



Annotated Case Report Form (CRF) for REGISTRY Periodic Dataset

Version 2016-10-R1

Enroll-HD

A worldwide observational study for Huntington's disease families

A CHDI Foundation Project

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1 Purpose of this Document

The purpose of this document is to provide an annotated view of the REGISTRY's eCRF (electronic Case Report Form) within the Enroll-HD system. It shows the source of the variable names provided in the Enroll-HD periodic dataset, which is available to the HD research community at large. The periodic dataset represents a data extract of the Enroll-HD Electronic Data Capture (EDC) database at a defined point in time. Information that could potentially identify a participant has been removed or de-identified within this dataset. When available, CDISC SDMT naming conventions were used.

The annotated view shows all forms, variables, and variable names used within the periodic dataset. Forms and variables that are not provided in the dataset are not shown in the annotated forms. Variables that have been transformed for de-identification reasons are shown in the transformed manner in the annotated view.

The variables and data files of the dataset are described in detail within the [data dictionary](#) for the Enroll-HD plus periodic dataset.

2 Forms and Data Files

Forms are CRF entry screens that are displayed to data entry personnel and show how data is entered in the eCRF. Data files are sets of variables that define how the data are represented. The following table defines how forms and data files are related.

Form / Data File	Profile	Participation	PharmacTx	NutSuppl	NonPharmacTx	Comorbid	R3	R2
<i>Enrollment</i>	✓	✓						
<i>Demog</i>	✓							
<i>HD CC</i>	✓							
<i>PharmacTx</i>			✓					
<i>NutSuppl</i>				✓				
<i>NonPharmacTx</i>					✓			
<i>Comorbid</i>						✓		
<i>End</i>		✓						
<i>Mortality</i>	✓							
<i>Variable BL</i>							✓	✓
<i>Variable FUP</i>							✓	✓
<i>Motor</i>							✓	✓
<i>TFC</i>							✓	✓
<i>Function</i>							✓	✓

Form / Data File	Profile	Participation	Pharmaco Tx	NutSuppl	NonPharmacoTx	Comorbid	R3	R2
<i>PBA-s</i>							✓	
<i>Cognitive</i>							✓	✓
<i>HADS-SIS</i>							✓	
<i>SF36-v1</i>								✓
<i>SF36-v2</i>							✓	
<i>HADS-SIS</i>							✓	
<i>CSSRS BL</i>							✓	
<i>CSSRS FUP</i>							✓	
<i>Behaviour</i>							✓	
<i>BDI</i>								✓
<i>Hamilton</i>								✓

The data files “Profile” and “Participation” are not displayed on an entry form but consist of variables of various forms. It contains key information like subject, study and region identifiers and some visit-independent subject information, e.g. the subject’s latest HD classification. Please refer to the [data dictionary](#) for detailed information.

3 Form „Enrollment“ (R3)

Enrollment [enrlmnt1] 5452_1

Day of informed consent: rfidy

[varitems12]

Participant category: genotype unknown 1 pre-manifest/pre-motor-manifest HD 2 manifest carrier 3 genotype negative 4 family control 5 **hdcat**

Optional Components: [enrlmnt2] 359_1

Family History: yes 1 no 0 fhx

Label of the variable "hdcat"

Variable "hdcat"

Coded value "2" of variable „hdcat“, item "pre-manifest [..]"


4 Form "Enrollment" (R2)

Enrollment [enrlmnt1] S452_1

Day of informed consent:

rfcdy

5 Form “Demographics (Demog)”

Demographics (invariable) [dm1] 116_1		
Age at enrollment:	<input type="text"/>	age
Gender:	<input type="radio"/> female f <input type="radio"/> male m	sex
[dm2]		
Ethnicity:	<input type="radio"/> Caucasian 1 <input type="radio"/> American - Black 2 <input type="radio"/> Hispano or Latino Origin 3 <input type="radio"/> American Indian/Native American/Amerindian 8 <input type="radio"/> Asian 16 <input type="radio"/> mixed 15 <input type="radio"/> other 6	race
[dm4]		
Handedness: 	<input type="radio"/> right 1 <input type="radio"/> left 2 <input type="radio"/> mixed 3	handed

6 Form “HD Clinical Characteristics (HD CC)”

Family History <small>[hdcc6] 594_1</small>		
Mother affected:	<input type="radio"/> yes 1 <input type="radio"/> no 0	momhd
Age at onset of symptoms in mother:	<input type="text"/> years	momagesx
Father affected:	<input type="radio"/> yes 1 <input type="radio"/> no 0	dadhd
Age at onset of symptoms in father:	<input type="text"/> years	dadagesx

HD Clinical Characteristics and Age-of-Onset <small>[hdcc2] 531_1</small>		
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? <small>[539] 539_1</small>	age (years)	
	<input type="text"/> ccdepage	
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? <small>[545] 545_1</small>	age (years)	
	<input type="text"/> ccirbage	
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? <small>[551] 551_1</small>	age (years)	
	<input type="text"/> ccvabage	
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? <small>[557] 557_1</small>	age (years)	
	<input type="text"/> ccaptage	

Has perseverative/obsessive behaviors ever been a part of the participant's medical history? yes 1 no 0 ccpob

At what age did perseverative/obsessive behaviour begin? [563] 563_1
 age (years) _____
 ccpobage

Has psychosis (hallucinations or delusions) ever been a part of the participant's medical history? yes 1 no 0 ccpsy

At what age did psychosis (hallucinations or delusions) begin? [569] 569_1
 age (years) _____
 ccpsyage

Does the participant have a family history of a psychotic illness in a first degree relative: yes 1 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: yes 1 no 0 cccog

At what age did cognitive impairment first start to have an impact on daily life? [576] 576_1
 age (years) _____
 cccogage

History of HD Motor Symptoms [hdcc7] 3918_1

Have motor symptoms ever been a part of the participant's medical history? yes 1 no 0 ccmtr

At what age did the participant's motor symptoms begin? [533] 533_1
 age (years) _____
 ccmtrage

HD History [hdhac] 2976_1

Symptoms first noted by participant: sxsubj

Symptoms first noted by family: sxfam

Date of clinical HD diagnosis: hddiagn

Can you, as a rater, estimate the time of symptom onset: yes 1 no 0 sxest

Rater's estimate of symptom onset: sxrater

Confidence with which this estimation is made: high 1 low 2 sxestcfd

What are these symptoms? [symptoms] 2988_1

	motor	cognitive	psychiatric	oculomotor	other	mixed	
Initial major symptom noted by participant	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	sxsubjm
Initial major symptom noted by family	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	sxfamm
Rater's judgement of initial major symptom	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5	<input type="radio"/> 6	sxraterm

Suicial Behavior [hdcc2] 3918_1

Previous suicidal ideation or attempts? yes 1 no 0 hxsid

Local genetic test [hdcc5] 601_1

Has an HD genetic test been done? yes 1 no 0 hdtest

7 Form “Pharmacotherapy (PharmacTx)”

Medications (Pharmacotherapy) [med] 222_1

Drug name	Indication	Total Daily Dose / Unit	Frequency	Route	Start day	Ongoing	End day
1. <input type="text"/> modify decod	<input type="text"/> modify decod	<input type="text"/> cmdostot <input type="text"/> cmdosu cmdose	---- 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	---- p.o. 1 p.r. 2 s.c. 3 i.m. 4 i.v. 5 nasal 6 td 7 sl 8 inh 9 other 10	<input type="text"/> cmstidy	<input type="checkbox"/> 1 cmenrf	<input type="text"/> cmendy
2. <input type="text"/> modify decod	<input type="text"/> modify decod	<input type="text"/> cmdostot <input type="text"/> cmdosu cmdose	----	----	<input type="text"/> cmstidy	<input type="checkbox"/> 1 cmenrf	<input type="text"/> cmendy
3. <input type="text"/> modify decod	<input type="text"/> modify decod	<input type="text"/> cmdostot <input type="text"/> cmdosu cmdose	----	----	<input type="text"/> cmstidy	<input type="checkbox"/> 1 cmenrf	<input type="text"/> cmendy

8 Form “Nutritional Supplements (NutSuppl)”

Nutritional Supplements [3905] ,Nutritional Supplements 3905_1											
Type	Total Daily Dose		Unit	Frequency		Start day	Ongoing	End day			
1. <input type="text" value="----"/>	cmcat	<input type="text"/>	cmdostot	<input type="text" value="----"/>	cmdosunit	<input type="text" value="----"/>	cmdosfrq	<input type="text"/>	cmstdy	<input type="checkbox"/> 1 cmenrf <input type="text"/>	cmendy
vitamin & supplements 1 herbs (extracts) 2 herbs (teas) 3 other natural remedies 4 aromatherapies 5 homeopathic remedies 6											
g 1 mg 2 IU 3 spoons 4 tablets 5 drops 6 capsule 7 other 8											
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											
2. <input type="text" value="----"/>	cmcat	<input type="text"/>	cmdostot	<input type="text" value="----"/>	cmdosunit	<input type="text" value="----"/>	cmdosfrq	<input type="text"/>	cmstdy	<input type="checkbox"/> 1 cmenrf <input type="text"/>	cmendy
3. <input type="text" value="----"/>	cmcat	<input type="text"/>	cmdostot	<input type="text" value="----"/>	cmdosunit	<input type="text" value="----"/>	cmdosfrq	<input type="text"/>	cmstdy	<input type="checkbox"/> 1 cmenrf <input type="text"/>	cmendy

9 Form “Non-Pharmacologic Therapies (NonPharmaTx)”

Non-Pharmacologic Therapies [3894] Non-Pharmacologic Therapies 3894_1

	Therapy	Number of times	Frequency	Start day	Ongoing	End day		
1.	----- 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	<input type="text"/> cmtrt	<input type="text"/> cmfrq	----- daily 1 weekly 2 monthly 3 as needed 4	<input type="text"/> cmdosfrq	<input type="text"/> cmstdy	<input type="checkbox"/> 1 cmnrf	<input type="text"/> cmendy
2.	-----	<input type="text"/> cmtrt	<input type="text"/> cmfrq	-----	<input type="text"/> cmdosfrq	<input type="text"/> cmstdy	<input type="checkbox"/> 1 cmnrf	<input type="text"/> cmendy
3.	-----	<input type="text"/> cmtrt	<input type="text"/> cmfrq	-----	<input type="text"/> cmdosfrq	<input type="text"/> cmstdy	<input type="checkbox"/> 1 cmnrf	<input type="text"/> cmendy

10 Form “Comorbid Conditions (Comorbid)”

Past Disorders and Comorbidities [group] NH 201_1

Condition		Body system code	Start day	Ongoing	End day
1. <input type="text"/>	modify <input type="text"/> decod ↗ mhterm	---- <input type="text"/> 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	<input type="text"/> mhstsys	<input type="text"/> mhstdy <input type="checkbox"/> 1 mhenrf	<input type="text"/> mhendy
2. <input type="text"/>	modify <input type="text"/> decod ↗ mhterm	---- <input type="text"/>	<input type="text"/> mhstsys	<input type="text"/> mhstdy <input type="checkbox"/> 1 mhenrf	<input type="text"/> mhendy
3. <input type="text"/>	modify <input type="text"/> decod ↗ mhterm	---- <input type="text"/>	<input type="text"/> mhstsys	<input type="text"/> mhstdy <input type="checkbox"/> 1 mhenrf	<input type="text"/> mhendy
4. <input type="text"/>	modify <input type="text"/> decod ↗ mhterm	---- <input type="text"/>	<input type="text"/> mhstsys	<input type="text"/> mhstdy <input type="checkbox"/> 1 mhenrf	<input type="text"/> mhendy
5. <input type="text"/>	modify <input type="text"/> decod ↗ mhterm	---- <input type="text"/>	<input type="text"/> mhstsys	<input type="text"/> mhstdy <input type="checkbox"/> 1 mhenrf	<input type="text"/> mhendy
6. <input type="text"/>	modify <input type="text"/> decod ↗ mhterm	---- <input type="text"/>	<input type="text"/> mhstsys	<input type="text"/> mhstdy <input type="checkbox"/> 1 mhenrf	<input type="text"/> mhendy

11 Form “Mortality”

Death Report Form [mortrpt] 2040_1

Age of death: years dssage

Place of death: dsplace

- home 1
- hospital 2
- nursing home 3
- hospice care 4
- unknown 5

Cause of death: dsend

- pneumonia 1
- other infection 2
- cancer 3
- stroke 4
- trauma 5
- suicide 6
- other 7

12 Form “Variable Items - Baseline Visit (Variable BL)” (R3)

[varitems1]

General Variable Items I [often] 637_1

[varitems2]

Weight (kg) weight

Height (cm) height

BMI: bmi

[varitems3]

Does the participant currently drink alcohol? yes 1 no 0 alcab

Units per week: alcunits

Does the participant currently smoke? yes 1 no 0 tobab

Packyears: packy

Does the participant currently use drugs? yes 1 no 0 drugab

Drug use for non-medical reasons? [787] 787_1

	Abuse	Frequency
Marijuana	<input type="text"/> mar yes 1 no 0	<input type="text"/> marfrq seldom 1 occasionally 2 frequently 3
Heroin	<input type="text"/> her yes 1 no 0	<input type="text"/> herfrq seldom 1 occasionally 2 frequently 3
Cocaine	<input type="text"/> coc yes 1 no 0	<input type="text"/> cocfrq seldom 1 occasionally 2 frequently 3
Club drugs (Ecstasy, GHB, Roofies)	<input type="text"/> clb yes 1 no 0	<input type="text"/> clbfrq seldom 1 occasionally 2 frequently 3

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

General Variable Items II [rarely] 658_1

[varitems7]

Marital status: maristat


- single 1
- married 3
- partnership 2
- divorced 4
- widowed 5
- legally separated 6

[varitems8]

Residence: res

- rural 1
- village 2
- town 3
- city 4

[varitems10]

ISCED education level:  isced

- ISCED 0 0
- ISCED 1 1
- ISCED 2 2
- ISCED 3 3
- ISCED 4 4
- ISCED 5 5
- ISCED 6 6

13 Form “Variable Items - Baseline Visit (Variable BL)” (R2)

[varitems1]

General Variable Items [general] 632_1

[varitems2]

Weight (kg)	Weight (lbs)
<input type="text"/> weight	<input type="text"/> weight_2
Height (cm)	Height (inches)
<input type="text"/> height	<input type="text"/> height_2

BMI: bmi

[varitems8]

Residence: res

- rural 1
- village 2
- town 3
- city 4

[varitems7]

Marital status: maristat

- single 1
- married 3
- partnership 2
- divorced 4
- widowed 5

14 Form “Variable Items - Follow-Up Visit (Variable FUP)” (R3)

[varitems1]

General Variable Items I [often] 637_1

[varitems2]

Weight (kg) weight

Height (cm) height

BMI: bmi

[varitems3]

Does the participant currently drink alcohol? yes 1 no 0 alcab

Units per week: alcunits

Does the participant currently smoke? yes 1 no 0 tobab

Packyears: packy

Does the participant currently use drugs? yes 1 no 0 drugab

Drug use for non-medical reasons? [787] 787_1

	Abuse	Frequency
Marijuana	<input type="text"/> mar yes 1 no 0	<input type="text"/> marfrq seldom 1 occasionally 2 frequently 3
Heroin	<input type="text"/> her yes 1 no 0	<input type="text"/> herfrq seldom 1 occasionally 2 frequently 3
Cocaine	<input type="text"/> coc yes 1 no 0	<input type="text"/> cocfrq seldom 1 occasionally 2 frequently 3
Club drugs (Ecstasy, GHB, Roofies)	<input type="text"/> clb yes 1 no 0	<input type="text"/> clbfrq seldom 1 occasionally 2 frequently 3

Amphetamines	<input type="text" value="----"/> <input type="button" value="▼"/> amp	<input type="text" value="----"/> <input type="button" value="▼"/> ampfrq
	yes 1	seldom 1
	no 0	occasionally 2
		frequently 3
Ritalin	<input type="text" value="----"/> <input type="button" value="▼"/> rit	<input type="text" value="----"/> <input type="button" value="▼"/> ritfrq
	yes 1	seldom 1
	no 0	occasionally 2
		frequently 3
Hallucinogens	<input type="text" value="----"/> <input type="button" value="▼"/> hal	<input type="text" value="----"/> <input type="button" value="▼"/> halfrq
	yes 1	seldom 1
	no 0	occasionally 2
		frequently 3
Inhalants	<input type="text" value="----"/> <input type="button" value="▼"/> inh	<input type="text" value="----"/> <input type="button" value="▼"/> inhfrq
	yes 1	seldom 1
	no 0	occasionally 2
		frequently 3
Opium	<input type="text" value="----"/> <input type="button" value="▼"/> opi	<input type="text" value="----"/> <input type="button" value="▼"/> opifrq
	yes 1	seldom 1
	no 0	occasionally 2
		frequently 3
Painkillers	<input type="text" value="----"/> <input type="button" value="▼"/> pak	<input type="text" value="----"/> <input type="button" value="▼"/> pakfrq
	yes 1	seldom 1
	no 0	occasionally 2
		frequently 3
Barbiturates/sedatives	<input type="text" value="----"/> <input type="button" value="▼"/> bar	<input type="text" value="----"/> <input type="button" value="▼"/> barfrq
	yes 1	seldom 1
	no 0	occasionally 2
		frequently 3

Tranquilizers

yes 1 no 0 seldom 1 occasionally 2 frequently 3

General Variable Items II [rarely] 638 1

General Variable items of previous visits:

Participant category	----	(invalid)
Occupation		(invalid)
Employment	----	(invalid)
Marital status	----	(invalid)
Residence	----	(invalid)
ISCED education level	----	(invalid)
Years of education		(invalid)

This table contains information about value of "Participant Category", "Occupation", etc. populated from the previous visit

Any changes to the rarely changing General Variable Items above:

yes 1 no 0

updsc

[varitem12]

Participant category:

- genotype unknown 1
- pre-manifest/pre-motor-manifest HD 2
- manifest/motor-manifest HD 3
- genotype negative 4
- family control 5
- community control 6

hdcat

[varitem7]

Marital status:

- single 1
- married 3
- partnership 2
- divorced 4
- widowed 5
- legally separated 6

maristat

[varitem8]

Residence: res

rural 1
 village 2
 town 3
 city 4

[varitem10]

ISCED education level:  iscd

ISCED 0 0
 ISCED 1 1
 ISCED 2 2
 ISCED 3 3
 ISCED 4 4
 ISCED 5 5
 ISCED 6 6

varitem11

Since the last visit have there been [checkbox] 836_1

Any changes to participant's medication? yes 1 no 0 updmed

Any changes to participant's comorbid conditions? yes 1 no 0 updmh

Any updates to the clinical characteristics and/or onset of HD? yes 1 no 0 updhhd

15 Form “Variable Items - Follow-Up Visit (Variable FUP)” (R2)

[varitems1]

General Variable Items [general] 652_1

[varitems2]

Weight (kg)	Weight (lbs)
<input type="text"/> weight	<input type="text"/> weight_2
Height (cm)	Height (inches)
<input type="text"/> height	<input type="text"/> height_2

BMI: bmi

16 Form “UHDRS Motor/Diagnostic Confidence (Motor)”

[motor2]

General [motor] 132_1

Motor score (TMS):

motscore

Motor score (TMS) incomplete:

miscore

Motor Assessment [135] 135_1

Ocular pursuit: [136] 136_1

Horizontal	Vertical
<input type="radio"/> 0	<input type="radio"/> 0
<input type="radio"/> 1	<input type="radio"/> 1
<input type="radio"/> 2	<input type="radio"/> 2
<input type="radio"/> 3	<input type="radio"/> 3
<input type="radio"/> 4 ocularh	<input type="radio"/> 4 ocularv

0 = complete (normal)

1 = jerky movement

2 = interrupted pursuits/full range

3 = incomplete range

4 = cannot pursue

Saccade initiation: [140] 140_1

Horizontal	Vertical
<input type="radio"/> 0	<input type="radio"/> 0
<input type="radio"/> 1	<input type="radio"/> 1
<input type="radio"/> 2	<input type="radio"/> 2
<input type="radio"/> 3	<input type="radio"/> 3
<input type="radio"/> 4 sacinith	<input type="radio"/> 4 sacinitv

0 = normal

1 = increased latency only

2 = suppressible blinks or head movements to initiate

3 = unsuppressible head movements

4 = cannot initiate saccades

<p><u>Saccade velocity:</u> [144] 144_1</p>	<table border="0"> <thead> <tr> <th style="text-align: center;">Horizontal</th> <th style="text-align: center;">Vertical</th> <th></th> </tr> </thead> <tbody> <tr> <td><input type="radio"/> 0</td> <td><input type="radio"/> 0</td> <td>0 = normal</td> </tr> <tr> <td><input type="radio"/> 1</td> <td><input type="radio"/> 1</td> <td>1 = mild slowing</td> </tr> <tr> <td><input type="radio"/> 2</td> <td><input type="radio"/> 2</td> <td>2 = moderate slowing</td> </tr> <tr> <td><input type="radio"/> 3</td> <td><input type="radio"/> 3</td> <td>3 = severely slow, full range</td> </tr> <tr> <td><input type="radio"/> 4 <small>sacvelh</small></td> <td><input type="radio"/> 4 <small>sacvelv</small></td> <td>4 = incomplete range</td> </tr> </tbody> </table>	Horizontal	Vertical		<input type="radio"/> 0	<input type="radio"/> 0	0 = normal	<input type="radio"/> 1	<input type="radio"/> 1	1 = mild slowing	<input type="radio"/> 2	<input type="radio"/> 2	2 = moderate slowing	<input type="radio"/> 3	<input type="radio"/> 3	3 = severely slow, full range	<input type="radio"/> 4 <small>sacvelh</small>	<input type="radio"/> 4 <small>sacvelv</small>	4 = incomplete range	
Horizontal	Vertical																			
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<p><u>Dysarthria:</u></p>	<table border="0"> <tbody> <tr> <td><input type="radio"/> 0 = normal</td> <td>0</td> <td></td> </tr> <tr> <td><input type="radio"/> 1 = unclear, no need to repeat</td> <td>1</td> <td></td> </tr> <tr> <td><input type="radio"/> 2 = must repeat to be understood</td> <td>2</td> <td></td> </tr> <tr> <td><input type="radio"/> 3 = mostly incomprehensible</td> <td>3</td> <td></td> </tr> <tr> <td><input type="radio"/> 4 = anarthria</td> <td>4</td> <td></td> </tr> </tbody> </table>	<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		<p>dysarth</p>			
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<input type="radio"/> 2 = must repeat to be understood	2																			
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<input type="radio"/> 4 = anarthria	4																			
<p><u>Tongue protrusion:</u></p>	<table border="0"> <tbody> <tr> <td><input type="radio"/> 0 = can hold tongue fully protruded for 10 sec</td> <td>0</td> <td></td> </tr> <tr> <td><input type="radio"/> 1 = cannot keep fully protruded for 10 sec</td> <td>1</td> <td></td> </tr> <tr> <td><input type="radio"/> 2 = cannot keep fully protruded for 5 sec</td> <td>2</td> <td></td> </tr> <tr> <td><input type="radio"/> 3 = cannot fully protrude tongue</td> <td>3</td> <td></td> </tr> <tr> <td><input type="radio"/> 4 = cannot protrude tongue beyond lips</td> <td>4</td> <td></td> </tr> </tbody> </table>	<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		<p>tongue</p>			
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<input type="radio"/> 3 = cannot fully protrude tongue	3																			
<input type="radio"/> 4 = cannot protrude tongue beyond lips	4																			
<p><u>Finger taps:</u> [150] 150_1</p>	<table border="0"> <thead> <tr> <th style="text-align: center;">Right</th> <th style="text-align: center;">Left</th> <th></th> </tr> </thead> <tbody> <tr> <td><input type="radio"/> 0</td> <td><input type="radio"/> 0</td> <td>0 = normal ($\geq 15/5$ sec.)</td> </tr> <tr> <td><input type="radio"/> 1</td> <td><input type="radio"/> 1</td> <td>1 = mild slowing, reduction in amplitude (11-14/5 sec.)</td> </tr> <tr> <td><input type="radio"/> 2</td> <td><input type="radio"/> 2</td> <td>2 = moderately impaired (7-10/5 sec.)</td> </tr> <tr> <td><input type="radio"/> 3</td> <td><input type="radio"/> 3</td> <td>3 = severely impaired (3-6/5 sec.)</td> </tr> <tr> <td><input type="radio"/> 4 <small>fingtapr</small></td> <td><input type="radio"/> 4 <small>fingtapl</small></td> <td>4 = can barely perform task (0-2/5 sec.)</td> </tr> </tbody> </table>	Right	Left		<input type="radio"/> 0	<input type="radio"/> 0	0 = normal ($\geq 15/5$ sec.)	<input type="radio"/> 1	<input type="radio"/> 1	1 = mild slowing, reduction in amplitude (11-14/5 sec.)	<input type="radio"/> 2	<input type="radio"/> 2	2 = moderately impaired (7-10/5 sec.)	<input type="radio"/> 3	<input type="radio"/> 3	3 = severely impaired (3-6/5 sec.)	<input type="radio"/> 4 <small>fingtapr</small>	<input type="radio"/> 4 <small>fingtapl</small>	4 = can barely perform task (0-2/5 sec.)	
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<u>Pronate/supinate-hands:</u>	<u>Right</u>	<u>Left</u>		
[154] 154_1	<input type="radio"/> 0	<input type="radio"/> 0	0 = normal	
	<input type="radio"/> 1	<input type="radio"/> 1	1 = mild slowing and/or irregular	
	<input type="radio"/> 2	<input type="radio"/> 2	2 = moderate slowing and irregular	
	<input type="radio"/> 3	<input type="radio"/> 3	3 = severe slowing and irregular	
	<input type="radio"/> 4 prosupr	<input type="radio"/> 4 prosupl	4 = cannot perform	
<u>Luria:</u>	<input type="radio"/> 0 = ≥ 4 in 10 sec, no cue			luria
	<input type="radio"/> 1 = < 4 in 10 sec, no cue			
	<input type="radio"/> 2 = ≥ 4 in 10 sec with cues			
	<input type="radio"/> 3 = < 4 in 10 sec with cues			
	<input type="radio"/> 4 = cannot perform			
<u>Rigidity-arms:</u> [159] 159_1	<u>Right</u>	<u>Left</u>		
	<input type="radio"/> 0	<input type="radio"/> 0	0 = absent	
	<input type="radio"/> 1	<input type="radio"/> 1	1 = slight or present only with activation	
	<input type="radio"/> 2	<input type="radio"/> 2	2 = mild to moderate	
	<input type="radio"/> 3	<input type="radio"/> 3	3 = severe, full range of motion	
	<input type="radio"/> 4 rigarmr	<input type="radio"/> 4 rigarml	4 = severe with limited range	
<u>Bradykinesia-body:</u>	<input type="radio"/> 0 = normal			brady
	<input type="radio"/> 1 = minimally slow (?normal)			
	<input type="radio"/> 2 = mildly but clearly slow			
	<input type="radio"/> 3 = moderately slow, some hesitation			
	<input type="radio"/> 4 = markedly slow, long delays in initiation			

Maximal dystonia: [164] 164_1

Trunk	RUE	LUE	RLE	LLE	
<input type="radio"/> 0	<input type="radio"/> 0	<input type="radio"/> 0	<input type="radio"/> 0	<input type="radio"/> 0	0 = absent
<input type="radio"/> 1	<input type="radio"/> 1	<input type="radio"/> 1	<input type="radio"/> 1	<input type="radio"/> 1	1 = slight/intermittent
<input type="radio"/> 2	<input type="radio"/> 2	<input type="radio"/> 2	<input type="radio"/> 2	<input type="radio"/> 2	2 = mild/common or moderate/intermittent
<input type="radio"/> 3	<input type="radio"/> 3	<input type="radio"/> 3	<input type="radio"/> 3	<input type="radio"/> 3	3 = moderate/common
<input type="radio"/> 4 dysttrnk	<input type="radio"/> 4 dystrue	<input type="radio"/> 4 dystlue	<input type="radio"/> 4 dystrie	<input type="radio"/> 4 dystlle	4 = marked/prolonged

Maximal chorea: [171] 171_1

Face	BOL	Trunk	RUE	LUE	RLE	LLE	
<input type="radio"/> 0	<input type="radio"/> 0	<input type="radio"/> 0	<input type="radio"/> 0	<input type="radio"/> 0	<input type="radio"/> 0	<input type="radio"/> 0	0 = absent
<input type="radio"/> 1	<input type="radio"/> 1	<input type="radio"/> 1	<input type="radio"/> 1	<input type="radio"/> 1	<input type="radio"/> 1	<input type="radio"/> 1	1 = slight/intermittent
<input type="radio"/> 2	<input type="radio"/> 2	<input type="radio"/> 2	<input type="radio"/> 2	<input type="radio"/> 2	<input type="radio"/> 2	<input type="radio"/> 2	2 = mild/common or moderate/intermittent
<input type="radio"/> 3	<input type="radio"/> 3	<input type="radio"/> 3	<input type="radio"/> 3	<input type="radio"/> 3	<input type="radio"/> 3	<input type="radio"/> 3	3 = moderate/common
<input type="radio"/> 4 chorface	<input type="radio"/> 4 chorbol	<input type="radio"/> 4 chortrnk	<input type="radio"/> 4 chorruue	<input type="radio"/> 4 chorlue	<input type="radio"/> 4 chorrie	<input type="radio"/> 4 chorlle	4 = marked/prolonged

Gait:

- 0 = normal gait, narrow base 0
- 1 = wide base and/or slow 1
- 2 = wide base and walks with difficulty 2
- 3 = walks only with assistance 3
- 4 = cannot attempt 4

gait

<p><u>Tandem walking:</u></p>	<p><input type="radio"/> 0 = normal for 10 steps 0</p> <p><input type="radio"/> 1 = 1 to 3 deviations from straight line 1</p> <p><input type="radio"/> 2 = >3 deviations 2</p> <p><input type="radio"/> 3 = cannot complete 3</p> <p><input type="radio"/> 4 = cannot attempt 4</p>	<p>tandem</p>
<p><u>Retropulsion pull test:</u></p>	<p><input type="radio"/> 0 = normal 0</p> <p><input type="radio"/> 1 = recovers spontaneously 1</p> <p><input type="radio"/> 2 = would fall if not caught 2</p> <p><input type="radio"/> 3 = tends to fall spontaneously 3</p> <p><input type="radio"/> 4 = cannot stand 4</p>	<p>retropls</p>

Diagnostic Confidence [motor3] .DCL 185_1

<p>Diagnostic confidence level (DCL):</p>	<p><input type="radio"/> 0 = normal (no abnormalities) 0</p> <p><input type="radio"/> 1 = non-specific motor abnormalities (less than 50 % confidence) 1</p> <p><input type="radio"/> 2 = motor abnormalities that may be signs of HD (50 - 89 % confidence) 2</p> <p><input type="radio"/> 3 = motor abnormalities that are likely signs of HD (90 - 98 % confidence) 3</p> <p><input type="radio"/> 4 = motor abnormalities that are unequivocal signs of HD (\geq 99 % confidence) 4</p>	<p>diagconf</p>
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17 Form “UHDRS Total Funtional Capacity (TFC)”

General [tfc] 893_1		
Functional score:	<input type="text"/>	tfcscore
Functional Capacity [functcap] 895_1		
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

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

General [function] 849_1	
Functional assessment score:	<input type="text"/> fascore
Functional score incomplete:	<input type="text"/> fscore

Independence Scale [indep1] .Independence 983_1	
Subject's independence in %:	<input type="radio"/> 100 = no special care needed 100 <input type="radio"/> 95 95 <input type="radio"/> 90 = no physical care needed if difficult tasks are avoided 90 <input type="radio"/> 85 85 <input type="radio"/> 80 = pre-disease level of employment changes or ends; cannot perform household chores to pre-disease level, may need help with finances 80 <input type="radio"/> 75 75 <input type="radio"/> 70 = self-care maintained for bathing, limited household duties, e.g. cooking and use of knives, driving terminates; unable to manage finances 70 <input type="radio"/> 65 65 <input type="radio"/> 60 = needs minor assistance in dressing, toileting, bathing; food must be cut for subject 60 <input type="radio"/> 55 55 <input type="radio"/> 50 = 24-hour supervision appropriate; assistance required for bathing, eating, toileting 50 <input type="radio"/> 45 45 <input type="radio"/> 40 = chronic care facility needed; limited self feeding, liquified diet 40 <input type="radio"/> 35 35 <input type="radio"/> 30 = subject provides minimal assistance in own feeding, bathing, toileting 30 <input type="radio"/> 25 25 <input type="radio"/> 20 = no speech, must be fed 20 <input type="radio"/> 15 15 <input type="radio"/> 10 = tube fed, total bed care 10 <input type="radio"/> 5 5

19 Form “Problem Behaviours Assessment Short (PBA-s)”

General [general] 2623_1			
[pbas1]			
Domain scores: [2624] 2624_1	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 [2630] .PBA-s 2630_1			
1. Depressed mood: [2631] 2631_1	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	pbas1sv
	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	pbas1fr
	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	pbas1wo

2. Suicidal ideation: [2635] 2635_1	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	pbas2sv
	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	pbas2fr
	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	pbas2wo
3. Anxiety: [2639] 2639_1	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	pbas3sv
	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

<p>4. Irritability: [2643] 2643_1</p>	<p>a. Severity:</p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas4sv</p>
	<p>b. Frequency:</p>	<p><input type="radio"/> 0 = never/almost never 0</p> <p><input type="radio"/> 1 = seldom (less than once/week) 1</p> <p><input type="radio"/> 2 = sometimes (up to four times a week) 2</p> <p><input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3</p> <p><input type="radio"/> 4 = daily/almost daily for most (or all) of day 4</p>	<p>pbas4fr</p>
	<p>c. Worst:</p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas4wo</p>
<p>5. Angry or aggressive behaviour: [2647] 2647_1</p>	<p>a. Severity:</p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas5sv</p>
	<p>b. Frequency:</p>	<p><input type="radio"/> 0 = never/almost never 0</p> <p><input type="radio"/> 1 = seldom (less than once/week) 1</p> <p><input type="radio"/> 2 = sometimes (up to four times a week) 2</p> <p><input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3</p> <p><input type="radio"/> 4 = daily/almost daily for most (or all) of day 4</p>	<p>pbas5fr</p>
	<p>c. Worst:</p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas5wo</p>

<p><u>6. Lack of initiative (apathy):</u> [2651] 2651_1</p>	<p><u>a. Severity:</u></p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas6sv</p>
	<p><u>b. Frequency:</u></p>	<p><input type="radio"/> 0 = never/almost never 0</p> <p><input type="radio"/> 1 = seldom (less than once/week) 1</p> <p><input type="radio"/> 2 = sometimes (up to four times a week) 2</p> <p><input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3</p> <p><input type="radio"/> 4 = daily/almost daily for most (or all) of day 4</p>	<p>pbas6fr</p>
	<p><u>c. Worst:</u></p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas6wo</p>
<p><u>7. Perseverative thinking or behaviour:</u> [2655] 2655_1</p>	<p><u>a. Severity:</u></p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas7sv</p>
	<p><u>b. Frequency:</u></p>	<p><input type="radio"/> 0 = never/almost never 0</p> <p><input type="radio"/> 1 = seldom (less than once/week) 1</p> <p><input type="radio"/> 2 = sometimes (up to four times a week) 2</p> <p><input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3</p> <p><input type="radio"/> 4 = daily/almost daily for most (or all) of day 4</p>	<p>pbas7fr</p>
	<p><u>c. Worst:</u></p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas7wo</p>

<p>8. Obsessive-Compulsive Behaviours: [2659] 2659_1</p>	<p>a. Severity:</p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas8sv</p>
	<p>b. Frequency:</p>	<p><input type="radio"/> 0 = never/almost never 0</p> <p><input type="radio"/> 1 = seldom (less than once/week) 1</p> <p><input type="radio"/> 2 = sometimes (up to four times a week) 2</p> <p><input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3</p> <p><input type="radio"/> 4 = daily/almost daily for most (or all) of day 4</p>	<p>pbas8fr</p>
	<p>c. Worst:</p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas8wo</p>
<p>9. Delusions / paranoid thinking: [2663] 2663_1</p>	<p>a. Severity:</p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas9sv</p>
	<p>b. Frequency:</p>	<p><input type="radio"/> 0 = never/almost never 0</p> <p><input type="radio"/> 1 = seldom (less than once/week) 1</p> <p><input type="radio"/> 2 = sometimes (up to four times a week) 2</p> <p><input type="radio"/> 3 = frequently (most days/5, 6 or 7 times a week) 3</p> <p><input type="radio"/> 4 = daily/almost daily for most (or all) of day 4</p>	<p>pbas9fr</p>
	<p>c. Worst:</p>	<p><input type="radio"/> 0 = absent 0</p> <p><input type="radio"/> 1 = slight, questionable 1</p> <p><input type="radio"/> 2 = mild (present, not a problem) 2</p> <p><input type="radio"/> 3 = moderate (symptom causing problem) 3</p> <p><input type="radio"/> 4 = severe (almost intolerable for carer) 4</p>	<p>pbas9wo</p>

10. Hallucinations: [2667] 2667_1

a. Severity:

- 0 = absent 0
- 1 = slight, questionable 1
- 2 = mild (present, not a problem) 2
- 3 = moderate (symptom causing problem) 3
- 4 = severe (almost intolerable for carer) 4

pbas10sv

Please specify [modsv] 2669_1

- Modality of hallucinations:
- auditory 1
 - visual 2
 - tactile 3
 - olfactory 4
 - gustatory 5

pbas10sm

b. Frequency:

- 0 = never/almost never 0
- 1 = seldom (less than once/week) 1
- 2 = sometimes (up to four times a week) 2
- 3 = frequently (most days/5, 6 or 7 times a week) 3
- 4 = daily/almost daily for most (or all) of day 4

pbas10fr

c. Worst:

- 0 = absent 0
- 1 = slight, questionable 1
- 2 = mild (present, not a problem) 2
- 3 = moderate (symptom causing problem) 3
- 4 = severe (almost intolerable for carer) 4

pbas10wo

Please specify [modwo] 2673_1

- Modality of hallucinations:
- auditory 1
 - visual 2
 - tactile 3
 - olfactory 4
 - gustatory 5

pbas10wm

11. Disoriented Behaviour: [2675] 2675_1

a. Severity: pbas11sv

- 0 = absent 0
- 1 = slight, questionable 1
- 2 = mild (present, not a problem) 2
- 3 = moderate (symptom causing problem) 3
- 4 = severe (almost intolerable for carer) 4

b. Frequency: pbas11fr

- 0 = never/almost never 0
- 1 = seldom (less than once/week) 1
- 2 = sometimes (up to four times a week) 2
- 3 = frequently (most days/5, 6 or 7 times a week) 3
- 4 = daily/almost daily for most (or all) of day 4

c. Worst: pbas11wo

- 0 = absent 0
- 1 = slight, questionable 1
- 2 = mild (present, not a problem) 2
- 3 = moderate (symptom causing problem) 3
- 4 = severe (almost intolerable for carer) 4

Information [pba1] PBA 1006_1

i) Is informant a relative? pbainfo

- spouse or partner 1
- parent 2
- sibling 3
- child 4
- other relative 5
- friend or neighbor 6
- professional care worker 7
- other 8
- no informant - participant came alone 9

ii) Is informant a household member? pbahshd

- household member (i.e. relative or friend who lives with participant) 1
- not a household member but has frequent contact with participant (most days) 2
- not a household member and sees participant less than three or four times a week 3
- staff of residential care home or hospital 4

20 Form “Core and Extended Cognitive Assessment (Cognitive)” (R3)

[cogs1]

Specifics [cogn3] .Cognitive Assessment 2288_1

Did the participant complete the assessment in their native language and with normal or corrected-to-normal vision and hearing? yes 1 no 0 gen1

Did the participant complete the assessment in their native language? yes 1 no 0 gen2

At what age did the participant learn the language used? years gen3

Did the participant have normal/corrected-to-normal hearing and vision? yes 1 no 0 gen4

Was vision uncorrected (e.g. no glasses during visit)? yes 1 no 0 gen5

Was hearing uncorrected (e.g. no hearing aid worn)? yes 1 no 0 gen6




Core Cognitive Assessment [cognitive] 2341_1




[sdmt1]

Symbol Digit Modality Test completed:  yes 1 no 0 sdmt

Total correct: sdmt1

Total errors: sdmt2

[verfct1]			
Verbal Fluency Test (Category) completed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0		verfct
Category:	<input type="text" value="----"/> <input type="text" value="animals 1"/> <input type="text" value="other 2"/>		verfctd
Total correct (1 min):	<input type="text"/>		verfct5
Total intrusion errors:	<input type="text"/>		verfct6
Total perseverative errors:	<input type="text"/>		verfct7
[scnt1]			
Stroop Color Naming Test completed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0		scnt
Total correct:	<input type="text"/>		scnt1
Total errors:	<input type="text"/>		scnt2
Total self-corrected errors:	<input type="text"/>		scnt3
[swrt1]			
Stroop Word Reading Test completed: 	<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

Extended Cognitive Assessment [cognitiveex] 2342_1			
[sit1]			
Stroop Interference Test completed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0		sit
Total correct:	<input type="text"/>		sit1
Total errors:	<input type="text"/>		sit2
Total self-corrected errors:	<input type="text"/>		sit3
[tm1]			
Trailmaking Test completed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0		trl
Trailmaking Test [2780] 2780_1			
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
[verfit1]			
Verbal Fluency Test (Letters) completed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0		verfit
Total correct (3 min):	<input type="text"/>		verfit05
Total intrusion errors:	<input type="text"/>		verfit06
Total perseverative errors:	<input type="text"/>		verfit07

Extended Neuropsychological Assessment [tests] 2777_1

[hvlt1]

Hopkins Verbal Learning Test-R completed (optional):

yes 1 no 0

hvlt

Hopkins Verbal Learning Test-R [2741] 2741_1

Used form:

---- ▾

hvlt4

form 1 1

form 2 2

form 3 3

Trial 1: correct:

hvltt11

Trial 2: correct:

hvltt21

Trial 3: correct:

hvltt31

Delayed recall correct:

hvlt1

Total repetitions (trials 1-3 & delayed):

hvlt2

Total intrusions (trials 1-3 & delayed):

hvlt3

Recognition: true positives:

hvlt4

Recognition: false positives:

hvlt5

[drs1]

Dementia Rating Scale-2
completed (optional):

yes 1 no 0

mdrs

Dementia Rating Scale-2 [2789] 2789_1

Attention:

mdrs1

Initiation / perseveration:

mdrs2

Construction:

mdrs3

Conceptualization:

mdrs4

Memory:

mdrs5

21 Form “Core and Extended Cognitive Assessment (Cognitive)” (R2)

[cogs1]

Cognitive Assessment [cogtest] 2332_1				
[verfit1]	Verbal Fluency Test - Total correct:	<input type="text"/>		
		verfit05		
[sdmt1]	Symbol Digit Modality Test - Total correct:	<input type="text"/>		
		sdmt1		
Stroop Interference Test: [sdmt] 2333_1	[scnt1]	Colour naming - Total correct:	<input type="text"/>	scnt1
	[swrt1]	Word reading - Total correct:	<input type="text"/>	swrt1
	[sit1]	Interference - Total correct:	<input type="text"/>	sit1

Extended Neuropsychological Assessment [tests] 2777_1		
[hvit1]		
Hopkins Verbal Learning Test-R completed (optional):	<input type="radio"/> yes 1 <input type="radio"/> no 0	hvit
Hopkins Verbal Learning Test-R [2753] 2753_1		
Used form:	<input type="text" value="----"/> form 1 1 form 2 2 form 3 3	hvitd
Trial 1: correct:	<input type="text"/>	hvit11
Trial 2: correct:	<input type="text"/>	hvit21
Trial 3: correct:	<input type="text"/>	hvit31
Delayed recall correct:	<input type="text"/>	hvit1
Total repetitions (trials 1-3 & delayed):	<input type="text"/>	hvit2
Total intrusions (trials 1-3 & delayed):	<input type="text"/>	hvit3
Recognition: true positives:	<input type="text"/>	hvit4
Recognition: false positives:	<input type="text"/>	hvit5

[drs1]

Dementia Rating Scale-2 completed (optional): yes 1 no 0 mdrs

Dementia Rating Scale-2 [2789] 2789_1

Attention: mdrs1

Initiation / perseveration: mdrs2

Construction: mdrs3

Conceptualization: mdrs4

Memory: mdrs5

22 Form “Premature End of Study (End)”

[end1]

General [42966] DS 2828_1		
Day of end of study:	<input type="text"/>	rfendy
End of Study [end] DS 2830_1		
Specify primary reason for patient's premature discontinuation from study:	<input type="radio"/> event or intercurrent illness of a nature requiring withdrawal 1 <input type="radio"/> request of primary care physician, site investigator 2 <input type="radio"/> subject's request (includes carer/spouse/legal representative's request) 3 <input type="radio"/> failure of subject to return to follow-up visit and failure to be located by investigator 4 <input type="radio"/> institutionalized (will not be followed further) 5 <input type="radio"/> other 6	dsterm

23 Form “Hospital Anxiety and Depression Scale/Snaith Irritability Scale (HADS-SIS)”

General [hads] JHADS 1972_3		
Anxiety subscore:	<input type="text"/>	anxscore
Depression subscore:	<input type="text"/>	hads_depscore
Irritability subscore:	<input type="text"/>	irrscore
Outward irritability subscore:	<input type="text"/>	outscore
Inward irritability subscore:	<input type="text"/>	inwscore

24 Form “Short Form Health Survey – 36v1 (SF-36)”

[sf36v1_1]

General [1809] 1809_1	
SF-36 score:	<input type="text"/> sfscore

25 Form “Short Form Health Survey – 36v2 (SF-36)”

[sf36v2_2]

Scoring [1922] 1922_1	
SF-36 v.2 score:	<input type="text"/>
	sfscore_v2

26 Form "CSSRS-BL"

[cssrs2]

Suicidal Ideation - For Lifetime, rate the period when the participant felt the most suicidal. [2092] 2092_1

1. **Wish to be dead:** [2093] 2093_1 Have you wished you were dead or wished you could go to sleep and not wake up? yes 1 no 0 sid1

2. **Non-Specific Active Suicidal Thoughts:** [2097] 2097_1 Have you actually had any thoughts of killing yourself? yes 1 no 0 sid2

Suicidal Ideation (continued) [2104] 2104_1

3. **Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act:** [2102] 2102_1 Have you been thinking about how you might do this? yes 1 no 0 sid3

4. **Active Suicidal Ideation with Some Intent to Act, without Specific Plan:** [2106] 2106_1 Have you had these thoughts and had some intention of acting on them? yes 1 no 0 sid4

5. **Active Suicidal Ideation with Specific Plan and Intent:** [2110] 2110_1 Have you started to work out or worked out the details of how to kill yourself? Do you intend to carry out this plan? yes 1 no 0 sid5

Intensity of Ideation - Most Severe [2114] 2114_1

Most Severe Ideation: [2115] 2115_1 Type # (1-5): 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

Frequency: [2118] 2118_1 How many times have you had these thoughts? Less than once a week 1 int2
 Once a week 2
 2-5 times in week 3
 Daily or almost daily 4
 Many times each day 5

Duration: [2120] 2120_1 When you have the thoughts, how long do they last? Fleeting - few seconds or minutes 1 int3
 Less than 1 hour/some of the time 2
 1-4 hours/a lot of time 3
 4-8 hours/most of day 4
 More than 8 hours/persistent or continuous 5

Controllability: [2122] 2122_1	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: [2124] 2124_1	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: [2126] 2126_1	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 [2128] 2128_1			
Actual Attempt: [2129] 2129_1	Actual attempt:	<input type="radio"/> yes 1 <input type="radio"/> no 0 Total # of attempts: <input type="text"/>	sbh-1 sbh-1n
	Has subject engaged in Non-Suicidal Self-Injurious Behavior?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sbh-2
Interrupted Attempt: [2135] 2135_1	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 Total # of interrupted: <input type="text"/>	sbh-3 sbh-3n
Aborted Attempt: [2140] 2140_1	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?	<input type="radio"/> yes 1 <input type="radio"/> no 0 Total # of aborted: <input type="text"/>	sbh-4 sbh-4n
Preparatory Acts or Behavior: [2145] 2145_1	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)?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sbh-5
Suicidal Behavior: [2149] 2149_1	Suicidal behaviour was present during the assessment period?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sbh-6

Answer for Actual Attempts Only (2151) (0-9999) (10) (1)

Most recent attempt: [2152] 2152_1	Day of most recent attempt:	<input type="text"/>	attmp10y
	Actual Lethality/Medical Damage:	<input type="text"/> <ul style="list-style-type: none"> No physical damage 0 Minor physical damage 1 Moderate physical damage 2 Moderately severe physical damage 3 Severe physical damage 4 Death 5 	attmp11
	Potential Lethality:	<input type="text"/> <ul style="list-style-type: none"> not likely to result in injury 0 likely to result in injury 1 likely to result in death 2 	attmp12
Most lethal attempt: [2157] 2157_1	Day of most lethal attempt:	<input type="text"/>	attmp20y
	Actual Lethality/Medical Damage:	<input type="text"/> <ul style="list-style-type: none"> No physical damage 0 Minor physical damage 1 Moderate physical damage 2 Moderately severe physical damage 3 Severe physical damage 4 Death 5 	attmp21
	Potential Lethality:	<input type="text"/> <ul style="list-style-type: none"> not likely to result in injury 0 likely to result in injury 1 likely to result in death 2 	attmp22
Initial/First attempt: [2162] 2162_1	Day of Initial/First Attempt:	<input type="text"/>	attmp30y
	Actual Lethality/Medical Damage:	<input type="text"/> <ul style="list-style-type: none"> No physical damage 0 Minor physical damage 1 Moderate physical damage 2 Moderately severe physical damage 3 Severe physical damage 4 Death 5 	attmp31
	Potential Lethality:	<input type="text"/> <ul style="list-style-type: none"> not likely to result in injury 0 likely to result in injury 1 likely to result in death 2 	attmp32

27 Form "CSSRS-FUP"

[cssrs2]

Suicidal Ideation - Rate the period since last visit. [2168] 2168_1		
1. Wish to be dead: [2169] 2169_1	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
2. Non-Specific Active Suicidal Thoughts: [2173] 2173_1	Have you actually had any thoughts of killing yourself?	<input type="radio"/> yes 1 <input type="radio"/> no 0 sid2
Suicidal Ideation (continued) [2177] .C-9885 2177_1		
3. Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act: [2178] 2178_1	Have you been thinking about how you might do this?	<input type="radio"/> yes 1 <input type="radio"/> no 0 sid3
4. Active Suicidal Ideation with Some Intent to Act, without Specific Plan: [2182] 2182_1	Have you had these thoughts and had some intention of acting on them?	<input type="radio"/> yes 1 <input type="radio"/> no 0 sid4
5. Active Suicidal Ideation with Specific Plan and Intent: [2186] 2186_1	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
Intensity of Ideation - Most Severe [2190] .C-9886 2190_1		
Most Severe Ideation: [2191] 2191_1	Type # (1-5):	<input type="radio"/> Wish to be dead 1 <input type="radio"/> Non-Specific Active Suicidal Thoughts 2 <input type="radio"/> Active Suicidal Ideation with Any Methods (not Plan) without Intent to Act 3 <input type="radio"/> Active Suicidal Ideation with Some Intent to Act, without Specific Plan 4 <input type="radio"/> Active Suicidal Ideation with Specific Plan and Intent 5 <input type="text"/> int1
Frequency: [2194] 2194_1	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: [2196] 2196_1	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: [2198] 2198_1	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: [2200] 2200_1	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: [2202] 2202_1	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 [2204] 2204_1			
Actual Attempt: [2205] 2205_1	Actual attempt:	<input type="radio"/> yes 1 <input type="radio"/> no 0	sbh1
	Total # of attempts:	<input type="text"/>	sbh1n
	Has subject engaged in Non-Suicidal Self-Injurious Behavior?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sbh2
Interrupted Attempt: [2211] 2211_1	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
Aborted Attempt: [2216] 2216_1	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?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sbh4
	Total # of aborted:	<input type="text"/>	sbh4n
Preparatory Acts or Behavior: [2221] 2221_1	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)?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sbh5
Suicidal Behavior: [2225] 2225_1	Suicidal behaviour was present during the assessment period?	<input type="radio"/> yes 1 <input type="radio"/> no 0	sbh6
Completed Suicide: [2227] 2227_1	Completed suicide was present during the assessment period:	<input type="radio"/> yes 1 <input type="radio"/> no 0	sbh7

Answer for Actual Attempts Only [2230] 2230_1

Most lethal attempt: [2230] 2230_1

Day of most lethal attempt:

Actual Lethality/Medical Damage:

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:

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

atmp2dy

atmp21

atmp22

28 Form "Behaviour" (R3)

[behavior2]

General [behavior] 951_1

Behavioral score: behscore

Behavioral score incomplete: bscore

[behavior2]

Sub-scores: [998] 998_1

Depression: behaviour_depscore

Drive/executive function: defscore

Irritability/aggression: behaviour_irascore

Psychosis: behaviour_pyscore

Behavioral Assessment [954] 954_1

Depressed mood: [955] 955_1

Frequency: 0 = never or almost never 0 1 = seldom, less than once a week 1 2 = sometimes, at least once a week 2 3 = frequently, several times a week 3 4 = very frequently, most of the time 4 deprfr

Severity: 0 = no mood disturbance 0 1 = questionable or equivocal 1 2 = mild, responds to redirection and reassurance 2 3 = moderately depressed, expresses distress 3 4 = severe, significant suffering and loss of functioning 4 deprsv

Low self-esteem/guilt: [958] 958_1

Frequency: 0 = never or almost never 0 1 = seldom, less than once a week 1 2 = sometimes, at least once a week 2 3 = frequently, several times a week 3 4 = very frequently, most of the time 4 guiltfr

Severity: 0 = no evidence 0 1 = questionable or equivocal 1 2 = mild, definitely present 2 3 = moderate, some distress 3 4 = severe 4 guiltsv

Anxiety: [961] 961_1	Frequency:	<input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4	anxifr
	Severity:	<input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = questionable or equivocal 1 <input type="radio"/> 2 = mild, responds to reassurance 2 <input type="radio"/> 3 = moderate, impacts on everyday life 3 <input type="radio"/> 4 = severe, causing a profound restriction of activities 4	anxsv
Suicidal thoughts: [964] 964_1	Frequency:	<input type="radio"/> 0 = not thinking about suicide or self harm 0 <input type="radio"/> 1 = seldom thinking about suicide - less than once a month 1 <input type="radio"/> 2 = sometimes thinking about suicide - at least once a month 2 <input type="radio"/> 3 = frequently thinking about suicide - at least once a week 3 <input type="radio"/> 4 = often thinks about suicide - sometimes for days and weeks on end 4	suicfr
	Severity:	<input type="radio"/> 0 = no suicidal thoughts 0 <input type="radio"/> 1 = no thoughts at current time, but person talks about suicide as a potential option 1 <input type="radio"/> 2 = fleeting thoughts about it 2 <input type="radio"/> 3 = seriously considered suicide but has no plan 3 <input type="radio"/> 4 = has a plan and is actively preparing 4	suicsv
Disruptive or aggressive behavior: [967] 967_1	Frequency:	<input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a month 1 <input type="radio"/> 2 = sometimes, at least once a month 2 <input type="radio"/> 3 = frequently, at least once a week 3 <input type="radio"/> 4 = very frequently, everyday 4	aggrfr
	Severity:	<input type="radio"/> 0 = behavior well-controlled 0 <input type="radio"/> 1 = verbal threats or intimidating behavior 1 <input type="radio"/> 2 = mild physically or verbally threatening behavior 2 <input type="radio"/> 3 = clear physical threat (moderately aggressive), bumping, shoving, verbal outburst 3 <input type="radio"/> 4 = clear physical threat (severe aggression) striking/hitting, or definite intention to cause injury 4	aggrsv
Irritable behavior: [970] 970_1	Frequency:	<input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4	irritfr
	Severity:	<input type="radio"/> 0 = behavior well-controlled 0 <input type="radio"/> 1 = questionable or equivocal 1 <input type="radio"/> 2 = definite but mild 2 <input type="radio"/> 3 = moderate, others change their behavior to avoid irritating subject 3 <input type="radio"/> 4 = severe irritability 4	irritsv

<p>Perseverative/obsessional thinking: [973] 973_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4 </p> <p> <input type="radio"/> 0 = thinking is always flexible 0 <input type="radio"/> 1 = questionable or equivocal 1 <input type="radio"/> 2 = gets stuck on certain ideas but can be easily redirected 2 <input type="radio"/> 3 = moderate - gets stuck on certain ideas, difficult to redirect 3 <input type="radio"/> 4 = severe - gets stuck on certain ideas, and does not respond to redirection 4 </p>	<p>obsessfr</p> <p>obsesssv</p>
<p>Compulsive behavior: [976] 976_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4 </p> <p> <input type="radio"/> 0 = behavior always well-controlled 0 <input type="radio"/> 1 = equivocal - has a mild impulse not sufficient to act on 1 <input type="radio"/> 2 = mild - has impulse, acts on impulse, but can stop 2 <input type="radio"/> 3 = moderate - has impulse, acts on it and sometimes cannot stop 3 <input type="radio"/> 4 = severe - has impulse, acts on it and cannot stop 4 </p>	<p>compulfr</p> <p>compulsv</p>
<p>Delusions: [979] 979_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = seldom, less than once a month 1 <input type="radio"/> 2 = sometimes, at least once a month 2 <input type="radio"/> 3 = frequently, at least once a week 3 <input type="radio"/> 4 = very frequently, sometimes for days on end 4 </p> <p> <input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = has delusional idea(s), not sure it is true 1 <input type="radio"/> 2 = convinced of idea(s) but allows that the idea is not true 2 <input type="radio"/> 3 = utterly convinced of the idea(s) 3 <input type="radio"/> 4 = utterly convinced of the idea(s), behavior is determined by the delusion(s) 4 </p>	<p>delusfr</p> <p>delussv</p>
<p>Hallucinations: [982] 982_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = no evidence of hallucinations 0 <input type="radio"/> 1 = seldom, less than once a month 1 <input type="radio"/> 2 = sometimes, at least once a month 2 <input type="radio"/> 3 = frequently, at least once a week 3 <input type="radio"/> 4 = often, sometimes for days on end 4 </p> <p> <input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = has hallucinations, but doubts they are real 1 <input type="radio"/> 2 = convinced of the reality of the hallucinations, but allows that it is possible that they are not real 2 <input type="radio"/> 3 = utterly convinced of the hallucinations being real, but not acting on them 3 <input type="radio"/> 4 = severe - has hallucinations that are vivid, subject is utterly convinced they are real and the hallucinations severely disrupt behavior 4 </p>	<p>hallucfr</p> <p>hallucsv</p>

<p>Apathy: [985] 985_1</p>	<p>Frequency:</p>	<p> <input type="radio"/> 0 = never 0 <input type="radio"/> 1 = seldom apathetic, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4 </p>	<p>apathfr</p>
	<p>Severity:</p>	<p> <input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = equivocal 1 <input type="radio"/> 2 = mild apathy - subject not initiating conversation or activity but is responsive 2 <input type="radio"/> 3 = moderate apathy - sometimes responds to efforts to get involved in conversation/activities 3 <input type="radio"/> 4 = severe apathy - generally unresponsive to attempts to involve subject in activities or conversation 4 </p>	<p>apathsv</p>
<p>Behavioral Milestones: [988] 988_1</p>	<p>Does the examiner believe the participant is confused?</p>	<p><input type="radio"/> 1 = yes 1 <input type="radio"/> 0 = no 0</p>	<p>confus</p>
	<p>Does the examiner believe the participant is demented?</p>	<p><input type="radio"/> 1 = yes 1 <input type="radio"/> 0 = no 0</p>	<p>dement</p>
	<p>Does the examiner believe the participant is depressed?</p>	<p><input type="radio"/> 1 = yes 1 <input type="radio"/> 0 = no 0</p>	<p>depressam</p>
	<p>Does the participant require pharmacotherapy for depression?</p>	<p><input type="radio"/> 1 = yes 1 <input type="radio"/> 0 = no 0</p>	<p>deprfr</p>
	<p>Does the participant require pharmacotherapy for irritability?</p>	<p><input type="radio"/> 1 = yes 1 <input type="radio"/> 0 = no 0</p>	<p>irritfr</p>
<p>Information sources: [994] 994_1</p>	<p>Was the behavioral assessment information obtained from:</p>	<p> <input type="radio"/> 1 = participant only 1 <input type="radio"/> 2 = participant and family/companion 2 </p>	<p>isobt</p>

29 Form “Behaviour” (R2)

[behavior2]

General [behavior] 951_1			
Behavioral score:	<input type="text"/>		behscore
Behavioral score incomplete:	<input type="text"/>		biscore
Behavioral Assessment [955-9] 956_1			
Depressed mood: [955] 955_1	Frequency:	<input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4	deprfr
	Severity:	<input type="radio"/> 0 = no mood disturbance 0 <input type="radio"/> 1 = questionable or equivocal 1 <input type="radio"/> 2 = mild, responds to redirection and reassurance 2 <input type="radio"/> 3 = moderately depressed, expresses distress 3 <input type="radio"/> 4 = severe, significant suffering and loss of functioning 4	deprsv
Low self-esteem/guilt: [958] 958_1	Frequency:	<input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4	guilfr
	Severity:	<input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = questionable or equivocal 1 <input type="radio"/> 2 = mild, definitely present 2 <input type="radio"/> 3 = moderate, some distress 3 <input type="radio"/> 4 = severe 4	guilsv
Anxiety: [961] 961_1	Frequency:	<input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4	anulfr
	Severity:	<input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = questionable or equivocal 1 <input type="radio"/> 2 = mild, responds to reassurance 2 <input type="radio"/> 3 = moderate, impacts on everyday life 3 <input type="radio"/> 4 = severe, causing a profound restriction of activities 4	ansiv

<p>Suicidal thoughts: [964] 964_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = not thinking about suicide or self harm 0 <input type="radio"/> 1 = seldom thinking about suicide - less than once a month 1 <input type="radio"/> 2 = sometimes thinking about suicide - at least once a month 2 <input type="radio"/> 3 = frequently thinking about suicide - at least once a week 3 <input type="radio"/> 4 = often thinks about suicide - sometimes for days and weeks on end 4 </p> <p> <input type="radio"/> 0 = no suicidal thoughts 0 <input type="radio"/> 1 = no thoughts at current time, but person talks about suicide as a potential option 1 <input type="radio"/> 2 = fleeting thoughts about it 2 <input type="radio"/> 3 = seriously considered suicide but has no plan 3 <input type="radio"/> 4 = has a plan and is actively preparing 4 </p>	<p>suicfr</p> <p>suicsv</p>
<p>Disruptive or aggressive behavior: [967] 967_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a month 1 <input type="radio"/> 2 = sometimes, at least once a month 2 <input type="radio"/> 3 = frequently, at least once a week 3 <input type="radio"/> 4 = very frequently, everyday 4 </p> <p> <input type="radio"/> 0 = behavior well-controlled 0 <input type="radio"/> 1 = verbal threats or intimidating behavior 1 <input type="radio"/> 2 = mild physically or verbally threatening behavior 2 <input type="radio"/> 3 = clear physical threat (moderately aggressive), bumping, shoving, verbal outburst 3 <input type="radio"/> 4 = clear physical threat (severe aggression) striking/hitting, or definite intention to cause injury 4 </p>	<p>aggrfr</p> <p>aggrsv</p>
<p>Irritable behavior: [970] 970_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4 </p> <p> <input type="radio"/> 0 = behavior well-controlled 0 <input type="radio"/> 1 = questionable or equivocal 1 <input type="radio"/> 2 = definite but mild 2 <input type="radio"/> 3 = moderate, others change their behavior to avoid irritating subject 3 <input type="radio"/> 4 = severe irritability 4 </p>	<p>irritfr</p> <p>irritsv</p>
<p>Perseverative/obsessional thinking: [973] 973_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4 </p> <p> <input type="radio"/> 0 = thinking is always flexible 0 <input type="radio"/> 1 = questionable or equivocal 1 <input type="radio"/> 2 = gets stuck on certain ideas but can be easily redirected 2 <input type="radio"/> 3 = moderate - gets stuck on certain ideas, difficult to redirect 3 <input type="radio"/> 4 = severe - gets stuck on certain ideas, and does not respond to redirection 4 </p>	<p>obsessfr</p> <p>obsesssv</p>

<p>Compulsive behavior: [976] 976_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = never or almost never 0 <input type="radio"/> 1 = seldom, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4 </p> <p> <input type="radio"/> 0 = behavior always well-controlled 0 <input type="radio"/> 1 = equivocal - has a mild impulse not sufficient to act on 1 <input type="radio"/> 2 = mild - has impulse, acts on impulse, but can stop 2 <input type="radio"/> 3 = moderate - has impulse, acts on it and sometimes cannot stop 3 <input type="radio"/> 4 = severe - has impulse, acts on it and cannot stop 4 </p>	<p>compulfr</p> <p>compulsv</p>
<p>Delusions: [979] 979_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = seldom, less than once a month 1 <input type="radio"/> 2 = sometimes, at least once a month 2 <input type="radio"/> 3 = frequently, at least once a week 3 <input type="radio"/> 4 = very frequently, sometimes for days on end 4 </p> <p> <input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = has delusional idea(s), not sure it is true 1 <input type="radio"/> 2 = convinced of idea(s) but allows that the idea is not true 2 <input type="radio"/> 3 = utterly convinced of the idea(s) 3 <input type="radio"/> 4 = utterly convinced of the idea(s), behavior is determined by the delusion(s) 4 </p>	<p>delusfr</p> <p>delussv</p>
<p>Hallucinations: [982] 982_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = no evidence of hallucinations 0 <input type="radio"/> 1 = seldom, less than once a month 1 <input type="radio"/> 2 = sometimes, at least once a month 2 <input type="radio"/> 3 = frequently, at least once a week 3 <input type="radio"/> 4 = often, sometimes for days on end 4 </p> <p> <input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = has hallucinations, but doubts they are real 1 <input type="radio"/> 2 = convinced of the reality of the hallucinations, but allows that it is possible that they are not real 2 <input type="radio"/> 3 = utterly convinced of the hallucinations being real, but not acting on them 3 <input type="radio"/> 4 = severe - has hallucinations that are vivid, subject is utterly convinced they are real and the hallucinations severely disrupt behavior 4 </p>	<p>hallucfr</p> <p>hallucsv</p>
<p>Apathy: [985] 985_1</p>	<p>Frequency:</p> <p>Severity:</p>	<p> <input type="radio"/> 0 = never 0 <input type="radio"/> 1 = seldom apathetic, less than once a week 1 <input type="radio"/> 2 = sometimes, at least once a week 2 <input type="radio"/> 3 = frequently, several times a week 3 <input type="radio"/> 4 = very frequently, most of the time 4 </p> <p> <input type="radio"/> 0 = no evidence 0 <input type="radio"/> 1 = equivocal 1 <input type="radio"/> 2 = mild apathy - subject not initiating conversation or activity but is responsive 2 <input type="radio"/> 3 = moderate apathy - sometimes responds to efforts to get involved in conversation/activities 3 <input type="radio"/> 4 = severe apathy - generally unresponsive to attempts to involve subject in activities or conversation 4 </p>	<p>apathfr</p> <p>apathsv</p>

<p>Behavioral Milestones: [988] 988_1</p>	<p>Does the examiner believe the participant is confused?</p> <p>Does the examiner believe the participant is demented?</p> <p>Does the examiner believe the participant is depressed?</p> <p>Does the participant require pharmacotherapy for depression?</p> <p>Does the participant require pharmacotherapy for irritability?</p>	<p><input type="radio"/> 1 = yes <input type="radio"/> 0 = no</p> <p><input type="radio"/> 1 = yes <input type="radio"/> 0 = no</p> <p><input type="radio"/> 1 = yes <input type="radio"/> 0 = no</p> <p><input type="radio"/> 1 = yes <input type="radio"/> 0 = no</p> <p><input type="radio"/> 1 = yes <input type="radio"/> 0 = no</p>	<p>confus</p> <p>dement</p> <p>deprexam</p> <p>deprfr</p> <p>irrtfr</p> <p>isbt</p>
<p>Information sources: [994] 994_1</p>	<p>Was the behavioral assessment information obtained from:</p>	<p><input type="radio"/> 1 = participant only ¹</p> <p><input type="radio"/> 2 = participant and family/companion ²</p>	

30 Form "Hamilton"

[ham1]

General [2344] 2344_1	
Hamilton Score:	<input type="text"/> hamscore

Revision History

Version	Summary of Changes
2016-10-R1	Initial version of annotated CRF for the first REGISTRY Periodic Dataset.