



**ENROLL-DOC-2006-EN-1.12**

**Enroll-HD Annotated CRF**

**Documentation**

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## 1 Preamble

The purpose of this document is to provide the annotated view of the Enroll-HD eCRF (*electronic Case Report Form*). The annotated view shows all forms, variables and its variable names used within the study. The forms and variables are described in detail in detail within the data management requirements [1] and data dictionary [2] of the study.

## 2 Visit Form Schedule

The visit form schedule defines the assignment of forms to visit types:

eCRF Form	General	Family History	Baseline	Follow Up	Phone Contact	Unscheduled	Premature End
Demographic Data (Demog)	✓						
HD Clinical Characteristics (HD CC)	✓						
CAG Report (CAG)	(✓)						
Pharmacotherapy (PharmacoTx)	✓						
Nutritional Supplements (NutSuppl)	✓						
Non-Pharmacologic Therapies (Non-PharmacoTx)	✓						
Comorbid Conditions (Comorbid)	✓						
Clinical Trials Form (Clinical Trials)	✓						
Reportable Event (Event)	✓						
Mortality	✓						
Family History (FHx)		✓					
Enrollment into Enroll-HD (Enrollment)			✓				
Medical History (MHx)			✓				

eCRF Form	General	Family History	Baseline	Follow Up	Phone Contact	Unscheduled	Premature End
Variable Items Baseline (Variable)			✓				
Variable Items Follow Up (Variable)				✓		✓	
UHDRS® Motor/Diagnostic Confidence (Motor)			✓	✓		✓	
UHDRS® Total Functional Capacity (TFC)			✓	✓		✓	
UHDRS® Functional Assessment (Function)			✓	✓		✓	
Problem Behaviours Assessment – Short (PBA-s)			✓	✓		✓	
Core and Extended Cognitive Assessment (Cognitive)			✓	✓		✓	
Bio Specimens for Bio Banking (Samples)			(✓)	(✓)			
Hospital Anxiety and Depression Scale - Snaith Irritability Scale (HADS-SIS)			✓	✓		✓	
Columbia-Suicide Severity Rating Scale (C-SSRS) – Baseline			(✓)	(✓)		✓	
Columbia-Suicide Severity Rating Scale (C-SSRS) – Follow Up			(✓)	(✓)		✓	
Mini Mental State Examination (MMSE)			✓	✓		✓	
Physiotherapy Outcome Measures (Physio)			✓	✓		✓	

eCRF Form	General	Family History	Baseline	Follow Up	Phone Contact	Unscheduled	Premature End
Short Form Health Survey – 12v2 (SF12)			✓	✓		✓	
Caregivers Quality of Life Questionnaire (CareQoL)			✓	✓		✓	
Client Service Receipt Inventory (CSRI)			✓	✓		✓	
Work Productivity and Activity Impairment-Specific Health Problem (WPAI-SH)			✓	✓		✓	
Follow-up on Missed Visit (Missed Visit)					✓		
Premature End of Study (End)					✓		✓
Monitoring Baseline Visit (Monitoring BL)			✓				
Monitoring Follow Up Visit (Monitoring FUP)				✓			
Monitoring General Visit (Monitoring Gen)	✓						
Monitoring General Family History (Monitoring FHx)		✓					
Monitoring Event Form (Monitoring Event)	✓	✓	✓	✓	✓	✓	✓

Table 1: Visit Assessment Schedule


### 3 eCRF Forms

#### 3.1 Enrollment into Enroll-HD (Enrollment)

Enrollment		
Date of informed consent:	<input type="text" value="mon/dd/yyyy"/>	rfstdtc
Signed by:	<input type="radio"/> participant <sup>1</sup> <input type="radio"/> legal representative <sup>2</sup>	sgntr
Participant category:	<input type="radio"/> genotype unknown <sup>1</sup> <input type="radio"/> pre-manifest/pre-motor-manifest HD <sup>2</sup> <input type="radio"/> manifest/motor-manifest HD <sup>3</sup> <input type="radio"/> genotype negative <sup>4</sup> <input type="radio"/> family control <sup>5</sup> <input type="radio"/> community control <sup>6</sup>	hdcatt
Inclusion criteria (community control):		
No history of or no concurrent major central nervous system disorder (e.g. Stroke, Parkinson's disease, Multiple Sclerosis, etc.):	<input type="radio"/> yes <sup>1</sup> <input type="radio"/> no <sup>0</sup>	ic1
Optional Components:	Family History: <input type="radio"/> yes <sup>1</sup> <input type="radio"/> no <sup>0</sup> Biosamples for use in research: <input type="radio"/> yes <sup>1</sup> <input type="radio"/> no <sup>0</sup> Linking clinical information from previous studies: <input type="radio"/> yes <sup>1</sup> <input type="radio"/> no <sup>0</sup> Participation in sub-studies: <input type="radio"/> yes <sup>1</sup> <input type="radio"/> no <sup>0</sup> Contact between visits: <input type="radio"/> yes <sup>1</sup> <input type="radio"/> no <sup>0</sup> Contact regarding other research studies: <input type="radio"/> yes <sup>1</sup> <input type="radio"/> no <sup>0</sup> Contact regarding post-mortem tissue collection: <input type="radio"/> yes <sup>1</sup> <input type="radio"/> no <sup>0</sup>	fhx bsp rtrspctv nvl cntct cntctst cntctpmt
IDs in other Studies (please enter on the Clinical Trials CRF)		
COHORT HDID:	<input type="text"/>	ch_id
PREDICT HDID:	<input type="text"/>	pd_id



### 3.2 Demographic Data (Demog)

Demographics (invariable)		
Date of birth:	<input type="text" value="mon/dd/yyyy"/>	brthdtc
Gender:	<input type="radio"/> female <small>f</small> <input type="radio"/> male <small>m</small>	sex
Ethnicity:	<input type="radio"/> American Indian/Native American/Amerindian <small>8</small> <input type="radio"/> Alaska Native/Inuit <small>5</small> <input type="radio"/> African - North <small>12</small> <input type="radio"/> African - South <small>11</small> <input type="radio"/> American - Black <small>2</small> <input type="radio"/> Asian - West <small>13</small> <input type="radio"/> Asian - East <small>14</small> <input type="radio"/> Caucasian <small>1</small> <input type="radio"/> Native Hawaiian or Other Pacific Islander <small>4</small> <input type="radio"/> Hispano or Latino Origin <small>3</small> <input type="radio"/> mixed <small>15</small> <input type="radio"/> other <small>6</small>	race
Handedness: 	<input type="radio"/> right <small>1</small> <input type="radio"/> left <small>2</small> <input type="radio"/> mixed <small>3</small>	handed

### 3.3 Medical History (MHx)

General		
Assessment date:	<input type="text" value="mon/dd/yyyy"/>	mhdte
Past Medical History		
Has the participant had alcohol problems in the past?	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> unknown 9999	hxalcab
Has the participant ever smoked?	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> unknown 9999	hxtobab
Cigarettes per day:	<input type="text"/>	hxtobcpd
Years of smoking:	<input type="text"/>	hxtobyos
Has the participant ever abused drugs?	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> unknown 9999	hxdrugab
Drug use for non-medical reasons?		
	Abuse:	Frequency:
Marijuana:	<input type="text" value="----"/> <input type="button" value="v"/> hxmar yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxmarfrq seldom 1 occasionally 2 frequently 3
Heroin:	<input type="text" value="----"/> <input type="button" value="v"/> hxher yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxherfrq seldom 1 occasionally 2 frequently 3
Cocaine:	<input type="text" value="----"/> <input type="button" value="v"/> hxcoc yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxcocfrq seldom 1 occasionally 2 frequently 3
Club drugs (Ecstasy, GHB, Roofies):	<input type="text" value="----"/> <input type="button" value="v"/> hxclb yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxclbfrq seldom 1 occasionally 2 frequently 3
Amphetamines:	<input type="text" value="----"/> <input type="button" value="v"/> hxamp yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxampfrq seldom 1 occasionally 2 frequently 3
Ritalin:	<input type="text" value="----"/> <input type="button" value="v"/> hxrit yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxritfrq seldom 1 occasionally 2 frequently 3
Hallucinogens:	<input type="text" value="----"/> <input type="button" value="v"/> hxhal yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxhalfrq seldom 1 occasionally 2 frequently 3
Inhalants:	<input type="text" value="----"/> <input type="button" value="v"/> hxinh yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxinhfrq seldom 1 occasionally 2 frequently 3

Opium:	<input type="text" value="----"/> <input type="button" value="v"/> hxopi yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxopifrq seldom 1 occasionally 2 frequently 3
Painkillers:	<input type="text" value="----"/> <input type="button" value="v"/> hxpak yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxpakfrq seldom 1 occasionally 2 frequently 3
Barbiturates/sedatives:	<input type="text" value="----"/> <input type="button" value="v"/> hxbar yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxbarfrq seldom 1 occasionally 2 frequently 3
Tranquilizers:	<input type="text" value="----"/> <input type="button" value="v"/> hxtrq yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxtrqfrq seldom 1 occasionally 2 frequently 3
Other:	<input type="text" value="----"/> <input type="button" value="v"/> hxoth yes 1 no 0	<input type="text" value="----"/> <input type="button" value="v"/> hxothfrq seldom 1 occasionally 2 frequently 3

### 3.4 HD Clinical Characteristics (HD CC)

General	
Participant category:	<div> <div>----</div> <div> genotype unknown 1  pre-manifest/pre-motor-manifest HD 2  manifest/motor-manifest HD 3  genotype negative 4  family control 5  community control 6 </div> </div>
hdcac	
Family History	
Mother affected:	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> unknown 9999
momhd	
Age at onset of symptoms in mother:	<div> <div></div> <div>years</div> </div>
momagesx	
Father affected:	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> unknown 9999
dadhd	
Age at onset of symptoms in father:	<div> <div></div> <div>years</div> </div>
dadagesx	

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

HD Clinical Characteristics and Age-of-Onset	
Has depression (includes treatment with antidepressants with or without a formally-stated diagnosis of depression) ever been a part of the participant's medical history?	<input type="radio"/> yes 1 <input type="radio"/> no 0
ccdep	
At what age did the depression begin?	
age (years):	year of onset:
<div></div> ccdepag	<div>yyyy</div> ccdepyr
Has irritability ever been a part of the participant's medical history?	<input type="radio"/> yes 1 <input type="radio"/> no 0
ccirb	
At what age did the irritability begin?	
age (years):	year of onset:
<div></div> ccirbag	<div>yyyy</div> ccirbyr
Has violent or aggressive behavior ever been a part of the participant's medical history?	<input type="radio"/> yes 1 <input type="radio"/> no 0
ccvab	
At what age did violent or aggressive behaviour begin?	
age (years):	year of onset:
<div></div> ccvabag	<div>yyyy</div> ccvabyr

Has apathy ever been a part of the participant's medical history:	<input type="radio"/> yes 1 <input type="radio"/> no 0	ccapt
At what age did apathy begin?		
age (years):      year of onset:		
<div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">ccaptage</div> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">yyyy</div> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">ccaptyr</div> </div>		
Has perseverative/obsessive behaviors ever been a part of the participant's medical history:	<input type="radio"/> yes 1 <input type="radio"/> no 0	ccpob
At what age did perseverative/obsessive behaviour begin?		
age (years):      year of onset:		
<div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">ccpobage</div> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">yyyy</div> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">ccpobyr</div> </div>		
Has psychosis (hallucinations or delusions) ever been a part of the participant's medical history:	<input type="radio"/> yes 1 <input type="radio"/> no 0	ccpsy
At what age did psychosis (hallucinations or delusions) begin?		
age (years):      year of onset:		
<div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">ccpsyage</div> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">yyyy</div> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">ccpsyr</div> </div>		
Does the participant have a family history of a psychotic illness in a first degree relative:		
<input type="radio"/> yes 1 <input type="radio"/> no 0		
ccpsyfh		
Has significant cognitive impairment (severe enough to impact on work or activities of daily living) or dementia ever been a part of the participant's medical history:	<input type="radio"/> yes 1 <input type="radio"/> no 0	cccog
At what age did cognitive impairment first start to have an impact on daily life?		
age (years):      year of onset:		
<div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">cccogage</div> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">yyyy</div> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">cccogyr</div> </div>		

### History of HD Motor Symptoms

Have motor symptoms compatible with HD ever been a part of the participant's medical history?	<input type="radio"/> yes 1 <input type="radio"/> no 0	ccmtr
At what age did the participant's motor symptoms begin?		
age (years):      year of onset:		
<div style="display: flex; justify-content: space-between; align-items: center;"> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">ccmtrage</div> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">yyyy</div> <div style="border: 1px solid black; width: 60px; height: 20px; display: flex; align-items: center; justify-content: center;">ccmtryr</div> </div>		

HD History - Participant and Family			
Symptoms first noted by participant:	<input type="text" value="mon/yyyy"/>		sxssubj
Initial major symptom noted by participant:	<input type="radio"/> motor 1 <input type="radio"/> cognitive 2 <input type="radio"/> psychiatric 3 <input type="radio"/> oculomotor 4 <input type="radio"/> other 5 <input type="radio"/> mixed 6		sxssubjm
Mixed symptoms:	motor:	<input type="checkbox"/>	sxs_m
	cognitive:	<input type="checkbox"/>	sxs_c
	psychiatric:	<input type="checkbox"/>	sxs_p
	oculomotor:	<input type="checkbox"/>	sxs_o
Symptoms first noted by family:	<input type="text" value="mon/yyyy"/>		sxfam
Initial major symptom noted by family:	<input type="radio"/> motor 1 <input type="radio"/> cognitive 2 <input type="radio"/> psychiatric 3 <input type="radio"/> oculomotor 4 <input type="radio"/> other 5 <input type="radio"/> mixed 6		sxfamm
Mixed symptoms:	motor:	<input type="checkbox"/>	sxf_m
	cognitive:	<input type="checkbox"/>	sxf_c
	psychiatric:	<input type="checkbox"/>	sxf_p
	oculomotor:	<input type="checkbox"/>	sxf_o

HD History - Rater			
Date of clinical HD diagnosis:	<input type="text" value="mon/yyyy"/>		hddiagn
Can you, as a rater, estimate the time of symptom onset:	<input type="radio"/> yes 1 <input type="radio"/> no 0		sxest
Rater's estimate of symptom onset:	<input type="text" value="mon/yyyy"/>		sxrater
Confidence with which this estimation is made:	<input type="radio"/> high 1 <input type="radio"/> low 2		sxestcfd
Please specify why you, as a rater, can not estimate symptom onset (without additional external information) at the moment:	<input type="radio"/> participant can not provide information (mute, or cognitively too impaired) 1 <input type="radio"/> information provided deemed unreliable 2		sxreas
What is your best guess of how many years ago symptom onset took place:	<input type="radio"/> < 5 1 <input type="radio"/> < 10 2 <input type="radio"/> < 15 3 <input type="radio"/> < 20 4 <input type="radio"/> > 20 5		sxgs
Date of data entry:	<input type="text"/>		sxgsdte
Rater's judgement of initial major symptom:	<input type="radio"/> motor 1 <input type="radio"/> cognitive 2 <input type="radio"/> psychiatric 3 <input type="radio"/> oculomotor 4 <input type="radio"/> other 5 <input type="radio"/> mixed 6		sxraterm
Mixed symptoms:	motor: <input type="checkbox"/> cognitive: <input type="checkbox"/> psychiatric: <input type="checkbox"/> oculomotor: <input type="checkbox"/>		sxr_m sxr_c sxr_p sxr_o

Suicidal Behavior	
Previous suicidal ideation or attempts?	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> unknown 9999

Local genetic test	
Has an genetic test been done?	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> unknown 9999

Comments	
Comments:	<input type="radio"/> yes 1 <input type="radio"/> no 0
Enter comment:	<input type="text"/>

### 3.5 CAG Report (CAG)

General	
Date of report:	mon/dd/yyyy <span style="float: right;">lbdtc</span>
CAG Analysis	
Specimen type:	<input type="radio"/> blood 1 <span style="float: right;">lbspec</span> <input type="radio"/> brain (postmortem) 2 <input type="radio"/> unknown 9999
Source of information:	<input type="radio"/> laboratory report 1 <span style="float: right;">lbsrc</span> <input type="radio"/> medical records/correspondence 2 <input type="radio"/> participant/companion self-report 3
CAG analysis results (number of CAG repeats):	Were the exact repeat lengths given? <input type="radio"/> yes 1 <input type="radio"/> no 0 <span style="float: right;">lbrpt</span>
<div style="display: flex; justify-content: space-between;"> <div> <p>CAG repeat length: Tolerance:</p> <p>Allele 1 (smaller allele): <input type="text"/> allele1l <span style="float: right;">allele1t</span></p> <div style="border: 1px solid black; padding: 5px; width: 150px;">           0 0 1 1 2 2 3 3 4 4 5 5 6 6 7 7 8 8 9 9         </div> <p>Allele 2 (larger allele): <input type="text"/> allele2l <span style="float: right;">allele2t</span></p> <div style="border: 1px solid black; padding: 5px; width: 150px;">           0 0 1 1 2 2 3 3 4 4 5 5 6 6 7 7 8 8 9 9         </div> </div> <div> <p>CAG repeat information (larger allele): <span style="float: right;">lbrng</span></p> <div style="border: 1px solid black; padding: 5px; width: 150px;">           normal 1            &lt;27 b27            27-35 27_35            36-39 36_39            &gt;35 a35            &gt;36 a36            &gt;37 a37            &gt;38 a38            &gt;39 a39            &gt;40 a40         </div> </div> </div>	
Analyzing laboratory:	<input type="text"/> <span style="float: right;">lbnam</span>
Comments:	<input type="radio"/> yes 1 <input type="radio"/> no 0 <span style="float: right;">cmt</span> Enter comment: <input type="text"/> <span style="float: right;">coval</span>



### 3.6 Pharmacotherapy (PharmacoTx)

Medications (Pharmacotherapy)													
Drug name:	Indication:	Dose:	Unit:	Morn:	Noon:	Eve:	Night:	Frequency:	Route:	Start date:	Ongoing:	Stop date:	
1. <input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/> daily 1 every 2nd day 2 every 3rd day 3 weekly 4 every 2nd week 5 monthly 6 every 2nd month 7 every 3rd month 8 annually 9 as needed 10	<input type="text"/> p.o. 1 p.r. 2 s.c. 3 i.m. 4 i.v. 5 nasal 6 id. 7 al. 8 inh. 9 other 10	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>

### 3.7 Nutritional Supplements (NutSuppl)

Nutritional Supplements													
Supplement:	Type:	Dose:	Unit:	Morn:	Noon:	Eve:	Night:	Frequency:	Start date:	Ongoing:	Stop date:		
1. <input type="text"/>	<input type="text"/> Vitamin & supplements 1 herbs (extracts) 2 herbs (teas) 3 other natural remedies 4 aromatherapies 5 homeopathic remedies 6 high calorie diet 7	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/> daily 1 every other day 2 every third day 3 weekly 4 every other week 5 monthly 6 every other month 7 every quarter 8 annually 9 as needed 10	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

### 3.8 Clinical Trials Form (Clinical Trials)

Clinical Trials									
Clinical trial name:	Participant ID in trial:	Date of enrollment:	What is ppt current clinical trial status?	End date of participation:					
1. <input type="text"/>	CTF: <input type="text"/> ⇒ ctnm	<input type="text"/> subjid	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
active 1 completed 2 discontinued prematurely 3									

### 3.9 Non-Pharmacologic Therapies (Non-PharmacTx)

Non-Pharmacologic Therapies							
Therapy:	Number of times:	Frequency:	Start date:	Ongoing:	Stop date:		
1. <input type="text" value="----"/> <small>cmtrt</small>	<input type="text" value=""/> <small>cmfrq</small>	<input type="text" value="----"/> <small>cmdosfrq</small>	<input type="text" value="mon/dd/yyyy"/> <small>cmstdtc</small>	<input type="checkbox"/> <small>cmenrf</small>	<input type="text" value="mon/dd/yyyy"/> <small>cmendtc</small>		
Physical therapy 1 Occupational therapy 2 Psychotherapy 3 Counseling 4 Speech/Language therapy 5 Swallowing therapy 6 Music therapy 7 Relaxation therapy (meditation, massage, yoga, etc.) 8 Acupuncture 9							
daily 1 weekly 2 monthly 3 as needed 4							

### 3.10 Comorbid Conditions (Comorbid)

Past Disorders and Comorbidities					
Condition:	Body system code:	Start date:	Ongoing:	End date:	
1. <input type="text" value=""/> ICD-10: <input type="text" value=""/> <small>mhterm</small>	<input type="text" value="----"/> <small>mhbodsys</small>	<input type="text" value="mon/dd/yyyy"/> <small>mhstdtc</small>	<input type="checkbox"/> <small>mhenrf</small>	<input type="text" value="mon/dd/yyyy"/> <small>mhendtc</small>	
cardiovascular 1 pulmonary 2 neurologic 3 ENT 4 gynecologic/urologic 5 reproductive 6 gastrointestinal 7 metabolic/endocrine 8 hemato/lymphatic 9 dermatological 10 psychiatric 11 musculoskeletal 12 allergy/immunologic 13 ophthalmological 14 hepatobiliary 15 renal 16 other 17					

ICD-10 codes, terms and text ©World Health Organization 2011

### 3.11 Mortality

General		
Assessment date:	<input type="text" value="mon/dd/yyyy"/>	dstdtc

Death Report Form		
Date of death:	<input type="text" value="mon/dd/yyyy"/>	dssdtc
Place of death:	<input type="radio"/> home 1 <input type="radio"/> hospital 2 <input type="radio"/> nursing home 3 <input type="radio"/> hospice care 4 <input type="radio"/> unknown 9999	dsplace
Cause of death:	<input type="radio"/> pneumonia 1 <input type="radio"/> other infection 2 <input type="radio"/> cancer 3 <input type="radio"/> stroke 4 <input type="radio"/> trauma 5 <input type="radio"/> suicide 6 <input type="radio"/> other 7 <input type="radio"/> unknown 9999 Please specify: <input type="text"/>	dsend
Was an autopsy performed?	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> unknown 9999 Result of autopsy: <input type="text"/>	dsautopr
Information obtained primarily from:	<input type="radio"/> spouse/family 1 <input type="radio"/> friend 2 <input type="radio"/> physician/nurse 3 <input type="radio"/> patient's medical record 4 <input type="radio"/> obituary in newspaper 5 <input type="radio"/> death certificate 6 <input type="radio"/> other 7 Please specify: <input type="text"/>	dsinfo
Comments?	<input type="radio"/> yes 1 <input type="radio"/> no 0 Comment: <input type="text"/>	dscom

### 3.12 Variable Items Baseline (Variable)

General			
Date of visit:	<input type="text"/>		svstdtc
General Variable Items I			
Is participant part of mobile clinic site:	<input type="radio"/> yes 1 <input type="radio"/> no 0		mclinic
Weight:	<input type="text"/> kg	weight <input type="text"/> lbs	weight_2
Height:	<input type="text"/> cm	height <input type="text"/> inches	height_2
BMI:	<input type="text"/>		bmi
Does the participant currently drink alcohol?	<input type="radio"/> yes 1 <input type="radio"/> no 0		alcab
	Units per week: <input type="text"/>		alcunits
Does the participant currently smoke?	<input type="radio"/> yes 1 <input type="radio"/> no 0		tobab
	Cigarettes per day: <input type="text"/>		tobcpd
	Years of smoking: <input type="text"/>		tobyos
Current caffeine use?	<input type="radio"/> yes 1 <input type="radio"/> no 0		cafab
	Do you drink more than 3 cups of coffee, tea and cola drinks combined per day? <input type="radio"/> yes 1 <input type="radio"/> no 0		cafpd
Does the participant currently use drugs?	<input type="radio"/> yes 1 <input type="radio"/> no 0		drugab
Drug use for non-medical reasons:			
	Abuse:	Frequency:	
Marijuana:	<input type="text"/> ----- <input type="text"/> mar yes 1 no 0	<input type="text"/> ----- <input type="text"/> marfrq seldom 1 occasionally 2 frequently 3	
Heroin:	<input type="text"/> ----- <input type="text"/> her yes 1 no 0	<input type="text"/> ----- <input type="text"/> herfrq seldom 1 occasionally 2 frequently 3	
Cocaine:	<input type="text"/> ----- <input type="text"/> coc yes 1 no 0	<input type="text"/> ----- <input type="text"/> cocfrq seldom 1 occasionally 2 frequently 3	
Club drugs (Ecstasy, GHB, Roofies):	<input type="text"/> ----- <input type="text"/> clb yes 1 no 0	<input type="text"/> ----- <input type="text"/> clbfrq seldom 1 occasionally 2 frequently 3	
Amphetamines:	<input type="text"/> ----- <input type="text"/> amp yes 1 no 0	<input type="text"/> ----- <input type="text"/> ampfrq seldom 1 occasionally 2 frequently 3	

Ritalin:	<input type="text" value="----"/> rit yes 1 no 0	<input type="text" value="----"/> ritfrq seldom 1 occasionally 2 frequently 3
Hallucinogens:	<input type="text" value="----"/> hal yes 1 no 0	<input type="text" value="----"/> halfrq seldom 1 occasionally 2 frequently 3
Inhalants:	<input type="text" value="----"/> inh yes 1 no 0	<input type="text" value="----"/> inhfrq seldom 1 occasionally 2 frequently 3
Opium:	<input type="text" value="----"/> opi yes 1 no 0	<input type="text" value="----"/> opifrq seldom 1 occasionally 2 frequently 3
Painkillers:	<input type="text" value="----"/> pak yes 1 no 0	<input type="text" value="----"/> pakfrq seldom 1 occasionally 2 frequently 3
Barbiturates/sedatives:	<input type="text" value="----"/> bar yes 1 no 0	<input type="text" value="----"/> barfrq seldom 1 occasionally 2 frequently 3
Tranquilizers:	<input type="text" value="----"/> trq yes 1 no 0	<input type="text" value="----"/> trqfrq seldom 1 occasionally 2 frequently 3
Other:	<input type="text" value="----"/> oth yes 1 no 0	<input type="text" value="----"/> othfrq seldom 1 occasionally 2 frequently 3

General Variable Items II		
Marital status:	<input type="radio"/> single 1 <input type="radio"/> married 3 <input type="radio"/> partnership 2 <input type="radio"/> divorced 4 <input type="radio"/> widowed 5 <input type="radio"/> legally separated 6	maristat
Residence:	<input type="radio"/> rural 1 <input type="radio"/> village 2 <input type="radio"/> town 3 <input type="radio"/> city 4	res
ISCED education level:	<input type="radio"/> ISCED 0 0 <input type="radio"/> ISCED 1 1 <input type="radio"/> ISCED 2 2 <input type="radio"/> ISCED 3 3 <input type="radio"/> ISCED 4 4 <input type="radio"/> ISCED 5 5 <input type="radio"/> ISCED 6 6	isced
Years of education:	<input type="text"/> years	eduyrs
Occupation:	<input type="text"/> ⇌ empjob	
Employment:	<input type="radio"/> full-time employed 1 <input type="radio"/> part-time employed 2 <input type="radio"/> self employed 3 <input type="radio"/> not employed 4	jobclas
Status:	<input type="radio"/> paid 1 <input type="radio"/> unpaid 2	jobpaid

Reason:	<input type="radio"/> sick leave 1	emplnrsn
	<input type="radio"/> retirement 2	
	<input type="radio"/> working in the home (e.g. caring for children) 3	
	<input type="radio"/> unemployed 4	
	<input type="radio"/> training/college 5	
	Retired due to: <input type="radio"/> ill health 1 <input type="radio"/> age 2	emplnrd
Do you receive incapacity benefit/social security or disability benefit?	<input type="radio"/> yes 1 <input type="radio"/> no 0	ssdb
Do you intend to return to work?	<input type="radio"/> yes 1 <input type="radio"/> no 0	rtrnwk
Since when have you been unemployed/retired?	<input type="text" value="yyyy"/>	rtrddur
Additional Employment Section:		
Have you had to stop or reduce work due to your health?	<input type="radio"/> yes 1 <input type="radio"/> no 0	rdcwkc
	How many days <input type="text"/> days in the last 6 months have you had off work because of HD?	rdcwkd
	How many <input type="text"/> hours/week fewer hours per week have you worked because of HD?	rdcwkhw

### 3.13 Variable Items Follow Up (Variable)

General			
Date of visit:	<input type="text"/>		svstdtc
<b>General Variable Items I</b>			
Is participant part of mobile clinic site:	<input type="radio"/> yes 1 <input type="radio"/> no 0		mclinic
Weight:	<input type="text"/> kg	weight <input type="text"/> lbs	weight_2
Height:	<input type="text"/> cm	height <input type="text"/> inches	height_2
BMI:	<input type="text"/>		bmi
Does the participant currently drink alcohol?	<input type="radio"/> yes 1 <input type="radio"/> no 0		alcab
Units per week:	<input type="text"/>		alcunits
Does the participant currently smoke?	<input type="radio"/> yes 1 <input type="radio"/> no 0		tobab
Cigarettes per day:	<input type="text"/>		tobcpd
Years of smoking:	<input type="text"/>		tobyos
Current caffeine use?	<input type="radio"/> yes 1 <input type="radio"/> no 0		cafab
Do you drink more than 3 cups of coffee, tea and cola drinks combined per day?	<input type="radio"/> yes 1 <input type="radio"/> no 0		cafpd
Does the participant currently use drugs?	<input type="radio"/> yes 1 <input type="radio"/> no 0		drugab
Drug use for non-medical reasons:			
	Abuse:	Frequency:	
Marijuana:	<input type="text"/> ----- <input type="text"/> mar yes 1 no 0	<input type="text"/> ----- <input type="text"/> marfrq seldom 1 occasionally 2 frequently 3	
Heroin:	<input type="text"/> ----- <input type="text"/> her yes 1 no 0	<input type="text"/> ----- <input type="text"/> herfrq seldom 1 occasionally 2 frequently 3	
Cocaine:	<input type="text"/> ----- <input type="text"/> coc yes 1 no 0	<input type="text"/> ----- <input type="text"/> cocfrq seldom 1 occasionally 2 frequently 3	
Club drugs (Ecstasy, GHB, Roofies):	<input type="text"/> ----- <input type="text"/> clb yes 1 no 0	<input type="text"/> ----- <input type="text"/> clbfrq seldom 1 occasionally 2 frequently 3	
Amphetamines:	<input type="text"/> ----- <input type="text"/> amp yes 1 no 0	<input type="text"/> ----- <input type="text"/> ampfrq seldom 1 occasionally 2 frequently 3	

Ritalin:	<input type="text" value="----"/> rit yes 1 no 0	<input type="text" value="----"/> ritfrq seldom 1 occasionally 2 frequently 3
Hallucinogens:	<input type="text" value="----"/> hal yes 1 no 0	<input type="text" value="----"/> halfrq seldom 1 occasionally 2 frequently 3
Inhalants:	<input type="text" value="----"/> inh yes 1 no 0	<input type="text" value="----"/> inhfrq seldom 1 occasionally 2 frequently 3
Opium:	<input type="text" value="----"/> opi yes 1 no 0	<input type="text" value="----"/> opifrq seldom 1 occasionally 2 frequently 3
Painkillers:	<input type="text" value="----"/> pak yes 1 no 0	<input type="text" value="----"/> pakfrq seldom 1 occasionally 2 frequently 3
Barbiturates/sedatives:	<input type="text" value="----"/> bar yes 1 no 0	<input type="text" value="----"/> barfrq seldom 1 occasionally 2 frequently 3
Tranquilizers:	<input type="text" value="----"/> trq yes 1 no 0	<input type="text" value="----"/> trqfrq seldom 1 occasionally 2 frequently 3
Other:	<input type="text" value="----"/> oth yes 1 no 0	<input type="text" value="----"/> othfrq seldom 1 occasionally 2 frequently 3



General Variable Items II		
Any changes to the rarely changing General Variable Items above:	<input type="radio"/> yes 1 <input type="radio"/> no 0	updsc
Participant category:	<input type="radio"/> genotype unknown 1 <input type="radio"/> pre-manifest/pre-motor-manifest HD 2 <input type="radio"/> manifest/motor-manifest HD 3 <input type="radio"/> genotype negative 4 <input type="radio"/> family control 5 <input type="radio"/> community control 6	hdcat
Marital status:	<input type="radio"/> single 1 <input type="radio"/> married 3 <input type="radio"/> partnership 2 <input type="radio"/> divorced 4 <input type="radio"/> widowed 5 <input type="radio"/> legally separated 6	maristat
Residence:	<input type="radio"/> rural 1 <input type="radio"/> village 2 <input type="radio"/> town 3 <input type="radio"/> city 4	res
ISCED education level: 	<input type="radio"/> ISCED 0 0 <input type="radio"/> ISCED 1 1 <input type="radio"/> ISCED 2 2 <input type="radio"/> ISCED 3 3 <input type="radio"/> ISCED 4 4 <input type="radio"/> ISCED 5 5 <input type="radio"/> ISCED 6 6	iscsed
Years of education:	<input type="text"/> years	eduyrs
Occupation:	<input type="text"/> ⇨ empjob	
Employment:	<input type="radio"/> full-time employed 1 <input type="radio"/> part-time employed 2 <input type="radio"/> self employed 3 <input type="radio"/> not employed 4	jobclas
Status:	<input type="radio"/> paid 1 <input type="radio"/> unpaid 2	jobpaid
Reason:	<input type="radio"/> sick leave 1 <input type="radio"/> retirement 2 <input type="radio"/> working in the home (e.g. caring for children) 3 <input type="radio"/> unemployed 4 <input type="radio"/> training/college 5	emplnrsn
Retired due to:	<input type="radio"/> ill health 1 <input type="radio"/> age 2	emplnrd
Do you receive incapacity benefit/social security or disability benefit?	<input type="radio"/> yes 1 <input type="radio"/> no 0	ssdb
Do you intend to return to work?	<input type="radio"/> yes 1 <input type="radio"/> no 0	rtrnwk
Since when have you been unemployed/retired?	<input type="text"/> yyyy	rtrddur

### Additional Employment Section

Have you had to stop or reduce work due to your health?	<input type="radio"/> yes 1 <input type="radio"/> no 0	rdcwkw
How many days in the last 6 months have you had off work because of HD?	<input type="text"/> days	rdcwkd
How many fewer hours per week have you worked because of HD?	<input type="text"/> hours/week	rdcwkhw


### Since the last visit have there been

Any changes to participant's medication?	<input type="radio"/> yes 1 <input type="radio"/> no 0	updmed
Any changes to participant's comorbid conditions?	<input type="radio"/> yes 1 <input type="radio"/> no 0	updmh
Any updates to family history?	<input type="radio"/> yes 1 <input type="radio"/> no 0	updfh
Any updates to the clinical characteristics and/or onset of HD?	<input type="radio"/> yes 1 <input type="radio"/> no 0	updhdh
Any changes to the optional components?	<input type="radio"/> yes 1 <input type="radio"/> no 0	updopt
Family History:	<input type="radio"/> yes 1 <input type="radio"/> no 0	fhx
Biosamples for use in research:	<input type="radio"/> yes 1 <input type="radio"/> no 0	bsp
Linking clinical information from previous studies:	<input type="radio"/> yes 1 <input type="radio"/> no 0	rtspctv
Participation in sub-studies:	<input type="radio"/> yes 1 <input type="radio"/> no 0	nvl
Contact between visits:	<input type="radio"/> yes 1 <input type="radio"/> no 0	cntct
Contact regarding other research studies:	<input type="radio"/> yes 1 <input type="radio"/> no 0	cntctst
Contact regarding post-mortem tissue collection:	<input type="radio"/> yes 1 <input type="radio"/> no 0	cntctpmt
Has the participant had a brain MRI?	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> unknown 9999	updmri
Date of MRI:	<input type="text"/> mon/dd/yyyy	mridtc

### 3.14 UHDRS® Motor/Diagnostic Confidence (Motor)

General			
Assessment date:	<input type="text" value="mon/dd/yyyy"/>		qsdtc
Rater code:	<input type="text"/>		raterid
Motor score (TMS):	<input type="text"/>		motscore
Motor score (TMS) incomplete:	<input type="text"/>		miscore

Motor Assessment 			
Ocular pursuit:	Horizontal:	Vertical:	
	<input type="radio"/>	<input type="radio"/>	0 = complete (normal)
	<input type="radio"/>	<input type="radio"/>	1 = jerky movement
	<input type="radio"/>	<input type="radio"/>	2 = interrupted pursuits/full range
	<input type="radio"/>	<input type="radio"/>	3 = incomplete range
	<input type="radio"/> ocularh	<input type="radio"/> ocularv	4 = cannot pursue
Saccade initiation:	Horizontal:	Vertical:	
	<input type="radio"/>	<input type="radio"/>	0 = normal
	<input type="radio"/>	<input type="radio"/>	1 = increased latency only
	<input type="radio"/>	<input type="radio"/>	2 = suppressible blinks or head movements to initiate
	<input type="radio"/>	<input type="radio"/>	3 = unsuppressible head movements
	<input type="radio"/> sacinith	<input type="radio"/> sacinitv	4 = cannot initiate saccades
Saccade velocity:	Horizontal:	Vertical:	
	<input type="radio"/>	<input type="radio"/>	0 = normal
	<input type="radio"/>	<input type="radio"/>	1 = mild slowing
	<input type="radio"/>	<input type="radio"/>	2 = moderate slowing
	<input type="radio"/>	<input type="radio"/>	3 = severely slow, full range
	<input type="radio"/> sacvelh	<input type="radio"/> sacvelv	4 = incomplete range
Dysarthria:	<input type="radio"/> 0 = normal 0 <input type="radio"/> 1 = unclear, no need to repeat 1 <input type="radio"/> 2 = must repeat to be understood 2 <input type="radio"/> 3 = mostly incomprehensible 3 <input type="radio"/> 4 = anarthria 4		dysarth
Tongue protrusion:	<input type="radio"/> 0 = can hold tongue fully protruded for 10 sec 0 <input type="radio"/> 1 = cannot keep fully protruded for 10 sec 1 <input type="radio"/> 2 = cannot keep fully protruded for 5 sec 2 <input type="radio"/> 3 = cannot fully protrude tongue 3 <input type="radio"/> 4 = cannot protrude tongue beyond lips 4		tongue
Finger taps:	Right:	Left:	
	<input type="radio"/>	<input type="radio"/>	0 = normal (≥15/5 sec.)
	<input type="radio"/>	<input type="radio"/>	1 = mild slowing, reduction in amplitude (11-14/5 sec.)
	<input type="radio"/>	<input type="radio"/>	2 = moderately impaired (7-10/5 sec.)
	<input type="radio"/>	<input type="radio"/>	3 = severely impaired (3-6/5 sec.)
	<input type="radio"/> fingtapr	<input type="radio"/> fingtapl	4 = can barely perform task (0-2/5 sec.)

<u>Pronate/supinate-hands:</u>	Right:	Left:						
	<input type="radio"/>	<input type="radio"/>	0 = normal					
	<input type="radio"/>	<input type="radio"/>	1 = mild slowing and/or irregular					
	<input type="radio"/>	<input type="radio"/>	2 = moderate slowing and irregular					
	<input type="radio"/>	<input type="radio"/>	3 = severe slowing and irregular					
	<input type="radio"/> prosupr	<input type="radio"/> prosupl	4 = cannot perform					
<u>Luria:</u>	<input type="radio"/> 0 = $\geq 4$ in 10 sec, no cue 0 <input type="radio"/> 1 = $< 4$ in 10 sec, no cue 1 <input type="radio"/> 2 = $\geq 4$ in 10 sec with cues 2 <input type="radio"/> 3 = $< 4$ in 10 sec with cues 3 <input type="radio"/> 4 = cannot perform 4					luria		
<u>Rigidity-arms:</u>	Right:	Left:						
	<input type="radio"/>	<input type="radio"/>	0 = absent					
	<input type="radio"/>	<input type="radio"/>	1 = slight or present only with activation					
	<input type="radio"/>	<input type="radio"/>	2 = mild to moderate					
	<input type="radio"/>	<input type="radio"/>	3 = severe, full range of motion					
	<input type="radio"/> rigarmr	<input type="radio"/> rigarml	4 = severe with limited range					
<u>Bradykinesia-body:</u>	<input type="radio"/> 0 = normal 0 <input type="radio"/> 1 = minimally slow (?normal) 1 <input type="radio"/> 2 = mildly but clearly slow 2 <input type="radio"/> 3 = moderately slow, some hesitation 3 <input type="radio"/> 4 = markedly slow, long delays in initiation 4					brady		
<u>Maximal dystonia:</u>	Trunk:	RUE:	LUE:	RLE:	LLE:			
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	0 = absent		
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1 = slight/intermittent		
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2 = mild/common or moderate/intermittent		
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3 = moderate/common		
	<input type="radio"/> dysttrnk	<input type="radio"/> dysttrue	<input type="radio"/> dystlue	<input type="radio"/> dystrie	<input type="radio"/> dystlle	4 = marked/prolonged		
<u>Maximal chorea:</u>	Face:	BOL:	Trunk:	RUE:	LUE:	RLE:	LLE:	
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	0 = absent
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1 = slight/intermittent
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2 = mild/common or moderate/intermittent
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3 = moderate/common
	<input type="radio"/> chorface	<input type="radio"/> chorbol	<input type="radio"/> chortrnk	<input type="radio"/> chorruue	<input type="radio"/> chorlue	<input type="radio"/> chorrie	<input type="radio"/> chorlle	4 = marked/prolonged
<u>Gait:</u>	<input type="radio"/> 0 = normal gait, narrow base 0 <input type="radio"/> 1 = wide base and/or slow 1 <input type="radio"/> 2 = wide base and walks with difficulty 2 <input type="radio"/> 3 = walks only with assistance 3 <input type="radio"/> 4 = cannot attempt 4					gait		
<u>Tandem walking:</u>	<input type="radio"/> 0 = normal for 10 steps 0 <input type="radio"/> 1 = 1 to 3 deviations from straight line 1 <input type="radio"/> 2 = $> 3$ deviations 2 <input type="radio"/> 3 = cannot complete 3 <input type="radio"/> 4 = cannot attempt 4					tandem		
<u>Retropulsion pull test:</u>	<input type="radio"/> 0 = normal 0 <input type="radio"/> 1 = recovers spontaneously 1 <input type="radio"/> 2 = would fall if not caught 2 <input type="radio"/> 3 = tends to fall spontaneously 3 <input type="radio"/> 4 = cannot stand 4					retropuls		

**Diagnostic Confidence**Diagnostic confidence level  
(DCL):

- ☐ 0 = normal (no abnormalities) 0
- ☐ 1 = non-specific motor abnormalities (less than 50 % confidence) 1
- ☐ 2 = motor abnormalities that may be signs of HD (50 - 89 % confidence) 2
- ☐ 3 = motor abnormalities that are likely signs of HD (90 - 98 % confidence) 3
- ☐ 4 = motor abnormalities that are unequivocal signs of HD (≥ 99 % confidence) 4

diagconf

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### 3.15 UHDRS® Total Functional Capacity (TFC)

General		
Assessment date:	<input type="text" value="mon/dd/yyyy"/>	qsdtc
Rater code:	<input type="text"/>	raterid
Functional score:	<input type="text"/>	tfcscor

Functional Capacity		
Occupation:	<input type="radio"/> 0 = unable 0 <input type="radio"/> 1 = marginal work only 1 <input type="radio"/> 2 = reduced capacity for usual job 2 <input type="radio"/> 3 = normal 3	occupatn
Finances:	<input type="radio"/> 0 = unable 0 <input type="radio"/> 1 = major assistance 1 <input type="radio"/> 2 = slight assistance 2 <input type="radio"/> 3 = normal 3	finances
Domestic chores:	<input type="radio"/> 0 = unable 0 <input type="radio"/> 1 = impaired 1 <input type="radio"/> 2 = normal 2	chores
ADL:	<input type="radio"/> 0 = total care 0 <input type="radio"/> 1 = gross tasks only 1 <input type="radio"/> 2 = minimal impairment 2 <input type="radio"/> 3 = normal 3	adl
Care level:	<input type="radio"/> 0 = full time skilled nursing 0 <input type="radio"/> 1 = home or chronic care 1 <input type="radio"/> 2 = home 2	carelevl
Information Sources:	Was the information obtained from: <input type="radio"/> 1 = participant only 1 <input type="radio"/> 2 = participant and family/companion 2	tfcsrc

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### 3.16 UHDRS® Functional Assessment (Function)

General		
Assessment date:	<input type="text" value="mon/dd/yyyy"/>	qsdte
Rater code:	<input type="text"/>	raterid
Functional assessment score:	<input type="text"/>	fascore
Functional score incomplete:	<input type="text"/>	fiscore
Independence scale in %:	<input type="text"/>	indpsclp

Functional Assessment		
	yes	no
Could subject engage in gainful employment in his/her accustomed work:	<input type="radio"/>	<input type="radio"/> emplust
Could subject engage in any kind of gainful employment?	<input type="radio"/>	<input type="radio"/> emplany
Could subject engage in any kind of volunteer or non-gainful work?	<input type="radio"/>	<input type="radio"/> volunt
Could subject manage his/her finances (monthly) without any help?	<input type="radio"/>	<input type="radio"/> fafinan
Could subject shop for groceries without help?	<input type="radio"/>	<input type="radio"/> grocery
Could subject handle money as a purchaser in a simple cash (shop) transaction?	<input type="radio"/>	<input type="radio"/> cash
Could subject supervise children without help?	<input type="radio"/>	<input type="radio"/> supchild
Could subject operate an automobile safely and independently?	<input type="radio"/>	<input type="radio"/> drive
Could subject do his/her own housework without help?	<input type="radio"/>	<input type="radio"/> housewrk
Could subject do his/her own laundry (wash/dry) without help?	<input type="radio"/>	<input type="radio"/> laundry
Could participant prepare his/her own meals without help?	<input type="radio"/>	<input type="radio"/> prepmeal
Could subject use the telephone without help?	<input type="radio"/>	<input type="radio"/> telephon
Could subject take his/her own medications without help?	<input type="radio"/>	<input type="radio"/> ownmeds
Could subject feed himself/herself without help?	<input type="radio"/>	<input type="radio"/> feedself
Could subject dress himself/herself without help?	<input type="radio"/>	<input type="radio"/> dress
Could subject bathe himself/herself without help?	<input type="radio"/>	<input type="radio"/> bathe
Could subject use public transport to get to places without help?	<input type="radio"/>	<input type="radio"/> pubtrans
Could subject walk to places in his/her neighbourhood without help?	<input type="radio"/>	<input type="radio"/> walknbr
Could subject walk without falling?	<input type="radio"/>	<input type="radio"/> walkfall
Could subject walk without help?	<input type="radio"/>	<input type="radio"/> walkhelp
Could subject comb hair without help?	<input type="radio"/>	<input type="radio"/> comb
Could subject transfer between chairs without help?	<input type="radio"/>	<input type="radio"/> trnchair
Could subject get in and out of bed without help?	<input type="radio"/>	<input type="radio"/> bed
Could subject use toilet/commode without help?	<input type="radio"/>	<input type="radio"/> toilet
Could subject's care still be provided at home?	<input type="radio"/>	<input type="radio"/> carehome

**Information sources**

Was the functional  
assessment information  
obtained from:

☐ subject only 1 ☐ subject and family/companion 2

fasrc

**Independence Scale**

Subject's independence  
in %:

- ☐ 100 = no special care needed 100
- ☐ 95 = 95
- ☐ 90 = no physical care needed if difficult tasks are avoided 90
- ☐ 85 = 85
- ☐ 80 = pre-disease level of employment changes or ends; cannot perform household chores to pre-disease level, may need help with finances 80
- ☐ 75 = 75
- ☐ 70 = self-care maintained for bathing, limited household duties, e.g. cooking and use of knives, driving terminates; unable to manage finances 70
- ☐ 65 = 65
- ☐ 60 = needs minor assistance in dressing, toileting, bathing; food must be cut for subject 60
- ☐ 55 = 55
- ☐ 50 = 24-hour supervision appropriate; assistance required for bathing, eating, toileting 50
- ☐ 45 = 45
- ☐ 40 = chronic care facility needed; limited self feeding, liquified diet 40
- ☐ 35 = 35
- ☐ 30 = subject provides minimal assistance in own feeding, bathing, toileting 30
- ☐ 25 = 25
- ☐ 20 = no speech, must be fed 20
- ☐ 15 = 15
- ☐ 10 = tube fed, total bed care 10
- ☐ 5 = 5


indep scl

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### 3.17 Problem Behaviours Assessment – Short (PBA-s)

General			
Assessment date:	<input type="text" value="mon/dd/yyyy"/>		qsdtc
Language of paper form (PBF):	<div> <div>----</div> <div> U.S. English 1  Spanish (LA) 2  Brazilian Portuguese 3  Canadian French 6  French 7  Czech 8  Danish 9  German 10  Spanish 11  Italian 12  Dutch 13  Norwegian 14  Polish 15  Portuguese 16  Russian 17  Finnish 18  Swedish 19 </div> </div>		langpbf
Rater code:	<input type="text"/>		raterid
Domain scores:	Depression:	<input type="text"/>	depscore
	Irritability/aggression:	<input type="text"/>	irascore
	Psychosis:	<input type="text"/>	psyscore
	Apathy:	<input type="text"/>	aptscore
	Executive function:	<input type="text"/>	exfscore

Problem Behaviours Assessment for HD 			
1. Depressed mood:	a. Severity:	<input type="radio"/> 0 = absent 0	pbas1sv
		<input type="radio"/> 1 = slight, questionable 1	
		<input type="radio"/> 2 = mild (present, not a problem) 2	
		<input type="radio"/> 3 = moderate (symptom causing problem) 3	
		<input type="radio"/> 4 = severe (almost intolerable for carer) 4	
	b. Frequency:	<input type="radio"/> 0 = never/almost never 0	pbas1fr
		<input type="radio"/> 1 = seldom (less than once/week) 1	
		<input type="radio"/> 2 = sometimes (up to four times a week) 2	
		<input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3	
c. Worst:	<input type="radio"/> 0 = absent 0	pbas1wo	
	<input type="radio"/> 1 = slight, questionable 1		
2. Suicidal ideation:	a. Severity:	<input type="radio"/> 0 = absent 0	pbas2sv
		<input type="radio"/> 1 = slight, questionable 1	
		<input type="radio"/> 2 = mild (present, not a problem) 2	
		<input type="radio"/> 3 = moderate (symptom causing problem) 3	
		<input type="radio"/> 4 = severe (almost intolerable for carer) 4	
	b. Frequency:	<input type="radio"/> 0 = never/almost never 0	pbas2fr
		<input type="radio"/> 1 = seldom (less than once/week) 1	
		<input type="radio"/> 2 = sometimes (up to four times a week) 2	
		<input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3	
c. Worst:	<input type="radio"/> 0 = absent 0	pbas2wo	
	<input type="radio"/> 1 = slight, questionable 1		
3. Anxiety:	a. Severity:	<input type="radio"/> 0 = absent 0	pbas3sv
		<input type="radio"/> 1 = slight, questionable 1	
		<input type="radio"/> 2 = mild (present, not a problem) 2	
		<input type="radio"/> 3 = moderate (symptom causing problem) 3	
		<input type="radio"/> 4 = severe (almost intolerable for carer) 4	

	b. Frequency:	<input type="radio"/> 0 = never/almost never 0 <input type="radio"/> 1 = seldom (less than once/week) 1 <input type="radio"/> 2 = sometimes (up to four times a week) 2 <input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3 <input type="radio"/> 4 = daily/almost daily for most (or all) of day 4	pbas3fr
	c. Worst:	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas3wo
4. Irritability:	a. Severity:	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas4sv
	b. Frequency:	<input type="radio"/> 0 = never/almost never 0 <input type="radio"/> 1 = seldom (less than once/week) 1 <input type="radio"/> 2 = sometimes (up to four times a week) 2 <input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3 <input type="radio"/> 4 = daily/almost daily for most (or all) of day 4	pbas4fr
	c. Worst:	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas4wo
5. Angry or aggressive behaviour:	a. Severity:	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas5sv
	b. Frequency:	<input type="radio"/> 0 = never/almost never 0 <input type="radio"/> 1 = seldom (less than once/week) 1 <input type="radio"/> 2 = sometimes (up to four times a week) 2 <input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3 <input type="radio"/> 4 = daily/almost daily for most (or all) of day 4	pbas5fr
	c. Worst:	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas5wo
6. Lack of initiative (apathy):	a. Severity:	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas6sv
	b. Frequency:	<input type="radio"/> 0 = never/almost never 0 <input type="radio"/> 1 = seldom (less than once/week) 1 <input type="radio"/> 2 = sometimes (up to four times a week) 2 <input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3 <input type="radio"/> 4 = daily/almost daily for most (or all) of day 4	pbas6fr
	c. Worst:	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas6wo
7. Perseverative thinking or behaviour:	a. Severity:	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas7sv
	b. Frequency:	<input type="radio"/> 0 = never/almost never 0 <input type="radio"/> 1 = seldom (less than once/week) 1 <input type="radio"/> 2 = sometimes (up to four times a week) 2 <input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3 <input type="radio"/> 4 = daily/almost daily for most (or all) of day 4	pbas7fr

	<u>c. Worst:</u>	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas7wo
8. Obsessive-Compulsive Behaviours:	<u>a. Severity:</u>	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas8sv
	<u>b. Frequency:</u>	<input type="radio"/> 0 = never/almost never 0 <input type="radio"/> 1 = seldom (less than once/week) 1 <input type="radio"/> 2 = sometimes (up to four times a week) 2 <input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3 <input type="radio"/> 4 = daily/almost daily for most (or all) of day 4	pbas8fr
	<u>c. Worst:</u>	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas8wo
	<u>a. Severity:</u>	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas9sv
	<u>b. Frequency:</u>	<input type="radio"/> 0 = never/almost never 0 <input type="radio"/> 1 = seldom (less than once/week) 1 <input type="radio"/> 2 = sometimes (up to four times a week) 2 <input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3 <input type="radio"/> 4 = daily/almost daily for most (or all) of day 4	pbas9fr
	<u>c. Worst:</u>	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas9wo
10. Hallucinations:	<u>a. Severity:</u>	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas10sv
	Please specify:		
	Modality of hallucinations:	<input type="checkbox"/> auditory	pbas10sm_1
		<input type="checkbox"/> visual	pbas10sm_2
		<input type="checkbox"/> tactile	pbas10sm_3
		<input type="checkbox"/> olfactory	pbas10sm_4
		<input type="checkbox"/> gustatory	pbas10sm_5
	<u>b. Frequency:</u>	<input type="radio"/> 0 = never/almost never 0 <input type="radio"/> 1 = seldom (less than once/week) 1 <input type="radio"/> 2 = sometimes (up to four times a week) 2 <input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3 <input type="radio"/> 4 = daily/almost daily for most (or all) of day 4	pbas10fr
	<u>c. Worst:</u>	<input type="radio"/> 0 = absent 0 <input type="radio"/> 1 = slight, questionable 1 <input type="radio"/> 2 = mild (present, not a problem) 2 <input type="radio"/> 3 = moderate (symptom causing problem) 3 <input type="radio"/> 4 = severe (almost intolerable for carer) 4	pbas10wo
	Please specify:		
Modality of hallucinations:	<input type="checkbox"/> auditory	pbas10wm_1	
	<input type="checkbox"/> visual	pbas10wm_2	
	<input type="checkbox"/> tactile	pbas10wm_3	
	<input type="checkbox"/> olfactory	pbas10wm_4	
	<input type="checkbox"/> gustatory	pbas10wm_5	

11. Disoriented Behaviour:	a. Severity:	<input type="radio"/> 0 = absent 0	pbas11sv
		<input type="radio"/> 1 = slight, questionable 1	
		<input type="radio"/> 2 = mild (present, not a problem) 2	
		<input type="radio"/> 3 = moderate (symptom causing problem) 3	
		<input type="radio"/> 4 = severe (almost intolerable for carer) 4	
	b. Frequency:	<input type="radio"/> 0 = never/almost never 0	pbas11fr
		<input type="radio"/> 1 = seldom (less than once/week) 1	
		<input type="radio"/> 2 = sometimes (up to four times a week) 2	
		<input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3	
		<input type="radio"/> 4 = daily/almost daily for most (or all) of day 4	
	c. Worst:	<input type="radio"/> 0 = absent 0	pbas11wo
		<input type="radio"/> 1 = slight, questionable 1	
<input type="radio"/> 2 = mild (present, not a problem) 2			
<input type="radio"/> 3 = moderate (symptom causing problem) 3			
<input type="radio"/> 4 = severe (almost intolerable for carer) 4			

### Information

i) Is informant a relative?	<input type="radio"/> spouse or partner 1	pbainfo	
	<input type="radio"/> parent 2		
	<input type="radio"/> sibling 3		
	<input type="radio"/> child 4		
	<input type="radio"/> other relative 5		
	<input type="radio"/> friend or neighbor 6		
	<input type="radio"/> professional care worker 7		
	<input type="radio"/> other 8		
	<input type="radio"/> no informant - participant came alone 9		
	ii) Is informant a household member?		<input type="radio"/> household member (i.e. relative or friend who lives with participant ) 1
<input type="radio"/> not a household member but has frequent contact with participant (most days) 2			
<input type="radio"/> not a household member and sees participant less than three or four times a week 3			
<input type="radio"/> staff of residential care home or hospital 4			
General comments:		<div></div>	coval

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### 3.18 Core and Extended Cognitive Assessment (Cognitive)

General		
Assessment date:	<input type="text" value="mm/dd/yyyy"/>	assdate
Language of paper form (PBF):	<input type="text" value="---"/> <ul style="list-style-type: none"> <li>U.S. English 1</li> <li>Spanish (LA) 2</li> <li>Brazilian Portuguese 3</li> <li>Canadian French 6</li> <li>French 7</li> <li>Czech 8</li> <li>Danish 9</li> <li>German 10</li> <li>Spanish 11</li> <li>Italian 12</li> <li>Dutch 13</li> <li>Norwegian 14</li> <li>Polish 15</li> <li>Portuguese 16</li> <li>Russian 17</li> <li>Finnish 18</li> <li>Swedish 19</li> </ul>	langpbf
Rater code:	<input type="text"/>	raterid

Specifics		
Did the participant complete the assessment in their native language and with normal or corrected-to-normal vision and hearing?	<input type="radio"/> yes <input type="radio"/> no	gen1
Did the participant complete the assessment in their native language?	<input type="radio"/> yes <input type="radio"/> no	gen2
At what age did the participant learn the language used?	<input type="text"/> years	gen3
Did the participant have normal/corrected-to-normal hearing and vision?	<input type="radio"/> yes <input type="radio"/> no	gen4
Was vision uncorrected (e.g. no glasses during visit)?	<input type="radio"/> yes <input type="radio"/> no	gen5
Was hearing uncorrected (e.g. no hearing aid worn)?	<input type="radio"/> yes <input type="radio"/> no	gen6

Core Cognitive Assessment		
Symbol Digit Modality Test completed:	<input type="radio"/> yes <input type="radio"/> no	sdmc
Total correct:	<input type="text"/>	sdmc1
Total errors:	<input type="text"/>	sdmc2
Reason:	<input type="text" value="---"/> <ul style="list-style-type: none"> <li>cognitive impairment 1</li> <li>motor impairment 2</li> <li>mental state 3</li> <li>physical health 4</li> <li>visual impairment 5</li> <li>language barrier 6</li> <li>refusal 7</li> <li>study conflict 8</li> <li>scheduling issue 9</li> <li>site error 10</li> </ul>	sdmc3
Verbal Fluency Test (Category) completed:	<input type="radio"/> yes <input type="radio"/> no	verfc
Category:	<input type="text" value="---"/> <ul style="list-style-type: none"> <li>animals 1</li> <li>other 2</li> </ul>	verfcd
Please specify:	<input type="text"/>	verfcsa
Total correct 0-15 seconds:	<input type="text"/>	verfc1
Total correct 16-30 seconds:	<input type="text"/>	verfc2
Total correct 31-45 seconds:	<input type="text"/>	verfc3

Total correct 46-60 seconds:	<input type="text"/>	verfc4
Total correct (1 min):	<input type="text"/>	verfc5
Total intrusion errors:	<input type="text"/>	verfc6
Total perseverative errors:	<input type="text"/>	verfc7
Reason:	<input type="text"/> cognitive impairment 1 motor impairment 2 mental state 3 physical health 4 visual impairment 5 language barrier 6 refusal 7 study conflict 8 scheduling issue 9 site error 10	verfc8
Stroop Color Naming Test completed: <input type="checkbox"/>	<input type="radio"/> yes 1 <input type="radio"/> no 0	scnc
Total correct:	<input type="text"/>	scnc1
Total errors:	<input type="text"/>	scnc2
Total self-corrected errors:	<input type="text"/>	scnc3
Reason:	<input type="text"/> cognitive impairment 1 motor impairment 2 mental state 3 physical health 4 visual impairment 5 language barrier 6 refusal 7 study conflict 8 scheduling issue 9 site error 10	scnc4
Stroop Word Reading Test completed: <input type="checkbox"/>	<input type="radio"/> yes 1 <input type="radio"/> no 0	swrt
Total correct:	<input type="text"/>	swrt1
Total errors:	<input type="text"/>	swrt2
Total self-corrected errors:	<input type="text"/>	swrt3
Reason:	<input type="text"/> cognitive impairment 1 motor impairment 2 mental state 3 physical health 4 visual impairment 5 language barrier 6 refusal 7 study conflict 8 scheduling issue 9 site error 10	swrt4

Extended Cognitive Assessment		
Stroop Interference Test completed: <input type="checkbox"/>	<input type="radio"/> yes 1 <input type="radio"/> no 0	st
Total correct:	<input type="text"/>	st1
Total errors:	<input type="text"/>	st2
Total self-corrected errors:	<input type="text"/>	st3
Trailmaking Test completed: <input type="checkbox"/>	<input type="radio"/> yes 1 <input type="radio"/> no 0	tr
Trailmaking Test:		
Part A: time to complete:	<input type="text"/> sec	tr1a1
Part A: total correct:	<input type="text"/>	tr1a2
Part A: total errors:	<input type="text"/>	tr1a3
Part B: time to complete:	<input type="text"/> sec	tr1b1
Part B: total correct:	<input type="text"/>	tr1b2
Part B: total errors:	<input type="text"/>	tr1b3

Verbal Fluency Test (Letters)		<input type="radio"/> yes 1	<input type="radio"/> no 0	
completed:				verfb
Letter 1:	Total correct 0-15 seconds:	<input type="text"/>		verfb1
	Total correct 16-30 seconds:	<input type="text"/>		verfb12
	Total correct 31-45 seconds:	<input type="text"/>		verfb13
	Total correct 46-60 seconds:	<input type="text"/>		verfb14
	Total correct 0-60 seconds:	<input type="text"/>		verfb15
Letter 2:	Total correct 0-15 seconds:	<input type="text"/>		verfb21
	Total correct 16-30 seconds:	<input type="text"/>		verfb22
	Total correct 31-45 seconds:	<input type="text"/>		verfb23
	Total correct 46-60 seconds:	<input type="text"/>		verfb24
	Total correct 0-60 seconds:	<input type="text"/>		verfb25
Letter 3:	Total correct 0-15 seconds:	<input type="text"/>		verfb31
	Total correct 16-30 seconds:	<input type="text"/>		verfb32
	Total correct 31-45 seconds:	<input type="text"/>		verfb33
	Total correct 46-60 seconds:	<input type="text"/>		verfb34
	Total correct 0-60 seconds:	<input type="text"/>		verfb35
Subscores:	Total correct 0-15 seconds:	<input type="text"/>		verfb01
	Total correct 16-30 seconds:	<input type="text"/>		verfb02
	Total correct 31-45 seconds:	<input type="text"/>		verfb03
	Total correct 46-60 seconds:	<input type="text"/>		verfb04
	Total correct (3 min):	<input type="text"/>		verfb05
	Total intrusion errors:	<input type="text"/>		verfb06
	Total perseverative errors:	<input type="text"/>		verfb07

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**Verbal Fluency Test (Category):** Instructions/scoring guidelines were developed by the University of Ulm, Faculty of Medicine, EHDN Cognitive Phenotype Working Group. The Categorical Fluency Test is available in the public domain and is referenced in Lezak, MD, Howieson, D.B., & Loring, D.W. (2004). Neuropsychological Assessment (4th ed.). New York: Oxford University Press.

**Trail Making Test:** Instructions were adapted from PREDICT-HD and scoring guidelines developed by the University of Ulm, Faculty of Medicine, EHDN Cognitive Phenotype Working Group.

**Verbal Fluency Test (Letters):** © 1999 Huntington Study Group. All Rights Reserved. Note: The Letter Verbal Fluency Test is available in the public domain and is referenced in Lezak, MD, Howieson, D.B., & Loring, D.W. (2004). Neuropsychological Assessment (4th ed.). New York: Oxford University Press. Instructions/scoring guidelines were adapted by the EHDN Cognitive Phenotype Working Group. Cognitive raters are advised to refer to the regionally adapted version of this manual where they can find the regional variations for letters to be used.

### 3.19 Reportable Event (Event)

General		
Assessment date:	<input type="text" value="mon/dd/yyyy"/>	evtdtc

Reportable Event		
Reportable event codes:	<input type="radio"/> suicide attempts 1 <input type="radio"/> completed suicide 2 <input type="radio"/> mental health event requiring hospitalization 3 <input type="radio"/> death (other than suicide, any cause) 4	evtcode
Event term:	<input type="text"/>	evtterm

Details of Reportable Event		
Onset date:	<input type="text" value="mon/dd/yyyy"/>	evtstdtc
Date estimated:	<input type="radio"/> yes 1 <input type="radio"/> no 0	stdtcest
Describe briefly circumstances and nature of event:	<input type="text"/>	evt
List any relevant tests, laboratory data, history:	<input type="text"/>	evttst
Is the report:	<input type="radio"/> initial 1 <input type="radio"/> follow-up 2 <input type="radio"/> final 3	evtpatt

Resolution of Event		
Resolved:	<input type="radio"/> yes 1 <input type="radio"/> no 0	evtongo
End date:	<input type="text" value="mon/dd/yyyy"/>	evtendtc

Interventions		
Medication:	<input type="radio"/> yes 1 <input type="radio"/> no 0	evtcm
Describe:	<input type="text"/>	evtcmssc
Behavioral/Lifestyle:	<input type="radio"/> yes 1 <input type="radio"/> no 0	evtbls
Describe:	<input type="text"/>	evtblssc
Other:	<input type="radio"/> yes 1 <input type="radio"/> no 0	evtoth
Describe:	<input type="text"/>	evtothssc

DSMC Review		
Status of DSMC review:	<input type="radio"/> pending review 1 <input type="radio"/> ongoing review 2 <input type="radio"/> closed/completed review 3	evtdsmc



### 3.20 Premature End of Study (End)

General		
Assessment date:	<input type="text"/>	dsdtc

End of Study		
Specify primary reason for participant's premature discontinuation from study:	<input type="radio"/> event or intercurrent illness of a nature requiring withdrawal <sup>1</sup> <input type="radio"/> request of primary care physician, site investigator <sup>2</sup> <input type="radio"/> participant's request (includes carer/spouse/authorized representative's request) <sup>3</sup> <input type="radio"/> lost to follow up <sup>4</sup> <input type="radio"/> institutionalized (will not be followed further) <sup>5</sup> <input type="radio"/> unable to obtain research CAG determination <sup>8</sup> <input type="radio"/> other <sup>6</sup>	dsterm
Please specify the reason for the participant's request:	<input type="radio"/> unable to travel <sup>1</sup> <input type="radio"/> participant unwilling to continue <sup>2</sup> <input type="radio"/> participant moved away from the study site <sup>3</sup>	dsreas
Please specify:	<input type="text"/>	termoth
Have the participant's samples held at site been destroyed?	<input type="radio"/> yes <sup>1</sup> <input type="radio"/> no <sup>0</sup>	dssd

### 3.21 Family History (FHx)

Participant Data [fhx1]		
Gender:	<input type="radio"/> f = female [f] <input type="radio"/> m = male [m]	sex
Year of birth:	<input type="text" value="yyyy"/>	brthy
Vital status:	<input type="radio"/> 1 = alive [1] <input type="radio"/> 2 = dead [2] <input type="radio"/> 9999 = unknown [9999]	vstat
HD status:	<input type="radio"/> 1 = manifest carrier [1] <input type="radio"/> 2 = pre-manifest carrier, genetically confirmed [2] <input type="radio"/> 3 = not a carrier, genetic test done [3] <input type="radio"/> 9999 = unknown, no genetic test done [9999]	hdstat
Availability of DNA samples:	<input type="radio"/> 1 = yes [1] <input type="radio"/> 0 = no [0]	dna
Participant in Enroll-HD:	<input type="radio"/> 1 = yes [1] <input type="radio"/> 2 = no [2] <input type="radio"/> 9999 = unknown [9999]	registry

### 3.22 Bio Specimens for Bio Banking (Samples)

Enroll-HD Biosamples Collection		
LAB-ID:	<input type="text"/>	labid
Collection of whole blood required:	<input type="text" value="yes 1"/> <input type="text" value="no 0"/>	wb
Whole Blood Tubes		
Date and time of collection:	<input type="text" value="mm/dd/yyyy"/> times <input type="text" value="hh:mm"/>	tsdtc
Bar code:	<input type="text"/>	barcode
State:	<input type="text" value="state"/> arrived 1 test 2 damaged 3 at site 4 shipped 5 deleted 6 destroyed 7	state
Room Temperature Shipment		
Courier:	<input type="text" value="DHL 1"/> FedEx 2 World Courier US Marten 10	courier
Airway bill no:	<input type="text"/>	airwayn
Date of shipment:	<input type="text" value="mm/dd/yyyy"/>	shpdtc
Date of notification:	<input type="text"/>	ntfydtc
Date of receipt:	<input type="text"/>	rcvdtc
Total shipping time:	<input type="text"/>	shptime
Resubmit notification to BioRep:	<input type="checkbox"/>	resubmit

Laboratory Results/Evaluation of Specimen/Biobank									
Type:	Sample:	Source:	Qty:	Process state:	Outcome:	Date Completed:			
1. <input type="text" value="----"/> <input type="button" value="v"/>	<input type="text" value="type"/>	<input type="text" value="id"/>	<input type="text" value="sourceid"/>	<input type="text" value="qty"/>	<input type="text" value="----"/> <input type="button" value="v"/>	<input type="text" value="substate"/>	<input type="text" value="----"/> <input type="button" value="v"/>	<input type="text" value="outcome"/>	<input type="text" value="complitdc"/>
Whole Blood 1					package lost 0		pass 1		
DNA 2					culture prep. 1		failed 2		
Cell Line 3					culture prep. (r) 2				
PBMCs 4					duplicated 3				
SQC 5					split (buffy c.) 4				
					split (culture) 5				
					test only 9				
					buffy coat prep. 10				
					submitted 11				
					stored safely 12				
					archived 13				
					RNA prep. 14				
					buffy coat (r) 15				
					biopsy freeze 16				
					frozen (culture) 17				
					frozen (culture, r) 18				
					requires quality c. 19				
					test only (frozen) 20				
					damaged 21				
					self-processed 22				
					virtual culture 23				
					DNA prep. 24				
					work order init. 25				
					plasma prep. 26				
					plasma prep. (r) 27				
					stored safely (r) 28				
					virus stock s. 29				
					frozen stored safely 30				
					split (dna) 31				
					redraw problems 49				
					split (buffy c., r) 50				
					split (culture, r) 51				
					derived 100				

### 3.23 Hospital Anxiety and Depression Scale - Snaith Irritability Scale (HADS-SIS)

General		
Assessment date:	<input type="text" value="mon/dd/yyyy"/>	qsdtc
Language of paper form (PBF):	<input type="text" value="----"/> <ul style="list-style-type: none"> <li>U.S. English 1</li> <li>Brazilian Portuguese 3</li> <li>Spanish (LA North) 4</li> <li>Spanish (LA South) 5</li> <li>Canadian French 6</li> <li>French 7</li> <li>Czech 8</li> <li>Danish 9</li> <li>German 10</li> <li>Spanish 11</li> <li>Italian 12</li> <li>Dutch 13</li> <li>Norwegian 14</li> <li>Polish 15</li> <li>Portuguese 16</li> <li>Russian 17</li> <li>Finnish 18</li> <li>Swedish 19</li> </ul>	langpbf
Anxiety subscore:	<input type="text"/>	anxscore
Depression subscore:	<input type="text"/>	depscore
Irritability subscore:	<input type="text"/>	irrscore
Outward irritability subscore:	<input type="text"/>	outscore
Inward irritability subscore:	<input type="text"/>	inwscore

HADS - SIS 		
1. I feel tense or 'wound up':	<input type="radio"/> most of the time 3 <input type="radio"/> a lot of the time 2 <input type="radio"/> from time to time, occasionally 1 <input type="radio"/> not at all 0	hads1a
2. I still enjoy the things I used to enjoy:	<input type="radio"/> definitely as much 0 <input type="radio"/> not quite so much 1 <input type="radio"/> only a little 2 <input type="radio"/> hardly at all 3	hads1d
3. I get a sort of frightened feeling as if something awful is about to happen:	<input type="radio"/> very definitely and quite badly 3 <input type="radio"/> yes, but not too badly 2 <input type="radio"/> a little, but it doesn't worry me 1 <input type="radio"/> not at all 0	hads2a
4. I lose my temper and shout or snap at others:	<input type="radio"/> yes, definitely 3 <input type="radio"/> yes, sometimes 2 <input type="radio"/> no, not much 1 <input type="radio"/> no, not at all 0	sis1
5. I can laugh and see the funny side of things:	<input type="radio"/> as much as I always could 0 <input type="radio"/> not quite so much now 1 <input type="radio"/> definitely not so much now 2 <input type="radio"/> not at all 3	hads2d
6. I am patient with other people:	<input type="radio"/> all of the time 0 <input type="radio"/> most of the time 1 <input type="radio"/> some of the time 2 <input type="radio"/> hardly ever 3	sis2
7. I feel cheerful:	<input type="radio"/> never 3 <input type="radio"/> not often 2 <input type="radio"/> sometimes 1 <input type="radio"/> most of the time 0	hads3d

8. I get angry with myself and call myself names:	<input type="radio"/> yes, definitely 3 <input type="radio"/> sometimes 2 <input type="radio"/> not often 1 <input type="radio"/> no, not at all 0	sis3
9. I can sit at ease and feel relaxed:	<input type="radio"/> definitely 0 <input type="radio"/> usually 1 <input type="radio"/> not often 2 <input type="radio"/> not at all 3	hads3a
10. I feel as if I am slowed down:	<input type="radio"/> nearly all the time 3 <input type="radio"/> very often 2 <input type="radio"/> sometimes 1 <input type="radio"/> not at all 0	hads4d
11. I feel like harming myself:	<input type="radio"/> yes, definitely 3 <input type="radio"/> yes, sometimes 2 <input type="radio"/> no, not much 1 <input type="radio"/> no, not at all 0	sis4
12. Worrying thoughts go through my mind:	<input type="radio"/> a great deal of the time 3 <input type="radio"/> a lot of the time 2 <input type="radio"/> not too often 1 <input type="radio"/> very little 0	hads4a
13. I have lost interest in my appearance:	<input type="radio"/> definitely 3 <input type="radio"/> I don't take as much care as I should 2 <input type="radio"/> I may not take quite as much care 1 <input type="radio"/> I take just as much care as ever 0	hads5d
14. The thought of hurting myself occurs to me:	<input type="radio"/> sometimes 3 <input type="radio"/> not very often 2 <input type="radio"/> hardly ever 1 <input type="radio"/> not at all 0	sis5
15. I feel restless as if I have to be on the move:	<input type="radio"/> very much indeed 3 <input type="radio"/> quite a lot 2 <input type="radio"/> not very much 1 <input type="radio"/> not at all 0	hads5a
16. I look forward with enjoyment to things:	<input type="radio"/> as much as I ever did 0 <input type="radio"/> rather less than I used to 1 <input type="radio"/> definitely less than I used to 2 <input type="radio"/> hardly at all 3	hads6d
17. I feel I might lose control and hit or hurt someone:	<input type="radio"/> sometimes 3 <input type="radio"/> occasionally 2 <input type="radio"/> rarely 1 <input type="radio"/> never 0	sis6
18. I get a sort of frightened feeling like 'butterflies' in the stomach:	<input type="radio"/> not at all 0 <input type="radio"/> occasionally 1 <input type="radio"/> quite often 2 <input type="radio"/> very often 3	hads6a
19. People upset me so that I feel like slamming doors or banging about:	<input type="radio"/> yes, often 3 <input type="radio"/> yes, sometimes 2 <input type="radio"/> only occasionally 1 <input type="radio"/> not at all 0	sis7
20. I get sudden feelings of panic:	<input type="radio"/> very often indeed 3 <input type="radio"/> quite often 2 <input type="radio"/> not very often 1 <input type="radio"/> not at all 0	hads7a
21. I can enjoy a good book or radio or television programme:	<input type="radio"/> often 0 <input type="radio"/> sometimes 1 <input type="radio"/> not often 2 <input type="radio"/> very seldom 3	hads7d
22. Lately I have been getting annoyed with myself:	<input type="radio"/> very much so 3 <input type="radio"/> rather a lot 2 <input type="radio"/> not much 1 <input type="radio"/> not at all 0	sis8


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Snaith Irritability Scale is public domain. Original Reference : Snaith, R.P. (1978). A clinical scale for the self-assessment of irritability. British Journal of Psychiatry, 132, 164-171.

### 3.24 Columbia-Suicide Severity Rating Scale (C-SSRS) – Baseline

General			
Assessment date:	<input type="text" value="mon/dd/yyyy"/>		qsdtc
Rater code:	<input type="text"/>		raterid

Suicidal Ideation - For Lifetime, rate the period when the participant felt the most suicidal. 			
<b>1. Wish to be dead:</b>			
Have you wished you were dead or wished you could go to sleep and not wake up?	<input type="radio"/> yes 1 <input type="radio"/> no 0		sid1
Please describe:	<input type="text"/>		sid1sc
<b>2. Non-Specific Active Suicidal Thoughts:</b>			
Have you actually had any thoughts of killing yourself?	<input type="radio"/> yes 1 <input type="radio"/> no 0		sid2
Please describe:	<input type="text"/>		sid2sc

Suicidal Ideation (continued)			
<b>3. Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act:</b>	Have you been thinking about how you might do this?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sid3
	Please describe:	<input type="text"/>	sid3sc
<b>4. Active Suicidal Ideation with Some Intent to Act, without Specific Plan:</b>	Have you had these thoughts and had some intention of acting on them?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sid4
	Please describe:	<input type="text"/>	sid4sc
<b>5. Active Suicidal Ideation with Specific Plan and Intent:</b>	Have you started to work out or worked out the details of how to kill yourself? Do you intend to carry out this plan?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sid5
	Please describe:	<input type="text"/>	sid5sc

Intensity of Ideation - Most Severe			
Most Severe Ideation:	Type # (I-5):	<div>----</div> <div> Wish to be dead 1  Non-Specific Active Suicidal Thoughts 2  Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act 3  Active Suicidal Ideation with Some Intent to Act, without Specific Plan 4  Active Suicidal Ideation with Specific Plan and Intent 5 </div>	int1
	Description of Ideation:	<div></div>	int1sc
Frequency:	How many times have you had these thoughts?	<input type="radio"/> Less than once a week 1 <input type="radio"/> Once a week 2 <input type="radio"/> 2-5 times in week 3 <input type="radio"/> Daily or almost daily 4 <input type="radio"/> Many times each day 5	int2
Duration:	When you have the thoughts, how long do they last?	<input type="radio"/> Fleeting - few seconds or minutes 1 <input type="radio"/> Less than 1 hour/some of the time 2 <input type="radio"/> 1-4 hours/a lot of time 3 <input type="radio"/> 4-8 hours/most of day 4 <input type="radio"/> More than 8 hours/persistent or continuous 5	int3
Controllability:	Could/can you stop thinking about killing yourself or wanting to die if you want to?	<input type="radio"/> Easily able to control thoughts 1 <input type="radio"/> Can control thoughts with little difficulty 2 <input type="radio"/> Can control thoughts with some difficulty 3 <input type="radio"/> Can control thoughts with a lot of difficulty 4 <input type="radio"/> Unable to control thoughts 5 <input type="radio"/> Does not attempt to control thoughts 0	int4
Deterrents:	Are there things - anyone or anything (e.g. family, religion, pain of death) - that stopped you from wanting to die or acting on thoughts of committing suicide?	<input type="radio"/> Deterrents definitely stopped you 1 <input type="radio"/> Deterrents probably stopped you 2 <input type="radio"/> Uncertain that deterrents stopped you 3 <input type="radio"/> Deterrents most likely did not stop you from attempting suicide 4 <input type="radio"/> Deterrents definitely did not stop you 5 <input type="radio"/> Does not apply; wish to die only 0	int5
Reasons for Ideation:	What sort of reasons did you have for thinking about wanting to die or killing yourself?	<input type="radio"/> Completely to get attention, revenge or a reaction from others 1 <input type="radio"/> Mostly to get attention, revenge or a reaction from others. 2 <input type="radio"/> Equally to get attention, revenge or a reaction from others 3 <input type="radio"/> Mostly to end or stop the pain (you couldn't go on living with the pain or how you were feeling). 4 <input type="radio"/> Completely to end or stop the pain (you couldn't go on living with the pain or how you were feeling). 5 <input type="radio"/> Does not apply 0	int6

Suicidal Behavior			
Actual Attempt:			
Actual attempt:	<input type="radio"/> yes 1 <input type="radio"/> no 0		sbh1
	Total # of attempts:	<div></div>	sbh1n
	Please describe:	<div></div>	sbh1sc
Has subject engaged in Non-Suicidal Self-Injurious Behavior?	<input type="radio"/> yes 1 <input type="radio"/> no 0		sbh2



Interrupted Attempt:

Has there been a time when you started to do something to end your life but someone or something stopped you before you actually did anything?

☐ yes 1 ☐ no 0

sbh3

Total # of interrupted:

sbh3n

Please describe:

sbh3sc

Aborted Attempt:

Has there been a time when you started to do something to try to end your life but you stopped yourself before you actually did anything?

☐ yes 1 ☐ no 0

sbh4

Total # of aborted:

sbh4n

Please describe:

sbh4sc

Preparatory Acts or Behavior:

Have you taken any steps towards making a suicide attempt or preparing to kill yourself (such as collecting pills, getting a gun, giving valuables away or writing a suicide note)?

☐ yes 1 ☐ no 0

sbh5

Please describe:

sbh5sc

Suicidal Behavior:

Suicidal behaviour was present during the assessment period?

☐ yes 1 ☐ no 0

sbh6


Answer for Actual Attempts Only			
Most recent attempt:	Date:	<input type="text" value="mon/dd/yyyy"/>	attmpt1
	Actual Lethality/Medical Damage:	<input type="text" value="----"/> No physical damage 0 Minor physical damage 1 Moderate physical damage 2 Moderately severe physical damage 3 Severe physical damage 4 Death 5	attmpt11
	Potential Lethality:	<input type="text" value="----"/> not likely to result in injury 0 likely to result in injury 1 likely to result in death 2	attmpt12
Most lethal attempt:	Date:	<input type="text" value="mon/dd/yyyy"/>	attmpt2
	Actual Lethality/Medical Damage:	<input type="text" value="----"/> No physical damage 0 Minor physical damage 1 Moderate physical damage 2 Moderately severe physical damage 3 Severe physical damage 4 Death 5	attmpt21
	Potential Lethality:	<input type="text" value="----"/> not likely to result in injury 0 likely to result in injury 1 likely to result in death 2	attmpt22
Initial/First attempt:	Date:	<input type="text" value="mon/dd/yyyy"/>	attmpt3
	Actual Lethality/Medical Damage:	<input type="text" value="----"/> No physical damage 0 Minor physical damage 1 Moderate physical damage 2 Moderately severe physical damage 3 Severe physical damage 4 Death 5	attmpt31
	Potential Lethality:	<input type="text" value="----"/> not likely to result in injury 0 likely to result in injury 1 likely to result in death 2	attmpt32

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### 3.25 Columbia-Suicide Severity Rating Scale (C-SSRS) – Follow Up

General			
Assessment date:	<input type="text" value="mon/dd/yyyy"/>		qsdtc
Rater code:	<input type="text"/>		raterid

Suicidal Ideation - Rate the period since last visit. 			
<b>1. Wish to be dead:</b>			
Have you wished you were dead or wished you could go to sleep and not wake up?	<input type="radio"/> yes 1 <input type="radio"/> no 0		sid1
Please describe:	<input type="text"/>		sid1sc
<b>2. Non-Specific Active Suicidal Thoughts:</b>			
Have you actually had any thoughts of killing yourself?	<input type="radio"/> yes 1 <input type="radio"/> no 0		sid2
Please describe:	<input type="text"/>		sid2sc

Suicidal Ideation (continued)			
<b>3. Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act:</b>	Have you been thinking about how you might do this?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sid3
	Please describe:	<input type="text"/>	sid3sc
<b>4. Active Suicidal Ideation with Some Intent to Act, without Specific Plan:</b>	Have you had these thoughts and had some intention of acting on them?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sid4
	Please describe:	<input type="text"/>	sid4sc
<b>5. Active Suicidal Ideation with Specific Plan and Intent:</b>	Have you started to work out or worked out the details of how to kill yourself? Do you intend to carry out this plan?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sid5
	Please describe:	<input type="text"/>	sid5sc

Intensity of Ideation - Most Severe			
Most Severe Ideation:	Type # (1-5):	<input type="text" value="----"/>	int1
	Wish to be dead 1 Non-Specific Active Suicidal Thoughts 2 Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act 3 Active Suicidal Ideation with Some Intent to Act, without Specific Plan 4 Active Suicidal Ideation with Specific Plan and Intent 5		
Description of Ideation:	<input type="text"/>		int1sc

Frequency:	How many times have you had these thoughts?	<input type="radio"/> Less than once a week 1 <input type="radio"/> Once a week 2 <input type="radio"/> 2-5 times in week 3 <input type="radio"/> Daily or almost daily 4 <input type="radio"/> Many times each day 5	int2
Duration:	When you have the thoughts, how long do they last?	<input type="radio"/> Fleeting - few seconds or minutes 1 <input type="radio"/> Less than 1 hour/some of the time 2 <input type="radio"/> 1-4 hours/a lot of time 3 <input type="radio"/> 4-8 hours/most of day 4 <input type="radio"/> More than 8 hours/persistent or continuous 5	int3
Controllability:	Could/can you stop thinking about killing yourself or wanting to die if you want to?	<input type="radio"/> Easily able to control thoughts 1 <input type="radio"/> Can control thoughts with little difficulty 2 <input type="radio"/> Can control thoughts with some difficulty 3 <input type="radio"/> Can control thoughts with a lot of difficulty 4 <input type="radio"/> Unable to control thoughts 5 <input type="radio"/> Does not attempt to control thoughts 0	int4
Deterrents:	Are there things - anyone or anything (e.g. family, religion, pain of death) - that stopped you from wanting to die or acting on thoughts of committing suicide?	<input type="radio"/> Deterrents definitely stopped you 1 <input type="radio"/> Deterrents probably stopped you 2 <input type="radio"/> Uncertain that deterrents stopped you 3 <input type="radio"/> Deterrents most likely did not stop you from attempting suicide 4 <input type="radio"/> Deterrents definitely did not stop you 5 <input type="radio"/> Does not apply; wish to die only 0	int5
Reasons for Ideation:	What sort of reasons did you have for thinking about wanting to die or killing yourself?	<input type="radio"/> Completely to get attention, revenge or a reaction from others 1 <input type="radio"/> Mostly to get attention, revenge or a reaction from others. 2 <input type="radio"/> Equally to get attention, revenge or a reaction from others 3 <input type="radio"/> Mostly to end or stop the pain (you couldn't go on living with the pain or how you were feeling). 4 <input type="radio"/> Completely to end or stop the pain (you couldn't go on living with the pain or how you were feeling). 5 <input type="radio"/> Does not apply 0	int6

Suicidal Behavior			
<u>Actual Attempt:</u>			
Actual attempt:	<input type="radio"/> yes 1 <input type="radio"/> no 0		sbh1
Total # of attempts:	<input type="text"/>		sbh1n
Please describe:	<input type="text"/>		sbh1sc
Has subject engaged in Non-Suicidal Self-Injurious Behavior?	<input type="radio"/> yes 1 <input type="radio"/> no 0		sbh2
<u>Interrupted Attempt:</u>			
Has there been a time when you started to do something to end your life but someone or something stopped you before you actually did anything?	<input type="radio"/> yes 1 <input type="radio"/> no 0		sbh3
Total # of interrupted:	<input type="text"/>		sbh3n
Please describe:	<input type="text"/>		sbh3sc

Aborted Attempt:

Has there been a time when you started to do something to try to end your life but you stopped yourself before you actually did anything?

☐ yes 1 ☐ no 0

sbh4

Total # of aborted:

sbh4n

Please describe:

sbh4sc

Preparatory Acts or Behavior:

Have you taken any steps towards making a suicide attempt or preparing to kill yourself (such as collecting pills, getting a gun, giving valuables away or writing a suicide note)?

☐ yes 1 ☐ no 0

sbh5

Please describe:

sbh5sc

Suicidal Behavior:

Suicidal behaviour was present during the assessment period?

☐ yes 1 ☐ no 0

sbh6

Completed Suicide:

Completed suicide was present during the assessment period:

☐ yes 1 ☐ no 0

sbh7

**Answer for Actual Attempts Only**

Most lethal attempt:

Date:

attmpt2

Actual

Lethality/Medical  
Damage:

attmpt21

No physical damage 0  
Minor physical damage 1  
Moderate physical damage 2  
Moderately severe physical damage 3  
Severe physical damage 4  
Death 5


Potential  
Lethality:

attmpt22

not likely to result in injury 0  
likely to result in injury 1  
likely to result in death 2

### 3.26 Mini Mental State Examination (MMSE)



General	
Assessment date:	<input type="text" value="mon/dd/yyyy"/> <span>qsdtc</span>
Language of paper form (PBF):	<div> <div>----</div> <div> U.S. English 1  Spanish (LA) 2  Brazilian Portuguese 3  Canadian French 6  French 7  Czech 8  Danish 9  German 10  Spanish 11  Italian 12  Dutch 13  Norwegian 14  Polish 15  Portuguese 16  Russian 17  Finnish 18  Swedish 19 </div> </div> <span>langpbf</span>
Rater code:	<input type="text"/> <span>raterid</span>
MMSE score:	<input type="text"/> <span>mmsetotal</span>

Mini-Mental State Exam 			
<b>Orientation to time - What is the ...</b>			
	incorrect	correct	
Year?	<input type="radio"/>	<input type="radio"/> mmse011	
Season?	<input type="radio"/>	<input type="radio"/> mmse012	
Month of the year?	<input type="radio"/>	<input type="radio"/> mmse013	
Day of the week?	<input type="radio"/>	<input type="radio"/> mmse014	
Date?	<input type="radio"/>	<input type="radio"/> mmse015	
<b>Orientation to place - Where are you now? What is the ...</b>			
	incorrect	correct	
State (province)?	<input type="radio"/>	<input type="radio"/> mmse021	
County (or city/town)?	<input type="radio"/>	<input type="radio"/> mmse022	
City/town (or part of city/neighborhood)?	<input type="radio"/>	<input type="radio"/> mmse023	
Building (name or type)?	<input type="radio"/>	<input type="radio"/> mmse024	
Floor of the building (room number or address)?	<input type="radio"/>	<input type="radio"/> mmse025	
<b>Registration:</b>			
	incorrect	correct	
Word 1:	<input type="radio"/>	<input type="radio"/> mmse031	
Word 2:	<input type="radio"/>	<input type="radio"/> mmse032	
Word 3:	<input type="radio"/>	<input type="radio"/> mmse033	
<b>Attention and calculation (Serial 7s):</b>			
	incorrect	correct	
[Step 1]:	<input type="radio"/>	<input type="radio"/> mmse041	
[Step 2]:	<input type="radio"/>	<input type="radio"/> mmse042	
[Step 3]:	<input type="radio"/>	<input type="radio"/> mmse043	
[Step 4]:	<input type="radio"/>	<input type="radio"/> mmse044	
[Step 5]:	<input type="radio"/>	<input type="radio"/> mmse045	

<b>Recall:</b>		incorrect	correct
Word 1:	<input type="radio"/>	<input type="radio"/>	mmse051
Word 2:	<input type="radio"/>	<input type="radio"/>	mmse052
Word 3:	<input type="radio"/>	<input type="radio"/>	mmse053
<b>Naming - What is this?</b>		incorrect	correct
1 [Pencil or pen]:	<input type="radio"/>	<input type="radio"/>	mmse061
2 [Watch]:	<input type="radio"/>	<input type="radio"/>	mmse062
<b>Repetition:</b>		incorrect	correct
No ifs, ands or buts:	<input type="radio"/>	<input type="radio"/>	mmse07
<b>Comprehension:</b>		incorrect	correct
Take in right hand:	<input type="radio"/>	<input type="radio"/>	mmse081
Fold in half:	<input type="radio"/>	<input type="radio"/>	mmse082
Put on floor (or table):	<input type="radio"/>	<input type="radio"/>	mmse083
<b>Reading:</b>		incorrect	correct
Close your eyes:	<input type="radio"/>	<input type="radio"/>	mmse09
<b>Writing:</b>		incorrect	correct
Sentence:	<input type="radio"/>	<input type="radio"/>	mmse10
<b>Drawing:</b>		incorrect	correct
Figure:	<input type="radio"/>	<input type="radio"/>	mmse11

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### 3.27 Physiotherapy Outcome Measures (Physio)

General	
Assessment date:	<input type="text" value="mon/dd/yyyy"/> <span>qsdtc</span>
Timed Up and Go Test	
Timed "Up and Go" performed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0 <span>tug</span>
Total time:	<input type="text"/> sec <span>tug1</span>
30 Second Chair Stand Test	
30 second chair stand test performed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0 <span>scst</span>
Number of times the participant stands in 30 seconds:	<input type="text"/> <span>scst1</span>

Timed "Up & Go": Podsiadlo D, Richardson S. The Timed "Up & Go": a test of basic functional mobility for frail elderly persons, J Am Geriatr Soc. 1991; 39(2):142-8.

In HD: Busse ME, Wiles CM, Rosser AE. Mobility and falls in people with Huntington's disease. J Neurol Neurosurg Psychiatry. 2009; 80(1): 88-90.  
 30 Second Chair Test: McCarthy EK, Horvat MA, Holtsberg PA, Wisenbaker JM. Repeated chair stands as a measure of lower limb strength in sexagenarian women, J Gerontol A Biol Sci Med Sci. 2004; 59(11): 1207-12

In HD: Khalil H, van Deursen R, Quinn L, et al. F18 Clinical measurement of sit to stand performance in people with Huntington's disease: reliability and validity for 30 seconds chair sit to stand test, J Neurol Neurosurg Psychiatry 2010;81(Suppl 1):A28-A28



### 3.28 Short Form Health Survey – 12v2 (SF12)

General	
Assessment date:	<input type="text" value="mon/dd/yyyy"/> <span>qsdtc</span>
Language of paper form (PBF):	<input type="text" value="----"/> <span>langpbf</span> U.S. English 1 Brazilian Portuguese 3 Spanish (LA North) 4 Spanish (LA South) 5 Canadian French 6 French 7 Czech 8 Danish 9 German 10 Spanish 11 Italian 12 Dutch 13 Norwegian 14 Polish 15 Portuguese 16 Russian 17 Finnish 18 Swedish 19

Scoring	
Online scoring:	<input type="text" value="pending 0"/> <span>scoring</span> pending 0 succeeded 1 failed 2 failed (2) 3 error 4
Physical Functioning (PF):    Role-Physical (RP):    Bodily Pain (BP):    General Health (GH):	
Domain scores:	<input type="text"/> pf <input type="text"/> rp <input type="text"/> bp <input type="text"/> gh
Vitality (VT):    Social Functioning (SF):    Role-Emotional (RE):    Mental Health (MH):	
Domain scores:	<input type="text"/> vt <input type="text"/> sf <input type="text"/> re <input type="text"/> mh
Physical Component (PCS):    Mental Component (PCS):	
Summary scales:	<input type="text"/> pcs <input type="text"/> mcs

SF12 Health Survey 			
1. In general, would you say your health is:	<input type="radio"/> Excellent 1 <input type="radio"/> Very good 2 <input type="radio"/> Good 3 <input type="radio"/> Fair 4 <input type="radio"/> Poor 5		sf12_1
2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?	a) Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf:	<input type="radio"/> Yes, limited a lot 1 <input type="radio"/> Yes, limited a little 2 <input type="radio"/> No, not limited at all 3	sf12_2
	b) Climbing several flights of stairs:	<input type="radio"/> Yes, limited a lot 1 <input type="radio"/> Yes, limited a little 2 <input type="radio"/> No, not limited at all 3	sf12_3
3. During the past week, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?	a) Accomplished less than you would like:	<input type="radio"/> All of the time 1 <input type="radio"/> Most of the time 2 <input type="radio"/> Some of the time 3 <input type="radio"/> A little of the time 4 <input type="radio"/> None of the time 5	sf12_4
	b) Were limited in the kind of work or other activities:	<input type="radio"/> All of the time 1 <input type="radio"/> Most of the time 2 <input type="radio"/> Some of the time 3 <input type="radio"/> A little of the time 4 <input type="radio"/> None of the time 5	sf12_5
4. During the past week, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?	a) Accomplished less than you would like:	<input type="radio"/> All of the time 1 <input type="radio"/> Most of the time 2 <input type="radio"/> Some of the time 3 <input type="radio"/> A little of the time 4 <input type="radio"/> None of the time 5	sf12_6
	b) Did work or other activities less carefully than usual:	<input type="radio"/> All of the time 1 <input type="radio"/> Most of the time 2 <input type="radio"/> Some of the time 3 <input type="radio"/> A little of the time 4 <input type="radio"/> None of the time 5	sf12_7

5. During the past week, how much did pain interfere with your normal work (including both work outside the home and housework)?	<input type="radio"/> Not at all 1 <input type="radio"/> A little bit 2 <input type="radio"/> Moderately 3 <input type="radio"/> Quite a bit 4 <input type="radio"/> Extremely 5		sf12_8
6. These questions are about how you feel and how things have been with you during the past week. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past week...:			
a) Have you felt calm and peaceful?	<input type="radio"/> All of the time 1 <input type="radio"/> Most of the time 2 <input type="radio"/> Some of the time 3 <input type="radio"/> A little of the time 4 <input type="radio"/> None of the time 5		sf12_9
b) Did you have a lot of energy?	<input type="radio"/> All of the time 1 <input type="radio"/> Most of the time 2 <input type="radio"/> Some of the time 3 <input type="radio"/> A little of the time 4 <input type="radio"/> None of the time 5		sf12_10
c) Have you felt downhearted and depressed?	<input type="radio"/> All of the time 1 <input type="radio"/> Most of the time 2 <input type="radio"/> Some of the time 3 <input type="radio"/> A little of the time 4 <input type="radio"/> None of the time 5		sf12_11
7. During the past week, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?	<input type="radio"/> All of the time 1 <input type="radio"/> Most of the time 2 <input type="radio"/> Some of the time 3 <input type="radio"/> A little of the time 4 <input type="radio"/> None of the time 5		sf12_12

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 (SF-12v2® Health Survey Standard, United States (English))

### 3.29 Caregivers Quality of Life Questionnaire (CareQoL)

General	
Assessment date:	<input type="text" value="mm/dd/yyyy"/>
Language of paper form (PBF):	<input type="text" value="---"/> U.S. English 1 Spanish (LA) 2 Brazilian Portuguese 3 Canadian French 6 French 7 Czech 8 Danish 9 German 10 Spanish 11 Italian 12 Dutch 13 Norwegian 14 Polish 15 Portuguese 16 Russian 17 Finnish 18 Swedish 19
Information About Yourself	
ID of caregiver:	<input type="text"/>
Does the caregiver have a unique HD identifier (HDID)?	<input type="radio"/> yes 1 <input type="radio"/> no 0
Caregiver's HDID:	<input type="text"/>
1. What is your year of birth?	<input type="text" value="yyyy"/>
2. What is your gender?	<input type="radio"/> female f <input type="radio"/> male m
3. Country of residence:	<input type="text" value="---"/> Andorra AD United Arab Emirates AE Afghanistan AF Antigua and Barbuda AG Anguilla AI Albania AL Armenia AM Angola AO Argentina AR American Samoa AS Austria AT Australia AU Aruba AW Åland Islands AX Azerbaijan AZ Bosnia and Herzegovina BA Barbados BB Bangladesh BD Belgium BE Burkina Faso BF Bulgaria BG Bahrain BH Burundi BI Benin BJ Saint Barthélemy BL Bermuda BM Brunei Darussalam BN Bolivia, Plurinational State Of BO Bonaire, Sint Eustakus and Saba BQ Brazil BR Bahamas BS Bhutan BT Bouvet Island BV Botswana BW Belarus BY Belize BZ Canada CA Cocos (Keeling) Islands CC Congo, The Democratic Republic Of The CD Central African Republic CF Congo CG Switzerland CH Côte D'Ivoire CI Cook Islands CK Chile CL Cameroon CM China CN Colombia CO Costa Rica CR Cuba CU Cape Verde CV Curaçao CW Christmas Island CX Cyprus CY Czech Republic CZ

Germany DE  
 Djibouti DJ  
 Denmark DK  
 Dominica DM  
 Dominican Republic DO  
 Algeria DZ  
 Ecuador EC  
 Estonia EE  
 Egypt EG  
 Western Sahara EH  
 Eritrea ER  
 Spain ES  
 Ethiopia ET  
 Finland FI  
 Fiji FJ  
 Falkland Islands (Malvinas) FK  
 Micronesia, Federated States OF FM  
 Faroe Islands FO  
 France FR  
 Gabon GA  
 United Kingdom GB  
 Grenada GD  
 Georgia GE  
 French Guiana GF  
 Guernsey GG  
 Ghana GH  
 Gibraltar GI  
 Greenland GL  
 Gambia GM  
 Guinea GN  
 Guadeloupe GP  
 Equatorial Guinea GQ  
 Greece GR  
 South Georgia and the South Sandwich Islands GS  
 Guatemala GT  
 Guam GU  
 Guinea-Bissau GW  
 Guyana GY  
 Hong Kong HK  
 Heard and McDonald Islands HM  
 Honduras HN  
 Croatia HR  
 Haiti HT  
 Hungary HU  
 Indonesia ID  
 Ireland IE  
 Israel IL  
 Isle of Man IM  
 India IN  
 Iraq IQ  
 Iran, Islamic Republic Of IR  
 Iceland IS  
 Italy IT  
 Jersey JE  
 Jamaica JM  
 Jordan JO  
 Japan JP  
 Kenya KE  
 Kyrgyzstan KG  
 Cambodia KH  
 Kiribati KI  
 Comoros KM  
 Saint Kitts And Nevis KN  
 Korea, Democratic People's Republic Of KP  
 Korea, Republic of KR  
 Kuwait KW  
 Cayman Islands KY  
 Kazakhstan KZ  
 Lao People's Democratic Republic LA  
 Lebanon LB  
 Saint Lucia LC  
 Liechtenstein LI  
 Sri Lanka LK  
 Liberia LR  
 Lesotho LS  
 Lithuania LT  
 Luxembourg LV  
 Latvia LV  
 Libya LY  
 Morocco MA  
 Monaco MC  
 Moldova, Republic of MD  
 Montenegro ME  
 Saint Martin MF  
 Madagascar MG  
 Marshall Islands MH  
 Macedonia, the Former Yugoslav Republic Of MK  
 Mali ML  
 Myanmar MM  
 Mongolia MN  
 Macao MO  
 Northern Mariana Islands MP  
 Martinique MQ  
 Mauritania MR  
 Montserrat MS  
 Malta MT  
 Mauritius MU  
 Maldives MV  
 Malawi MW  
 Mexico MX

	Malaysia MY Mozambique MZ Namibia NA New Caledonia NC Niger NE Norfolk Island NF Nigeria NG Nicaragua NI Netherlands NL Norway NO Nepal NP Nauro NR Niue NU New Zealand NZ Oman OM Panama PA Peru PE French Polynesia PF Papua New Guinea PG Philippines PH Pakistan PK Poland PL Saint Pierre And Miquelon PM Pitcairn PN Puerto Rico PR Palestinian Territory, Occupied PS Portugal PT Palau PW Paraguay PY Qatar QA Réunion RE Romania RO Serbia RS Russian Federation RU Rwanda RW Saudi Arabia SA Solomon Islands SB Seychelles SC Sudan SD Sweden SE Singapore SG Saint Helena, Ascension and Tristan Da Cunha SH Slovenia SI Svalbard And Jan Mayen SJ Slovakia SK Sierra Leone SL San Marino SM Senegal SN Somalia SO Suriname SR South Sudan SS Sao Tome and Principe ST El Salvador SV Sint Maarten (Dutch part) SX Syrian Arab Republic SY Swaziland SZ Turks and Caicos Islands TC Chad TD Togo TG Thailand TH Tajikistan TJ Tokelau TK East Timor TL Turkmenistan TM Tunisia TN Tonga TO East Timor TP Turkey TR Trinidad and Tobago TT Tuvalu TV Taiwan, Province Of China TW Tanzania, United Republic of TZ Ukraine UA Uganda UG United States US Uruguay UY Uzbekistan UZ Holy See (Vatican City State) VA Saint Vincent And The Grenadines VC Venezuela, Bolivarian Republic of VE Virgin Islands, British VG Virgin Islands, U.S. VI Viet Nam VN Vanuatu VU Wallis and Futuna WF Samoa WS Yemen YE Mayotte YT South Africa ZA Zambia ZM Zimbabwe ZW	
4. How many years of formal education have you had?	<input type="text"/> years	cq0i6
5. Do you have a job:	<input type="radio"/> yes, full time 1 <input type="radio"/> yes, part time 1 <input type="radio"/> no 6	cq0i7
6. What is your marital status:	<input type="radio"/> single 1 <input type="radio"/> married 2 <input type="radio"/> partnership 2 <input type="radio"/> divorced 4 <input type="radio"/> widowed 5 <input type="radio"/> legally separated 6	cq0i8

7. How long have you known about Huntington's Disease in the family of the affected person(s)?  years cq089

8. How long have you been caring for any Huntington's Disease affected person(s)?  years cq090

9. Are you the main carer for the HD affected person(s)? ☐ yes ☐ no cq091

10. The HD affected person(s) is/are my:

☐ sibling cq0912\_1

☐ spouse/partner cq0912\_2

☐ parent cq0912\_3

☐ child cq0912\_4

☐ other cq0912\_5

Please specify:  cq0912a

11. Have you previously cared for any other person(s) with Huntington's Disease? ☐ yes ☐ no cq0913

If so, what is/was their relationship to you?

The affected person is/was my:  cq0913a

12. Do you have children who are at risk/carrier /symptomatic? ☐ yes ☐ no cq0914

13. How many persons live in your household?  cq0915

14. Do you live in the same household as the HD person(s)? ☐ yes ☐ no cq0916

## Quality of Life

	0 - dissatisfied	1	2	3	4	5	6	7	8	9	10 - satisfied	
1. How satisfied are you with your physical health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq091
2. How satisfied are you with your psychological health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq092
3. How satisfied are you with what you have achieved in life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq093
4. How satisfied are you with family relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq094
5. How satisfied are you with your relationships with your friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq095
6. How satisfied are you with feeling a part of your social environment?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq096
7. How satisfied are you with the medical treatment that your HD relative(s) receive(s)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq097
8. How satisfied are you with the way other people behave towards the HD person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq098
9. How satisfied are you with the professional support you receive?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq099

## Life aspects

	0 - never	1	2	3	4	5	6	7	8	9	10 - always	
1. I feel a sense of loss;	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq0910
2. I feel a sense of grieving;	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq0911
3. I feel happy;	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq0912
4. I feel a sense of anguish;	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq0913
5. I feel full of fear;	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cq0914



6. I feel safe:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi15
7. I feel guilty:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi16
8. I feel financially disadvantaged:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi17
9. I feel isolated:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi18
10. I feel there is hope for the future:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi19
11. I feel exhausted:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi20
12. I feel supported:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi21
13. I feel depressed:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi22
14. I feel sad:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi23
15. I feel stressed:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi24
16. I feel worried about the genetic consequences of Huntington's Disease:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi25
17. I feel that my own needs are important to others:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi26
18. I feel lonely:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi27
19. I feel that Huntington's Disease brought something positive to my life:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi28
20. I feel comforted by my beliefs (religious, philosophical or spiritual):	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi29
21. I feel that I can cope:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi30
22. I feel that Huntington's Disease has made me a stronger person:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi31
23. I feel that I have had a duty of care forced on me:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi32
24. I feel like I don't know who I am anymore:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi33
25. I feel that my role as a carer is rewarding:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi34
26. I feel restricted by a regimented daily routine:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi35
27. I feel restricted by having to provide continuous care:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi36
28. I feel resentful:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi37
29. I feel embarrassed by the behaviour of my HD relative(s):	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi38
30. I feel ashamed of the behaviour of my HD relative(s):	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi39
31. I feel frustrated by the misconceptions of others towards my HD relative(s):	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi40
32. I feel threatened:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi41
33. I feel frustrated by the discrimination of others toward my HD:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi42
34. I feel restricted by the need to maintain secrecy about Huntington's Disease in the family:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi43
35. I feel I have enough time for myself:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi44
36. I feel I get enough sleep:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi45
37. I feel I have somebody to turn to for assistance if I am overwhelmed:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi46
38. I feel satisfied with my overall quality of life:	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	cqoi47

#### Improvements

1. Is there anything else related to your caring role that you feel hasn't been covered in this questionnaire?

☐ yes ☐ no

cqoi17

Could you please describe what it is?

cqoi17a

2. As a carer of someone with HD, is there anything that affects you most?

☐ yes ☐ no

cqoi18

positive:

cqoi18a

negative:


cqoi18b



3. Can you think of anything that would most improve your quality of life as a carer?		<input type="radio"/> yes <input type="radio"/> no	cqol19
Could you please describe what it is?	<input type="text"/>		cqol19a
4. Have you taken any action to achieve this?		<input type="radio"/> yes <input type="radio"/> no	cqol20
What action have you taken?	<input type="text"/>		cqol20a

The European Huntington's disease Quality of Life Working Group carer questionnaire (2006). Aubeeluck & The European Huntington's disease Quality of Life Working Group, modified from Aubeeluck (2005). © Aubeeluck & Buchanan 2005. For enquiries, please contact [permissions@euro-hd.net](mailto:permissions@euro-hd.net)

### 3.30 Client Service Receipt Inventory (CSRI)

General 		
Assessment date:	<input type="text" value="mon/dd/yyyy"/>	qsdtc
<b>Hospital and Residential Services in the last 6 months</b>		
Neurology outpatient visit:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri1
Use in the last 6 months because of your HD:	<input type="text"/> visits	csri1a
Use in the last 6 months for other reasons:	<input type="text"/> visits	csri1b
Other hospital outpatient visit:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri2
Use in the last 6 months because of your HD:	<input type="text"/> visits	csri2a
Use in the last 6 months for other reasons:	<input type="text"/> visits	csri2b
Ambulatory or same day surgery:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri3
Use in the last 6 months because of your HD:	<input type="text"/> visits	csri3a
Use in the last 6 months for other reasons:	<input type="text"/> visits	csri3b
Nursing or residential home:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri4
Use in the last 6 months because of your HD:	<input type="text"/> days	csri4a
Use in the last 6 months for other reasons:	<input type="text"/> days	csri4b
Inpatient hospital stay:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri5
Use in the last 6 months because of your HD:	<input type="text"/> days	csri5a
Use in the last 6 months for other reasons:	<input type="text"/> days	csri5b

Inpatient hospital stay - intensive care unit (ICU):	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri6
Use in the last 6 months because of your HD:	<input type="text"/> days	csri6a
Use in the last 6 months for other reasons:	<input type="text"/> days	csri6b
Hospital emergency room visits:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri61
Use in the last 6 months because of your HD:	<input type="text"/> days	csri61a
Use in the last 6 months for other reasons:	<input type="text"/> days	csri61b
Other inpatient hospital stay:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri7
Use in the last 6 months because of your HD:	<input type="text"/> days	csri7a
Use in the last 6 months for other reasons:	<input type="text"/> days	csri7b

#### Primary and Community Care Services in the last 6 months

General practitioner (GP) or internist/family doctor:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri8
Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri8a
Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri8b
Physical Therapist (PT):	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri9
Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri9a
Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri9b
Psychiatrist:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri10
Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri10a
Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri10b

Psychologist/psychotherapist:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri11
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri11a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri11b
Counsellor:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri12
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri12a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri12b
Family therapist/marriage guidance:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri13
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri13a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri13b
Dietician/nutritionist:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri14
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri14a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri14b
Clinical geneticist:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri15
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri15a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri15b
Social worker:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri16
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri16a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri16b

Social worker:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri16
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri16a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri16b
Practice nurse (nurse practitioner or physician assistant):	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri17
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri17a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri17b
Home healthcare nurse:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri18
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri18a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri18b
Speech therapist:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri19
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri19a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri19b
Home help/home care worker:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri20
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri20a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri20b
Acupuncturist:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri21
	Use in the last 6 months because of your HD:	<input type="text"/> contacts	csri21a
	Use in the last 6 months for other reasons:	<input type="text"/> contacts	csri21b

Homeopath:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri22
	Use in the last 6 months because of your HD: <input type="text"/> contacts	csri22a
	Use in the last 6 months for other reasons: <input type="text"/> contacts	csri22b
Herbalist:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri23
	Use in the last 6 months because of your HD: <input type="text"/> contacts	csri23a
	Use in the last 6 months for other reasons: <input type="text"/> contacts	csri23b
Aromatherapy:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri24
	Use in the last 6 months because of your HD: <input type="text"/> contacts	csri24a
	Use in the last 6 months for other reasons: <input type="text"/> contacts	csri24b
Reflexologist:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri25
	Use in the last 6 months because of your HD: <input type="text"/> contacts	csri25a
	Use in the last 6 months for other reasons: <input type="text"/> contacts	csri25b
Other service:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri26

#### Investigations / Diagnostic Tests in the last 6 months

Genetic test:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri27
	No. in the last 6 months: <input type="text"/>	csri27a
	Why did you have this test/investigation? <input type="text"/>	csri27sc
Magnetic Resonance Image (MRI):	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri28
	No. in the last 6 months: <input type="text"/>	csri28a
	Why did you have this test/investigation? <input type="text"/>	csri28sc

CT/CAT scan:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri29
No. in the last 6 months:	<input type="text"/>	csri29a
Why did you have this test/investigation?	<input type="text"/>	csri29sc
Electroencephalogram (EEG):	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri30
No. in the last 6 months:	<input type="text"/>	csri30a
Why did you have this test/investigation?	<input type="text"/>	csri30sc
Blood test:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri31
No. in the last 6 months:	<input type="text"/>	csri31a
Why did you have this test/investigation?	<input type="text"/>	csri31sc

<b>Informal Care</b>		
Personal care (e.g. bathing, dressing):	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri32
Average no. of hours per week:	<input type="text"/> hours	csri32a
Any other information?	<input type="text"/>	csri32sc
Help inside the home (e.g. cooking, cleaning):	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri33
Average no. of hours per week:	<input type="text"/> hours	csri33a
Any other information?	<input type="text"/>	csri33sc
Help outside the home (e.g. shopping):	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri34
Average no. of hours per week:	<input type="text"/> hours	csri34a
Any other information?	<input type="text"/>	csri34sc
Other:	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri35
Average no. of hours per week:	<input type="text"/> hours	csri35a
Any other information?	<input type="text"/>	csri35sc

Adaptations to the Home			
Stairlift:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri36
	Was this in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri36a
Handrails:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri37
	Was this in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri37a
Ramps:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri38
	Was this in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri38a
Shower/bath relocation:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri39
	Was this in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri39a
Toilet relocation:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri40
	Was this in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri40a
Redesign kitchen:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri41
	Was this in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri41a
Chair raises/special chair:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri42
	Was this in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri42a
Bed moved downstairs:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri43
	Was this in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri43a
Hospital bed:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri44
	Was this in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri44a
Other:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri45
	Was this in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri45a




Aids or Devices			
Wheelchair:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri46
	Did you receive it in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri46a
Crutches/sticks:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri47
	Did you receive it in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri47a
Zimmer frame:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri48
	Did you receive it in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri48a
Commode:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri49
	Did you receive it in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri49a
Bath board:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri50
	Did you receive it in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri50a
Pressure relieving cushions/mattress:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri51
	Did you receive it in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri51a
Adapted eating utensils:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri52
	Did you receive it in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri52a
Other:	<input type="radio"/> yes 1 <input type="radio"/> no 0		csri53
	Did you receive it in the last 6 months?	<input type="radio"/> yes 1 <input type="radio"/> no 0	csri53a

Beecham, J. and Knapp, M. (2001) Costing psychiatric interventions. In: Measuring Mental Health Needs, 2nd edition (ed. G. Thornicroft) London: Gaskell, adapted for use in HD by The University of Ulm, Faculty of Medicine, EHDN Health Economics Working Group.

### 3.31 Work Productivity and Activity Impairment-Specific Health Problem (WPAI-SH)

General			
Assessment date:	<input type="text" value="mon/dd/yyyy"/>		qsdtc
Language of paper form (PBF):	<div> <div>----</div> <div> U.S. English 1  Spanish (LA) 2  Brazilian Portuguese 3  Canadian French 6  French 7  Czech 8  Danish 9  German 10  Spanish 11  Italian 12  Dutch 13  Norwegian 14  Polish 15  Portuguese 16  Russian 17  Finnish 18  Swedish 19 </div> </div>		langpbf
Scores:	Work time missed due to HD:	<input type="text"/> %	wpaiscr1
	Impairment while working due to HD:	<input type="text"/> %	wpaiscr2
	Overall work impairment due to HD:	<input type="text"/> %	wpaiscr3
	Activity impairment due to HD:	<input type="text"/> %	wpaiscr4

Work Productivity and Activity Impairment Questionnaire: Specific Health Problem (WPAI-SHP) 	
1. Are you currently employed (working for pay)?	<input type="radio"/> 1 = yes   1 <input type="radio"/> 0 = no   0
The next questions are about the past seven days, not including today.	
2. During the past seven days, how many hours did you miss from work because of problems associated with Huntington's disease?	<input type="text"/> hours
3. During the past seven days, how many hours did you miss from work because of any other reason, such as vacation, holidays, time off to participate in this study?	<input type="text"/> hours
4. During the past seven days, how many hours did you actually work?	<input type="text"/> hours

5. During the past seven days, how much did Huntington's disease affect your productivity while you were working?	<input type="radio"/> 0 = HD had no effect on my work 0	wpai05
	<input type="radio"/> 1 = 1	
	<input type="radio"/> 2 = 2	
	<input type="radio"/> 3 = 3	
	<input type="radio"/> 4 = 4	
	<input type="radio"/> 5 = 5	
	<input type="radio"/> 6 = 6	
	<input type="radio"/> 7 = 7	
	<input type="radio"/> 8 = 8	
	<input type="radio"/> 9 = 9	
	<input type="radio"/> 10 = HD completely prevented me from working 10	
6. During the past seven days, how much did Huntington's disease affect your ability to do your regular daily activities, other than work at a job?	<input type="radio"/> 0 = HD had no effect on my daily activities 0	wpai06
	<input type="radio"/> 1 = 1	
	<input type="radio"/> 2 = 2	
	<input type="radio"/> 3 = 3	
	<input type="radio"/> 4 = 4	
	<input type="radio"/> 5 = 5	
	<input type="radio"/> 6 = 6	
	<input type="radio"/> 7 = 7	
	<input type="radio"/> 8 = 8	
	<input type="radio"/> 9 = 9	
	<input type="radio"/> 10 = HD completely prevented me from doing my daily activities 10	

Reilly MC, Zbrozek AS, Dukes EM. The validity and reproducibility of a work productivity and activity impairment instrument. *Pharmacoeconomics* 1993; 4(5):353-65.

### 3.32 Follow-up on Missed Visit (Missed Visit)

Documentation of Missed Follow-Up		
Date info obtained:	<input type="text" value="mon/dd/yyyy"/>	mvdctc
Source of information:	<input type="radio"/> 1 = participant <sup>1</sup> <input type="radio"/> 2 = spouse/partner <sup>2</sup> <input type="radio"/> 3 = next of kin (family or friends) <sup>3</sup> <input type="radio"/> 4 = physician <sup>4</sup> <input type="radio"/> 5 = nurse <sup>5</sup> <input type="radio"/> 6 = other (e.g. hearsay, obituary in newspaper, death certificate) <sup>6</sup>	mvsrcc
Reason for missed follow-up visit:	<input type="radio"/> 0 = participant involved in a clinical trial, for which the suspension of Enroll-HD visits is requested <sup>0</sup> <input type="radio"/> 1 = participant alive, unable to attend FUP, open to future FUPs <sup>1</sup> <input type="radio"/> 2 = participant alive, objects to further FUP visits, open to further phone contacts <sup>2</sup> <input type="radio"/> 3 = participant alive, objects to further FUP visits and to further phone contacts <sup>3</sup> <input type="radio"/> 4 = participant alive, lost to FUP <sup>4</sup> <input type="radio"/> 5 = participant dead <sup>5</sup> <input type="radio"/> 6 = status unclear <sup>6</sup>	mvrscn
If participant is alive:		
Level of care required:	<input type="radio"/> 0 = The participant does not require any help for basic activities of daily living (un/dressing, washing/bathing, getting up/going to bed). <sup>0</sup> <input type="radio"/> 1 = The participant requires some help to manage basic activities of daily living (typically < 4h support per day), but no full-time supervision. <sup>1</sup> <input type="radio"/> 2 = The participant requires extensive help to manage basic activities of daily living (typically ≥ 4h support per day), and full-time supervision with additional help as required. <sup>2</sup>	crvlvl
Date since full-time dependency:	<input type="text" value="mon/dd/yyyy"/>	dpdctc

## 4 Monitoring Report Forms

### 4.1 Monitoring Baseline Visit (Monitoring BL)

Monitoring Form		
Monitoring visit date:	<input type="text" value="mon/dd/yyyy"/>	mvdtc
Proof of participant's existence found on-site:	<input type="radio"/> yes 1 <input type="radio"/> no 0	mvproof
Proof of participant's visit found on-site:	<input type="radio"/> yes 1 <input type="radio"/> no 0	mvproofv
HDID accurate:	<input type="radio"/> yes 1 <input type="radio"/> no 0	mvhdid
Please provide the correct HDID here:	<input type="text"/>	mvhdidc
General comments about the findings:	<input type="text"/>	mvcmnt
Form:	State:	Comment:
<input type="text" value="----"/> mvform	<input type="text" value="----"/> mvfstate	<input type="text" value="----"/> mvfcmt
Enrollment 1 Variable 3 MHx 6 Samples 11 Motor 12 TFC 13 Function 14 Cognitive 15 MMSE 16 Physio 17 PBA-s 18 CSRI 19 CareQoL 20 SF12 21 HADS-SIS 22 C-SSRS 23 WPAI-SHP 24	accurate 1 not accurate 2	
Flag biosample:	<input type="checkbox"/>	mvsample
Flag data:	<input type="checkbox"/>	mvdata

## 4.2 Monitoring Follow Up Visit (Monitoring FUP)

Monitoring Form		
Monitoring visit date:	<input type="text" value="mon/dd/yyyy"/>	mvdtc
Proof of participant's visit found on-site:	<input type="radio"/> yes 1 <input type="radio"/> no 0	mvproofv
HDID accurate:	<input type="radio"/> yes 1 <input type="radio"/> no 0	mvhdid
	Please provide the correct HDID here: <input type="text"/>	mvhdidc
General comments about the findings:	<input type="text"/>	mvcmnt
Form:	State:	Comment:
<input type="text" value="----"/> mvform	<input type="text" value="----"/> mvfstate	<input type="text" value="----"/> mvfcmt
Variable 3 Samples 11 Motor 12 TFC 13 Function 14 Cognitive 15 MMSE 16 Physio 17 PBA-s 18 CSRI 19 CareQoL 20 SF12 21 HADS-SIS 22 C-SSRS 23 WPAI-SHP 24	accurate 1 not accurate 2	
Flag biosample:	<input type="checkbox"/>	mvsample
Flag data:	<input type="checkbox"/>	mvdata

### 4.3 Monitoring General Visit (Monitoring Gen)

Informed Consent					
Participant:	Version No.	Dated:	Informed consent:	ICF:	
ICF:	<input type="text" value="icfversion"/>	<input type="text" value="mon/dd/yyyy"/>	icfdtc	<input type="text" value="----"/>	mvic
			accurate 1 not accurate 2 missing 3	<input type="text" value="----"/>	mvic1
				incorrect 1 incomplete 2 optional components incorrect 3	
Has ICF been checked and is it accurate:	<input type="text" value="----"/>				mvica
	yes 1 no 0				
Caregiver:	Version No.	Dated:	Informed consent:	ID:	Substudy:
ICF:	<input type="text" value="icfversion"/>	<input type="text" value="mon/dd/yyyy"/>	icfdtc	<input type="text" value="----"/>	icfstate
			accurate 1 not accurate 2 missing 3	<input type="text" value="icfid"/>	<input type="checkbox" value="icfsub"/>
Comment:	<input type="text"/>				mvic2

Monitoring Form		
Monitoring visit date:	<input type="text" value="mon/dd/yyyy"/>	mvdtc
General comments about the findings:	<input type="text"/>	
		mvcmnt
Form:	State:	Comment:
<input type="text" value="----"/>	<input type="text" value="----"/>	<input type="text"/>
mvform	mvfstate	mvfcmt
Demog 2 HD CC 4 CAG 5 Comorbid 7 PharmacoTx 8 NonPharmacoTx 9 NutSuppl 10 Clinical Trials 28 Event 26 Mortality 25 End 27	accurate 1 not accurate 2	
Flag data:	<input type="checkbox"/>	mvdata

#### 4.4 Monitoring General Family History (Monitoring FHx)

Monitoring Form			
Monitoring visit date:	<input type="text" value="mon/dd/yyyy"/>		mvdrtc
General comments about the findings:	<div><div></div></div>		mvcmt
Family member:	State:	Comment:	
<div><div></div><div>mvnode</div></div>	<div><div>----</div><div>▼</div><div>mvfstate</div></div>	<div><div></div><div>mvfcmt</div></div>	
	accurate 1 not accurate 2		
Flag data:	<input type="checkbox"/>		mvddata



## 5 Monitoring Event Forms

### 5.1 Monitoring Event Form (Monitoring Event)

Monitoring Event		
PI name:	<input type="text"/>	me_pi
Date reported:	<input type="text" value="mon/dd/yyyy"/>	me_dtc
Type:	<input type="radio"/> PV 1 <input type="radio"/> issue 2	me_type

Issues		
Issues:	<div><div>----</div><div>Biosamples bs Study Procedures sp ICF icf IT issues it HDID print out page issues (missing/illegible/incorrect) hdid Source documents missing sdm NTF missing ntf Other 88</div></div>	me_issues

Protocol Violations	
Category:	<div> <div>----</div> <div>▼</div> </div> <div> <div>informed consent form - participant <i>pv_p1cf</i></div> <div>informed consent form - caregiver <i>pv_c1cf</i></div> <div>Safety <i>pv_safe</i></div> <div>Data Protection <i>pv_dp</i></div> <div>Inclusion/Exclusion <i>pv_ie</i></div> <div>Biosamples <i>pv_bsp</i></div> <div>Other <i>pv_oth</i></div> </div> <div> <div>Please specify:</div> <div> <div></div> <div>▼</div> </div> </div>
PV Informed consent form - participant:	<div> <div>----</div> <div>▼</div> </div> <div> <div>Consent form completed after data collected 1</div> <div>HIPAA form missing or not signed 2</div> <div>Incorrectly dated/signed (or missing date/signature) ICF by site personnel 3</div> <div>Incorrectly dated or undated by participant but supporting documents document correct date 4</div> <div>Legal Representative printed incorrect name on ICF 5</div> <div>Missing consent form 6</div> <div>Missing core study components box 7</div> <div>Missing optional component checkbox - FHE 8</div> <div>Missing optional component checkbox - Biosamples 9</div> <div>Missing optional component checkbox - Sub-studies 10</div> <div>Missing optional component checkbox - Linking clinical info 11</div> <div>Missing optional component checkbox - Contact between visits 12</div> <div>Missing optional component checkbox - Contact other research 13</div> <div>Missing optional component checkbox - Contact post-mortem tissue donation 14</div> <div>Missing pages of ICF 15</div> <div>No copy of ICF given to participant 16</div> <div>Local ICF procedures not adhered to (e.g. time missing) 18</div> <div>Only photocopy of ICF onsite 19</div> <div>Sections of ICF crossed out 20</div> <div>Signature for participant missing 21</div> <div>Site failed to sign/date correction to ICF 22</div> <div>Site specific info missing from consent form 23</div> <div>Whiteout used 24</div> <div>Wrong person consented 25</div> <div>Wrong type of consent used 26</div> <div>Wrong version of consent used 27</div> <div>Missing or incomplete printed name by site personnel 28</div> <div>Missing or incomplete printed name by participant and no supporting documentation onsite to confirm ICF belongs to this participant 29</div> <div>Missing or incomplete printed name by participant with supporting documentation present onsite to confirm ICF belongs to this participant 30</div> <div>Incorrectly dated or undated by participant with no supporting documentation of date of consent 31</div> <div>Legal Representative missing, incomplete or incorrect date on ICF 32</div> <div>Legal Representative signature missing (only if Legal Representative is required) 33</div> <div>Legal Representative missing relationship or other specified information 34</div> <div>Missing statement from independent witness (only if witness is required) 35</div> <div>Missing multiple optional component check boxes - incl. Biosamples 36</div> <div>Missing multiple optional component check boxes - excl. Biosamples 37</div> <div>Participant/legal representative/witness failed to sign/date correction to ICF 38</div> </div>

	<p>Site staff completed checkboxes on behalf of participant 38</p> <p>Inappropriate use of legal representative consent (participant able to consent on their own behalf) 40</p> <p>Participants/legal representative date different to date on site personnel signature line 41</p> <p>Wrong version of HIPAA used 42</p> <p>Other 88</p> <p>Please specify: <input type="text"/></p>	pv_pict_om
PV Informed consent form - caregiver:	<p>-----</p> <p>Incorrectly dated/signed (or missing date/signature) ICF by site personnel 3</p> <p>Missing or incorrect information by caregiver but supporting documents document correct data 4</p> <p>Missing consent form but QoL completed 5</p> <p>Missing optional component checkbox - Sub-studies 10</p> <p>Signature for caregiver missing 21</p> <p>Wrong person consented 25</p> <p>Wrong type of consent used 26</p> <p>Wrong version of consent used (using a not current version) 27</p> <p>Missing core study components box - haven't completed the checkboxes as applicable 28</p> <p>Incorrectly dated/signed (or missing date/signature) ICF by caregiver 29</p> <p>Printed name of caregiver missing or incomplete and no supporting documentation onsite to confirm ICF belongs to this caregiver 30</p> <p>Printed name of caregiver missing or incomplete with supporting documentation present onsite to confirm ICF belongs to this caregiver 31</p> <p>Photocopy only onsite 32</p> <p>Whiteout used 33</p> <p>Site specific info missing from consent form 34</p> <p>Site failed to sign/date correction to ICF 35</p> <p>Sections of ICF crossed out 36</p> <p>HIPAA form missing or not signed 37</p> <p>Site staff completed checkboxes on behalf of caregiver 38</p> <p>Caregiver date different to date on site personnel signature line 39</p> <p>Wrong version of HIPAA used 40</p> <p>Other 88</p> <p>Please specify: <input type="text"/></p>	pv_cicf
PV Safety:	<p>-----</p> <p>No CSSRS completed with present suicidal ideation 28</p> <p>No Reportable Event filled in/submitted within 48 hrs 29</p> <p>No Serious Adverse Event form filled in/submitted within 24hrs 30</p> <p>Lumbar puncture when safety blood out of range without waiver 31</p> <p>Other 88</p> <p>Please specify: <input type="text"/></p>	pv_cicf_oth
PV Data Protection:	<p>-----</p> <p>HDID creation form not stored securely 30</p> <p>Vulnerable data stored incorrectly (electronic) 31</p> <p>Vulnerable data stored incorrectly (paper) 32</p> <p>Specific participant's study data shared outside of study site personnel 33</p> <p>Identifying information specific to one participant shared outside of study site personnel 34</p> <p>Other 88</p> <p>Please specify: <input type="text"/></p>	pv_safe_oth
		pv_dp
		pv_dp_oth

PV Inclusion/exclusion:	<input type="text"/>	<input type="button" value="v"/>	pv_ie
	Criteria not met for enrollment 33 Other 88		
	Please specify:	<input type="text"/>	pv_ie_oth
PV Biosamples:	<input type="text"/>	<input type="button" value="v"/>	pv_bsp
	Participant chose "no" for additional biosamples and additional samples collected 1 CSF volume out of range (>25mls) 2 Samples not stored in accordance with protocol and unusable 3 Blood volume out of range 4 Other 88		
	Please specify:	<input type="text"/>	pv_bsp_oth
All data to be quarantined:	<input type="radio"/> yes 1 <input type="radio"/> no 0		pv_rq
Biosamples affected:	<input type="radio"/> yes 1 <input type="radio"/> no 0		pv_bs
Sample quarantine request submitted:	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> no samples available 2		bs_rq

Monitoring Event		
Description:	<input type="text"/>	me_desc
Action taken/to be taken:	<input type="text"/>	me_act
Note to file available:	<input type="radio"/> yes 1 <input type="radio"/> no 0 <input type="radio"/> n/a 2	me_ntf
Status:	<input type="radio"/> open 1 <input type="radio"/> resolved 2	me_stat
Resolution date:	<input type="text" value="mon/dd/yyyy"/>	me_rdtc
Resolution notes:	<input type="text"/>	me_rnote
Sample quarantine release:	<input type="radio"/> yes 1 <input type="radio"/> no 0	qrel

## References

<b>[1]</b>	CHDI Foundation, Inc., <i>Enroll-HD Data Management Requirements</i> , ENROLL-REQ-2005-EN, Version 1.12, 2021
<b>[2]</b>	CHDI Foundation, Inc., <i>Enroll-HD Data Dictionary</i> , ENROLL-SPC-2002-EN, Version 1.12, 11-Nov-2021

## Approval

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	<b>Name</b>	<b>Date</b>	<b>Signature</b>
<b>Author</b>	Gunter Antoneag	16-Nov-2021	
<b>Review</b>	Torsten Illmann	17-Nov-2021	
<b>Approval</b>	Nicole Piller	24-Jan-2022	

## Revision Index

Date	Version	Chapter	Summary of Change(s) and if applicable Reason for Change(s)
31-Oct-2015	1.7	---	Initial version of annotated CRF of Enroll-HD study, release 1.7.
06-Oct-2016	1.7.1	3.22, 3.24, 3.25, 3.29, 3.29	Slight revisions. Forms Samples, C- SSRS BL, C- SSRS FUP, CareQoL, CSRI added.
31-Dec-2017	1.9	---	Include update of 1.9 release
24-Jan-2022	1.12	3.21, 5.1, 3.18	Updated FHx form and Monitoring Event form. Use of new template; updated copyright information added to Core & Extended Cognitive CRF