FHx	FHx	id2	number					Available upon SRC approval
Unique subject identifier	SUPPMH	ENR	FHx	FHx	subjid	text					Available upon SRC approval
Type of relation	SUPPMH	ENR	FHx	FHx	reltype	text	Mother, brother sister, son, daughter, uncle, aunt, niece, nephew, spouse ...				Available upon SRC approval
Unique subject identifier 2	SUPPMH	ENR	FHx	FHx	subjid2	text					Available upon SRC approval
Percentage of genetic similarity	SUPPMH	ENR	FHx	FHx	genpct	number					Available upon SRC approval

Section “families”

Label	Domain	Study	Cat	Form	Variable	Type	Parameter	Coding	Unit	Transformation	Availability
Study ID	SUPPMH	ENR	FHx	FHx	studyid	Text	- Enroll-HD	- ENR			Available upon SRC approval
Family ID	SUPPMH	ENR	FHx	FHx	fmlyid	number	-	-			Not available
Family ID (recoded)	SUPPMH	ENR	FHx	FHx	fmlyid	number	-	-			Available upon SRC approval
Name	SUPPMH	ENR	FHx	FHx	visit	text	- "Family History"	-			Available upon SRC approval
Family history tree status	SUPPMH	ENR	FHx	FHx	visstat	text	- editing - plausible - signed - reviewing - completed	-			Available upon SRC approval
Number of family members in the tree	SUPPMH	ENR	FHx	FHx	mbrcnt	number	-	-			Available upon SRC approval
Number of Enroll-HD participants in the tree	SUPPMH	ENR	FHx	FHx	subjcnt	number	-	-			Available upon SRC approval
Number of family member spouses	SUPPMH	ENR	FHx	FHx	spcnt	number	-	-			Available upon SRC approval
Number of sibship counts	SUPPMH	ENR	FHx	FHx	sibcnt	number	-	-			Available upon SRC approval
Number of generations	SUPPMH	ENR	FHx	FHx	gencnt	number	-	-			Available upon SRC approval
Number of donors	SUPPMH	ENR	FHx	FHx	dnrcnt	number	-	-			Available upon SRC approval
Number parental consanguinities	SUPPMH	ENR	FHx	FHx	cnsent	number	-	-			Available upon SRC approval

Revision History

Please refer to the PDS change log overview document for details of variable inclusion, variable exclusion, and changes to variable coding.