



Annotated Case Report Form (CRF) for Enroll-HD 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 Enroll-HD's eCRF (electronic Case Report Form). 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	PharmacoTx	NutSuppl	NonPharmacoTx	Comorbid	Event	Enroll
<i>Enrollment</i>		✓						
<i>Demog</i>	✓							
<i>MHx</i>								✓
<i>HD CC</i>	✓							
<i>PharmacoTx</i>			✓					
<i>NutSuppl</i>				✓				
<i>NonPharmacoTx</i>					✓			
<i>Comorbid</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	PharmacoTx	NutSuppl	NonPharmacoTx	Comorbid	Event	Enroll
<i>PBA-s BL</i>								✓
<i>Cognitive</i>								✓
<i>HADS-SIS</i>								✓
<i>MMSE</i>								✓
<i>Physio</i>								✓
<i>SF12</i>								✓
<i>WPAI-SHP</i>								✓
<i>CSSRS BL</i>								✓
<i>CSSRS FUP</i>								✓
<i>Event</i>							✓	
<i>End</i>		✓						
<i>Missed Visit</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”

Enrollment [enrlmnt1] 5452_1

Day of informed consent: rfidy

[varitems12]

Participant category:

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

Optional Components: [enrlmnt2] 359_1


Family History: no 0 fhx

Variable “hdcat”

Label of the variable “hdcat”

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

4 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:	race
	<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
[dm4]	
Handedness: 	handed
	<input type="radio"/> right 1 <input type="radio"/> left 2 <input type="radio"/> mixed 3

5 Form “Medical History (MHx)”

Past Medical History [mhx4] 376_1

Has the participant had alcohol problems in the past? yes 1 no 0 hxalcab

Has the participant ever smoked? yes 1 no 0 hxtobab

Packyears: hxpacky

Has the participant ever abused drugs? yes 1 no 0 hxdrugab

Drug use for non-medical reasons? [384] 384_1

	Abuse	Frequency
Marijuana	<input type="text" value="----"/> hxmar yes 1 no 0	<input type="text" value="----"/> hxmarfrq seldom 1 occasionally 2 frequently 3
Heroin	<input type="text" value="----"/> hxher yes 1 no 0	<input type="text" value="----"/> hxherfrq seldom 1 occasionally 2 frequently 3
Cocaine	<input type="text" value="----"/> hxcoc yes 1 no 0	<input type="text" value="----"/> hxcocfrq seldom 1 occasionally 2 frequently 3
Club drugs (Ecstasy, GHB, Roofies)	<input type="text" value="----"/> hxclb yes 1 no 0	<input type="text" value="----"/> hxclbfrq seldom 1 occasionally 2 frequently 3

Amphetamines	<input type="text" value="----"/> yes 1 no 0	<input type="text" value="----"/> seldom 1 occasionally 2 frequently 3
Ritalin	<input type="text" value="----"/> yes 1 no 0	<input type="text" value="----"/> seldom 1 occasionally 2 frequently 3
Hallucinogens	<input type="text" value="----"/> yes 1 no 0	<input type="text" value="----"/> seldom 1 occasionally 2 frequently 3
Inhalants	<input type="text" value="----"/> yes 1 no 0	<input type="text" value="----"/> seldom 1 occasionally 2 frequently 3
Opium	<input type="text" value="----"/> yes 1 no 0	<input type="text" value="----"/> seldom 1 occasionally 2 frequently 3
Painkillers	<input type="text" value="----"/> yes 1 no 0	<input type="text" value="----"/> seldom 1 occasionally 2 frequently 3
Barbiturates/sedatives	<input type="text" value="----"/> yes 1 no 0	<input type="text" value="----"/> seldom 1 occasionally 2 frequently 3
Tranquilizers	<input type="text" value="----"/> yes 1 no 0	<input type="text" value="----"/> seldom 1 occasionally 2 frequently 3

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>	<input type="text"/> age (years)	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>	<input type="text"/> age (years)	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>	<input type="text"/> age (years)	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>	<input type="text"/> age (years)	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 [hdlhc] 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 sxvest

Rater's estimate of symptom onset: sxrater

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

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

Suicidal 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

NOTE: This form is part of the “profile” dataset!

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="----"/> <small>cmcat</small>	<input type="text"/> <small>cmdostot</small>	<input type="text" value="----"/> <small>cmdosunit</small>	<input type="text" value="----"/> <small>cmdosfrq</small>	<input type="text"/> <small>cmstdy</small>	<input type="checkbox"/> 1 <small>cmenf</small>	<input type="text"/> <small>cmendy</small>
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="----"/> <small>cmcat</small>	<input type="text"/> <small>cmdostot</small>	<input type="text" value="----"/> <small>cmdosunit</small>	<input type="text" value="----"/> <small>cmdosfrq</small>	<input type="text"/> <small>cmstdy</small>	<input type="checkbox"/> 1 <small>cmenf</small>	<input type="text"/> <small>cmendy</small>
3. <input type="text" value="----"/> <small>cmcat</small>	<input type="text"/> <small>cmdostot</small>	<input type="text" value="----"/> <small>cmdosunit</small>	<input type="text" value="----"/> <small>cmdosfrq</small>	<input type="text"/> <small>cmstdy</small>	<input type="checkbox"/> 1 <small>cmenf</small>	<input type="text"/> <small>cmendy</small>

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.	<div style="border: 1px solid black; padding: 2px;">----</div> <ul style="list-style-type: none"> 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"/>	<input type="text"/>	<div style="border: 1px solid black; padding: 2px;">----</div> <ul style="list-style-type: none"> daily 1 weekly 2 monthly 3 as needed 4 	<input type="text"/>	<input type="checkbox"/> 1 <input type="text"/>
2.	<div style="border: 1px solid black; padding: 2px;">----</div>	<input type="text"/>	<input type="text"/>	<div style="border: 1px solid black; padding: 2px;">----</div>	<input type="text"/>	<input type="checkbox"/> 1 <input type="text"/>
3.	<div style="border: 1px solid black; padding: 2px;">----</div>	<input type="text"/>	<input type="text"/>	<div style="border: 1px solid black; padding: 2px;">----</div>	<input type="text"/>	<input type="checkbox"/> 1 <input type="text"/>

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="button" value="v"/> mhbodsys	<input type="text"/> mhstdy	<input type="checkbox"/> 1 mhenrf	<input type="text"/> mhendy
		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			
2. <input type="text"/>	modify <input type="text"/> decod ↗ mhterm	---- <input type="button" value="v"/> mhbodsys	<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="button" value="v"/> mhbodsys	<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="button" value="v"/> mhbodsys	<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="button" value="v"/> mhbodsys	<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="button" value="v"/> mhbodsys	<input type="text"/> mhstdy	<input type="checkbox"/> 1 mhenrf	<input type="text"/> mhendy

11 Form “Reportable Event Monitoring (Event)”

General [3007] 3007_1	
Day of report:	<input type="text"/> evtdy
Reportable Event [3009] 3009_1	
Reportable event codes:	<input type="radio"/> suicide attempts 01 evtcode <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
Event term:	<input type="text"/> modify decod evtterm
Details of Reportable Event [3014] 3014_1	
Onset day:	<input type="text"/> evtstdy
Date estimated:	<input type="radio"/> yes 1 <input type="radio"/> no 0 stdtcest
Resolved:	<input type="radio"/> yes 1 <input type="radio"/> no 0 evtongo
End day:	<input type="text"/> evtendy
DSMC Review [4750] 4750_1	
Status of DSMC review:	<input type="radio"/> pending review 1 evtdsmc <input type="radio"/> ongoing review 2 <input type="radio"/> closed/completed review 3

12 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

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

General Variable Items I [often] 657_1			
[varitems2]			
Weight (kg)	<input type="text"/>	weight	
Height (cm)	<input type="text"/>	height	
BMI:	<input type="text"/>		bmi
[varitems3]			
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
	Packyears:	<input type="text"/>	packy
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? [787] 787_1		

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

General Variable Items II [rarely] 628_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

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	emplhrsn
Retired due to:	<input type="radio"/> ill health 1 <input type="radio"/> age 2	emplnrd
<hr/>		
[varitems15]		
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 [varitems14] AC 3920 _1

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

[varitems11]

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

General Variable Items I [often] 657_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: alcurits

Does the participant currently smoke? yes 1 no 0 tobab

Packyears: packy

Current caffeine use? yes 1 no 0 cafab

Do you drink more than 3 cups of coffee, tea and cola drinks combined per day? yes 1 no 0 cafpd

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" value="----"/> her yes 1 no 0	<input type="text" value="----"/> herfrq seldom 1 occasionally 2 frequently 3
Cocaine	<input type="text" value="----"/> coc yes 1 no 0	<input type="text" value="----"/> cocfrq seldom 1 occasionally 2 frequently 3
Club drugs (Ecstasy, GHB, Roofies)	<input type="text" value="----"/> clb yes 1 no 0	<input type="text" value="----"/> clbfrq seldom 1 occasionally 2 frequently 3
Amphetamines	<input type="text" value="----"/> amp yes 1 no 0	<input type="text" value="----"/> 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 pak pakfrq
 yes 1 seldom 1
 no 0 occasionally 2
 frequently 3

Barbiturates/sedatives bar barfrq
 yes 1 seldom 1
 no 0 occasionally 2
 frequently 3

Tranquilizers trq trqfrq
 yes 1 seldom 1
 no 0 occasionally 2
 frequently 3

General Variable Items II [rarely] (0001)

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

[varitems12]

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

[varitems7]

Marital status: single 1 maristat
 married 3
 partnership 2
 divorced 4
 widowed 5
 legally separated 6

Residence:	<input type="radio"/> rural 1 <input type="radio"/> village 2 <input type="radio"/> town 3 <input type="radio"/> city 4	res
<hr/>		
[varitem10]		
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
<hr/>		
[varitem13]		
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	emplhrsn
Retired due to:	<input type="radio"/> ill health 1 <input type="radio"/> age 2	emplnrd
<hr/>		
[varitem15]		
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 [varItems14] SC 3926_1

Have you had to stop or reduce work due to your health? yes 1 no 0 rdcwk

How many days in the last 6 months have you had off work because of HD? days rdcwkd

How many fewer hours per week have you worked because of HD? hours/week rdcwkhw

[varItems11]

Since the last visit have there been [chklist] 036_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 “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 | 0 = complete (normal) |
| <input type="radio"/> 1 | <input type="radio"/> 1 | 1 = jerky movement |
| <input type="radio"/> 2 | <input type="radio"/> 2 | 2 = interrupted pursuits/full range |
| <input type="radio"/> 3 | <input type="radio"/> 3 | 3 = incomplete range |
| <input type="radio"/> 4 ocularh | <input type="radio"/> 4 ocularv | 4 = cannot pursue |

Saccade initiation: [140] 140_1

Horizontal Vertical

- | | | |
|----------------------------------|----------------------------------|---|
| <input type="radio"/> 0 | <input type="radio"/> 0 | 0 = normal |
| <input type="radio"/> 1 | <input type="radio"/> 1 | 1 = increased latency only |
| <input type="radio"/> 2 | <input type="radio"/> 2 | 2 = suppressible blinks or head movements to initiate |
| <input type="radio"/> 3 | <input type="radio"/> 3 | 3 = unsuppressible head movements |
| <input type="radio"/> 4 sacinith | <input type="radio"/> 4 sacinitv | 4 = cannot initiate saccades |

Saccade velocity: [144] 144_1

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 <i>sacvelh</i>	<input type="radio"/> 4 <i>sacvelv</i>	4 = incomplete range

Dysarthria: dysarth

- 0 = normal 0
- 1 = unclear, no need to repeat 1
- 2 = must repeat to be understood 2
- 3 = mostly incomprehensible 3
- 4 = anarthria 4

Tongue protrusion: tongue

- 0 = can hold tongue fully protruded for 10 sec 0
- 1 = cannot keep fully protruded for 10 sec 1
- 2 = cannot keep fully protruded for 5 sec 2
- 3 = cannot fully protrude tongue 3
- 4 = cannot protrude tongue beyond lips 4

Finger taps: [150] 150_1

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 <i>fingtapr</i>	<input type="radio"/> 4 <i>fingtapl</i>	4 = can barely perform task (0-2/5 sec.)

<p><u>Bradykinesia-body:</u></p>	<p><input type="radio"/> 0 = normal 0</p> <p><input type="radio"/> 1 = minimally slow (?normal) 1</p> <p><input type="radio"/> 2 = mildly but clearly slow 2</p> <p><input type="radio"/> 3 = moderately slow, some hesitation 3</p> <p><input type="radio"/> 4 = markedly slow, long delays in initiation 4</p>	brady																																																
<p><u>Maximal dystonia:</u> [164] 164_1</p>	<table border="0"> <thead> <tr> <th>Trunk</th> <th>RUE</th> <th>LUE</th> <th>RLE</th> <th>LLE</th> <th></th> </tr> </thead> <tbody> <tr> <td><input type="radio"/> 0</td> <td><input type="radio"/> 0</td> <td><input type="radio"/> 0</td> <td><input type="radio"/> 0</td> <td><input type="radio"/> 0</td> <td>0 = absent</td> </tr> <tr> <td><input type="radio"/> 1</td> <td><input type="radio"/> 1</td> <td><input type="radio"/> 1</td> <td><input type="radio"/> 1</td> <td><input type="radio"/> 1</td> <td>1 = slight/intermittent</td> </tr> <tr> <td><input type="radio"/> 2</td> <td><input type="radio"/> 2</td> <td><input type="radio"/> 2</td> <td><input type="radio"/> 2</td> <td><input type="radio"/> 2</td> <td>2 = mild/common or moderate/intermittent</td> </tr> <tr> <td><input type="radio"/> 3</td> <td><input type="radio"/> 3</td> <td><input type="radio"/> 3</td> <td><input type="radio"/> 3</td> <td><input type="radio"/> 3</td> <td>3 = moderate/common</td> </tr> <tr> <td><input type="radio"/> 4 dysttrnk</td> <td><input type="radio"/> 4 dyst RUE</td> <td><input type="radio"/> 4 dyst LUE</td> <td><input type="radio"/> 4 dyst RLE</td> <td><input type="radio"/> 4 dyst LLE</td> <td>4 = marked/prolonged</td> </tr> </tbody> </table>	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 dyst RUE	<input type="radio"/> 4 dyst LUE	<input type="radio"/> 4 dyst RLE	<input type="radio"/> 4 dyst LLE	4 = marked/prolonged													
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<p><u>Gait:</u></p>	<p><input type="radio"/> 0 = normal gait, narrow base 0</p> <p><input type="radio"/> 1 = wide base and/or slow 1</p> <p><input type="radio"/> 2 = wide base and walks with difficulty 2</p> <p><input type="radio"/> 3 = walks only with assistance 3</p> <p><input type="radio"/> 4 = cannot attempt 4</p>	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>	tandem																																																
<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>	retropls																																																

<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		0	Luria
	<input type="radio"/> 1 = < 4 in 10 sec, no cue		1	
	<input type="radio"/> 2 = ≥ 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	
<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		0	brady
	<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	

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 dyst RUE	<input type="radio"/> 4 dyst LUE	<input type="radio"/> 4 dyst RLE	<input type="radio"/> 4 dyst LLE	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 chor RUE	<input type="radio"/> 4 chor LUE	<input type="radio"/> 4 chor RLE	<input type="radio"/> 4 chor LLE	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

Tandem walking:

- 0 = normal for 10 steps 0
- 1 = 1 to 3 deviations from straight line 1
- 2 = >3 deviations 2
- 3 = cannot complete 3
- 4 = cannot attempt 4

tandem

Retropulsion pull test:

- 0 = normal 0
- 1 = recovers spontaneously 1
- 2 = would fall if not caught 2
- 3 = tends to fall spontaneously 3
- 4 = cannot stand 4

retropls

Diagnostic Confidence [motor3] .DCL 185_1

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 (\geq 99 % confidence) 4

diagconf

16 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

17 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 982_1	
Subject's independence in %:	indep1
	<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

18 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 pbainfo

i) Is informant a relative? pbahshd



- 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

19 Form “Core and Extended Cognitive Assessment (Cognitive)”

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?	<input type="radio"/> yes 1 <input type="radio"/> no 0 gen1
Did the participant complete the assessment in their native language?	<input type="radio"/> yes 1 <input type="radio"/> no 0 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 1 <input type="radio"/> no 0 gen4
Was vision uncorrected (e.g. no glasses during visit)?	<input type="radio"/> yes 1 <input type="radio"/> no 0 gen5
Was hearing uncorrected (e.g. no hearing aid worn)?	<input type="radio"/> yes 1 <input type="radio"/> no 0 gen6

Core Cognitive Assessment [cognitive] 2341_1	
[sdmt1]	
Symbol Digit Modality Test completed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0 sdmt
Total correct:	<input type="text"/> sdmt1
Total errors:	<input type="text"/> sdmt2
[verfct1]	
Verbal Fluency Test (Category) completed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0 verfct
Category:	<input type="text" value="----"/> verfctd animals 1 other 2
Total correct (1 min):	<input type="text"/> verfct5
Total intrusion errors:	<input type="text"/> verfct6
Total perseverative errors:	<input type="text"/> verfct7

Extended Cognitive Assessment [cognitbass] 2342_1			
[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
[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

Trailmaking Test completed:	<input type="radio"/> yes 1 <input type="radio"/> no 0		trl
<hr/>			
Trailmaking Test [2780] 2780_1			
Part A: time to complete:	<input type="text"/>	sec	trla1
Part A: total correct:	<input type="text"/>		trla2
Part A: total errors:	<input type="text"/>		trla3
Part B: time to complete:	<input type="text"/>	sec	trlb1
Part B: total correct:	<input type="text"/>		trlb2
Part B: total errors:	<input type="text"/>		trlb3
<hr/>			
[verflt1]			
Verbal Fluency Test (Letters) completed:	<input type="radio"/> yes 1 <input type="radio"/> no 0		verflt
<hr/>			
Total correct (3 min):	<input type="text"/>		verflt05
Total intrusion errors:	<input type="text"/>		verflt06
Total perseverative errors:	<input type="text"/>		verflt07

20 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



21 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

22 Form “Mini Mental State Examination (MMSE) (US)”

General [mmse] 3070_1	
MMSE score:	<input type="text"/>
	mmsetotal

23 Form “Physiotherapy Outcomes Measures (Physio)”

Timed Up and Go Test [tug01] .TUG 3055_1		
Timed "Up and Go" performed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0	tug
Total time:	<input type="text"/> sec	tug1
30 Second Chair Stand Test [scst1] .30sec Chair Stand 3073_1		
30 second chair stand test performed: 	<input type="radio"/> yes 1 <input type="radio"/> no 0	scst
Number of times the participant stands in 30 seconds:	<input type="text"/>	scst1

24 Form “Short Form Health Survey – 12v2 (SF-12)”

Scoring [3931] 3931_1

Online scoring: scoring

pending 0
 succeeded 1
 failed 2
 failed (2) 3
 error 4

Domain scores Physical Functioning (PF) Role-Physical (RP) Bodily Pain (BP) General Health (GH)

Norm-based scores pf rp bp gh

Domain scores Vitality (VT) Social Functioning (SF) Role-Emotional (RE) Mental Health (MH)

Norm-based scores vt sf re mh

Summary Scale Measures Physical Component (PCS) Mental Component (MCS)

 pcs mcs

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

General [general] 3146_1			
Scores: [3147] 3147_1	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

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):	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	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 “Missed Visit”

Documentation of Missed Follow-Up [mvfup] 4052_1

Source of information: mvsrc

- 1 = participant 1
- 2 = spouse/partner 2
- 3 = next of kin (family or friends) 3
- 4 = physician 4
- 5 = nurse 5
- 6 = other (e.g. hearsay, obituary in newspaper, death certificate) 6

Reason for missed follow-up visit: mvrsn

- 1 = participant alive, unable to attend FUP, open to future FUPs 1
- 2 = participant alive, objects to further FUP visits, open to further phone contacts 2
- 3 = participant alive, objects to further FUP visits and to further phone contacts 3
- 4 = participant alive, lost to FUP 4
- 5 = participant dead 5
- 6 = status unclear 6

If participant is alive [4056] 4056_1

Level of care required: crlvl

- 0 = The participant does not require any help for basic activities of daily living (un/dressing, washing/bathing, getting up/going to bed). 0
- 1 = The participant requires some help to manage basic activities of daily living (typically < 4h support per day), but no full-time supervision. 1
- 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. 2

Days since full-time dependency: dpdy



Revision History

Version	Summary of Changes
2015-01-R1	Initial version of annotated CRF for the first Enroll-HD Periodic Dataset.
2015-10-R1	Revised version of annotated CRF for the second Enroll-HD Periodic Dataset. Changes: Total daily dose in Forms PharmacTx, NutSuppl, Basline and follow-up version of PBA-s.
2016-10-R1	Revised version of annotated CRF for the first Enroll-HD Plus Periodic Dataset. Changes: Forms CSSRS-BL, CSSRS-FUP added, Day of end of study added to form "Premature End", Optional Components removed from Enrollment (except Family History), Chapter Forms and Data Files revised