## TRACKID

## TrackOn>HD

# Track-HD/TrackOn-HD Data Dictionary Periodic and Specified Datasets 

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## Track-HD/TrackOn-HD

A prospective observational biomarker study in participants with premanifest and early Huntington's disease (HD)

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## 1 Overview

This Data Dictionary is intended to be used with all Track-HD (THD) / TrackOn-HD (TON) dataset releases, including public datasets (PDS) and specified datasets (SPS).

This document includes variable information, a brief overview of constituent data sources, dataset structure, variable attributes, information on special values representation and data release availability (PDS/SPS).

## 2 Structure of the Dataset

### 2.1 Data Sources

This Track-HD/TrackOn-HD dataset encompasses data from both Track-HD and TrackOn-HD studies. A brief overview of these data sources is described below.

TRACK-HD (THD) was a prospective observational biomarker study in participants with premanifest and early Huntington's disease (HD). Track-HD assessed longitudinal data collected at baseline, 12 months, 24 and 36 months at sites in Leiden (Netherlands), London (UK), Paris (France), and Vancouver (Canada). Individuals without HD but carrying the mutant HTT gene (ie, premanifest HD), patients with early HD, and healthy control individuals matched by age and sex to the combined HD groups were included in the study. Data were collected with 3T MRI, clinical, cognitive, quantitative motor, oculomotor, and neuropsychiatric assessments.

TrackOn-HD (TON) followed on from Track-HD aiming to investigate compensatory mechanisms in premanifest gene carriers. Baseline, 12 and 24 month data on premanifest gene carriers and healthy controls was collected from the same four sites including 3T MRI, task and resting state fMRI, DTI, clinical, cognitive, quantitative motor, and neuropsychiatric assessments.

### 2.2 Data Files within the Dataset

THD/TON PDS is comprised of 11 data files, each of which fall into one of three categories:

Participant-based: profile, pharmacotx, comorbid, family

These contain non-study-specific information about the participant. This information is relevant to all studies.

Study-based: participation, assessment

These contain study specific information about a participant.

Visit-based: track, trackon, mri, ishd, oculomotor, morphometric

These contain visit specific information about a participant.

Each PDS data file is described in Table 1.

Table 1 Track-HD/TrackOn-HD dataset release data file descriptions.

| Data file | Type | Studies | Description |
| :--- | :--- | :--- | :--- |
| profile | Participant | THD, TON | General and participant related data, <br> some of which may be annually <br> updated. |
| pharmacotx | Participant | THD, TON | Information about pharmacological <br> therapies. |
| comorbid | Participant | THD, TON | Information about comorbid conditions <br> and surgeries. |
| family | Study | THD, TON | Information on family members of each <br> participant. |
| participation |  | THD, TON | Provides study specific information <br> about study participation. Includes <br> participant identifier, participant <br> status, study start day, study end day <br> (in event of participant withdrawal or <br> death). Note: If a participant is enrolled <br> in several studies, one line per study |
| participation is provided. |  |  |  |


| trackon | Visit | TON | Data from the TrackOn-HD study. |
| :--- | :--- | :--- | :--- |
| ishd | Visit | THD | Data from ISHD scale. ISHD is a diary- <br> type assessment of irritable and <br> aggressive behaviour over the course <br> of one week. So for each visit, there are <br> 7 assessements which corresponds to 7 <br> rows for each participant's visit. |
| oculomotor | Visit | THD, TON | Data from Oculomotor scale. <br> Oculomotor assessment has many <br> sessions per participant's visit, which <br> corresponds to one row per session. |
| mri_aquisitions | Visit | THD, TON | Iventory of all MRIs conducted within <br> the study. |
| misit morphometrics | Visit | THD, TON | Measurements from performed MRIs <br> in each visit. |
| assessment | Visit | THD, TON | Visit-specific information about which <br> assessments were performed at each <br> visit (per study). |
| samples | Visit-specific information about |  |  |
| samples that were performed at each |  |  |  |
| visit (per study). |  |  |  |

### 2.3 Structure of Variables

This Data Dictionary lists all variables in Chapter 3, 4 and 5, with the appropriate attributes specified in Table 2.

Table 2 Data dictionary column fields.

| Attribute | Description |
| :--- | :--- |
| Label | Variable label |
| Form | Corresponding Form |
| Variable | Internal variable name. |
| Data Type | Boolean: Represents the values 1 (yes) and 0 (no). |
|  | Number: Represents number or floating-point data values. |
|  | Text: Represents alphanumeric string data values. |


|  | Date: The date type is represented as the number of days relative to the date of <br> the participant's THD Visit 1 visit date. <br> Single choice: Variable with assigned coding list of options where one item can be <br> selected. The value within an export provided in the dataset is taken from the <br> underlying coding available options list. The list of options is defined as <br> parameters in the data dictionary tables. |
| :--- | :--- |
| Parameter | Parameter value of coded variables (optional). |
| Coding | Internal parameter value of coded variables (optional). |
| Unit | Unit of input field (optional). |
| Availability | All variables in the Track-HD/TrackOn-HD dataset are listed in the Data <br> Dictionary. This availability column allows the researcher to identify which <br> variables are available in the PDS ("PDS"), which are available via special request <br> ("available upon SRC approval"), and which are restricted ("not available"). |

### 2.4 Representation of Special Values

## Date Values

## Transformation of date values

To minimize participant identification risk, the Track-HD/TrackOn-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 Track-HD Visit 1 visit date and the date of interest. Date values that refer to date of birth or symptom onset are transformed into age values.

It should be noted that date values are negative, if the date refers to a point in time before THD Visit 1. This is typical for start dates of medications and comorbid conditions.

For example, date values for a participant with a THD Visit 1 date of 2020-11-01 (YYYY-MM-DD) would read as follows in Table 3.

Table 3 Date representation.

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

## Alphanumeric characters

When opening the ".csv" files in Microsoft Excel, this should be done using UTF-8 encoding (Data-> Import Text -> File Origin: UTF-8) to ensure that values like "é" or " $\mu$ " are correctly displayed (Figure 1).


Figure 1 Window defining relevant importing options.

### 2.5 Data availability

This Data Dictionary details all variables collected in Track-HD and TrackOn-HD.
Periodic datasets (PDS), prepared from the Track-HD/TrackOn-HD electronic data capture (EDC) include the majority of variables collected. Variables included in the PDS are highlighted in green. Each Track-HD/TrackOn-HD PDS goes through stringent quality control and deidentification procedures prior to release. To this end, certain variables are transformed 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 Track-HD/TrackON-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 column 'Availability' indicates these three classes of variables using the color-coding shown in Table 4.

## Table 4 Availability type description.

| Availability | Meaning |
| :--- | :--- |
| PDS | Included in the PDS. |
| Available upon SRC approval | Not included in the PDS but available via SPS request contingent on <br> SRC approval. |
| Not available | Restricted variables which are nnot available in the PDS or via SPS <br> request. |

## 3 Participant-Based Data Files

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

There are the following participant-based data files:

- profile
- pharmacotx
- comorbid
- family

In general, these data files may contain one, more than one or no entry per participant. An index (variable "seq") distinguishes different entries.

### 3.1 Data File "profile" (Participant Profile)

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :---: | :---: |
| Recoded HDID | THD,TON | Key Vars | subjid | text |  |  | PDS |  |
| Region (Europe <br> or Northern <br> America) | THD,TON | Key Vars | region | text |  |  | PDS |  |
| Recoded Site ID <br> (TRACK-HD/-ON <br> HD specific) | THD,TON | Key Vars | siteid | number |  |  | Not <br> Available |  |

### 3.1.1 Form "Demographics"

## Section Demographics (invariable)

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Date of birth | THD,TON | Demog | brthdtc | date |  |  |  | Not Available |
| Date of birth (precision) | THD,TON | Demog | brthdtc__ prec | single- <br> choice |  |  |  | Not Available |
| Sex | THDTON | Demos |  | single- | - female | -1 |  | PDS |
| Sex | , TON | mog | sex | choice | - male | -2 |  | PDS |
|  |  |  |  |  | - Caucasian | -1 |  | PDS |
|  |  |  |  |  | - African - Black | -1 |  | PDS |
|  |  |  |  |  | - African - North | -2 |  | PDS |
|  |  |  |  |  | - Asian - West | -3 |  | PDS |
| Ethnicity | THD,TON | Demog | ethnic |  | - Asian - East | -4 |  | PDS |
|  |  |  |  |  | - mixed | -5 |  | PDS |
|  |  |  |  |  | - American - Black | -2 |  | PDS |
|  |  |  |  |  | - American - Latin | -3 |  | PDS |
|  |  |  |  |  | - other | -6 |  | PDS |


|  |  |  |  |  | - unknown | - 7 | PDS |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Subject's statement | THD,TON | Demog | ethnicself | text |  |  | Not Available |
| Handedness | THD,TON | Demog | handness | singlechoice | - right | -1 | PDS |
|  |  |  |  |  | - left | -2 | PDS |
|  |  |  |  |  | - mixed | - 3 | PDS |
| Education level | THD | Demog | education | single- <br> choice | - ISCED 0 - nursery school | - 0 | PDS |
|  |  |  |  |  | - ISCED 1 - primary school (key stage 1, 2) | -1 | PDS |
|  |  |  |  |  | - ISCED 2 - comprehensive school/college (key stage 3) | -2 | PDS |
|  |  |  |  |  | - ISCED 3 - sixth form (key stage 4) | - 3 | PDS |
|  |  |  |  |  | - ISCED 4 - college of further education | -4 | PDS |
|  |  |  |  |  | - ISCED 5 - university (further/higher education institutions) | - 5 | PDS |
|  |  |  |  |  | - ISCED 6 - tertiary studies leading to an advanced research qualification | -6 | PDS |
| Sum - right | TON | Demog | edinventleft | number |  |  | PDS |
| Sum - left | TON | Demog | edinventright | number |  |  | PDS |
| Writing - right | TON | Demog | writingleft | number |  |  | PDS |
| Writing - left | TON | Demog | writingright | number |  |  | PDS |

### 3.2 Data File "pharmacotx (Pharmacotherapy)"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :---: | :---: |
| Recoded HDID | THD,TON | Key Vars | subjid | text |  |  |  | PDS |
| Study ID | THD,TON | Key Vars | studyid | text | - THD <br> - <br> $-\quad$ TON <br> THD/TON | PDS |  |  |
| Sequence | THD,TON | Key Vars | seq | number |  |  |  |  |

### 3.2.1 Form "Medication"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Drug name -WHO-DD <br> Modified Term | THD,TON | Medication | cmtrt__modify | text |  |  |  | PDS |
| Drug name -WHO-DD Drug Code | THD,TON | Medication | cmtrt__decod | text |  |  |  | Available upon SRC approval |
| Drug name Internal Drug Code | THD,TON | Medication | cmtrt__decod_r | text |  |  |  | PDS |
| Dose | THD,TON | Medication | cmdostot | number |  |  |  | PDS |
| Unit | THD,TON | Medication | cmdosunit | text |  |  |  | PDS |
| Regimen | THD,TON | Medication | regimen | singlechoice | - ATC | - atc |  | PDS |
|  |  |  |  |  | - b.i.d. | - bid |  |  |
|  |  |  |  |  | - b.i.w. | - biw |  |  |
|  |  |  |  |  | - nocte | - hs |  |  |
|  |  |  |  |  | - p.r.n. | - prn |  |  |
|  |  |  |  |  | - q.2h. | - q2h |  |  |
|  |  |  |  |  | - q. 3 h . | -q3h |  |  |
|  |  |  |  |  | - q.4h. | - q4h |  |  |


|  |  |  |  |  | - o.d. | - qd |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - q.h. | -qh |  |
|  |  |  |  |  | - q.i.d. | - qid |  |
|  |  |  |  |  | - q.i.w. | - qiw |  |
|  |  |  |  |  | - q.o.d. | - qod |  |
|  |  |  |  |  | - q.o.w. | - qow |  |
|  |  |  |  |  | - q.w. | - qw |  |
|  |  |  |  |  | - STAT | - stat |  |
|  |  |  |  |  | - t.i.d. | - tid |  |
|  |  |  |  |  | - t.i.w. | - tiw |  |
| Regimen per day | THD,TON | Medication | frequent | text |  |  | PDS |
| Route | THD,TON | Medication | route | singlechoice | - p.o. | -0 | PDS |
|  |  |  |  |  | - p.r. | -1 |  |
|  |  |  |  |  | - s.c. | -2 |  |
|  |  |  |  |  | - i.m. | -3 |  |
|  |  |  |  |  | - i.v. | -4 |  |
|  |  |  |  |  | - nasal | -5 |  |
|  |  |  |  |  | - td | -6 |  |
| Start day | THD,TON | Medication | cmstdy | number |  |  | PDS |
| Start day (precision) | THD,TON | Medication | cmstdy__prec | singlechoice | - precision in day | -d | Not <br> Available |
|  |  |  |  |  | - precision in month | - m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Ongoing | THD,TON | Medication | cmenrf | boolean | - no | -0 | PDS |
|  |  |  |  |  | - yes | -1 |  |
| End day | THD,TON | Medication | cmendy | number |  |  | PDS |
| End day (precision) | THD,TON | Medication | cmendy__prec | text | - precision in day | -d |  |



### 3.3 Data File "comorbid (Comorbid Conditions)"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Recoded HDID | THD,TON | Key Vars | subjid | text |  |  |  |  |
| Study ID (THD or <br> TON) | THD,TON | Key Vars | studyid | text | $-\quad$ THD <br> - <br> $-\quad$ TON <br> THD/TON | PDS |  |  |
| Sequence | THD,TON | Key Vars | seq | number |  |  |  |  |
|  |  |  |  |  |  |  |  |  |  |

### 3.3.1 Form "Comorbidities"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| Disorders (ICD10 <br> Modified Term) | THD,TON | Comorbid | mhterm__modify | text |  |  | PDS |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Condition - Code (coded by MedDRA) | THD,TON | Comorbid | mhterm_decod | text |  |  | Available upon SRC approval |
| Disorders (ICD10 Code) | THD,TON | Comorbid | mhterm__decod_r | text |  |  | PDS |
| Start day | THD,TON | Comorbid | mhstdy | number |  |  |  |
| Start day (precision) | THD,TON | Comorbid | mhstdy_prec | singlechoice | - precision in day | -d | Not Available |
|  |  |  |  |  | - precision in month | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Ongoing | THD,TON | Comorbid | mhenrf | boolean | - no | -0 | PDS |
|  |  |  |  |  | - yes | -1 |  |
| End day | THD,TON | Comorbid | mhendy | number |  |  |  |
| End day (precision) | THD,TON | Comorbid | mhendy__prec | singlechoice | - precision in day | -d | Not Available |
|  |  |  |  |  | - precision in month | -m |  |
|  |  |  |  |  | - precision in years | - y |  |

### 3.4 Data File "family" (Family information)

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :---: | :---: |
| Recoded Family <br> ID | TON,THD | Key Vars | fmlyid | number |  |  |  | PDS |
| Family member <br> ID | TON,THD | Key Vars | id | number |  |  |  |  |
| Raw Family <br> member ID | TON,THD | Key Vars | id_raw | number |  |  | Not |  |
| Available |  |  |  |  |  |  |  |  |


| Recoded Family <br> member ID | TON,THD | Key Vars | id_r | number |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :---: |
| HDID | TON,THD | Key Vars | hdid | text |  | PDS |  |
| Recoded HDID | TON,THD | Key Vars | subjid | text |  | Not <br> Available |  |
| Study ID | TON,THD | Key Vars | studyid | text |  | PDS |  |
| Visit Number | TON,THD | Key Vars | visitnum | number |  |  | Not <br> Available |
| Visit | TON,THD | Key Vars | visit | text | - Family History |  | PDS |
| Form Number | TON,THD | Key Vars | nr | number |  | Not <br> Available |  |
| Visit Status | TON,THD | Key Vars | visstat | text | - completed | PDS |  |

### 3.4.1 Form "Family History"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Age of onset first symptoms | TON,THD | Family History | onset | number |  |  |  | PDS |
| Other family member ID | TON,THD | Family History | othid_original | number |  |  |  | Not Available |
| Recoded other family member ID | TON,THD | Family History | othid | number |  |  |  | PDS |
| Diagnosed by physician | TON,THD | Family History | physician | singlechoice | - yes | -1 |  |  |
|  |  |  |  |  | - no | -2 |  |  |
|  |  |  |  |  | - unknown | -3 |  |  |
| Diagnosed by physician | TON,THD | Family History | hddiagnb | singlechoice | - yes | -1 |  |  |
|  |  |  |  |  | - no | -2 |  |  |
|  |  |  |  |  | - unknown | -3 |  |  |


| Parent family member ID 1 | TON,THD | Family History | pid1_original | number |  |  | Not Available |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Recoded parent family member ID 1 | TON,THD | Family History | pid1 | number |  |  | PDS |
| Parent family member ID 2 | TON,THD | Family History | pid2_original | number |  |  | Not Available |
| Recoded parent family member ID 2 | TON,THD | Family History | pid2 | number |  |  |  |
| Special type of this node or type of relationship to other family member | TON,THD | Family History | type | text | - "infertile" <br> - "childless" <br> - "bitwin" <br> - "monotwin" <br> - "donor |  | PDS |
| Age at data entry | TON,THD | Family History | age | number |  |  |  |
| Cause | TON,THD | Family History | cause | text |  |  | Not <br> Available |
| Gender | TON,THD | Family History | sex | singlechoice | - female | -1 | PDS |
|  |  |  |  |  | - male | -2 |  |
| Year of birth | TON,THD | Family History | birth | number |  |  | Not <br> Available |
| Alive? | TON,THD | Family History | alive | singlechoice | - yes | -1 | PDS |
|  |  |  |  |  | - no | -2 |  |
|  |  |  |  |  | - unknown | -3 |  |
| Vital status | TON,THD | Family History | survstat | singlechoice | - alive | -1 |  |
|  |  |  |  |  | - dead | -2 |  |
|  |  |  |  |  | - unknown | -3 |  |
| Year of death | TON,THD | Family History | death | number |  |  | Not Available |


| Age of death | TON,THD | Family <br> History | Dssage | number |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| Recoded Spouse <br> ID 3 | TON,THD | Family <br> History | spid_r_3 | number |  | PDS |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :---: | :---: |
| Spouse ID 4 | TON,THD | Family <br> History | spid_4 | number |  |  | Not <br> Available |
| Recoded Spouse <br> ID 4 | TON,THD | Family <br> History | spid_r_4 | number |  |  | PDS |

## 4 Study-Based Data Files

### 4.1 Data File "participation"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Recoded HDID | THD,TON | Key Vars | subjid | text |  |  |  | PDS |
| Study Name (TRACK-HD or TRACK-ON HD) | THD,TON | Key Vars | study | text |  |  |  | PDS |
| Study ID | THD,TON | Key Vars | studyid | text |  |  |  | PDS |
| Site Index (per subject \& study) | THD,TON | Key Vars | seq | number |  |  |  | Not Available |
| Participant status | THD,TON | Key Vars | subjstat | text |  |  |  | PDS |
| Visit 1 | TON,THD | Key Vars | visit1 | text |  |  |  | PDS |
| Visit 2 | TON,THD | Key Vars | visit2 | text |  |  |  | PDS |
| Visit 3 | TON,THD | Key Vars | visit3 | text |  |  |  | PDS |
| Visit 4 | TON,THD | Key Vars | visit4 | text |  |  |  | PDS |
| Visit 1 day | TON,THD | Key Vars | vis1dy | text |  |  |  | PDS |
| Visit 2 day | TON,THD | Key Vars | vis2dy | text |  |  |  | PDS |
| Visit 3 day | TON,THD | Key Vars | vis3dy | text |  |  |  | PDS |
| Visit 4 day | TON,THD | Key Vars | vis4dy | text |  |  |  | PDS |

### 4.1.1 Form "Demog"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Age at <br> enrollment | THD, <br> TON | Demog | age | number |  |  |  |


| Comments | TON,THD | Demog | generalcmt | text |  | Not Available |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Subject Group by Iowa (Langbehn DR, 2004) | THD | Demog | sgroup_iowa | singlechoice | - control; <br> - HD stage1 <br> - HD stage2 <br> - preHD A <br> - preHD B | Available upon SRC approval |

### 4.1.2 Form "Eligibility"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Date of enrolment | THD,TON | Eligibility | rfstdtc | date |  |  |  |  |
| Date of enrolment (precision) | THD,TON | Eligibility | rfstdtc__ prec | singlechoice | - precision in day | -d |  |  |
|  |  |  |  |  | - precision in month | -m |  |  |
|  |  |  |  |  | - precision in years | - y |  |  |
| Signature of subject | THD, TON | Eligibility | signp | boolean | - no | - 0 |  | Not |
|  |  |  |  |  | - yes | -1 |  | Available |
| Signature of investigator | THD,TON | Eligibility | signi | boolean | - no | -0 |  |  |
|  |  |  |  |  | - yes | -1 |  |  |
| Ability to tolerate MRI and sample donation | THD | Eligibility | incl01 | boolean | - no | -0 |  |  |
|  |  |  |  |  | - yes | -1 |  |  |
| Subject will be either | THD | Eligibility | incl02_thd | singlechoice | - control subject | - 0 |  | PDS |
|  |  |  |  |  | - premanifest gene carrier | -1 |  |  |
|  |  |  |  |  | - early HD | - 2 |  |  |
| Relation to subject | THD,TON | Eligibility | relation | singlechoice | - Partner/spouse of the subject, not at risk | -1 |  |  |


|  |  |  |  |  | - HD normal repeat length sibling or HD normal repeat length control volunteer | - 2 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| $\begin{aligned} & \text { Positive genetic } \\ & \text { test with CAG } \\ & \text { repeat length >= } \\ & 40^{1} \end{aligned}$ | THD,TON | Eligibility | incl02c | boolean | - no <br> - yes | -0 -1 |  |
| Disease burden score (CAG- $\text { 35.5)*age > } 250$ | THD, TON | Eligibility | incl02d | boolean | $\begin{array}{\|l\|} \hline- \text { no } \\ \hline- \text { yes } \end{array}$ | -0 -1 |  |
| Absence of diagnostic motor features according to the UHDRS 99 | THD | Eligibility | incl02e | boolean | - no ${ }^{\text {n }}$ - yes | -0 -1 |  |
| Positive genetic test with CAG repeat length >= 40 (if early HD) ${ }^{1}$ | THD | Eligibility | incl02f | boolean | $\begin{array}{\|l\|} \hline- \text { no } \\ \hline- \text { yes } \end{array}$ | -0 -1 | Not Available |
| Presence of diagnostic motor features according to the UHDRS 99 | THD | Eligibility | incl02g | boolean | - no - yes | -0 -1 |  |
| Shoulson and Fahn stage 1 (TFC $>=11$ to <= 13) or 2 (TFC >= 7 to <= 10) assessed according to | THD | Eligibility | incl02h | boolean | - no <br>  <br> - yes | -0 -1 |  |

${ }^{1}$ When participants were enrolled in the study, they were all resized, and some of them had a smaller CAG than the original sizing on the genetics report. For these cases, a waiver was granted so that they could be included in the study.

| UHDRS total functional capacity |  |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Stage 3 (TFC <= 6) or greater at time of enrolment | THD | Eligibility | excl01 | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Younger than 18 years of age | THD | Eligibility | excl02 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Older than 65 years of age | THD | Eligibility | excl03 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Major psychiatric disorder at time of enrolment | THD,TON | Eligibility | excl04 | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Concomitant significant neurological disorder | THD,TON | Eligibility | excl05 | boolean | - no | - 0 | Available upon SRC |
|  |  |  |  |  | - yes | -1 |  |
| Concomitant significant medical illness | THD,TON | Eligibility | excl06 | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Unsuitability for MRI, e.g. <br> claustrophobia, metal implants | THD,TON | Eligibility | excl07 | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 | Not |
| Unwillingness to donate blood | THD,TON | Eligibility | excl08 | boolean | - no | - 0 | Available |
|  |  |  |  |  | - yes | -1 |  |
| History of significant head injury | THD,TON | Eligibility | excl09 | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | - 1 |  |
| Predictable noncompliance by | THD,TON | Eligibility | excl10 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |


| drug and/or alcohol abuse |  |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Significant hand injuries that preclude either writing or rapid computerized responding | THD,TON | Eligibility | excl11 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Participant in Predict-HD | THD,TON | Eligibility | excl12 | boolean | - no | - 0 | Available upon SRC approval |
|  |  |  |  |  | - yes | -1 |  |
| Currently participating in a clinical drug trial | THD,TON | Eligibility | excl13 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Former TRACKHD subject | TON | Eligibility | thdsbj | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Date of TRACKHD enrolment | TON | Eligibility | thdrfstdtc | date |  |  | Not Available |
| Date of TRACKHD enrolment (precision) | TON | Eligibility | thdrfstdtc__prec | single- <br> choice | - precision in day | -d |  |
|  |  |  |  |  | - precision in month | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Last TRACK-HD visit | TON | Eligibility | thdlstvst | singlechoice | - Visit 1 | -1 | PDS |
|  |  |  |  |  | - Visit 2 | -2 |  |
|  |  |  |  |  | - Visit 3 | - 3 |  |
|  |  |  |  |  | - Visit 4 | -4 |  |
| Date of last TRACK-HD visit | TON | Eligibility | thdlstvstdtc | date |  |  | Not |
|  | TON | Eligibility | thdlstvstdtc__prec | singlechoice | - precision in day | -d | Available |
|  |  |  |  |  | - precision in month | -m |  |


| Date of last TRACK-HD visit (precision) |  |  |  |  | - precision in years | - y |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Day of last <br> TRACK-HD visit | TON | Eligibility | thdlstvstdy | number |  |  | PDS |
| Ability to tolerate MRI | TON | Eligibility | ic3 | boolean | $\begin{array}{\|} \hline- \text { no } \\ \hline \text { - yes } \\ \hline \end{array}$ | -0 | Not Available |
| Subject will be either | TON | Eligibility | incl02_ton | singlechoice | - control subject <br> - premanifest gene carrier | -1 | PDS |
| Presence of motor scores > 5 according to the UHDRS 99 | TON | Eligibility | ic6 | boolean | $\frac{- \text { no }}{- \text { yes }}$ | -0 -1 | Not <br> Available |
| Age 18 to 65 years | TON | Eligibility | ic7 | boolean | $\frac{- \text { no }}{- \text { yes }}$ | -0 |  |
| Known history of epilepsy | TON | Eligibility | ec2 | boolean | $\begin{array}{\|l} \hline \text { - no } \\ \hline \text { - yes } \end{array}$ | -0 -1 | Available upon SRC approval |
| Diagnostic confidence scores of 4 according to the UHDRS 99 | TON | Eligibility | ec12 | boolean | - no | -0 -1 | Not <br> Available |
| Subject is | TON | Eligibility | eligible | singlechoice | $\begin{aligned} & \hline- \text { not eligible } \\ & \hline- \text { eligible } \end{aligned}$ | -0 |  |

### 4.1.3 Form "End"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | vailability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |


| Did the subject complete the study? | THD,TON | End | complete | boolean | - no | - 0 | PDS |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - yes | -1 |  |
| Specify primary reason for subject's premature discontinuation from study: | THD,TON | End | discon | singlechoice | - death | - 0 |  |
|  |  |  |  |  | - event or illness necessitating withdrawal | -1 |  |
|  |  |  |  |  | - request of primary care physician | - 2 |  |
|  |  |  |  |  | - subject's request | -3 |  |
|  |  |  |  |  | - failure of subject to return to next visit and failure to be located by investigator | -4 |  |
|  |  |  |  |  | - Institutionalized (will not be followed further) | - 5 |  |
|  |  |  |  |  | - Other | -6 |  |
|  |  |  |  |  | - failure to complete the required study procedures, regardless of reason | - 7 |  |
|  |  |  |  |  | - the site investigator feels that it is in the best interest of the subject | -8 |  |
| Please specify | THD,TON | End | disconspec | text |  |  | Not <br> Available |
| Does a request for additional withdrawal of material from the study exist? |  |  |  |  | - no | -0 |  |
|  | THD,TON | End | withdrawal | boolean | - yes | -1 |  |
| Please select each withdrawn | THD | End | withdrawn__data | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |


| material Biosamples |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Please select |  |  |  |  | - no | -0 |
| material - MRI scans | THD | End | withdrawn__samples | boolean | - yes | -1 |
| Please select |  |  |  |  | - no | -0 |
| material - All <br> other data | THD | End | withdrawn__scans | boolean | - yes | -1 |
| Latest visit data available and approved for analysis | THD, TON | End | last_visit | singlechoice | - No visit | -0 |
|  |  |  |  |  | - Visit 1 | -1 |
|  |  |  |  |  | - Visit 2 | -2 |
|  |  |  |  |  | - Visit 3 | -3 |

### 4.2 Data File "assessment"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Recoded HDID |  | Key Vars | subjid | text |  |  |  | PDS |
| Study Identifier (THD or TON) |  | Key Vars | studyid | text |  |  |  | PDS |
| Study |  | Key Vars | study | text |  |  |  |  |
| Visit Name |  | Key Vars | visit | text |  |  |  | PDS |
| Day of visit (ref. <br> to baseline) |  | Key Vars | visdy | number |  |  |  | PDS |
| Visit Status |  | Key Vars | visstat | text | - editing <br> - plausible <br> - signed <br> - reviewing |  |  | PDS |


|  |  |  |  | - completed <br> - checked |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Apathy-c Form | Key Vars | Apathy-c | number | - available | -1 | PDS |
| Apathy-s Form | Key Vars | Apathy-s | number | - available | -1 | PDS |
| BDI | Key Vars | BDI | number | - available | -1 | PDS |
| CAG History Form | Key Vars | CAG History | number | - available | -1 | PDS |
| Cognitive Form | Key Vars | Cognitive | number | - available | -1 | PDS |
| FrSBe-F Form | Key Vars | FrSBe-F | number | - available | -1 | PDS |
| FrSBe-S Form | Key Vars | FrSBe-S | number | - available | -1 | PDS |
| Function Form | Key Vars | Function | number | - available | -1 | PDS |
| Graphimetry Form | Key Vars | Graphimetry | number | - available | -1 | PDS |
| HADS-SIS Form | Key Vars | HADS-SIS | number | - available | -1 | PDS |
| HD History Form | Key Vars | HD History | number | - available | -1 | PDS |
| HDQ-D2-c Form | Key Vars | HDQ-D2-c | number | - available | -1 | PDS |
| HDQ-D2-p Form | Key Vars | HDQ-D2-p | number | - available | -1 | PDS |
| Irritability-c Form | Key Vars | Irritability-c | number | - available | -1 | PDS |
| Irritability-s Form | Key Vars | Irritability-s | number | - available | -1 | PDS |
| ISHD Form | Key Vars | ISHD | number | - available | -1 | PDS |
| Key Variables | Key Vars | Key Vars | number | - available | -1 | PDS |
| Medical History Form | Key Vars | Medical History | number | - available | - 1 | PDS |
| Motor Form | Key Vars | Motor | number | - available | -1 | PDS |
| MRI Form | Key Vars | MRI | number | - available | -1 | PDS |
| MRI 1,5T Form | Key Vars | MRI 1,5T | number | - available | -1 | PDS |
| MRI 3T Form | Key Vars | MRI 3T | number | - available | -1 | PDS |
| fMRI QC Form | Key Vars | fMRI QC | number | - available | -1 | PDS |
| MRI DTI QC Form | Key Vars | MRI DTI QC | number | - available | -1 | PDS |
| Oculomotor Form | Key Vars | Oculomotor | number | - available | -1 | PDS |
| PBA-s Form | Key Vars | PBA-s | number | - available | -1 | PDS |


| Physical Activities Form | Key Vars | Physical Activities | number | - available | -1 | PDS |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| PSQI Form | Key Vars | PSQI | number | - available | -1 | PDS |
| QMotor Form | Key Vars | QMotor | number | - available | -1 | PDS |
| QOLI Form | Key Vars | QOLI | number | - available | -1 | PDS |
| Samples Form | Key Vars | Samples | number | - available | -1 | PDS |
| Samples ACD Form | Key Vars | Samples ACD | number | - available | - 1 | PDS |
| Samples EDTA PX Form | Key Vars | Samples EDTA PX | number | - available | - 1 | PDS |
| Samples EDTA ACD Form | Key Vars | Samples EDTA ACD | number | - available | - 1 | PDS |
| Samples Other Form | Key Vars | Samples Other | number | - available | -1 | PDS |
| SF-36v2 Form | Key Vars | SF-36v2 | number | - available | -1 | PDS |
| TFC Form | Key Vars | TFC | number | - available | -1 | PDS |
| TMS Form | Key Vars | TMS | number | - available | -1 | PDS |
| Variable Items Form | Key Vars | Variable Items | number | - available | -1 | PDS |

## 5 Visit-Based Data Files

### 5.1 Form Schedules of Visits per Study

The information regarding the completeness of each form per Visit type (Visit1, Visit2, Visit3, Visit4) and per Study is in Table 5.

Table 5 Form completeness per study per visit type.

| form | Visit 1 | Visit 2 | Visit 3 | Visit 4 |
| :---: | :---: | :---: | :---: | :---: |
| Apathy-c | TON | TON | THD, TON | THD |
| Apathy-s | TON | TON | THD, TON | THD |
| BDIII | THD, TON | THD, TON | THD, TON | THD |
| CAG History | THD, TON |  |  |  |
| Cognitive | THD, TON | THD, TON | THD, TON | THD |
| fMRI QC |  |  | TON |  |
| FrSBe-F | THD, TON | THD, TON | THD, TON | THD |
| FrSBe-S | THD, TON | THD, TON | THD, TON | THD |
| Function | THD, TON | THD, TON | THD, TON | THD |
| Graphimetry | THD | THD |  |  |
| HADS-SIS | THD, TON | THD, TON | THD, TON | THD |
| HD History | THD |  | THD | THD |
| HDQ-D2-c | TON |  |  | THD |
| HDQ-D2-p | TON |  |  | THD |
| Irritability-c | TON | TON | THD, TON | THD |
| Irritability-s | TON | TON | THD, TON | THD |
| ISHD | THD | THD | THD |  |
| Medical History | THD, TON |  |  |  |
| Motor | THD, TON | THD, TON | THD, TON | THD |
| MRI | TON | TON | TON |  |
| MRI 1.5T | THD | THD |  |  |
| MRI 3T | THD | THD | THD | THD |
| MRI DTI QC | THD | THD | THD | THD |
| Oculomotor | THD, TON | THD, TON | THD | THD |
| PBA-s | THD | THD | THD | THD |
| Physical <br> Activities | TON |  |  | THD |
| PSQI |  |  | THD | THD |
| QMotor | THD, TON | THD, TON | THD, TON | THD |
| QOLI | THD, TON | THD | THD | THD |
| Samples | TON | TON | TON |  |


| Samples ACD | THD, TON | THD | THD |  |
| :--- | :--- | :--- | :--- | :--- |
| Samples EDTA <br> ACD | THD | THD | THD | THD |
| Samples EDTA <br> PX | THD | THD | THD | THD |
| Samples Other | TON | TON | TON |  |
| SF-36v2 | THD | THD | THD |  |
| TFC | THD, TON | THD, TON | THD, TON | THD |
| TMS | TON | TON | TON |  |
| Variable Items | THD, TON | THD, TON | THD, TON | THD |

### 5.2 Key Variables for all studies

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Recoded HDID |  | Key Vars | subjid | text |  |  |  | PDS |
| Study ID |  | Key Vars | studyid | text |  |  |  | PDS |
| Visit Number |  | Key Vars | visitnum | number |  |  |  | Not Available |
| Form Number |  | Key Vars | nr | number |  |  |  | Not Available |
| Row Number |  | Key Vars | enr | number |  |  |  | Not Available |
| Visit Date |  | Key Vars | visdat | date |  |  |  | Not Available |
| Day of visit (ref. <br> to baseline) |  | Key Vars | visdy | number |  |  |  | PDS |
| Visit Status |  | Key Vars | visstat | text | - editing <br> - plausible <br> - signed <br> - reviewing <br> - completed <br> - checked |  |  | PDS |

### 5.3 Data files "track" and "trackon"

### 5.3.1 Form "Apathy-c"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Date of data obtained | THD (V3,V4); <br> TON (V1,V2,V3) | Apathy-c | acjcdtc_c | date |  |  |  | Not Available |
| Date data obtained (precision) | THD <br> (V3,V4); <br> TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | Apathy-c | acjcdtc_prec_c | singlechoice | - precision in days m | -d |  |  |
| Day of data obtained | $\begin{array}{\|l\|l} \hline \text { THD } \\ \text { (V3,V4) } \\ \hline \end{array}$ | Apathy-c | acjcdy_c | number |  |  |  | PDS |
| Date data obtained (precision) | $\begin{aligned} & \hline \text { THD (V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \\ & \hline \end{aligned}$ | Apathy-c | acjcdy_c__prec | singlechoice | - precision in days m | -d |  | Not Available |
| Score | THD (V3,V4); <br> TON (V1,V2,V3) | Apathy-c | apathycscore_c | number |  |  |  |  |
| Is he/she interested in learning new things? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-c | learning_ c | singlechoice | - not at all | -0 |  |  |
|  |  |  |  |  | - slightly | -1 |  |  |
|  |  |  |  |  | - some | -2 |  |  |
|  |  |  |  |  | - a lot | -3 |  |  |
| Does anything interest him/her? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-c | interest_ c | singlechoice | - not at all | -0 |  |  |
|  |  |  |  |  | - slightly | -1 |  |  |
|  |  |  |  |  | - some | -2 |  |  |
|  |  |  |  |  | - a lot | -3 |  |  |


| Does someone have to tell him/her what to do each day? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-c | todo_c | single- <br> choice | - not at all | - 0 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Is he/she concerned about his/her condition? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-c | condition_ c | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Is he/she indifferent to things? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-c | indifferent_ c | single- <br> choice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Does he/she put much effort into things? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-c | effort_c | single- <br> choice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Is he/she always looking for something to do? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-c | something_c | single- <br> choice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Does he/she have plans and goals for the future? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-c | future_c | singlechoice | - not at all | - 0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Does he/she have motivation? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-c | motivation_c | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | -3 |
|  |  | Apathy-c | energy_c |  | - not at all | -0 |



### 5.3.2 Form "Apathy-s"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Availability |  |  |  |  |  |  |  |
| Date of data <br> obtained | THD <br> (V3,V4); <br> TON <br> (V1,V2,V3) | Apathy-s | acjcdtc | Not |  |  |  |
| Available |  |  |  |  |  |  |  |



| Are you indifferent to things? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Apathy-s | indifferent | single- <br> choice | - not at all | - 0 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Do you put much effort into things? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-s | effort | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Are you always looking for something to do? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-s | something | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Do you have plans and goals for the future? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-s | future_apathy | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | - 2 |
|  |  |  |  |  | - a lot | - 3 |
| Do you have motivation? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-s | motivation | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Do you have energy for daily activities? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-s | energy_apathy | single- <br> choice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Are you unconcerned with many things? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-s | unconcern | single- <br> choice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
|  |  | Apathy-s | push |  | - not at all | -0 |


| Do you need a push to get started on things? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \\ & \hline \end{aligned}$ |  |  | singlechoice | - slightly | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Do you feel neither happy nor sad, just in between, no matter what happens? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-s | between | single- <br> choice | - not at all | - 0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Do you think you are apathetic? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Apathy-s | apathetic | single- <br> choice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | -3 |

### 5.3.3 Form "BDI II"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Beck Depression Score | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | BDI | bditotal | number |  |  |  | PDS |
| 1. Sadness | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | BDI | asad | singlechoice | - I do not feel sad | -0 |  |  |
|  |  |  |  |  | - I feel sad much of the time | -1 |  |  |
|  |  |  |  |  | - I am sad all the time | - 2 |  |  |
|  |  |  |  |  | - I am so sad or unhappy that I can't stand it | - 3 |  |  |
| 2. Pessimism | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \end{aligned}$ | BDI | bdiscourage | singlechoice | - I am not discouraged about my future | - 0 |  |  |




|  |  |  |  |  | - I would kill myself if I had the chance | - 3 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 10. Crying | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | BDI | jcry | single- <br> choice | - I don't cry any more than I used to | -0 |
|  |  |  |  |  | - I cry more than I used to | -1 |
|  |  |  |  |  | - I cry over every little thing | -2 |
|  |  |  |  |  | - I feel like crying, but I can't | - 3 |
| 11. Agitation | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | BDI | kagitation | single- <br> choice | - I am no more restless or wound up than usual | -0 |
|  |  |  |  |  | - I feel more restless or wound up than usual | -1 |
|  |  |  |  |  | - I am so restless or agitated that it's hard to stay still | -2 |
|  |  |  |  |  | - I am so restless or agitated that I have to keep moving or doing something | -3 |
| 12. Loss of Interest | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | BDI | linterest | singlechoice | - I have not lost interest in other people or activities | -0 |
|  |  |  |  |  | - I am less interested in other people or things than before | -1 |
|  |  |  |  |  | - I have lost most of my interest in other people or things | - 2 |
|  |  |  |  |  | - It's hard to get interested in anything | -3 |
| 13. <br> Indecisiveness | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,, V3,V4); } \end{aligned}$ | BDI | mdesicions | singlechoice | - I make decisions about as well as ever | -0 |



$\left.\begin{array}{|c|c|} & \\ \hline\end{array} \left\lvert\, \begin{array}{l|l|l|}\hline \begin{array}{l}-1 \text { am much less interested } \\ \text { in sex now }\end{array} & -2 \\ \begin{array}{l}- \text { I have lost interest in sex } \\ \text { completely }\end{array} & -3\end{array}\right.\right]$

### 5.3.4 Form "CAG History"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Date of <br> laboratory report | THD <br> (V1); <br> TON <br> (V1) | CAG <br> History | datecag | date |  |  |  |  |
| Date of <br> laboratory report <br> (precision) | THD <br> (V1); <br> TON <br> (V1) | CAG <br> History | datecag_prec |  |  |  |  |  |


| Allele 2 CAG repeat length (larger allele) | THD <br> (V1); <br> TON <br> (V1) | CAG History | allelelarge | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Analyzing laboratory | $\begin{aligned} & \text { THD } \\ & \text { (V1); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | CAG <br> History | analyselab | text |  |  |  |
| Comments | THD <br> (V1); <br> TON <br> (V1) | CAG History | commentcag | boolean | - no -yes | -0 -1 | Not Available |
| Enter comment | THD <br> (V1); <br> TON <br> (V1) | CAG History | commentcagtxt | text |  |  |  |

### 5.3.5 Form "Cognitive"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Recent hand or <br> wrist injuries | TON <br> (V1,V2,V3) | Cognitive | injuries | boolean | - no |  |  |
| Recent pain in <br> hand or wrist | TON <br> (V1,V2,V3) | Cognitive | pain_cogn | bes | -0 |  |  |
| History of <br> arthritis in hand <br> or wrist | TON <br> (V1,V2,V3) | Cognitive | arthritis | boolean | - no | -1 |  |
| Musical <br> expertise, <br> expertise as a <br> typist, extensive | TON <br> (V1,V2,V3) | Cognitive | expertise | boolean | - no | - yes | -0 |


|  | use of video <br> games or <br> extensive use of <br> SMS (texting) |  |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| Digital <br> Fingerprint (MD5) of the RAW Data | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | spot_md5 | text |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Hit rate | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | spot_setsize5_hitrate | number |  |  |  |
| Hit rate | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | spot_setsize7_ hitrate | number |  |  |  |
| Correct rejection rate | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | spot_setsize5_ correjectrate | number |  |  |  |
| Correct rejection rate | $\begin{array}{\|l} \hline \text { THD } \\ (\mathrm{V} 2, \mathrm{~V} 3, \mathrm{~V} 4) ; \\ \text { TON } \\ (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ \hline \end{array}$ | Cognitive | spot_setsize7_ correjectrate | number |  |  |  |
| Number correct | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | spot_setsize5_k | number |  |  |  |
| Number correct | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | spot_setsize7_k | number |  |  |  |
| Total percent correct | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | spot_setsize5_ percentcorrect | number |  |  | \% |


| Total percent correct | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \\ & \hline \end{aligned}$ | Cognitive | spot_setsize7_ percentcorrect | number |  |  | \% |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - not started | -0 |  |  |
| Test completed | (V1.V2.V3) | Cognitive | msearch_ton |  | - yes | -1 |  |  |
|  |  |  |  |  | - partial data | -2 |  |  |
| Total number correctly found in 1 min | $\begin{aligned} & \hline \text { THD (V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | msearch_totcorr_1min | number |  |  |  |  |
| Total number correctly found in 2 min | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | msearch_totcorr_2min | number |  |  |  |  |
| Total number of incorrectly <br> identified <br> symbols in 2 <br> min | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | msearch_totincorr_2min | number |  |  |  |  |
|  |  |  |  |  | - not started | - 0 |  |  |
|  |  | Cognitive | circle | single- | - yes | -1 |  |  |
|  |  |  |  |  | - partial data | -2 |  |  |
| RAW data | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | circle_raw | text |  |  |  | Not |
| Digital <br> Fingerprint (MD5) of the RAW Data | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | circle_md5 | text |  |  |  | Available |
| Number of rotations completed | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \end{aligned}$ | Cognitive | circle_ind_all_numrot | number |  |  |  | PDS |

$\left.\begin{array}{|l|l|l|l|l|l|l|l|} & \begin{array}{l}\text { TON } \\ \text { (V1,V2,V3) }\end{array} & & & & & & \\ \hline \begin{array}{l}\text { Number of } \\ \text { deviations } \\ \text { beyond outer } \\ \text { edge of annulus }\end{array} & \begin{array}{l}\text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON } \\ \text { (V1,V2,V3) }\end{array} & \text { Cognitive } & \begin{array}{l}\text { circle_ind_all_outerr_ } \\ \text { numdev }\end{array} & \text { number }\end{array}\right)$

$\left.\begin{array}{|l|l|l|l|l|l|l|l|}\begin{array}{l}\text { Mean radius } \\ \text { over all sampled } \\ \text { points }\end{array} & \begin{array}{l}\text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON } \\ \text { (V1,V2,V3) }\end{array} & \text { Cognitive } & \begin{array}{l}\text { circle_ind_ } \\ \text { all_radius_mean }\end{array} & \text { number }\end{array}\right)$


| Mean theta over all sampled points | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | circle_dir_ all_theta_mean | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Mean radius over all sampled points | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | circle_dir_ all_radius_mean | number |  |  |  |
|  |  |  |  |  | - not started | -0 |  |
| Cancellation <br> Task completed | (V1,V2,V3) | Cognitive | cancel | singlechoice | - yes | -1 |  |
|  |  |  |  |  | - partial data | -2 |  |
| Digit Number of Errors in | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | cancel_digit_errors_45s | number |  |  |  |
| Digit Number of Errors in | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | cancel_digit_errors_90s | number |  |  |  |
| Digit Number correct in | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | cancel_digit_ <br> totalcorrect_45s | number |  |  |  |
| Digit Number correct in | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | cancel_digit_ totalcorrect_90s | number |  |  |  |
| Figure_Number of Errors in | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | cancel_fig_errors_45s | number |  |  |  |
| Figure_Number of Errors in | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | cancel_fig_errors_90s | number |  |  |  |
| Figure Number correct in | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | ```cancel_fig_totalcorrect_ 45s``` | number |  |  |  |
| Figure Number correct in | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | Cognitive | cancel_fig_totalcorrect_ 90s | number |  |  |  |
| Digital <br> Fingerprint (MD5) of the RAW Data | TON (V1,V2,V3) | Cognitive | cancel_md5 | text |  |  | Not <br> Available |


| Reason for noncompletion | TON (V1) | Cognitive | cancel_noncompl | singlechoice | - subject unable to complete | -1 | PDS |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - STOP THE TASK protocol applied | - 2 |  |
|  |  |  |  |  | - equipment failure | -3 |  |
|  |  |  |  |  | - other | -4 |  |
| RAW data | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | cancel_raw | text |  |  | Not Available |
| Counting, Centimeters of ink laid within the annulus | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | Cognitive | $\begin{aligned} & \text { circle_cnt_direct_all_ } \\ & \text { ann_lgth } \end{aligned}$ | number |  |  |  |
| Counting, Total <br> Number of <br> Correct <br> Numbers <br> counted aloud | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | circle_cnt_ direct_totalcorrect | number |  |  |  |
| Counting, Total <br> Number of <br> Numbers <br> counted aloud | TON (V1,V2,V3) | Cognitive | circle_cnt_ direct_totalnumber | number |  |  | PDS |
| Counting, Centimeters of ink laid within the annulus | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | circle_cnt_ indirect_all_ ann_lgth | number |  |  |  |
| Counting, Total <br> Number of <br> Correct <br> Numbers <br> counted aloud | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | Cognitive | circle_cnt_ indirect_totalcorrect | number |  |  |  |
| Counting, Total Number of | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | circle_cnt_ indirect_totalnumber | number |  |  |  |


| Numbers counted aloud |  |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Reason for noncompletion | TON (V1) | Cognitive | circle_noncompl | single- <br> choice | - subject unable to complete | -1 | Not <br> Available |
|  |  |  |  |  | - STOP THE TASK protocol applied | - 2 |  |
|  |  |  |  |  | - equipment failure | -3 |  |
|  |  |  |  |  | - other | -4 |  |
| Please explain | $\begin{aligned} & \hline \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | circle_noncompl_cmnt | text |  |  |  |
| IQ Covariate completed | THD (V1); TON (V1) | Cognitive | iq | single- <br> choice | - not started | - 0 | PDS |
|  |  |  |  |  | - yes | -1 |  |
|  |  |  |  |  | - partial data | - 2 |  |
| Test | TON (V1) | Cognitive | iq_test | single- <br> choice | - NART-2 | -1 |  |
|  |  |  |  |  | - ANART | -2 |  |
|  |  |  |  |  | - DART | - 3 |  |
|  |  |  |  |  | - Echelle de vocabulaire Mill Hill | -4 |  |
| Reason for noncompletion | TON (V2,V3) | Cognitive | mrot_noncompl | single- <br> choice | - subject unable to complete | -1 |  |
|  |  |  |  |  | - STOP THE TASK protocol applied | - 2 |  |
|  |  |  |  |  | - equipment failure | - 3 |  |
|  |  |  |  |  | - other | -4 |  |
| Please explain | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | Cognitive | mrot_noncompl_cmnt | text |  |  | Not Available |
| Self Paced <br> Tapping Task completed | TON(V1,V2,V3) | Cognitive | ptap | single- <br> choice | - not started | - 0 | PDS |
|  |  |  |  |  | - yes | -1 |  |
|  |  |  |  |  | - partial data | -2 |  |


| Average signed deviation from target intervals | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | ptap_3hz_ all_self_iti_ asgnd | number |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Standard deviation of intertap intervals | TON (V1,V2,V3) | Cognitive | ptap_3hz_all_self_iti_sd | number |  |  |
| Average signed deviation from target intervals | TON (V1,V2,V3) | Cognitive | ptap_3hz_all_tone_iti_ asgnd | number |  |  |
| Standard deviation of intertap intervals | TON (V1,V2,V3) | Cognitive | ptap_3hz_ <br> all_tone_iti_sd | number |  |  |
| Reason for noncompletion | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | ptap_noncompl | singlechoice | - subject unable to complete | -1 |
|  |  |  |  |  | - STOP THE TASK protocol applied | -2 |
|  |  |  |  |  | - equipment failure | -3 |
|  |  |  |  |  | - other | -4 |
| Symbol Digit <br> Modalities Test (SDMT) completed | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | sdmt | singlechoice | - not started | -0 |
|  |  |  |  |  | - yes | -1 |
|  |  |  |  |  | - partial data | - 2 |
| Reason for noncompletion | TON (V2,V3) | Cognitive | sdmt_noncompl | singlechoice | - subject unable to complete | -1 |
|  |  |  |  |  | - STOP THE TASK protocol applied | - 2 |
|  |  |  |  |  | - equipment failure | -3 |
|  |  |  |  |  | - other | -4 |
| Reason for noncompletion | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | spot_noncompl | singlechoice | - subject unable to complete | -1 |


|  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| orientation-2 and 6 |  |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Trials responded correctly for orientation-3 and 5 | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | mrot_ang3_ percentcor | number |  |  | \% |
| Trials responded correctly for orientation-4 | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | mrot_ang4_ percentcor | number |  |  | \% |
| Mean response times for correctly responded to "same" trials at orientation-1 | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | mrot_corang1same_ meanrt | number |  |  |  |
| Mean response times for correctly responded to "same" trials at orientation - 2 and 6 | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | mrot_corang2same_ meanrt | number |  |  |  |
| Mean response times for correctly responded to "same" trials at orientation-3 and 5 | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | mrot_corang3same_ meanrt | number |  |  |  |


| Mean response times for correctly responded to "same" trials at orientation-4 | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | mrot_corang4same_ meanrt | number |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| mean response times | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | mrot_corsame_meanrt | number |  |  |  |  |
| speed of rotation | $\begin{aligned} & \hline \text { THD (V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Cognitive | mrot_corsame_ rotationspeed | number |  |  | ms/degree |  |
| Do you suffer | THD |  |  |  | - no | -0 |  |  |
| from smell problems | (V1,V2,V3) | Cognitive | smellproblems | boolean | - yes | -1 |  |  |
| Please specify | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | smellproblemsspec | text |  |  |  | Not Available |
| Do you suffer | THD |  |  |  | - no | - 0 |  |  |
| from taste problems | (V1,V2,V3) | Cognitive | tasteproblems | boolean | - yes | -1 |  | PDS |
| Please specify | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | tasteproblemsspec | text |  |  |  | Not <br> Available |
| History of |  |  |  |  | - never smoked | -1 |  |  |
| smoking | (V1,V2, V3) | Cognitive | smoking | choice | - ex-smoker | -2 |  |  |
| tobacco |  |  |  |  | - currently smokes | -3 |  |  |
| How many cigarettes per day | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | numbercigarettes | number |  |  |  | PDS |
| How many cigars per day | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | numbercigars | number |  |  |  |  |
| Other per day | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | numberothers | number |  |  |  |  |


| Do you inhale | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | inhalation | boolean | - no | - 0 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - yes | -1 |  |
| When did you start | $\begin{aligned} & \hline \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | startsmoking | number |  |  |  |
| When did you stop | $\begin{aligned} & \hline \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | stopsmoking | number |  |  |  |
| Did your smell ability change after stopping | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | smellchanges | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Please specify | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | smellchangesspec | text |  |  | Not Available |
| Symbol Digit <br> Modalities Test (SDMT) completed | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | digit | boolean | - no | - 0 | PDS |
|  |  |  |  |  | - yes | - 1 |  |
| Stroop Test - <br> Word Reading <br> Condition <br> completed | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | stroop_thd | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | - 1 |  |
| Number of words correct in 45 seconds | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | swr_correct | number |  |  |  |
| Start time | THD (V1,V2) | Cognitive | swr_start__h | number |  |  | Not Available |
| Start time | THD (V1,V2) | Cognitive | swr_start__m | number |  |  |  |
| Finish time | THD (V1,V2) | Cognitive | swr_finish_h | number |  |  |  |
| Finish time | THD (V1,V2) | Cognitive | swr_finish__m | number |  |  |  |
| Trail Making <br> Test Part A completed | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | traila | boolean | - no | - 0 | PDS |
|  |  |  |  |  | - yes | -1 |  |


| Time to complete Trails A | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | traila_time | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Start time | THD (V1,V2) | Cognitive | triala_start__h | number |  |  | Not <br> Available |
| Start time | THD (V1,V2) | Cognitive | triala_start__m | number |  |  |  |
| Finish time | THD (V1,V2) | Cognitive | triala_finish__h | number |  |  |  |
| Finish time | THD (V1,V2) | Cognitive | triala_finish_m | number |  |  |  |
| Number of errors | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | triala_error | number |  |  | PDS |
| Trail Making |  |  |  |  | - no | -0 |  |
| Test Part B completed | (V1,V2,V3) | Cognitive | trailb | boolean | - yes | -1 |  |
| Time to complete Trails B | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Cognitive | trailb_time | number |  |  |  |
| Start time | THD (V1,V2) | Cognitive | trialb_start__h | number |  |  | Not <br> Available |
| Start time | THD (V1,V2) | Cognitive | trialb_start__m | number |  |  |  |
| Finish time | THD (V1,V2) | Cognitive | trialb_finish__h | number |  |  |  |
| Finish time | THD (V1,V2) | Cognitive | trialb_finish__m | number |  |  |  |
| Number of errors | $\begin{array}{\|l\|} \hline \text { THD } \\ (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ \hline \end{array}$ | Cognitive | trialb_error | number |  |  | PDS |
| Point of View <br> Task completed | THD (V1) | Cognitive | pov | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| RAW data | THD (V1) | Cognitive | pov_raw | text |  |  | Not Available |
| Speeded | THD (V1,V2) | Cognitive | st | boolean | - no | -0 | PDS |
| Tapping Task completed |  |  |  |  | - yes | -1 |  |


| RAW data | THD (V1,V2) | Cognitive | stap_raw | text |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Digital <br> Fingerprint (MD5) of the RAW Data | THD (V1,V2) | Cognitive | stap_md5 | text |  |  | Not <br> Available |
| Mean of intertap intervals (all trials) | THD (V1,V2) | Cognitive | stap_alltrials_ intertapinterval_ mean | number |  |  | PDS |
| Standard <br> Deviation of intertap intervals (all trials) | THD (V1,V2) | Cognitive | stap_alltrials_ intertapinterval_stddev | number |  |  |  |
| Start time | THD (V1) | Cognitive | stap_start__h | number |  |  | Not <br> Available |
| Start time | THD (V1) | Cognitive | stap_start__m | number |  |  |  |
| Finish time | THD (V1) | Cognitive | stap_finish__h | number |  |  |  |
| Finish time | THD (V1) | Cognitive | stap_finish__m | number |  |  |  |
| Speeded |  |  |  |  | - no | - 0 |  |
| Tapping Task with Serial 2s completed | THD (V1,V2) | Cognitive | st2_cogn | boolean | - yes | - 1 | PDS |
| RAW data | THD (V1,V2) | Cognitive | stap2_raw | text |  |  |  |
| Digital <br> Fingerprint (MD5) of the RAW Data | THD (V1,V2) | Cognitive | stap2_md5 | text |  |  | Not Available |
| 100 No Tap | THD (V1,V2) | Cognitive | stap2_trial1_ subtract_cogn | number |  |  | PDS |


| 100 No Tap | THD (V1,V2) | Cognitive | stap2_trial1_errors_cogn | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 99 Tap | THD (V1,V2) | Cognitive | stap2_trial2_ subtract_cogn | number |  |  |  |
| 99 Tap | THD (V1,V2) | Cognitive | stap2_trial2_errors_cogn | number |  |  |  |
| 98 Tap | THD (V1,V2) | Cognitive | stap2_trial3_ subtract_cogn | number |  |  |  |
| 98 Tap | THD (V1,V2) | Cognitive | stap2_trial3_errors_cogn | number |  |  |  |
| 97 Tap | THD (V1,V2) | Cognitive | stap2_trial4_ subtract_cogn | number |  |  |  |
| 97 Tap | THD (V1,V2) | Cognitive | stap2_trial4_errors_cogn | number |  |  |  |
| 96 Tap | THD (V1,V2) | Cognitive | stap2_trial5_ subtract_cogn | number |  |  |  |
| 96 Tap | THD (V1,V2) | Cognitive | stap2_trial5_errors_cogn | number |  |  |  |
| 95 Tap | THD (V1,V2) | Cognitive | stap2_trial6_ subtract_cogn | number |  |  |  |
| 95 Tap | THD (V1,V2) | Cognitive | stap2_trial6_errors_cogn | number |  |  |  |
| Mean of intertap intervals (all trials) | THD (V1,V2) | Cognitive | stap2_alltrials_ intertapinterval_ mean | number |  |  |  |
| Standard <br> Deviation of intertap intervals (all trials) | THD (V1,V2) | Cognitive | stap2_alltrials_ intertapinterval_ stddev | number |  |  |  |
| Start time | THD (V1) | Cognitive | stap2_start__h | number |  |  | Not Available |
| Start time | THD (V1) | Cognitive | stap2_start__m | number |  |  |  |
| Finish time | THD (V1) | Cognitive | stap2_finish_h | number |  |  |  |
| Finish time | THD (V1) | Cognitive | stap2_finish__m | number |  |  |  |
|  |  | Cognitive | pt | boolean | - no | -0 | PDS |


| Self Paced <br> Tapping Task completed | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ |  |  |  | - yes | - 1 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Standard deviation of intertap intervals | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | ptap_3hz_alltrials_ tone_intertapinterval_ stddev | number |  |  |  |
| Standard deviation of intertap intervals | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | ptap_3hz_alltrials_ self_intertapinterval_ stddev | number |  |  |  |
| Standard deviation of intertap intervals | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | ptap_182hz_alltrials_ tone_intertapinterval_ stddev | number |  |  |  |
| Standard deviation of intertap intervals | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | ptap_182hz_alltrials_ self_intertapinterval_ stddev | number |  |  |  |
| Average signed deviation from target intervals | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | ptap_3hz_alltrials_ tone_intertapinterval_ avgsigneddev | number |  |  |  |
| Average signed deviation from target intervals | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | ptap_3hz_alltrials_ self_intertapinterval_ avgsigneddev | number |  |  |  |
| Average signed deviation from target intervals | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | ptap_182hz_ alltrials tone_intertapinterval_ avgsigneddev | number |  |  |  |
| Average signed deviation from target intervals | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | ptap_182hz_ alltrials self_intertapinterval_ avgsigneddev | number |  |  |  |
| Start time | THD (V1) | Cognitive | ptap_start__h | number |  |  | Not Available |


| Start time | THD (V1) | Cognitive | ptap_start__m | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Finish time | THD (V1) | Cognitive | ptap_finish__h | number |  |  |  |
| Finish time | THD (V1) | Cognitive | ptap_finish__m | number |  |  |  |
| Emotion |  |  |  |  | - no | -0 |  |
| Recognition <br> Task completed | (V1,V2, V3, V4) | Cognitive | emo | boolean | - yes | -1 | PDS |
| RAW data | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_raw | text |  |  |  |
| Digital <br> Fingerprint (MD5) of the RAW Data | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_md5 | text |  |  | Not Available |
| Negative <br> Emotions - Total number correct | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_negative_ numbercorrect | number |  |  |  |
| Number of anger stims responded to as Anger | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_responses_ anger_anger | number |  |  |  |
| Number of anger stims responded to as Disgust | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_responses_ anger_disgust | number |  |  | PDS |
| Number of anger stims responded to as Fear | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_responses_ anger_fear | number |  |  |  |
| Number of anger stims responded to as Happiness | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_responses_ anger_happiness | number |  |  |  |







| Number of surprise stims responded to as Fear | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_responses_ surprise_fear | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Number of surprise stims responded to as Happiness | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_responses_ surprise_happiness | number |  |  |  |
| Number of surprise stims responded to as Neutral | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_responses_ surprise_neutral | number |  |  |  |
| Number of surprise stims responded to as Sadness | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_responses_ surprise_sadness | number |  |  |  |
| Number of surprise stims responded to as Surprise | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | emo_responses_ surprise_surprise | number |  |  |  |
| Spot the Change <br> Task completed | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | stc | boolean | $\begin{array}{\|l\|} \hline-\mathrm{no} \\ \hline-\mathrm{ye} \\ \hline \end{array}$ | -0 |  |
| Hit rate | THD (V1) | Cognitive | spot_setsize3_hitrate | number |  |  |  |
| Correct rejection rate | THD (V1) | Cognitive | spot_setsize3_ correctrejectrate | number |  |  |  |
| Number correct | THD (V1) | Cognitive | spot_setsize3_k | number |  |  |  |
| Total percent correct | THD (V1) | Cognitive | spot_setsize3_ percentcorrect | number |  |  | \% |
| Smell <br> Identification <br> Test (UPSIT-20) <br> completed | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit | boolean | - no - yes | -0 -1 |  |


| Odor 1 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit1 | singlechoice | - a | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - b | -2 |
|  |  |  |  |  | - c | -3 |
|  |  |  |  |  | - d | -4 |
| Odor 2 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit2 | singlechoice | - a | -1 |
|  |  |  |  |  | - b | -2 |
|  |  |  |  |  | - c | -3 |
|  |  |  |  |  | -d | -4 |
| Odor 3 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit3 | singlechoice | - a | -1 |
|  |  |  |  |  | - b | -2 |
|  |  |  |  |  | - c | -3 |
|  |  |  |  |  | -d | -4 |
| Odor 4 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit4 | singlechoice | - a | -1 |
|  |  |  |  |  | - b | -2 |
|  |  |  |  |  | - c | -3 |
|  |  |  |  |  | -d | -4 |
| Odor 5 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit5 | singlechoice | - a | -1 |
|  |  |  |  |  | - b | -2 |
|  |  |  |  |  | - c | -3 |
|  |  |  |  |  | - d | -4 |
| Odor 6 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit6 | singlechoice | - a | -1 |
|  |  |  |  |  | - b | -2 |
|  |  |  |  |  | - c | -3 |
|  |  |  |  |  | -d | -4 |
| Odor 7 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit7 | singlechoice | - a | -1 |
|  |  |  |  |  | - b | -2 |
|  |  |  |  |  | - c | -3 |
|  |  |  |  |  | -d | -4 |
| Odor 8 |  | Cognitive | upsit8 |  | - a | -1 |



|  |  |  |  |  | - c | - 3 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - d | -4 |  |
| Odor 26 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit26 | singlechoice | - a | -1 |  |
|  |  |  |  |  | - b | -2 |  |
|  |  |  |  |  | - c | -3 |  |
|  |  |  |  |  | - d | -4 |  |
| Odor 27 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit27 | singlechoice | - a | -1 |  |
|  |  |  |  |  | - b | -2 |  |
|  |  |  |  |  | - c | -3 |  |
|  |  |  |  |  | - d | -4 |  |
| Odor 28 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit28 | singlechoice | - a | -1 |  |
|  |  |  |  |  | - b | -2 |  |
|  |  |  |  |  | - c | -3 |  |
|  |  |  |  |  | - d | -4 |  |
| Odor 29 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit29 | singlechoice | - a | -1 |  |
|  |  |  |  |  | - b | -2 |  |
|  |  |  |  |  | - c | - 3 |  |
|  |  |  |  |  | - d | -4 |  |
| Odor 30 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsit30 | singlechoice | - a | -1 |  |
|  |  |  |  |  | - b | -2 |  |
|  |  |  |  |  | - c | - 3 |  |
|  |  |  |  |  | -d | -4 |  |
| Total number of correct responses | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Cognitive | upsitresponses | number |  |  |  |
| Circle Tracing Task completed | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Cognitive | ct | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |



| Digital <br> Fingerprint (MD5) of the RAW Data | THD (V3,V4) | Cognitive | cosh_md5 | text |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Trials expected | THD (V3,V4) | Cognitive | cosh_numtrialsexpected | number |  |  |  |
| Trials administered | THD (V3,V4) | Cognitive | cosh_all_ numadministered | number |  |  |  |
| Incorrect responses | THD (V3,V4) | Cognitive | cosh_all_ numincorrect | number |  |  |  |
| Switch trials | THD (V3,V4) | Cognitive | cosh_letswi_ wpc_percentcor | number |  |  | \% |
| Non-switch trials | THD (V3,V4) | Cognitive | cosh_letnos_ wpc_percentcor | number |  |  | \% |
| Switch trials | THD (V3,V4) | Cognitive | $\begin{aligned} & \text { cosh_corletswi200_ } \\ & \text { wpc_rt } \end{aligned}$ | number |  |  |  |
| Non-switch trials | THD (V3,V4) | Cognitive | cosh_corletnos200_ <br> wpc_rt | number |  |  |  |
| Word at 200 ISI | THD (V3,V4) | Cognitive | cosh_corwor200_ <br> wpc_switchcost | number |  |  |  |
| Letter at 200 ISI | THD (V3,V4) | Cognitive | cosh_corlet200_ wpc_switchcost | number |  |  |  |
| Word at 1200 ISI | THD (V3) | Cognitive | cosh_corwor1200_ <br> wpc_switchcost | number |  |  |  |
| Letter at 1200 ISI | THD (V3) | Cognitive | cosh_corlet1200_ <br> wpc_switchcost | number |  |  |  |
| 200 ISI | THD (V3,V4) | Cognitive | cosh_cor200_ <br> wpc_interference | number |  |  |  |
| 1200 ISI | THD (V3) | Cognitive | cosh_cor1200_ wpc_interference | number |  |  |  |
| Map Search Test completed | THD (V3,V4) | Cognitive | msearch_thd | boolean | - no | -0 |  |

PDS

| Number of <br> deviations <br> inside inner <br> edge of annulus | THD (V3) | Cognitive | circle_direct_alltrials_ <br> insideerror__ <br> numdeviations | number |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Mental Rotation <br> Task completed | THD (V3,V4) | Cognitive | mrot_thd | boolean | - no | -0 |
|  | - yes | -1 |  |  |  |  |

### 5.3.6 Form "Frontal Systems Behaviour Inventory (FrSBe-F)"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Total FrSBe score | THD (V1,V2, V3, V4); TON (V1,V2,V3) | FrSBe-F | frsbescore_f | number |  |  |  | PDS |
| Apathy | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2, V3, V4); } \\ & \text { TON } \\ & \text { (V1,V2, } \mathrm{V} 3 \text { ) } \\ & \hline \end{aligned}$ | FrSBe-F | apathyscore_f | number |  |  |  |  |
| Disinhibition | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2, V3, V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \\ & \hline \end{aligned}$ | FrSBe-F | disinhibscore_f | number |  |  |  |  |
| Executive Dysfunction | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2, V3, V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \\ & \hline \end{aligned}$ | FrSBe-F | execdysscore_f | number |  |  |  |  |
| 1. Speaks only when spoken to | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2, V3, V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-F | frontf1ba | singlechoice | - almost never <br> - seldom <br> - sometimes | -1 -2 -3 |  | Not <br> Available |



| 7. Makes the <br> same mistakes <br> over and over, <br> does not learn <br> from past <br> experience | THD <br> (V1,V2,V3,V4); <br> TON <br> (V1,V2,V3) |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


|  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| 18. Talks out of <br> turn, interrupts <br> others in <br> conversations | THD <br> (V1,V2,V3,V4); <br> TON <br> (V1,V2,V3) |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| 24. Shows little emotion, is unconcerned and unresponsive | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-F | frontf24b | single- <br> choice | - almost never | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 25. Forgets to do things but then remembers when prompted or when it is too late | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-F | frontf25b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | - 5 |
| 26. Is inflexible, unable to change routines | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-F | frontf26b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | - 5 |
| 27. Gets in trouble with the law or authorities | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-F | frontf27b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 28. Does risky things just for the heck of it | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-F | frontf28b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 29. Is slow moving, lacks energy, inactive | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \end{aligned}$ | FrSBe-F | frontf29b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |



| acting (for |  |  |  |  | - sometimes | -3 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| example, | (V1,V2,V3) |  |  |  | - seldom | -4 |
| finances before spending money) |  |  |  |  | - almost never | - 5 |
|  |  |  |  |  | - almost always | -1 |
| strategies to | THD |  |  |  | - frequently | -2 |
| remember | (V1,V2, V3, V4); |  |  | single- | - sometimes | -3 |
|  | TON |  |  | choice | - seldom | -4 |
| writes notes to self) |  |  |  |  | - almost never | -5 |
|  |  |  |  |  | - almost always | -1 |
|  |  |  |  |  | - frequently | -2 |
|  | TON | FrSBe-F | frontf37b |  | - sometimes | -3 |
|  | (V1,V2,V3) |  |  |  | - seldom | -4 |
|  |  |  |  |  | - almost never | -5 |
|  |  |  |  |  | - almost always | -1 |
|  | THD |  |  |  | - frequently | -2 |
| in sex | TON | FrSBe-F | frontf38b | choice | - sometimes | -3 |
|  | (V1,V2,V3) |  |  |  | - seldom | -4 |
|  |  |  |  |  | - almost never | -5 |
| 39. Cares about |  |  |  |  | - almost always | -1 |
| his/her | THD |  |  |  | - frequently | -2 |
| appearance (for |  | FrSBe-F | frontf39b | choice | - sometimes | -3 |
| example, daily | (V1,V2,V3) |  |  |  | - seldom | -4 |
| grooming) |  |  |  |  | - almost never | -5 |
| 40. Benefits from feedback, accepts | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \end{aligned}$ | FrSBe-F | frontf40b | singlechoice | - almost always | -1 |
|  |  |  |  |  | - frequently | -2 |
|  |  |  |  |  | - sometimes | -3 |



| 46. Starts conversations spontaneously | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ |  | singlechoice | - frequently | - 2 |
| :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  | - sometimes | - 3 |
|  |  |  |  | - seldom | -4 |
|  |  |  |  | - almost never | - 5 |

### 5.3.7 Form "Frontal Systems Behaviour Inventory (FrSBe-S)"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Total FrSBe score | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | FrSBe-S | frsbescore | number |  |  |  | PDS |
| Apathy | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | FrSBe-S | apathyscore | number |  |  |  |  |
| Disinhibition | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | FrSBe-S | disinhibscore | number |  |  |  |  |
| Executive Dysfunction | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | FrSBe-S | execdysscore | number |  |  |  |  |
| 1. I speak only when spoken to | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp1b | singlechoice | - almost never | -1 |  | Not <br> Available |
|  |  |  |  |  | - seldom | -2 |  |  |
|  |  |  |  |  | - sometimes | -3 |  |  |
|  |  |  |  |  | - frequently | -4 |  |  |
|  |  |  |  |  | - almost always | -5 |  |  |


| 2. I am easily angered or irritated; I have emotional outbursts without good reason | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp2b | singlechoice | - almost never | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | - 5 |
| 3. Repeat certain actions or get stuck on certain ideas | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp3b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 4. I do things impulsively | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp4b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 5. Mix up a sequence, get confused when doing several things in a row | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp5b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 6. Laugh or cry easily | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp6b | single- <br> choice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 7. Make the same mistakes over and over, | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \end{aligned}$ | FrSBe-S | frontp7b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |



| 13. Am unaware of my problems or when I make mistakes | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ |  |  |  | - seldom | - 2 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  | single- | - sometimes | - 3 |
|  |  |  |  | choice | - frequently | -4 |
|  |  |  |  |  | - almost always | - 5 |
| 14. Sit around doing nothing | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp15b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 15. Am disorganized | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp16b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 16. Lose control of my urine or bowels and it doesn't seem to bother me | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp17b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 17. Cannot do two things at once (for example, talk and prepare a meal) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp18b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 18. Talk out of turn, interrupt others in conversations | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp19b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - frequently | -4 |


|  |  |  |  |  | - almost always | -5 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - almost never | -1 |
| 19. Show poor | THD |  |  |  | - seldom | -2 |
| judgement, poor |  | FrSBe-S | frontp20b | single- | - sometimes | -3 |
| problem solver | (V1,V2,V3) |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 20. Make up |  |  |  |  | - almost never | -1 |
| fantastic stories | THD |  |  |  | - seldom | -2 |
| when unable to |  | FrSBe-S | frontp21b |  | - sometimes | -3 |
| remember | (V1, V2, V3) |  |  |  | - frequently | -4 |
| something |  |  |  |  | - almost always | -5 |
| 21. Have lost |  |  |  |  | - almost never | -1 |
| interest in things |  |  |  |  | - seldom | -2 |
| that used to be |  | FrSBe-S | frontp22b | single- | - sometimes | -3 |
| fun or important | (V1,v2,V3) |  |  |  | - frequently | -4 |
| to me |  |  |  |  | - almost always | -5 |
|  |  |  |  |  | - almost never | -1 |
| 22. Say one | THD |  |  |  | - seldom | -2 |
| thing, then do | (V1,V2,V3,V4); | FrSBe-S | frontp23b | single- | - sometimes | -3 |
| another thing |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
|  |  |  |  |  | - almost never | -1 |
| Start things | THD |  |  |  | - seldom | -2 |
| but fail to finish | (V1,V2,V3,V4); | FrSBe-S | frontp24b | single- | - sometimes | -3 |
| them, 'peter out' | (V1,V2,V3) |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 24. Show little emotion, am | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \end{aligned}$ | FrSBe-S | frontp25b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |


| unconcerned and unresponsive | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ |  |  |  | - frequently | -4 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - almost always | -5 |
| 25. Forget to do things but then remember when prompted or when it is too late | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp26b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 26. Am inflexible, unable to change routines | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp27b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 27. Get in trouble with the law or authorities | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp28b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 28. Do risky things just for the heck of it | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp29b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
| 29. Am slow moving, lack energy, inactive | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp30b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | -5 |
|  |  | FrSBe-S | frontp31b |  | - almost never | -1 |


| 30. Am overly silly, have a childish sense of humor | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ |  |  |  | - seldom | - 2 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  | single- | - sometimes | - 3 |
|  |  |  |  | choice | - frequently | -4 |
|  |  |  |  |  | - almost always | - 5 |
| 31. Find that food has no taste or smell | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp32b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | - 5 |
| 32. Swear | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp33b | singlechoice | - almost never | -1 |
|  |  |  |  |  | - seldom | -2 |
|  |  |  |  |  | - sometimes | -3 |
|  |  |  |  |  | - frequently | -4 |
|  |  |  |  |  | - almost always | - 5 |
| 33. Apologize for misbehaviour (for example, apologize for swearing) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | FrSBe-S | frontp34b | singlechoice | - almost always | -1 |
|  |  |  |  |  | - frequently | - 2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - seldom | -4 |
|  |  |  |  |  | - almost never | - 5 |
| 34. Pay attention, concentrates even when there are distractions | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | FrSBe-S | frontp35b | singlechoice | - almost always | -1 |
|  |  |  |  |  | - frequently | -2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - seldom | -4 |
|  |  |  |  |  | - almost never | - 5 |
| 35. Think things through before acting (for example, consider finances | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | FrSBe-S | frontp36b | singlechoice | - almost always | -1 |
|  |  |  |  |  | - frequently | -2 |
|  |  |  |  |  | - sometimes | - 3 |
|  |  |  |  |  | - seldom | -4 |
|  |  |  |  |  | - almost never | - 5 |


| before spending money) |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - almost always | -1 |
| strategies to | THD |  |  |  | - frequently | -2 |
| remember | (V1,V2,V3,V4); | FrSBe-S | frontp37b | single- | - sometimes | - 3 |
| (for example | TON | FrSBe-S | frontp37b | choice | - seldom | -4 |
| write notes to myself) |  |  |  |  | - almost never | - 5 |
|  |  |  |  |  | - almost always | -1 |
|  | THD |  |  |  | - frequently | -2 |
| 37. Am able to | TC | FrSBe-S | frontp38b | single- | - sometimes | -3 |
|  | (V1,V2,V3) |  |  |  | - seldom | -4 |
|  |  |  |  |  | - almost never | -5 |
|  |  |  |  |  | - almost always | -1 |
|  | THD |  |  |  | - frequently | -2 |
| 38. Am <br> interested in sex | (V1,V2,V3, V4); <br> TON | FrSBe-S | frontp39b | singlechoice | - sometimes | -3 |
|  | (V1,V2,V3) |  |  |  | - seldom | -4 |
|  |  |  |  |  | - almost never | -5 |
|  |  |  |  |  | - almost always | -1 |
| 39. Care about | THD |  |  |  | - frequently | -2 |
| my appearance (for example | (V1,V2,V3, V4); <br> TON | FrSBe-S | frontp40b | singlechoice | - sometimes | -3 |
| daily grooming) | (V1,V2,V3) |  |  |  | - seldom | -4 |
|  |  |  |  |  | - almost never | -5 |
| 40. Benefit from |  |  |  |  | - almost always | -1 |
| feedback, accept | THD |  |  |  | - frequently | -2 |
| constructive | (V1,V2,V3, V4); <br> TON | FrSBe-S | frontp41b | singlechoice | - sometimes | -3 |
| criticism from | (V1.V2.V3) |  |  |  | - seldom | -4 |
| others |  |  |  |  | - almost never | - 5 |
|  |  | FrSBe-S | frontp42b |  | - almost always | -1 |


| 41. Get involved <br> with activities <br> spontaneously <br> (such as hobbies) | THD <br> (V1,V2,V3,V4); <br> TON <br> (V1,V2,V3) |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |

### 5.3.8 Form "Function"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Functional <br> Assessment <br> Score | $\begin{array}{\|l} \hline \text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON } \\ \text { (V1,V2, V3) } \\ \hline \end{array}$ | Function | fascore | number |  |  |  |  |
| Could subject engage in gainful employment in his/her accustomed work | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Function | emplus | boolean | - no | -0 |  |  |
|  |  |  |  |  | - yes | -1 |  |  |
| Could subject engage in any kind of gainful employment? | $\begin{array}{\|l} \hline \text { THD } \\ \text { (V1,V2, V3, V4); } \\ \text { TON } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | Function | emplany | boolean | - no | -0 |  |  |
|  |  |  |  |  | - yes | -1 |  |  |
| Could subject engage in any kind of volunteer or non- gainful work? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Function | volunt | boolean | - no | -0 |  | PDS |
|  |  |  |  |  | - yes | -1 |  |  |
| Could subject manage his/her finances (monthly) without any help? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Function | fafinan | boolean | - no | -0 |  |  |
|  |  |  |  |  | - yes | -1 |  |  |
| Could subject shop for | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4); } \end{aligned}$ | Function | grocery | boolean | - no | -0 |  |  |
|  |  |  |  |  | - yes | -1 |  |  |


| groceries without help? | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Could subject handle money as a purchaser in a simple cash (shop) transaction? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Function | cash | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |
| Could subject supervise children without help? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Function | supchild | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |
| Could subject operate an automobile safely and independently? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Function | drive | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |
| Could subject do his/her own housework without help? | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Function | housewrk | boolean | - no | - 0 |
|  |  |  |  |  | - yes | - 1 |
| Could subject do his/her own laundry (wash/dry) without help? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Function | laundry | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |
| Could subject prepare his/her own meals without help? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Function | prepmeal | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |
| Could subject use the telephone without help? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \end{aligned}$ | Function | telephon | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |


|  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
|  |  |  |  |  |


| Could subject walk without help? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ |  |  |  | - yes | -1 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Could subject comb hair without help? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Function | comb | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Could subject transfer between chairs without help? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \\ & \hline \end{aligned}$ | Function | trnchair | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Could subject get in and out of bed without help? | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Function | bed | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | - 1 |  |
| Could subject use toilet/commode without help? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Function | toilet | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Could subject's care still be provided at home? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Function | carehome | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Was the functional assessment information obtained from | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Function | fasrc | single <br> choice |  |  | Available upon SRC approval |
| Subject's independence in \% | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Function | indepscl | single choice | - no special care needed <br> - <br> - no physical care needed if difficult tasks are avoided | $\begin{aligned} & -100 \\ & -95 \\ & -90 \end{aligned}$ | PDS |




### 5.3.9 Form "Graphimetry"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| For right hand <br> form | THD <br> (V1,V2) | Graphimetry | rhandrest | boolean |  |  |  |
| For left hand <br> form | THD <br> (V1,V2) | Graphimetry | Ihandrest | boolean |  | Available |  |

5.3.10 Form "Hospital Anxiety/Depression Scale - Snaith Irritability Scale (HADS-SIS)"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Anxiety subscore | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | HADSSIS | anxscore | number |  |  |  |  |
| Depression subscore | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | HADSSIS | depscore | number |  |  |  | PDS |
| Irritability subscore | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2, V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | HADSSIS | irrscore | number |  |  |  |  |


| Outward irritability subscore | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | HADSSIS | outwardirrscore | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Inward irritability subscore | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | HADSSIS | inwardirrscore | number |  |  |  |
| I feel tense or 'wound up' | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | HADSSIS | tense | singlechoice | - not at all | -0 | Available upon SRC approval |
|  |  |  |  |  | - from time to time, occasionally | -1 |  |
|  |  |  |  |  | - a lot of the time | -2 |  |
|  |  |  |  |  | - most of the time | -3 |  |
| I still enjoy the things I used to enjoy | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | HADSSIS | enjoy | singlechoice | - definitely as much | -0 |  |
|  |  |  |  |  | - not quite so much | -1 |  |
|  |  |  |  |  | - only a little | -2 |  |
|  |  |  |  |  | - hardly at all | -3 |  |
| I get a sort of frightened feeling as if something awful is about to happen | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | HADSSIS | frighten | singlechoice | - not at all | -0 |  |
|  |  |  |  |  | - a little, but it doesn'?t worry me | -1 |  |
|  |  |  |  |  | - yes, but not too badly | - 2 |  |
|  |  |  |  |  | - very definitetly and quite badly | -3 |  |
| I lose my temper and shout or snap at others | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | HADSSIS | temper_hads | singlechoice | - no, not at all | -0 |  |
|  |  |  |  |  | - no, not much | -1 |  |
|  |  |  |  |  | - yes, sometimes | -2 |  |
|  |  |  |  |  | - yes, definitely | - 3 |  |
|  |  |  | laugh |  | - as much as I always could | -0 |  |





### 5.3.11 Form "HD History"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Indicate who provided the information - subject only | THD <br> (V1,V3,V4); <br> TON <br> (General) | HD History | informants_1 | boolean | - no | -0 |  | PDS |
|  |  |  |  |  | - yes | -1 |  |  |



|  | TON (General) |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| At what age did irritability begin | THD (V1,V3,V4); TON (General) | HD History | irritage | number |  |  |
| Has violent or aggressive behaviour ever been a part of the subject's HD clinical features | THD (V1,V3,V4); TON (General) | HD History | violent | boolean | - no - yes | -0 -1 |
| At what age did violent/aggressive behaviour begin | THD (V1,V3,V4); TON (General) | HD History | violentage | number |  |  |
| Has apathy ever been a part of the subject's HD clinical features | THD (V1,V3,V4); TON (General) | HD History | apathy | boolean | - no -yes | -0 -1 |
| At what age did apathy begin | THD (V1,V3,V4); TON (General) | HD History | apathyage | number |  |  |
| At what age did perseverative/obsessive behaviours begin | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V3,V4); } \\ & \text { TON } \\ & \text { (General) } \\ & \hline \end{aligned}$ | HD History | obsessage | number |  |  |
| Has perseverative/obsessive behaviours ever been a part of the subject's HD clinical features | THD (V1,V3,V4); TON (General) | HD History | obsessive | boolean | - no <br> - yes | -0 -1 |
|  |  |  | psychosis | boolean | - no | -0 |



| Day of ideation | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 3, \mathrm{~V} 4) \end{aligned}$ | HD <br> History | suicidaldy | number |  |  | PDS |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Date of ideation (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V3,V4) } \end{aligned}$ | HD History | suicidaldy__prec | singlechoice | - precision in days m | -d | Not Available |
|  |  |  |  |  | - no | -0 | PDS |
| Did subject receive hospital treatment | (V1,V3,V4); <br> TON <br> (General) | HD <br> History | suicidaltreat | boolean | - yes | -1 |  |
|  | THD |  |  |  | - no | - 0 |  |
| Previous suicide attempts | $\begin{aligned} & \text { (V1,V3,V4); } \\ & \text { TON } \\ & \text { (General) } \end{aligned}$ | HD <br> History | suicide | boolean | - yes | -1 |  |
| Date of attempt | $\begin{aligned} & \text { THD } \\ & \text { (V1,V3,V4); } \\ & \text { TON } \\ & \text { (General) } \\ & \hline \end{aligned}$ | HD <br> History | dtcsuicide | date |  |  | Not <br> Available |
| Date of attempt (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V3,V4); } \\ & \text { TON } \\ & \text { (General) } \\ & \hline \end{aligned}$ | HD <br> History | dtcsuicide__prec | date |  |  |  |
| Day of attempt | $\begin{aligned} & \text { THD } \\ & \text { (V1,V3,V4) } \end{aligned}$ | HD <br> History | suicidedy | number |  |  | PDS |
| Date of attempt (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V3,V4) } \end{aligned}$ | HD History | suicidedy__prec | singlechoice | - precision in days m | -d | Not Available |
|  | THD |  |  |  | - no | -0 | PDS |
| Did subject receive hospital treatment | $\begin{aligned} & \text { (V1,V3,V4); } \\ & \text { TON } \\ & \text { (General) } \\ & \hline \end{aligned}$ | HD <br> History | suicidetreat | boolean | - yes | -1 |  |
|  |  |  |  |  | - no | -0 |  |
| Previous self-harm | $\begin{aligned} & \text { (V1,V3,V4); } \\ & \text { TON } \\ & \text { (General) } \\ & \hline \end{aligned}$ | HD <br> History | selfharm | boolean | - yes | -1 |  |


| Date of self-harm | THD (V1,V3,V4); TON (General) | HD <br> History | dtcselfharm | date |  |  | Not |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Date of self-harm (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V3,V4); } \\ & \text { TON } \\ & \text { (General) } \\ & \hline \end{aligned}$ | HD <br> History | dtcselfharm__prec | date |  |  | Available |
| Date of self-harm | $\begin{aligned} & \hline \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 4) \end{aligned}$ | HD History | selfharmdy | number |  |  | PDS |
| Date of self-harm (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V3,V4) } \end{aligned}$ | HD History | selfharmdy__prec | singlechoice | - precision in days m | -d | Not Available |
|  | THD |  |  |  | - no | -0 | PDS |
| Did subject receive hospital treatment | (V1,V4); <br> TON <br> (General) | HD <br> History | selfharmtreat | boolean | - yes | - 1 |  |
| Age of HD diagnosed | THD (V1) | HD History | hddiagnosed | number |  |  |  |
| HD diagnosis day | THD (V1) | HD <br> History | hddiagnoseddy | number |  |  |  |
| HD diagnosis (month) | THD (V1) | HD History | hddiagnosed__month | number |  |  | Not Available |
| HD diagnosis (date) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V3,V4) } \end{aligned}$ | HD History | hddiagnosed_r | date |  |  |  |
| HD diagnosis (year) | THD (V1) | HD History | hddiagnosed__year | number |  |  |  |
| Age of symptoms first noted by subject | THD (V1) | HD History | symptomssubject | number |  |  | PDS |
| Age of symptoms first noted by subject (day) | THD (V1) | HD History | symptomssubjectdy | number |  |  |  |
| Age of symptoms first noted by subject (month) | THD (V1) | HD History | symptomssubject__month | number |  |  | Not Available |


| Age of symptoms first noted by subject (date) | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 3, \mathrm{~V} 4) \end{aligned}$ | HD <br> History | symptomssubject_r | date |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Age of symptoms first noted by subject (year) | THD (V1) | HD <br> History | symptomssubject__year | number |  |  |  |
| Age of symptoms first noted by family | THD (V1) | HD <br> History | symptomsfamily | number |  |  | PDS |
| Symptoms first noted by family day | THD (V1) | HD <br> History | symptomsfamilydy | number |  |  |  |
| Age of symptoms first noted by family (month) | THD (V1) | HD History | symptomsfamily__month | number |  |  | Not <br> Available |
| Symptoms first noted by family date | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 3, \mathrm{~V} 4) \end{aligned}$ | HD <br> History | symptomsfamily_r | date |  |  |  |
| Age of symptoms first noted by family (year) | THD (V1) | HD <br> History | symptomsfamily__year | number |  |  |  |
| Age of rater's estimate of symptom onset | THD (V1) | HD <br> History | raterestimate | number |  |  | PDS |
| Rater's estimate of symptom onset day | THD (V1) | HD History | raterestimatedy | number |  |  |  |
| Rater's estimate of symptom onset (month) | THD (V1) | HD <br> History | raterestimate__month | number |  |  | Not Available |
| Rater's estimate of symptom onset | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 3, \mathrm{~V} 4) \end{aligned}$ | HD History | raterestimate_r | date |  |  |  |
| Rater's estimate of symptom onset (year) | THD (V1) | HD <br> History | raterestimate__year | number |  |  |  |
| Initial major symptom noted by subject | THD (V1) | HD <br> History | majorsymptomsubject | singlechoice | - motor | -1 | PDS |
|  |  |  |  |  | - cognitive | -2 |  |
|  |  |  |  |  | - psychiatric | -3 |  |
|  |  |  |  |  | - oculomotor | -4 |  |
|  |  |  |  |  | - other | - 5 |  |
|  |  |  |  |  | - mixed | -6 |  |
|  | THD (V1) |  | majorsymptomfamily |  | - motor | -1 |  |


| Initial major symptom noted by family |  | HD History |  | singlechoice | - cognitive | -2 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - psychiatric | -3 |  |
|  |  |  |  |  | - oculomotor | -4 |  |
|  |  |  |  |  | - other (e.g. weight loss, insomnia) | -5 |  |
|  |  |  |  |  | - mixed | -6 |  |
| Rater's judgement of initial major symptom | THD (V1) | HD History | majorsymptomrater | singlechoice | - motor | -1 |  |
|  |  |  |  |  | - cognitive | -2 |  |
|  |  |  |  |  | - psychiatric | -3 |  |
|  |  |  |  |  | - oculomotor | -4 |  |
|  |  |  |  |  | - other (e.g. weight loss, insomnia) | -5 |  |
|  |  |  |  |  | - mixed | -6 |  |
| Comment? | THD (V1) | HD <br> History | commenthistory | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 | Not <br> Available |
| Comment | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V3,V4) } \end{aligned}$ | HD History | commenthistorytxt | text |  |  |  |

### 5.3.12 Form "HDQ-D2-c"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Had difficulty carrying things without dropping them | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c01 | singlechoice | - never | -1 |  | PDS |
|  |  |  |  |  | - very rarely | -2 |  |  |
|  |  |  |  |  | - infrequently | -3 |  |  |
|  |  |  |  |  | - sometimes | -4 |  |  |
|  |  |  |  |  | - often | -5 |  |  |
|  |  |  |  |  | - most of the time | -6 |  |  |


|  |  |  |  |  | - all of the time | - 7 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Lacked |  |  |  |  | - infrequently | - 3 |
| confidence with | IV |  | hdqd2c02 |  | - sometimes | -4 |
| his/her balance | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | - 6 |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Had difficulty |  |  |  |  | - infrequently | - 3 |
| walking |  |  | hdqd2c03 | single- | - sometimes | -4 |
| independently | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | - 6 |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Had difficulty |  |  |  |  | - infrequently | - 3 |
| doing jobs |  |  | hdqd2c04 |  | - sometimes | -4 |
| around the house | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | -7 |
| Had difficulty maintaining his/her weight | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c05 | single- <br> choice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |


| Had difficulty doing his/her hobby | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c06 | single- <br> choice | - never | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Had difficulty dressing himself/herself | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c07 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Felt cautious about swallowing food or drink | THD <br> (V4); <br> TON <br> (V1) | HDQ-D2- <br> c | hdqd2c08 | single- <br> choice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Found it hard to manage eating on his/her own | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & c \end{aligned}$ | hdqd2c09 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  | hdqd2c10 |  | - never | -1 |


| Could not operate a television | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ |  | single- <br> choice | - very rarely | -2 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Got tired easily | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c11 | single- <br> choice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Felt dissatisfied with his/her sleep | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c12 | single- <br> choice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Lacked confidence in doing more than one thing at a time | THD <br> (V4); <br> TON <br> (V1) | HDQ-D2- <br> C | hdqd2c13 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Took too long to do things | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \end{aligned}$ | HDQ-D2- <br> c | hdqd2c14 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |


|  | TON |  |  |  | - infrequently | - 3 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | (V1) |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | - 6 |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  |  |  | - never | -1 |
| Lacked |  |  |  |  | - very rarely | - 2 |
| confidence with |  |  |  |  | - infrequently | - 3 |
| expressing |  |  | hdqd2c15 | single- | - sometimes | -4 |
| his/her thoughts |  |  |  |  | - often | -5 |
| with words |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | - 2 |
| Could not |  |  |  |  | - infrequently | - 3 |
|  |  |  | hdqd2c16 |  | - sometimes | -4 |
| properly | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  | hdqd2c17 |  | - sometimes | -4 |
|  | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | - 6 |
|  |  |  |  |  | - all of the time | - 7 |
| Had difficulty remembering day to day things | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \end{aligned}$ | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c18 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |


|  | $\begin{aligned} & \text { TON } \\ & \text { (V1) } \end{aligned}$ |  |  |  | - sometimes | -4 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Found it hard to organize his/her day | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c19 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Could not follow a conversation properly | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c20 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Could not remember what day and month it is | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c21 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Worried about the impact of Huntington's on his/her family | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c22 | single- <br> choice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |




|  |  |  |  |  | - most of the time | -6 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Had problems |  |  |  |  | - infrequently | - 3 |
| with being | $\begin{aligned} & 1 V \\ & T C \end{aligned}$ | HDQ-D2- | hdqd2c27 | single- | - sometimes | -4 |
| independent |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Did not feel |  |  |  |  | - infrequently | - 3 |
| confident in |  | HDQ-D2- | hdqd2c28 | single- | - sometimes | -4 |
| himself/herself | (V1) |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  | THD |  |  |  | - infrequently | -3 |
| Felt down or |  |  | hdqd2c29 | single- | - sometimes | -4 |
|  | (V1) |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Lacked confidence in fulfilling his/her personal wishes in life | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c30 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |


|  |  |  |  |  | - all of the time | - 7 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - never | -1 |
| Had problems |  |  |  |  | - very rarely | -2 |
| with maintaining | THD |  |  |  | - infrequently | - 3 |
| a meaningful role | $\begin{aligned} & \text { TV } \\ & \text { To } \end{aligned}$ |  | hdqd2c31 |  | - sometimes | -4 |
| in his/her | (V1) |  |  |  | - often | - 5 |
| immediate family |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Had financial | THD |  |  |  | - infrequently | -3 |
| concerns for the | TON |  | hdqd2c32 |  | - sometimes | -4 |
| futu | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  | TH |  |  |  | - infrequently | -3 |
| Felt irritated | TON |  | hdqd2c33 | single- | - sometimes | -4 |
|  | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Lost his/her temper easily | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c34 | single- <br> choice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |


| Did not feel keen on going out to socialize | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c35 | single- <br> choice | - never | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | - 6 |
|  |  |  |  |  | - all of the time | - 7 |
| Felt conscious of people's attitude to his/her condition (i.e. Huntington's) | THD <br> (V4); <br> TON <br> (V1) | HDQ-D2- <br> C | hdqd2c36 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Had problems with getting support from his/her family or friends | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & c \end{aligned}$ | hdqd2c37 | single- <br> choice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Felt dissatisfied with local services/advice in relation to Huntington's | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c38 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | -7 |
|  |  |  | hdqd2c39 |  | - never | -1 |


| Felt dissatisfied with medical management of Huntington's | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ |  | single- <br> choice | - very rarely | -2 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Had problems with accessing information about Huntington's | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | hdqd2c40 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all of the time | - 7 |
| Overall, how would you rate the quality of life of your partner/family member | THD (V4) | HDQ-D2- <br> c | gnrlp01_c | singlechoice | - poor | -1 |
|  |  |  |  |  | - fair | - 2 |
|  |  |  |  |  | - good | - 3 |
|  |  |  |  |  | - very good | -4 |
|  |  |  |  |  | - excellent | - 5 |
| Overall, how would you rate the quality of life of your partner/family member | $\begin{aligned} & \text { TON } \\ & \text { (V1) } \end{aligned}$ | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { c } \end{aligned}$ | gnrlp01_c_ton | single- <br> choice | - poor | -1 |
|  |  |  |  |  | - fair | -2 |
|  |  |  |  |  | - good | - 3 |
|  |  |  |  |  | - very good | -4 |
|  |  |  |  |  | - excellent | - 5 |
| In the past month, how often have you seen your partner/family member | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & c \end{aligned}$ | gnrlc09_c | single- <br> choice | - never | -1 |
|  |  |  |  |  | - 1-3 times | -2 |
|  |  |  |  |  | - every week | -3 |
|  |  |  |  |  | - everyday | -4 |




### 5.3.13 Form "HDQ-D2-p"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Had difficulty carrying things without dropping them | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \mathrm{p} \end{aligned}$ | hdqd2p01 | singlechoice | - never | -1 |  |  |
|  |  |  |  |  | - very rarely | -2 |  |  |
|  |  |  |  |  | - infrequently | - 3 |  |  |
|  |  |  |  |  | - sometimes | -4 |  |  |
|  |  |  |  |  | - often | - 5 |  |  |
|  |  |  |  |  | - most of the time | -6 |  |  |
|  |  |  |  |  | - all the time | - 7 |  |  |
| Lacked confidence with your balance | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { p } \end{aligned}$ | hdqd2p02 | singlechoice | - never | -1 |  |  |
|  |  |  |  |  | - very rarely | - 2 |  | PDS |
|  |  |  |  |  | - infrequently | -3 |  |  |
|  |  |  |  |  | - sometimes | -4 |  |  |
|  |  |  |  |  | - often | - 5 |  |  |
|  |  |  |  |  | - most of the time | -6 |  |  |
|  |  |  |  |  | - all the time | - 7 |  |  |
| Had difficulty walking independently | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \end{aligned}$ | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { p } \end{aligned}$ | hdqd2p03 | singlechoice | - never | -1 |  |  |
|  |  |  |  |  | - very rarely | -2 |  |  |
|  |  |  |  |  | - infrequently | -3 |  |  |


|  | TON |  |  |  | - sometimes | -4 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Had difficulty |  |  |  |  | - infrequently | -3 |
| doing jobs |  | HDQ-D2- | hdqd2p04 | single- | - sometimes | -4 |
| around the house | (V |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Had difficulty |  |  |  |  | - infrequently | -3 |
| maintaining your |  | HDQ-D2- | hdqd2p05 | single- | - sometimes | -4 |
| weight | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  | THD |  |  |  | - infrequently | -3 |
| Had difficulty |  | HDQ-D2- | hdqd2p06 | single- | - sometimes | -4 |
|  | (V1 |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Had difficulty dressing yourself | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { p } \end{aligned}$ | hdqd2p07 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |


|  |  |  |  |  | - often | - 5 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Felt cautious |  |  |  |  | - infrequently | -3 |
| about swallowing |  | HDQ-D2- | hdqd2p08 | single- | - sometimes | -4 |
| food or drink | $1 \mathrm{~V}$ |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Found it hard to |  |  |  |  | - infrequently | -3 |
| manage eating |  | HDQ-D2- | hdqd2p09 | single- | - sometimes | -4 |
| on your own | (V1) |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Could not |  |  |  |  | - infrequently | -3 |
| operate a |  | HDQ-D2- | hdqd2p10 | single- | - sometimes | -4 |
| television | (V1) |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Got tired easily | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \mathrm{p} \end{aligned}$ | hdqd2p11 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |


|  |  |  |  |  | - most of the time | -6 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
| Felt dissatisfied |  | HDQ-D2- | hdqd2p12 | single- | - sometimes | -4 |
|  | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
| Lacked |  |  |  |  | - very rarely | -2 |
| confidence in |  |  |  |  | - infrequently | - 3 |
| doing more than | Tic | HDQ-D2- | hdqd2p13 | single- | - sometimes | -4 |
| one thing at a | (V1) |  |  |  | - often | -5 |
| time |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  | THD |  |  |  | - infrequently | -3 |
| Took too long to |  | HDQ-D2- | hdqd2p14 | singlechoice | - sometimes | -4 |
|  | (V1) |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Lacked confidence with expressing your thoughts with words | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \mathrm{p} \end{aligned}$ | hdqd2p15 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |


|  |  |  |  |  | - all the time | - 7 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Could not | THD |  |  |  | - infrequently | -3 |
|  |  |  | hdqd2p16 |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  | hdqd2p17 |  | - sometimes | -4 |
|  | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  |  |  | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
| Had difficulty |  |  |  |  | - infrequently | - 3 |
| remembering day |  |  | hdqd2p18 |  | - sometimes | -4 |
| to day things | (V1) |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Found it hard to organize your day | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & p \end{aligned}$ | hdqd2p19 | single- <br> choice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |


| Could not follow a conversation properly | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & p \end{aligned}$ | hdqd2p20 | single- <br> choice | - never | - 1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | - 6 |
|  |  |  |  |  | - all the time | - 7 |
| Could not remember what day and month it is | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & p \end{aligned}$ | hdqd2p21 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Worried about the impact of Huntington's on your family | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \mathrm{p} \end{aligned}$ | hdqd2p22 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Worried about showing symptoms of Huntington's disease progression | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { p } \end{aligned}$ | hdqd2p23 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | -3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  |  |  | hdqd2p24 |  | - never | -1 |


| Found it hard to feel hopeful about the future | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & p \end{aligned}$ |  | singlechoice | - very rarely | -2 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Could not easily get motivated to do things | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \mathrm{p} \end{aligned}$ | hdqd2p25 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Found it hard to get on with your life | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \mathrm{p} \end{aligned}$ | hdqd2p26 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Had problems with being independent | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { p } \end{aligned}$ | hdqd2p27 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | -5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
|  | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \end{aligned}$ | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { p } \end{aligned}$ | hdqd2p28 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |


| Did not feel confident in yourself | $\begin{aligned} & \text { TON } \\ & \text { (V1) } \end{aligned}$ |  |  |  | - infrequently | - 3 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | - 6 |
|  |  |  |  |  | - all the time | - 7 |
| Felt down or depressed | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { p } \end{aligned}$ | hdqd2p29 | single- <br> choice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Lacked confidence in fulfilling your personal wishes in life | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & p \end{aligned}$ | hdqd2p30 | single- <br> choice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Had problems with maintaining a meaningful role in your immediate family | THD <br> (V4); <br> TON <br> (V1) | $\begin{aligned} & \text { HDQ-D2- } \\ & \text { p } \end{aligned}$ | hdqd2p31 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |
|  |  |  |  |  | - sometimes | -4 |
|  |  |  |  |  | - often | - 5 |
|  |  |  |  |  | - most of the time | -6 |
|  |  |  |  |  | - all the time | - 7 |
| Had financial concerns for the future | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \end{aligned}$ | $\begin{aligned} & \text { HDQ-D2- } \\ & \mathrm{p} \end{aligned}$ | hdqd2p32 | singlechoice | - never | -1 |
|  |  |  |  |  | - very rarely | -2 |
|  |  |  |  |  | - infrequently | - 3 |




$\left.\begin{array}{|l|l|l|l|l|l|l|l|} & \begin{array}{l}\text { TON } \\ \text { (V1) }\end{array} & & & & & & \\ \hline \begin{array}{l}\text { Hopes and } \\ \text { worries (SHW) }\end{array} & \begin{array}{l}\text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) }\end{array} & \begin{array}{l}\text { HDQ-D2- } \\ p\end{array} & \text { scale5_p }\end{array}\right)$
5.3.14 Form "Irritability-c"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| Date data obtained | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> C | irtycdtc | date |  |  | Not <br> Available |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Date data obtained (precision) | $\begin{aligned} & \hline \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> C | irtycdtc_prec | singlechoice |  |  |  |
| Day of data obtained | $\begin{aligned} & \hline \text { THD } \\ & \text { (V3,V4) } \end{aligned}$ | Irritability- <br> C | irtycdy | number |  |  | PDS |
| Date data obtained (precision) | THD (V3,V4); TON (V1,V2,V3) | Irritability- <br> C | irtycdy__ prec | singlechoice | - precision in days m | -d | Not Available |
| Score | $\begin{aligned} & \hline \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> C | irtycscore | number |  |  | PDS |
| Is he/she easily irritated | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> C | irritation_c | singlechoice |  | - FALSE |  |
| Does he/she pout if things don't go his/her way | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> c | pout_c | singlechoice | - not at all | -0 |  |
|  |  |  |  |  | - slightly | -1 |  |
|  |  |  |  |  | - some | -2 |  |
|  |  |  |  |  | - a lot | -3 |  |
| Does he/she have good control of his/her temper with the family (or | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> C | temperfamily_ c | singlechoice | - not at all | -0 |  |
|  |  |  |  |  | - slightly | -1 |  |
|  |  |  |  |  | - some | -2 |  |
|  |  |  |  |  | - a lot | - 3 |  |


| persons living <br> with him) |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| Do disagreements often lead to arguments | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 3, \mathrm{~V} 4) ; \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Irritability- <br> c |  | singlechoice | - slightly | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Can he/she appreciate a different point of view from his/hers | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 3, \mathrm{~V} 4) ; \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> C | appreciation_c | single- <br> choice | - not at all | - 0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Does he/she yell a lot | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> c | yell_c | single- <br> choice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Is he/she able to control his/her temper with persons outside the family | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> c | temper_c | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Do you consider him/her to be irritable | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4) } \end{aligned}$ | Irritability- <br> c | irritability_c | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |
| Do you consider him/her to be irritable | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> c | irritability | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | - 3 |

### 5.3.15 Form "Irritability-s"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| Date data obtained | THD <br> (V3,V4); <br> TON <br> (V1,V2,V3) | Irritabilitys | irtypdtc | date |  |  | Not |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Date data obtained (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Irritabilitys | irtypdtc__prec | singlechoice |  |  | Available |
| Day of data obtained | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V3,V4) } \\ \hline \end{array}$ | Irritabilitys | irtypdy | singlechoice |  |  | PDS |
| Date data obtained (precision) | $\begin{array}{\|l} \hline \text { THD } \\ \text { (V3,V4); } \\ \text { TON } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | Irritabilitys | irtypdy__ prec | number | - precision in days m | -d | Not <br> Available |
| Score | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \\ & \hline \end{aligned}$ | Irritabilitys | irtysscore | number |  |  | PDS |
| Are you easily irritated | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritabilitys | irritation | singlechoice | - not at all | -0 |  |
|  |  |  |  |  | - slightly | -1 |  |
|  |  |  |  |  | - some | -2 |  |
|  |  |  |  |  | - a lot | -3 |  |
| Do you pout if things don't go your way | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritabilitys | pout | singlechoice | - not at all | - 0 |  |
|  |  |  |  |  | - slightly | -1 |  |
|  |  |  |  |  | - some | -2 |  |
|  |  |  |  |  | - a lot | -3 |  |
| Do you have good control of your temper with the family (or | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Irritabilitys | temperfamily | singlechoice | - not at all | -0 |  |
|  |  |  |  |  | - slightly | -1 |  |
|  |  |  |  |  | - some | -2 |  |
|  |  |  |  |  | - a lot | -3 |  |


| persons living with you) |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - not at all | - 0 |
| Do little things | (V3,V4); | Irritability- |  | single- | - slightly | -1 |
| off the handle | TON |  | fyof | choice | - some | - 2 |
|  |  |  |  |  | - a lot | - 3 |
|  | THD |  |  |  | - not at all | -0 |
| Do you adjust | (V3,V4); | Irritability- |  | single- | - slightly | -1 |
| in plans | TON |  | adjusting | choice | - some | -2 |
|  | (V1,V2,V3) |  |  |  | - a lot | - 3 |
| When you lose | THD |  |  |  | - not at all | -0 |
| your temper, do | (V3,V4); | Irritability- |  | single- | - slightly | -1 |
| you have a hard | TON |  | calmdown | choice | - some | -2 |
| down again | (V1,V2,V3) |  |  |  | - a lot | -3 |
|  |  |  |  |  | - not at all | -0 |
| Do you insist on | (V3,V4); | Irritability- |  | single- | - slightly | -1 |
| way | TON |  |  | choice | - some | - 2 |
|  | (V1, V2, 3 ) |  |  |  | - a lot | - 3 |
|  | THD |  |  |  | - not at all | -0 |
| Are you easily | (V3,V4); | Irritability- | agitation | single- | - slightly | -1 |
| minor problems | TON |  | agitation | choice | - some | -2 |
|  | (V1,V2,V3) |  |  |  | - a lot | -3 |
| Can you discuss problems together and agree to a | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 3, \mathrm{~V} 4) \text {; } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritabilitys | discussion | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | -3 |


| reasonable solution |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Do | THD |  |  |  | - not at all | -0 |
| disagreements | (V3, V4); | Irritability- | disagreement | single- | - slightly | -1 |
| often lead to | TON |  | disagreement | choice | - some | -2 |
| arguments | (V1,V2,V3) |  |  |  | - a lot | -3 |
| Can you |  |  |  |  | - not at all | -0 |
| appreciate a | (V3,V4); | Irritability- |  | single- | - slightly | -1 |
| view from your | TON |  | appreciation | choice | - some | -2 |
| own | (V1,V2, V3) |  |  |  | - a lot | - 3 |
|  | THD |  |  |  | - not at all | -0 |
| Do you y | (V3, V4); | Irritability- | yell | single- | - slightly | -1 |
| Do you | TON |  | yell | choice | - some | -2 |
|  | (V1,V2,V3) |  |  |  | - a lot | -3 |
| Are you able to |  |  |  |  | - not at all | -0 |
| control your | (V3,V4); | Irritability- |  | single- | - slightly | -1 |
| persons outside | TON |  | temper | choice | - some | -2 |
| the family | (V1,V2,V3) |  |  |  | - a lot | -3 |
| Do you consider yourself to be irritable | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Irritability- <br> s | irritability_s | singlechoice | - not at all | -0 |
|  |  |  |  |  | - slightly | -1 |
|  |  |  |  |  | - some | -2 |
|  |  |  |  |  | - a lot | -3 |

### 5.3.16 Form "Medical History"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :---: | :---: |
|  |  |  | illnessbirth | boolean | - no | -0 |  | PDS |


| Birth trauma or serious neonatal illness | THD <br> (V1); <br> TON <br> (V1) | Medical History |  |  | - yes | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | THD |  |  |  | - no | -0 |
| years) serious illness | $\begin{aligned} & \text { (V1); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | History | illnesschild | boolean | - yes | -1 |
|  | THD |  |  |  | - no | -0 |
| years) serious illness | $\begin{array}{\|l\|} \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | History | illnessadolescent | boolean | - yes | -1 |
|  | THD |  |  |  | - no | -0 |
| serious illness | $\begin{array}{\|l\|} \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | History | illnessadult | boolean | - yes | -1 |
| gery | THD |  |  |  | - no | -0 |
| requiring general anaesthesia | $\begin{aligned} & \text { (V1); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | History | majorsurgery | boolean | - yes | -1 |
|  | THD |  |  |  | - never abused | -1 |
| History of alcohol | (V1); | Medical | alcoholabuse | single- | - previous abuse | -2 |
|  | (V1) | History |  |  | - current abuse | -3 |
| Alcohol units per week | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | alcunits_mhx | number |  |  |
| History of drug abuse | THD <br> (V1); <br> TON <br> (V1) | Medical History | druguse | singlechoice | - never abused | -1 |
|  |  |  |  |  | - ex-drug abuser | -2 |
|  |  |  |  |  | - current abuse | -3 |
|  |  |  | marijuana | boolean | - no | -0 |


| Marijuana - Harmful use | THD <br> (V1); <br> TON <br> (V1) | Medical History |  |  | - yes | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | THD |  |  |  | - seldom | -1 |
| Marijuana - Frequency | (V1); | Medical | marijuanafreq | single- | - occasionally | -2 |
|  | (V1) |  |  |  | - frequently | -3 |
|  | THD |  |  |  | - no | -0 |
| Heroin - Harmful use | $\begin{array}{\|l\|} \hline \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | History | heroin | boolean | - yes | -1 |
|  |  |  |  |  | - seldom | -1 |
| Frequency | THD |  | heroinfreq | single- | - occasionally | -2 |
|  |  |  |  |  | - frequently | -3 |
|  | THD |  |  |  | - no | -0 |
| Cocaine - Harmful use | $\begin{array}{\|l\|} \hline \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | History | cocaine | boolean | - yes | -1 |
|  | THD |  |  |  | - seldom | -1 |
| Cocaine - Frequency | (V1); | Medical | cocainefreq | single- | - occasionally | -2 |
|  | (V1) |  |  |  | - frequently | - 3 |
| b druss (Ecstacy, | THD |  |  |  | - no | -0 |
| GHB, Roofies) Harmful use | $\begin{aligned} & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | History | clubdrugs | boolean | - yes | -1 |
| Club drugs (Ecstacy, GHB, Roofies) Frequency | $\begin{array}{\|l} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | clubdrugsfreq | singlechoice | - seldom | -1 |
|  |  |  |  |  | - occasionally | -2 |
|  |  |  |  |  | - frequently | -3 |
|  |  |  | amphetamines | boolean | - no | -0 |


| Amphetamines Harmful use | THD <br> (V1); <br> TON <br> (V1) | Medical History |  |  | - yes | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Amphetamines Frequency | THD <br> (V1); <br> TON <br> (V1) | Medical History | amphetaminesfreq | singlechoice | - seldom | -1 |
|  |  |  |  |  | - occasionally | -2 |
|  |  |  |  |  | - frequently | - 3 |
| Ritalin - Harmful use | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | ritalin | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |
| Ritalin - Frequency | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1) } \end{array}$ | Medical History | ritalinfreq | singlechoice | - seldom | -1 |
|  |  |  |  |  | - occasionally | -2 |
|  |  |  |  |  | - frequently | -3 |
| Hallucinogens Harmful use | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1); } \\ & \text { TON } \\ & \text { (V1) } \end{aligned}$ | Medical History | hallucinogen | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |
| Hallucinogens Frequency | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | hallucinogenfreq | singlechoice | - seldom | -1 |
|  |  |  |  |  | - occasionally | -2 |
|  |  |  |  |  | - frequently | -3 |
| Inhalants - Harmful use | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | inhalants | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |
| Inhalants - Frequency | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | inhalantsfreq | singlechoice | - seldom | -1 |
|  |  |  |  |  | - occasionally | -2 |
|  |  |  |  |  | - frequently | -3 |
| Opium - Harmful use |  |  | opium | boolean | - no | -0 |


|  | THD <br> (V1); <br> TON <br> (V1) | Medical History |  |  | - yes | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | THD |  |  |  | - seldom | -1 |
| Opium - Frequency | (V1); | Medical | opiumfrea | single- | - occasionally | -2 |
|  | (V1) |  |  |  | - frequently | -3 |
| Painkillers used for | THD |  |  |  | - no | -0 |
| Harmful use | $\begin{array}{\|l} \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | History | painkiller | boolean | - yes | -1 |
| Painkillers used for |  |  |  |  | - seldom | -1 |
| non-medical reasons - | THD |  | painkillerfreq | single- | - occasionally | -2 |
| Frequency |  |  |  |  | - frequently | -3 |
| Barbiturates/sedatives | THD |  |  |  | - no | - 0 |
| reasons - Harmful use | $\begin{array}{\|l} \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | History | barbiturate | boolean | - yes | -1 |
| Barbiturates/sedatives |  |  |  |  | - seldom | -1 |
| use for non-medical | $\begin{aligned} & \text { 1HD } \\ & \text { (V1): } \end{aligned}$ |  | barbituratefreq |  | - occasionally | -2 |
| reasons - Frequency |  |  |  |  | - frequently | - 3 |
| Tranquilizers used for | THD |  |  |  | - no | -0 |
| Harmful use | $\begin{aligned} & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | History | tranquilizer | boolean | - yes | -1 |
| Tranquilizers used for non- medical reasons Frequency | $\begin{array}{\|l} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | tranquilizerfreq | singlechoice | - seldom | -1 |
|  |  |  |  |  | - occasionally | -2 |
|  |  |  |  |  | - frequently | -3 |


| other - Harmful use | THD <br> (V1); <br> TON <br> (V1) | Medical History | other_mhx | boolean | - no | -0 -1 | Available upon SRC approval |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| other - Frequency | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | otherfreq | singlechoice | - seldom | -1 |  |
|  |  |  |  |  | - occasionally | -2 |  |
|  |  |  |  |  | - frequently | -3 |  |
| History of smoking tobacco | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | Medical History | smoking_hx | singlechoice | - never smoked | -1 | PDS |
|  |  |  |  |  | - ex-smoker | -2 |  |
|  |  |  |  |  | - currently smokes | -3 |  |
| Cigarettes per day | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | cigperday | number |  |  |  |
| other - Years of smoking | THD <br> (V1); <br> TON <br> (V1) | Medical History | smokyears | number |  |  |  |
| Does the subject have any allergies? | $\mid$ THD <br> (V1); <br> TON <br> (V1) | Medical History | allergies | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Please list allergies | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | allergieslist | text |  |  | Not Available |
| Psychiatric History - <br> Depression | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | depression_hx | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 | PDS |


|  | THD |  |  |  | - no | - 0 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| OCD | $\begin{array}{\|l} \hline \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | History |  | boolean | - yes | -1 |
| Psychiatric History - <br> Psychosis | THD <br> (V1); <br> TON <br> (V1) | Medical History | psychosis_hx | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |
| Psychiatric History - <br> Suicidal ideation | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Medical History | suicidal_hx | boolean | - no | -0 |
|  |  |  |  |  | - yes | -1 |
| Psychiatric History Suicide attempt | THD | Medical History | suicide_hx | boolean | - no | -0 |
|  | $\begin{aligned} & \text { TV1; } \\ & \text { TON } \\ & \text { (V1) } \end{aligned}$ |  |  |  | - yes | -1 |

### 5.3.17 Form "Motor"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Completeness of motor score | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Motor | cmplms | numeric |  |  |  | Available upon SRC approval |
| Motor score | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | Motor | motscore | number |  |  |  | PDS |
| Ocular pursuit Horizontal | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Motor | ocularh | single- <br> choice | - complete (normal) | -0 |  |  |
|  |  |  |  |  | - jerky movement | -1 |  |  |
|  |  |  |  |  | - interrupted pursuits/full range | -2 |  |  |




|  | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ |  |  | singlechoice | - mild slowing, reduction in amplitude (11-14/5 sec.) | -1 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - moderately impaired (7$10 / 5 \mathrm{sec}$.) | -2 |  |
|  |  |  |  |  | - severely impaired (3-6/5 sec.) | - 3 |  |
|  |  |  |  |  | - can barely perform task (02/5 sec.) | -4 |  |
| Pronate/supinatehands - Right | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Motor | prosupr | singlechoice | - normal | - 0 |  |
|  |  |  |  |  | - mild slowing and/or irregular | -1 |  |
|  |  |  |  |  | - moderate slowing and irregular | -2 |  |
|  |  |  |  |  | - severe slowing and irregular | - 3 |  |
|  |  |  |  |  | - cannot perform | -4 |  |
| Pronate/supinatehands - Left | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Motor | prosupl | singlechoice | - normal | -0 |  |
|  |  |  |  |  | - mild slowing and/or irregular | -1 |  |
|  |  |  |  |  | - moderate slowing and irregular | -2 |  |
|  |  |  |  |  | - severe slowing and irregular | - 3 |  |
|  |  |  |  |  | - cannot perform | -4 |  |
| Luria | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Motor | luria | singlechoice | - > | -0 |  |
|  |  |  |  |  | - <4 in 10 sec , no cue | -1 |  |
|  |  |  |  |  | - > | -2 |  |
|  |  |  |  |  | - <4 in 10 sec with cues | -3 |  |
|  |  |  |  |  | - cannot perform | -4 |  |
|  |  | Motor | rigarmr |  | - absent | - 0 |  |


| Rigidity-arms Right | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ |  |  |  | - slight or present only with activation | - 1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  | single- | - mild to moderate | -2 |
|  |  |  |  | choice | - severe, full range of motion | - 3 |
|  |  |  |  |  | - severe with limited range | -4 |
| Rigidity-arms Left | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Motor | rigarml | singlechoice | - absent | - 0 |
|  |  |  |  |  | - slight or present only with activation | - 1 |
|  |  |  |  |  | - mild to moderate | -2 |
|  |  |  |  |  | - severe, full range of motion | - 3 |
|  |  |  |  |  | - severe with limited range | -4 |
| Bradykinesiabody | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Motor | brady | singlechoice | - normal | -0 |
|  |  |  |  |  | - minimally slow (?normal) | -1 |
|  |  |  |  |  | - mildly but clearly slow | -2 |
|  |  |  |  |  | - moderately slow, some hesitation | - 3 |
|  |  |  |  |  | - markedly slow, long delays in initiation | -4 |
| Maximal dystonia - Trunk | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Motor | dysttrnk | singlechoice | - absent | -0 |
|  |  |  |  |  | - slight/intermittent | -1 |
|  |  |  |  |  | - mild/common or moderate/intermittent | - 2 |
|  |  |  |  |  | - moderate/common | -3 |
|  |  |  |  |  | - marked/prolonged | -4 |
| Maximal dystonia <br> - RUE | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Motor | dystrue | single- <br> choice | - absent | -0 |
|  |  |  |  |  | - slight/intermittent | -1 |
|  |  |  |  |  | - mild/common or moderate/intermittent | - 2 |




| Maximal chorea LLE | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ |  |  | singlechoice | - slight/intermittent | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - mild/common or moderate/intermittent | -2 |
|  |  |  |  |  | - moderate/common | -3 |
|  |  |  |  |  | - marked/prolonged | -4 |
| Gait | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Motor | gait | singlechoice | - normal gait, narrow base | -0 |
|  |  |  |  |  | - wide base and/or slow | -1 |
|  |  |  |  |  | - wide base and walks with difficulty | -2 |
|  |  |  |  |  | - walks only with assistance | -3 |
|  |  |  |  |  | - cannot attempt | -4 |
| Tandem walking | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Motor | tandem | singlechoice | - normal for 10 steps | -0 |
|  |  |  |  |  | - 1 to 3 deviations from straight line | -1 |
|  |  |  |  |  | - >3 deviations | -2 |
|  |  |  |  |  | - cannot complete | -3 |
|  |  |  |  |  | - cannot attempt | -4 |
| Retropulsion pull test | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Motor | retropls | singlechoice | - normal | -0 |
|  |  |  |  |  | - recovers spontaneously | -1 |
|  |  |  |  |  | - would fall if not caught | -2 |
|  |  |  |  |  | - tends to fall spontaneously | -3 |
|  |  |  |  |  | - cannot stand | -4 |
| Diagnostic confidence level (DCL) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Motor | diagconf | single- <br> choice | - normal (no abnormalities) | -0 |
|  |  |  |  |  | - non-specific motor abnormalities (less than 50 \% confidence) | -1 |
|  |  |  |  |  | - motor abnormalities that may be signs of HD (50-89 \% confidence) | -2 |


5.3.18 Form "Short Behavioural Assessment (PBA-s)"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Behavioural score | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3,V4) } \\ \hline \end{array}$ | PBA-s | basscore | number |  |  |  | PDS |
| Depressed mood Severity | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basdepr | single- <br> choice | - absent | -0 |  |  |
|  |  |  |  |  | - questionable | -1 |  |  |
|  |  |  |  |  | - low mood is present intermittently but does |  |  |  |
|  |  |  |  |  | everyday function; rate 2 <br> if subject can easily enjoy amusing activities or visits from friends | - 2 |  |  |


|  |  |  |  |  | - subject feels sad much of the time and takes no pleasure from things that he/she usually enjoys, but may still be able to cheer up sometimes with a big effort; rate 3 if low mood has definite effect on subject's lifestyle, e.g. unable to enjoy company of friends or amusing diversions <br> - subject feels sad and utterly miserable all day, takes no pleasure from things that he/she usually enjoys, does not cheer up anytime | -3 <br>  <br>  <br>  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Depressed mood Frequency | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basdeprfre | singlechoice | - never/almost never | - 0 |
|  |  |  |  |  | - seldom (less than once/week) | -1 |
|  |  |  |  |  | - sometimes (up to four times a week) | - 2 |
|  |  |  |  |  | - frequently (most days/5, 6 or 7 times a week) | - 3 |
|  |  |  |  |  | - daily/almost daily for most (or all) of day | -4 |
| Depressed mood Worst | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basdeprworst | singlechoice | - absent | -0 |
|  |  |  |  |  | - questionable | -1 |



|  |  |  | from this as means to <br> retain control of destiny |  |
| :--- | :--- | :--- | :--- | :--- | :--- |


| Suicidal ideation Worst | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | bassuicworst | singlechoice | - absent | - 0 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - questionable; also rate <br> 1 if subject plans suicide at a later date when disease is more severe but obtains comfort from this as means to retain control of destiny | -1 |
|  |  |  |  |  | - sometimes very pessimistic with fleeting suicidal ideation | - 2 |
|  |  |  |  |  | - subject has pervasive and distressing feelings of hopelessness and more prolonged or frequent suicidal ideation, but has not yet acted on this in any way | - 3 |
|  |  |  |  |  | - subject has attempted suicide or has made preparations such as saving up tablets or planning ways to avoid discovery when doing it | -4 |
|  |  |  |  |  | - absent | -0 |
| Anxiety - Severity | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basanx | singlechoice | - questionable, vague unease (also rate 1 if subject's only worry or anxiety is about prognosis of HD) | -1 |





|  |  |  |  |  | - subject very irritable and loses temper over trivial matters; household members have to be careful what they say and do to avoid problems; rate 3 if subject's appearance and behaviour suggestive of angry mood, such that outbursts would almost certainly have occurred if care had not been taken to placate subject or to keep out of his/her way <br> - subject very irritable and loses temper without any obvious reason at all; living with him/her is like walking on eggshells | -3 <br>  <br>  <br>  <br>  <br> -4 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Irritability - Frequency | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basirritfre | singlechoice | - never/almost never | - 0 |
|  |  |  |  |  | - seldom (less than once/week) | -1 |
|  |  |  |  |  | - sometimes (up to 4 times a week) | - 2 |
|  |  |  |  |  | - frequently (most days/5, 6 or 7 times a week) | - 3 |
|  |  |  |  |  | - daily/almost daily for most (or all) of day | -4 |



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|  |  |  |  |  | - subject has temper tantrums so severe that relationship with carers is compromised, creating risk that subject will be rejected; rate 4 if there has been any kind of actual physical assault (includes pushing, shoving, hitting, biting, scratching, kicking) or threatening behaviour involving weapons | -4 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Angry or aggressive behaviour - Frequency | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basbehfre | singlechoice | - never/almost never | - 0 |
|  |  |  |  |  | - seldom (less than once/week) | -1 |
|  |  |  |  |  | - sometimes (up to 4 times a week) | -2 |
|  |  |  |  |  | - frequently (most days/5, 6 or 7 times a week) | -3 |
|  |  |  |  |  | - daily/almost daily for most (or all) of day | -4 |
| Angry or aggressive behaviour - Worst | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basbehworst | singlechoice | - normal | -0 |
|  |  |  |  |  | - questionable | -1 |






|  |  |  |  |  | - needs overt or repeated prompting to perform routine household tasks; mail may be left unopened for long periods; living environment has deteriorated beyond socially acceptable limits (or would have done so without intervention of carers) <br> - subject no longer makes any attempt to perform these tasks, even with overt prompting, and is living in squalor (or would be without intervention of carers) | -3 <br>  <br>  <br>  <br>  <br> -4 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Household chores - <br> Frequency | THD (V3) | PBA-s | bashhchoresfre | single- <br> choice | - never/almost never | -0 |
|  |  |  |  |  | - seldom (less than once/week) | -1 |
|  |  |  |  |  | - sometimes (up to 4 times a week) | - 2 |
|  |  |  |  |  | - frequently (most days/5, 6 or 7 times a week) | - 3 |
|  |  |  |  |  | - daily/almost daily for most (or all) of day | -4 |
|  | THD (V3,V4) | PBA-s | baspersev |  | - symptom absent | -0 |






|  |  |  |  |  | - subject clearly enjoys <br> social contacts with <br> others but is less <br> proactive in organising <br> social activities with <br> friends and relatives, and leaves it to others to organise these activities <br> - makes little or no effort to keep up with friends and leaves it to others to initiate any social contacts; appears to obtain less enjoyment from social contacts <br> - displays no interest in friends / relatives and does not engage in social activities, or may actively resist these | -2 <br>  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Social activities Frequency | THD (V3) | PBA-s | bassocactfre | singlechoice | - never/almost never | - 0 |
|  |  |  |  |  | - seldom (less than once/week) | -1 |
|  |  |  |  |  | - sometimes (up to 4 times a week) | - 2 |
|  |  |  |  |  | - frequently (most days/5, 6 or 7 times a week) | - 3 |
|  |  |  |  |  | - daily/almost daily for most (or all) of day | -4 |
| Spontaneous conversation - Severity | THD (V3,V4) | PBA-s | bassconv | singlechoice | - symptom absent | -0 |
|  |  |  |  |  | - questionable or trivial | -1 |




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|  |  |  |  |  | - no longer performs any household tasks, even if prompted repeatedly; never initiates activities, and displays no interest in hobbies or pastimes; markedly impoverished speech, rarely initiates new topics of conversation except in relation to own needs; active choices limited to selecting TV programmes to watch, and perhaps switching on or changing channel to do this | - 4 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Lack of initiative (apathy) - Frequency | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basapathfre | singlechoice | - never/almost never | -0 |
|  |  |  |  |  | - seldom (less than once/week) | -1 |
|  |  |  |  |  | - sometimes (up to 4 times a week) | - 2 |
|  |  |  |  |  | - frequently (most days/5, 6 or 7 times a week) | -3 |
|  |  |  |  |  | - daily/almost daily for most (or all) of day | - 4 |
| Lack of initiative (apathy) - Worst | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | basapathworst | singlechoice | - symptom absent | -0 |
|  |  |  |  |  | - questionable | -1 |

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|  |  |  |  |  | - no longer performs any household tasks, even if prompted repeatedly; never initiates activities, and displays no interest in hobbies or pastimes; markedly impoverished speech, rarely initiates new topics of conversation except in relation to own needs; active choices limited to selecting TV programmes to watch, and perhaps switching on or changing channel to do this | -4 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Obsessive-compulsive behaviours - Severity | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | basobscomp |  | - symptom absent | - 0 |  |
|  |  |  |  |  | - questionable or trivial | -1 |  |
|  |  |  |  | singlechoice | - obsessional thoughts or mild compulsive behaviours which do not interfere with everyday life or cause subject significant distress; rate 2 if subject has mild obsessive- compulsive traits such as double checking (a small number of times) that doors are locked or ashtrays empty at night | - 2 |  |


|  |  |  |  |  | - obsessive-compulsive behaviours are present to a degree which interferes with everyday life or causes significant distress for subject; rate <br> 3 if subject displays mild ritualistic behaviours such as hand-washing, turning lights on and off repetitively 'evening-up' after touching things by touching with the other hand too <br> - obsessional phenomena cause serious distress, are time consuming (>1 hour/day) or significantly interfere with the person's normal routine, occupational functioning or usual social activities or relationships | -3 <br>  <br>  <br>  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Obsessive-compulsive behaviours - Frequency | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | basobscompfre | singlechoice | - never/almost never | - 0 |
|  |  |  |  |  | - seldom (less than once/week) | -1 |
|  |  |  |  |  | - sometimes (up to 4 times a week) | -2 |
|  |  |  |  |  | - frequently (most days/5, 6 or 7 times a week) | -3 |


|  |  |  |  |  | - daily/almost daily for most (or all) of day | -4 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Obsessive-compulsive behaviours - Worst | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | basobscompworst | singlechoice | - symptom absent | - 0 |
|  |  |  |  |  | - questionable or trivial | -1 |
|  |  |  |  |  | - obsessional thoughts or mild compulsive |  |
|  |  |  |  |  | behaviours which do not |  |
|  |  |  |  |  | interfere with everyday |  |
|  |  |  |  |  | significant distress; rate |  |
|  |  |  |  |  | 2 if subject has mild | - 2 |
|  |  |  |  |  | traits such as double |  |
|  |  |  |  |  | checking (a small |  |
|  |  |  |  |  | number of times) that |  |
|  |  |  |  |  | doors are locked or ashtrays empty at night |  |
|  |  |  |  |  | - obsessive-compulsive |  |
|  |  |  |  |  | behaviours are present to a degree which |  |
|  |  |  |  |  | interferes with everyday |  |
|  |  |  |  |  |  |  |
|  |  |  |  |  | distress for subject; rate |  |
|  |  |  |  |  | 3 if subject displays mild ritualistic behaviours | -3 |
|  |  |  |  |  | such as hand-washing, |  |
|  |  |  |  |  | turning lights on and off |  |
|  |  |  |  |  | repetitively or "evening- |  |
|  |  |  |  |  | by touching with the |  |
|  |  |  |  |  | other hand too |  |


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|  |  |  |  |  |  | significantly with <br> everyday care |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |

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$\left.\begin{array}{|l|l|l|l|l|l|l|l|} & & & & & \begin{array}{l}\text { - delusions: false beliefs, } \\ \text { held with unshakeable } \\ \text { conviction, which are } \\ \text { not shared by other } \\ \text { members of subject's } \\ \text { social and cultural group } \\ \text { and have been present } \\ \text { continuously for at least } \\ 7 \text { days }\end{array} & -4\end{array}\right\}$

\begin{tabular}{|c|c|c|c|c|c|c|c|}
\hline \multicolumn{2}{|l|}{} \& \& \& \& \begin{tabular}{l}
- overvalued ideas are present for much of the day, and subject behaves as if these beliefs were true, although he/she can be persuaded (with difficulty) that he/she is mistaken; \\
- delusions: false beliefs, held with unshakeable conviction, which are not shared by other members of subject's social and cultural group and have been present continuously for at least 7 days
\end{tabular} \& -3

-4 \& <br>

\hline \multirow{4}{*}{Hallucinations - Severity} \& \multirow{4}{*}{$$
\begin{aligned}
& \text { THD } \\
& \text { (V1,V2,V3,V4) }
\end{aligned}
$$} \& \multirow{4}{*}{PBA-s} \& \multirow{4}{*}{bashall} \& \multirow{4}{*}{singlechoice} \& - symptom absent \& 0 \& <br>

\hline \& \& \& \& \& - questionable or trivial \& -1 \& <br>
\hline \& \& \& \& \& - subject reports experiencing hallucinations (when asked) but these do not appear to cause any distress or affect subject's behaviour \& -2 \& <br>
\hline \& \& \& \& \& - hallucinations which affect subject's behaviour (e.g. looking for source of hidden voices or putting cotton wool in ears) but do not \& -3 \& <br>
\hline
\end{tabular}

|  |  |  |  | appear to cause much <br> distress |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |


|  |  |  |  |  | - daily/almost daily for most (or all) of day | -4 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Worst | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | bashallworst | singlechoice | - symptom absent | -0 |  |
|  |  |  |  |  | - questionable or trivial | -1 |  |
|  |  |  |  |  | - subject reports experiencing hallucinations (when asked) but these do not appear to cause any distress or affect subject's behaviour | - 2 |  |
|  |  |  |  |  | - hallucinations which affect subject's behaviour (e.g. looking for source of hidden voices or putting cotton wool in ears) but do not appear to cause much distress | -3 |  |
|  |  |  |  |  | - subject is clearly distressed by hallucinations and preoccupied with them | -4 |  |
| Modality of hallucinations - auditory | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | bashallmodw__1 | boolean | - no | -0 | Available upon SRC approval |
|  |  |  |  |  | - yes | -1 |  |
| Modality of hallucinations - visual | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | bashallmodw__2 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Modality of hallucinations - tactile | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | bashallmodw__3 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |


| Modality of hallucinations olfactory | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | bashallmodw__4 | boolean | - no | - 0 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - yes | -1 |  |
| Modality of hallucinations gustatory | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | bashallmodw__5 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Disoriented Behaviour Severity | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basorient | singlechoice | - symptom absent | -0 | PDS |
|  |  |  |  |  | - questionable or trivial (e.g. subject gets day wrong $\pm$ one day, or fails to recognise people when meeting them out of their normal context) | -1 |  |
|  |  |  |  |  | - subject does not seem to be fully aware of surroundings or the passage of time, but this does not cause significant practical problems | - 2 |  |
|  |  |  |  |  | - evidence of confusion at night (subject appears disoriented in time, place or person to an extent that causes practical problems for carers) but normal during daylight hours | -3 |  |


|  |  |  |  |  | - subject is confused and disoriented all the time, unaware of time of day/day of week/date and wrongly identifying surroundings or the people around him (e.g. mistakes nursing home for a prison and nursing staff as prison wardens) and consequently resists efforts of carers to look after him/her | -4 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Disoriented Behaviour Frequency | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basorientfre | singlechoice | - never/almost never | -0 |
|  |  |  |  |  | - seldom (less than once/week) | -1 |
|  |  |  |  |  | - sometimes (up to 4 times a week) | - 2 |
|  |  |  |  |  | - frequently (most days/5, 6 or 7 times a week) | - 3 |
|  |  |  |  |  | - daily/almost daily for most (or all) of day | -4 |
| Disoriented Behaviour Worst | $\begin{aligned} & \text { THD } \\ & \text { (V2,V3,V4) } \end{aligned}$ | PBA-s | basorientworst |  | - symptom absent | -0 |
|  |  |  |  | single- <br> choice | - questionable or trivial (e.g. subject gets day wrong $\pm$ day, or fails to recognise people when meeting them out of their normal context) | -1 |


|  |  |  |  |  | - subject does not seem to be fully aware of surroundings or the passage of time, but this does not cause significant practical problems <br> - evidence of confusion at night (subject appears disoriented in time, place or person to an extent that causes practical problems for carers) but normal during daylight hours <br> - subject is confused and disoriented all the time, unaware of time of day/day of week/date and wrongly identifying surroundings or the people around him (e.g. mistakes nursing home for a prison and nursing staff as prison wardens) and consequently resists efforts of carers to look after him/her | -2 <br>  <br>  <br> -3 <br> -3 <br>  <br>  <br> -4 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Comment | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | bascomment | text |  |  | Not Available |
| Is informant a relative? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | PBA-s | basrelative | singlechoice | - spouse or partner <br> - parent | -1 | PDS |


|  |  |  |  | -3 |
| :--- | :--- | :--- | :--- | :--- | :--- |

### 5.3.19 Form "Physical Activities"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Teens activity available | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \end{aligned}$ | Physical Activities | rteens | boolean | - no | -0 |  | PDS |
|  |  |  |  |  | - yes | -1 |  |  |








| - Weekly frequency | $\begin{array}{\|l\|l} \text { TON } \\ \text { (V1) } \end{array}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 30s activity - <br> Moderate activity <br> - Weekly - min | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Physical <br> Activities | r3mwmin | number |  |  |
| 30s activity - <br> Moderate activity <br> - Monthly - <br> frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | r3mmfq | number |  |  |
| 30s activity - <br> Moderate activity <br> - Monthly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | r3mmmin | number |  |  |
| 30s activity - <br> Moderate activity - Never | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | r3mn__1 | boolean | $\begin{array}{\|l\|} \hline- \text { no } \\ \hline \\ \hline- \text { yes } \end{array}$ | -0 |
| 30s activity - <br> Light activity - <br> Daily - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | r3ldmin | number |  |  |
| 30s activity Light activity Weekly frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | r3lwfq | number |  |  |
| 30s activity - <br> Light activity - <br> Weekly - min | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Physical <br> Activities | r3lwmin | number |  |  |
| 30s activity Light activity - | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \end{aligned}$ | Physical Activities | r31mfq | number |  |  |








| Monthly frequency | $\begin{aligned} & \text { TON } \\ & \text { (V1) } \end{aligned}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Teens activity - <br> Vigorous activity - <br> Monthly - min | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | Physical <br> Activities | wtvmmin | number |  |  |
|  | THD |  |  |  | - no | - 0 |
| Never | TON <br> (V1) | Activities | Wtv |  | - yes | -1 |
| Teens activity - <br> Moderate activity <br> - Daily - min | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | Physical <br> Activities | wtmdmin | number |  |  |
| Teens activity - <br> Moderate activity <br> - Weekly - <br> frequency | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \end{aligned}$ | Physical <br> Activities | wtmwfq | number |  |  |
| Teens activity - <br> Moderate activity <br> - Weekly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | wtmwmin | number |  |  |
| Teens activity - <br> Moderate activity <br> - Monthly - <br> frequency | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | Physical <br> Activities | wtmmfq | number |  |  |
| Teens activity - <br> Moderate activity <br> - Monthly - min | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | Physical <br> Activities | wtmmmin | number |  |  |
| Teens activity Moderate activity <br> - Never | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \end{aligned}$ | Physical <br> Activities | wtmn__1 | boolean | - no | -0 -1 |



|  | $\begin{array}{\|l\|l} \text { TON } \\ \text { (V1) } \end{array}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 20s activity - <br> Vigorous activity - <br> Daily - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w2vdmin | number |  |  |
| 20s activity - <br> Vigorous activity - <br> Weekly - <br> frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w2vwfq | number |  |  |
| 20s activity - <br> Vigorous activity - <br> Weekly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w2vwmin | number |  |  |
| 20s activity - <br> Vigorous activity - <br> Monthly - <br> frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w2vmfq | number |  |  |
| 20s activity - <br> Vigorous activity - <br> Monthly - min | $\begin{array}{\|l\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Physical <br> Activities | w2vmmin | number |  |  |
| 20s activity - <br> Vigorous activity Never | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Physical <br> Activities | w2vn_1 ${ }^{1}$ | boolean | - no <br> - yes | -0 -1 |
| 20s activity - <br> Moderate activity <br> - Daily - min | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Physical <br> Activities | w2mdmin | number |  |  |
| 20s activity Moderate activity | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \end{aligned}$ | Physical Activities | w2mwfq | number |  |  |


| - Weekly frequency | $\begin{array}{\|l\|l} \text { TON } \\ \text { (V1) } \end{array}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 20s activity - <br> Moderate activity <br> - Weekly - min | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Physical <br> Activities | w2mwmin | number |  |  |
| 20s activity - <br> Moderate activity <br> - Monthly - <br> frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w2mmfq | number |  |  |
| 20s activity - <br> Moderate activity <br> - Monthly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w2mmmin | number |  |  |
| 20s activity - <br> Moderate activity - Never | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w2mn_1 | boolean | $\begin{array}{\|l\|} \hline- \text { no } \\ \hline \\ \hline- \text { yes } \end{array}$ | -0 |
| 20s activity - <br> Light activity - <br> Daily - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w2ldmin | number |  |  |
| 20s activity Light activity Weekly frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w2lwfq | number |  |  |
| 20s activity - <br> Light activity - <br> Weekly - min | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Physical <br> Activities | w2lwmin | number |  |  |
| 20s activity Light activity - | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \hline \end{array}$ | Physical Activities | w2lmfq | number |  |  |



| Monthly frequency | $\begin{aligned} & \text { TON } \\ & \text { (V1) } \end{aligned}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 30s activity - <br> Vigorous activity - <br> Monthly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w3vmmin | number |  |  |
|  |  |  |  |  | - no | - 0 |
| Vigorous activity Never | TON (V1) | Activities | w3vn__1 | boolean | - yes | -1 |
| 30s activity - <br> Moderate activity <br> - Daily - min | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | Physical <br> Activities | w3mdmin | number |  |  |
| 30s activity - <br> Moderate activity <br> - Weekly - <br> frequency | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \end{aligned}$ | Physical <br> Activities | w3mwfq | number |  |  |
| 30s activity - <br> Moderate activity <br> - Weekly - min | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \end{aligned}$ | Physical <br> Activities | w3mwmin | number |  |  |
| 30s activity - <br> Moderate activity <br> - Monthly - <br> frequency | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \end{aligned}$ | Physical <br> Activities | w3mmfq | number |  |  |
| 30s activity - <br> Moderate activity <br> - Monthly - min | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | Physical <br> Activities | w3mmmin | number |  |  |
| 30s activity - <br> Moderate activity <br> - Never | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \end{aligned}$ | Physical <br> Activities | w3mn__1 | boolean | - no | -0 -1 |



|  | $\begin{aligned} & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 40s activity - <br> Vigorous activity - <br> Daily - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w4vdmin | number |  |  |
| 40s activity - <br> Vigorous activity - <br> Weekly - <br> frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w4vwfq | number |  |  |
| 40s activity - <br> Vigorous activity - <br> Weekly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w4vwmin | number |  |  |
| 40s activity - <br> Vigorous activity - <br> Monthly - <br> frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w4vmfq | number |  |  |
| 40s activity - <br> Vigorous activity - <br> Monthly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w4vmmin | number |  |  |
| 40s activity - <br> Vigorous activity Never | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w4vn_1 | boolean | - no - yes | -0 -1 |
| 40s activity - <br> Moderate activity <br> - Daily - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w4mdmin | number |  |  |
| 40s activity Moderate activity | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \end{aligned}$ | Physical Activities | w4mwfq | number |  |  |





|  | $\begin{aligned} & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 50s activity Light activity Daily - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w51dmin | number |  |  |
| 50s activity Light activity Weekly frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w5lwfq | number |  |  |
| 50s activity Light activity Weekly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w5lwmin | number |  |  |
| 50s activity Light activity Monthly frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w5Imfq | number |  |  |
| 50s activity Light activity Monthly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w5Immin | number |  |  |
| 50s activity Light activity Never | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \end{aligned}$ | Physical <br> Activities | w5ln_1 | boolean | - no -yes | -0 -1 |
| 50s activity Score | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | w5score | number |  |  |
| Teens activity available | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \end{aligned}$ | Physical Activities | hteens | boolean | - no | -0 |







|  | $\begin{array}{\|l\|l} \text { TON } \\ \text { (V1) } \end{array}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 30s activity - <br> Vigorous activity - <br> Daily - min | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Physical <br> Activities | h3vdmin | number |  |  |
| 30s activity - <br> Vigorous activity - <br> Weekly - <br> frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h3vwfq | number |  |  |
| 30s activity - <br> Vigorous activity Weekly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h3vwmin | number |  |  |
| 30s activity - <br> Vigorous activity - <br> Monthly - <br> frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h3vmfq | number |  |  |
| 30s activity - <br> Vigorous activity - <br> Monthly - min | $\begin{array}{\|l\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Physical <br> Activities | h3vmmin | number |  |  |
| 30s activity - <br> Vigorous activity - <br> Never | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V4); } \\ \text { TON } \\ \text { (V1) } \\ \hline \end{array}$ | Physical <br> Activities | h3vn_1 ${ }^{1}$ | boolean | - no <br> - yes | -0 -1 |
| 30s activity - <br> Moderate activity <br> - Daily - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h3mdmin | number |  |  |
| 30s activity Moderate activity | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \end{aligned}$ | Physical Activities | h3mwfq | number |  |  |




| Monthly frequency | $\begin{aligned} & \text { TON } \\ & \text { (V1) } \end{aligned}$ |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 40s activity - <br> Vigorous activity - <br> Monthly - min | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \end{aligned}$ | Physical <br> Activities | h4vmmin | number |  |  |
|  |  |  |  |  | - no | - 0 |
| Vigorous activity Never | TON (V1) | Activities | h4vn__1 | boolean | - yes | -1 |
| 40s activity - <br> Moderate activity <br> - Daily - min | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | Physical <br> Activities | h4mdmin | number |  |  |
| 40s activity - <br> Moderate activity <br> - Weekly - <br> frequency | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \end{aligned}$ | Physical <br> Activities | h4mwfq | number |  |  |
| 40s activity - <br> Moderate activity <br> - Weekly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h4mwmin | number |  |  |
| 40s activity - <br> Moderate activity <br> - Monthly - <br> frequency | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \end{aligned}$ | Physical <br> Activities | h4mmfq | number |  |  |
| 40s activity - <br> Moderate activity <br> - Monthly - min | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | Physical <br> Activities | h4mmmin | number |  |  |
| 40s activity - <br> Moderate activity <br> - Never | $\begin{aligned} & \text { THD } \\ & \text { (V4); } \end{aligned}$ | Physical <br> Activities | h4mn__1 | boolean | - no | -0 -1 |


|  | TON (V1) |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 40s activity Light activity Daily - min | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \\ & \text { TON } \\ & \text { (V1) } \\ & \hline \end{aligned}$ | Physical <br> Activities | h4ldmin | number |  |  |
| 40s activity Light activity Weekly frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h4lwfq | number |  |  |
| 40s activity Light activity Weekly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h4lwmin | number |  |  |
| 40s activity Light activity Monthly frequency | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h4lmfq | number |  |  |
| 40s activity Light activity Monthly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h41mmin | number |  |  |
| 40s activity Light activity Never | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h4ln_1 | boolean | - no -yes | -0 -1 |
| 40s activity - <br> Score | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h4score | number |  |  |
| 50+s activity available | $\begin{aligned} & \hline \text { THD } \\ & \text { (V4); } \end{aligned}$ | Physical Activities | hfifty | boolean | - no <br> - yes | -0 |




| Monthly - <br> frequency | TON <br> (V1) |  |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| 50s activity - <br> Light activity - <br> Monthly - min | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h5Immin | number |  |  |  |
| 50s activity - <br> Light activity - <br> Never | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h5ln_1 |  | boolean | - yes |  |
| 50s activity - <br> Score | THD <br> (V4); <br> TON <br> (V1) | Physical <br> Activities | h5score | number |  | -0 |  |

### 5.3.20 Form "Pittsburgh Sleep Quality Index (PSQI)"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| When have you <br> usually gone to <br> bed at night? <br> Usual bed time: | THD <br> (V3,V4) | PSQI | bedtime_h | number |  |  |  |  |
| When have you <br> usually gone to <br> bed at night? <br> Usual bed time: - <br> : | THD <br> (V3,V4) | PSQI | bedtime_min | number |  |  | m | PDS |
| How long (in <br> minutes) has it <br> usually take you | THD <br> (V3,V4) | PSQI | fallasleep | number |  |  |  |  |


| to fall asleep each night? |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| When have you usually gotten up in the morning? Usual getting up time: | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 3, \mathrm{~V} 4) \end{aligned}$ | PSQI | getup__h | number |  |  |
| When have you usually gotten up in the morning? Usual getting up time: - : | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 3, \mathrm{~V} 4) \end{aligned}$ | PSQI | getup__min | number |  |  |
| How many hours of actual sleep did you get at night? | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 3, \mathrm{~V} 4) \end{aligned}$ | PSQI | sleepnight | number |  |  |
|  |  |  |  |  | - not during the past month | -0 |
| Cannot get to sleep within 30 | THD | PSOI | sleep30 | single- | - less than once a week | -1 |
| minutes | (V3,V4) |  | sleep30 | choice | - once or twice a week | -2 |
|  |  |  |  |  | - three or more times a week | -3 |
| Wake up in the |  |  |  |  | - not during the past month | -0 |
| middle of the | THD |  |  | single- | - less than once a week | -1 |
| night or early | (V3,V4) |  | w | choice | - once or twice a week | -2 |
| morning |  |  |  |  | - three or more times a week | -3 |
|  |  |  |  |  | - not during the past month | -0 |
| Have to get up to | THD |  |  | single- | - less than once a week | -1 |
| bathroom | (V3,V4) | PS | bathroom | choice | - once or twice a week | -2 |
|  |  |  |  |  | - three or more times a week | -3 |
|  |  |  |  |  | - not during the past month | -0 |
| comfortably | (V3,V4) | PSQI | breathe | choice | - less than once a week | -1 |
|  |  |  |  |  | - once or twice a week | -2 |



| During the past month, how would you rate your sleep quality overall? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4) } \end{aligned}$ | PSQI | sleepquality | singlechoice | - very good | - 0 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - fairly good | -1 |
|  |  |  |  |  | - fairly bad | -2 |
|  |  |  |  |  | - very bad | - 3 |
| How often have you taken medicine (prescribe or "over the counter") to help you sleep? | $\begin{aligned} & \text { THD } \\ & \text { (V3,V4) } \end{aligned}$ | PSQI | medicine | singlechoice | - not during the past month | -0 |
|  |  |  |  |  | - less than once a week | -1 |
|  |  |  |  |  | - once or twice a week | -2 |
|  |  |  |  |  | - three or more times a week | - 3 |
| How often have you had trouble staying awake while driving, eating meals, or engaging in social activity? | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 3, \mathrm{~V} 4) \end{aligned}$ | PSQI | trouble | singlechoice | - not during the past month | - 0 |
|  |  |  |  |  | - less than once a week | -1 |
|  |  |  |  |  | - once or twice a week | -2 |
|  |  |  |  |  | - three or more times a week | - 3 |
| During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done? | THD <br> (V3,V4) | PSQI | enthusiasm | single- <br> choice | - no problem at all | -0 |
|  |  |  |  |  | - only a very slight problem | -1 |
|  |  |  |  |  | - somewhat of a problem | -2 |
|  |  |  |  |  | - a very big problem | - 3 |
| Sleep behaviour: Do you have a bed partner or roommate? | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 3, \mathrm{~V} 4) \end{aligned}$ | PSQI | roommate | singlechoice | - no bed partner or roommate | -1 |
|  |  |  |  |  | - partner / roommate in other room | - 2 |
|  |  |  |  |  | - partner in same room, but not same bed | - 3 |



| 1. Subjective <br> sleep quality | THD <br> (V3,V4) | PSQI | subsleepquality | number |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| 2. Sleep latency | THD <br> (V3,V4) | PSQI | sleeplatency | number |  |  |  |
| 3. Sleep duration | THD <br> (V3,V4) | PSQI | sleepduration | number |  |  |  |
| 4. Habitual sleep <br> efficiency | THD <br> (V3,V4) | PSQI | sleepefficiency | number |  |  |  |
| 5. Sleep <br> disturbances | THD <br> (V3,V4) | PSQI | sleepdisturbances | number |  |  |  |
| 6. Use of sleeping <br> medication | THD <br> (V3,V4) | PSQI | sleepmedication | number |  |  |  |
| 7. Daytime <br> dysfunction | THD <br> (V3,V4) | PSQI | daytimedys | number |  |  |  |

### 5.3.21 Form "QMotor"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Distance (Mean) | TON <br> (V1,V2,V3) | QMotor | fps_dis_eo_mnx | number |  |  |  |  |
| Surface (Mean) | TON <br> (V1,V2,V3) | QMotor | fps_sur_eo_mnx | number |  |  |  |  |
| Velocity (Mean) | TON <br> (V1,V2,V3) | QMotor | fps_vel_eo_mnx | number |  |  |  |  |
| Grip Force-Force <br> variablity - <br> STDEV/ <br> MEAN*100 <br> (Coefficient of <br> Variation) | TON <br> (V1,V2,V3) | QMotor | Ihx_gf_lx_cvf | number |  |  | PDS |  |




| Position Index Mean of sum of velocity of position changes during static phase (Mean) | TON (V1,V2) | QMotor | llx_pos_rx_mnx | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Qmotor Analysis File | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | QMotor | qmotorcsv | text |  |  |  |
| Qmotor Analyse |  |  |  |  | - no | - 0 |  |
| uploaded and imported: | (V1,V2,V3) | QMotor | qmotorcsvsuccess | boolean | - yes | -1 | Not Available |
| Last Qmotor analysis variables import report | TON (V1,V2,V3) | QMotor | qmotor_import_report | text |  |  |  |
| Contact Time | TON (V1,V2) | QMotor | t50_ct_na_pct | number |  |  |  |
| Force Variability (Coefficient of Variation) | TON (V1,V2) | QMotor | t50_fv_na_cvf | number |  |  |  |
| Inter Onset Interval (Mean) | $\begin{aligned} & \hline \text { TON } \\ & \text { (V1,V2,V3) } \\ & \hline \end{aligned}$ | QMotor | tsf_ioi_lx_mnx | number |  |  |  |
| Inter Onset Interval (Standard Deviation) | TON (V1,V2,V3) | QMotor | tsf_ioi_lx_std | number |  |  | PDS |
| Inter Onset Interval (Mean) | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | QMotor | tsf_ioi_rx_mnx | number |  |  |  |
| Inter Onset Interval (Standard Deviation) | TON (V1,V2,V3) | QMotor | tsf_ioi_rx_ std | number |  |  |  |




| Speeded |  |  |  |  | - no | - 0 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| with Serial 2s completed | (V1,V2,V3) | QMotor | st2 | boolean | - yes | -1 |  |
| 100 No Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial1_ subtract | number |  |  |  |
| 100 No Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial1_ errors | number |  |  |  |
| 99 Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial2_ subtract | number |  |  |  |
| 99 Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial2_ errors | number |  |  |  |
| 98 Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial3_ subtract | number |  |  | S |
| 98 Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial3_ errors | number |  |  | dS |
| 97 Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial4_ subtract | number |  |  |  |
| 97 Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial4_ errors | number |  |  |  |
| 96 Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial5_ subtract | number |  |  |  |
| 96 Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial5_ errors | number |  |  |  |
| 95 Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial6_ subtract | number |  |  |  |
| 95 Tap | $\begin{aligned} & \text { THD (V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | QMotor | stap2_trial6_ errors | number |  |  |  |
| GAITRite | THD (V1,V2) | QMotor | gaitfile | text |  |  | Not Available |

### 5.3.22 Form "Quality of Life"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Total Quality of Life Score | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \\ & \hline \end{aligned}$ | QOLI | qoliscore | number |  |  |  |  |
| Health and functioning subscale score | THD (V1,V2,V3,V4); TON (V1) | QOLI | healthscore | number |  |  |  |  |
| Social and economic subscale score | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \\ & \hline \end{aligned}$ | QOLI | socialscore | number |  |  |  | PDS |
| Psychological/spiritual subscale score | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \\ & \hline \end{aligned}$ | QOLI | psychscore | number |  |  |  |  |
| Family subscale score | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \\ & \hline \end{aligned}$ | QOLI | familyscore | number |  |  |  |  |
| 1. Your health? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | health | singlechoice | - very dissatisfied | -1 |  | Not Available |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |  |
|  |  |  |  |  | - slightly dissatisfied | -3 |  |  |
|  |  |  |  |  | - slightly satisfied | -4 |  |  |
|  |  |  |  |  | - moderately satisfied | -5 |  |  |
|  |  |  |  |  | - very satisfied | -6 |  |  |
| 2. Your health care? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | healthcare | singlechoice | - very dissatisfied | -1 |  | PDS |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |  |
|  |  |  |  |  | - slightly dissatisfied | -3 |  |  |
|  |  |  |  |  | - slightly satisfied | -4 |  |  |
|  |  |  |  |  | - moderately satisfied | -5 |  |  |


|  |  |  |  |  | - very satisfied | -6 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 3. The amount of pain that you have? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | pain_qol | single- <br> choice | - very dissatisfied | -1 | Not <br> Available |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |
|  |  |  |  |  | - slightly dissatisfied | -3 |  |
|  |  |  |  |  | - slightly satisfied | -4 |  |
|  |  |  |  |  | - moderately satisfied | - 5 |  |
|  |  |  |  |  | - very satisfied | -6 |  |
| 4. The amount of energy you have for everyday activities? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | energy_qol | singlechoice | - very dissatisfied | -1 | PDS |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |
|  |  |  |  |  | - slightly dissatisfied | -3 |  |
|  |  |  |  |  | - slightly satisfied | -4 |  |
|  |  |  |  |  | - moderately satisfied | - 5 |  |
|  |  |  |  |  | - very satisfied | -6 |  |
| 5. Your ability to take care of yourself without help? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | withouthelp | single- <br> choice | - very dissatisfied | -1 | Not <br> Available |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |
|  |  |  |  |  | - slightly dissatisfied | - 3 |  |
|  |  |  |  |  | - slightly satisfied | -4 |  |
|  |  |  |  |  | - moderately satisfied | - 5 |  |
|  |  |  |  |  | - very satisfied | -6 |  |
| 6. The amount of control you have over your life? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | control_qol | single- <br> choice | - very dissatisfied | -1 | PDS |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |
|  |  |  |  |  | - slightly dissatisfied | -3 |  |
|  |  |  |  |  | - slightly satisfied | -4 |  |
|  |  |  |  |  | - moderately satisfied | - 5 |  |
|  |  |  |  |  | - very satisfied | -6 |  |
|  |  | QOLI | chance | singlechoice | - very dissatisfied | -1 |  |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |


| 7. Your chances of living as long as you would like? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ |  |  |  | - slightly dissatisfied | -3 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - slightly satisfied | -4 |  |
|  |  |  |  |  | - moderately satisfied | - 5 |  |
|  |  |  |  |  | - very satisfied | -6 |  |
| 8. Your family's health? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | healthfam | singlechoice | - very dissatisfied | -1 |  |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |
|  |  |  |  |  | - slightly dissatisfied | -3 |  |
|  |  |  |  |  | - slightly satisfied | -4 |  |
|  |  |  |  |  | - moderately satisfied | - 5 |  |
|  |  |  |  |  | - very satisfied | -6 |  |
| 9. Your children? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | children_qol | singlechoice | - very dissatisfied | -1 |  |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |
|  |  |  |  |  | - slightly dissatisfied | -3 |  |
|  |  |  |  |  | - slightly satisfied | -4 |  |
|  |  |  |  |  | - moderately satisfied | - 5 |  |
|  |  |  |  |  | - very satisfied | -6 |  |
| 10. Your family's happiness? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | happiness | singlechoice | - very dissatisfied | -1 | Not <br> Available |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |
|  |  |  |  |  | - slightly dissatisfied | -3 |  |
|  |  |  |  |  | - slightly satisfied | -4 |  |
|  |  |  |  |  | - moderately satisfied | - 5 |  |
|  |  |  |  |  | - very satisfied | -6 |  |
| 11. Your sex life? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | sex | single- <br> choice | - very dissatisfied | -1 |  |
|  |  |  |  |  | - moderately dissatisfied | -2 |  |
|  |  |  |  |  | - slightly dissatisfied | -3 |  |
|  |  |  |  |  | - slightly satisfied | -4 |  |
|  |  |  |  |  | - moderately satisfied | - 5 |  |
|  |  |  |  |  | - very satisfied | -6 |  |


| 12. Your spouse, lover, or partner? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | spouse | singlechoice | - very dissatisfied | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - moderately dissatisfied | -2 |
|  |  |  |  |  | - slightly dissatisfied | -3 |
|  |  |  |  |  | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | -5 |
|  |  |  |  |  | - very satisfied | -6 |
| 13. Your friends? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | friends | singlechoice | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
|  |  |  |  |  | - slightly dissatisfied | -3 |
|  |  |  |  |  | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | - 5 |
|  |  |  |  |  | - very satisfied | -6 |
| 14. The emotional support you get from your family? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | support | singlechoice | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
|  |  |  |  |  | - slightly dissatisfied | - 3 |
|  |  |  |  |  | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | - 5 |
|  |  |  |  |  | - very satisfied | -6 |
| 15. The emotional support you get from people other than your family? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | supportother | singlechoice | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
|  |  |  |  |  | - slightly dissatisfied | - 3 |
|  |  |  |  |  | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | - 5 |
|  |  |  |  |  | - very satisfied | -6 |
| 16. Your ability to take care of family responsibilities? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | response | singlechoice | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
|  |  |  |  |  | - slightly dissatisfied | - 3 |
|  |  |  |  |  | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | - 5 |


|  |  |  |  |  | - very satisfied | -6 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
| 17. How useful you | THD <br> (V1, V2, V3, V4); | Q01 |  | single- | - slightly dissatisfied | -3 |
| are to others? | TON (V1) | QOLI | us | choice | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | -5 |
|  |  |  |  |  | - very satisfied | -6 |
|  |  |  |  |  | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
| 18. The amount of | (V1,V2,V3, V4); |  | worries | single- | - slightly dissatisfied | -3 |
| worries in your life? | TON (V1) | QOL | worries | choice | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | -5 |
|  |  |  |  |  | - very satisfied | -6 |
|  |  |  |  |  | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
| 19. Your | (V1, V2, V3, V4); | , |  | single- | - slightly dissatisfied | -3 |
| neighborhood? | TON (V1) | OLI | neis | choice | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | -5 |
|  |  |  |  |  | - very satisfied | -6 |
|  |  |  |  |  | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
| 20. Your home, apartment or place | THD <br> (V1, V2 V3, V4); | QOLI | home | single- | - slightly dissatisfied | -3 |
| where you live? | TON (V1) |  |  | choice | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | -5 |
|  |  |  |  |  | - very satisfied | -6 |
| 21. Your job (if employed)? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | job | singlechoice | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
|  |  |  |  |  | - slightly dissatisfied | -3 |
|  |  |  |  |  | - slightly satisfied | -4 |




| 31. Your life in general? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ |  |  | singlechoice | - moderately dissatisfied | -2 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - slightly dissatisfied | -3 |
|  |  |  |  |  | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | - 5 |
|  |  |  |  |  | - very satisfied | -6 |
| 32. Your personal appearance? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | appearance | singlechoice | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
|  |  |  |  |  | - slightly dissatisfied | -3 |
|  |  |  |  |  | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | - 5 |
|  |  |  |  |  | - very satisfied | -6 |
| 33. Yourself in general? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | yourself | singlechoice | - very dissatisfied | -1 |
|  |  |  |  |  | - moderately dissatisfied | -2 |
|  |  |  |  |  | - slightly dissatisfied | -3 |
|  |  |  |  |  | - slightly satisfied | -4 |
|  |  |  |  |  | - moderately satisfied | - 5 |
|  |  |  |  |  | - very satisfied | -6 |
| 1. Your health? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | imphealth | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | - 2 |
|  |  |  |  |  | - slightly unimportant | -3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |
| 2. Your health care? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | imphealthcare | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | - 2 |
|  |  |  |  |  | - slightly unimportant | -3 |
|  |  |  |  |  | - slightly important | -4 |



|  |  |  |  |  | - very important | -6 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 7. Living as long as you would like? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impliving | single- <br> choice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | - 2 |
|  |  |  |  |  | - slightly unimportant | - 3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |
| 8. Your family's health? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | imphealthfam | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | - 2 |
|  |  |  |  |  | - slightly unimportant | -3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |
| 9. Your children? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impchildren | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | -2 |
|  |  |  |  |  | - slightly unimportant | - 3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |
| 10. Your family's happiness? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | imphappiness | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | - 2 |
|  |  |  |  |  | - slightly unimportant | -3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |


| 11. Your sex life? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impsexlife | singlechoice | - very unimportant | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - moderately unimportant | -2 |
|  |  |  |  |  | - slightly unimportant | -3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | -5 |
|  |  |  |  |  | - very important | -6 |
| 12. Your spouse, lover, or partner? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impspouse | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | -2 |
|  |  |  |  |  | - slightly unimportant | -3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |
| 13. Your friends? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impfriends | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | -2 |
|  |  |  |  |  | - slightly unimportant | - 3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | -5 |
|  |  |  |  |  | - very important | -6 |
| 14. The emotional support you get from your family? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impsupport | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | -2 |
|  |  |  |  |  | - slightly unimportant | - 3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | -5 |
|  |  |  |  |  | - very important | -6 |
|  |  | QOLI | impsupportother |  | - very unimportant | -1 |


| 15. The emotional support you get from people other than your family? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ |  |  | singlechoice | - moderately unimportant | -2 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - slightly unimportant | -3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | -5 |
|  |  |  |  |  | - very important | -6 |
| 16. Taking care of family responsibilities? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impresponse | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | - 2 |
|  |  |  |  |  | - slightly unimportant | -3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |
| 17. Being useful to others? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impuseful | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | - 2 |
|  |  |  |  |  | - slightly unimportant | - 3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |
| 18. Having no worries? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impworries | single- <br> choice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | - 2 |
|  |  |  |  |  | - slightly unimportant | -3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |
| 19. Your neighborhood? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impneighbor | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | - 2 |





|  |  |  |  |  | - very important | -6 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - very unimportant | -1 |
|  | THD |  |  |  | - moderately unimportant | - 2 |
| 32. Your personal | (V1,V2, V3, V4); | QOLI | impappearance | single- | - slightly unimportant | -3 |
|  | TON (V1) |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |
| 33. Are you to yourself? | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1) } \end{aligned}$ | QOLI | impyourself | singlechoice | - very unimportant | -1 |
|  |  |  |  |  | - moderately unimportant | -2 |
|  |  |  |  |  | - slightly unimportant | -3 |
|  |  |  |  |  | - slightly important | -4 |
|  |  |  |  |  | - moderately important | - 5 |
|  |  |  |  |  | - very important | -6 |

### 5.3.23 Form "Samples ACD"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| CAG smaller <br> allele | THD <br> (V1); <br> TON <br> (V1) | Samples <br> ACD | cagsmaller__value | number |  |  |  |
| CAG larger allele | THD <br> (V1); <br> TON <br> (V1) | Samples <br> ACD | caglarger_value | number |  |  |  |

### 5.3.24 Form "SF-36v2"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Physical <br> Functioning (PF) | $\begin{aligned} & \hline \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | SF-36v2 | pfsubscore | number |  |  |  | PDS |
| Physical <br> Functioning (PF) | THD (V3) | SF-36v2 | pf | number |  |  |  | Available upon SRC approval |
| Physical <br> Functioning (PF) | THD (V3) | SF-36v2 | pf_nbs | number |  |  |  | Not Available |
| Role-Physical (RP) | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | SF-36v2 | rpsubscore | number |  |  |  | PDS |
| Role-Physical (RP) | THD (V3) | SF-36v2 | rp | number |  |  |  | Available upon SRC approval |
| Role-Physical (RP) | THD (V3) | SF-36v2 | rp_nbs | number |  |  |  | $\begin{gathered} \text { Not } \\ \text { Available } \end{gathered}$ |
| Bodily Pain (BP) | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | SF-36v2 | bpsubscore | number |  |  |  | PDS |
| Bodily Pain (BP) | THD (V3) | SF-36v2 | bp | number |  |  |  | Available upon SRC approval |
| Bodily Pain (BP) | THD (V3) | SF-36v2 | bp_nbs | number |  |  |  | Not Available |
| General Health (GH) | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | SF-36v2 | ghsubscore | number |  |  |  | PDS |
| General Health (GH) | THD (V3) | SF-36v2 | gh | number |  |  |  | Available upon SRC approval |
| General Health (GH) | THD (V3) | SF-36v2 | gh_nbs | number |  |  |  | Not Available |



| Physical <br> Component <br> Summary (PCS) | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | SF-36v2 | pcsum | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Mental <br> Component <br> Summary (MCS) | THD (V3) | SF-36v2 | mcs | number |  |  | Available upon SRC approval |
| Mental <br> Component <br> Summary (MCS) | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | SF-36v2 | mcsum | number |  |  | PDS |
| 1. In general, would you say your health is? | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | SF-36v2 | general_sf36 | singlechoice | - poor | -1 |  |
|  |  |  |  |  | - fair 3.4 | -2 |  |
|  |  |  |  |  | - excellent | - 5 |  |
| 2. Compared to one year ago, how would you rate your health in general now? | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | SF-36v2 | compared | singlechoice | - much better now than one year ago | -1 | Available upon SRC approval |
|  |  |  |  |  | - somewhat better now than one year ago | - 2 |  |
|  |  |  |  |  | - about the same as one year ago | - 3 |  |
|  |  |  |  |  | - somewhat worse now than one year ago | - 4 |  |
|  |  |  |  |  | - much worse now than one year ago | - 5 |  |
| Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | SF-36v2 | activitiesv | singlechoice | - yes, limited a lot | -1 |  |
|  |  |  |  |  | - yes, limited a little | -2 |  |
|  |  |  |  |  | - No, not limited at all | - 3 |  |
| Moderate activities, such as | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | SF-36v2 | activitiesm | singlechoice | - yes, a lot | -1 |  |
|  |  |  |  |  | - yes, a little | -2 |  |


| moving a table, pushing a vacuum cleaner, bowling, or playing golf |  |  |  |  | - not at all | -3 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - yes, a lot | -1 |
| Lifting or carrying groceries | THD <br> (V1,V2, V3) | SF-36v2 | lifting | singlechoice | - yes, a little | -2 |
|  |  |  |  |  | - not at all | -3 |
|  |  |  |  |  | - yes, a lot | -1 |
| Climbing several flights of stairs | THD <br> (V1,V2,V3) | SF-36v2 | climbings | singlechoice | - yes, a little | -2 |
|  |  |  |  |  | - not at all | -3 |
|  |  |  |  |  | - yes, a lot | -1 |
| flight of | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | SF-36v2 | climbingo | singlechoice | - yes, a little | -2 |
|  |  |  |  |  | - not at all | -3 |
|  |  |  |  |  | - yes, a lot | -1 |
| Bending, kneeling or stooping | $\begin{aligned} & \text { THD } \\ & \text { (V1, V2, V3) } \end{aligned}$ | SF-36v2 | bending | singlechoice | - yes, a little | -2 |
|  |  |  |  |  | - not at all | -3 |
| Walking more |  |  |  |  | - yes, a lot | -1 |
| than a mile | THD | SF-36v2 | walkingm | single- | - yes, a little | -2 |
| kilometres) | (V1,V2,V3) |  |  |  | - not at all | -3 |
| Walking several |  |  |  |  | - yes, a lot | -1 |
| hundred yards | (V1, V2, V3) | SF-36v2 | walkings | singlechoice | - yes, a little | -2 |
| (metres) |  |  |  |  | - not at all | -3 |
|  |  |  |  |  | - yes, a lot | -1 |
| hundred yards | (V1, V2, V3) | SF-36v2 | walkingo | singlechoice | - yes, a little | -2 |
| (metres) |  |  |  |  | - not at all | -3 |
| Bathing or dressing yourself | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | SF-36v2 | bathing | singlechoice | - yes, a lot | -1 |
|  |  |  |  |  | - yes, a little | -2 |
|  |  |  |  |  | - not at all | -3 |


| Cut down on the amount of time you spent on work or other activities | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | SF-36v2 | physiccut | singlechoice | - all of the time | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - most of the time | -2 |
|  |  |  |  |  | - some of the time | - 3 |
|  |  |  |  |  | - a little of the time | -4 |
|  |  |  |  |  | - none of the time | - 5 |
| Accomplished less than you would like | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | SF-36v2 | physicacc | singlechoice | - all of the time | -1 |
|  |  |  |  |  | - most of the time | -2 |
|  |  |  |  |  | - some of the time | - 3 |
|  |  |  |  |  | - a little of the time | -4 |
|  |  |  |  |  | - none of the time | - 5 |
| Were limited in the kind of work or other activities | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | SF-36v2 | physiclimit | singlechoice | - all of the time | -1 |
|  |  |  |  |  | - most of the time | -2 |
|  |  |  |  |  | - some of the time | - 3 |
|  |  |  |  |  | - a little of the time | -4 |
|  |  |  |  |  | - none of the time | -5 |
| Had difficulty performing the work or other activities (for example, it took extra effort) | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | SF-36v2 | physicdiff | single- <br> choice | - all of the time | -1 |
|  |  |  |  |  | - most of the time | -2 |
|  |  |  |  |  | - some of the time | -3 |
|  |  |  |  |  | - a little of the time | -4 |
|  |  |  |  |  | - none of the time | - 5 |
| Cut down on the amount of time you spent on work or other activities | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | SF-36v2 | emotioncut | singlechoice | - all of the time | -1 |
|  |  |  |  |  | - most of the time | -2 |
|  |  |  |  |  | - some of the time | - 3 |
|  |  |  |  |  | - a little of the time | -4 |
|  |  |  |  |  | - none of the time | -5 |
| Accomplished less than you would like | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | SF-36v2 | emotionacc | singlechoice | - all of the time | -1 |
|  |  |  |  |  | - most of the time | -2 |
|  |  |  |  |  | - some of the time | - 3 |



| work (including <br> both work <br> outside the home <br> and housework)? |  |  |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |



| visiting with <br> friends, relatives, <br> etc.)? |  |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |

### 5.3.25 Form "UHDRS Total Functional Capacity (TFC)"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| Functional score | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TFC | tfcscore | number |  |  | PDS |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Completeness of functional score | TON (V1,V2,V3) | TFC | cmpltfc | number |  |  | Available upon SRC approval |
| Occupation | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TFC | occupatn | singlechoice | - unable | -0 | PDS |
|  |  |  |  |  | - marginal work only | -1 |  |
|  |  |  |  |  | - reduced capacity for usual job | - 2 |  |
|  |  |  |  |  | - normal | -3 |  |
| Finances | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | TFC | finances_tfc | singlechoice | - unable | -0 |  |
|  |  |  |  |  | - major assistance | -1 |  |
|  |  |  |  |  | - slight assistance | -2 |  |
|  |  |  |  |  | - normal | - 3 |  |
| Domestic chores | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TFC | chores | singlechoice | - unable | -0 |  |
|  |  |  |  |  | - impaired | -1 |  |
|  |  |  |  |  | - normal | -2 |  |
| ADL | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TFC | adl | single- <br> choice | - total care | -0 |  |
|  |  |  |  |  | - gross tasks only | -1 |  |
|  |  |  |  |  | - minimal impairment | -2 |  |
|  |  |  |  |  | - normal | -3 |  |
| Care level | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TFC | carelevl | single- <br> choice | - full time skilled nursing | -0 |  |
|  |  |  |  |  | - home or chronic care | -1 |  |
|  |  |  |  |  | - home | -2 |  |
| Was the information obtained from | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \end{aligned}$ | TFC | tfcsrc | singlechoice | - participant only | -1 | Available upon SRC approval |


| TON <br> (V1,V2,V3) |  | - participant and <br> family/companion | -2 | $\square$ |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |

### 5.3.26 Form "UHDRS Total Motor Score (TMS)"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Hemisphere assessed | TON <br> (V1,V2,V3) | TMS | hemisphere | single- <br> choice | - right | - left | -1 |  |


| Long Latency Reflex (LLR) | TON | TMS | Ir | boolean | - no | -0 | PDS |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | (V1,V2, V3) | TMS | Ilr |  | - yes | -1 |  |
| Stimulation intensity used for LLR | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | Ilr_intensity | number |  |  |  |
| RAW data | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | Ilr_raw | text |  |  | Not Available |
| Transcranial magnetic | TON | MS | tms | boolean | - no | -0 | PDS |
| stimulation | (V1,V2,V3) | S | tms | boolean | - yes | -1 |  |
| Resting motor threshold | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | TMS | tms_thrhld_resting | number |  |  |  |
| Active motor threshold | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | TMS | tms_thrhld_ active | number |  |  |  |
| I/O rest | TON | TMS | tms_iorest | boolean | - no | -0 |  |
|  | (V1,V2,V3) |  |  |  | - yes | -1 |  |
| 110\% resting motor threshold | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | tms_iorest_ 110_motor | number |  |  |  |
| $130 \%$ resting motor threshold | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | tms_iorest_ 130_motor | number |  |  |  |
| 150\% resting motor threshold | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | tms_iorest_ 150_motor | number |  |  |  |
| RAW data | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | tms_iorest_ 110_raw | text |  |  | Not <br> Available |
| RAW data | $\begin{aligned} & \hline \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | TMS | tms_iorest_ 130_raw | text |  |  |  |
| RAW data | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | TMS | tms_iorest_ 150_raw | text |  |  |  |
| I/O active | TON | TMS | tms_ioactv | boolean | - no | -0 | PDS |
|  | $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ |  |  |  | - yes | -1 |  |
| 125\% active motor threshold | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | tms_ioact_ 125_motor | number |  |  |  |


| 150\% active motor threshold | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | tms_ioact_ 150_motor | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| 175\% active motor threshold | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | TMS | tms_ioact_ 175_motor | number |  |  |  |
| RAW data | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | tms_ioact_ 125_raw | text |  |  | Not Available |
| RAW data | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | TMS | tms_ioact_ 150_raw | text |  |  |  |
| RAW data | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | tms_ioact_ 175_raw | text |  |  |  |
| Short latency sensory | TON |  |  |  | - no | - 0 | PDS |
| afferent inhibition (SAI) | (V1,V2, V3) | TMS | tms_sai | boolean | - yes | -1 |  |
| Stimulation intensity for unconditioned MEP | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | TMS | tms_sai_intens_mep | number |  |  |  |
| N20+2 | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | TMS | isi_n202 | number |  |  |  |
| N20+4 | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | TMS | isi_n204 | number |  |  |  |
| N20+12 | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | TMS | fisi_n2012 | number |  |  |  |
| N20+14 | $\begin{aligned} & \hline \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | TMS | fisi_n2014 | number |  |  |  |
| RAW data | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | TMS | tms_sai_raw | text |  |  | Not Available |
|  | TON |  |  |  | - no | - 0 |  |
| Optional rapid | (V1,V2,V3) | TMS | pas | olean | - yes | -1 |  |
| Comment available | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | comment | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Comment | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | commentspc | text |  |  |  |




| Cortical silent period duration at 175\% AMT | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | TMS | tms_ioactv_175_spd | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| MEP area at 175\% AMT/Cortical silent period duration at 175\% AMT | TON (V1,V2,V3) | TMS | tms_ioactv_ 175_area_spd | number |  |  |  |
| Short latency sensory afferent inhibition (SAI) | TON (V1,V2,V3) | TMS | tms_sai_anlys | boolean | - no | -0 -1 |  |
| Conditioned MEP size N20+2/unconditioned MEP size | TON (V1,V2) | TMS | tms_sai_n202_size | number |  |  |  |
| Conditioned MEP size N20+4/unconditioned MEP size | TON (V1,V2) | TMS | tms_sai_n204_size | number |  |  |  |
| Conditioned MEP size N20+12/unconditioned MEP size | TON (V1,V2) | TMS | tms_sai_n2012_size | number |  |  |  |
| Conditioned MEP size N20+14/unconditioned MEP size | TON (V1,V2) | TMS | tms_sai_n2014_size | number |  |  |  |
| Optional rapid PAS | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | TMS | pas_anlys | boolean | - no | -0 | Not Available |

### 5.3.27 Form "Variable Items"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Availability |  |  |  |  |  |  |  |
| Date of visit | THD <br> (V1,V2,V3,V4); | Variable <br> Items | svstdtc | date |  | Not |  |


|  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |


| Current alcohol consumption | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Variable Items | alcunits | numeric |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| What is the highest degree that you have completed? | $\begin{aligned} & \text { THD (V2,V3); } \\ & \text { TON (V1,V3) } \end{aligned}$ | Variable Items | highest_education | text |  |  | Not <br> Available |
| Had the |  |  |  |  | - no | -0 |  |
| Medication forms been updated to the current status? | $\begin{aligned} & \text { (V2,V3,V4); } \\ & \text { TON (V2,V3) } \end{aligned}$ | Variable Items | comorbmedcheck | boolean | - yes | -1 |  |
| Current education level (ISCED 2010) | $\begin{aligned} & \text { THD (V3); TON } \\ & \text { (V1) } \end{aligned}$ | Variable Items | isced | singlechoice | - ISCED 0 | -0 | PDS |
|  |  |  |  |  | - ISCED 1 | -1 |  |
|  |  |  |  |  | - ISCED 2 | -2 |  |
|  |  |  |  |  | - ISCED 3 | -3 |  |
|  |  |  |  |  | - ISCED 4 | -4 |  |
|  |  |  |  |  | - ISCED 5 | -5 |  |
|  |  |  |  |  | - ISCED 6 | -6 |  |
| Is the partner/spouse the same person as at visit 1 | THD (V3) | Variable Items | maritalstatuspers | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Are you currently participating in a clinical drug trial | THD (V3, V4) | Variable Items | cltrial | boolean | - no | -0 -1 | Available upon SRC approval |
| Subject group | THD (V3,V4) | Variable Items | sgroup_thd | singlechoice | - control subject | -0 | PDS |
|  |  |  |  |  | - premanifest gene carrier | -1 |  |


|  |  |  |  |  | - early-HD | -2 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Relation to subject | THD (V3) | Variable Items | relation_thd_v3 | singlechoice | - sibling/non-gene carrier | -1 |  |
|  |  |  |  |  | - partner/spouse of preHD subject | -2 |  |
|  |  |  |  |  | - partner/spouse of earlyHD subject | -3 |  |
| Missing highest degree been collected at Visit 2 | THD (V3) | Variable Items | check_he_v2 | boolean |  |  | Not Available |
| What is the highest degree that you have completed? (V2) | THD (V3) | Variable Items | highest_education_v2 | text |  |  |  |
| Is the partner/spouse the same person as at all previous visits | THD (V4) | Variable Items | samepartner | singlechoice | - no, different to all previous visits | -0 | PDS |
|  |  |  |  |  | - yes, same at all visits | -1 |  |
|  |  |  |  |  | - no, same at some previous visits | -2 |  |
| Partner in previous visit visit 1 | THD (V4) | Variable Items | samepartnervisits_1 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Partner in previous visit visit 2 | THD (V4) | Variable Items | samepartnervisits_2 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Partner in previous visit visit 3 | THD (V4) | Variable Items | samepartnervisits_3 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
|  |  |  | relation |  | - sibling/non-gene carrier | -1 |  |


| Relation to subject | $\begin{aligned} & \text { THD (V4); TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Variable Items |  | singlechoice | ```- cohabiting partner/spouse of pre-HD subject``` | - 2 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | ```- cohabiting partner/spouse of early-HD subject``` | - 3 |  |
| Signature of subject for V4 | THD (V4) | Variable Items | signpv4 | boolean | - no | - 0 | Not Available |
|  |  |  |  |  | - yes | -1 |  |
| Visit day | THD (V4) | Variable Items | svstdy | number |  |  |  |
| Subject group | TON(V1,V2,V3) | Variable Items | sgroup_ton | singlechoice | - control subject | -1 |  |
|  |  |  |  |  | - premanifest gene carrier | -2 |  |
|  |  |  |  |  | $\qquad$ HD) | - 3 |  |
|  |  |  |  |  | - premanifest gene carrier (TRACK-HD) | -4 |  |
| Do you have a companion who will be completing questionnaires? | TON(V1,V2,V3) | Variable Items | qscmp | boolean | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 | PDS |
| Is it the same companion as at all previous TRACK-HD visits? | TON(V1,V2,V3) | Variable Items | cmpvs | singlechoice | - no, different to all previous visits | - 0 |  |
|  |  |  |  |  | - yes, same at all visits | -1 |  |
|  |  |  |  |  | - no, same at some previous visits | - 2 |  |
| Specify previous <br> TRACK-HD visit(s) <br> - visit 1 | TON (V1) | Variable Items | cmpvsn__1 | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
|  | TON (V1) |  | cmpvsn__2 | boolean | - no | -0 |  |


| Specify previous TRACK-HD visit(s) - visit 2 |  | Variable Items |  |  | - yes | -1 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Specify previous |  | V |  |  | - no | -0 |  |
| TRACK-HD visit(s) <br> - visit 3 | TON (V1) | Items | cmpvsn__3 | boolean | - yes | -1 |  |
| Specify previous |  |  |  |  | - no | -0 |  |
| TRACK-HD visit(s) <br> - visit 4 | TON (V1) | Items | cmpvsn__4 | boolean | - yes | -1 |  |
|  |  |  |  |  | - spouse or partner | -1 |  |
|  |  |  |  |  | - parent | -2 |  |
|  |  |  |  |  | - sibling | - 3 |  |
|  | TON | Variable |  | single- | - child | -4 |  |
| inforr | (V1, V2, V3) | Items | cmpstat | choice | - other relative | - 5 |  |
|  |  |  |  |  | - friend or neighbour | -6 |  |
|  |  |  |  |  | - professional care worker | - 7 |  |
|  |  |  |  |  | - other | -8 |  |
|  |  |  |  |  | - household member (i.e. relative or friend who lives with subject) | -1 |  |
| Is informant a household | TON | Variable | cmphh | single- | - not a household member but has frequent contact with subject (most days) | - 2 |  |
| member? |  |  |  |  | - not a household member and sees subject less than three or four times a week | -3 |  |
|  |  |  |  |  | - staff of residential care home or hospital | -4 |  |
| Signature of companion if | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | Variable Items | cmpsg | boolean | - no | -0 | Not Available |


| completing companion questionnaires? |  |  |  |  | - yes | -1 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Disease Burden Score | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | Variable Items | dbscore | number |  |  |  |
| Known history of |  | Variable | -1 | bo | - no | - 0 |  |
| epilepsy | TON (V2,V3) | Items | ec1 | boolean | - yes | -1 |  |
| Concomitant |  |  |  |  | - no | -0 |  |
| neurological disorder | TON(V2, ${ }^{\text {( }}$ ) | Items | ec2 | boolean | - yes | -1 |  |
| Concomitant |  |  |  |  | - no | - 0 |  |
| medical illness |  | Items |  |  | - yes | -1 |  |
| History of |  | Variable |  |  | - no | - 0 | PDS |
| injury | TON(V2,V3) | Items | ec4 | oolean | - yes | -1 |  |
| Predictable non- |  |  |  |  | - no | - 0 |  |
| drug and/or alcohol abuse | (V2,V3) | Items | ecs | boolean | - yes | -1 |  |
| Significant hand |  |  |  |  | - no | -0 |  |
| preclude either <br> writing or rapid <br> computerized <br> responding | TON (V2,V3) | Variable Items | ec6 | boolean | - yes | -1 |  |
| Currently participating in a clinical drug trial | TON (V2,V3) | Variable Items | ec7 | boolean | - no | -0 -1 | Available upon SRC approval |


| Subject is | TON (V2,V3) | Variable Items | eligible | single- <br> choice | - no longer eligible | -0 | Not <br> Available |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - still eligible | -1 |  |
| Had the HD History form been updated to the current status? | TON (V2,V3) | Variable Items | hdcccheck | boolean | - no | -0 |  |
|  |  |  |  |  | - yes | -1 |  |
| Is it the same companion as at Track-On HD visit 1? | TON (V2) | Variable Items | cmpvston | boolean | - no | -0 | PDS |
|  |  |  |  |  | - yes | -1 |  |
| Current education level (ISCED 2011) | TON (V3) | Variable Items | isced_2011 | singlechoice | - ISCED 0 | -0 |  |
|  |  |  |  |  | - ISCED 1 | -1 |  |
|  |  |  |  |  | - ISCED 2 | -2 |  |
|  |  |  |  |  | - ISCED 3 | - 3 |  |
|  |  |  |  |  | - ISCED 4 | -4 |  |
|  |  |  |  |  | - ISCED 5 | - 5 |  |
|  |  |  |  |  | - ISCED 6 | -6 |  |
|  |  |  |  |  | - ISCED 7 | - 7 |  |
|  |  |  |  |  | - ISCED 8 | -8 |  |
| Is it the same companion as at all previous Track-On HD visits? | TON (V3) | Variable Items | cmpvston_all | singlechoice | - no, different to all previous visits | -0 |  |
|  |  |  |  |  | - yes, same at all visits | -1 |  |
|  |  |  |  |  | - no, same at some previous visits | - 2 |  |

### 5.4 Data file "oculomotor"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Recoded HDID | THD <br> (V1,V2,V3,V4); <br> TON (V1,V2) | Key Vars | subjid | text |  |  |  |  |
| Study ID | THD <br> (V1,V2,V3,V4); <br> TON (V1,V2) | Key Vars | studyid | text |  |  |  |  |
| Visit Number | THD <br> (V1,V2,V3,V4); <br> TON (V1,V2) | Key Vars | visitnum | number |  |  |  |  |
| Form Number | THD <br> (V1,V2,V3,V4); <br> TON (V1,V2) | Key Vars | nr | number |  |  | Not |  |
| Row Number | THD <br> (V1,V2,V3,V4); <br> TON (V1,V2) | Key Vars | enr | number |  |  |  |  |
| Visit | THD <br> (V1,V2,V3,V4); <br> TON (V1,V2) | Key Vars | visit | text |  |  |  |  |



### 5.4.1 Form "Oculomotor"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| LatencyMeter File (LDF) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | Oculomotor | Idffile | text |  |  |  |  |
| Oculomotor <br> Analysis File | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1,V2) } \\ & \hline \end{aligned}$ | Oculomotor | oculomcsv | text |  |  |  | Not <br> Available |
| Import Report | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1,V2) } \\ & \hline \end{aligned}$ | Oculomotor | oab_import_report | text |  |  |  |  |
| Oculomotor |  |  |  |  | - no | - 0 |  | PDS |
| successfully <br> uploaded and imported: | TON (V1) | Oculomotor | oculomotorcsvsuccess | boolean | - yes | -1 |  |  |
| Saccades <br> Accepted | TON (V1) | Oculomotor | acc | number |  |  |  |  |
| Error rate | TON (V1) | Oculomotor | err | number |  |  |  |  |
| Latency Median | TON (V1) | Oculomotor | latmed | number |  |  |  |  |
| Latency <br> Standard <br> Deviation | TON (V1) | Oculomotor | latsd | number |  |  |  |  |
| Duration Mean | TON (V1) | Oculomotor | durmn | number |  |  |  |  |
| Duration <br> Standard <br> Deviation | TON (V1) | Oculomotor | dursd | number |  |  |  |  |


| Mean Velocity Mean | TON (V1) | Oculomotor | mvelmn | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Mean Velocity <br> Standard <br> Deviation | TON (V1) | Oculomotor | mvelsd | number |  |  |  |
| Amplitude Mean | TON (V1) | Oculomotor | ampmn | number |  |  |  |
| Amplitude <br> Standard <br> Deviation | TON (V1) | Oculomotor | ampsd | number |  |  |  |
| Velocity <br> Function Slope | TON (V1) | Oculomotor | velsl | number |  |  |  |
| Velocity Function Intercept | TON (V1) | Oculomotor | velin | number |  |  |  |
| LATER model mu | TON (V1) | Oculomotor | latmu | number |  |  |  |
| LATER model sigma | TON (V1) | Oculomotor | latsig | number |  |  |  |
| LATER model sigma epsilon | TON (V1) | Oculomotor | latse | number |  |  |  |
| Protocol | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON (V1,V2) } \\ \hline \end{array}$ | Oculomotor | protocol | single- <br> choice | $\begin{aligned} & \hline \text { - CON } \\ & \text { - THD } \\ & \text { - TON } \\ & \hline \end{aligned}$ | - CON |  |
| Session | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4); } \\ & \text { TON (V1,V2) } \end{aligned}$ | Oculomotor | session | text |  |  | Not |
| Comment | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3,V4); } \\ \text { TON (V1,V2) } \\ \hline \end{array}$ | Oculomotor | comment | text |  |  | Available |
|  |  |  |  |  | - no | -0 |  |
| Ishihara RGcb | THD (V1) | Ocu | rgcb | boolean | - yes | -1 | PDS |



| LATENCY total <br> (med) - CON2 | THD <br> (V1,V2,V3,V4) | Oculomotor | Itmc2 | number |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| LATENCY total <br> (med) - CON3 | THD <br> (V1,V2,V3,V4) | Oculomotor | Itmc3 | number |  |  |
| LATENCY total <br> (med) - PRO | THD <br> (V1,V2,V3,V4) | Oculomotor | Itmpr | number |  |  |
| LATENCY total <br> (SD) - <br> CONTOTAL | THD <br> (V1,V2,V3,V4) | Oculomotor | Itsct | number |  |  |
| LATENCY total <br> (SD) - CON1 | THD <br> (V1,V2,V3,V4) | Oculomotor | Itsc1 | number |  |  |
| LATENCY total <br> (SD) - CON2 | THD <br> (V1,V2,V3,V4) | Oculomotor | Itsc2 | number |  |  |
| LATENCY total <br> (SD) - CON3 | THD <br> (V1,V2,V3,V4) | Oculomotor | Itsc3 | number |  |  |
| LATENCY total <br> (SD) - PRO | THD <br> (V1,V2,V3,V4) | Oculomotor | Itspr | number |  |  |
| LATENCY pro <br> (med) - <br> CONTOTAL | THD <br> (V1,V2,V3,V4) | Oculomotor | Ipmct |  |  |  |
| LATENCY pro <br> (med) - CON1 | THD <br> (V1,V2,V3,V4) | Oculomotor | Ipmc1 | number |  |  |
| LATENCY pro <br> (med) - CON2 | THD <br> (V1,V2,V3,V4) | Oculomotor | Ipmc2 | number |  |  |
| LATENCY pro <br> (med) - CON3 | THD <br> (V1,V2,V3,V4) | Oculomotor | Ipmc3 | number |  |  |
| LATENCY pro <br> (SD) - <br> CONTOTAL | THD <br> (V1,V2,V3,V4) | Oculomotor | Ipsct |  |  |  |
| LATENCY pro <br> (SD) - CON1 | THD <br> (V1,V2,V3,V4) | Oculomotor | Ipsc1 |  |  |  |





| ERROR pro (\%) CON2 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Oculomotor | eppc2 | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| ERROR pro (\%) CON3 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2, V3, V4) } \end{aligned}$ | Oculomotor | eppc3 | number |  |  |  |
| ERROR anti (\%) CONTOTAL | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Oculomotor | eapct | number |  |  |  |
| ERROR anti (\%) CON1 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2, V3, V4) } \end{aligned}$ | Oculomotor | eapc1 | number |  |  |  |
| ERROR anti (\%) CON2 | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Oculomotor | eapc2 | number |  |  |  |
| ERROR anti (\%) CON3 | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2, V3, V4) } \end{aligned}$ | Oculomotor | eapc3 | number |  |  |  |
| Condition | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | Oculomotor | condition | singlechoice | $\begin{array}{\|l\|} \hline \text { - ANTI } \\ \text { - CON } \\ \text { - PRO } \\ \hline \end{array}$ | - ANTI | Not <br> Available |
| Snellen Acuity 20/200-100\% <br> Chart | THD (V3) | Oculomotor | count_100_1 | number |  |  |  |
| Snellen Acuity 20/160-100\% <br> Chart | THD (V3) | Oculomotor | count_100_ 2 | number |  |  |  |
| Snellen Acuity 20/125-100\% <br> Chart | THD (V3) | Oculomotor | count_100_3 | number |  |  | PDS |
| Snellen Acuity 20/100-100\% <br> Chart | THD (V3) | Oculomotor | count_100_4 | number |  |  |  |
| Snellen Acuity 20/80-100\% <br> Chart | THD (V3) | Oculomotor | count_100_ 5 | number |  |  |  |


| Snellen Acuity <br> $20 / 64-100 \%$ <br> Chart | THD (V3) | Oculomotor | count_100_6 | number |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Snellen Acuity <br> $20 / 50-100 \%$ <br> Chart | THD (V3) | Oculomotor | count_100_7 | number |  |  |
| Snellen Acuity <br> $20 / 40-100 \%$ <br> Chart | THD (V3) | Oculomotor | count_100_8 | number |  |  |
| Snellen Acuity <br> 20/32-100\% <br> Chart | THD (V3) | Oculomotor | count_100_9 | number |  |  |
| Snellen Acuity <br> $20 / 25-100 \%$ <br> Chart | THD (V3) | Oculomotor | count_100_10 | number |  |  |
| Snellen Acuity <br> $20 / 20-100 \%$ <br> Chart | THD (V3) | Oculomotor | count_100_11 | number |  |  |
| Snellen Acuity <br> $20 / 16-100 \%$ <br> Chart | THD (V3) | Oculomotor | count_100_12 | number |  |  |
| Snellen Acuity - <br> Total Correct - <br> $100 \%$ Chart | THD (V3) | Oculomotor | count_100_total | number |  |  |
| Snellen Acuity <br> 20/200-2.5\% <br> Chart | THD (V3) | Oculomotor | count_25_1 | number |  |  |
| Snellen Acuity <br> $20 / 160-2.5 \% ~$ <br> Chart | THD (V3) | Oculomotor | count_25_2 | number |  |  |
| Snellen Acuity <br> $20 / 125-2.5 \% ~$ <br> Chart | THD (V3) | Oculomotor | count_25_3 | number |  |  |


| Snellen Acuity <br> 20/100-2.5\% <br> Chart | THD (V3) | Oculomotor | count_25_4 | number |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Snellen Acuity <br> $20 / 80-2.5 \%$ <br> Chart | THD (V3) | Oculomotor | count_25_5 | number |  |  |
| Snellen Acuity <br> $20 / 64-2.5 \%$ <br> Chart | THD (V3) | Oculomotor | count_25_6 | number |  |  |
| Snellen Acuity <br> 20/50-2.5\% <br> Chart | THD (V3) | Oculomotor | count_25_7 | number |  |  |
| Snellen Acuity <br> 20/40-2.5\% <br> Chart | THD (V3) | Oculomotor | count_25_8 | number |  |  |
| Snellen Acuity <br> $20 / 32-2.5 \%$ <br> Chart | THD (V3) | Oculomotor | count_25_9 | number |  |  |
| Snellen Acuity <br> $20 / 25-2.5 \% ~$ <br> Chart | THD (V3) | Oculomotor | count_25_10 | number |  |  |
| Snellen Acuity <br> $20 / 20-2.5 \%$ <br> Chart | THD (V3) | Oculomotor | count_25_11 | number |  |  |
| Snellen Acuity <br> 20/16-2.5\% <br> Chart | THD (V3) | Oculomotor | count_25_12 | number |  |  |
| Snellen Acuity - <br> Total Correct - <br> $2.5 \% ~ C h a r t ~$ | THD (V3) | Oculomotor | count_25_total | number |  |  |
| Snellen Acuity <br> $20 / 200-1.25 \% ~$ <br> Chart | THD (V3) | Oculomotor | count_125_1 | number |  |  |


| Snellen Acuity <br> 20/160-1.25\% <br> Chart THD (V3) Oculomotor count_125_2 number <br> Snellen Acuity <br> $20 / 125-1.25 \%$ <br> Chart THD (V3) Oculomotor count_125_3 number |  |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Snellen Acuity <br> $20 / 100-1.25 \%$ <br> Chart | THD (V3) | Oculomotor | count_125_4 | number |  |  |
| Snellen Acuity <br> 20/80-1.25\% <br> Chart | THD (V3) | Oculomotor | count_125_5 | number |  |  |
| Snellen Acuity <br> 20/64-1.25\% <br> Chart | THD (V3) | Oculomotor | count_125_6 | number |  |  |
| Snellen Acuity <br> $20 / 50-1.25 \%$ <br> Chart | THD (V3) | Oculomotor | count_125_7 | number |  |  |
| Snellen Acuity <br> $20 / 40-1.25 \%$ <br> Chart | THD (V3) | Oculomotor | count_125_8 | number |  |  |
| Snellen Acuity <br> $20 / 32-1.25 \% ~$ <br> Chart | THD (V3) | Oculomotor | count_125_9 | number |  |  |
| Snellen Acuity <br> $20 / 25-1.25 \% ~$ <br> Chart | THD (V3) | Oculomotor | count_125_10 | number |  |  |
| Snellen Acuity <br> $20 / 20-1.25 \% ~$ <br> Chart | THD (V3) | Oculomotor | count_125_11 | number |  |  |
| Snellen Acuity <br> $20 / 16-1.25 \% ~$ <br> Chart | THD (V3) | Oculomotor | count_125_12 | number |  |  |


| Snellen Acuity - <br> Total Correct - <br> 1.25\% Chart | THD (V3) | Oculomotor | count_125_total | number |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Snellen visual acuity equivalent | THD (V3) | Oculomotor | snellenvae | singlechoice | 20/200 | -1 |
|  |  |  |  |  | - 20/160 | -2 |
|  |  |  |  |  | - 20/125 | -3 |
|  |  |  |  |  | - 20/100 | -4 |
|  |  |  |  |  | - 20/80 | -5 |
|  |  |  |  |  | - 20/64 | -6 |
|  |  |  |  |  | - 20/50 | -7 |
|  |  |  |  |  | - 20/40 | -8 |
|  |  |  |  |  | - 20/32 | -9 |
|  |  |  |  |  | - 20/25 | -10 |
|  |  |  |  |  | - 20/20 | -11 |
|  |  |  |  |  | - 20/16 | -12 |

### 5.5 Data file "mri_aquisitions"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Recoded HDID | THD <br> (V1,V2,V3,V4); <br> TON <br> (V1,V2,V3) | Key Vars | subjid | text |  |  |  |  |
| Study ID | THD <br> (V1,V2,V3,V4); <br> TON <br> (V1,V2,V3) | Key Vars | studyid | text |  |  | PDS |  |
| Visit Number | THD <br> (V1,V2,V3,V4); | Key Vars | visitnum | number |  |  |  |  |


|  | TON <br> (V1,V2,V3) |  |  |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Form Number | THD <br> (V1,V2,V3,V4); <br> TON <br> (V1,V2,V3) | Key Vars |  |  |  |  | nr | now |
| :--- |

### 5.5.1 Form "Magnetic resonance imaging (MRI)"



| Study ID | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | MRI | stdyid | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Scan ID | TON $(\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3)$ | MRI | scanid | number |  |  |  |
| Scan description | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | MRI | scandesc | text |  |  | Not Available |
| Date of scan | TON (V1,V2,V3) | MRI | scandtc | date |  |  |  |
| Date of scan (precision) | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | MRI | scandtc__ prec | singlechoice | - precision in days | -d |  |
|  |  |  |  |  | - precision in months | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Scan day | TON (V1,V2,V3) | MRI | scandy | number |  |  | PDS |
| Date of scan (precision) | TON(V1,V2,V3) | MRI | scandy__prec | singlechoice | - precision in days | -d | Not Available |
|  |  |  |  |  | - precision in months | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| No | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | MRI | scanuplds | number |  |  | PDS |
| MRI type | TON(V1,V2,V3) | MRI | mritype_ton | singlechoice | - unknown | -0 |  |
|  |  |  |  |  | - MRI | -1 |  |
|  |  |  |  |  | - fMRI 3 | - 2 |  |
|  |  |  |  |  | - DTI | -3 |  |
| Subtype | TON(V1,V2,V3) | MRI | subtype | singlechoice | - T1W | -1 |  |
|  |  |  |  |  | - T1W repeat | -2 |  |
|  |  |  |  |  | - T2W | -3 |  |
|  |  |  |  |  | - Resting state | -4 |  |
|  |  |  |  |  | - Working memory task | - 5 |  |
|  |  |  |  |  | - Motor task | -6 |  |
|  |  |  |  |  | - Practice | - 7 |  |
|  |  |  |  |  | - Field mapping | -8 |  |
|  |  |  |  |  | - Generic | -9 |  |



| CEST/MTR QC | TON (V3) | MRI | cestmtrqc | singlechoice | - fail | -0 | PDS |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - pass | -1 |  |
|  |  |  |  |  | - borderline | -2 |  |
| CEST/MTR QC comment | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | MRI | cestmtrqccomment | text |  |  | Not Available |
| DTI QC | TON(V1,V2,V3) | MRI | dtiqc | singlechoice | - fail | -0 | PDS |
|  |  |  |  |  | - pass | -1 |  |
|  |  |  |  |  | - borderline | -2 |  |
| Full DTI QC report upload | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | MRI | dtiqcreport | text |  |  | Not Available |
| DTI QC comment | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | MRI | dtiqccomment | text |  |  | 隹 |
| fMRI QC | $\begin{aligned} & \text { TON } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | MRI | fmriqc | singlechoice | - fail | -0 | PDS |
|  |  |  |  |  | - pass | -1 |  |
|  |  |  |  |  | - borderline | -2 |  |
| fMRI QC comment | $\begin{aligned} & \text { TON } \\ & \text { (V1,V2,V3) } \end{aligned}$ | MRI | fmriqccomment | text |  |  | Not Available |

### 5.5.2 Form "Magnetic resonance imaging (MRI 1.5T)"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Technologist's name | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | tname | text |  |  |  | Not Available |
| Quality check | THD(V1,V2) | MRI 1.5T | tqc | singlechoice | - good | -1 |  | PDS |
|  |  |  |  |  | - poor | -2 |  |  |
| Comment | $\begin{aligned} & \hline \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | MRI 1.5T | tcomment | text |  |  |  | Not Available |
| Technologist has confirmed that | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | tconfirm | boolean | - no | - 0 |  | PDS |
|  |  |  |  |  | - yes | -1 |  |  |


| the images have been acquired and quality checked according to the Site Operations Guide |  |  |  |  |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Radiologist's comment available | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | rcommentyn | text | - no | - 0 |  |
|  |  |  |  |  | - yes | -1 |  |
|  |  |  |  |  | - same as for 3T | -2 |  |
| Radiologist's name | $\begin{array}{\|l\|} \hline \text { THD } \\ (\mathrm{V} 1, \mathrm{~V} 2) \end{array}$ | MRI 1.5T | rname | text |  |  |  |
| Date of read | $\begin{array}{\|l\|} \hline \text { THD } \\ (\mathrm{V} 1, \mathrm{~V} 2) \end{array}$ | MRI 1.5T | dtcread | date |  |  |  |
| Date of read (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | dtcread__ prec | singlechoice | - precision in days | -d | Available |
|  |  |  |  |  | - precision in months | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Comment | $\begin{array}{\|l\|} \hline \text { THD } \\ (\mathrm{V} 1, \mathrm{~V} 2) \end{array}$ | MRI 1.5T | rcomment | text |  |  |  |
| Radiologist has confirmed that | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | rconfirm | boolean | - the images are suitable for the Track-Hd study | -1 |  |
|  |  |  |  |  | - the images are not suitable for the Track-HD study | - 2 |  |
| Quality control result | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | MRI 1.5T | resultsum | singlechoice | - pass | -1 | PDS |
|  |  |  |  |  | - fail | -2 |  |
|  |  |  |  |  | - borderline | - 3 |  |
| Full report upload | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | fullreport | text |  |  | Not |
| QC comment | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | MRI 1.5T | qccomment | text |  |  | Available |


| MRI type | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | mritype | single- <br> choice | - unknown | - 0 | PDS |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - T1W | -1 |  |
|  |  |  |  |  | - T1W repeat | -2 |  |
|  |  |  |  |  | - T2W | - 3 |  |
|  |  |  |  |  | - DTI | -4 |  |
| Scan description | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | scandesc | text |  |  |  |
| Date of scan | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | scandtc | date |  |  | Not |
| Date of scan (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | scandtc__ prec | singlechoice | - precision in days | -d | Available |
|  |  |  |  |  | - precision in months | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Scan day | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | MRI 1.5T | scandy | number |  |  | PDS |
| Scan ID | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | MRI 1.5T | scanid | number |  |  |  |
| QC Status | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2) } \end{aligned}$ | MRI 1.5T | scanstatus | single- <br> choice | - passed | -1 |  |
|  |  |  |  |  | - failed | -2 |  |
|  |  |  |  |  | - deleted | - 3 |  |
| No | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | MRI 1.5T | scanuplds | number |  |  |  |
| Study ID | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2) \end{aligned}$ | MRI 1.5T | stdyid | number |  |  |  |

### 5.5.3 Form "Magnetic resonance imaging (MRI 3T)"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Technologist's <br> name | THD <br> (V1,V2,V3,V4) | MRI 3T | tname | text |  |  | Not |

\begin{tabular}{|c|c|c|c|c|c|c|c|}
\hline \& THD \& \& \& single- \& - good \& -1 \& \multirow{2}{*}{PDS} \\
\hline \& (V1,V2,V3,V4) \& \& \& choice \& - poor \& -2 \& \\
\hline Comment \& \[
\begin{aligned}
\& \hline \text { THD } \\
\& \text { (V1,V2,V3,V4) }
\end{aligned}
\] \& MRI 3T \& tcomment \& text \& \& \& Not Available \\
\hline Technologist has confirmed that the images have been acquired and quality checked according to the Site Operations Guide \& \[
\begin{aligned}
\& \text { THD } \\
\& \text { (V1,V2,V3,V4) }
\end{aligned}
\] \& MRI 3T \& tconfirm \& boolean \& \begin{tabular}{l} 
- no \\
\hline - yes
\end{tabular} \& -0

-1 \& PDS <br>

\hline Radiologist's comment available \& \[
$$
\begin{aligned}
& \text { THD } \\
& \text { (V1,V2,V3,V4) }
\end{aligned}
$$

\] \& MRI 3T \& rcommentyn \& boolean \& - no \& -0 \& \multirow{6}{*}{| Not |
| :--- |
| Available |} <br>

\hline Radiologist's name \& $$
\begin{array}{|l|}
\hline \text { THD } \\
\text { (V1,V2, V3, V4) } \\
\hline
\end{array}
$$ \& MRI 3T \& rname \& text \& \& \& <br>

\hline Date of read \& $$
\begin{array}{|l}
\hline \text { THD } \\
\text { (V1,V2, V3, V4) }
\end{array}
$$ \& MRI 3T \& dtcread \& date \& \& \& <br>

\hline Date of read (precision) \& \[
$$
\begin{aligned}
& \text { THD } \\
& \text { (V1,V2,V3,V4) }
\end{aligned}
$$

\] \& MRI 3T \& dtcread__ prec \& singlechoice \& | - precision in days |
| :--- |
| - precision in months |
| - precision in years | \& $-d$

$-m$
$-y$ \& <br>

\hline Comment \& $$
\begin{array}{|l|}
\hline \text { THD } \\
\text { (V1,V2, V3, V4) } \\
\hline
\end{array}
$$ \& MRI 3T \& rcomment \& text \& \& \& <br>

\hline Radiologist has confirmed that \& \[
$$
\begin{aligned}
& \text { THD } \\
& \text { (V1,V2, V3,V4) }
\end{aligned}
$$

\] \& MRI 3T \& rconfirm \& boolean \& | - the images are suitable for the Track-Hd study |
| :--- |
| - the images are not suitable for the Track-HD study | \& -1

-2 \& <br>
\hline \& \& MRI 3T \& resultsum \& \& - pass \& -1 \& PDS <br>
\hline
\end{tabular}

| Quality control <br> result | THD <br> (V1,V2,V3,V4) |  | single- <br> choice | - fail | - borderline | -2 | -3 |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Full report <br> upload | THD <br> (V1,V2,V3,V4) | MRI 3T | fullreport | text |  |  |  |
| QC comment | THD <br> $(V 1, V 2, V 3, V 4)$ | MRI 3T | qccomment | text |  |  |  |

### 5.5.4 Form "Magnetic resonance imaging (fMRI QC)"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Study ID | $\begin{array}{\|l\|} \hline \text { TON } \\ \text { (V3) } \\ \hline \end{array}$ | $\begin{aligned} & \text { F-MRI } \\ & \text { QC } \end{aligned}$ | stdyid | text |  |  |  | PDS |
| Scan ID | $\begin{aligned} & \hline \text { TON } \\ & \text { (V3) } \\ & \hline \end{aligned}$ | F-MRI QC | scanid | number |  |  |  |  |
| Scan description | $\begin{aligned} & \text { TON } \\ & \text { (V3) } \end{aligned}$ | F-MRI QC | scandesc | text |  |  |  | Not <br> Available |
| Date of scan | $\begin{aligned} & \hline \text { TON } \\ & \text { (V3) } \end{aligned}$ | $\begin{aligned} & \text { F-MRI } \\ & \text { QC } \end{aligned}$ | scandtc | date |  |  |  |  |
| Date of scan (precision) | $\begin{aligned} & \text { TON } \\ & \text { (V3) } \end{aligned}$ | F-MRI QC | scandtc__ prec | singlechoice | - precision in days <br> - precision in months <br> - precision in years | $\begin{aligned} & \hline-d \\ & -m \\ & -y \\ & \hline \end{aligned}$ |  |  |
| Scan day | $\begin{aligned} & \text { TON } \\ & \text { (V3) } \\ & \hline \end{aligned}$ | F-MRI QC | scandy | number |  |  |  | PDS |
| No | $\begin{array}{\|l\|} \hline \text { TON } \\ \text { (V3) } \\ \hline \end{array}$ | $\begin{aligned} & \hline \mathrm{F}-\mathrm{MRI} \\ & \mathrm{QC} \end{aligned}$ | scanuplds | number |  |  |  |  |
| MRI type (THD) | $\begin{aligned} & \text { TON } \\ & \text { (V3) } \end{aligned}$ | $\begin{aligned} & \text { F-MRI } \\ & \text { QC } \end{aligned}$ | mritype_thd | singlechoice | - unknown | - 0 |  | Not <br> Available |
|  |  |  |  |  | - T1W | -1 |  |  |
|  |  |  |  |  | - T1W repeat | -2 |  |  |
|  |  |  |  |  | - T2W | -3 |  |  |


|  |  |  |  |  | - DTI | -4 |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| QC Status | $\begin{array}{\|l\|l\|l\|} \hline \text { TON } \\ \text { (V3) } \end{array}$ | $\begin{aligned} & \text { F-MRI } \\ & \text { QC } \end{aligned}$ | scanstatus | singlechoice | - passed | -1 | PDS |
|  |  |  |  |  | - failed | -2 |  |
|  |  |  |  |  | - deleted | -3 |  |
| fMRI QC comment | $\begin{array}{\|l\|} \hline \text { TON } \\ \text { (V3) } \\ \hline \end{array}$ | $\begin{array}{\|l\|} \hline \text { F-MRI } \\ \text { QC } \\ \hline \end{array}$ | fmriqccomment | text |  |  | Not Available |
| RS fMRI QC | $\begin{array}{\|l\|l\|} \hline \text { TON } \\ \text { (V3) } \end{array}$ | $\begin{aligned} & \text { F-MRI } \\ & \text { QC } \end{aligned}$ | rsfmriqc | singlechoice | - fail | -0 | PDS |
|  |  |  |  |  | - pass | -1 |  |
|  |  |  |  |  | - borderline | -2 |  |
| RS fMRI QC comment | $\begin{array}{\|l\|} \hline \text { TON } \\ \text { (V3) } \\ \hline \end{array}$ | $\begin{aligned} & \hline \text { F-MRI } \\ & \text { QC } \end{aligned}$ | rsfmriqccomment | text |  |  | Not Available |
| TF fMRI QC | TON <br> (V3) | $\begin{aligned} & \text { F-MRI } \\ & \text { QC } \end{aligned}$ | tfmriqc | singlechoice | - fail | -0 | PDS |
|  |  |  |  |  | - pass | -1 |  |
|  |  |  |  |  | - borderline | -2 |  |

### 5.5.5 Form "Magnetic resonance imaging (MRI DTI QC)"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Study ID | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,v3,V4) } \\ & \hline \end{aligned}$ | MRI DTI QC | stdyid | number |  |  |  | PDS |
| Scan ID | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | $\begin{aligned} & \text { MRI DTI } \\ & \text { QC } \\ & \hline \end{aligned}$ | scanid | number |  |  |  |  |
| Scan description | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | MRI DTI QC | scandesc | text |  |  |  | Not Available |
| Date of scan | $\begin{aligned} & \hline \text { THD } \\ & \text { (V1, V2,V3,V4) } \end{aligned}$ | $\begin{aligned} & \text { MRI DTI } \\ & \text { QC } \\ & \hline \end{aligned}$ | scandtc | date |  |  |  |  |
| Date of scan (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3,V4) } \end{aligned}$ | MRI DTI QC | scandtc__ prec | singlechoice | - precision in days | -d |  |  |
|  |  |  |  |  | - precision in months | -m |  |  |
|  |  |  |  |  | - precision in years | - y |  |  |


| Scan day | THD <br> (V1,V2,V3,V4) | MRI DTI <br> QC | scandy | number |  | PDS |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Date of scan <br> (precision) | THD <br> (V1,V2,V3,V4) | MRI DTI <br> QC | scandy_prec |  |  |  |

### 5.6 Data file "mri_morphometrics"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :---: | :---: |
| Recoded HDID |  | Key Vars | subjid | text |  |  |  | PDS |
| Study ID |  | Key Vars | studyid | text |  |  |  | PDS |

5.6.1 Form "Morphometric"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| MIDAS scan ID 1 | $\begin{aligned} & \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | scan_1 | number |  |  |  |  |
| MIDAS scan ID 2 | $\begin{aligned} & \hline \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | scan_2 | number |  |  |  |  |
| MIDAS scan ID 3 | $\begin{aligned} & \hline \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | scan_3 | number |  |  |  |  |
| MIDAS scan ID 4 | THD | Morphometric | scan_4 | number |  |  |  |  |
| Visit 1 Scan date | $\begin{aligned} & \hline \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | scandate_1 | date |  |  |  | Not |
| Visit 2 Scan date | $\begin{aligned} & \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | scandate_2 | date |  |  |  |  |
| Visit 3 Scan date | $\begin{aligned} & \hline \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | scandate_3 | date |  |  |  |  |
| Visit 4 Scan date | THD | Morphometric | scandate_4 | date |  |  |  |  |
| Visit 1 Study site | TON | Morphometric | study_site_1 | text |  |  |  |  |
| Visit 2 Study site | TON | Morphometric | study_site_2 | text |  |  |  |  |
| Visit 3 Study site | TON | Morphometric | study_site_3 | text |  |  |  |  |
| Scan day at Visit <br> 1 | $\begin{aligned} & \hline \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | scandy_1 | number |  |  |  |  |
| Scan day at Visit $2$ | $\begin{aligned} & \hline \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | scandy_2 | number |  |  |  |  |
| Scan day at Visit 3 | $\begin{aligned} & \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | scandy_3 | number |  |  |  | PDS |
| Scan day at Visit 4 | THD | Morphometric | scandy_4 | number |  |  |  |  |
| Brain volume at visit 1 generated by UCL's semi- | THD, TON | Morphometric | brain_1 | number |  |  | $\mathrm{cm}^{3}$ |  |



| BBSI brain change visit 4 to 2 | THD | Morphometric | bbsi_4_2 | number |  |  | $\mathrm{cm}^{3}$ |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| BBSI brain change visit 4 to 3 | THD | Morphometric | bbsi_4_3 | number |  |  | $\mathrm{cm}^{3}$ |
| Caudate volume at visit 1 generated by UCL's semiautomated MIDAS software | $\begin{aligned} & \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | caudate_1 | number |  |  | $\mathrm{cm}^{3}$ |
| Caudate volume at visit 2 generated by UCL's semiautomated MIDAS software | THD | Morphometric | caudate_2 | number |  |  | $\mathrm{cm}^{3}$ |
| Caudate volume at visit 3 | THD | Morphometric | caudate_3 | number |  |  | $\mathrm{cm}^{3}$ |
| Caudate volume at visit 1 generated by IOWA's BRAINS software | $\begin{aligned} & \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | caudate_iowa_1 | number |  |  | $\mathrm{cm}^{3}$ |
| Caudate volume at visit 2 generated by IOWA's BRAINS software | $\begin{aligned} & \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | caudate_iowa_ 2 | number |  |  | $\mathrm{cm}^{3}$ |
| Caudate volume at visit 3 generated by | $\begin{aligned} & \text { THD, } \\ & \text { TON } \end{aligned}$ | Morphometric | caudate_iowa_3 | number |  |  | $\mathrm{cm}^{3}$ |








| Globus pallidus <br> volume at visit 2 | THD, <br> TON | Morphometric | striatum_2 | number |  |  | $\mathrm{cm}^{3}$ |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Globus pallidus <br> volume at visit 3 | THD, <br> TON | Morphometric | striatum_3 | number |  |  |  |
| Globus pallidus <br> volume at visit 4 | THD | Morphometric | striatum_4 | number |  | $\mathrm{cm}^{3}$ |  |
| Globus pallidus <br> volume at visit 1 | THD, <br> TON | Morphometric | globus_1 | number |  |  |  |
| Globus pallidus <br> volume at visit 2 | THD, <br> TON | Morphometric | globus_2 | number |  | $\mathrm{cm}^{3}$ |  |
| Globus pallidus <br> volume at visit 3 | THD, <br> TON | Morphometric | globus_3 | number |  | $\mathrm{cm}^{3}$ |  |
| Globus pallidus <br> volume at visit 4 | THD | Morphometric | globus_4 | number |  | $\mathrm{cm}^{3}$ |  |

### 5.7 Data file "ishd"

| Label | Study <br> (Visit) | Form | Variable | Type | Parameter | Coding | Unit |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Recoded HDID | THD <br> (V1,V2,V3) | Key Vars | subjid | text |  |  |  |
| Study ID | THD <br> (V1,V2,V3) | Key Vars | studyid | text |  |  |  |
| Visit | THD <br> (V1,V2,V3) | Key Vars | visit | text |  |  |  |
| Visit Number | THD <br> (V1,V2,V3) | Key Vars | visitnum | number |  |  |  |
| Form Number | THD (V3) | Key Vars | nr | number |  |  |  |
| Row Number | THD (V3) | Key Vars | enr | number |  |  |  |


| Visit Date | THD <br> (V1,V2,V3) | Key Vars | visdat | date |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Day of visit (ref. <br> to baseline) | THD <br> (V1,V2,V3) | Key Vars | visdy | number |  |  |
| Visit Status | THD <br> (V1,V2,V3) | Key Vars | visstat | PDS |  |  |

### 5.7.1 Form "Irritability Scale for Huntington's Disease (ISHD)"

| Label | Study (Visit) | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Irritability | THD (V3) | ISHD | irritabweekscore | number |  |  |  | PDS |
| Verbal Outburst | THD (V3) | ISHD | verbalweekscore | number |  |  |  |  |
| Physical Aggression | THD (V3) | ISHD | physicalweekscore | number |  |  |  |  |
| Overall | THD (V3) | ISHD | overallweekscore | number |  |  |  |  |
| Date | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | ISHD | dtc | date |  |  |  | Not Available |
| Date (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | ISHD | dtc__prec | single- <br> choice | - precision in days | -d |  |  |
|  |  |  |  |  | - precision in months | -m |  |  |
|  |  |  |  |  | - precision in years | - y |  |  |
| Day of ISHD | $\begin{array}{\|l\|} \hline \text { THD } \\ \text { (V1,V2,V3) } \\ \hline \end{array}$ | ISHD | ishddy | number |  |  |  | PDS |
| Date (precision) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | ISHD | ishddy__prec | singlechoice | - precision in days | -d |  | Not Available |
|  |  |  |  |  | - precision in months | -m |  |  |
|  |  |  |  |  | - precision in years | - y |  |  |


| Irritable moods (severity) | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | ISHD | moods | singlechoice | - Subject was not irritable at all today | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - Seemed to be in a bad mood, might have become angry if not treated with tact | -2 |
|  |  |  |  |  | - Appearance and behaviour suggesting that he/she was feeling angry; became cross or angry with very little provocation, or gave impression that outburst would have occurred if care had not been taken to placate subject or keep out of the way | -3 |
|  |  |  |  |  | - Obviously feeling very angry; any contact with subject was like walking on eggshells | -4 |
| How often was the subject irritable today | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | ISHD | irritable | singlechoice | - Subject was not irritable at all today | -1 |
|  |  |  |  |  | - One short spell of moody or irritable behaviour in the course of the day | - 2 |
|  |  |  |  |  | - Several (2-5) spells of moody or irritable behaviour in the course of the day | -3 |
|  |  |  |  |  | - Continuously, or almost continuously throughout the day | -4 |


| Angry verbal outbursts (severity) | $\begin{aligned} & \text { THD } \\ & (\mathrm{V} 1, \mathrm{~V} 2, \mathrm{~V} 3) \end{aligned}$ | ISHD | outbursts | single- <br> choice | - No angry verbal outbursts today | -1 |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - Became mildly cross (e.g. when confronted with frustrating situations) | - 2 |
|  |  |  |  |  | - Verbally hostile, sarcastic or nasty, or using foul language | -3 |
|  |  |  |  |  | - Shouting, verbally intimidating behaviour or uttering threats | -4 |
| How many angry verbal outbursts did the subject have today | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | ISHD | verbalourbursts | singlechoice | - No angry verbal outbursts today | - 1 |
|  |  |  |  |  | - One angry verbal outburst only | - 2 |
|  |  |  |  |  | - Several (2-5) angry verbal outbursts in the course of the day | -3 |
|  |  |  |  |  | - Angry verbal outbursts occurred continuously, or almost continuously, throughout the day | -4 |
| Physical aggression (severity) | $\begin{aligned} & \text { THD } \\ & \text { (V1,V2,V3) } \end{aligned}$ | ISHD | aggression | single- <br> choice | - No aggressive incidents today | -1 |
|  |  |  |  |  | - Aggression against property (slamming doors, kicking furniture, breaking things deliberately) | - 2 |



| Overall | THD (V3) | ISHD | overallscore | number |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |

### 5.8 Data file "samples"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Recoded HDID | TON,THD | Key Vars | subjid | text |  |  |  | PDS |
| Study ID | TON,THD | Key Vars | studyid | text |  |  |  |  |
| Visit Number | TON,THD | Key Vars | visitnum | number |  |  |  | Not <br> Available |
| Form Number | TON,THD | Key Vars | nr | number |  |  |  |  |
| Row Number | TON,THD | Key Vars | enr | number |  |  |  |  |
| Visit | TON,THD | Key Vars | visit | number |  |  |  | PDS |
| Visit Date | TON,THD | Key Vars | visdat | date |  |  |  | Not Available |
| Day of visit (ref. to baseline) | TON,THD | Key Vars | visdy | number |  |  |  | PDS |
| Visit Status | TON,THD | Key Vars | visstat | text | - editing <br> - plausible <br> - signed <br> - reviewing <br> - completed <br> - checked |  |  |  |
| Form | TON,THD | Key Vars | form | text | Samples <br> - Samples ACD <br> - Samples EDTA ACD <br> - Samples EDTA PX |  |  |  |

### 5.8.1 Form "Samples"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Date of Laboratory Report | TON | Samples | Ibdtc | date |  |  |  | Not |
| Specimen | TON | Samples | specimentype | number |  |  |  | Available |
| Product | TON | Samples | producttype | singlechoice |  |  |  |  |
| Container | TON | Samples | containertype | singlechoice |  |  |  | PDS |
| Bar code | TON | Samples | barcode | text |  |  |  |  |
| Quantity | TON | Samples | quantity | number |  |  |  |  |
| Shipped? | TON | Samples | shipped | boolean | - no <br> - yes | -0 |  |  |
| Notified | TON | Samples | notified | boolean | $\begin{aligned} & \hline- \text { no } \\ & \hline- \text { yes } \\ & \hline \end{aligned}$ |  |  |  |
| Receipt state | TON | Samples | submstate | number |  |  |  |  |
| Outcome | TON | Samples | finalstate | boolean | - no <br> - yes | -0 |  | Available |
| Date Completed | TON | Samples | completeddate | date |  |  |  |  |
| Date Completed (precision) | TON | Samples | completeddate__prec | singlechoice | - precision in days <br> - precision in months <br> - precision in years | $\begin{array}{\|l\|} \hline-d \\ \hline-m \\ \hline-y \\ \hline \end{array}$ |  |  |
| ID | TON | Samples | inv_id | number |  |  |  |  |
| Date of shipment: | TON | Samples | shipdtc | date |  |  |  |  |


| Date of shipment (precision) | TON | Samples | shipdtc__ prec | singlechoice | - precision in days | -d |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  |  |  |  |  | - precision in months | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Airway bill no | TON | Samples | airwaybillnum | number |  |  |  |
| Date of notification | TON | Samples | requestdate | date |  |  |  |
| Date of notification (precision) | TON | Samples | requestdate__prec | singlechoice | - precision in days | -d |  |
|  |  |  |  |  | - precision in months | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Date of receipt | TON | Samples | receiptdate | date |  |  |  |
| Date of receipt (precision) | TON | Samples | receiptdate__prec | singlechoice | - precision in days | -d |  |
|  |  |  |  |  | - precision in months | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Total shipping time | TON | Samples | shiptime__h | number |  |  | h |
| Total shipping time - : | TON | Samples | shiptime__min | number |  |  | min |

### 5.8.2 Form "Samples ACD"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit | Availability |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Date of <br> Laboratory <br> Report | THD,TON | Samples <br> ACD | lbdtc | date |  |  |  |  |
| Should CAG be <br> determined by <br> BioRep? | THD,TON | Samples <br> ACD | determinecag | boolean | - no |  |  |  |
| Specimen THD,TON Samples <br> ACD specimentype nes |  |  |  |  |  |  |  |  |
| Product | THD,TON | Samples <br> ACD | producttype | single-choice |  | -1 |  |  |




### 5.8.3 Form "Samples ACD (other)"



| Product | TON | Samples <br> ACD <br> (other) | producttype | single-choice |  |  |  |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Container | TON | Samples <br> ACD <br> (other) | containertype | single-choice |  |  |  |
| Bar code | TON | Samples <br> ACD <br> (other) | barcode | text |  |  |  |
| Quantity | TON | Samples <br> ACD <br> (other) | quantity | number |  |  |  |
| Notified | TON | Samples <br> ACD <br> (other) | notified | boolean | - no | - yes |  |
| Receipt state | TON | Samples <br> ACD <br> (other) | submstate | number |  |  |  |
| Outcome | TON | Samples <br> ACD <br> (other) | finalstate | boolean | - no | - |  |
| Date Completed | TON | Samples <br> ACD <br> (other) | completeddate | date |  | -1 |  |


| Date of shipment: | TON | Samples <br> ACD <br> (other) | shipdtc | date |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Date of shipment (precision) | TON | Samples <br> ACD <br> (other) | shipdtc__ prec | single-choice | - precision in days | -d |  |
|  |  |  |  |  | - precision in months | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Airway bill no | TON | Samples <br> ACD <br> (other) | airwaybillnum | number |  |  |  |
| Date of notification | TON | Samples <br> ACD <br> (other) | requestdate | date |  |  |  |
| Date of notification (precision) | TON | Samples <br> ACD <br> (other) | requestdate__prec | single-choice | - precision in days | -d |  |
|  |  |  |  |  | - precision in months | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Date of receipt | TON | Samples <br> ACD <br> (other) | receiptdate | date |  |  |  |
| Date of receipt (precision) | TON | Samples <br> ACD <br> (other) | receiptdate__prec | single-choice | - precision in days | -d |  |
|  |  |  |  |  | - precision in months | - m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Total shipping time | TON | Samples <br> ACD <br> (other) | shiptime__h | number |  |  | h |
| Total shipping time - : | TON | Samples <br> ACD <br> (other) | shiptime__min | number |  |  | min |

### 5.8.4 Form "Samples EDTA/PX"

| Label | Study | Form | Variable | Type | Parameter | Coding | Unit |
| :--- | :--- | :--- | :--- | :--- | :--- | :--- | :--- |
| Availability |  |  |  |  |  |  |  |
| Date and Time <br> of Sampling | THD | Samples <br> EDTA/PX | specimendate | date |  |  |  |




### 5.8.5 Form "Samples EDTA/ACD"



| Date of notification | THD | Samples <br> EDTA/ACD | requestdate | date |  |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Date of notification (precision) | THD | Samples <br> EDTA/ACD | requestdate__prec | single-choice | - precision in days | -d |  |
|  |  |  |  |  | - precision in months | -m |  |
|  |  |  |  |  | - precision in years | - y |  |
| Date of receipt | THD | Samples EDTA/ACD | receiptdate | date |  |  |  |
| Date of receipt (precision) | THD | Samples <br> EDTA/ACD | receiptdate__prec | single-choice | - precision in days | $\begin{aligned} & \hline-\mathrm{d} \\ & -\mathrm{m} \\ & -\mathrm{y} \\ & \hline \end{aligned}$ |  |
|  |  |  |  |  | - precision in months |  |  |
|  |  |  |  |  | - precision in years |  |  |
| Total shipping time | THD | Samples <br> EDTA/ACD | shiptime__h | number |  |  | h |
| Total shipping time - : | THD | Samples <br> EDTA/ACD | shiptime__min | number |  |  | min |

## 6 Bibliography

Langbehn DR, B. R. (2004). A new model for prediction of the age of onset and penetrance for Huntington's disease based on CAG length. CLINICAL GENETICS, 267-277.

## Revision History

| Document | Summary of Changes |
| :--- | :--- |
| TRACK-HD/TRACKON-HD <br> Data Dictionary PDS1 | Initial version. July 2021 |

