

# CLaSP

## CLaSP - Care of Late Stage Parkinsonism

Subject Label Expression: T1:Cover:IngPatID

Date of Birth Expression:

Gender Expression:

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# Visit Schedule

	T1	T2	T3	T4	Unscheduled
Cover	1				
End of treatment				1	
Version of Informed Consent	1				
Baseline Information	1				
Inclusion/Exclusion Information	1				
Diagnostic criteria	1				
Randomization		1			
Visit, Location and Current Medications	1	1	1	1	
Comorbidities	1	1	1	1	
Last Assessment	1	1	1	1	
Semistructured Interview	1				
EQ-5D - Patient	1	1	1	1	
PDQ-8 - Patient	1	1	1	1	
SMiLE - Patient	1	1	1	1	
Likert Scale - Patient	1	1	1	1	
GDS - Patient	1	1	1	1	
EQ-5D - Carer	1	1	1	1	
DEMQOL-PROXY - Carer	1	1	1	1	
Likert Scale - Carer	1	1	1	1	
Zarit Burden Interview - Carer	1	1	1	1	
Activities of Daily Living (UPDRS-ADL, part II)	1	1	1	1	R
CGI - Clinician	1	1	1	1	
CGI - Patient	1	1	1	1	
CGI - Carer	1	1	1	1	
Hoehn and Yahr Staging	1	1	1	1	
UPDRSI	1	1	1	1	
UPDRSIII	1	1	1	1	R
UPDRSIV	1	1	1	1	
ICB-DDS	1	1	1	1	
Activities of Daily Living (Schwab & England)	1	1	1	1	
MMSE	1	1	1	1	
Pill Questionnaire	1	1	1	1	
NPI-NH-Delusions	1	1	1	1	
NPI-NH-Hallucinations	1	1	1	1	
NPI-NH-Agitation/Aggression	1	1	1	1	
NPI-NH-Depression/Dysphoria	1	1	1	1	
NPI-NH-Anxiety	1	1	1	1	
NPI-NH-Elation/Euphoria	1	1	1	1	
NPI-NH-Apathy/Indifference	1	1	1	1	
NPI-NH-Disinhibition	1	1	1	1	
NPI-NH-Irritability/Lability	1	1	1	1	
NPI-NH-Aberrant Motor Behavior	1	1	1	1	
NPI-NH-Sleep and nighttime behavior disorders	1	1	1	1	
NPI-NH-Appetite and eating changes	1	1	1	1	
NMS-Scale	1	1	1	1	
ESAS-(PD, revision)	1	1	1	1	
Charlson Index	1	1	1	1	
Recommendations	1	1	1	1	
Recommendations followed		1	1	1	
Barriers Questionnaire		1			
Resource Utilization (Part 1)	1	1	1		
Resource Utilization (Part 2)	1	1	1		
Resource Utilization (Part 3)	1	1	1		
Resource Utilization (Part 4)	1	1	1		
Clock Drawing	1	1	1	1	
Lexical Fluency	1	1	1	1	
Assessment Summary	1	1	1	1	
Authorization	1	1	1	1	
Adverse Event					R
Allied health intervention - REMOVED	1				

**CLaSP CRF**  
Care of Late Stage Parkinsonism**COVER****Patient Number** IngPatNo**Site-Number** IngSite

As Patient number please enter only the sequencing patient number for your site/center. The PatientID is generated automatically.

**Patient ID** IngPatID**Study Center** strSite strSite\_check**Written informed consent**

Patient given written informed consent

 catInfCons☐ Please tick if consent was given via **CONSULTEE** catC\_Consultee

If consent was given via consultee the question  
'Patient given written informed consent' has to be answered with YES

Date patient consented (dd/mm/yyyy)

 dtmInfCons

Version of initial informed consent

 catC\_Vers

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngSite	IngSite	IngSite	Integer	99	See Appendix	
2	IngPatNo	IngPatNo	IngPatNo	Integer	999, Mandatory		
3	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
4	strSite	strSite	strSite	Text	255	See Appendix	
5	strSite_check	strSite_check	strSite_check	Text	300	See Appendix	
6	catInfCons	catInfCons	catInfCons	Category	3, Mandatory		1=Yes 0=No
7	catIC_Consultee	catIC_Consultee	catIC_Consultee	Category	46, Optional		1=Please tick If consent was given via CONSULTEE
8	dtmInfCons	dtmInfCons	dtmInfCons	Date/Time	dd/mm/yyyy, Mandatory		
9	catIC_Vers	catIC_Vers	catIC_Vers	Category	4		1=V01F 2=V02F 3=V03F 4=V04F 5=V05F 6=V06F 7=V07F 8=V08F 9=V09F 10=V10F



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Care of Late Stage Parkinsonism  
END OF TREATMENT



Patient ID

IngPatID

Has the patient reached end of treatment

catEndofTreat

If yes, reason for end of treatment

☐ Withdrawal of consent by patient cat\_EOT\_a

dtm\_EOT\_a

(dd/mm/yyyy)

☐ Patient is lost-to-follow-up cat\_EOT\_b

dtm\_EOT\_b

(Date of last contact; dd/mm/yyyy)

☐ Study treatment stopped by patient wish, but agrees in further data documentation cat\_EOT\_c

dtm\_EOT\_c

(Date of treatment stop; dd/mm/yyyy)

☐ Death cat\_EOT\_d

dtm\_EOT\_d

(Date of death; dd/mm/yyyy)

Place of death:

str\_Place\_o\_D

Cause of death:

cat\_Cause\_of\_D

if other please specify:

str\_C\_o\_D\_O

☐ Other reasons for end of treatment cat\_EOT\_e

dtm\_EOT\_e

(Date of end of treatment; dd/mm/yyyy)

please specify:

str\_EOT\_e

DATE OF AUTHORIZATION

dtmAuthorize

☐ EoT form authorized by investigator

catAuthorize2

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catEndofTreat	catEndofTreat	catEndofTreat	Category	3, Mandatory		1=Yes 0=No
3	cat_EOT_a	cat_EOT_a	cat_EOT_a	Category	32, Optional		1=Withdrawal of consent by patient
4	dtm_EOT_a	dtm_EOT_a	dtm_EOT_a	Date/Time	dd/mm/yyyy		
5	cat_EOT_b	cat_EOT_b	cat_EOT_b	Category	28, Optional		1=Patient is lost-to-follow-up
6	dtm_EOT_b	dtm_EOT_b	dtm_EOT_b	Date/Time	dd/mm/yyyy		
7	cat_EOT_c	cat_EOT_c	cat_EOT_c	Category	81, Optional		See Appendix
8	dtm_EOT_c	dtm_EOT_c	dtm_EOT_c	Date/Time	dd/mm/yyyy		
9	cat_EOT_d	cat_EOT_d	cat_EOT_d	Category	5, Optional		1=Death
10	dtm_EOT_d	dtm_EOT_d	dtm_EOT_d	Date/Time	dd/mm/yyyy		
11	str_Place_o_D	str_Place_o_D	str_Place_o_D	Text	255		
12	cat_Cause_of_D	cat_Cause_of_D	cat_Cause_of_D	Category	17		1=Parkinson disease 9=Other
13	str_C_o_D_O	str_C_o_D_O	str_C_o_D_O	Text	255		
14	cat_EOT_e	cat_EOT_e	cat_EOT_e	Category	34, Optional		9=Other reasons for end of treatment
15	dtm_EOT_e	dtm_EOT_e	dtm_EOT_e	Date/Time	dd/mm/yyyy		
16	str_EOT_e	str_EOT_e	str_EOT_e	Text	255		
17	dtmAuthorize	dtmAuthorize	dtmAuthorize	Date/Time	dd/mm/yyyy		
18	catAuthorize2	catAuthorize2	catAuthorize2	Category	35		1=EoT form authorized by Investigator



**CLaSP CRF**  
Care of Late Stage Parkinsonism

**VERSION OF INFORMED CONSENT**

Only document if there is a new version of written informed consent. The initial version which has been entered on the cover form needs not to be documented again.



Patient ID  IngPatID

Version No. of IC	IC signed by patient	Date patient signed (dd/mm/yyyy)	original filed
<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
catICVersion2	catNewVersion	catNewVerSigned	catOrigFiled

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
Repeating Question Group: , Borders: Yes, RowStatus: No, RowNumbers: Yes, DisplayRows: 10, InitialRows: 10, Min Repeats: 1, Max Repeats: 100, Main Row Type: Multi-Line, Sub Row Type: Multi-Line							
2	catICversion2	catICversion2	catICversion2	Category	4, Optional		1=V01F 2=V02F 3=V03F 4=V04F 5=V05F 6=V06F 7=V07F 8=V08F 9=V09F 10=V10F
3	catNewVersigned	catNewVersigned	catNewVersigned	Category	3, Optional		1=Yes 0=No
4	dtmNewVerSigned	dtmNewVerSigned	dtmNewVerSigned	Date/Time	dd/mm/yyyy, Optional		
5	catOrigFiled	catOrigFiled	catOrigFiled	Category	3, Optional		1=Yes 0=No



**CLaSP CRF**  
**Care of Late Stage Parkinsonism**  
**BASELINE INFORMATION**



Patient ID

IngPatID

Year of Birth:  
(yyyy)

IngYoB

Year of IC

IngYear\_IC

Calculated Age:

IngCalcAge

Gender:

catGender

Residential care setting information:

catCareInfo

Age on onset:

IngAgeOnOnset

Marital status:

catMarStat

Education: Years of full time education:

IngYearsOfEdu

Current diagnosis Parkinsonism?

catCurrDiagPark

Current diagnosis Dementia?

catCurrDiagDem

Final diagnosis after consultation

catFinDiagCon

if other please specify

strFinDiagConOt

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	IngYear_IC	IngYear_IC	IngYear_IC	Integer	9999, Mandatory, Hidden	datepart( years, T1:Cover:dtmInfCons)	
3	IngYoB	IngYoB	IngYoB	Integer	9999, Mandatory		
4	IngCalcAge	IngCalcAge	IngCalcAge	Integer	999	T1:PatientStatus:IngYear_IC-T1:PatientStatus:IngYoB	
5	catGender	catGender	catGender	Category	6, Mandatory		1=male 2=female
6	catCareInfo	catCareInfo	catCareInfo	Category	27, Mandatory		1=1 = Nursing home or similar 2=2 = Home
7	IngAgeOnOnset	IngAgeOnOnset	IngAgeOnOnset	Integer	999, Mandatory		
8	catMartStat	catMartStat	catMartStat	Category	49, Mandatory		See Appendix
9	IngYearsOfEdu	IngYearsOfEdu	IngYearsOfEdu	Integer	999		
10	catCurrDiagPark	catCurrDiagPark	catCurrDiagPark	Category	3, Mandatory		1=Yes 0=No
11	catCurrDiagDem	catCurrDiagDem	catCurrDiagDem	Category	3, Mandatory		1=Yes 0=No
12	catFinDiagCon	catFinDiagCon	catFinDiagCon	Category	43, Mandatory		See Appendix
13	strFinDiagConOt	strFinDiagConOt	strFinDiagConOt	Text	100		



**CLaSP CRF**  
**Care of Late Stage Parkinsonism**  
**INCLUSION / EXCLUSION**



Patient ID

IngPatID

**Inclusion Criteria**

1. Disease duration of at least 7 years

catIndu1

**AND**

2. Hoehn and Yahr stages IV or V during On

catIndu2

**OR**

3. Schwab and England stage 50% or less in On

catIndu3

**Exclusion Criteria**

1. Hoehn and Yahr stages I - III

catExclu1

2. Symptomatic Parkinsonism?

catExclu2

Symptomatic Parkinsonism e.g. normal pressure hydrocephalus or drug-induced Parkinsonism (onset following treatment with drugs known to cause Parkinsonism), except if persisting following discontinuation of the causative drug

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catIndu1	catIndu1	catIndu1	Category	3		1=Yes 0=No
3	catIndu2	catIndu2	catIndu2	Category	14		1=Yes 0=No 9=Not applicable
4	catIndu3	catIndu3	catIndu3	Category	14		1=Yes 0=No 9=Not applicable
5	catExclu1	catExclu1	catExclu1	Category	3		0=No 1=Yes
6	catExclu2	catExclu2	catExclu2	Category	3		0=No 1=Yes



**CLaSP CRF**  
Care of Late Stage Parkinsonism

## DIAGNOSTIC CRITERIA



Patient ID

 IngPatID

### Questions

Q1: Bradykinesia

Q2: Rigidity

(Judged on passive movement of major joints with patient relaxed in sitting position. Cogwheeling to be ignored.)

Q3: Resting tremor

(head, upper and lower extremities)

Q4: Postural instability

(Response to sudden, strong posterior displacement produced by pull on shoulders while patient erect with eyes open and feet slightly apart. Patient is prepared.)

Q5 Supportive criteria for IDP

Unilateral onset:

Presence of resting tremor:

Persistent asymmetry:

Progressive disease:

Good response on levodopa:

Severe levodopa induced chorea:

Levodopa response > 5 years:

Clinical course of disease > 10 years:

### Answers

  cat\_Q1\_Brady

  cat\_Q2\_Rigid

  cat\_Q3\_Rest\_Tre

  cat\_Q4\_Post\_Ins

  cat\_Q5\_Y\_N\_Q1

  cat\_Q5\_Y\_N\_Q2

  cat\_Q5\_Y\_N\_Q3

  cat\_Q5\_Y\_N\_Q4

  cat\_Q5\_Y\_N\_Q5

  cat\_Q5\_Y\_N\_Q6

  cat\_Q5\_Y\_N\_Q7

  cat\_Q5\_Y\_N\_Q8

Q6: Supportive of parkinsonism / Red flags

Cerebellar syndrome:

(gait ataxia, with cerebellar dysarthria, limb ataxia and cerebellar oculomotor function (MSA))

Poorly levodopa responsive:  
(parkinsonism)

Autonomic failure:

(urinary incontinence, orthostatic decrease of blood pressure, erectile dysfunction (MSA))

Babinski sign with hyperreflexia:  
(MSA, vascular parkinsonism)

  cat\_Q6\_Y\_N\_Q1

  cat\_Q6\_Y\_N\_Q2

  cat\_Q6\_Y\_N\_Q3

  cat\_Q6\_Y\_N\_Q4

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_Q1_Brady	cat_Q1_Brady	cat_Q1_Brady	Category	15		0=0 = not present 1=1 = present
3	cat_Q2_Rlgid	cat_Q2_Rlgid	cat_Q2_Rlgid	Category	74		See Appendix
4	cat_Q3_Rest_Tre	cat_Q3_Rest_Tre	cat_Q3_Rest_Tre	Category	96		See Appendix
5	cat_Q4_Post_Ins	cat_Q4_Post_Ins	cat_Q4_Post_Ins	Category	71		See Appendix
6	cat_Q5_Y_N_Q1	cat_Q5_Y_N_Q1	cat_Q5_Y_N_Q1	Category	3		1=Yes 0=No
7	cat_Q5_Y_N_Q2	cat_Q5_Y_N_Q2	cat_Q5_Y_N_Q2	Category	3		1=Yes 0=No
8	cat_Q5_Y_N_Q3	cat_Q5_Y_N_Q3	cat_Q5_Y_N_Q3	Category	3		1=Yes 0=No
9	cat_Q5_Y_N_Q4	cat_Q5_Y_N_Q4	cat_Q5_Y_N_Q4	Category	3		1=Yes 0=No
10	cat_Q5_Y_N_Q5	cat_Q5_Y_N_Q5	cat_Q5_Y_N_Q5	Category	3		1=Yes 0=No
11	cat_Q5_Y_N_Q6	cat_Q5_Y_N_Q6	cat_Q5_Y_N_Q6	Category	3		1=Yes 0=No
12	cat_Q5_Y_N_Q7	cat_Q5_Y_N_Q7	cat_Q5_Y_N_Q7	Category	3		1=Yes 0=No
13	cat_Q5_Y_N_Q8	cat_Q5_Y_N_Q8	cat_Q5_Y_N_Q8	Category	3		1=Yes 0=No
14	cat_Q6_Y_N_Q1	cat_Q6_Y_N_Q1	cat_Q6_Y_N_Q1	Category	3		1=Yes 0=No
15	cat_Q6_Y_N_Q2	cat_Q6_Y_N_Q2	cat_Q6_Y_N_Q2	Category	3		1=Yes 0=No
16	cat_Q6_Y_N_Q3	cat_Q6_Y_N_Q3	cat_Q6_Y_N_Q3	Category	3		1=Yes 0=No
17	cat_Q6_Y_N_Q4	cat_Q6_Y_N_Q4	cat_Q6_Y_N_Q4	Category	3		1=Yes 0=No

Stridor (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q5
Rapidly progressive parkinsonism: (PSP, MSA, Lewy body disease, CBD)	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q6
Postural instability within 3 years (MSA) with falls in 1st year (PSP):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q7
Dysphagia within 5 years (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q8
Orofacial dystonia (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q9
Disproportionate antecollis (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q10
Retrocollis (PSP):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q11
Camptocormia (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q12
Pisa syndrome (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q13
Contractures of hand/feet (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q14
Inspiratory sighs (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q15
Severe dysphonia (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q16
Severe dysarthria (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q17
New or increased snoring (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q18
Cold hands and feet (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q19
Pathological laughter and crying (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q20
Jerky, myoclonic action/postural tremor (MSA):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q21
Vertical gaze palsy/slowness of vertical saccades (PSP):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q22
Severe amnesia, afasia, agnosia (Alzheimer):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q23
Early cognitive problems with frontal characteristics (PSP):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q24
Hallucination or delusions not related to medication: (Lewy body, Alzheimer)	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q25
Definite encephalitis (encephalitis lethargica):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q26
Oculogyric crisis:	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q27
Alien limb syndrome (CBD):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q28
Symmetrical parkinsonism (PSP, MSA, Lewy body):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q29
Presence of focal sign and symptoms consistent with stroke: (Vascular)	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q30
An acute or delayed progressive onset (Vascular):	<input type="checkbox"/>	<input type="checkbox"/>	cat_Q6_Y_N_Q31

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
18	cat_Q6_Y_N_Q5	cat_Q6_Y_N_Q5	cat_Q6_Y_N_Q5	Category	3		1=Yes 0=No
19	cat_Q6_Y_N_Q6	cat_Q6_Y_N_Q6	cat_Q6_Y_N_Q6	Category	3		1=Yes 0=No
20	cat_Q6_Y_N_Q7	cat_Q6_Y_N_Q7	cat_Q6_Y_N_Q7	Category	3		1=Yes 0=No
21	cat_Q6_Y_N_Q8	cat_Q6_Y_N_Q8	cat_Q6_Y_N_Q8	Category	3		1=Yes 0=No
22	cat_Q6_Y_N_Q9	cat_Q6_Y_N_Q9	cat_Q6_Y_N_Q9	Category	3		1=Yes 0=No
23	cat_Q6_Y_N_Q10	cat_Q6_Y_N_Q10	cat_Q6_Y_N_Q10	Category	3		1=Yes 0=No
24	cat_Q6_Y_N_Q11	cat_Q6_Y_N_Q11	cat_Q6_Y_N_Q11	Category	3		1=Yes 0=No
25	cat_Q6_Y_N_Q12	cat_Q6_Y_N_Q12	cat_Q6_Y_N_Q12	Category	3		1=Yes 0=No
26	cat_Q6_Y_N_Q13	cat_Q6_Y_N_Q13	cat_Q6_Y_N_Q13	Category	3		1=Yes 0=No
27	cat_Q6_Y_N_Q14	cat_Q6_Y_N_Q14	cat_Q6_Y_N_Q14	Category	3		1=Yes 0=No
28	cat_Q6_Y_N_Q15	cat_Q6_Y_N_Q15	cat_Q6_Y_N_Q15	Category	3		1=Yes 0=No
29	cat_Q6_Y_N_Q16	cat_Q6_Y_N_Q16	cat_Q6_Y_N_Q16	Category	3		1=Yes 0=No
30	cat_Q6_Y_N_Q17	cat_Q6_Y_N_Q17	cat_Q6_Y_N_Q17	Category	3		1=Yes 0=No
31	cat_Q6_Y_N_Q18	cat_Q6_Y_N_Q18	cat_Q6_Y_N_Q18	Category	3		1=Yes 0=No
32	cat_Q6_Y_N_Q19	cat_Q6_Y_N_Q19	cat_Q6_Y_N_Q19	Category	3		1=Yes 0=No
33	cat_Q6_Y_N_Q20	cat_Q6_Y_N_Q20	cat_Q6_Y_N_Q20	Category	3		1=Yes 0=No
34	cat_Q6_Y_N_Q21	cat_Q6_Y_N_Q21	cat_Q6_Y_N_Q21	Category	3		1=Yes 0=No
35	cat_Q6_Y_N_Q22	cat_Q6_Y_N_Q22	cat_Q6_Y_N_Q22	Category	3		1=Yes 0=No
36	cat_Q6_Y_N_Q23	cat_Q6_Y_N_Q23	cat_Q6_Y_N_Q23	Category	3		1=Yes 0=No
37	cat_Q6_Y_N_Q24	cat_Q6_Y_N_Q24	cat_Q6_Y_N_Q24	Category	3		1=Yes 0=No
38	cat_Q6_Y_N_Q25	cat_Q6_Y_N_Q25	cat_Q6_Y_N_Q25	Category	3		1=Yes 0=No
39	cat_Q6_Y_N_Q26	cat_Q6_Y_N_Q26	cat_Q6_Y_N_Q26	Category	3		1=Yes 0=No
40	cat_Q6_Y_N_Q27	cat_Q6_Y_N_Q27	cat_Q6_Y_N_Q27	Category	3		1=Yes 0=No
41	cat_Q6_Y_N_Q28	cat_Q6_Y_N_Q28	cat_Q6_Y_N_Q28	Category	3		1=Yes 0=No
42	cat_Q6_Y_N_Q29	cat_Q6_Y_N_Q29	cat_Q6_Y_N_Q29	Category	3		1=Yes 0=No
43	cat_Q6_Y_N_Q30	cat_Q6_Y_N_Q30	cat_Q6_Y_N_Q30	Category	3		1=Yes 0=No
44	cat_Q6_Y_N_Q31	cat_Q6_Y_N_Q31	cat_Q6_Y_N_Q31	Category	3		1=Yes 0=No

History of repeated head injury (trauma):

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cat\_Q6\_Y\_N\_Q32

Neuroleptic treatment at onset of disease (medication induced):

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cat\_Q6\_Y\_N\_Q33

Assymetric presentation of 2:

- 2 of limb rigidity, limb dystonia, limb myoclonus, orobuccal or limb apraxia, cortical sensory deficit, alien limb phenomena (CBD)
- 2 of executive dysfunction, behavioral changes, visuospatial deficits (CBD)

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cat\_Q6\_Y\_N\_Q34

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cat\_Q6\_Y\_N\_Q35

Agrammatical speech (CBD):

--	--

cat\_Q6\_Y\_N\_Q36

MPTP exposure:

--	--

cat\_Q6\_Y\_N\_Q37

more than one affected relative:

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
45	cat_Q6_Y_N_Q32	cat_Q6_Y_N_Q32	cat_Q6_Y_N_Q32	Category	3		1=Yes 0=No
46	cat_Q6_Y_N_Q33	cat_Q6_Y_N_Q33	cat_Q6_Y_N_Q33	Category	3		1=Yes 0=No
47	cat_Q6_Y_N_Q34	cat_Q6_Y_N_Q34	cat_Q6_Y_N_Q34	Category	3		1=Yes 0=No
48	cat_Q6_Y_N_Q35	cat_Q6_Y_N_Q35	cat_Q6_Y_N_Q35	Category	3		1=Yes 0=No
49	cat_Q6_Y_N_Q36	cat_Q6_Y_N_Q36	cat_Q6_Y_N_Q36	Category	3		1=Yes 0=No
50	cat_Q6_Y_N_Q37	cat_Q6_Y_N_Q37	cat_Q6_Y_N_Q37	Category	3		1=Yes 0=No



CLaSP CRF  
Care of Late Stage Parkinsonism  
RANDOMIZATION



Patient ID  IngPatID

Was the patient randomized?  catRandomize

Date of randomization  dtmRandomize

Result of randomization  catRandomResult

Was the patient treated as randomized?  catRandomOK

If the patient was NOT treated as randomized, please specify reason: strRandomNotOK

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catRandomize	catRandomize	catRandomize	Category	7, Mandatory		1=1 = Yes 0=0 = No
3	dtmRandomize	dtmRandomize	dtmRandomize	Date/Time	dd/mm/yyyy		
4	catRandomResult	catRandomResult	catRandomResult	Category	16		1=1 = Standard 2=2 = Intervention
5	catRandomOK	catRandomOK	catRandomOK	Category	7		1=1 = Yes 0=0 = No
6	strRandomNotOK	strRandomNotOK	strRandomNotOK	Text	300		



**CLaSP CRF**  
Care of Late Stage Parkinsonism  
**VISIT, LOCATION and**  
**CURRENT MEDICATION**



Patient ID

 IngPatID

Date of Visit (dd/mm/yyyy)

 dtmDateOfVis

Patient status

 catPatStatus

Please document end of treatment form if patient status is not alive.

Seen Where (location):

 strHelp catSeenWhere

Information from caregiver from whom?

 catInfoCareGi

other relationship

 strInfoCG\_oth
1. Blood pressure  
(lying)

systolic

 IngBP\_Lg\_syst (mmHG)

diastolic

 IngBP\_Lg\_dias (mmHG)

☐ Please tick if 1st blood pressure was taken sitting instead of lying.
catBP\_sit2. Blood pressure  
(standing after three minutes)

systolic

 IngBP\_Sg\_syst (mmHG)

diastolic

 IngBP\_Sg\_dias (mmHG)

☐ Please tick if 2nd blood pressure was taken sitting instead of standing.
catBP\_sit2**Current medications/treatments**

1. L-Dopa

 catLDop
L-Doa equivalent dose  
(daily dose in mg)Number of  
daily intakesa) ☐ L-dopa/bensarizide catLDop\_a
 IngMgpdLD\_a
 IntLDop\_a
b) ☐ No catLDop\_b
 IngMgpdLD\_b
 IntLDop\_b
c) ☐ L-dopa/carbidopa catLDop\_c
 IngMgpdLD\_c
 IntLDop\_c
d) ☐ No catLDop\_d
 IngMgpdLD\_d
 IntLDop\_d
e) ☐ Duodopa catLDop\_e
 IngMgpdLD\_e
 IntLDop\_e
f) ☐ Slow release formulations of levodopa catLDop\_f
 IngMgpdLD\_f
 IntLDop\_f
☐ Other catLDop\_g
 IngMgpdLD\_g
 IntLDop\_g
☐ No catLDop\_h  
if other please specify:  strLDopOther

2. Dopamine Agonist

 catDoAgo
Daily dose  
in mgNumber of  
daily intakesa) ☐ Bromocriptine catDoAgo\_a
 IngMgpdDo\_Ago\_a
 IntDopaAgo\_a
b) ☐ No catDoAgo\_b
 IngMgpdDo\_Ago\_b
 IntDopaAgo\_b
☐ Release of Pramipexole catDoAgo\_b2

 IntDopaAgo\_c
c) ☐ Ropinirole catDoAgo\_c
 IngMgpdDo\_Ago\_c
 IntDopaAgo\_d
☐ Release of Ropinirole catDoAgo\_c2

 IntDopaAgo\_e
d) ☐ Piribedil catDoAgo\_d
 IngMgpdDo\_Ago\_d
 IntDopaAgo\_e
e) ☐ No catDoAgo\_e
 IngMgpdDo\_Ago\_e
 IntDopaAgo\_f
f) ☐ Rotigotine catDoAgo\_f
 IngMgpdDo\_Ago\_f
 IntDopaAgo\_g
g) ☐ No catDoAgo\_g
 IngMgpdDo\_Ago\_g
 IntDopaAgo\_h
h) ☐ Apomorphine, pen catDoAgo\_h
 IngMgpdDo\_Ago\_h
 IntDopaAgo\_i
☐ Apomorphine, pump? catDoAgo\_i
 IngMgpdDo\_Ago\_i
 IntDopaAgo\_j
☐ No catDoAgo\_j
 IngMgpdDo\_Ago\_j
 IntDopaAgo\_k
☐ Other catDoAgo\_k
 IngMgpdDo\_Ago\_k
 IntDopaAgo\_l
☐ No catDoAgo\_l
 IngMgpdDo\_Ago\_l
 IntDopaAgo\_m

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmDateOfVis	dtmDateOfVis	dtmDateOfVis	Date/Time	dd/mm/yyyy		
3	catPatStatus	catPatStatus	catPatStatus	Category	42		See Appendix
4	Hotlink			Hotlink		Unscheduled:End_of_treatm	
5	catSeenWhere	catSeenWhere	catSeenWhere	Category	26		See Appendix
6	strHelp	strHelp	strHelp	Text	2, Optional		
7	catInfoCareGi	catInfoCareGi	catInfoCareGi	Category	26		1=1 = Partner (wife/husband) 2=2 = Son 3=3 = Daughter 9=9 = Other
8	strInfoCG_oth	strInfoCG_oth	strInfoCG_oth	Text	50		
9	IngBP_Lg_syst	IngBP_Lg_syst	IngBP_Lg_syst	Integer	999		
10	IngBP_Lg_dias	IngBP_Lg_dias	IngBP_Lg_dias	Integer	999		
11	catBP_sit	catBP_sit	catBP_sit	Category	69, Optional		1=Please tick if 1st blood pressure was taken sitting instead of lying.
12	IngBP_Sg_syst	IngBP_Sg_syst	IngBP_Sg_syst	Integer	999		
13	IngBP_Sg_dias	IngBP_Sg_dias	IngBP_Sg_dias	Integer	999		
14	catBP_sit2	catBP_sit2	catBP_sit2	Category	72, Optional		1=Please tick if 2nd blood pressure was taken sitting instead of standing.
15	catLdop	catLdop	catLdop	Category	3		1=Yes 0=No
16	IngMgpdLD_a	realMgpdLD_a	realMgpdLD_a	Real	9999.999		
17	catLdop_a	catLdop_a	catLdop_a	Category	18, Optional		1=L-dopa/bensarizide 0=No
18	intLdop_a	intLdop_a	intLdop_a	Integer	99		
19	catLdop_b	catLdop_b	catLdop_b	Category	16, Optional		1=L-dopa/carbidopa 0=No
20	IngMgpdLD_b	realMgpdLD_b	realMgpdLD_b	Real	9999.999		
21	intLdop_b	intLdop_b	intLdop_b	Integer	99		
22	catLdop_c	catLdop_c	catLdop_c	Category	27, Optional		1=L-dopa/carbidopa/entacapone 0=No
23	IngMgpdLD_c	realMgpdLD_c	realMgpdLD_c	Real	9999.999		
24	intLdop_c	intLdop_c	intLdop_c	Integer	99		
25	catLdop_d	catLdop_d	catLdop_d	Category	7, Optional		1=Duodopa 0=No
26	IngMgpdLD_d	realMgpdLD_d	realMgpdLD_d	Real	9999.999		
27	intLdop_d	intLdop_d	intLdop_d	Integer	99		
28	catLdop_e	catLdop_e	catLdop_e	Category	37, Optional		1=Slow release formulations of levodopa 0=No
29	IngMgpdLD_e	realMgpdLD_e	realMgpdLD_e	Real	9999.999		
30	intLdop_e	intLdop_e	intLdop_e	Integer	99		
31	catLdop_f	catLdop_f	catLdop_f	Category	5, Optional		1=Other 0=No
32	IngMgpdLD_f	realMgpdLD_f	realMgpdLD_f	Real	9999.999		
33	intLdop_f	intLdop_f	intLdop_f	Integer	99		
34	strL_DopaOther	strL_DopaOther	strL_DopaOther	Text	100		
35	catDoAgo	catDoAgo	catDoAgo	Category	3		1=Yes 0=No
36	catDoAgo_a	catDoAgo_a	catDoAgo_a	Category	13, Optional		1=Bromocriptine 0=No
37	IngMgpdDo_Ago_a	realMgpdDo_Ago_a	realMgpdDo_Ago_a	Real	9999.999		
38	intDopaAgo_a	intDopaAgo_a	intDopaAgo_a	Integer	99		
39	catDoAgo_b	catDoAgo_b	catDoAgo_b	Category	11, Optional		1=Pramipexole 0=No
40	IngMgpdDo_Ago_b	realMgpdDo_Ago_b	realMgpdDo_Ago_b	Real	9999.999		
41	intDopaAgo_b	intDopaAgo_b	intDopaAgo_b	Integer	99		
42	catDoAgo_b2	catDoAgo_b2	catDoAgo_b2	Category	16		1=standard release 2=slow release
43	intDopaAgo_c	intDopaAgo_c	intDopaAgo_c	Integer	99		
44	catDoAgo_c	catDoAgo_c	catDoAgo_c	Category	10, Optional		1=Ropinirole 0=No
45	IngMgpdDo_Ago_c	realMgpdDo_Ago_c	realMgpdDo_Ago_c	Real	9999.999		
46	catDoAgo_c2	catDoAgo_c2	catDoAgo_c2	Category	16		1=standard release 2=slow release
47	IngMgpdDo_Ago_d	realMgpdDo_Ago_d	realMgpdDo_Ago_d	Real	9999.999		
48	intDopaAgo_d	intDopaAgo_d	intDopaAgo_d	Integer	99		
49	catDoAgo_d	catDoAgo_d	catDoAgo_d	Category	9, Optional		1=Piribedil 0=No
50	IngMgpdDo_Ago_e	realMgpdDo_Ago_e	realMgpdDo_Ago_e	Real	9999.999		
51	intDopaAgo_e	intDopaAgo_e	intDopaAgo_e	Integer	99		
52	catDoAgo_e	catDoAgo_e	catDoAgo_e	Category	10, Optional		1=Rotigotine 0=No
53	IngMgpdDo_Ago_f	realMgpdDo_Ago_f	realMgpdDo_Ago_f	Real	9999.999		
54	intDopaAgo_f	intDopaAgo_f	intDopaAgo_f	Integer	99		
55	catDoAgo_f	catDoAgo_f	catDoAgo_f	Category	16, Optional		1=Apomorphine, pen 0=No
56	IngMgpdDo_Ago_g	realMgpdDo_Ago_g	realMgpdDo_Ago_g	Real	9999.999		
57	intDopaAgo_g	intDopaAgo_g	intDopaAgo_g	Integer	99		
58	catDoAgo_g	catDoAgo_g	catDoAgo_g	Category	18, Optional		1=Apomorphine, pump? 0=No
59	IngMgpdDo_Ago_h	realMgpdDo_Ago_h	realMgpdDo_Ago_h	Real	9999.999		
60	intDopaAgo_h	intDopaAgo_h	intDopaAgo_h	Integer	99		
61	catDoAgo_h	catDoAgo_h	catDoAgo_h	Category	5, Optional		1=Other 0=No

if other please specify:

strDopaAgoOther

## 3. IMAOB

catIMAOB

a) ☐ Rasagiline

catIMAOB\_a

☐ Nob) ☐ Selegiline

catIMAOB\_b

☐ NoDaily dose  
in mg

IngMgpdIMAOB\_a

IngMgpdIMAOB\_b

Number of  
daily intakes

IntIMAOB\_a

IntIMAOB\_b

## 4. ICOMT

catICOMT

a) ☐ Entacapone

catICOMT\_a

☐ Nob) ☐ Tolcapone

catICOMT\_b

☐ NoDaily dose  
in mg

IngMgpdICOMT\_a

IngMgpdICOMT\_b

Number of  
daily intakes

IntICOMT\_a

IntICOMT\_b

## 5. Anticholinergic Antiparkinsonian Medication

catAntichol

a) ☐ Biperidon

catAntichol\_a

☐ Nob) ☐ Trihexiphenidyl

catAntichol\_b

☐ NoDaily dose  
in mg

IngMgAntichol\_a

IngMgAntichol\_b

Number of  
daily intakes

IntAntichol\_a

IntAntichol\_b

Indication for anticholinergic antiparkinsonian medication

catAntichol\_Ind

## 6. Amantadine

catAmanta

Daily dose  
in mg

IngMgAmanta

Number of  
daily intakes

IntAmanta

## 7. Functional Neurosurgery

catNeurosurg

Please specify type of functional surgery

catNeurosurgType

## 8. Antidepressant

catAntidep

Daily dose  
in mg

IngMgAntidep

Please specify antidepressant drug

catAntidepMed

if other drug, please specify

strAntidepOth

Indication for antidepressant medication

catAntidepInd

## 9. Anxiolytic

catAnxiolytic

## 10. Hypnotic

catHypnotic

## 11. Psychostimulant

catPsychostim

## 12. Antipsychotics

catAntipsy

a) ☐ Clozapine

catAntipsy\_a

b) ☐ Quetiapine

catAntipsy\_b

Daily dose  
in mg

IngMgAntipsy\_a

IngMgAntipsy\_b

## 13. Botulinum Toxin

catBotTox

IngMgBotTox

## 14. Laxative

catLaxative

## 15. Drugs for dementia

catDementia

a) ☐ Rivastigmine

catDementia\_a

b) ☐ Donepezil

catDementia\_b

c) ☐ Memantine

catDementia\_c

IngMgDement\_a

IngMgDement\_b

IngMgDement\_c

## 16. Antihypotensive agent

catAntihyp

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
62	strDopaAgoOther	strDopaAgoOther	strDopaAgoOther	Text	100		
63	catMAOB	catMAOB	catMAOB	Category	3		1=Yes 0=No
64	IngMgpdMAOB_a	realMgpdMAOB_a	realMgpdMAOB_a	Real	9999.999		
65	IntMAOB_a	IntMAOB_a	IntMAOB_a	Integer	99		
66	catMAOB_a	catMAOB_a	catMAOB_a	Category	10, Optional		1=Rasagiline 0=No
67	IngMgpdMAOB_b	realMgpdMAOB_b	realMgpdMAOB_b	Real	9999.999		
68	IntMAOB_b	IntMAOB_b	IntMAOB_b	Integer	99		
69	catMAOB_b	catMAOB_b	catMAOB_b	Category	10, Optional		1=Selegiline 0=No
70	catCOMT	catCOMT	catCOMT	Category	3		1=Yes 0=No
71	catCOMT_a	catCOMT_a	catCOMT_a	Category	10, Optional		1=Entacapone 0=No
72	IngMgpdCOMT_a	realMgpdCOMT_a	realMgpdCOMT_a	Real	9999.999		
73	IntCOMT_a	IntCOMT_a	IntCOMT_a	Integer	99		
74	catCOMT_b	catCOMT_b	catCOMT_b	Category	9, Optional		1=Tolcapone 0=No
75	IngMgpdCOMT_b	realMgpdCOMT_b	realMgpdCOMT_b	Real	9999.999		
76	IntCOMT_b	IntCOMT_b	IntCOMT_b	Integer	99		
77	catAntichol	catAntichol	catAntichol	Category	3		1=Yes 0=No
78	catAntichol_a	catAntichol_a	catAntichol_a	Category	9, Optional		1=Biperidon 0=No
79	IngMgAntichol_a	IngMgAntichol_a	IngMgAntichol_a	Real	9999.999		
80	IntAntichol_a	IntAntichol_a	IntAntichol_a	Integer	99		
81	catAntichol_b	catAntichol_b	catAntichol_b	Category	15, Optional		1=Trihexiphenidyl 0=No
82	IngMgAntichol_b	IngMgAntichol_b	IngMgAntichol_b	Real	9999.999		
83	IntAntichol_b	IntAntichol_b	IntAntichol_b	Integer	99		
84	catAntichol_Ind	catAntichol_Ind	catAntichol_Ind	Category	16		1=bradykinesia 2=tremor 3=urinary symptoms 4=drooling
85	catAmanta	catAmanta	catAmanta	Category	3		1=Yes 0=No
86	IngMgAmanta	IngMgAmanta	IngMgAmanta	Real	9999.999		
87	IntAmanta	IntAmanta	IntAmanta	Integer	99		
88	catNeurosurg	catNeurosurg	catNeurosurg	Category	3		1=Yes 0=No
89	catNeurosurgType	catNeurosurgType	catNeurosurgType	Category	11		1=Pallidotomy 2=DBS-STN 3=DBS-GPI
90	catAntidep	catAntidep	catAntidep	Category	3		1=Yes 0=No
91	IngMgAntiDep	IngMgAntiDep	IngMgAntiDep	Real	9999.999		
92	catAntidepMed	catAntidepMed	catAntidepMed	Category	11		1=SSRI 2=Tricyclic 3=Venlafaxine 4=Mirtazapine 99=Other
93	strAntidepOth	strAntidepOth	strAntidepOth	Text	100		
94	catAntidepInd	catAntidepInd	catAntidepInd	Category	22		1=Depression 2=Anxiety 3=Depression and Anxiety 4=Apathy 5=Sleep
95	catAnxiolytic	catAnxiolytic	catAnxiolytic	Category	3		1=Yes 0=No
96	catHypnotic	catHypnotic	catHypnotic	Category	3		1=Yes 0=No
97	catPsychostim	catPsychostim	catPsychostim	Category	3		1=Yes 0=No
98	catAntipsy	catAntipsy	catAntipsy	Category	3		1=Yes 0=No
99	IngMgAntipsy_a	IngMgAntipsy_a	IngMgAntipsy_a	Real	9999.999		
100	catAntipsy_a	catAntipsy_a	catAntipsy_a	Category	9, Optional		1=Clozapine
101	IngMgAntipsy_b	IngMgAntipsy_b	IngMgAntipsy_b	Real	9999.999		
102	catAntipsy_b	catAntipsy_b	catAntipsy_b	Category	10, Optional		1=Quetiapine
103	catBotTox	catBotTox	catBotTox	Category	3		1=Yes 0=No
104	IngMgBotTox	IngMgBotTox	IngMgBotTox	Real	9999.999		
105	catLaxative	catLaxative	catLaxative	Category	3		1=Yes 0=No
106	catDementia	catDementia	catDementia	Category	3		1=Yes 0=No
107	IngMgDement_a	IngMgDement_a	IngMgDement_a	Real	9999.999		
108	catDementia_a	catDementia_a	catDementia_a	Category	12, Optional		1=Rivastigmine
109	IngMgDement_b	IngMgDement_b	IngMgDement_b	Real	9999.999		
110	catDementia_b	catDementia_b	catDementia_b	Category	9, Optional		1=Donepezil
111	IngMgDement_c	IngMgDement_c	IngMgDement_c	Real	9999.999		
112	catDementia_c	catDementia_c	catDementia_c	Category	9, Optional		1=Memantine
113	catAntihyp	catAntihyp	catAntihyp	Category	3		1=Yes 0=No

- a) ☐ Midodrine catAntihyp\_a  IngMgAntihyp\_a
- b) ☐ Fludrocortison catAntihyp\_b  IngMgAntihyp\_b
- c) ☐ Other catAntihyp\_oth  IngMgAntihyp\_c

Please specify other Antihypotensive agent

strAntihyp\_oth

17. Other medication

strMED\_OTH

## Only at T2 onwards (T2-T4)!

Change in Parkinson Disease medication since last visit?

cat\_PDchange

- 1) ☐ Increase dose of following drug cat\_PDchange\_1

str\_PDchange\_1

- 2) ☐ Decrease dose of following drug cat\_PDchange\_2

str\_PDchange\_2

- 3) ☐ Add following drug cat\_PDchange\_3

str\_PDchange\_3

- 4) ☐ Stop following drug cat\_PDchange\_4

str\_PDchange\_4

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
114	IngMgAntihyp_a	IngMgAntihyp_a	IngMgAntihyp_a	Real	9999.999		
115	catAntihyp_a	catAntihyp_a	catAntihyp_a	Category	9, Optional		1=Midodrine
116	IngMgAntihyp_b	IngMgAntihyp_b	IngMgAntihyp_b	Real	9999.999		
117	catAntihyp_b	catAntihyp_b	catAntihyp_b	Category	14, Optional		1=Fludrocortison
118	IngMgAntihyp_c	IngMgAntihyp_c	IngMgAntihyp_c	Real	9999.999		
119	catAntihyp_oth	catAntihyp_oth	catAntihyp_oth	Category	5, Optional		1=Other
120	strAntihyp_oth	strAntihyp_oth	strAntihyp_oth	Text	100		
121	strMED_OTH	strMED_OTH	strMED_OTH	Text	300, Optional		
122	cat_PDchange	cat_PDchange	cat_PDchange	Category	3		1=Yes 0=No
123	cat_PDchange_1	cat_PDchange_1	cat_PDchange_1	Category	31, Optional		1=Increase dose of following drug
124	str_PDchange_1	str_PDchange_1	str_PDchange_1	Text	100		
125	cat_PDchange_2	cat_PDchange_2	cat_PDchange_2	Category	31, Optional		1=Decrease dose of following drug
126	str_PDchange_2	str_PDchange_2	str_PDchange_2	Text	100		
127	cat_PDchange_3	cat_PDchange_3	cat_PDchange_3	Category	18, Optional		1=Add following drug
128	str_PDchange_3	str_PDchange_3	str_PDchange_3	Text	100		
129	cat_PDchange_4	cat_PDchange_4	cat_PDchange_4	Category	19, Optional		1=Stop following drug
130	str_PDchange_4	str_PDchange_4	str_PDchange_4	Text	100		



**CLaSP CRF**  
**Care of Late Stage Parkinsonism**  
**COMORBIDITIES**



Patient ID

IngPatID

**Please list all relevant and current comorbidites which are not covered in Charlsons Comorbidity Index**

Any previous or ongoing comorbidites:

catQComL

How collected:

cat\_info\_corcol

**For DATE of comorbidity partial dates are allowed.**  
**If only months and year are known (eg June 1995), please enter 061995.**  
**If only the year is known please enter the year as 4-digit number.**

**Previous/ongoing Comorbidities****Date of Comorbidity****Ongoing**

1.  strCom1
2.  strCom2
3.  strCom3
4.  strCom4
5.  strCom5
6.  strCom6
7.  strCom7
8.  strCom8
9.  strCom9
10.  strCom10

- |                      |                      |          |
|----------------------|----------------------|----------|
| <input type="text"/> | <input type="text"/> | dtmCom1  |
| <input type="text"/> | <input type="text"/> | dtmCom2  |
| <input type="text"/> | <input type="text"/> | dtmCom3  |
| <input type="text"/> | <input type="text"/> | dtmCom4  |
| <input type="text"/> | <input type="text"/> | dtmCom5  |
| <input type="text"/> | <input type="text"/> | dtmCom6  |
| <input type="text"/> | <input type="text"/> | dtmCom7  |
| <input type="text"/> | <input type="text"/> | dtmCom8  |
| <input type="text"/> | <input type="text"/> | dtmCom9  |
| <input type="text"/> | <input type="text"/> | dtmCom10 |

- |                      |                      |              |
|----------------------|----------------------|--------------|
| <input type="text"/> | <input type="text"/> | catOnGoing1  |
| <input type="text"/> | <input type="text"/> | catOnGoing2  |
| <input type="text"/> | <input type="text"/> | catOnGoing3  |
| <input type="text"/> | <input type="text"/> | catOnGoing4  |
| <input type="text"/> | <input type="text"/> | catOnGoing5  |
| <input type="text"/> | <input type="text"/> | catOnGoing6  |
| <input type="text"/> | <input type="text"/> | catOnGoing7  |
| <input type="text"/> | <input type="text"/> | catOnGoing8  |
| <input type="text"/> | <input type="text"/> | catOnGoing9  |
| <input type="text"/> | <input type="text"/> | catOnGoing10 |

**Only at T2 onwards (T2-T4)!**

Treatment received since last assessment:

strComorbTreat

Test since last assessment:

strComorbTest

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catQComL	catQComL	catQComL	Category	3		1=Yes 0=No
3	cat_Info_corcol	cat_Info_corcol	cat_Info_corcol	Category	14		1=1 = patient 2=2 = carer 3=3 = hospital 4=4 = GP records
4	strCom1	strCom1	strCom1	Text	255		
5	dtmCom1	dtmCom1	dtmCom1	Date/Time	dd/mm/yyyy		
6	catOnGoing1	catOnGoing1	catOnGoing1	Category	3		1=Yes 0=No
7	strCom2	strCom2	strCom2	Text	255, Optional		
8	dtmCom2	dtmCom2	dtmCom2	Date/Time	dd/mm/yyyy, Optional		
9	catOnGoing2	catOnGoing2	catOnGoing2	Category	3, Optional		1=Yes 0=No
10	strCom3	strCom3	strCom3	Text	255, Optional		
11	dtmCom3	dtmCom3	dtmCom3	Date/Time	dd/mm/yyyy, Optional		
12	catOnGoing3	catOnGoing3	catOnGoing3	Category	3, Optional		1=Yes 0=No
13	strCom4	strCom4	strCom4	Text	255, Optional		
14	dtmCom4	dtmCom4	dtmCom4	Date/Time	dd/mm/yyyy, Optional		
15	catOnGoing4	catOnGoing4	catOnGoing4	Category	3, Optional		1=Yes 0=No
16	strCom5	strCom5	strCom5	Text	255, Optional		
17	catOnGoing5	catOnGoing5	catOnGoing5	Category	3, Optional		1=Yes 0=No
18	dtmCom5	dtmCom5	dtmCom5	Date/Time	dd/mm/yyyy, Optional		
19	strCom6	strCom6	strCom6	Text	255, Optional		
20	catOnGoing6	catOnGoing6	catOnGoing6	Category	3, Optional		1=Yes 0=No
21	dtmCom6	dtmCom6	dtmCom6	Date/Time	dd/mm/yyyy, Optional		
22	strCom7	strCom7	strCom7	Text	255, Optional		
23	dtmCom7	dtmCom7	dtmCom7	Date/Time	dd/mm/yyyy, Optional		
24	catOnGoing7	catOnGoing7	catOnGoing7	Category	3, Optional		1=Yes 0=No
25	strCom8	strCom8	strCom8	Text	255, Optional		
26	dtmCom8	dtmCom8	dtmCom8	Date/Time	dd/mm/yyyy, Optional		
27	catOnGoing8	catOnGoing8	catOnGoing8	Category	3, Optional		1=Yes 0=No
28	strCom9	strCom9	strCom9	Text	255, Optional		
29	dtmCom9	dtmCom9	dtmCom9	Date/Time	dd/mm/yyyy, Optional		
30	catOnGoing9	catOnGoing9	catOnGoing9	Category	3, Optional		1=Yes 0=No
31	strCom10	strCom10	strCom10	Text	255, Optional		
32	dtmCom10	dtmCom10	dtmCom10	Date/Time	dd/mm/yyyy, Optional		
33	catOnGoing10	catOnGoing10	catOnGoing10	Category	3, Optional		1=Yes 0=No
34	strComorbTreat	strComorbTreat	strComorbTreat	Text	500		
35	strComorbTest	strComorbTest	strComorbTest	Text	500		



CLaSP CRF  
Care of Late Stage Parkinsonism  
**LAST ASSESSMENT**



Patient ID

IngPatID

Assessment done:

catAssD

Date of Assessment:  
(dd/mm/yyyy)

dtmAssD

Assessment done by:

catAssDBy

if other health care professional please specify:

strAssDOther

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catAssD	catAssD	catAssD	Category	3		1=Yes 0=No
3	dtmAssD	dtmAssD	dtmAssD	Date/Time	dd/mm/yyyy		
4	catAssDBy	catAssDBy	catAssDBy	Category	35		See Appendix
5	strAssDOther	strAssDOther	strAssDOther	Text	100		



**CLaSP CRF**  
Care of Late Stage Parkinsonism

## SEMISTRUCTURED INTERVIEW



Patient ID

IngPatID

### 1. Participant (patient informant) interview

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

#### Residence of participant

- ☐ **1 = Option A, Participants living at home**  
☐ **2 = Option B, Participants living in residential care facilities/nursing homes**

catInterview1

Please attach SEMISTRUCTUED INTERVIEW

mmInterview1

### 2. Interview with partner/family member/friend informants

Assessed: ☐ Yes catAssQ2  
☐ No

Date test performed:

dtmExam2

Duration of test (minutes):

Ingduration\_AS2

Reason, if not assessed:

catAss\_Test\_P2

Other reason:

strAssessReas2

#### Residence of participant

- ☐ **1 = Option A, Partner/family member/friend of participants living at home**  
☐ **2 = Option B, Partner/family member/friend of participants living in residential care facilities/nursing homes**

catInterview2

Please attach SEMISTRUCTUED INTERVIEW

mmInterview2

#### 1. Please attach AUDIO RECORDING of interview

mmInterview1b

#### 2. Please attach AUDIO RECORDING of interview

mmInterview2b

Please attach the completed file  
'Semistructured interview'.

If necessary you can attach  
more than one file.

mmInterview

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catInterview1	catInterview1	catInterview1	Category	78		See Appendix
8	mmInterview1	mmInterview1	mmInterview1	Multimedia	0, Optional		
9	catAssQ2	catAssQ2	catAssQ2	Category	3, Mandatory		1=Yes 0=No
10	dtmExam2	dtmExam2	dtmExam2	Date/Time	dd/mm/yyyy		
11	Ingduration_As2	Ingduration_As2	Ingduration_As2	Integer	999		
12	catAss_Test_P2	catAss_Test_P2	catAss_Test_P2	Category	62		See Appendix
13	strAssessReas2	strAssessReas2	strAssessReas2	Text	500		
14	catInterview2	catInterview2	catInterview2	Category	73		See Appendix
15	mmInterview2	mmInterview2	mmInterview2	Multimedia	0, Optional		
16	mmInterview1b	mmInterview1b	mmInterview1b	Multimedia	0, Optional, Hidden		
17	mmInterview2b	mmInterview2b	mmInterview2b	Multimedia	0, Optional, Hidden		
Repeating Question Group: Please attach the completed file 'Semistructured Interview', Borders: Yes, RowStatus: No, RowNumbers: Yes, DisplayRows: 1, InitialRows: 1, Min Repeats: 1, Max Repeats: 3, Main Row Type: Single-Line, Sub Row Type: Multi-Line							
18	mmInterview	mmInterview	mmInterview	Multimedia	0, Optional, Hidden		



**CLaSP CRF**  
**Care of Late Stage Parkinsonism**  
**EQ-5D-3L (Patient)**



**Patient ID**

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Scale completed by:

catScaleComBy

**only possible if patient has dementia**

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

**By placing a tick in the drop-box in each group below, please indicate which statements best describe your own health state today.**

**1. Mobility**

catEQ5D3L\_Q1

**2. Self-Care**

catEQ5D3L\_Q2

**3. Usual Activities (e.g. work, study, housework, family or leisure activities)**

catEQ5D3L\_Q3

**4. Pain/Discomfort**

catEQ5D3L\_Q4

**5. Anxiety/Depression**

catEQ5D3L\_Q5

**To help people say how good or bad a health state is, by choosing a number on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.**

**Best = 100**

...

...

...

**Worst = 0**

Please try to enter your own health state today:

IngBestImagine

Optional: comment for discrepancy between carer and patient

strDISC\_P\_C

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
3	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catScaleComBy	catScaleComBy	catScaleComBy	Category	38		1=Patient 2=Carer 3=Formal carer (if in nursing home etc.)
6	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
7	strAssessReas	strAssessReas	strAssessReas	Text	500		
8	catEQ5D3L_Q1	catEQ5D3L_Q1	catEQ5D3L_Q1	Category	41		See Appendix
9	catEQ5D3L_Q2	catEQ5D3L_Q2	catEQ5D3L_Q2	Category	51		See Appendix
10	catEQ5D3L_Q3	catEQ5D3L_Q3	catEQ5D3L_Q3	Category	60		See Appendix
11	catEQ5D3L_Q4	catEQ5D3L_Q4	catEQ5D3L_Q4	Category	38		See Appendix
12	catEQ5D3L_Q5	catEQ5D3L_Q5	catEQ5D3L_Q5	Category	40		See Appendix
13	IngBestImagine	IngBestImagine	IngBestImagine	Integer	999		
14	strDISC_P_C	strDISC_P_C	strDISC_P_C	Text	300, Optional		



**CLaSP CRF**  
**Care of Late Stage Parkinsonism**  
**PDQ-8 (Patient)**



Patient ID

IngPatID

**Only available for patients without dementia!**

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:  dtmExam

Duration of test (minutes):  Ing\_duration\_As

Reason, if not assessed:  catAss\_Test\_P

Other reason:  strAssessReas

**Parkinson's Disease Quality of Life Questionnaire (PDQ-8)**

0 = Never  
 1 = Occasionally  
 2 = Sometimes  
 3 = Often  
 4 = Always

or cannot do at all

**Please enter the correct number from the Legend above.**

- |  |  |                 |   |
|--|--|-----------------|---|
| 1. Had difficulty getting around in public?                                | <input type="text"/> <span style="color: red;">IngPDQ8_Q1</span> | <b>retain 1</b> | <input type="text"/> <span style="color: red;">hidIngPDQ8_Q1</span> |
| 2. Had difficulty dressing yourself?                                       | <input type="text"/> <span style="color: red;">IngPDQ8_Q2</span> | <b>retain 2</b> | <input type="text"/> <span style="color: red;">hidIngPDQ8_Q2</span> |
| 3. Felt depressed?   | <input type="text"/> <span style="color: red;">IngPDQ8_Q3</span> | <b>retain 3</b> | <input type="text"/> <span style="color: red;">hidIngPDQ8_Q3</span> |
| 4. Had problems with your close personal relationships?                    | <input type="text"/> <span style="color: red;">IngPDQ8_Q4</span> | <b>retain 4</b> | <input type="text"/> <span style="color: red;">hidIngPDQ8_Q4</span> |
| 5. Had problems with your concentration, e.g. when reading or watching TV? | <input type="text"/> <span style="color: red;">IngPDQ8_Q5</span> | <b>retain 5</b> | <input type="text"/> <span style="color: red;">hidIngPDQ8_Q5</span> |
| 6. Felt unable to communicate with people properly?                        | <input type="text"/> <span style="color: red;">IngPDQ8_Q6</span> | <b>retain 6</b> | <input type="text"/> <span style="color: red;">hidIngPDQ8_Q6</span> |
| 7. Had painful muscle cramps or spasms?                                    | <input type="text"/> <span style="color: red;">IngPDQ8_Q7</span> | <b>retain 7</b> | <input type="text"/> <span style="color: red;">hidIngPDQ8_Q7</span> |
| 8. Felt embarrassed in public due to having Parkinson's disease?           | <input type="text"/> <span style="color: red;">IngPDQ8_Q8</span> | <b>retain 8</b> | <input type="text"/> <span style="color: red;">hidIngPDQ8_Q8</span> |

**Sum of scores of each question:**  IngSUMall

Optional: comment for discrepancy between carer and patient

strDISC\_P\_C

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	IngPDQ8_Q1	IngPDQ8_Q1	IngPDQ8_Q1	Integer	9		
8	hidIngPDQ8_Q1	hidIngPDQ8_Q1	hidIngPDQ8_Q1	Integer	9, Hidden	case(( isknown( PDQ8:IngPDQ8_Q1 ), PDQ8:IngPDQ8_Q1), (else, 0 ))	
9	IngPDQ8_Q2	IngPDQ8_Q2	IngPDQ8_Q2	Integer	9		
10	hidIngPDQ8_Q2	hidIngPDQ8_Q2	hidIngPDQ8_Q2	Integer	9, Hidden	case(( isknown( PDQ8:IngPDQ8_Q2 ), PDQ8:IngPDQ8_Q2), (else, 0 ))	
11	IngPDQ8_Q3	IngPDQ8_Q3	IngPDQ8_Q3	Integer	9		
12	hidIngPDQ8_Q3	hidIngPDQ8_Q3	hidIngPDQ8_Q3	Integer	9, Hidden	case(( isknown( PDQ8:IngPDQ8_Q3 ), PDQ8:IngPDQ8_Q3), (else, 0 ))	
13	IngPDQ8_Q4	IngPDQ8_Q4	IngPDQ8_Q4	Integer	9		
14	hidIngPDQ8_Q4	hidIngPDQ8_Q4	hidIngPDQ8_Q4	Integer	9, Hidden	case(( isknown( PDQ8:IngPDQ8_Q4 ), PDQ8:IngPDQ8_Q4), (else, 0 ))	
15	IngPDQ8_Q5	IngPDQ8_Q5	IngPDQ8_Q5	Integer	9		
16	hidIngPDQ8_Q5	hidIngPDQ8_Q5	hidIngPDQ8_Q5	Integer	9, Hidden	case(( isknown( PDQ8:IngPDQ8_Q5 ), PDQ8:IngPDQ8_Q5), (else, 0 ))	
17	IngPDQ8_Q6	IngPDQ8_Q6	IngPDQ8_Q6	Integer	9		
18	hidIngPDQ8_Q6	hidIngPDQ8_Q6	hidIngPDQ8_Q6	Integer	9, Hidden	case(( isknown( PDQ8:IngPDQ8_Q6 ), PDQ8:IngPDQ8_Q6), (else, 0 ))	
19	IngPDQ8_Q7	IngPDQ8_Q7	IngPDQ8_Q7	Integer	9		
20	hidIngPDQ8_Q7	hidIngPDQ8_Q7	hidIngPDQ8_Q7	Integer	9, Hidden	case(( isknown( PDQ8:IngPDQ8_Q7 ), PDQ8:IngPDQ8_Q7), (else, 0 ))	
21	IngPDQ8_Q8	IngPDQ8_Q8	IngPDQ8_Q8	Integer	9		
22	hidIngPDQ8_Q8	hidIngPDQ8_Q8	hidIngPDQ8_Q8	Integer	9, Hidden	case(( isknown( PDQ8:IngPDQ8_Q8 ), PDQ8:IngPDQ8_Q8), (else, 0 ))	
23	IngSUMall	IngSUMall	IngSUMall	Integer	99	See Appendix	
24	strDISC_P_C	strDISC_P_C	strDISC_P_C	Text	300, Optional		



**CLaSP CRF**  
Care of Late Stage Parkinsonism  
**SMILE (Patient)**



Patient ID

IngPatID

Assessed: ☐ Yes  
☐ No

catAssQ

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

only possible if patient has dementia

Scale completed by:

catScaleComBy

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

**1. Please first nominate areas which give meaning to your life, regardless of how satisfied or unsatisfied you are with these areas at the moment.**

(The number and order of your answers is not important.)

Areas :

Area 1:	<input type="text"/>	strArea1
Area 2:	<input type="text"/>	strArea2
Area 3:	<input type="text"/>	strArea3
Area 4:	<input type="text"/>	strArea4
Area 5:	<input type="text"/>	strArea5
Area 6:	<input type="text"/>	strArea6
Area 7:	<input type="text"/>	strArea7

retain1	<input type="text"/>	hidden_IngA1
retain2	<input type="text"/>	hidden_IngA2
retain3	<input type="text"/>	hidden_IngA3
retain4	<input type="text"/>	hidden_IngA4
retain5	<input type="text"/>	hidden_IngA5
retain6	<input type="text"/>	hidden_IngA6
retain7	<input type="text"/>	hidden_IngA7
	<input type="text"/>	hiddenIngSMILEsum

**2. Please rate how satisfied or unsatisfied you are with each nominated area. That is, how much - positively or negatively - the area affects your total meaning in life.**

How satisfied are you with:

Area 1:	<input type="text"/>	catArea1Sat	recalculate1	<input type="text"/>	hid_realnrCatA1	recalculate2	<input type="text"/>	hid_realnrCatA2
Area 2:	<input type="text"/>	catArea2Sat	recalculate3	<input type="text"/>	hid_realnrCatA3	recalculate4	<input type="text"/>	hid_realnrCatA4
Area 3:	<input type="text"/>	catArea3Sat	recalculate5	<input type="text"/>	hid_realnrCatA5	recalculate6	<input type="text"/>	hid_realnrCatA6
Area 4:	<input type="text"/>	catArea4Sat	recalculate7	<input type="text"/>	hid_realnrCatA7			
Area 5:	<input type="text"/>	catArea5Sat						
Area 6:	<input type="text"/>	catArea6Sat						
Area 7:	<input type="text"/>	catArea7Sat						

sum s:

hidRealRecSum

Index of Satisfaction (IoS):

RealNr\_IoS

**3. Please rate how important each area is for your total meaning in life. Try to distinguish between the areas as best possible by considering all numbers.**

How important is:

Area 1:	<input type="text"/>	catArea1Imp	hid_IngCatImA1	<input type="text"/>	hid_IngCatImA1	hid_IngCatImA2	<input type="text"/>	hid_IngCatImA2
Area 2:	<input type="text"/>	catArea2Imp	hid_IngCatImA3	<input type="text"/>	hid_IngCatImA3	hid_IngCatImA4	<input type="text"/>	hid_IngCatImA4
Area 3:	<input type="text"/>	catArea3Imp	hid_IngCatImA5	<input type="text"/>	hid_IngCatImA5	hid_IngCatImA6	<input type="text"/>	hid_IngCatImA6
Area 4:	<input type="text"/>	catArea4Imp	hid_IngCatImA7	<input type="text"/>	hid_IngCatImA7			
Area 5:	<input type="text"/>	catArea5Imp						
Area 6:	<input type="text"/>	catArea6Imp						
Area 7:	<input type="text"/>	catArea7Imp						

hidIngImpoSum (SUM W)

hidIngImpoSum

Index of Weighting (IoW):

IngImpIoW

Index of Weighted Satisfaction (IoWS):

RealNr\_IoWS

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catScaleComBy	catScaleComBy	catScaleComBy	Category	38		1=Patient 2=Carer 3=Formal carer (if in nursing home etc.)
6	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
7	strAssessReas	strAssessReas	strAssessReas	Text	500		
8	strArea1	strArea1	strArea1	Text	100		
9	hidden_IngA1	hidden_IngA1	hidden_IngA1	Integer	9, Hidden	case(( isknown( SMILE:strArea1), 1 ), ( else, 0 ) )	
10	strArea2	strArea2	strArea2	Text	100		
11	hidden_IngA2	hidden_IngA2	hidden_IngA2	Integer	9, Hidden	case(( isknown( SMILE:strArea2), 1 ), ( else, 0 ) )	
12	strArea3	strArea3	strArea3	Text	100		
13	hidden_IngA3	hidden_IngA3	hidden_IngA3	Integer	9, Hidden	case(( isknown( SMILE:strArea3), 1 ), ( else, 0 ) )	
14	strArea4	strArea4	strArea4	Text	100, Optional		
15	hidden_IngA4	hidden_IngA4	hidden_IngA4	Integer	9, Hidden	case(( isknown( SMILE:strArea4), 1 ), ( else, 0 ) )	
16	strArea5	strArea5	strArea5	Text	100, Optional		
17	hidden_IngA5	hidden_IngA5	hidden_IngA5	Integer	9, Hidden	case(( isknown( SMILE:strArea5), 1 ), ( else, 0 ) )	
18	strArea6	strArea6	strArea6	Text	100, Optional		
19	hidden_IngA6	hidden_IngA6	hidden_IngA6	Integer	9, Hidden	case(( isknown( SMILE:strArea6), 1 ), ( else, 0 ) )	
20	strArea7	strArea7	strArea7	Text	100, Optional		
21	hidden_IngA7	hidden_IngA7	hidden_IngA7	Integer	9, Hidden	case(( isknown( SMILE:strArea7), 1 ), ( else, 0 ) )	
22	hidIngSMILEsum	hidIngSMILEsum	hidIngSMILEsum	Integer	99, Hidden	See Appendix	
23	catArea1Sat	catArea1Sat	catArea1Sat	Category	24		See Appendix
24	hid_realnrCatA1	hid_realnrCatA1	hid_realnrCatA1	Real	999.9, Hidden	See Appendix	
25	hid_realnrCatA2	hid_realnrCatA2	hid_realnrCatA2	Real	999.9, Hidden	See Appendix	
26	hid_realnrCatA3	hid_realnrCatA3	hid_realnrCatA3	Real	999.9, Hidden	See Appendix	
27	hid_realnrCatA4	hid_realnrCatA4	hid_realnrCatA4	Real	999.9, Hidden	See Appendix	
28	catArea2Sat	catArea2Sat	catArea2Sat	Category	24		See Appendix
29	hid_realnrCatA5	hid_realnrCatA5	hid_realnrCatA5	Real	999.9, Hidden	See Appendix	
30	hid_realnrCatA6	hid_realnrCatA6	hid_realnrCatA6	Real	999.9, Hidden	See Appendix	
31	catArea3Sat	catArea3Sat	catArea3Sat	Category	24		See Appendix
32	hid_realnrCatA7	hid_realnrCatA7	hid_realnrCatA7	Real	999.9, Hidden	See Appendix	
33	catArea4Sat	catArea4Sat	catArea4Sat	Category	24		See Appendix
34	catArea5Sat	catArea5Sat	catArea5Sat	Category	24		See Appendix
35	hidRealRecSum	hidRealRecSum	hidRealRecSum	Real	999.99, Hidden	See Appendix	
36	catArea6Sat	catArea6Sat	catArea6Sat	Category	24		See Appendix
37	catArea7Sat	catArea7Sat	catArea7Sat	Category	24		See Appendix
38	RealNr_IoS	RealNr_IoS	RealNr_IoS	Real	999.99	SMILE:hidRealRecSum/SMILE:hidIngSMILEsum	
39	catArea1Imp	catArea1Imp	catArea1Imp	Category	23		See Appendix
40	hid_IngCatImA1	hid_IngCatImA1	hid_IngCatImA1	Integer	9, Hidden	case((isknown(SMILE:catArea1Imp), SMILE:catArea1Imp), (else, 0))	
41	hid_IngCatImA2	hid_IngCatImA2	hid_IngCatImA2	Integer	9, Hidden	case((isknown(SMILE:catArea2Imp), SMILE:catArea2Imp), (else, 0))	
42	hid_IngCatImA3	hid_IngCatImA3	hid_IngCatImA3	Integer	9, Hidden	case((isknown(SMILE:catArea3Imp), SMILE:catArea3Imp), (else, 0))	
43	hid_IngCatImA4	hid_IngCatImA4	hid_IngCatImA4	Integer	9, Hidden	case((isknown(SMILE:catArea4Imp), SMILE:catArea4Imp), (else, 0))	
44	catArea2Imp	catArea2Imp	catArea2Imp	Category	23		See Appendix
45	hid_IngCatImA5	hid_IngCatImA5	hid_IngCatImA5	Integer	9, Hidden	case((isknown(SMILE:catArea5Imp), SMILE:catArea5Imp), (else, 0))	
46	hid_IngCatImA6	hid_IngCatImA6	hid_IngCatImA6	Integer	9, Hidden	case((isknown(SMILE:catArea6Imp), SMILE:catArea6Imp), (else, 0))	
47	catArea3Imp	catArea3Imp	catArea3Imp	Category	23		See Appendix
48	hid_IngCatImA7	hid_IngCatImA7	hid_IngCatImA7	Integer	9, Hidden	case((isknown(SMILE:catArea7Imp), SMILE:catArea7Imp), (else, 0))	
49	catArea4Imp	catArea4Imp	catArea4Imp	Category	23		See Appendix
50	catArea5Imp	catArea5Imp	catArea5Imp	Category	23		See Appendix
51	catArea6Imp	catArea6Imp	catArea6Imp	Category	23		See Appendix
52	hidIngImpoSum	hidIngImpoSum	hidIngImpoSum	Integer	99, Hidden	See Appendix	
53	catArea7Imp	catArea7Imp	catArea7Imp	Category	23		See Appendix
54	IngImpIoW	IngImpIoW	IngImpIoW	Real	999.99	(SMILE:hidIngImpoSum/(7 * SMILE:hidIngSMILEsum))*100	
55	RealNr_IoWS	RealNr_IoWS	RealNr_IoWS	Real	999.99	See Appendix	

**CLaSP CRF**  
Care of Late Stage Parkinsonism  
**LIKERT SCALE (Patient)**



Patient ID  IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:  dtmExam

Duration of test (minutes):  Ing\_duration\_As

**only possible if patient has dementia**

Scale completed by:  catScaleComBy

Reason, if not assessed:  catAss\_Test\_P

Other reason:  strAssessReas

How satisfied are you with your overall care?

catCareLikP

How satisfied are you with your overall support?

catCareSupP

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatiID	IngPatiID	IngPatiID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catScaleComBy	catScaleComBy	catScaleComBy	Category	38		1=Patient 2=Carer 3=Formal carer (if in nursing home etc.)
6	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
7	strAssessReas	strAssessReas	strAssessReas	Text	500		
8	catCareLikP	catCareLikP	catCareLikP	Category	21		See Appendix
9	catCareSupP	catCareSupP	catCareSupP	Category	21, Optional, Hidden		See Appendix



CLaSP CRF  
Care of Late Stage Parkinsonism



**GERIATRIC DEPRESSION SCALE**  
**Short Form (Patient)**

Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

**only possible if patient has dementia**

Scale completed by:

catScaleComBy

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

**Directions to Patient:**

Please choose the best answer for how you have felt over the past week.

1. Are you basically satisfied with your life?
2. Have you dropped many of your activities and interests?
3. Do you feel that your life is empty?
4. Do you often get bored?
5. Are you in good spirits most of the time?
6. Are you afraid that something bad is going to happen to you?
7. Do you feel happy most of the time?
8. Do you often feel helpless?
9. Do you prefer to stay at home rather than go out and do things?
10. Do you feel you have more problems with memory than most?
11. Do you think it is wonderful to be alive now?
12. Do you feel pretty worthless the way you are now?
13. Do you feel full of energy?
14. Do you feel that your situation is hopeless?
15. Do you think that most people are better off than you are?

cat\_GDS\_Q1

hid\_GDS\_Q1  
hid\_GDS\_Q1

cat\_GDS\_Q2

hid\_GDS\_Q2  
hid\_GDS\_Q2

cat\_GDS\_Q3

hid\_GDS\_Q3  
hid\_GDS\_Q3

cat\_GDS\_Q4

hid\_GDS\_Q4  
hid\_GDS\_Q4

cat\_GDS\_Q5

hid\_GDS\_Q5  
hid\_GDS\_Q5

cat\_GDS\_Q6

hid\_GDS\_Q6  
hid\_GDS\_Q6

cat\_GDS\_Q7

hid\_GDS\_Q7  
hid\_GDS\_Q7

cat\_GDS\_Q8

hid\_GDS\_Q8  
hid\_GDS\_Q8

cat\_GDS\_Q9

hid\_GDS\_Q9  
hid\_GDS\_Q9

cat\_GDS\_Q10

hid\_GDS\_Q10  
hid\_GDS\_Q10

cat\_GDS\_Q11

hid\_GDS\_Q11  
hid\_GDS\_Q11

cat\_GDS\_Q12

hid\_GDS\_Q12  
hid\_GDS\_Q12

cat\_GDS\_Q13

hid\_GDS\_Q13  
hid\_GDS\_Q13

cat\_GDS\_Q14

hid\_GDS\_Q14  
hid\_GDS\_Q14

cat\_GDS\_Q15

hid\_GDS\_Q15  
hid\_GDS\_Q15

Total Score:

Ing\_GDS\_total

**A score > 5 points is suggestive of depression.**

**A score >= 10 points is almost always indicative of depression.**

**A score > 5 points should warrant a follow-up comprehensive assessment.**

Optional: comment for discrepancy between carer and patient

strDISC\_P\_C

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catScaleComBy	catScaleComBy	catScaleComBy	Category	38		1=Patient 2=Carer 3=Formal carer (if in nursing home etc.)
6	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
7	strAssessReas	strAssessReas	strAssessReas	Text	500		
8	cat_GDS_Q1	cat_GDS_Q1	cat_GDS_Q1	Category	3		1=Yes 0=No
9	hid_GDS_Q1	hid_GDS_Q1	hid_GDS_Q1	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q1=1, 0), ( GDS:cat_GDS_Q1=0, 1 ))	
10	cat_GDS_Q2	cat_GDS_Q2	cat_GDS_Q2	Category	3		1=Yes 0=No
11	hid_GDS_Q2	hid_GDS_Q2	hid_GDS_Q2	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q2=1, 1), ( GDS:cat_GDS_Q2=0, 0 ))	
12	cat_GDS_Q3	cat_GDS_Q3	cat_GDS_Q3	Category	3		1=Yes 0=No
13	hid_GDS_Q3	hid_GDS_Q3	hid_GDS_Q3	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q3=1, 1), ( GDS:cat_GDS_Q3=0, 0 ))	
14	cat_GDS_Q4	cat_GDS_Q4	cat_GDS_Q4	Category	3		1=Yes 0=No
15	hid_GDS_Q4	hid_GDS_Q4	hid_GDS_Q4	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q4=1, 1), ( GDS:cat_GDS_Q4=0, 0 ))	
16	cat_GDS_Q5	cat_GDS_Q5	cat_GDS_Q5	Category	3		1=Yes 0=No
17	hid_GDS_Q5	hid_GDS_Q5	hid_GDS_Q5	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q5=1, 0), ( GDS:cat_GDS_Q5=0, 1 ))	
18	cat_GDS_Q6	cat_GDS_Q6	cat_GDS_Q6	Category	3		1=Yes 0=No
19	hid_GDS_Q6	hid_GDS_Q6	hid_GDS_Q6	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q6=1, 1), ( GDS:cat_GDS_Q6=0, 0 ))	
20	cat_GDS_Q7	cat_GDS_Q7	cat_GDS_Q7	Category	3		1=Yes 0=No
21	hid_GDS_Q7	hid_GDS_Q7	hid_GDS_Q7	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q7=1, 0), ( GDS:cat_GDS_Q7=0, 1 ))	
22	cat_GDS_Q8	cat_GDS_Q8	cat_GDS_Q8	Category	3		1=Yes 0=No
23	hid_GDS_Q8	hid_GDS_Q8	hid_GDS_Q8	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q8=1, 1), ( GDS:cat_GDS_Q8=0, 0 ))	
24	cat_GDS_Q9	cat_GDS_Q9	cat_GDS_Q9	Category	3		1=Yes 0=No
25	hid_GDS_Q9	hid_GDS_Q9	hid_GDS_Q9	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q9=1, 1), ( GDS:cat_GDS_Q9=0, 0 ))	
26	cat_GDS_Q10	cat_GDS_Q10	cat_GDS_Q10	Category	3		1=Yes 0=No
27	hid_GDS_Q10	hid_GDS_Q10	hid_GDS_Q10	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q10=1, 1), ( GDS:cat_GDS_Q10=0, 0 ))	
28	cat_GDS_Q11	cat_GDS_Q11	cat_GDS_Q11	Category	3		1=Yes 0=No
29	hid_GDS_Q11	hid_GDS_Q11	hid_GDS_Q11	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q11=1, 0), ( GDS:cat_GDS_Q11=0, 1 ))	
30	cat_GDS_Q12	cat_GDS_Q12	cat_GDS_Q12	Category	3		1=Yes 0=No
31	hid_GDS_Q12	hid_GDS_Q12	hid_GDS_Q12	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q12=1, 1), ( GDS:cat_GDS_Q12=0, 0 ))	
32	cat_GDS_Q13	cat_GDS_Q13	cat_GDS_Q13	Category	3		1=Yes 0=No
33	hid_GDS_Q13	hid_GDS_Q13	hid_GDS_Q13	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q13=1, 0), ( GDS:cat_GDS_Q13=0, 1 ))	
34	cat_GDS_Q14	cat_GDS_Q14	cat_GDS_Q14	Category	3		1=Yes 0=No
35	hid_GDS_Q14	hid_GDS_Q14	hid_GDS_Q14	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q14=1, 1), ( GDS:cat_GDS_Q14=0, 0 ))	
36	cat_GDS_Q15	cat_GDS_Q15	cat_GDS_Q15	Category	3		1=Yes 0=No
37	hid_GDS_Q15	hid_GDS_Q15	hid_GDS_Q15	Integer	9, Optional, Hidden	case((GDS:cat_GDS_Q15=1, 1), ( GDS:cat_GDS_Q15=0, 0 ))	
38	Ing_GDS_total	Ing_GDS_total	Ing_GDS_total	Integer	99, Optional	See Appendix	
39	strDISC_P_C	strDISC_P_C	strDISC_P_C	Text	300, Optional		



**CLaSP CRF**  
**Care of Late Stage Parkinsonism**  
**EQ-5D-3L (Carer)**



Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

By placing a tick in one box in each group below, please indicate which statements best describe the Patient health state today.

## 1. Mobility

catEQ5D3LC\_Q1

## 2. Self-Care

catEQ5D3LC\_Q2

## 3. Usual Activities (e.g. work, study, housework, family or leisure activities)

catEQ5D3LC\_Q3

## 4. Pain/Discomfort

catEQ5D3LC\_Q4

## 5. Anxiety/Depression

catEQ5D3LC\_Q5

To help people say how good or bad a health state is, by choosing a number on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

Best = 100

...

...

Worst = 0

Please try to enter the best imaginable health state:

IngBestImagineC

Optional: comment for discrepancy between carer and patient

strDISC\_P\_C

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catEQ5D3LC_Q1	catEQ5D3LC_Q1	catEQ5D3LC_Q1	Category	41		See Appendix
8	catEQ5D3LC_Q2	catEQ5D3LC_Q2	catEQ5D3LC_Q2	Category	51		See Appendix
9	catEQ5D3LC_Q3	catEQ5D3LC_Q3	catEQ5D3LC_Q3	Category	60		See Appendix
10	catEQ5D3LC_Q4	catEQ5D3LC_Q4	catEQ5D3LC_Q4	Category	38		See Appendix
11	catEQ5D3LC_Q5	catEQ5D3LC_Q5	catEQ5D3LC_Q5	Category	40		See Appendix
12	IngBestImagineC	IngBestImagineC	IngBestImagineC	Integer	999		
13	strDISC_P_C	strDISC_P_C	strDISC_P_C	Text	300, Optional		



**CLaSP CRF**  
Care of Late Stage Parkinsonism  
**DEMQOL-PROXY (Carer)**  
(version 4)



Patient ID

IngPatID

**Only available for patients with dementia!**

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

**DEMQOL-Proxy is a 32 item interviewer-administered questionnaire answered by a caregiver.**

## 1. Feelings

**Please try to enter the best imaginable answer!**

Would you say, in the last week the patient (your relative) has felt:

1. cheerful?  catFeeling1
2. worried or anxious?  catFeeling2
3. frustrated?  catFeeling3
4. full of energy?  catFeeling4
5. sad?  catFeeling5
6. content?  catFeeling6
7. distressed?  catFeeling7
8. lively?  catFeeling8
9. irritable?  catFeeling9
10. fed-up?  catFeeling10

11. that he/she has things to look forward to?

catFeeling11

## 2. Memory

In the last week, how worried would you say has been the patient (your relative) about:

12. his/her memory in general?  catMemory12
13. forgetting things that happened a long time ago?  catMemory13
14. forgetting things that happened recently?  catMemory14
15. forgetting people's names?  catMemory15
16. forgetting where he/she is?  catMemory16
17. forgetting what day it is?  catMemory17
18. his/her thoughts being muddled?  catMemory18
19. difficulty making decisions?  catMemory19
20. making him/herself understood?  catMemory20

## 3. Everyday life

In the last week, how worried would you say has been the patient (your relative) about:

21. keeping him/herself clean (eg washing and bathing)?  catEveryDay21
22. keeping him/herself looking nice?  catEveryDay22
23. getting what he/she wants from the shop?  catEveryDay23

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
3	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catFeeling1	catFeeling1	catFeeling1	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
8	catFeeling2	catFeeling2	catFeeling2	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
9	catFeeling3	catFeeling3	catFeeling3	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
10	catFeeling4	catFeeling4	catFeeling4	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
11	catFeeling5	catFeeling5	catFeeling5	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
12	catFeeling6	catFeeling6	catFeeling6	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
13	catFeeling7	catFeeling7	catFeeling7	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
14	catFeeling8	catFeeling8	catFeeling8	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
15	catFeeling9	catFeeling9	catFeeling9	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
16	catFeeling10	catFeeling10	catFeeling10	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
17	catFeeling11	catFeeling11	catFeeling11	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
18	catMemory12	catMemory12	catMemory12	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
19	catMemory13	catMemory13	catMemory13	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
20	catMemory14	catMemory14	catMemory14	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
21	catMemory15	catMemory15	catMemory15	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
22	catMemory16	catMemory16	catMemory16	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
23	catMemory17	catMemory17	catMemory17	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
24	catMemory18	catMemory18	catMemory18	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
25	catMemory19	catMemory19	catMemory19	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
26	catMemory20	catMemory20	catMemory20	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
27	catEveryDay21	catEveryDay21	catEveryDay21	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
28	catEveryDay22	catEveryDay22	catEveryDay22	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
29	catEveryDay23	catEveryDay23	catEveryDay23	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all

24. using money to pay for things?	<input type="text"/>	<input type="text"/>	catEveryDay24
25. looking after his/her finances?	<input type="text"/>	<input type="text"/>	catEveryDay25
26. things taking longer than they used to?	<input type="text"/>	<input type="text"/>	catEveryDay26
27. getting in touch with people?	<input type="text"/>	<input type="text"/>	catEveryDay27
28. not having enough company?	<input type="text"/>	<input type="text"/>	catEveryDay28
29. not being able to help other people?	<input type="text"/>	<input type="text"/>	catEveryDay29
30. not playing a useful part in things?	<input type="text"/>	<input type="text"/>	catEveryDay30
31. his/her physical health?	<input type="text"/>	<input type="text"/>	catEveryDay31

Thinking about all of these things in the last week, how would you say the patient (your relative) would rate:

32. his/her quality of life overall?	<input type="text"/>	<input type="text"/>	catEveryDay32
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ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
30	catEveryDay24	catEveryDay24	catEveryDay24	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
31	catEveryDay25	catEveryDay25	catEveryDay25	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
32	catEveryDay26	catEveryDay26	catEveryDay26	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
33	catEveryDay27	catEveryDay27	catEveryDay27	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
34	catEveryDay28	catEveryDay28	catEveryDay28	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
35	catEveryDay29	catEveryDay29	catEveryDay29	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
36	catEveryDay30	catEveryDay30	catEveryDay30	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
37	catEveryDay31	catEveryDay31	catEveryDay31	Category	15		1=1 = a lot 2=2 = quite a bit 3=3 = a little 4=4 = not at all
38	catEveryDay32	catEveryDay32	catEveryDay32	Category	13		1=1 = very good 2=2 = good 3=3 = fair 4=4 = poor



**CLaSP CRF**  
**Care of Late Stage Parkinsonism**  
**LIKERT SCALE (Carer)**



**Patient ID**

IngPatID

**Assessed:** ☐ Yes catAssQ  
☐ No

**Date test performed:**  dtmExam

**Duration of test (minutes):**  Ing\_duration\_As

**Reason, if not assessed:**  catAss\_Test\_P

**Other reason:**  strAssessReas

**How satisfied are you with your overall support?**

 catCareSup

**How satisfied are you with your overall care?**

 catCareLik

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catCareSup	catCareSup	catCareSup	Category	21		See Appendix
8	catCareLik	catCareLik	catCareLik	Category	21, Optional, Hidden		See Appendix



**CLaSP CRF**  
**Care of Late Stage Parkinsonism**  
**ZARIT BURDEN Interview (Carer)**



Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

Choose a response number that best describes how you feel.

- 0 = Never  
 1 = Rarely  
 2 = Sometimes  
 3 = Quite frequently  
 4 = always

Please enter the correct number from the Legend above.

1. Do you feel that your relative asks for more help than he/she needs?
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
4. Do you feel embarrassed over your relative's behavior?
5. Do you feel angry when you are around your relative?
6. Do you feel that your relative currently affects your relationships with other family members or friends in a negative way?
7. Are you afraid what the future holds for your relative?
8. Do you feel your relative is dependent on you?
9. Do you feel strained when you are around your relative?
10. Do you feel your health has suffered because of your involvement with your relative?
11. Do you feel that you don't have as much privacy as you would like because of your relative?
12. Do you feel that your social life has suffered because you are caring for your relatives?
13. Do you feel uncomfortable about having friends over because of your relative?
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?
16. Do you feel that you will be unable to take care of your relative much longer?
17. Do you feel you have lost control of your life since your relative's illness?
18. Do you wish you could leave the care of your relative to someone else?
19. Do you feel uncertain about what to do about your relative?
20. Do you feel you should be doing more for your relative?
21. Do you feel you could do a better job in caring for your relative?
22. Overall, how burdened do you feel in caring for your relative?

<input type="text"/>	<span style="color: red;">IngZaBuInQ1</span>	<b>retain1</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q1</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ2</span>	<b>retain2</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q2</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ3</span>	<b>retain3</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q3</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ4</span>	<b>retain4</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q4</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ5</span>	<b>retain5</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q5</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ6</span>	<b>retain6</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q6</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ7</span>	<b>retain7</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q7</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ8</span>	<b>retain8</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q8</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ9</span>	<b>retain9</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q9</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ10</span>	<b>retain10</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q10</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ11</span>	<b>retain11</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q11</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ12</span>	<b>retain12</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q12</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ13</span>	<b>retain13</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q13</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ14</span>	<b>retain14</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q14</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ15</span>	<b>retain15</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q15</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ16</span>	<b>retain16</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q16</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ17</span>	<b>retain17</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q17</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ18</span>	<b>retain18</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q18</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ19</span>	<b>retain19</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q19</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ20</span>	<b>retain20</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q20</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ21</span>	<b>retain21</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q21</span>
<input type="text"/>	<span style="color: red;">IngZaBuInQ22</span>	<b>retain22</b>	<input type="text"/>	<span style="color: red;">hidIngZBI_Q22</span>

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	IngZaBuInQ1	IngZaBuInQ1	IngZaBuInQ1	Integer	9		
8	hidIngZBI_Q1	hidIngZBI_Q1	hidIngZBI_Q1	Integer	9, Hidden	See Appendix	
9	IngZaBuInQ2	IngZaBuInQ2	IngZaBuInQ2	Integer	9		
10	hidIngZBI_Q2	hidIngZBI_Q2	hidIngZBI_Q2	Integer	9, Hidden	See Appendix	
11	IngZaBuInQ3	IngZaBuInQ3	IngZaBuInQ3	Integer	9		
12	hidIngZBI_Q3	hidIngZBI_Q3	hidIngZBI_Q3	Integer	9, Hidden	See Appendix	
13	IngZaBuInQ4	IngZaBuInQ4	IngZaBuInQ4	Integer	9		
14	hidIngZBI_Q4	hidIngZBI_Q4	hidIngZBI_Q4	Integer	9, Hidden	See Appendix	
15	IngZaBuInQ5	IngZaBuInQ5	IngZaBuInQ5	Integer	9		
16	hidIngZBI_Q5	hidIngZBI_Q5	hidIngZBI_Q5	Integer	9, Hidden	See Appendix	
17	IngZaBuInQ6	IngZaBuInQ6	IngZaBuInQ6	Integer	9		
18	hidIngZBI_Q6	hidIngZBI_Q6	hidIngZBI_Q6	Integer	9, Hidden	See Appendix	
19	IngZaBuInQ7	IngZaBuInQ7	IngZaBuInQ7	Integer	9		
20	hidIngZBI_Q7	hidIngZBI_Q7	hidIngZBI_Q7	Integer	9, Hidden	See Appendix	
21	IngZaBuInQ8	IngZaBuInQ8	IngZaBuInQ8	Integer	9		
22	hidIngZBI_Q8	hidIngZBI_Q8	hidIngZBI_Q8	Integer	9, Hidden	See Appendix	
23	IngZaBuInQ9	IngZaBuInQ9	IngZaBuInQ9	Integer	9		
24	hidIngZBI_Q9	hidIngZBI_Q9	hidIngZBI_Q9	Integer	9, Hidden	See Appendix	
25	IngZaBuInQ10	IngZaBuInQ10	IngZaBuInQ10	Integer	9		
26	hidIngZBI_Q10	hidIngZBI_Q10	hidIngZBI_Q10	Integer	9, Hidden	See Appendix	
27	IngZaBuInQ11	IngZaBuInQ11	IngZaBuInQ11	Integer	9		
28	hidIngZBI_Q11	hidIngZBI_Q11	hidIngZBI_Q11	Integer	9, Hidden	See Appendix	
29	IngZaBuInQ12	IngZaBuInQ12	IngZaBuInQ12	Integer	9		
30	hidIngZBI_Q12	hidIngZBI_Q12	hidIngZBI_Q12	Integer	9, Hidden	See Appendix	
31	IngZaBuInQ13	IngZaBuInQ13	IngZaBuInQ13	Integer	9		
32	hidIngZBI_Q13	hidIngZBI_Q13	hidIngZBI_Q13	Integer	9, Hidden	See Appendix	
33	IngZaBuInQ14	IngZaBuInQ14	IngZaBuInQ14	Integer	9		
34	hidIngZBI_Q14	hidIngZBI_Q14	hidIngZBI_Q14	Integer	9, Hidden	See Appendix	
35	IngZaBuInQ15	IngZaBuInQ15	IngZaBuInQ15	Integer	9		
36	hidIngZBI_Q15	hidIngZBI_Q15	hidIngZBI_Q15	Integer	9, Hidden	See Appendix	
37	IngZaBuInQ16	IngZaBuInQ16	IngZaBuInQ16	Integer	9		
38	hidIngZBI_Q16	hidIngZBI_Q16	hidIngZBI_Q16	Integer	9, Hidden	See Appendix	
39	IngZaBuInQ17	IngZaBuInQ17	IngZaBuInQ17	Integer	9		
40	hidIngZBI_Q17	hidIngZBI_Q17	hidIngZBI_Q17	Integer	9, Hidden	See Appendix	
41	IngZaBuInQ18	IngZaBuInQ18	IngZaBuInQ18	Integer	9		
42	hidIngZBI_Q18	hidIngZBI_Q18	hidIngZBI_Q18	Integer	9, Hidden	See Appendix	
43	IngZaBuInQ19	IngZaBuInQ19	IngZaBuInQ19	Integer	9		
44	hidIngZBI_Q19	hidIngZBI_Q19	hidIngZBI_Q19	Integer	9, Hidden	See Appendix	
45	IngZaBuInQ20	IngZaBuInQ20	IngZaBuInQ20	Integer	9		
46	hidIngZBI_Q20	hidIngZBI_Q20	hidIngZBI_Q20	Integer	9, Hidden	See Appendix	
47	IngZaBuInQ21	IngZaBuInQ21	IngZaBuInQ21	Integer	9		
48	hidIngZBI_Q21	hidIngZBI_Q21	hidIngZBI_Q21	Integer	9, Hidden	See Appendix	
49	IngZaBuInQ22	IngZaBuInQ22	IngZaBuInQ22	Integer	9		
50	hidIngZBI_Q22	hidIngZBI_Q22	hidIngZBI_Q22	Integer	9, Hidden	See Appendix	

**Total score:**

IngSUM\_ZBI\_all

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
51	IngSUM_ZBI_all	IngSUM_ZBI_all	IngSUM_ZBI_all	Integer	99	See Appendix	



**CLaSP CRF**  
Care of Late Stage Parkinsonism  
**ACTIVITIES OF DAILY LIVING**  
**UPDRS-ADL Part II**

(Fahn 1987)



Patient ID

 IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:  dtmExamDuration of test (minutes):  Ing\_duration\_AsReason, if not assessed:  catAss\_Test\_POther reason:  strAssessReas**Status of patient during UPDRS II assessment (ON/OFF):**
 catAss\_onoff

Please enter the marked numbers (0, 1, 2, 3, 4) from the patient questionnaire for each question or choose the corresponding category.

**II. Activities of Daily Living****5. Speech**

IngADL5

 IngADL5

cat01UPDRS\_2\_5

**6. Salivation**

IngADL6

 IngADL6  
cat01UPDRS\_2\_6
**7. Swallowing**

IngADL7

 IngADL7  
cat01UPDRS\_2\_7
**8. Handwriting**

IngADL8

 IngADL8  
cat01UPDRS\_2\_8
**9. Cutting food and handling utensils**

IngADL9

 IngADL9  
cat01UPDRS\_2\_9
**10. Dressing**

IngADL10

 IngADL10  
cat01UPDRS\_2\_10
**11. Hygiene**

IngADL11

 IngADL11  
cat01UPDRS\_2\_11
**12. Turning in bed and adjusting bed clothes**

IngADL12

 IngADL12  
cat01UPDRS\_2\_12
**13. Falling (unrelated to freezing)**

IngADL13

 IngADL13  
cat01UPDRS\_2\_13
**14. Freezing when walking**

IngADL14

 IngADL14  
cat01UPDRS\_2\_14
**15. Walking**

IngADL15

 IngADL15  
cat01UPDRS\_2\_15
**16. Tremor**

IngADL16

 IngADL16  
cat01UPDRS\_2\_16
**17. Sensory complaints related to parkinsonism**

IngADL17

 IngADL17  
cat01UPDRS\_2\_17
**Total UPDRS-ADL, part II (calculated):**
 Ing01UPDRS\_2tot

Optional: comment for discrepancy between carer and patient

strDISC\_P\_C

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catAss_onoff	catAss_onoff	catAss_onoff	Category	3		1=ON 2=OFF
8	IngADL5	IngADL5	IngADL5	Integer	-9, Hidden	See Appendix	
9	cat01UPDRS_2_5	cat01UPDRS_2_5	cat01UPDRS_2_5	Category	62		See Appendix
10	IngADL6	IngADL6	IngADL6	Integer	-9, Hidden	See Appendix	
11	cat01UPDRS_2_6	cat01UPDRS_2_6	cat01UPDRS_2_6	Category	79		See Appendix
12	IngADL7	IngADL7	IngADL7	Integer	-9, Hidden	See Appendix	
13	cat01UPDRS_2_7	cat01UPDRS_2_7	cat01UPDRS_2_7	Category	43		See Appendix
14	IngADL8	IngADL8	IngADL8	Integer	-9, Hidden	See Appendix	
15	cat01UPDRS_2_8	cat01UPDRS_2_8	cat01UPDRS_2_8	Category	52		See Appendix
16	IngADL9	IngADL9	IngADL9	Integer	-9, Hidden	See Appendix	
17	cat01UPDRS_2_9	cat01UPDRS_2_9	cat01UPDRS_2_9	Category	67		See Appendix
18	IngADL10	IngADL10	IngADL10	Integer	-9, Hidden	See Appendix	
19	cat01UPDRS_2_10	cat01UPDRS_2_10	cat01UPDRS_2_10	Category	66		See Appendix
20	IngADL11	IngADL11	IngADL11	Integer	-9, Hidden	See Appendix	
21	cat01UPDRS_2_11	cat01UPDRS_2_11	cat01UPDRS_2_11	Category	85		See Appendix
22	IngADL12	IngADL12	IngADL12	Integer	-9, Hidden	See Appendix	
23	cat01UPDRS_2_12	cat01UPDRS_2_12	cat01UPDRS_2_12	Category	63		See Appendix
24	IngADL13	IngADL13	IngADL13	Integer	-9, Hidden	See Appendix	
25	cat01UPDRS_2_13	cat01UPDRS_2_13	cat01UPDRS_2_13	Category	47		See Appendix
26	IngADL14	IngADL14	IngADL14	Integer	-9, Hidden	See Appendix	
27	cat01UPDRS_2_14	cat01UPDRS_2_14	cat01UPDRS_2_14	Category	58		See Appendix
28	IngADL15	IngADL15	IngADL15	Integer	-9, Hidden	See Appendix	
29	cat01UPDRS_2_15	cat01UPDRS_2_15	cat01UPDRS_2_15	Category	64		See Appendix
30	IngADL16	IngADL16	IngADL16	Integer	-9, Hidden	See Appendix	
31	cat01UPDRS_2_16	cat01UPDRS_2_16	cat01UPDRS_2_16	Category	44		See Appendix
32	IngADL17	IngADL17	IngADL17	Integer	-9, Hidden	See Appendix	
33	cat01UPDRS_2_17	cat01UPDRS_2_17	cat01UPDRS_2_17	Category	66		See Appendix
34	Ing01UPDRS_2tot	Ing01UPDRS_2tot	Ing01UPDRS_2tot	Integer	-99	See Appendix	
35	strDISC_P_C	strDISC_P_C	strDISC_P_C	Text	300, Optional		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



**CGI - Clinical Global Impression**

Patient ID

IngPatID

**CGI - questions: completed by CLINICIAN**

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

**1. CGI-Severity overall**

How well has the participant been  
DURING THE WEEK PRECEDING THIS VISIT?

catCGIseverity

**2. CGI-Change** (only to be collected from T2 onwards)

Compared to the LAST VISIT, how much has the participant's health changed?

catCGIchange

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
3	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catCGIseverity	catCGIseverity	catCGIseverity	Category	26		See Appendix
8	catCGIchange	catCGIchange	catCGIchange	Category	24		See Appendix



CLaSP CRF  
Care of Late Stage Parkinsonism



CGI - Clinical Global Impression

Patient ID  IngPatID

CGI - questions: completed by PATIENT

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:  dtmExam

Duration of test (minutes):  Ing\_duration\_As

Reason, if not assessed:  catAss\_Test\_P

Other reason:  strAssessReas

1. CGI-Severity overall

How well has the participant been  
DURING THE WEEK PRECEDING THIS VISIT?

catCGIseverity

2. CGI-Change **(only to be collected from T2 onwards)**

Compared to the LAST VISIT, how much has the participant's health changed?

catCGIchange

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
3	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catCGIseverity	catCGIseverity	catCGIseverity	Category	26		See Appendix
8	catCGIchange	catCGIchange	catCGIchange	Category	24		See Appendix



**CLaSP CRF**  
Care of Late Stage Parkinsonism



**CGI - Clinical Global Impression**

Patient ID

IngPatID

**CGI - questions: completed by CARER**

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

**1. CGI-Severity overall**

How well has the participant been  
DURING THE WEEK PRECEDING THIS VISIT?

catCGIseverity

**2. CGI-Change** (only to be collected from T2 onwards)

Compared to the LAST VISIT, how much has the participant's health changed?

catCGIchange

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
3	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catCGIseverity	catCGIseverity	catCGIseverity	Category	26		See Appendix
8	catCGIchange	catCGIchange	catCGIchange	Category	24		See Appendix



CLaSP CRF  
Care of Late Stage Parkinsonism  
**HOEHN and YAHR STAGING**  
(Hoehn 1967)



Patient ID  IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:  dtmExam

Duration of test (minutes):  Ing\_duration\_As

Reason, if not assessed:  catAss\_Test\_P

Other reason:  strAssessReas

V. Modified Hoehn and Yahr Staging  
 catUPDRS5

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catUPDRS5	catUPDRS5	catUPDRS5	Category	95		See Appendix



CLaSP CRF  
Care of Late Stage Parkinsonism



UPDRS PART I (Fahn 1987)

Patient ID  IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:   dtmExam

Duration of test (minutes):  Ing\_duration\_As

Reason, if not assessed:  catAss\_Test\_P

Other reason:  strAssessReas

Please enter the marked numbers (0, 1, 2, 3, 4) from the questionnaire for each question.

I. Mentation, Behavior and Mood

1. Intellectual Impairment IngUPDRSI\_1  IngUPDRSI\_1  cat11UPDRS\_i\_1

2. Thought Disorder (due to dementia or drug intoxication) IngUPDRSI\_2  IngUPDRSI\_2  cat11UPDRS\_i\_2

3. Depression IngUPDRSI\_3  IngUPDRSI\_3  cat11UPDRS\_i\_3

4. Motivation/Initiative IngUPDRSI\_4  IngUPDRSI\_4  cat11UPDRS\_i\_4

Total UPDRS part I (calculated):  Ing11UPDRS\_itot

Optional: comment for discrepancy between carer and patient

strDISC\_P\_C

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	IngUPDRSI_1	IngUPDRSI_1	IngUPDRSI_1	Integer	-9, Hidden	case((Isknown( UPDRSI:cat11UPDRS_1_1 ), UPDRSI:cat11UPDRS_1_1), (else, 0))	
8	cat11UPDRS_1_1	cat11UPDRS_1_1	cat11UPDRS_1_1	Category	180		See Appendix
9	IngUPDRSI_2	IngUPDRSI_2	IngUPDRSI_2	Integer	-9, Hidden	case((Isknown( UPDRSI:cat11UPDRS_1_2 ), UPDRSI:cat11UPDRS_1_2), (else, 0))	
10	cat11UPDRS_1_2	cat11UPDRS_1_2	cat11UPDRS_1_2	Category	111		See Appendix
11	IngUPDRSI_3	IngUPDRSI_3	IngUPDRSI_3	Integer	-9, Hidden	case((Isknown( UPDRSI:cat11UPDRS_1_3 ), UPDRSI:cat11UPDRS_1_3), (else, 0))	
12	cat11UPDRS_1_3	cat11UPDRS_1_3	cat11UPDRS_1_3	Category	102		See Appendix
13	IngUPDRSI_4	IngUPDRSI_4	IngUPDRSI_4	Integer	-9, Hidden	case((Isknown( UPDRSI:cat11UPDRS_1_4 ), UPDRSI:cat11UPDRS_1_4), (else, 0))	
14	cat11UPDRS_1_4	cat11UPDRS_1_4	cat11UPDRS_1_4	Category	75		See Appendix
15	Ing11UPDRS_itot	Ing11UPDRS_itot	Ing11UPDRS_itot	Integer	-99	IngUPDRSI_1 + IngUPDRSI_2 + IngUPDRSI_3 + IngUPDRSI_4	
16	strDISC_P_C	strDISC_P_C	strDISC_P_C	Text	300, Optional		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



**UPDRS PART III**

(Fahn 1987)

Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

Please enter the marked numbers (0, 1, 2, 3, 4) from the questionnaire for each question.

**III. Motor Examination**

18. Speech

IngUPDRSIII\_18

IngUPDRSIII\_18

catUPDRS\_3\_18

19. Facial Expression

IngUPDRSIII\_19

IngUPDRSIII\_19

catUPDRS\_3\_19

20. Tremor at rest

Face

IngUPDRSIII\_20

IngUPDRSIII\_20

catUPDRS\_3\_20

Right Upper Extremity (RUE)

IngUPDRSIII\_20b

IngUPDRSIII\_20b

catUPDRS\_3\_20b

Left Upper Extremity (LUE)

IngUPDRSIII\_20c

IngUPDRSIII\_20c

catUPDRS\_3\_20c

Right Lower Extremity (RLE)

IngUPDRSIII\_20d

IngUPDRSIII\_20d

catUPDRS\_3\_20d

Left Lower Extremity (LLE)

IngUPDRSIII\_20e

IngUPDRSIII\_20e

catUPDRS\_3\_20e

21. Action or Postural Tremor of Hands

Right Upper Extremity (RUE)

IngUPDRSIII\_21

IngUPDRSIII\_21

catUPDRS\_3\_21

Left Upper Extremity (LUE)

IngUPDRSIII\_21b

IngUPDRSIII\_21b

catUPDRS\_3\_21b

22. Rigidity (Judged on passive movement of major joints with patient relaxed in sitting position. Cogwheeling to be ignored.)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	IngUPDRSIII_18	IngUPDRSIII_18	IngUPDRSIII_18	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_18 ), UPDRSIII:catUPDRS_3_18), (else, 0))	
8	catUPDRS_3_18	catUPDRS_3_18	catUPDRS_3_18	Category	53		See Appendix
9	IngUPDRSIII_19	IngUPDRSIII_19	IngUPDRSIII_19	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_19 ), UPDRSIII:catUPDRS_3_19), (else, 0))	
10	catUPDRS_3_19	catUPDRS_3_19	catUPDRS_3_19	Category	107		See Appendix
11	IngUPDRSIII_20	IngUPDRSIII_20	IngUPDRSIII_20	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_20 ), UPDRSIII:catUPDRS_3_20), (else, 0))	
12	catUPDRS_3_20	catUPDRS_3_20	catUPDRS_3_20	Category	96		See Appendix
13	IngUPDRSIII_20b	IngUPDRSIII_20b	IngUPDRSIII_20b	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_20b ), UPDRSIII:catUPDRS_3_20b), (else, 0))	
14	catUPDRS_3_20b	catUPDRS_3_20b	catUPDRS_3_20b	Category	96		See Appendix
15	IngUPDRSIII_20c	IngUPDRSIII_20c	IngUPDRSIII_20c	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_20c ), UPDRSIII:catUPDRS_3_20c), (else, 0))	
16	catUPDRS_3_20c	catUPDRS_3_20c	catUPDRS_3_20c	Category	96		See Appendix
17	IngUPDRSIII_20d	IngUPDRSIII_20d	IngUPDRSIII_20d	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_20d ), UPDRSIII:catUPDRS_3_20d), (else, 0))	
18	catUPDRS_3_20d	catUPDRS_3_20d	catUPDRS_3_20d	Category	96		See Appendix
19	IngUPDRSIII_20e	IngUPDRSIII_20e	IngUPDRSIII_20e	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_20e ), UPDRSIII:catUPDRS_3_20e), (else, 0))	
20	catUPDRS_3_20e	catUPDRS_3_20e	catUPDRS_3_20e	Category	96		See Appendix
21	IngUPDRSIII_21	IngUPDRSIII_21	IngUPDRSIII_21	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_21 ), UPDRSIII:catUPDRS_3_21), (else, 0))	
22	catUPDRS_3_21	catUPDRS_3_21	catUPDRS_3_21	Category	65		See Appendix
23	IngUPDRSIII_21b	IngUPDRSIII_21b	IngUPDRSIII_21b	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_21b ), UPDRSIII:catUPDRS_3_21b), (else, 0))	
24	catUPDRS_3_21b	catUPDRS_3_21b	catUPDRS_3_21b	Category	65		See Appendix

Neck	IngUPDRSIII_22	<input type="text"/>	IngUPDRSIII_22		catUPDRS_3_22
<input type="text"/>					
Right Upper Extremity (RUE)	IngUPDRSIII_22b	<input type="text"/>	IngUPDRSIII_22b		catUPDRS_3_22b
<input type="text"/>					
Left Upper Extremity (LUE)	IngUPDRSIII_22c	<input type="text"/>	IngUPDRSIII_22c		catUPDRS_3_22c
<input type="text"/>					
Right Lower Extremity (RLE)	IngUPDRSIII_22d	<input type="text"/>	IngUPDRSIII_22d		catUPDRS_3_22d
<input type="text"/>					
Left Lower Extremity (LLE)	IngUPDRSIII_22e	<input type="text"/>	IngUPDRSIII_22e		catUPDRS_3_22e
<input type="text"/>					

**23. Finger Taps (Patient taps thumb with index finger in rapid succession.)**

Right	IngUPDRSIII_23	<input type="text"/>	IngUPDRSIII_23		catUPDRS_3_23
<input type="text"/>					
Left	IngUPDRSIII_23b	<input type="text"/>	IngUPDRSIII_23b		catUPDRS_3_23b
<input type="text"/>					

**24. Hand Movements (Patient opens and closes hands in rapid succession.)**

Right	IngUPDRSIII_24	<input type="text"/>	IngUPDRSIII_24		catUPDRS_3_24
<input type="text"/>					
Left	IngUPDRSIII_24b	<input type="text"/>	IngUPDRSIII_24b		catUPDRS_3_24b
<input type="text"/>					

**25. Rapid Alternating Movements of Hands (Pronation-supination movements of hands, vertically and horizontally, with as large an amplitude as possible, both hands simultaneously.)**

Right	IngUPDRSIII_25	<input type="text"/>	IngUPDRSIII_25		catUPDRS_3_25
<input type="text"/>					
Left	IngUPDRSIII_25b	<input type="text"/>	IngUPDRSIII_25b		catUPDRS_3_25b
<input type="text"/>					

**26. Leg Agility (Patient taps heel on the ground in rapid succession picking up entire leg. Amplitude should be at least 3 inches.)**

Right	IngUPDRSIII_26	<input type="text"/>	IngUPDRSIII_26		catUPDRS_3_26
<input type="text"/>					
Left	IngUPDRSIII_26b	<input type="text"/>	IngUPDRSIII_26b		catUPDRS_3_26b
<input type="text"/>					

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
25	IngUPDRSIII_22	IngUPDRSIII_22	IngUPDRSIII_22	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_22 ), UPDRSIII:catUPDRS_3_22), (else, 0))	
26	catUPDRS_3_22	catUPDRS_3_22	catUPDRS_3_22	Category	74		See Appendix
27	IngUPDRSIII_22b	IngUPDRSIII_22b	IngUPDRSIII_22b	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_22b ), UPDRSIII:catUPDRS_3_22b), (else, 0))	
28	catUPDRS_3_22b	catUPDRS_3_22b	catUPDRS_3_22b	Category	74		See Appendix
29	IngUPDRSIII_22c	IngUPDRSIII_22c	IngUPDRSIII_22c	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_22c ), UPDRSIII:catUPDRS_3_22c), (else, 0))	
30	catUPDRS_3_22c	catUPDRS_3_22c	catUPDRS_3_22c	Category	74		See Appendix
31	IngUPDRSIII_22d	IngUPDRSIII_22d	IngUPDRSIII_22d	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_22d ), UPDRSIII:catUPDRS_3_22d), (else, 0))	
32	catUPDRS_3_22d	catUPDRS_3_22d	catUPDRS_3_22d	Category	74		See Appendix
33	IngUPDRSIII_22e	IngUPDRSIII_22e	IngUPDRSIII_22e	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_22e ), UPDRSIII:catUPDRS_3_22e), (else, 0))	
34	catUPDRS_3_22e	catUPDRS_3_22e	catUPDRS_3_22e	Category	74		See Appendix
35	IngUPDRSIII_23	IngUPDRSIII_23	IngUPDRSIII_23	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_23 ), UPDRSIII:catUPDRS_3_23), (else, 0))	
36	catUPDRS_3_23	catUPDRS_3_23	catUPDRS_3_23	Category	98		See Appendix
37	IngUPDRSIII_23b	IngUPDRSIII_23b	IngUPDRSIII_23b	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_23b ), UPDRSIII:catUPDRS_3_23b), (else, 0))	
38	catUPDRS_3_23b	catUPDRS_3_23b	catUPDRS_3_23b	Category	98		See Appendix
39	IngUPDRSIII_24	IngUPDRSIII_24	IngUPDRSIII_24	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_24 ), UPDRSIII:catUPDRS_3_24), (else, 0))	
40	catUPDRS_3_24	catUPDRS_3_24	catUPDRS_3_24	Category	98		See Appendix
41	IngUPDRSIII_24b	IngUPDRSIII_24b	IngUPDRSIII_24b	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_24b ), UPDRSIII:catUPDRS_3_24b), (else, 0))	
42	catUPDRS_3_24b	catUPDRS_3_24b	catUPDRS_3_24b	Category	98		See Appendix
43	IngUPDRSIII_25	IngUPDRSIII_25	IngUPDRSIII_25	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_25 ), UPDRSIII:catUPDRS_3_25), (else, 0))	
44	catUPDRS_3_25	catUPDRS_3_25	catUPDRS_3_25	Category	98		See Appendix
45	IngUPDRSIII_25b	IngUPDRSIII_25b	IngUPDRSIII_25b	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_25b ), UPDRSIII:catUPDRS_3_25b), (else, 0))	
46	catUPDRS_3_25b	catUPDRS_3_25b	catUPDRS_3_25b	Category	98		See Appendix
47	IngUPDRSIII_26	IngUPDRSIII_26	IngUPDRSIII_26	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_26 ), UPDRSIII:catUPDRS_3_26), (else, 0))	
48	catUPDRS_3_26	catUPDRS_3_26	catUPDRS_3_26	Category	98		See Appendix
49	IngUPDRSIII_26b	IngUPDRSIII_26b	IngUPDRSIII_26b	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_26b ), UPDRSIII:catUPDRS_3_26b), (else, 0))	
50	catUPDRS_3_26b	catUPDRS_3_26b	catUPDRS_3_26b	Category	98		See Appendix

27. Arising from Chair (Patient attempts to rise from a straightbacked chair, with arms folded across chest.)

catUPDRS\_3\_27

IngUPDRSIII\_27

IngUPDRSIII\_27

28. Posture

IngUPDRSIII\_28

IngUPDRSIII\_28

catUPDRS\_3\_28

29. Gait

IngUPDRSIII\_29

IngUPDRSIII\_29

catUPDRS\_3\_29

30. Postural Stability (Response to sudden, strong posterior displacement produced by pull on shoulders while patient erect with eyes open and feet slightly apart. Patient is prepared.)

catUPDRS\_3\_30

IngUPDRSIII\_30

IngUPDRSIII\_30

31. Body Bradykinesia and Hypokinesia (Combining slowness, hesitancy, decreased arm swing, small amplitude, and poverty of movement in general.)

catUPDRS\_3\_31

Total UPDRS part III (calculated):

IngUPDRSIII\_tot

IngUPDRSIII\_31

IngUPDRSIII\_31

Optional: comment for discrepancy between carer and patient

strDISC\_P\_C

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
51	catUPDRS_3_27	catUPDRS_3_27	catUPDRS_3_27	Category	91		See Appendix
52	IngUPDRSIII_27	IngUPDRSIII_27	IngUPDRSIII_27	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_27 ), UPDRSIII:catUPDRS_3_27), (else, 0))	
53	IngUPDRSIII_28	IngUPDRSIII_28	IngUPDRSIII_28	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_28 ), UPDRSIII:catUPDRS_3_28), (else, 0))	
54	catUPDRS_3_28	catUPDRS_3_28	catUPDRS_3_28	Category	89		See Appendix
55	IngUPDRSIII_29	IngUPDRSIII_29	IngUPDRSIII_29	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_29 ), UPDRSIII:catUPDRS_3_29), (else, 0))	
56	catUPDRS_3_29	catUPDRS_3_29	catUPDRS_3_29	Category	119		See Appendix
57	IngUPDRSIII_30	IngUPDRSIII_30	IngUPDRSIII_30	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_30 ), UPDRSIII:catUPDRS_3_30), (else, 0))	
58	catUPDRS_3_30	catUPDRS_3_30	catUPDRS_3_30	Category	71		See Appendix
59	catUPDRS_3_31	catUPDRS_3_31	catUPDRS_3_31	Category	123		See Appendix
60	IngUPDRSIII_31	IngUPDRSIII_31	IngUPDRSIII_31	Integer	-9, Hidden	case((Isknown( UPDRSIII:catUPDRS_3_31 ), UPDRSIII:catUPDRS_3_31), (else, 0))	
61	IngUPDRSIII_tot	IngUPDRSIII_tot	IngUPDRSIII_tot	Integer	-99	See Appendix	
62	strDISC_P_C	strDISC_P_C	strDISC_P_C	Text	300, Optional		



**CLaSP CRF**  
**Care of Late Stage Parkinsonism**  
**UPDRS PART IV** (Fahn 1987)



Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:  dtmExamDuration of test (minutes):  Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

Please enter the marked numbers (0, 1, 2, 3, 4)  
or (0,1) from the questionnaire for each question.

#### IV. Complications of Therapy (in the past week)

##### A. Dyskinesias

32. Duration: What proportion of the waking day are dyskinesias present?  
(Historical information.)

catUPDRS\_4\_32

IngUPDRSIV\_32

IngUPDRSIV\_32

33. Disability: How disabling are the dyskinesias? (Historical information;  
may be modified by office examination.)

catUPDRS\_4\_33

IngUPDRSIV\_33

IngUPDRSIV\_33

34. Painful Dyskinesias: How painful are the dyskinesias?

catUPDRS\_4\_34

IngUPDRSIV\_34

IngUPDRSIV\_34

35. Presence of Early Morning Dystonia (Historical information.)

catUPDRS\_4\_35

IngUPDRSIV\_35

IngUPDRSIV\_35

##### B. Clinical Fluctuations

36. Are 'off' periods predictable?

catUPDRS\_4\_36

IngUPDRSIV\_36

IngUPDRSIV\_36

37. Are 'off' periods unpredictable?

catUPDRS\_4\_37

IngUPDRSIV\_37

IngUPDRSIV\_37

38. Do 'off' periods come on suddenly, within a few seconds?

catUPDRS\_4\_38

IngUPDRSIV\_38

IngUPDRSIV\_38

39. What proportion of the waking day is the patient 'off' on average?

catUPDRS\_4\_39

IngUPDRSIV\_39

IngUPDRSIV\_39

##### C. Other Complications

40. Does the patient have anorexia, nausea, or vomiting?

catUPDRS\_4\_40

IngUPDRSIV\_40

IngUPDRSIV\_40

41. Any sleep disturbances, such as insomnia or hypersomnolence?

catUPDRS\_4\_41

IngUPDRSIV\_41

IngUPDRSIV\_41

42. Does the patient have symptomatic orthostasis?

catUPDRS\_4\_42

IngUPDRSIV\_42

IngUPDRSIV\_42

**Total UPDRS part IV (calculated):**

IngUPDRSIV\_tot

Optional: comment for discrepancy between carer and patient

strDISC\_P\_C

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	IngUPDRSIV_32	IngUPDRSIV_32	IngUPDRSIV_32	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_32 ), UPDRSIV:catUPDRS_4_32), (else, 0))	
8	catUPDRS_4_32	catUPDRS_4_32	catUPDRS_4_32	Category	19		See Appendix
9	IngUPDRSIV_33	IngUPDRSIV_33	IngUPDRSIV_33	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_33 ), UPDRSIV:catUPDRS_4_33), (else, 0))	
10	catUPDRS_4_33	catUPDRS_4_33	catUPDRS_4_33	Category	25		See Appendix
11	catUPDRS_4_34	catUPDRS_4_34	catUPDRS_4_34	Category	27		See Appendix
12	IngUPDRSIV_34	IngUPDRSIV_34	IngUPDRSIV_34	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_34 ), UPDRSIV:catUPDRS_4_34), (else, 0))	
13	IngUPDRSIV_35	IngUPDRSIV_35	IngUPDRSIV_35	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_35 ), UPDRSIV:catUPDRS_4_35), (else, 0))	
14	catUPDRS_4_35	catUPDRS_4_35	catUPDRS_4_35	Category	7		0=0 = No 1=1 = Yes
15	IngUPDRSIV_36	IngUPDRSIV_36	IngUPDRSIV_36	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_36 ), UPDRSIV:catUPDRS_4_36), (else, 0))	
16	catUPDRS_4_36	catUPDRS_4_36	catUPDRS_4_36	Category	7		0=0 = No 1=1 = Yes
17	IngUPDRSIV_37	IngUPDRSIV_37	IngUPDRSIV_37	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_37 ), UPDRSIV:catUPDRS_4_37), (else, 0))	
18	catUPDRS_4_37	catUPDRS_4_37	catUPDRS_4_37	Category	7		0=0 = No 1=1 = Yes
19	IngUPDRSIV_38	IngUPDRSIV_38	IngUPDRSIV_38	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_38 ), UPDRSIV:catUPDRS_4_38), (else, 0))	
20	catUPDRS_4_38	catUPDRS_4_38	catUPDRS_4_38	Category	7		0=0 = No 1=1 = Yes
21	IngUPDRSIV_39	IngUPDRSIV_39	IngUPDRSIV_39	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_39 ), UPDRSIV:catUPDRS_4_39), (else, 0))	
22	catUPDRS_4_39	catUPDRS_4_39	catUPDRS_4_39	Category	19		See Appendix
23	IngUPDRSIV_40	IngUPDRSIV_40	IngUPDRSIV_40	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_40 ), UPDRSIV:catUPDRS_4_40), (else, 0))	
24	catUPDRS_4_40	catUPDRS_4_40	catUPDRS_4_40	Category	7		0=0 = No 1=1 = Yes
25	IngUPDRSIV_41	IngUPDRSIV_41	IngUPDRSIV_41	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_41 ), UPDRSIV:catUPDRS_4_41), (else, 0))	
26	catUPDRS_4_41	catUPDRS_4_41	catUPDRS_4_41	Category	7		0=0 = No 1=1 = Yes
27	IngUPDRSIV_42	IngUPDRSIV_42	IngUPDRSIV_42	Integer	-9, Hidden	case((isknown( UPDRSIV:catUPDRS_4_42 ), UPDRSIV:catUPDRS_4_42), (else, 0))	
28	catUPDRS_4_42	catUPDRS_4_42	catUPDRS_4_42	Category	7		0=0 = No 1=1 = Yes
29	IngUPDRSIV_tot	IngUPDRSIV_tot	IngUPDRSIV_tot	Integer	-99	See Appendix	
30	strDISC_P_C	strDISC_P_C	strDISC_P_C	Text	300, Optional		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



## DOPAMINE DYSREGULATION SYNDROME

Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date of completing forms:  dtmExam

Duration of completing foms (minutes):  Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

### Features of Dopamine Dysregulation Syndrome

Over the past week, have you had unusually strong urges that are hard to control?  
Do you feel driven to do or think about something and find it hard to stop?

Score

IngDDS

### Scoring

0: Normal: No problems present.

1: Slight: Problems are present but usually do not cause any difficulties for the patient or family/caregiver.

2: Mild: Problems are present and usually cause a few difficulties in the patients personal and family life.

3: Moderate: Problems are present and usually cause a lot of difficulties in the patients personal and family life.

4: Severe: Problems are present and preclude the patients ability to carry out normal activities or social interactions or to maintain previous standards in personal and family life.

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	IngDDS	IngDDS	IngDDS	Integer	-9		



CLaSP CRF  
Care of Late Stage Parkinsonism



Patient ID

IngPatID

ACTIVITIES of DAILY LIVING, Schwab/England  
(Schwab 1969)

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:   dtmExam

Duration of test (minutes):  Ing\_duration\_As

Reason, if not assessed:  catAss\_Test\_P

Other reason:  strAssessReas

Please enter as value (0 - 100 in steps by 10) or choose a value from the drop down list.

VI. Modified Schwab and England Activities of Dailiy Living Scale

- ☐ 100% = Completely independent. Able to do all chores without slowness, difficulty or impairment. Essentially normal. Unaware of any difficulty. catUPDRSVI
- ☐ 90% = Completely independent. Able to do all chores with some degree of slowness, difficulty, and impairment. Might take twice as long.
- ☐ 80% = Beginning to have some difficulty. Able to do most chores. Takes twice as long. Conscious of difficulty and slowness.
- ☐ 70% = Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores.
- ☐ 60% = Some dependency. Can do most chores, but exceedingly slowly and with much effort. Errors; some impossible.
- ☐ 50% = More dependent. Help with half, slower, etc. Difficulty with everything.
- ☐ 40% = Very dependent. Can assist with all chores, but few alone.
- ☐ 30% = With effort, now and then does a few chores alone or begins alone. Much help needed.
- ☐ 20% = Nothing alone. Can be a slight help with some chores. Severe invalid.
- ☐ 10% = Total dependent, helpless. Complete invalid.
- ☐ 0% = Vegetative functions such as swallowing, bladder and bowel functions are not functioning. Bedridden.

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catUPDRSVI	catUPDRSVI	catUPDRSVI	Category	172		See Appendix



**CLaSP CRF**  
Care of Late Stage Parkinsonism



**MMSE (Mini Mental State Examination)**  
(Folstein 1975)

Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

**Enter for each correct answer 1 and for each wrong answer 0.**

**Scale 1: Orientation**

1. Year  catMMSE1  
2. Season  catMMSE2  
3. Date  catMMSE3  
4. Day  catMMSE4  
5. Month  catMMSE5  
6. State  catMMSE6  
7. Country  catMMSE7  
8. Town  catMMSE8  
9. Building  catMMSE9  
10. Floor  catMMSE10

IngMMSE1  IngMMSE1  
IngMMSE2  IngMMSE2  
IngMMSE3  IngMMSE3  
IngMMSE4  IngMMSE4  
IngMMSE5  IngMMSE5  
IngMMSE6  IngMMSE6  
IngMMSE7  IngMMSE7  
IngMMSE8  IngMMSE8  
IngMMSE9  IngMMSE9  
IngMMSE10  IngMMSE10

**Scale2: Retentiveness**

Examiner says all 3 words at once, requiring the person to then repeat all 3 words at once.

Please enter the spoken 'WORDS'.

Score 1 point for each correctly repeated word - total 3 possible points.

11. Word #1  strMMSE11  catMMSE11 IngMMSE11  IngMMSE11  
12. Word #2  strMMSE12  catMMSE12 IngMMSE12  IngMMSE12  
13. Word #3  strMMSE13  catMMSE13 IngMMSE13  IngMMSE13

**Scale 3: Attention and computational ability**

Ask the patient to begin with 100 and count backwards by 7. Stop after 5 subtractions (93, 86, 79, 72, 65). Score the total number of correct answers.

If the patient cannot or will not perform this task, ask him to spell a word with five letters backwards. The score is the number of letters in correct order.

Performed test  catMMSE\_scale3

**Backward counting**

14. '93'  catMMSE14  
15. '86'  catMMSE15  
16. '79'  catMMSE16  
17. '72'  catMMSE17  
18. '65'  catMMSE18

**Backward spelling**

Word asked  strMMSE\_scale3

Score

IngMMSE\_sc3b

IngMMSE\_sc3b2

IngMMSE\_sc3b2

IngMMSE\_scale3

IngMMSE\_scale3

IngMMSE\_sc3a

IngMMSE14  IngMMSE14  
IngMMSE15  IngMMSE15  
IngMMSE16  IngMMSE16  
IngMMSE17  IngMMSE17  
IngMMSE18  IngMMSE18  
IngMMSE19  IngMMSE19

**Scale 4: Memory performance**

Ask the patient if he can recall the 3 words you previously asked him to remember (Scale 2). Score 0-3.

19. Word #1  catMMSE19  
20. Word #2  catMMSE20  
21. Word #3  catMMSE21

IngMMSE19  IngMMSE19  
IngMMSE20  IngMMSE20  
IngMMSE21  IngMMSE21

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtnExam	dtnExam	dtnExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	IngMMSE1	IngMMSE1	IngMMSE1	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE1 ), MMSE:catMMSE1), (else, 0))	
8	catMMSE1	catMMSE1	catMMSE1	Category	8		0=0 points 1=1 point
9	IngMMSE2	IngMMSE2	IngMMSE2	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE2 ), MMSE:catMMSE2), (else, 0))	
10	catMMSE2	catMMSE2	catMMSE2	Category	8		0=0 points 1=1 point
11	IngMMSE3	IngMMSE3	IngMMSE3	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE3 ), MMSE:catMMSE3), (else, 0))	
12	catMMSE3	catMMSE3	catMMSE3	Category	8		0=0 points 1=1 point
13	IngMMSE4	IngMMSE4	IngMMSE4	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE4 ), MMSE:catMMSE4), (else, 0))	
14	catMMSE4	catMMSE4	catMMSE4	Category	8		0=0 points 1=1 point
15	IngMMSE5	IngMMSE5	IngMMSE5	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE5 ), MMSE:catMMSE5), (else, 0))	
16	catMMSE5	catMMSE5	catMMSE5	Category	8		0=0 points 1=1 point
17	IngMMSE6	IngMMSE6	IngMMSE6	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE6 ), MMSE:catMMSE6), (else, 0))	
18	catMMSE6	catMMSE6	catMMSE6	Category	8		0=0 points 1=1 point
19	IngMMSE7	IngMMSE7	IngMMSE7	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE7 ), MMSE:catMMSE7), (else, 0))	
20	catMMSE7	catMMSE7	catMMSE7	Category	8		0=0 points 1=1 point
21	IngMMSE8	IngMMSE8	IngMMSE8	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE8 ), MMSE:catMMSE8), (else, 0))	
22	catMMSE8	catMMSE8	catMMSE8	Category	8		0=0 points 1=1 point
23	IngMMSE9	IngMMSE9	IngMMSE9	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE9 ), MMSE:catMMSE9), (else, 0))	
24	catMMSE9	catMMSE9	catMMSE9	Category	8		0=0 points 1=1 point
25	IngMMSE10	IngMMSE10	IngMMSE10	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE10 ), MMSE:catMMSE10), (else, 0))	
26	catMMSE10	catMMSE10	catMMSE10	Category	8		0=0 points 1=1 point
27	catMMSE11	catMMSE11	catMMSE11	Category	8		0=0 points 1=1 point
28	IngMMSE11	IngMMSE11	IngMMSE11	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE11 ), MMSE:catMMSE11), (else, 0))	
29	strMMSE11	strMMSE11	strMMSE11	Text	20		
30	catMMSE12	catMMSE12	catMMSE12	Category	8		0=0 points 1=1 point
31	IngMMSE12	IngMMSE12	IngMMSE12	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE12 ), MMSE:catMMSE12), (else, 0))	
32	strMMSE12	strMMSE12	strMMSE12	Text	20		
33	IngMMSE13	IngMMSE13	IngMMSE13	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE13 ), MMSE:catMMSE13), (else, 0))	
34	catMMSE13	catMMSE13	catMMSE13	Category	8		0=0 points 1=1 point
35	strMMSE13	strMMSE13	strMMSE13	Text	20		
36	catMMSE_scale3	catMMSE_scale3	catMMSE_scale3	Category	46		See Appendix
37	IngMMSE14	IngMMSE14	IngMMSE14	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE14 ), MMSE:catMMSE14), (else, 0))	
38	strMMSE_scale3	strMMSE_scale3	strMMSE_scale3	Text	6		
39	catMMSE14	catMMSE14	catMMSE14	Category	8		0=0 points 1=1 point
40	IngMMSE15	IngMMSE15	IngMMSE15	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE15 ), MMSE:catMMSE15), (else, 0))	
41	IngMMSE_sc3b	IngMMSE_sc3b	IngMMSE_sc3b	Integer	-9		
42	catMMSE15	catMMSE15	catMMSE15	Category	8		0=0 points 1=1 point
43	IngMMSE16	IngMMSE16	IngMMSE16	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE16 ), MMSE:catMMSE16), (else, 0))	
44	catMMSE16	catMMSE16	catMMSE16	Category	8		0=0 points 1=1 point
45	IngMMSE17	IngMMSE17	IngMMSE17	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE17 ), MMSE:catMMSE17), (else, 0))	
46	IngMMSE_sc3b2	IngMMSE_sc3b2	IngMMSE_sc3b2	Integer	-9, Hidden	case((Isknown( MMSE:IngMMSE_sc3b ), MMSE:IngMMSE_sc3b), (else, 0))	
47	IngMMSE18	IngMMSE18	IngMMSE18	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE18 ), MMSE:catMMSE18), (else, 0))	
48	catMMSE17	catMMSE17	catMMSE17	Category	8		0=0 points 1=1 point
49	IngMMSE_sc3a	IngMMSE_sc3a	IngMMSE_sc3a	Integer	-9, Hidden	IngMMSE14 + IngMMSE15 + IngMMSE16 + IngMMSE17 + IngMMSE18	
50	IngMMSE_scale3	IngMMSE_scale3	IngMMSE_scale3	Integer	-9, Hidden	IngMMSE_sc3a + IngMMSE_sc3b2	
51	catMMSE18	catMMSE18	catMMSE18	Category	8		0=0 points 1=1 point
52	IngMMSE19	IngMMSE19	IngMMSE19	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE19 ), MMSE:catMMSE19), (else, 0))	
53	catMMSE19	catMMSE19	catMMSE19	Category	8		0=0 points 1=1 point
54	IngMMSE20	IngMMSE20	IngMMSE20	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE20 ), MMSE:catMMSE20), (else, 0))	
55	catMMSE20	catMMSE20	catMMSE20	Category	8		0=0 points 1=1 point
56	IngMMSE21	IngMMSE21	IngMMSE21	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE21 ), MMSE:catMMSE21), (else, 0))	
57	catMMSE21	catMMSE21	catMMSE21	Category	8		0=0 points 1=1 point

Scale 5: Speech

22. Identify and name a pencil
23. Identify and name a watch
24. Repetition of a sentence (only one trial)
25. Follow the command 'Take the paper in your hand'
26. Follow the command 'Fold it in half'
27. Follow command: 'Put it on the floor'
28. Read and obey the following: 'Close your eyes'
29. Write a sentence
30. Copy the drawing: interlocking pentagons
- IngMMSE22
- IngMMSE23
- IngMMSE24
- IngMMSE25
- IngMMSE26
- IngMMSE27
- IngMMSE28
- IngMMSE29
- IngMMSE30
- catMMSE22
- catMMSE23
- catMMSE24
- catMMSE25
- catMMSE26
- catMMSE27
- catMMSE28
- catMMSE29
- catMMSE30
- IngMMSE29
- IngMMSE30

Total MMSE (calculated)

Number of total questions attempted

Optional: comment for discrepancy between carer and patient

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
58	IngMMSE22	IngMMSE22	IngMMSE22	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE22 ), MMSE:catMMSE22), (else, 0))	
59	IngMMSE23	IngMMSE23	IngMMSE23	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE23 ), MMSE:catMMSE23), (else, 0))	
60	IngMMSE24	IngMMSE24	IngMMSE24	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE24 ), MMSE:catMMSE24), (else, 0))	
61	catMMSE22	catMMSE22	catMMSE22	Category	8		0=0 points 1=1 point
62	IngMMSE25	IngMMSE25	IngMMSE25	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE25 ), MMSE:catMMSE25), (else, 0))	
63	IngMMSE26	IngMMSE26	IngMMSE26	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE26 ), MMSE:catMMSE26), (else, 0))	
64	catMMSE23	catMMSE23	catMMSE23	Category	8		0=0 points 1=1 point
65	IngMMSE27	IngMMSE27	IngMMSE27	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE27 ), MMSE:catMMSE27), (else, 0))	
66	catMMSE24	catMMSE24	catMMSE24	Category	8		0=0 points 1=1 point
67	IngMMSE28	IngMMSE28	IngMMSE28	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE28 ), MMSE:catMMSE28), (else, 0))	
68	catMMSE25	catMMSE25	catMMSE25	Category	8		0=0 points 1=1 point
69	catMMSE26	catMMSE26	catMMSE26	Category	8		0=0 points 1=1 point
70	catMMSE27	catMMSE27	catMMSE27	Category	8		0=0 points 1=1 point
71	catMMSE28	catMMSE28	catMMSE28	Category	8		0=0 points 1=1 point
72	catMMSE29	catMMSE29	catMMSE29	Category	8		0=0 points 1=1 point
73	IngMMSE29	IngMMSE29	IngMMSE29	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE29 ), MMSE:catMMSE29), (else, 0))	
74	catMMSE30	catMMSE30	catMMSE30	Category	8		0=0 points 1=1 point
75	IngMMSE30	IngMMSE30	IngMMSE30	Integer	-9, Hidden	case((Isknown( MMSE:catMMSE30 ), MMSE:catMMSE30), (else, 0))	
76	IngMMSE_tot	IngMMSE_tot	IngMMSE_tot	Integer	-99	See Appendix	
77	IngMMSE_outOff	IngMMSE_outOff	IngMMSE_outOff	Integer	-99		
78	strDISC_P_C	strDISC_P_C	strDISC_P_C	Text	300, Optional		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



## PILL QUESTIONNAIRE

Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

### The Pill Questionnaire and scoring system

#### Pill Questionnaire

Score

No impact of cognitive deficits on daily living (no-impact group)

The patient is able to spontaneously and clearly describe medications including doses (mg. or color of tablet) and medication schedule.

0

The caregiver certifies that the patient can (or could) safely and reliably take medications on a daily basis without supervision.

1

Impact of cognitive deficits on daily living (impact group)

The caregiver certifies that the patient can (or could) no longer safely and reliably take medications on a daily basis without supervision.

2

The patient is not able to describe the schedule and nature (drugs and doses) of his/her treatment, even with the help of the examiner.

3

Please enter a number from the Pill Questionnaire scoring system above.

Pill Questionnaire Score:

IngPill\_Q\_Score

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
3	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	IngPill_Q_Score	IngPill_Q_Score	IngPill_Q_Score	Integer	9		



CLaSP CRF  
Care of Late Stage Parkinsonism

## NPI-NH - ASSESSMENT



Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:  dtmExam

Duration of test (minutes):  Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

## NPI-NH - A. DELUSIONS

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

### Screening Question:

Does the resident have beliefs that you know are not true? For example, saying that people are trying to harm him/her or steal from him/her. Has he/she said that family members or staff are not who they say they are or that his/her spouse is having an affair? Has the resident had any other unusual beliefs?

### A. DELUSIONS

cat\_NPI\_NH\_A\_Q1

### Subquestions:

- Does the resident believe that he/her is in danger - that others are planning to hurt him/her or have been hurting him/her?
- Does the resident believe that others are stealing from him/her?
- Does the resident believe that his/her spouse is having an affair?
- Does the resident believe that his/her family, staff members or others are not who they say they are?
- Does the resident believe that television or magazine figures are actually present in the room? (Does he/she try to talk or interact with them?)
- Does he/she believe any other unusual things that I haven't asked about?

### Yes/No

cat\_NPI\_NH\_A\_Q2  
 cat\_NPI\_NH\_A\_Q3  
 cat\_NPI\_NH\_A\_Q4  
 cat\_NPI\_NH\_A\_Q5  
 cat\_NPI\_NH\_A\_Q6  
 cat\_NPI\_NH\_A\_Q7

Comments:

str\_NPI\_NH\_A

If the Screening Question is confirmed, determine the frequency and severity of the delusions.

Frequency  Ing\_NPI\_NH\_A\_F

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	cat_NPI_NH_A_Q1	cat_NPI_NH_A_Q1	cat_NPI_NH_A_Q1	Category	53		See Appendix
8	cat_NPI_NH_A_Q2	cat_NPI_NH_A_Q2	cat_NPI_NH_A_Q2	Category	3		1=Yes 0=No
9	cat_NPI_NH_A_Q3	cat_NPI_NH_A_Q3	cat_NPI_NH_A_Q3	Category	3		1=Yes 0=No
10	cat_NPI_NH_A_Q4	cat_NPI_NH_A_Q4	cat_NPI_NH_A_Q4	Category	3		1=Yes 0=No
11	cat_NPI_NH_A_Q5	cat_NPI_NH_A_Q5	cat_NPI_NH_A_Q5	Category	3		1=Yes 0=No
12	cat_NPI_NH_A_Q6	cat_NPI_NH_A_Q6	cat_NPI_NH_A_Q6	Category	3		1=Yes 0=No
13	cat_NPI_NH_A_Q7	cat_NPI_NH_A_Q7	cat_NPI_NH_A_Q7	Category	3		1=Yes 0=No
14	str_NPI_NH_A	str_NPI_NH_A	str_NPI_NH_A	Text	255, Optional		
15	Ing_NPI_NH_A_F	Ing_NPI_NH_A_F	Ing_NPI_NH_A_F	Integer	9		

Frequency is rated as:  
1 = Rarely - less than once per week.  
2 = Sometimes - about once per week.  
3 = Often  
4 = Very often - several times per week but less than every day.  
- once or more per day.

Severity  Ing\_NPI\_NH\_A\_S

Severity is rated as:  
1 = Mild - delusions present but seem harmless and does not upset the resident that much.  
2 = Moderate - delusions are stressful and upsetting to the resident and cause unusual or strange behaviour.  
3 = Severe - delusions are very stressful and upsetting to the resident and cause a major amount of unusual or strange behaviour.

Occupational Disruptiveness  Ing\_NPI\_NH\_A\_OD

How much does this behavior upset you and/or create more work for you?

Occupational Disruptiveness is scored as:  
0 = Not at all  
1 = Minimally (almost no change in work routine)  
2 = Mildly (some change in work routine but little time rebudgeting required)  
3 = Moderate (disrupts work routine, requires time rebudgeting)  
4 = Severely (disrupts work routine, requires time rebudgeting)  
5 = Very Severely or Extremely (extremely, upsetting to staff and other residents, major time infringement)  
(very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
16	Ing_NPI_NH_A_S	Ing_NPI_NH_A_S	Ing_NPI_NH_A_S	Integer	9		
17	Ing_NPI_NH_A_OD	Ing_NPI_NH_A_OD	Ing_NPI_NH_A_OD	Integer	9		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



Patient ID

IngPatID

## NPI-NH - HALLUCINATIONS

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

### Screening Question:

Does the resident have hallucinations - meaning, does he/she see, hear, or experience things that are not present? (If 'Yes', ask for an example to determine if in fact it is a hallucination). Does the resident talk to people who are not there?

### B. HALLUCINATIONS

cat\_NPI\_NH\_B\_Q1

### Subquestions:

1. Does the resident act as if he/she hears voices or describe hearing voices?
2. Does the resident talk to people who are not there?
3. Does the resident see things that are not present or act like he/she sees things that are not present (people, animals, lights, etc)?
4. Does the resident smell things that others cannot smell?
5. Does the resident describe feeling things on his/her skin or act like he/she is feeling things crawling or touching him/her?
6. Does the resident say or act like he/she tastes things that are not present?
7. Does the resident describe any other unusual sensory experiences?

### Yes/No

cat\_NPI\_NH\_B\_Q2

cat\_NPI\_NH\_B\_Q3

cat\_NPI\_NH\_B\_Q4

cat\_NPI\_NH\_B\_Q5

cat\_NPI\_NH\_B\_Q6

cat\_NPI\_NH\_B\_Q7

cat\_NPI\_NH\_B\_Q8

Comments:

str\_NPI\_NH\_B

If the Screening Question is confirmed, determine the frequency and severity of the hallucinations.

Frequency

Ing\_NPI\_NH\_B\_F

Frequency is rated as:

- 1 = Rarely - less than once per week.  
 2 = Sometimes - about once per week.  
 3 = Often  
 4 = Very often - several times per week but less than every day.  
 - once or more per day.

Severity

Ing\_NPI\_NH\_B\_S

Severity is rated as:

- 1 = Mild - hallucinations present but seem harmless and does not upset the resident that much.  
 2 = Moderate - hallucinations are stressful and upsetting to the resident and cause unusual or strange behaviour  
 3 = Severe - hallucinations are very stressful and upsetting to the resident and cause a major amount of unusual or strange behaviour. (PRN medications may be required to control them).

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_B_Q1	cat_NPI_NH_B_Q1	cat_NPI_NH_B_Q1	Category	53		See Appendix
3	cat_NPI_NH_B_Q2	cat_NPI_NH_B_Q2	cat_NPI_NH_B_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_B_Q3	cat_NPI_NH_B_Q3	cat_NPI_NH_B_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_B_Q4	cat_NPI_NH_B_Q4	cat_NPI_NH_B_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_B_Q5	cat_NPI_NH_B_Q5	cat_NPI_NH_B_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_B_Q6	cat_NPI_NH_B_Q6	cat_NPI_NH_B_Q6	Category	3		1=Yes 0=No
8	cat_NPI_NH_B_Q7	cat_NPI_NH_B_Q7	cat_NPI_NH_B_Q7	Category	3		1=Yes 0=No
9	cat_NPI_NH_B_Q8	cat_NPI_NH_B_Q8	cat_NPI_NH_B_Q8	Category	3		1=Yes 0=No
10	str_NPI_NH_B	str_NPI_NH_B	str_NPI_NH_B	Text	255, Optional		
11	Ing_NPI_NH_B_F	Ing_NPI_NH_B_F	Ing_NPI_NH_B_F	Integer	9		
12	Ing_NPI_NH_B_S	Ing_NPI_NH_B_S	Ing_NPI_NH_B_S	Integer	9		

Occupational  
Disruptiveness

Ing\_NPI\_NH\_B\_00

How much does this behavior upset you and/or create more work for you?

- Occupational Disruptiveness is scored as:
- 0 = Not at all
  - 1 = Minimally (almost no change in work routine)
  - 2 = Mildly (some change in work routine but little time rebudgeting required)
  - 3 = Moderate (disrupts work routine, requires time rebudgeting)
  - 4 = Severely (disrupts work routine, requires time rebudgeting)
  - 5 = Very Severely or Extremely, upsetting to staff and other residents, major time infringement (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
13	Ing_NPI_NH_B_OD	Ing_NPI_NH_B_OD	Ing_NPI_NH_B_OD	Integer	9		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



Patient ID

IngPatID

## NPI-NH - AGITATION/AGGRESSION

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

### Screening Question:

Does the resident have periods when he/she refuses to let people help him/her? Is he/she hard to handle? Is he/she noisy or uncooperative? Does the resident attempt to hurt or hit others?

### C. AGITATION/AGGRESSION

cat\_NPI\_NH\_C\_Q1

### Subquestions:

- Does the resident get upset when people are trying to care for him/her or resist activities such as bathing or changing clothes?
- Does the resident always want things his/her own way?
- Is the resident uncooperative, resistive to help from others?
- Does the resident have any other behaviors that make him/her hard to handle?
- Does the resident shout, make loud noises, or swear angrily?
- Does the resident slam doors, kick furniture, throw things?
- Does the resident attempt to hurt or hit others?
- Does the resident have any other aggressive or agitated behaviors?

### Yes/No

cat\_NPI\_NH\_C\_Q2

cat\_NPI\_NH\_C\_Q3

cat\_NPI\_NH\_C\_Q4

cat\_NPI\_NH\_C\_Q5

cat\_NPI\_NH\_C\_Q6

cat\_NPI\_NH\_C\_Q7

cat\_NPI\_NH\_C\_Q8

cat\_NPI\_NH\_C\_Q9

Comments:

str\_NPI\_NH\_C

If the Screening Question is confirmed, determine the frequency and severity of the agitation/aggression.

Frequency

Ing\_NPI\_NH\_C\_F

Frequency is rated as:

- 1 = Rarely - less than once per week.  
 2 = Sometimes - about once per week.  
 3 = Often  
 4 = Very often - several times per week but less than every day.  
 - once or more per day.

Severity

Ing\_NPI\_NH\_C\_S

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_C_Q1	cat_NPI_NH_C_Q1	cat_NPI_NH_C_Q1	Category	53		See Appendix
3	cat_NPI_NH_C_Q2	cat_NPI_NH_C_Q2	cat_NPI_NH_C_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_C_Q3	cat_NPI_NH_C_Q3	cat_NPI_NH_C_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_C_Q4	cat_NPI_NH_C_Q4	cat_NPI_NH_C_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_C_Q5	cat_NPI_NH_C_Q5	cat_NPI_NH_C_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_C_Q6	cat_NPI_NH_C_Q6	cat_NPI_NH_C_Q6	Category	3		1=Yes 0=No
8	cat_NPI_NH_C_Q7	cat_NPI_NH_C_Q7	cat_NPI_NH_C_Q7	Category	3		1=Yes 0=No
9	cat_NPI_NH_C_Q8	cat_NPI_NH_C_Q8	cat_NPI_NH_C_Q8	Category	3		1=Yes 0=No
10	cat_NPI_NH_C_Q9	cat_NPI_NH_C_Q9	cat_NPI_NH_C_Q9	Category	3		1=Yes 0=No
11	str_NPI_NH_C	str_NPI_NH_C	str_NPI_NH_C	Text	255, Optional		
12	Ing_NPI_NH_C_F	Ing_NPI_NH_C_F	Ing_NPI_NH_C_F	Integer	9		
13	Ing_NPI_NH_C_S	Ing_NPI_NH_C_S	Ing_NPI_NH_C_S	Integer	9		

Severity is rated as:

- 1 = Mild - behavior is stressful for the resident, but can be controlled by the caregiver.  
 2 = Moderate - behaviors are stressful for and upsetting to the resident and are difficult to control.  
 3 = Severe - agitation is very stressful or upsetting to the resident and is very difficult or impossible to control.  
 There is a possibility they may injure themselves and medications are often required.

## Occupational Disruptiveness

Ing\_NPI\_NH\_C\_OD

How much does this behavior upset you and/or create more work for you?

Occupational Disruptiveness is scored as:

- 0 = Not at all  
 1 = Minimally (almost no change in work routine)  
 2 = Mildly (some change in work routine but little time rebudgeting required)  
 3 = Moderate (disrupts work routine, requires time rebudgeting)  
 4 = Severely (disrupts work routine, requires time rebudgeting)  
 5 = Very Severely or Extremely (extremely, upsetting to staff and other residents, major time infringement)  
 (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
14	Ing_NPI_NH_C_OD	Ing_NPI_NH_C_OD	Ing_NPI_NH_C_OD	Integer	9		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



Patient ID

IngPatID

## NPI-NH - DEPRESSION/DYSPHORIA

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

### Screening Question:

Does the resident seem sad or depressed? Does he/she say that he/she feels sad or depressed? Does the resident cry at times?

### D. DEPRESSION/DYSPHORIA

cat\_NPI\_NH\_D\_Q1

### Subquestions:

1. Does the resident cry at times?
2. Does the resident say, or act like he/she is depressed?
3. Does the resident put him/herself down or say that he/she feels like a failure?
4. Does the resident say that he/she is a bad person or deserves to be punished?
5. Does the resident seem very discouraged or say that he/she has no future?
6. Does the resident say he/she is a burden to the family or that the family would be better off without him/her?
7. Does the resident talk about wanting to die or about killing him/herself?
8. Does the resident show any other signs of depression or sadness?

### Yes/No

cat\_NPI\_NH\_D\_Q2

cat\_NPI\_NH\_D\_Q3

cat\_NPI\_NH\_D\_Q4

cat\_NPI\_NH\_D\_Q5

cat\_NPI\_NH\_D\_Q6

cat\_NPI\_NH\_D\_Q7

cat\_NPI\_NH\_D\_Q8

cat\_NPI\_NH\_D\_Q9

Comments:

str\_NPI\_NH\_D

If the Screening Question is confirmed, determine the frequency and severity of the depression/dysphoria.

Frequency

Ing\_NPI\_NH\_D\_F

Frequency is rated as:

1 = Rarely - less than once per week.

2 = Sometimes - about once per week.

3 = Often

4 = Very often - several times per week but less than every day.

- once or more per day.

Severity

Ing\_NPI\_NH\_D\_S

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_D_Q1	cat_NPI_NH_D_Q1	cat_NPI_NH_D_Q1	Category	53		See Appendix
3	cat_NPI_NH_D_Q2	cat_NPI_NH_D_Q2	cat_NPI_NH_D_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_D_Q3	cat_NPI_NH_D_Q3	cat_NPI_NH_D_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_D_Q4	cat_NPI_NH_D_Q4	cat_NPI_NH_D_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_D_Q5	cat_NPI_NH_D_Q5	cat_NPI_NH_D_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_D_Q6	cat_NPI_NH_D_Q6	cat_NPI_NH_D_Q6	Category	3		1=Yes 0=No
8	cat_NPI_NH_D_Q7	cat_NPI_NH_D_Q7	cat_NPI_NH_D_Q7	Category	3		1=Yes 0=No
9	cat_NPI_NH_D_Q8	cat_NPI_NH_D_Q8	cat_NPI_NH_D_Q8	Category	3		1=Yes 0=No
10	cat_NPI_NH_D_Q9	cat_NPI_NH_D_Q9	cat_NPI_NH_D_Q9	Category	3		1=Yes 0=No
11	str_NPI_NH_D	str_NPI_NH_D	str_NPI_NH_D	Text	255, Optional		
12	Ing_NPI_NH_D_F	Ing_NPI_NH_D_F	Ing_NPI_NH_D_F	Integer	9		
13	Ing_NPI_NH_D_S	Ing_NPI_NH_D_S	Ing_NPI_NH_D_S	Integer	9		

Severity is rated as:  
1 = Mild - depression is stressful for the resident but will usually change with the help of a caregiver.  
2 = Moderate - depression is stressful for the resident and is difficult to change by the caregiver.  
3 = Severe - depression is very upsetting and stressful for the resident and is very difficult or impossible to change.

Occupational  
Disruptiveness

Ing\_NPI\_NH\_D\_QD

How much does this behavior upset you and/or create more work for you?

Occupational Disruptiveness is scored as:  
0 = Not at all  
1 = Minimally (almost no change in work routine)  
2 = Mildly (some change in work routine but little time rebudgeting required)  
3 = Moderate (disrupts work routine, requires time rebudgeting)  
4 = Severely (disrupts work routine, requires time rebudgeting)  
5 = Very Severely or Extremely (extremely, upsetting to staff and other residents, major time infringement)  
(very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
14	Ing_NPI_NH_D_OD	Ing_NPI_NH_D_OD	Ing_NPI_NH_D_OD	Integer	9		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



Patient ID

IngPatID

## NPI-NH - ANXIETY

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

### Screening Question:

Is the resident very nervous, worried, or frightened for no reason? Does he/she seem very tense or unable to relax? Is the resident afraid to be apart from you or from others that he/she trusts?

E. ANXIETY

cat\_NPI\_NH\_E\_Q1

### Subquestions:

- Does the resident say that he/she is worried about planned events such as appointments or family visits?
- Does the resident have periods of feeling shaky, unable to relax, or feeling very tense?
- Does the resident have periods of (or complain of) shortness of breath, gasping, or sighing for no apparent reason other than being nervous?
- Does the resident complain of butterflies in his/her stomach, or of racing or pounding of the heart because of being nervous? (Symptoms not explained by ill health)
- Does the resident avoid certain places or situations that make him/her more nervous such as meeting with friends or participating in ward activities?
- Does the resident become nervous and upset when separated from you or from others that he/she trusts? (Does he/she cling to you to keep from being separated?)
- Does the resident show any other signs of anxiety?

Yes/No

cat\_NPI\_NH\_E\_Q2

cat\_NPI\_NH\_E\_Q3

cat\_NPI\_NH\_E\_Q4

cat\_NPI\_NH\_E\_Q5

cat\_NPI\_NH\_E\_Q6

cat\_NPI\_NH\_E\_Q7

cat\_NPI\_NH\_E\_Q8

Comments:

str\_NPI\_NH\_E

If the Screening Question is confirmed, determine the frequency and severity of the anxiety.

Frequency

Ing\_NPI\_NH\_E\_F

Frequency is rated as:

- 1 = Rarely - less than once per week.  
 2 = Sometimes - about once per week.  
 3 = Often - several times per week but less than every day.  
 4 = Very often - once or more per day.

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_E_Q1	cat_NPI_NH_E_Q1	cat_NPI_NH_E_Q1	Category	53		See Appendix
3	cat_NPI_NH_E_Q2	cat_NPI_NH_E_Q2	cat_NPI_NH_E_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_E_Q3	cat_NPI_NH_E_Q3	cat_NPI_NH_E_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_E_Q4	cat_NPI_NH_E_Q4	cat_NPI_NH_E_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_E_Q5	cat_NPI_NH_E_Q5	cat_NPI_NH_E_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_E_Q6	cat_NPI_NH_E_Q6	cat_NPI_NH_E_Q6	Category	3		1=Yes 0=No
8	cat_NPI_NH_E_Q7	cat_NPI_NH_E_Q7	cat_NPI_NH_E_Q7	Category	3		1=Yes 0=No
9	cat_NPI_NH_E_Q8	cat_NPI_NH_E_Q8	cat_NPI_NH_E_Q8	Category	3		1=Yes 0=No
10	str_NPI_NH_E	str_NPI_NH_E	str_NPI_NH_E	Text	255, Optional		
11	Ing_NPI_NH_E_F	Ing_NPI_NH_E_F	Ing_NPI_NH_E_F	Integer	9		

Severity

Ing\_NPI\_NH\_E\_S

Severity is rated as:  
1 = Mild - anxiety is stressful for the resident but will usually change with the help of a caregiver.  
2 = Moderate - anxiety is stressful for the resident and is difficult to change by the caregiver.  
3 = Severe - anxiety is very upsetting and stressful for the resident and is very difficult or impossible to change.

Occupational Disruptiveness

Ing\_NPI\_NH\_E\_OP

How much does this behavior upset you and/or create more work for you?  
Occupational Disruptiveness is scored as:  
0 = Not at all  
1 = Minimally (almost no change in work routine)  
2 = Mildly (some change in work routine but little time rebudgeting required)  
3 = Moderate (disrupts work routine, requires time rebudgeting)  
4 = Severely (disrupts work routine, requires time rebudgeting)  
5 = Very Severely or Disruptive, upsetting to staff and other residents, major time infringement)  
(very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
12	Ing_NPI_NH_E_S	Ing_NPI_NH_E_S	Ing_NPI_NH_E_S	Integer	9		
13	Ing_NPI_NH_E_OD	Ing_NPI_NH_E_OD	Ing_NPI_NH_E_OD	Integer	9		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



Patient ID

IngPatID

## NPI-NH - ELATION/EUPHORIA

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

### Screening Question:

Does the resident seem too cheerful or too happy for no reason? I don't mean normal happiness but, for example, laughing at things that others do not find funny?

F. ELATION/EUPHORIA

cat\_NPI\_NH\_F\_Q1

### Subquestions:

1. Does the resident appear to feel too good or to be too happy?
2. Does the resident find humor and laugh at things that others do not find funny?
3. Does the resident seem to have a childish sense of humor with a tendency to giggle or laugh inappropriately (such as when something unfortunate happens others)?
4. Does the resident tell jokes or say things that are not funny to others but seem funny to him/her?
5. Does the resident show any other signs of feeling too good or being too happy?

### Yes/No

<input type="text"/>	<input type="text"/>	cat_NPI_NH_F_Q2
<input type="text"/>	<input type="text"/>	cat_NPI_NH_F_Q3
<input type="text"/>	<input type="text"/>	cat_NPI_NH_F_Q4
<input type="text"/>	<input type="text"/>	cat_NPI_NH_F_Q5
<input type="text"/>	<input type="text"/>	cat_NPI_NH_F_Q6

Comments:

str\_NPI\_NH\_F

If the Screening Question is confirmed, determine the frequency and severity of the elation/euphoria.

Frequency

Ing\_NPI\_NH\_F\_F

Frequency is rated as:

- 1 = Rarely - less than once per week.  
 2 = Sometimes - about once per week.  
 3 = Often  
 4 = Very often - several times per week but less than every day.  
 - once or more per day.

Severity

Ing\_NPI\_NH\_F\_S

Severity is rated as:

- 1 = Mild - resident is too happy at times.  
 2 = Moderate - resident is too happy at times and this sometimes causes strange behavior.  
 3 = Severe - resident is almost always too happy and finds nearly everything to be funny.

Occupational  
Disruptiveness

Ing\_NPI\_NH\_F\_OD

How much does this behavior upset you and/or create more work for you?

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_F_Q1	cat_NPI_NH_F_Q1	cat_NPI_NH_F_Q1	Category	53		See Appendix
3	cat_NPI_NH_F_Q2	cat_NPI_NH_F_Q2	cat_NPI_NH_F_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_F_Q3	cat_NPI_NH_F_Q3	cat_NPI_NH_F_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_F_Q4	cat_NPI_NH_F_Q4	cat_NPI_NH_F_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_F_Q5	cat_NPI_NH_F_Q5	cat_NPI_NH_F_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_F_Q6	cat_NPI_NH_F_Q6	cat_NPI_NH_F_Q6	Category	3		1=Yes 0=No
8	str_NPI_NH_F	str_NPI_NH_F	str_NPI_NH_F	Text	255, Optional		
9	Ing_NPI_NH_F_F	Ing_NPI_NH_F_F	Ing_NPI_NH_F_F	Integer	9		
10	Ing_NPI_NH_F_S	Ing_NPI_NH_F_S	Ing_NPI_NH_F_S	Integer	9		
11	Ing_NPI_NH_F_OD	Ing_NPI_NH_F_OD	Ing_NPI_NH_F_OD	Integer	9		

Occupational Disruptiveness is scored as:  
0 = Not at all  
1 = Minimally (almost no change in work routine)  
2 = Mildly (some change in work routine but little time rebudgeting required)  
3 = Moderate (disrupts work routine, requires time rebudgeting)  
4 = Severely (disrupts work routine, upsetting to staff and other residents, major time infringement)  
5 = Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
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**CLaSP CRF**  
Care of Late Stage Parkinsonism



Patient ID

IngPatID

## NPI-NH - APATHY/INDIFFERENCE

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

### Screening Question:

Does the resident sit quietly without paying attention to things going on around him/her? Has he/she lost interest in doing things or lack motivation for participating in activities? Is it difficult to involve the resident in conversation or in group

activities?

### G. APATHY/INDIFFERENCE

cat\_NPI\_NH\_G\_Q1

### Subquestions:

1. Has the resident lost interest in the world around him/her?
2. Does the resident fail to start conversation? (score only if conversation is possible)
3. Does the resident fail to show emotional reactions that would be expected (happiness over the visit of a friend or family member, interest in the news or sports, etc)?
4. Has the resident lost interest in friends and family members?
5. Is the resident less enthusiastic about his/her usual interest?
6. Does the resident sit quietly without paying attention to things going on around him/her?
7. Does the resident show any other signs that he/she doesn't care about doing new things?

### Yes/No

cat\_NPI\_NH\_G\_Q2

cat\_NPI\_NH\_G\_Q3

cat\_NPI\_NH\_G\_Q4

cat\_NPI\_NH\_G\_Q5

cat\_NPI\_NH\_G\_Q6

cat\_NPI\_NH\_G\_Q7

cat\_NPI\_NH\_G\_Q8

Comments:

str\_NPI\_NH\_G

If the Screening Question is confirmed, determine the frequency and severity of the apathy/indifference.

Frequency

Ing\_NPI\_NH\_G\_F

Frequency is rated as:

- 1 = Rarely - less than once per week.  
 2 = Sometimes - about once per week.  
 3 = Often  
 4 = Very often - several times per week but less than every day.  
 - once or more per day.

Severity

Ing\_NPI\_NH\_G\_S

Severity is rated as:

- 1 = Mild - resident has a loss of interest in things at times, but this causes little change in their behavior or participation in activities.  
 2 = Moderate - resident has a major loss of interest in things, which can only be changed by powerful events such as visits from close relatives or family members.  
 3 = Severe - resident has completely lost interest and motivation.

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_G_Q1	cat_NPI_NH_G_Q1	cat_NPI_NH_G_Q1	Category	53		See Appendix
3	cat_NPI_NH_G_Q2	cat_NPI_NH_G_Q2	cat_NPI_NH_G_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_G_Q3	cat_NPI_NH_G_Q3	cat_NPI_NH_G_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_G_Q4	cat_NPI_NH_G_Q4	cat_NPI_NH_G_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_G_Q5	cat_NPI_NH_G_Q5	cat_NPI_NH_G_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_G_Q6	cat_NPI_NH_G_Q6	cat_NPI_NH_G_Q6	Category	3		1=Yes 0=No
8	cat_NPI_NH_G_Q7	cat_NPI_NH_G_Q7	cat_NPI_NH_G_Q7	Category	3		1=Yes 0=No
9	cat_NPI_NH_G_Q8	cat_NPI_NH_G_Q8	cat_NPI_NH_G_Q8	Category	3		1=Yes 0=No
10	str_NPI_NH_G	str_NPI_NH_G	str_NPI_NH_G	Text	255, Optional		
11	Ing_NPI_NH_G_F	Ing_NPI_NH_G_F	Ing_NPI_NH_G_F	Integer	9		
12	Ing_NPI_NH_G_S	Ing_NPI_NH_G_S	Ing_NPI_NH_G_S	Integer	9		

Occupational  
Disruptiveness

Ing\_NPI\_NH\_G\_OD

How much does this behavior upset you and/or create more work for you?

- Occupational Disruptiveness is scored as:
- 0 = Not at all
  - 1 = Minimally (almost no change in work routine)
  - 2 = Mildly (some change in work routine but little time rebudgeting required)
  - 3 = Moderate (disrupts work routine, requires time rebudgeting)
  - 4 = Severely (disrupts work routine, requires time rebudgeting)
  - 5 = Very Severely or Extremely (extremely upsetting to staff and other residents, major time infringement)  
(very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
13	Ing_NPI_NH_G_OD	Ing_NPI_NH_G_OD	Ing_NPI_NH_G_OD	Integer	9		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



Patient ID

IngPatID

## NPI-NH - DISINHIBITION

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

### Screening Question:

Does the resident do or say things that are not usually done or said in public? Does he/she seem to act impulsively without thinking? Does the resident say things that are insensitive or hurt people's feeling?

H. DISINHIBITION

cat\_NPI\_NH\_H\_Q1

### Subquestions:

1. Does the resident act impulsively without thinking of the consequences?
2. Does the resident talk to total strangers as if he/she knew them?
3. Does the resident say things to people that are insensitive or hurt their feelings?
4. Does the resident say crude things or make inappropriate sexual remarks?
5. Does the resident talk openly about very personal or private matters not usually discussed in public?
6. Does the resident fondle, touch or hug others in way that is not appropriate?
7. Does the resident show any other signs of loss of control of his/her impulses?

### Yes/No

cat\_NPI\_NH\_H\_Q2

cat\_NPI\_NH\_H\_Q3

cat\_NPI\_NH\_H\_Q4

cat\_NPI\_NH\_H\_Q5

cat\_NPI\_NH\_H\_Q6

cat\_NPI\_NH\_H\_Q7

cat\_NPI\_NH\_H\_Q8

Comments:

str\_NPI\_NH\_H

If the Screening Question is confirmed, determine the frequency and severity of the disinhibition.

Frequency

Ing\_NPI\_NH\_H\_F

Frequency is rated as:

- 1 = Rarely - less than once per week.  
 2 = Sometimes - about once per week.  
 3 = Often  
 4 = Very often - several times per week but less than every day.  
 - once or more per day.

Severity

Ing\_NPI\_NH\_H\_S

Severity is rated as:

- 1 = Mild - resident acts impulsively at times, but behavior is not difficult to change by caregiver.  
 2 = Moderate - resident is very impulsive and this behavior is difficult to change by the caregiver.  
 3 = Severe - resident is almost always impulsive and this behavior is nearly impossible to change.

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_H_Q1	cat_NPI_NH_H_Q1	cat_NPI_NH_H_Q1	Category	53		See Appendix
3	cat_NPI_NH_H_Q2	cat_NPI_NH_H_Q2	cat_NPI_NH_H_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_H_Q3	cat_NPI_NH_H_Q3	cat_NPI_NH_H_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_H_Q4	cat_NPI_NH_H_Q4	cat_NPI_NH_H_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_H_Q5	cat_NPI_NH_H_Q5	cat_NPI_NH_H_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_H_Q6	cat_NPI_NH_H_Q6	cat_NPI_NH_H_Q6	Category	3		1=Yes 0=No
8	cat_NPI_NH_H_Q7	cat_NPI_NH_H_Q7	cat_NPI_NH_H_Q7	Category	3		1=Yes 0=No
9	cat_NPI_NH_H_Q8	cat_NPI_NH_H_Q8	cat_NPI_NH_H_Q8	Category	3		1=Yes 0=No
10	str_NPI_NH_H	str_NPI_NH_H	str_NPI_NH_H	Text	255, Optional		
11	Ing_NPI_NH_H_F	Ing_NPI_NH_H_F	Ing_NPI_NH_H_F	Integer	9		
12	Ing_NPI_NH_H_S	Ing_NPI_NH_H_S	Ing_NPI_NH_H_S	Integer	9		

Occupational  
Disruptiveness

Ing\_NPI\_NH\_H\_Q04

How much does this behavior upset you and/or create more work for you?

- Occupational Disruptiveness is scored as:
- 0 = Not at all
  - 1 = Minimally (almost no change in work routine)
  - 2 = Mildly (some change in work routine but little time rebudgeting required)
  - 3 = Moderate (disrupts work routine, requires time rebudgeting)
  - 4 = Severely (disrupts work routine, requires time rebudgeting)
  - 5 = Very Severely or Extremely, upsetting to staff and other residents, major time infringement (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
13	Ing_NPI_NH_H_OD	Ing_NPI_NH_H_OD	Ing_NPI_NH_H_OD	Integer	9		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



Patient ID

IngPatID

## NPI-NH - IRRITABILITY/LABILITY

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

### Screening Question:

Does the resident get easily irritated or disturbed? Are his/her moods very changeable? Is he/she extremely impatient?

### I. IRRITABILITY/LABILITY

cat\_NPI\_NH\_I\_Q1

#### Subquestions:

1. Does the resident have a bad temper, flying 'off the handle' easily over little things?
2. Does the resident rapidly change moods from one to another, being fine one minute and angry the next?
3. Does the resident have sudden flashes of anger?
4. Is the resident impatient, having trouble coping with delays or waiting for planned activities or other things?
5. Is the resident easily irritated?
6. Is the resident argue or is he/she difficult to get along with?
7. Does the resident show any other signs of irritability?

#### Yes/No

<input type="checkbox"/>	<input type="checkbox"/>	cat_NPI_NH_I_Q2
<input type="checkbox"/>	<input type="checkbox"/>	cat_NPI_NH_I_Q3
<input type="checkbox"/>	<input type="checkbox"/>	cat_NPI_NH_I_Q4
<input type="checkbox"/>	<input type="checkbox"/>	cat_NPI_NH_I_Q5
<input type="checkbox"/>	<input type="checkbox"/>	cat_NPI_NH_I_Q6
<input type="checkbox"/>	<input type="checkbox"/>	cat_NPI_NH_I_Q7
<input type="checkbox"/>	<input type="checkbox"/>	cat_NPI_NH_I_Q8

Comments:

str\_NPI\_NH\_I

If the Screening Question is confirmed, determine the frequency and severity of the irritability/lability.

Frequency

☐

Ing\_NPI\_NH\_I\_F

Frequency is rated as:

- 1 = Rarely - less than once per week.  
 2 = Sometimes - about once per week.  
 3 = Often  
 4 = Very often - several times per week but less than every day.  
 - once or more per day.

Severity

☐

Ing\_NPI\_NH\_I\_S

Severity is rated as:

- 1 = Mild - resident is irritable at times but behavior is not difficult to change by the caregiver.  
 2 = Moderate - resident is very irritable and this behavior is difficult for the caregiver to change.  
 3 = Severe - resident is almost always irritable and this behavior is nearly impossible to change.

Occupational  
Disruptiveness
☐

Ing\_NPI\_NH\_I\_OD

How much does this behavior upset you and/or create more work for you?

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_I_Q1	cat_NPI_NH_I_Q1	cat_NPI_NH_I_Q1	Category	53		See Appendix
3	cat_NPI_NH_I_Q2	cat_NPI_NH_I_Q2	cat_NPI_NH_I_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_I_Q3	cat_NPI_NH_I_Q3	cat_NPI_NH_I_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_I_Q4	cat_NPI_NH_I_Q4	cat_NPI_NH_I_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_I_Q5	cat_NPI_NH_I_Q5	cat_NPI_NH_I_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_I_Q6	cat_NPI_NH_I_Q6	cat_NPI_NH_I_Q6	Category	3		1=Yes 0=No
8	cat_NPI_NH_I_Q7	cat_NPI_NH_I_Q7	cat_NPI_NH_I_Q7	Category	3		1=Yes 0=No
9	cat_NPI_NH_I_Q8	cat_NPI_NH_I_Q8	cat_NPI_NH_I_Q8	Category	3		1=Yes 0=No
10	str_NPI_NH_I	str_NPI_NH_I	str_NPI_NH_I	Text	255, Optional		
11	Ing_NPI_NH_I_F	Ing_NPI_NH_I_F	Ing_NPI_NH_I_F	Integer	9		
12	Ing_NPI_NH_I_S	Ing_NPI_NH_I_S	Ing_NPI_NH_I_S	Integer	9		
13	Ing_NPI_NH_I_OD	Ing_NPI_NH_I_OD	Ing_NPI_NH_I_OD	Integer	9		

Occupational Disruptiveness is scored as:

0 = Not at all

1 = Minimally (almost no change in work routine)

2 = Mildly (some change in work routine but little time rebudgeting required)

3 = Moderate (disrupts work routine, requires time rebudgeting)

4 = Severely

5 = Very Severely or Extremely (extremely upsetting to staff and other residents, major time infringement)

(very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
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**CLaSP CRF**  
Care of Late Stage Parkinsonism



Patient ID

IngPatID

## NPI-NH - ABERRANT MOTOR BEHAVIOR

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

### Screening Question:

Does the resident have repetitive activities or 'habits' that he/she performs over and over such as pacing, wheeling back and forth, picking at things, or winding string? (Do not include simple tremors or tongue movements).

### J. ABERRANT MOTOR BEHAVIOR

cat\_NPI\_NH\_J\_Q1

### Subquestions:

1. Does the resident pace or wheel around the facility with no reason?
2. Does the resident open or unpack drawers or closets over and over?
3. Does the resident repeatedly put on and take off clothing?
4. Does the resident engage in repetitive activities such as handling buttons, picking, wrapping string, moving bed sheets, etc.?
5. Does the resident have repetitive activities or 'habits' that he/she performs over and over?
6. Is the resident excessively fidgety?

### Yes/No

cat\_NPI\_NH\_J\_Q2

cat\_NPI\_NH\_J\_Q3

cat\_NPI\_NH\_J\_Q4

cat\_NPI\_NH\_J\_Q5

cat\_NPI\_NH\_J\_Q6

cat\_NPI\_NH\_J\_Q7

Comments:

str\_NPI\_NH\_J

If the Screening Question is confirmed, determine the frequency and severity of the aberrant motor activity.

Frequency

Ing\_NPI\_NH\_J\_F

Frequency is rated as:

- 1 = Rarely - less than once per week.  
 2 = Sometimes - about once per week.  
 3 = Often - several times per week but less than every day.  
 4 = Very often - once or more per day.

Severity

Ing\_NPI\_NH\_J\_S

Severity is rated as:

- 1 = Mild - resident has repetitive behaviors at times, but this does not change daily activities.  
 2 = Moderate - repetitive behaviors of the resident are very noticeable but can be controlled with help from the caregiver.  
 3 = Severe - repetitive behaviors are very noticeable and upsetting to the resident and are difficult or impossible to control by the caregiver.

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_J_Q1	cat_NPI_NH_J_Q1	cat_NPI_NH_J_Q1	Category	53		See Appendix
3	cat_NPI_NH_J_Q2	cat_NPI_NH_J_Q2	cat_NPI_NH_J_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_J_Q3	cat_NPI_NH_J_Q3	cat_NPI_NH_J_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_J_Q4	cat_NPI_NH_J_Q4	cat_NPI_NH_J_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_J_Q5	cat_NPI_NH_J_Q5	cat_NPI_NH_J_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_J_Q6	cat_NPI_NH_J_Q6	cat_NPI_NH_J_Q6	Category	3		1=Yes 0=No
8	cat_NPI_NH_J_Q7	cat_NPI_NH_J_Q7	cat_NPI_NH_J_Q7	Category	3		1=Yes 0=No
9	str_NPI_NH_J	str_NPI_NH_J	str_NPI_NH_J	Text	255, Optional		
10	Ing_NPI_NH_J_F	Ing_NPI_NH_J_F	Ing_NPI_NH_J_F	Integer	9		
11	Ing_NPI_NH_J_S	Ing_NPI_NH_J_S	Ing_NPI_NH_J_S	Integer	9		

Occupational  
Disruptiveness

Ing\_NPI\_NH\_I\_OP

How much does this behavior upset you and/or create more work for you?

- Occupational Disruptiveness is scored as:
- 0 = Not at all
  - 1 = Minimally (almost no change in work routine)
  - 2 = Mildly (some change in work routine but little time rebudgeting required)
  - 3 = Moderate (disrupts work routine, requires time rebudgeting)
  - 4 = Severely (disrupts work routine, upsetting to staff and other residents, major time infringement)
  - 5 = Very Severely or Disruptive (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
12	Ing_NPI_NH_J_OD	Ing_NPI_NH_J_OD	Ing_NPI_NH_J_OD	Integer	9		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



Patient ID

## NPI-NH - SLEEP AND NIGHTTIME BEHAVIOR DISORDERS

**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

This group of question should be directed only to caregivers who work the night shift and observe the resident directly or have acceptable knowledge (e.g., receive regular morning report) of the resident's nighttime activities. If the caregiver is not knowledgeable about the patient's nighttime behavior, mark this category 'NA'.

### Screening Question:

Does the resident have difficulty sleeping (do not count as present if the resident simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? Is he/she awake at night? Does he/she wander at night, get dressed, or go into others' rooms?

### K. SLEEP AND NIGHTTIME BEHAVIOR DISORDERS

cat\_NPI\_NH\_K\_Q1

### Subquestions:

- Does the resident have difficulty falling asleep?
- Does the resident get up during the night (do not count if the resident gets up once or twice per night only to go to the bathroom and falls back asleep immediately)?
- Does the resident wander, pace, or get involved in inappropriate activities at night?
- Does the resident wake up at night, dress, and plan to go out, thinking that it is morning and time to start the day?
- Does the resident wake up too early in the morning (before other residents)?
- Does the resident have any other nighttime behaviors that we haven't talked about?

Yes/No

cat\_NPI\_NH\_K\_Q2

cat\_NPI\_NH\_K\_Q3

cat\_NPI\_NH\_K\_Q4

cat\_NPI\_NH\_K\_Q5

cat\_NPI\_NH\_K\_Q6

cat\_NPI\_NH\_K\_Q7

Comments:

str\_NPI\_NH\_K

If the Screening Question is confirmed, determine the frequency and severity of the nighttime behavior.

Frequency

Ing\_NPI\_NH\_K\_F

Frequency is rated as:

- 1 = Rarely - less than once per week.  
2 = Sometimes - about once per week.  
3 = Often  
4 = Very often - several times per week but less than every day.  
- once or more per day.

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_K_Q1	cat_NPI_NH_K_Q1	cat_NPI_NH_K_Q1	Category	53		See Appendix
3	cat_NPI_NH_K_Q2	cat_NPI_NH_K_Q2	cat_NPI_NH_K_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_K_Q3	cat_NPI_NH_K_Q3	cat_NPI_NH_K_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_K_Q4	cat_NPI_NH_K_Q4	cat_NPI_NH_K_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_K_Q5	cat_NPI_NH_K_Q5	cat_NPI_NH_K_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_K_Q6	cat_NPI_NH_K_Q6	cat_NPI_NH_K_Q6	Category	3		1=Yes 0=No
8	cat_NPI_NH_K_Q7	cat_NPI_NH_K_Q7	cat_NPI_NH_K_Q7	Category	3		1=Yes 0=No
9	str_NPI_NH_K	str_NPI_NH_K	str_NPI_NH_K	Text	255, Optional		
10	Ing_NPI_NH_K_F	Ing_NPI_NH_K_F	Ing_NPI_NH_K_F	Integer	9		

**Severity**

Ing\_NPI\_NH\_K\_S

Severity is rated as:

- 1 = Mild - nighttime behaviors are present but not too stressful for the resident.  
2 = Moderate - nighttime behaviors are present and disturb others in the nursing home; more than one type of nighttime behavior may be present.  
3 = Severe - nighttime behaviors are present and the resident is very disturbed during the night.

**Occupational  
Disruptiveness**

Ing\_NPI\_NH\_K\_OD

How much does this behavior upset you and/or create more work for you?

Occupational Disruptiveness is scored as:

- 0 = Not at all  
1 = Minimally (almost no change in work routine)  
2 = Mildly (some change in work routine but little time rebudgeting required)  
3 = Moderate (disrupts work routine, requires time rebudgeting)  
4 = Severely (disrupts work routine, requires time rebudgeting)  
5 = Very Severely or Extremely (extremely, upsetting to staff and other residents, major time infringement)  
(very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
11	Ing_NPI_NH_K_S	Ing_NPI_NH_K_S	Ing_NPI_NH_K_S	Integer	9		
12	Ing_NPI_NH_K_OD	Ing_NPI_NH_K_OD	Ing_NPI_NH_K_OD	Integer	9		



**Instruction:** The screening question is asked to determine if the behavioral change is present or absent. If the answer to the screening question is negative, click 'No' and proceed to the next screening question (on the next page) without asking/answering the subquestions. If questions are inappropriate or a set of questions may not be applicable because of very impaired residents or residents with special medical circumstances then 'NA' (Not Applicable) should be marked.

Does the resident have an extremely good or poor appetite, changes in weight, or unusual eating habits (count as 'N/A' if the resident is incapacitated and has to be fed)? Has there been any change in type of food he/she prefers?

	cat_NP1_NP1_L_Q1
--	------------------

Comments: str\_NPT\_NH\_L

[illegible]

Frequency is rated as:

- 1 = Rarely - less than once per week.
- 2 = Sometimes - about once per week.
- 3 = Often - several times per week but less than every day.
- 4 = Very often - once or more per day.

Severity is rated as:

1 = Mild - changes in appetite or eating are present but have not led to changes in weight and are not disturbing.

2 = Moderate - changes in appetite or eating are present and cause minor changes in weight.

3 = Severe - obvious changes in appetite or eating are present and cause changes in weight, are abnormal, or upset the resident.

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_NPI_NH_L_Q1	cat_NPI_NH_L_Q1	cat_NPI_NH_L_Q1	Category	53		See Appendix
3	cat_NPI_NH_L_Q2	cat_NPI_NH_L_Q2	cat_NPI_NH_L_Q2	Category	3		1=Yes 0=No
4	cat_NPI_NH_L_Q3	cat_NPI_NH_L_Q3	cat_NPI_NH_L_Q3	Category	3		1=Yes 0=No
5	cat_NPI_NH_L_Q4	cat_NPI_NH_L_Q4	cat_NPI_NH_L_Q4	Category	3		1=Yes 0=No
6	cat_NPI_NH_L_Q5	cat_NPI_NH_L_Q5	cat_NPI_NH_L_Q5	Category	3		1=Yes 0=No
7	cat_NPI_NH_L_Q6	cat_NPI_NH_L_Q6	cat_NPI_NH_L_Q6	Category	3		1=Yes 0=No
8	cat_NPI_NH_L_Q7	cat_NPI_NH_L_Q7	cat_NPI_NH_L_Q7	Category	3		1=Yes 0=No
9	cat_NPI_NH_L_Q8	cat_NPI_NH_L_Q8	cat_NPI_NH_L_Q8	Category	3		1=Yes 0=No
10	cat_NPI_NH_L_Q9	cat_NPI_NH_L_Q9	cat_NPI_NH_L_Q9	Category	3		1=Yes 0=No
11	str_NPI_NH_L	str_NPI_NH_L	str_NPI_NH_L	Text	255, Optional		
12	Ing_NPI_NH_L_F	Ing_NPI_NH_L_F	Ing_NPI_NH_L_F	Integer	9		
13	Ing_NPI_NH_L_S	Ing_NPI_NH_L_S	Ing_NPI_NH_L_S	Integer	9		

**Occupational  
Disruptiveness**

Ing\_NPI\_NH\_L\_OD

**How much does this behavior upset you and/or create more work for you?**

Occupational Disruptiveness is scored as:

0 = Not at all

1 = Minimally

2 = Mildly (almost no change in work routine)

3 = Moderate (some change in work routine but little time rebudgeting required)

4 = Severely (disrupts work routine, requires time rebudgeting)

5 = Very Severely or Extremely (extremely, upsetting to staff and other residents, major time infringement)

(very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
14	Ing_NPI_NH_L_OD	Ing_NPI_NH_L_OD	Ing_NPI_NH_L_OD	Integer	9		



**CLaSP CRF**  
Care of Late Stage Parkinsonism

**NMS-Scale (Non-Motor Symptom assessment  
scale for Parkinson's Disease)**



Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Scale completed by:

catScaleComBy2

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

**SEVERITY:**

- 0 = None  
1 = Mild: symptoms present but causes little distress or disturbance to patient  
2 = Moderate: some distress or disturbance to patient  
3 = Severe: major source of distress or disturbance to patient

**FREQUENCY:**

- 1 = Rarely (<1/wk)  
2 = Often (1/wk)  
3 = Frequent (several times per week)  
4 = Very Frequent (daily or all the time)

**Domain 1: Cardiovascular including falls**

- Does the patient experience light-headedness, dizziness, weakness on standing from sitting or lying position?
- Does the patient fall because of fainting or blacking out?

**Severity**

**Frequency**

**Frequency  
x Severity**

Ing\_NMS\_Sev\_Q1

Ing\_NMS\_FREQ\_Q1

Ing\_NMS\_SEFR\_Q1

Ing\_NMS\_Sev\_Q2

Ing\_NMS\_FREQ\_Q2

Ing\_NMS\_SEFR\_Q2

**SCORE:**

Ing\_Score\_D1

Ing\_NMS\_Sev\_Q3

Ing\_NMS\_FREQ\_Q3

Ing\_NMS\_SEFR\_Q3

Ing\_NMS\_Sev\_Q4

Ing\_NMS\_FREQ\_Q4

Ing\_NMS\_SEFR\_Q4

Ing\_NMS\_Sev\_Q5

Ing\_NMS\_FREQ\_Q5

Ing\_NMS\_SEFR\_Q5

Ing\_NMS\_Sev\_Q7

Ing\_NMS\_FREQ\_Q7

Ing\_NMS\_SEFR\_Q7

**SCORE:**

Ing\_Score\_D2

**Domain 3: Mood / Cognition**

- Has the patient lost interest in his/her surroundings?
- Has the patient lost interest in doing things or lack motivation to start new activities?
- Does the patient feel nervous, worried or frightened for no apparent reason?
- Does the patient seem sad or depressed or has he/she reported such feelings?

Ing\_NMS\_Sev\_Q8

Ing\_NMS\_FREQ\_Q8

Ing\_NMS\_SEFR\_Q8

Ing\_NMS\_Sev\_Q9

Ing\_NMS\_FREQ\_Q9

Ing\_NMS\_SEFR\_Q9

Ing\_NMS\_Sev\_Q11

Ing\_NMS\_FREQ\_Q11

Ing\_NMS\_SEFR\_Q11

Ing\_NMS\_Sev\_Q12

Ing\_NMS\_FREQ\_Q12

Ing\_NMS\_SEFR\_Q12

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catScaleComBy2	catScaleComBy2	catScaleComBy2	Category	7		1=Patient 2=Carer
6	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
7	strAssessReas	strAssessReas	strAssessReas	Text	500		
8	Ing_NMS_Sev_Q1	Ing_NMS_Sev_Q1	Ing_NMS_Sev_Q1	Integer	9		
9	Ing_NMS_FREQ_Q1	Ing_NMS_FREQ_Q1	Ing_NMS_FREQ_Q1	Integer	9		
10	Ing_NMS_SEFR_Q1	Ing_NMS_SEFR_Q1	Ing_NMS_SEFR_Q1	Integer	99	See Appendix	
11	Ing_NMS_Sev_Q2	Ing_NMS_Sev_Q2	Ing_NMS_Sev_Q2	Integer	9		
12	Ing_NMS_FREQ_Q2	Ing_NMS_FREQ_Q2	Ing_NMS_FREQ_Q2	Integer	9		
13	Ing_NMS_SEFR_Q2	Ing_NMS_SEFR_Q2	Ing_NMS_SEFR_Q2	Integer	99	See Appendix	
14	Ing_Score_D1	Ing_Score_D1	Ing_Score_D1	Integer	99	sum( [ NMS_Scale:Ing_NMS_SEFR_Q1, NMS_Scale:Ing_NMS_SEFR_Q2 ] )	
15	Ing_NMS_Sev_Q3	Ing_NMS_Sev_Q3	Ing_NMS_Sev_Q3	Integer	9		
16	Ing_NMS_FREQ_Q3	Ing_NMS_FREQ_Q3	Ing_NMS_FREQ_Q3	Integer	9		
17	Ing_NMS_SEFR_Q3	Ing_NMS_SEFR_Q3	Ing_NMS_SEFR_Q3	Integer	99	See Appendix	
18	Ing_NMS_Sev_Q4	Ing_NMS_Sev_Q4	Ing_NMS_Sev_Q4	Integer	9		
19	Ing_NMS_FREQ_Q4	Ing_NMS_FREQ_Q4	Ing_NMS_FREQ_Q4	Integer	9		
20	Ing_NMS_SEFR_Q4	Ing_NMS_SEFR_Q4	Ing_NMS_SEFR_Q4	Integer	99	See Appendix	
21	Ing_NMS_Sev_Q5	Ing_NMS_Sev_Q5	Ing_NMS_Sev_Q5	Integer	9		
22	Ing_NMS_FREQ_Q5	Ing_NMS_FREQ_Q5	Ing_NMS_FREQ_Q5	Integer	9		
23	Ing_NMS_SEFR_Q5	Ing_NMS_SEFR_Q5	Ing_NMS_SEFR_Q5	Integer	99	See Appendix	
24	Ing_NMS_Sev_Q7	Ing_NMS_Sev_Q7	Ing_NMS_Sev_Q7	Integer	9		
25	Ing_NMS_FREQ_Q7	Ing_NMS_FREQ_Q7	Ing_NMS_FREQ_Q7	Integer	9		
26	Ing_NMS_SEFR_Q7	Ing_NMS_SEFR_Q7	Ing_NMS_SEFR_Q7	Integer	99	See Appendix	
27	Ing_Score_D2	Ing_Score_D2	Ing_Score_D2	Integer	99	See Appendix	
28	Ing_NMS_Sev_Q8	Ing_NMS_Sev_Q8	Ing_NMS_Sev_Q8	Integer	9		
29	Ing_NMS_FREQ_Q8	Ing_NMS_FREQ_Q8	Ing_NMS_FREQ_Q8	Integer	9		
30	Ing_NMS_SEFR_Q8	Ing_NMS_SEFR_Q8	Ing_NMS_SEFR_Q8	Integer	99	See Appendix	
31	Ing_NMS_Sev_Q9	Ing_NMS_Sev_Q9	Ing_NMS_Sev_Q9	Integer	9		
32	Ing_NMS_FREQ_Q9	Ing_NMS_FREQ_Q9	Ing_NMS_FREQ_Q9	Integer	9		
33	Ing_NMS_SEFR_Q9	Ing_NMS_SEFR_Q9	Ing_NMS_SEFR_Q9	Integer	99	See Appendix	
34	Ing_NMS_Sev_Q11	Ing_NMS_Sev_Q11	Ing_NMS_Sev_Q11	Integer	9		
35	IngNMS_FREQ_Q11	IngNMS_FREQ_Q11	IngNMS_FREQ_Q11	Integer	9		
36	IngNMS_SEFR_Q11	IngNMS_SEFR_Q11	IngNMS_SEFR_Q11	Integer	99	See Appendix	
37	Ing_NMS_Sev_Q12	Ing_NMS_Sev_Q12	Ing_NMS_Sev_Q12	Integer	9		
38	IngNMS_FREQ_Q12	IngNMS_FREQ_Q12	IngNMS_FREQ_Q12	Integer	9		
39	IngNMS_SEFR_Q12	IngNMS_SEFR_Q12	IngNMS_SEFR_Q12	Integer	99	See Appendix	

11. Does the patient have flat moods without the normal “highs” and “ lows”?

12. Does the patient have difficulty in experiencing pleasure from their usual activities or report that they lack pleasure?

 Ing\_NMS\_Sev\_Q13

 IngNMS\_FREQ\_Q13

 IngNMS\_SEFR\_Q13

 Ing\_NMS\_Sev\_Q14

 IngNMS\_FREQ\_Q14

 IngNMS\_SEFR\_Q14

**SCORE:**

 Ing\_Score\_D3

#### Domain 4: Perceptual problems/hallucinations

13. Does the patient indicate that he/she sees things that are not there?

14. Does the patient have beliefs that you know are not true? (For example, about being harmed, being robbed or being unfaithful)

15. Does the patient experience double vision?  
(2 separate real objects and not blurred vision)

 Ing\_NMS\_Sev\_Q15

 IngNMS\_FREQ\_Q15

 IngNMS\_SEFR\_Q15

 Ing\_NMS\_Sev\_Q16

 IngNMS\_FREQ\_Q16

 IngNMS\_SEFR\_Q16

 Ing\_NMS\_Sev\_Q17

 IngNMS\_FREQ\_Q17

 IngNMS\_SEFR\_Q17

**SCORE:**

 Ing\_Score\_D4

#### Domain 5: Attention / Memory

16. Does the patient have problems sustaining concentration during activities?  
(For example, reading or having a conversation)

17. Does the patient forget things that he/she has been told a short time ago or events that happened in the last few days?

18. Does the patient forget to do things?  
(For example, take tablets or turn off domestic appliances?)

 Ing\_NMS\_Sev\_Q18

 IngNMS\_FREQ\_Q18

 IngNMS\_SEFR\_Q18

 Ing\_NMS\_Sev\_Q19

 IngNMS\_FREQ\_Q19

 IngNMS\_SEFR\_Q19

 Ing\_NMS\_Sev\_Q20

 IngNMS\_FREQ\_Q20

 IngNMS\_SEFR\_Q20

**SCORE:**

 Ing\_Score\_D5

#### Domain 6: Gastrointestinal tract

19. Does the patient dribble saliva during the day?

20. Does the patient having difficulty swallowing?

21. Does the patient suffer from constipation?  
(Bowel action less than three times weekly)

 Ing\_NMS\_Sev\_Q21

 IngNMS\_FREQ\_Q21

 IngNMS\_SEFR\_Q21

 Ing\_NMS\_Sev\_Q22

 IngNMS\_FREQ\_Q22

 IngNMS\_SEFR\_Q22

 Ing\_NMS\_Sev\_Q23

 IngNMS\_FREQ\_Q23

 IngNMS\_SEFR\_Q23

**SCORE:**

 Ing\_Score\_D6

#### Domain 7: Urinary

22. Does the patient have difficulty holding urine? (Urgency)

23. Does the patient have to void within 2 hours of last voiding? (Frequency)

24. Does the patient have to get up regularly at night to pass urine? (Nocturia)

 Ing\_NMS\_Sev\_Q24

 IngNMS\_FREQ\_Q24

 IngNMS\_SEFR\_Q24

 Ing\_NMS\_Sev\_Q25

 IngNMS\_FREQ\_Q25

 IngNMS\_SEFR\_Q25

 Ing\_NMS\_Sev\_Q26

 IngNMS\_FREQ\_Q26

 IngNMS\_SEFR\_Q26

**SCORE:**

 Ing\_Score\_D7

#### Domain 8: Sexual function

25. Does the patient have altered interest in sex?  
(Very much increased or decreased, please underline)

26. Does the patient have problems having sex?

 Ing\_NMS\_Sev\_Q27

 IngNMS\_FREQ\_Q27

 IngNMS\_SEFR\_Q27

 Ing\_NMS\_Sev\_Q28

 IngNMS\_FREQ\_Q28

 IngNMS\_SEFR\_Q28

**SCORE:**

 Ing\_Score\_D8

#### Domain 9: Miscellaneous

27. Does the patient suffer from pain not explained by other known conditions?  
(Is it related to intake of drugs and is it relieved by antiparkinson drugs?)

 Ing\_NMS\_Sev\_Q29

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
40	Ing_NMS_Sev_Q13	Ing_NMS_Sev_Q13	Ing_NMS_Sev_Q13	Integer	9		
41	IngNMS_FREQ_Q13	IngNMS_FREQ_Q13	IngNMS_FREQ_Q13	Integer	9		
42	IngNMS_SEFR_Q13	IngNMS_SEFR_Q13	IngNMS_SEFR_Q13	Integer	99	See Appendix	
43	Ing_NMS_Sev_Q14	Ing_NMS_Sev_Q14	Ing_NMS_Sev_Q14	Integer	9		
44	IngNMS_FREQ_Q14	IngNMS_FREQ_Q14	IngNMS_FREQ_Q14	Integer	9		
45	IngNMS_SEFR_Q14	IngNMS_SEFR_Q14	IngNMS_SEFR_Q14	Integer	99	See Appendix	
46	Ing_Score_D3	Ing_Score_D3	Ing_Score_D3	Integer	99	See Appendix	
47	Ing_NMS_Sev_Q15	Ing_NMS_Sev_Q15	Ing_NMS_Sev_Q15	Integer	9		
48	IngNMS_FREQ_Q15	IngNMS_FREQ_Q15	IngNMS_FREQ_Q15	Integer	9		
49	IngNMS_SEFR_Q15	IngNMS_SEFR_Q15	IngNMS_SEFR_Q15	Integer	99	See Appendix	
50	Ing_NMS_Sev_Q16	Ing_NMS_Sev_Q16	Ing_NMS_Sev_Q16	Integer	9		
51	IngNMS_FREQ_Q16	IngNMS_FREQ_Q16	IngNMS_FREQ_Q16	Integer	9		
52	IngNMS_SEFR_Q16	IngNMS_SEFR_Q16	IngNMS_SEFR_Q16	Integer	99	See Appendix	
53	Ing_NMS_Sev_Q17	Ing_NMS_Sev_Q17	Ing_NMS_Sev_Q17	Integer	9		
54	IngNMS_FREQ_Q17	IngNMS_FREQ_Q17	IngNMS_FREQ_Q17	Integer	9		
55	IngNMS_SEFR_Q17	IngNMS_SEFR_Q17	IngNMS_SEFR_Q17	Integer	99	See Appendix	
56	Ing_Score_D4	Ing_Score_D4	Ing_Score_D4	Integer	99	See Appendix	
57	Ing_NMS_Sev_Q18	Ing_NMS_Sev_Q18	Ing_NMS_Sev_Q18	Integer	9		
58	IngNMS_SEFR_Q18	IngNMS_SEFR_Q18	IngNMS_SEFR_Q18	Integer	99	See Appendix	
59	IngNMS_FREQ_Q18	IngNMS_FREQ_Q18	IngNMS_FREQ_Q18	Integer	9		
60	Ing_NMS_Sev_Q19	Ing_NMS_Sev_Q19	Ing_NMS_Sev_Q19	Integer	9		
61	IngNMS_SEFR_Q19	IngNMS_SEFR_Q19	IngNMS_SEFR_Q19	Integer	99	See Appendix	
62	IngNMS_FREQ_Q19	IngNMS_FREQ_Q19	IngNMS_FREQ_Q19	Integer	9		
63	Ing_NMS_Sev_Q20	Ing_NMS_Sev_Q20	Ing_NMS_Sev_Q20	Integer	9		
64	IngNMS_FREQ_Q20	IngNMS_FREQ_Q20	IngNMS_FREQ_Q20	Integer	9		
65	IngNMS_SEFR_Q20	IngNMS_SEFR_Q20	IngNMS_SEFR_Q20	Integer	99	See Appendix	
66	Ing_Score_D5	Ing_Score_D5	Ing_Score_D5	Integer	99	See Appendix	
67	Ing_NMS_Sev_Q21	Ing_NMS_Sev_Q21	Ing_NMS_Sev_Q21	Integer	9		
68	IngNMS_FREQ_Q21	IngNMS_FREQ_Q21	IngNMS_FREQ_Q21	Integer	9		
69	IngNMS_SEFR_Q21	IngNMS_SEFR_Q21	IngNMS_SEFR_Q21	Integer	99	See Appendix	
70	Ing_NMS_Sev_Q22	Ing_NMS_Sev_Q22	Ing_NMS_Sev_Q22	Integer	9		
71	IngNMS_FREQ_Q22	IngNMS_FREQ_Q22	IngNMS_FREQ_Q22	Integer	9		
72	IngNMS_SEFR_Q22	IngNMS_SEFR_Q22	IngNMS_SEFR_Q22	Integer	99	See Appendix	
73	Ing_NMS_Sev_Q23	Ing_NMS_Sev_Q23	Ing_NMS_Sev_Q23	Integer	9		
74	IngNMS_FREQ_Q23	IngNMS_FREQ_Q23	IngNMS_FREQ_Q23	Integer	9		
75	IngNMS_SEFR_Q23	IngNMS_SEFR_Q23	IngNMS_SEFR_Q23	Integer	99	See Appendix	
76	Ing_Score_D6	Ing_Score_D6	Ing_Score_D6	Integer	99	See Appendix	
77	Ing_NMS_Sev_Q24	Ing_NMS_Sev_Q24	Ing_NMS_Sev_Q24	Integer	9		
78	IngNMS_FREQ_Q24	IngNMS_FREQ_Q24	IngNMS_FREQ_Q24	Integer	9		
79	IngNMS_SEFR_Q24	IngNMS_SEFR_Q24	IngNMS_SEFR_Q24	Integer	99	See Appendix	
80	Ing_NMS_Sev_Q25	Ing_NMS_Sev_Q25	Ing_NMS_Sev_Q25	Integer	9		
81	IngNMS_FREQ_Q25	IngNMS_FREQ_Q25	IngNMS_FREQ_Q25	Integer	9		
82	IngNMS_SEFR_Q25	IngNMS_SEFR_Q25	IngNMS_SEFR_Q25	Integer	99	See Appendix	
83	Ing_NMS_Sev_Q26	Ing_NMS_Sev_Q26	Ing_NMS_Sev_Q26	Integer	9		
84	IngNMS_FREQ_Q26	IngNMS_FREQ_Q26	IngNMS_FREQ_Q26	Integer	9		
85	IngNMS_SEFR_Q26	IngNMS_SEFR_Q26	IngNMS_SEFR_Q26	Integer	99	See Appendix	
86	Ing_Score_D7	Ing_Score_D7	Ing_Score_D7	Integer	99	See Appendix	
87	Ing_NMS_Sev_Q27	Ing_NMS_Sev_Q27	Ing_NMS_Sev_Q27	Integer	9		
88	IngNMS_FREQ_Q27	IngNMS_FREQ_Q27	IngNMS_FREQ_Q27	Integer	9		
89	IngNMS_SEFR_Q27	IngNMS_SEFR_Q27	IngNMS_SEFR_Q27	Integer	99	See Appendix	
90	Ing_NMS_Sev_Q28	Ing_NMS_Sev_Q28	Ing_NMS_Sev_Q28	Integer	9		
91	IngNMS_FREQ_Q28	IngNMS_FREQ_Q28	IngNMS_FREQ_Q28	Integer	9		
92	IngNMS_SEFR_Q28	IngNMS_SEFR_Q28	IngNMS_SEFR_Q28	Integer	99	See Appendix	
93	Ing_Score_D8	Ing_Score_D8	Ing_Score_D8	Integer	99	sum( [ NMS_Scale:IngNMS_SEFR_Q27, NMS_Scale:IngNMS_SEFR_Q28 ] )	
94	Ing_NMS_Sev_Q29	Ing_NMS_Sev_Q29	Ing_NMS_Sev_Q29	Integer	9		

28. Does the patient report a change in ability to taste or smell?

29. Does the patient report a recent change in weight (not related to dieting)?

30. Does the patient experience excessive sweating? (not related to hot weather)

6. Is the patient aware or has he/she been told about talking during sleep or moving about as if acting-out a dream?

10. Does the patient look dazed or unaware of what is going on? (Not just when drowsy or falling asleep?)

1.) Cardiovascular including falls

cat\_NMS\_S\_Q1

2) Sleep/fatigue

cat\_NMS\_S\_Q2

3) Mood /Cognition

cat\_NMS\_S\_Q3

4) Perceptual problems/hallucinations

cat\_NMS\_S\_Q4

5) Attention/ Memory

cat\_NMS\_S\_Q5

Ing\_NMS\_Sev\_Q6  Ing\_NMS\_FREQ\_Q6  Ing\_NMS\_SEFR\_Q6

Ing\_NMS\_Sev\_Q10  Ing\_NMS\_FREQ\_Q10  Ing\_NMS\_SEFR\_Q10

6) Gastrointestinal tract

7) Urinary

8) Sexual function

9) Miscellaneous

cat\_NMS\_S\_Q6

cat\_NMS\_S\_Q7

cat\_NMS\_S\_Q8

cat\_NMS\_S\_Q9

Ing\_NMS\_Sev\_Q30  Ing\_NMS\_FREQ\_Q30

Ing\_NMS\_Sev\_Q31  Ing\_NMS\_FREQ\_Q31

Ing\_NMS\_Sev\_Q32  Ing\_NMS\_FREQ\_Q32

IngNMS\_FREQ\_Q29  IngNMS\_SEFR\_Q29

IngNMS\_FREQ\_Q30  IngNMS\_SEFR\_Q30

IngNMS\_FREQ\_Q31  IngNMS\_SEFR\_Q31

IngNMS\_FREQ\_Q32  IngNMS\_SEFR\_Q32

Ing\_Score\_D9

SCORE:

TOTAL SCORE:

Ing\_Total\_Score

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
95	IngNMS_FREQ_Q29	IngNMS_FREQ_Q29	IngNMS_FREQ_Q29	Integer	9		
96	IngNMS_SEFR_Q29	IngNMS_SEFR_Q29	IngNMS_SEFR_Q29	Integer	99	See Appendix	
97	Ing_NMS_Sev_Q30	Ing_NMS_Sev_Q30	Ing_NMS_Sev_Q30	Integer	9		
98	IngNMS_FREQ_Q30	IngNMS_FREQ_Q30	IngNMS_FREQ_Q30	Integer	9		
99	IngNMS_SEFR_Q30	IngNMS_SEFR_Q30	IngNMS_SEFR_Q30	Integer	99	See Appendix	
100	Ing_NMS_Sev_Q31	Ing_NMS_Sev_Q31	Ing_NMS_Sev_Q31	Integer	9		
101	IngNMS_FREQ_Q31	IngNMS_FREQ_Q31	IngNMS_FREQ_Q31	Integer	9		
102	IngNMS_SEFR_Q31	IngNMS_SEFR_Q31	IngNMS_SEFR_Q31	Integer	99	See Appendix	
103	Ing_NMS_Sev_Q32	Ing_NMS_Sev_Q32	Ing_NMS_Sev_Q32	Integer	9		
104	IngNMS_FREQ_Q32	IngNMS_FREQ_Q32	IngNMS_FREQ_Q32	Integer	9		
105	IngNMS_SEFR_Q32	IngNMS_SEFR_Q32	IngNMS_SEFR_Q32	Integer	99	See Appendix	
106	Ing_Score_D9	Ing_Score_D9	Ing_Score_D9	Integer	99	See Appendix	
107	Ing_Total_Score	Ing_Total_Score	Ing_Total_Score	Integer	9999	See Appendix	
108	Ing_NMS_Sev_Q6	Ing_NMS_Sev_Q6	Ing_NMS_Sev_Q6	Integer	9, Optional, Hidden		
109	Ing_NMS_FREQ_Q6	Ing_NMS_FREQ_Q6	Ing_NMS_FREQ_Q6	Integer	9, Optional, Hidden		
110	Ing_NMS_SEFR_Q6	Ing_NMS_SEFR_Q6	Ing_NMS_SEFR_Q6	Integer	99, Optional, Hidden	See Appendix	
111	Ing_NMS_Sev_Q10	Ing_NMS_Sev_Q10	Ing_NMS_Sev_Q10	Integer	9, Optional, Hidden		
112	IngNMS_FREQ_Q10	IngNMS_FREQ_Q10	IngNMS_FREQ_Q10	Integer	9, Optional, Hidden		
113	IngNMS_SEFR_Q10	IngNMS_SEFR_Q10	IngNMS_SEFR_Q10	Integer	99, Optional, Hidden	See Appendix	
114	cat_NMS_S_Q6	cat_NMS_S_Q6	cat_NMS_S_Q6	Category	3, Optional, Hidden		1=Yes 0=No
115	cat_NMS_S_Q1	cat_NMS_S_Q1	cat_NMS_S_Q1	Category	3, Optional, Hidden		1=Yes 0=No
116	cat_NMS_S_Q7	cat_NMS_S_Q7	cat_NMS_S_Q7	Category	3, Optional, Hidden		1=Yes 0=No
117	cat_NMS_S_Q2	cat_NMS_S_Q2	cat_NMS_S_Q2	Category	3, Optional, Hidden		1=Yes 0=No
118	cat_NMS_S_Q8	cat_NMS_S_Q8	cat_NMS_S_Q8	Category	3, Optional, Hidden		1=Yes 0=No
119	cat_NMS_S_Q3	cat_NMS_S_Q3	cat_NMS_S_Q3	Category	3, Optional, Hidden		1=Yes 0=No
120	cat_NMS_S_Q4	cat_NMS_S_Q4	cat_NMS_S_Q4	Category	3, Optional, Hidden		1=Yes 0=No
121	cat_NMS_S_Q9	cat_NMS_S_Q9	cat_NMS_S_Q9	Category	3, Optional, Hidden		1=Yes 0=No
122	cat_NMS_S_Q5	cat_NMS_S_Q5	cat_NMS_S_Q5	Category	3, Optional, Hidden		1=Yes 0=No



**CLaSP CRF**  
Care of Late Stage Parkinsonism



**ESAS (PD)**

Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Scale completed by

catScaleComBy3

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

**Edmonton Symptom Assessment System (ESAS)**

Please enter the number that best describes how you feel NOW

Pain  Ing\_ESAS\_Q1

Tiredness  Ing\_ESAS\_Q2

Nausea  Ing\_ESAS\_Q3

Depression  Ing\_ESAS\_Q4

Anxiety  Ing\_ESAS\_Q5

Drowsiness  Ing\_ESAS\_Q6

Lack of Appetite  Ing\_ESAS\_Q7

Wellbeing  Ing\_ESAS\_Q8

Shortness of Breath  Ing\_ESAS\_Q9

Other Problem  Ing\_ESAS\_Q10

Please specify other Problem:

str\_Other\_Q10

**SCORING:**

No (Feeling/Situation) = 0

1  
2  
...  
8  
9

**Worst Possible (Feeling/Situation) = 10**

**Parkinson's Disease Symptom Assessment**

Stiffness  Ing\_ESAS\_Q11

Constipation  Ing\_ESAS\_Q12

Swallowing  Ing\_ESAS\_Q13

Confusion  Ing\_ESAS\_Q14

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catScaleComBy3	catScaleComBy3	catScaleComBy3	Category	18		1=Patient 2=Caregiver 3=Caregiver assisted
6	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
7	strAssessReas	strAssessReas	strAssessReas	Text	500		
8	Ing_ESAS_Q1	Ing_ESAS_Q1	Ing_ESAS_Q1	Integer	99		
9	Ing_ESAS_Q2	Ing_ESAS_Q2	Ing_ESAS_Q2	Integer	99		
10	Ing_ESAS_Q3	Ing_ESAS_Q3	Ing_ESAS_Q3	Integer	99		
11	Ing_ESAS_Q4	Ing_ESAS_Q4	Ing_ESAS_Q4	Integer	99		
12	Ing_ESAS_Q5	Ing_ESAS_Q5	Ing_ESAS_Q5	Integer	99		
13	Ing_ESAS_Q6	Ing_ESAS_Q6	Ing_ESAS_Q6	Integer	99		
14	Ing_ESAS_Q7	Ing_ESAS_Q7	Ing_ESAS_Q7	Integer	99		
15	Ing_ESAS_Q8	Ing_ESAS_Q8	Ing_ESAS_Q8	Integer	99		
16	Ing_ESAS_Q9	Ing_ESAS_Q9	Ing_ESAS_Q9	Integer	99		
17	Ing_ESAS_Q10	Ing_ESAS_Q10	Ing_ESAS_Q10	Integer	99		
18	str_Other_Q10	str_Other_Q10	str_Other_Q10	Text	255		
19	Ing_ESAS_Q11	Ing_ESAS_Q11	Ing_ESAS_Q11	Integer	99		
20	Ing_ESAS_Q12	Ing_ESAS_Q12	Ing_ESAS_Q12	Integer	99		
21	Ing_ESAS_Q13	Ing_ESAS_Q13	Ing_ESAS_Q13	Integer	99		
22	Ing_ESAS_Q14	Ing_ESAS_Q14	Ing_ESAS_Q14	Integer	99		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



# CHARLSON COMORBIDITY SCORING

Patient ID

IngPatID

Assessed: ☐ Yes catAss\_Q  
☐ No

Date test performed:

dtmExam

Duration of test (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

Will the patient live long enough to benefit from a specific screening measure or medical intervention?

catAss\_CCI

Scoring: Age

catAge\_CCI

hid\_Ing\_Age\_CCI

hid\_Ing\_Age\_CCI

## 1 Point

- ☐ Myocardial Infarction catCCI\_Q1
- ☐ Congestive Heart Failure catCCI\_Q2
- ☐ Peripheral Vascular Disease catCCI\_Q3
- ☐ Cerebrovascular Disease catCCI\_Q4
- ☐ Dementia catCCI\_Q5
- ☐ COPD catCCI\_Q6
- ☐ Connective Tissue Disease catCCI\_Q7
- ☐ Peptic Ulcer Disease catCCI\_Q8
- ☐ Diabetes Mellitus without end-organ damage catCCI\_Q9
- ☐ Mild liver disease catCCI\_Q10

retain\_Q1  hid\_Ing\_CCI\_Q1

retain\_Q2  hid\_Ing\_CCI\_Q2

retain\_Q3  hid\_Ing\_CCI\_Q3

retain\_Q4  hid\_Ing\_CCI\_Q4

retain\_Q5  hid\_Ing\_CCI\_Q5

retain\_Q6  hid\_Ing\_CCI\_Q6

retain\_Q7  hid\_Ing\_CCI\_Q7

retain\_Q8  hid\_Ing\_CCI\_Q8

retain\_Q9  hid\_Ing\_CCI\_Q9

retain\_Q10  hid\_Ing\_CCI\_Q10

## 2 Points

- ☐ Hemiplegia catCCI\_Q11
- ☐ Leukemia catCCI\_Q12
- ☐ Malignant Lymphoma catCCI\_Q13
- ☐ Diabetes Mellitus with end-organ damage catCCI\_Q14
- ☐ Moderate to Severe Chronic Kidney Disease catCCI\_Q15
- ☐ Solid Tumor without metastasis catCCI\_Q16

retain\_Q11  hid\_Ing\_CCI\_Q11

retain\_Q12  hid\_Ing\_CCI\_Q12

retain\_Q13  hid\_Ing\_CCI\_Q13

retain\_Q14  hid\_Ing\_CCI\_Q14

retain\_Q15  hid\_Ing\_CCI\_Q15

retain\_Q16  hid\_Ing\_CCI\_Q16

## 3 Points

- ☐ Moderate or severe liver disease catCCI\_Q17

retain\_Q17  hid\_Ing\_CCI\_Q17

## 6 Points

- ☐ Metastatic solid tumor catCCI\_Q18
- ☐ AIDS catCCI\_Q19

retain\_Q18  hid\_Ing\_CCI\_Q18

retain\_Q19  hid\_Ing\_CCI\_Q19

**Charlson Index:**

Ing\_CCI\_Score

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catAss_CCI	catAss_CCI	catAss_CCI	Category	3		1=Yes 0=No
8	hid_Ing_Age_CCI	hid_Ing_Age_CCI	hid_Ing_Age_CCI	Integer	9, Optional, Hidden	See Appendix	
9	catAge_CCI	catAge_CCI	catAge_CCI	Category	19		See Appendix
10	hid_Ing_CCI_Q1	hid_Ing_CCI_Q1	hid_Ing_CCI_Q1	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q1), 1 ), ( else, 0 ))	
11	catCCI_Q1	catCCI_Q1	catCCI_Q1	Category	21, Optional		1=Myocardial Infarction
12	hid_Ing_CCI_Q2	hid_Ing_CCI_Q2	hid_Ing_CCI_Q2	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q2), 1 ), ( else, 0 ))	
13	catCCI_Q2	catCCI_Q2	catCCI_Q2	Category	24, Optional		1=Congestive Heart Failure
14	hid_Ing_CCI_Q3	hid_Ing_CCI_Q3	hid_Ing_CCI_Q3	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q3), 1 ), ( else, 0 ))	
15	catCCI_Q3	catCCI_Q3	catCCI_Q3	Category	27, Optional		1=Peripheral Vascular Disease
16	hid_Ing_CCI_Q4	hid_Ing_CCI_Q4	hid_Ing_CCI_Q4	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q4), 1 ), ( else, 0 ))	
17	catCCI_Q4	catCCI_Q4	catCCI_Q4	Category	23, Optional		1=Cerebrovascular Disease
18	hid_Ing_CCI_Q5	hid_Ing_CCI_Q5	hid_Ing_CCI_Q5	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q5), 1 ), ( else, 0 ))	
19	catCCI_Q5	catCCI_Q5	catCCI_Q5	Category	8, Optional		1=Dementia
20	hid_Ing_CCI_Q6	hid_Ing_CCI_Q6	hid_Ing_CCI_Q6	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q6), 1 ), ( else, 0 ))	
21	catCCI_Q6	catCCI_Q6	catCCI_Q6	Category	4, Optional		1=COPD
22	hid_Ing_CCI_Q7	hid_Ing_CCI_Q7	hid_Ing_CCI_Q7	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q7), 1 ), ( else, 0 ))	
23	catCCI_Q7	catCCI_Q7	catCCI_Q7	Category	25, Optional		1=Connective Tissue Disease
24	hid_Ing_CCI_Q8	hid_Ing_CCI_Q8	hid_Ing_CCI_Q8	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q8), 1 ), ( else, 0 ))	
25	catCCI_Q8	catCCI_Q8	catCCI_Q8	Category	20, Optional		1=Peptic Ulcer Disease
26	hid_Ing_CCI_Q9	hid_Ing_CCI_Q9	hid_Ing_CCI_Q9	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q9), 1 ), ( else, 0 ))	
27	catCCI_Q9	catCCI_Q9	catCCI_Q9	Category	42, Optional		1=Diabetes Mellitus without end-organ damage
28	hid_Ing_CCI_Q10	hid_Ing_CCI_Q10	hid_Ing_CCI_Q10	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q10), 1 ), ( else, 0 ))	
29	catCCI_Q10	catCCI_Q10	catCCI_Q10	Category	18, Optional		1=Mild liver disease
30	hid_Ing_CCI_Q11	hid_Ing_CCI_Q11	hid_Ing_CCI_Q11	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q11), 2 ), ( else, 0 ))	
31	catCCI_Q11	catCCI_Q11	catCCI_Q11	Category	10, Optional		1=Hemiplegia
32	hid_Ing_CCI_Q12	hid_Ing_CCI_Q12	hid_Ing_CCI_Q12	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q12), 2 ), ( else, 0 ))	
33	catCCI_Q12	catCCI_Q12	catCCI_Q12	Category	8, Optional		1=Leukemia
34	hid_Ing_CCI_Q13	hid_Ing_CCI_Q13	hid_Ing_CCI_Q13	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q13), 2 ), ( else, 0 ))	
35	catCCI_Q13	catCCI_Q13	catCCI_Q13	Category	18, Optional		1=Malignant Lymphoma
36	hid_Ing_CCI_Q14	hid_Ing_CCI_Q14	hid_Ing_CCI_Q14	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q14), 2 ), ( else, 0 ))	
37	catCCI_Q14	catCCI_Q14	catCCI_Q14	Category	39, Optional		1=Diabetes Mellitus with end-organ damage
38	hid_Ing_CCI_Q15	hid_Ing_CCI_Q15	hid_Ing_CCI_Q15	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q15), 2 ), ( else, 0 ))	
39	catCCI_Q15	catCCI_Q15	catCCI_Q15	Category	41, Optional		1=Moderate to Severe Chronic Kidney Disease
40	hid_Ing_CCI_Q16	hid_Ing_CCI_Q16	hid_Ing_CCI_Q16	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q16), 2 ), ( else, 0 ))	
41	catCCI_Q16	catCCI_Q16	catCCI_Q16	Category	30, Optional		1=Solid Tumor without metastasis
42	hid_Ing_CCI_Q17	hid_Ing_CCI_Q17	hid_Ing_CCI_Q17	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q17), 3 ), ( else, 0 ))	
43	catCCI_Q17	catCCI_Q17	catCCI_Q17	Category	32, Optional		1=Moderate or severe liver disease
44	hid_Ing_CCI_Q18	hid_Ing_CCI_Q18	hid_Ing_CCI_Q18	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q18), 6 ), ( else, 0 ))	
45	catCCI_Q18	catCCI_Q18	catCCI_Q18	Category	22, Optional		1=Metastatic solid tumor
46	hid_Ing_CCI_Q19	hid_Ing_CCI_Q19	hid_Ing_CCI_Q19	Integer	9, Optional, Hidden	case(( isknown( Charlson_Index:catCCI_Q19), 6 ), ( else, 0 ))	
47	catCCI_Q19	catCCI_Q19	catCCI_Q19	Category	4, Optional		1=AIDS
48	Ing_CCI_Score	Ing_CCI_Score	Ing_CCI_Score	Integer	999	See Appendix	



**CLaSP CRF**  
Care of Late Stage Parkinsonism



## RECOMMENDATIONS

Patient ID

 IngPatID

### Dopaminergic treatment change recommended

catRecoQ1  
 Name of drug  strChangeRec1  
 Type of treatment   catRecoQ1\_type  
 Daily dose  realRecU1  
 Unit   catUnitRec1 other unit  strRecU1  
 Changes to medication (optional to complete)  
 strRecoQ1

### Non-dopaminergic treatment change recommended

catRecoQ2  
 Name of drug  strChangeRec2  
 Type of treatment   catRecoQ2\_type  
 Daily dose  realRecU2  
 Unit   catUnitRec2 other unit  strRecU2  
 Changes to medication (optional to complete)  
 strRecoQ2

### Medications for mental health issues recommended

catRecoQ3  
 Name of drug  strChangeRec3  
 Type of treatment   catRecoQ3\_type  
 Daily dose  realRecU3  
 Unit   catUnitRec3 other unit  strRecU3  
 Changes to medication (optional to complete)  
 strRecoQ3

### Allied health intervention referral recommended

#### (PT) Physiotherapy done

cat\_AHI\_a  
  cat\_AHI\_a\_nRef  
 New referral   str\_Ref\_Crit\_a  
 Referral criteria fulfilled   cat\_AHI\_Aim\_a  
 Aims  strRecoQ3

#### (SLT) Speech and language therapy

cat\_AHI\_b  
  cat\_AHI\_b\_nRef  
 New referral   str\_Ref\_Crit\_b  
 Referral criteria fulfilled   str\_AHI\_Aim\_b  
 Aims

#### (OT) Occupational therapy

cat\_AHI\_c  
  cat\_AHI\_c\_nRef  
 New referral   str\_Ref\_Crit\_c  
 Referral criteria fulfilled   str\_AHI\_Aim\_c  
 Aims

#### Parkinson nurse referral recommended

catAHINurse  
  catAHINurs\_nRef  
 New referral

#### Psychosocial interventions recommended

catAHIPsycho

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catRecoQ1	catRecoQ1	catRecoQ1	Category	3		1=Yes 0=No
3	strChangeRec1	strChangeRec1	strChangeRec1	Text	100		
4	catRecoQ1_type	catRecoQ1_type	catRecoQ1_type	Category	27		See Appendix
5	realRecU1	realRecU1	realRecU1	Real	99999.999		
6	strRecU1	strRecU1	strRecU1	Text	100		
7	catUnitRec1	catUnitRec1	catUnitRec1	Category	17		1=milligram 2=microgram 3=gram 4=ounce, apothecary 9=other
8	strRecoQ1	strRecoQ1	strRecoQ1	Text	300, Optional		
9	catRecoQ2	catRecoQ2	catRecoQ2	Category	3		1=Yes 0=No
10	strChangeRec2	strChangeRec2	strChangeRec2	Text	100		
11	catRecoQ2_type	catRecoQ2_type	catRecoQ2_type	Category	27		See Appendix
12	realRecU2	realRecU2	realRecU2	Real	99999.999		
13	catUnitRec2	catUnitRec2	catUnitRec2	Category	17		1=milligram 2=microgram 3=gram 4=ounce, apothecary 9=other
14	strRecU2	strRecU2	strRecU2	Text	100		
15	strRecoQ2	strRecoQ2	strRecoQ2	Text	300, Optional		
16	catRecoQ3	catRecoQ3	catRecoQ3	Category	3		1=Yes 0=No
17	strChangeRec3	strChangeRec3	strChangeRec3	Text	100		
18	catRecoQ3_type	catRecoQ3_type	catRecoQ3_type	Category	27		See Appendix
19	realRecU3	realRecU3	realRecU3	Real	99999.999		
20	strRecU3	strRecU3	strRecU3	Text	100		
21	catUnitRec3	catUnitRec3	catUnitRec3	Category	17		1=milligram 2=microgram 3=gram 4=ounce, apothecary 9=other
22	strRecoQ3	strRecoQ3	strRecoQ3	Text	300, Optional		
23	catAll_Rec_Q1	catAll_Rec_Q1	catAll_Rec_Q1	Category	3		1=Yes 0=No
24	cat_AHI_a	cat_AHI_a	cat_AHI_a	Category	3		1=Yes 0=No
25	cat_AHI_a_nRef	cat_AHI_a_nRef	cat_AHI_a_nRef	Category	3		1=Yes 0=No
26	str_Ref_Crit_a	cat_Ref_Crit_a	cat_Ref_Crit_a	Category	3		1=Yes 0=No
27	cat_AHI_Aim_a	str_AHI_Aim_a	str_AHI_Aim_a	Text	255		
28	cat_AHI_b	cat_AHI_b	cat_AHI_b	Category	3		1=Yes 0=No
29	cat_AHI_b_nRef	cat_AHI_b_nRef	cat_AHI_b_nRef	Category	3		1=Yes 0=No
30	str_Ref_Crit_b	cat_Ref_Crit_b	cat_Ref_Crit_b	Category	3		1=Yes 0=No
31	str_AHI_Aim_b	str_AHI_Aim_b	str_AHI_Aim_b	Text	255		
32	cat_AHI_c	cat_AHI_c	cat_AHI_c	Category	3		1=Yes 0=No
33	cat_AHI_c_nRef	cat_AHI_c_nRef	cat_AHI_c_nRef	Category	3		1=Yes 0=No
34	str_Ref_Crit_c	cat_Ref_Crit_c	cat_Ref_Crit_c	Category	3		1=Yes 0=No
35	str_AHI_Aim_c	str_AHI_Aim_c	str_AHI_Aim_c	Text	255		
36	catAHINurse	catAHINurse	catAHINurse	Category	3		1=Yes 0=No
37	catAHINurs_nRef	catAHINurs_nRef	catAHINurs_nRef	Category	3		1=Yes 0=No
38	catAHIPsycho	catAHIPsycho	catAHIPsycho	Category	3		1=Yes 0=No

New referral

catAHIPsyc\_nRef

Psychosocial intervention

catAHIIIntervent

if other please specify

str\_AHI\_OtCar

Referral to other specialties

catRef\_O\_S

Which

catRef\_Which

if other please specify

str\_Ref\_Which\_O

DOPA-Start:dtmRecoD1

DOPA-End:dtmRecoD2

N-DOPA-Start:dtmRecoD3

N-DOPA-End:dtmRecoD4

MH-Start:dtmRecoD5

MH-End:dtmRecoD6

PT ongoing

catOnGo\_AHI\_a

PT start

dtmAHI\_a

PT stop

dtmAHI\_aa

SLT ong

catOnGo\_AHI\_b

SLT start

dtmAHI\_b

SLT stop

dtmAHI\_bb

OT ong

catOnGo\_AHI\_c

OT start

dtmAHI\_c

OT stop

dtmAHI\_cc

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
39	catAHIPsync_nRef	catAHIPsync_nRef	catAHIPsync_nRef	Category	3		1=Yes 0=No
40	catAHIIIntervent	catAHIIIntervent	catAHIIIntervent	Category	19		1=1 = Psychologist 2=2 = Respite 3=3 = Social services 9=9 = Other
41	str_AHI_OtCar	str_AHI_OtCar	str_AHI_OtCar	Text	255		
42	catRef_O_S	catRef_O_S	catRef_O_S	Category	3		1=Yes 0=No
43	catRef_Which	catRef_Which	catRef_Which	Category	7		1=Urology 9=Other
44	str_Ref_Which_O	str_Ref_Which_O	str_Ref_Which_O	Text	255		
45	dtmRecoD2	dtmRecoD2	dtmRecoD2	Date/Time	dd/mm/yyyy, Optional, Hidden		
46	dtmRecoD3	dtmRecoD3	dtmRecoD3	Date/Time	dd/mm/yyyy, Optional, Hidden		
47	dtmRecoD4	dtmRecoD4	dtmRecoD4	Date/Time	dd/mm/yyyy, Optional, Hidden		
48	dtmRecoD5	dtmRecoD5	dtmRecoD5	Date/Time	dd/mm/yyyy, Optional, Hidden		
49	dtmRecoD6	dtmRecoD6	dtmRecoD6	Date/Time	dd/mm/yyyy, Optional, Hidden		
50	dtmRecoD1	dtmRecoD1	dtmRecoD1	Date/Time	dd/mm/yyyy, Optional, Hidden		
51	dtmAHI_a	dtmAHI_a	dtmAHI_a	Date/Time	dd/mm/yyyy, Optional, Hidden		
52	catOnGo_AHI_a	catOnGo_AHI_a	catOnGo_AHI_a	Category	3, Optional, Hidden		1=Yes 0=No
53	dtmAHI_aa	dtmAHI_aa	dtmAHI_aa	Date/Time	dd/mm/yyyy, Optional, Hidden		
54	catOnGo_AHI_b	catOnGo_AHI_b	catOnGo_AHI_b	Category	3, Optional, Hidden		1=Yes 0=No
55	dtmAHI_b	dtmAHI_b	dtmAHI_b	Date/Time	dd/mm/yyyy, Optional, Hidden		
56	dtmAHI_bb	dtmAHI_bb	dtmAHI_bb	Date/Time	dd/mm/yyyy, Optional, Hidden		
57	catOnGo_AHI_c	catOnGo_AHI_c	catOnGo_AHI_c	Category	3, Optional, Hidden		1=Yes 0=No
58	dtmAHI_c	dtmAHI_c	dtmAHI_c	Date/Time	dd/mm/yyyy, Optional, Hidden		
59	dtmAHI_cc	dtmAHI_cc	dtmAHI_cc	Date/Time	dd/mm/yyyy, Optional, Hidden		



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## RECOMMENDATIONS FOLLOWED ?

Patient ID

IngPatID

**Only at T2 onwards (T2-T4)!**

### Evaluation of Implementation

Recommendations followed

catRec\_Foll

Recommendation followed by whom, what frequency, duration

str\_Rec\_Foll\_by

#### 1. Dopaminergic treatment change

catDopa\_Treat\_C

if partially, please specify

catDopa\_Treat\_P

Ongoing

catDOPA\_C

Start

dtmDOPASTart

Stop

dtmDOPASTop

Data source for outcome measure

catSource\_Dopa

Other data source

strSource\_Dopa

#### 2. Non-dopaminergic treatment change

catNoDo\_Treat\_C

if partially, please specify

strNDopa\_Trea\_P

Ongoing

catNDOPA\_C

Start

dtmNDOPASTart

Stop

dtmNDOPASTop

Data source for outcome measure

catSource\_NDopa

Other data source

strSource\_NDopa

#### 3. Medications for mental health issues

catMed\_MHI

if partially, please specify

strMH\_Trea\_P

Ongoing

catMH\_C

Start

dtmMHstart

Stop

dtmMHstop

Data source for outcome measure

catSource\_Ment

Other data source

strSource\_Meant

#### 4. Physiotherapy

catRecPT

if partially, please specify

strRecPT

Ongoing

catRecPT2

Start

dtmPTstart

Stop

dtmPTstop

#### 5. Speech and language therapy

catRecSLT

if partially, please specify

strRecSLT

Ongoing

catRecSLT2

Start

dtmSLTstart

Stop

dtmSLTstop

#### 6. Occupational therapy

catRecOT

if partially, please specify

strRecOT

Ongoing

catRecOT2

Start

dtmOTstart

Stop

dtmOTstop

#### 7. Parkinson nurse referral recommended

catRecPN

if partially, please specify

strRecPN

Ongoing

catRecPN2

Start

dtmPNstart

Stop

dtmPNstop

#### 8. Psychosocial interventions recommended

catRecPI

if partially, please specify

strRecPI

Ongoing

catRecPI2

Start

dtmPIstart

Stop

dtmPIstop

#### 9. Referral to other specialties

catRecROS

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catRec_Foll	catRec_Foll	catRec_Foll	Category	9		1=Yes 0=No 2=Partially 3=Not known
3	str_Rec_Foll_by	str_Rec_Foll_by	str_Rec_Foll_by	Text	500		
4	catDopa_Treat_C	catDopa_Treat_C	catDopa_Treat_C	Category	9		1=Yes 0=No 2=Partially 3=Unknown
5	catDopa_Treat_P	strDopa_Treat_P	strDopa_Treat_P	Text	300		
6	dtmDOPASTart	dtmDOPASTart	dtmDOPASTart	Date/Time	dd/mm/yyyy		
7	catDOPA_C	catDOPA_C	catDOPA_C	Category	3		1=Yes 0=No
8	dtmDOPASTop	dtmDOPASTop	dtmDOPASTop	Date/Time	dd/mm/yyyy		
9	catSource_Dopa	catSource_Dopa	catSource_Dopa	Category	22		See Appendix
10	strSource_Dopa	strSource_Dopa	strSource_Dopa	Text	100		
11	catNoDo_Treat_C	catNoDo_Treat_C	catNoDo_Treat_C	Category	9		1=Yes 0=No 2=Partially 3=Unknown
12	strNDopa_Trea_P	strNDopa_Trea_P	strNDopa_Trea_P	Text	300		
13	dtmNDOPASTop	dtmNDOPASTop	dtmNDOPASTop	Date/Time	dd/mm/yyyy		
14	dtmNDOPASTart	dtmNDOPASTart	dtmNDOPASTart	Date/Time	dd/mm/yyyy		
15	catNDOPA_C	catNDOPA_C	catNDOPA_C	Category	3		1=Yes 0=No
16	catSource_NDopa	catSource_NDopa	catSource_NDopa	Category	22		See Appendix
17	strSource_NDopa	strSource_NDopa	strSource_NDopa	Text	100		
18	catMed_MHI	catMed_MHI	catMed_MHI	Category	9		1=Yes 0=No 2=Partially 3=Unknown
19	strMH_Trea_P	strMH_Trea_P	strMH_Trea_P	Text	300		
20	catMH_C	catMH_C	catMH_C	Category	3		1=Yes 0=No
21	dtmMHstart	dtmMHstart	dtmMHstart	Date/Time	dd/mm/yyyy		
22	dtmMHstop	dtmMHstop	dtmMHstop	Date/Time	dd/mm/yyyy		
23	catSource_Ment	catSource_Ment	catSource_Ment	Category	22		See Appendix
24	strSource_Meant	strSource_Meant	strSource_Meant	Text	100		
25	catRecPT	catRecPT	catRecPT	Category	9		1=Yes 0=No 2=Partially 3=Unknown
26	strRecPT	strRecPT	strRecPT	Text	300		
27	dtmPTstart	dtmPTstart	dtmPTstart	Date/Time	dd/mm/yyyy		
28	dtmPTstop	dtmPTstop	dtmPTstop	Date/Time	dd/mm/yyyy		
29	catRecPT2	catRecPT2	catRecPT2	Category	3		1=Yes 0=No
30	catRecSLT	catRecSLT	catRecSLT	Category	9		1=Yes 0=No 2=Partially 3=Unknown
31	strRecSLT	strRecSLT	strRecSLT	Text	300		
32	dtmSLTstart	dtmSLTstart	dtmSLTstart	Date/Time	dd/mm/yyyy		
33	dtmSLTstop	dtmSLTstop	dtmSLTstop	Date/Time	dd/mm/yyyy		
34	catRecSLT2	catRecSLT2	catRecSLT2	Category	3		1=Yes 0=No
35	catRecOT	catRecOT	catRecOT	Category	9		1=Yes 0=No 2=Partially 3=Unknown
36	strRecOT	strRecOT	strRecOT	Text	300		
37	dtmOTstart	dtmOTstart	dtmOTstart	Date/Time	dd/mm/yyyy		
38	dtmOTstop	dtmOTstop	dtmOTstop	Date/Time	dd/mm/yyyy		
39	catRecOT2	catRecOT2	catRecOT2	Category	3		1=Yes 0=No
40	catRecPN	catRecPN	catRecPN	Category	9		1=Yes 0=No 2=Partially 3=Unknown
41	strRecPN	strRecPN	strRecPN	Text	300		
42	dtmPNstart	dtmPNstart	dtmPNstart	Date/Time	dd/mm/yyyy		
43	dtmPNstop	dtmPNstop	dtmPNstop	Date/Time	dd/mm/yyyy		
44	catRecPN2	catRecPN2	catRecPN2	Category	3		1=Yes 0=No
45	catRecPI	catRecPI	catRecPI	Category	9		1=Yes 0=No 2=Partially 3=Unknown
46	strRecPI	strRecPI	strRecPI	Text	300		
47	dtmPIstart	dtmPIstart	dtmPIstart	Date/Time	dd/mm/yyyy		
48	dtmPIstop	dtmPIstop	dtmPIstop	Date/Time	dd/mm/yyyy		
49	catRecPI2	catRecPI2	catRecPI2	Category	3		1=Yes 0=No
50	catRecROS	catRecROS	catRecROS	Category	9		1=Yes 0=No 2=Partially 3=Unknown

if partially, please specify

Ongoing

catRecROS2

Start

dtmROSstart

Stop

dtmROSstop

Data source for outcome measure:

catSource\_OTCM

if other carer support please specify:

str\_Dat\_srce\_O

Number of carers:

Ing\_EOT\_Nr\_o\_C

Relationship to carers

strNum\_Rel\_Care

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
51	strRecROS	strRecROS	strRecROS	Text	300		
52	dtmROSstart	dtmROSstart	dtmROSstart	Date/Time	dd/mm/yyyy		
53	dtmROSstop	dtmROSstop	dtmROSstop	Date/Time	dd/mm/yyyy		
54	catRecROS2	catRecROS2	catRecROS2	Category	3		1=Yes 0=No
55	catSource_OTCM	catSource_OTCM	catSource_OTCM	Category	35, Optional, Hidden		See Appendix
56	str_Dat_srce_O	str_Dat_srce_O	str_Dat_srce_O	Text	255, Optional, Hidden		
57	strNum_Rel_Care	strNum_Rel_Care	strNum_Rel_Care	Text	500, Optional, Hidden		
58	Ing_EOT_Nr_o_C	Ing_EOT_Nr_o_C	Ing_EOT_Nr_o_C	Integer	99, Optional, Hidden		



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## BARRIERS QUESTIONNAIRE

Patient ID

IngPatID

The patient is a participant in the CLaSP-study. You have received a management advice of the movement disorder specialist for this participant. We would like to have insight in the barriers you have encountered following this advice.

We present 13 statements for which we would like to ask you to assess whether they were a barrier in following up the advice.

I could not follow (in total) the management advice, ...

- ☐ 1. ... because I lacked the necessary specific knowledge. catBarrQue1
- ☐ 2. ... because I do not agree with the advice. catBarrQue2
- ☐ 3. ... because I have no confidence in the movement disorder specialist. catBarrQue3
- ☐ 4. ... because the advice contradicts previous practice habits and routines. catBarrQue4
- ☐ 5. ... because patient preference could not be reconciled with the advice. catBarrQue5
- ☐ 6. ... because the advice had a user unfriendly format. catBarrQue6
- ☐ 7. ... because the advice lacked actuality. catBarrQue7
- ☐ 8. ... because there were other contradictory advices. catBarrQue8
- ☐ 9. ... because there was a lack of (financial) reimbursement. catBarrQue9
- ☐ 10. ... because of a lack of time. catBarrQue10
- ☐ 11. ... because of a higher risk on malpractice liability. catBarrQue11
- ☐ 12. ... because I do not expect an improved outcome for the patient. catBarrQue12
- ☐ 13. ... because I lacked the necessary self-efficacy. catBarrQue13
- ☐ 14. ... because other: catBarrQue14

Specify other

strBarrQue14

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catBarrQue1	catBarrQue1	catBarrQue1	Category	57, Optional		1=1. ... because I lacked the necessary specific knowledge.
3	catBarrQue2	catBarrQue2	catBarrQue2	Category	46, Optional		1=2. ... because I do not agree with the advice.
4	catBarrQue3	catBarrQue3	catBarrQue3	Category	72, Optional		1=3. ... because I have no confidence in the movement disorder specialist.
5	catBarrQue4	catBarrQue4	catBarrQue4	Category	76, Optional		1=4. ... because the advice contradicts previous practice habits and routines.
6	catBarrQue5	catBarrQue5	catBarrQue5	Category	74, Optional		1=5. ... because patient preference could not be reconciled with the advice.
7	catBarrQue6	catBarrQue6	catBarrQue6	Category	55, Optional		1=6. ... because the advice had a user unfriendly format.
8	catBarrQue7	catBarrQue7	catBarrQue7	Category	43, Optional		1=7. ... because the advice lacked actuality.
9	catBarrQue8	catBarrQue8	catBarrQue8	Category	54, Optional		1=8. ... because there were other contradictory advices.
10	catBarrQue9	catBarrQue9	catBarrQue9	Category	61, Optional		1=9. ... because there was a lack of (financial) reimbursement.
11	catBarrQue10	catBarrQue10	catBarrQue10	Category	34, Optional		1=10. ... because of a lack of time.
12	catBarrQue11	catBarrQue11	catBarrQue11	Category	58, Optional		1=11. ... because of a higher risk on malpractice liability.
13	catBarrQue12	catBarrQue12	catBarrQue12	Category	68, Optional		1=12. ... because I do not expect an improved outcome for the patient.
14	catBarrQue13	catBarrQue13	catBarrQue13	Category	53, Optional		1=13. ... because I lacked the necessary self-efficacy.
15	catBarrQue14	catBarrQue14	catBarrQue14	Category	22, Optional		1=14. ... because other:
16	strBarrQue14	strBarrQue14	strBarrQue14	Text	300, Optional		



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## RESOURCE UTILIZATION (Part 1)

Patient ID

 IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date of completing forms:  dtmExam

Duration of completing forms (minutes):  Ing\_duration\_As

Reason, if not assessed:  catAss\_Test\_P  
Other reason:  strAssessReas

### 1. Course of illness and Resource Use

1.1 In what year was your Parkinson's disease diagnosed?

 IngPDDIag

1.2 Which doctor is looking after your Parkinson's disease?

- ☐ Neurologist catPDDoc1  
☐ General Practitioner catPDDoc2  
☐ Elderly Care Physician catPDDoc3  
☐ Geriatrician catPDDoc4  
☐ Other catPDDoc5

1.2 Which doctor is looking after your Parkinson's disease?

 catPDDoc

specify other

 strPDDoc5

1.3 How often did you consult your primary care physician for Parkinson's disease during the past 3 months?

Number of visits

 IngPDconsult

1.4 How often did you consult your neurologist/geriatrician for Parkinson's disease during the past 3 months?

Number of visits

 IngPDconsult2

1.5 Did you consult further doctors/specialists about your Parkinson's disease in the last 3 months (in addition to seeing your primary Parkinson's physician)?

 catFurtSpec

Physician / Specialist

- ☐ Urologist catFurtSpec1  
☐ Psychiatrist catFurtSpec2  
☐ Ear, nose and throat specialist catFurtSpec3  
☐ Dermatologist catFurtSpec4  
☐ Radiologist catFurtSpec5  
☐ Psychologist catFurtSpec6  
☐ Dentist catFurtSpec7  
☐ Parkinson's disease nurse catFurtSpec8

 strFurtSpec9  
 strFurtSpec10  
 strFurtSpec11

Number of visits

 IngFurtSpec1  
 IngFurtSpec2  
 IngFurtSpec3  
 IngFurtSpec4  
 IngFurtSpec5  
 IngFurtSpec6  
 IngFurtSpec7  
 IngFurtSpec8  
 IngFurtSpec9  
 IngFurtSpec10  
 IngFurtSpec11

1.6 Did you receive further therapy (apart from medication) during the past 3 months due to Parkinson's disease?

 catFurtTher

Therapy

- ☐ Physiotherapy catFurtTher1  
☐ Massage catFurtTher2  
☐ Occupational therapy catFurtTher3  
☐ Speech training catFurtTher4  
☐ Nurse catFurtTher5

Number of visits

 IngFurtTher1  
 IngFurtTher2  
 IngFurtTher3  
 IngFurtTher4  
 IngFurtTher5

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	IngPDDiag	IngPDDiag	IngPDDiag	Integer	9999		
8	catPDDoc1	catPDDoc1	catPDDoc1	Category	11, Optional		1=Neurologist
9	catPDDoc	catPDDoc	catPDDoc	Category	20, Optional, Hidden		1=General Practitioner 2=Neurologist 3=Both do 4=Not known
10	catPDDoc2	catPDDoc2	catPDDoc2	Category	20, Optional		1=General Practitioner
11	catPDDoc3	catPDDoc3	catPDDoc3	Category	22, Optional		1=Elderly Care Physician
12	catPDDoc4	catPDDoc4	catPDDoc4	Category	12, Optional		1=Geriatrician
13	catPDDoc5	catPDDoc5	catPDDoc5	Category	5, Optional		1=Other
14	strPDDoc5	strPDDoc5	strPDDoc5	Text	100		
15	IngPDconsult	IngPDconsult	IngPDconsult	Integer	99		
16	IngPDconsult2	IngPDconsult2	IngPDconsult2	Integer	99		
17	catFurtSpec	catFurtSpec	catFurtSpec	Category	3		1=Yes 0=No
18	IngFurtSpec1	IngFurtSpec1	IngFurtSpec1	Integer	99		
19	catFurtSpec1	catFurtSpec1	catFurtSpec1	Category	9, Optional		1=Urologist
20	IngFurtSpec2	IngFurtSpec2	IngFurtSpec2	Integer	99		
21	catFurtSpec2	catFurtSpec2	catFurtSpec2	Category	12, Optional		1=Psychiatrist
22	IngFurtSpec3	IngFurtSpec3	IngFurtSpec3	Integer	99		
23	catFurtSpec3	catFurtSpec3	catFurtSpec3	Category	31, Optional		1=Ear, nose and throat specialist
24	IngFurtSpec4	IngFurtSpec4	IngFurtSpec4	Integer	99		
25	catFurtSpec4	catFurtSpec4	catFurtSpec4	Category	13, Optional		1=Dermatologist
26	IngFurtSpec5	IngFurtSpec5	IngFurtSpec5	Integer	99		
27	catFurtSpec5	catFurtSpec5	catFurtSpec5	Category	11, Optional		1=Radiologist
28	IngFurtSpec6	IngFurtSpec6	IngFurtSpec6	Integer	99		
29	catFurtSpec6	catFurtSpec6	catFurtSpec6	Category	12, Optional		1=Psychologist
30	IngFurtSpec7	IngFurtSpec7	IngFurtSpec7	Integer	99		
31	catFurtSpec7	catFurtSpec7	catFurtSpec7	Category	7, Optional		1=Dentist
32	IngFurtSpec8	IngFurtSpec8	IngFurtSpec8	Integer	99		
33	catFurtSpec8	catFurtSpec8	catFurtSpec8	Category	25, Optional		1=Parkinson's disease nurse
34	strFurtSpec9	strFurtSpec9	strFurtSpec9	Text	25, Optional		
35	IngFurtSpec9	IngFurtSpec9	IngFurtSpec9	Integer	99		
36	strFurtSpec10	strFurtSpec10	strFurtSpec10	Text	25, Optional		
37	IngFurtSpec10	IngFurtSpec10	IngFurtSpec10	Integer	99		
38	strFurtSpec11	strFurtSpec11	strFurtSpec11	Text	25, Optional		
39	IngFurtSpec11	IngFurtSpec11	IngFurtSpec11	Integer	99		
40	catFurtTher	catFurtTher	catFurtTher	Category	3		1=Yes 0=No
41	IngFurtTher1	IngFurtTher1	IngFurtTher1	Integer	99		
42	catFurtTher1	catFurtTher1	catFurtTher1	Category	13, Optional		1=Physiotherapy
43	IngFurtTher2	IngFurtTher2	IngFurtTher2	Integer	99		
44	catFurtTher2	catFurtTher2	catFurtTher2	Category	7, Optional		1=Massage
45	IngFurtTher3	IngFurtTher3	IngFurtTher3	Integer	99		
46	catFurtTher3	catFurtTher3	catFurtTher3	Category	20, Optional		1=Occupational therapy
47	IngFurtTher4	IngFurtTher4	IngFurtTher4	Integer	99		
48	catFurtTher4	catFurtTher4	catFurtTher4	Category	15, Optional		1=Speech training
49	IngFurtTher5	IngFurtTher5	IngFurtTher5	Integer	99		
50	catFurtTher5	catFurtTher5	catFurtTher5	Category	5, Optional		1=Nurse

- ☐ Counseling catFurtTher6  IngFurtTher6  
☐ Others, which ones catFurtTher7  IngFurtTher7  
 strFurtTher7

### Inpatient treatment in hospital

1.7 Were you treated as an inpatient in hospitals during the past 3 months (at least one night) due to Parkinson's disease?  
If so, please indicate the reason and the length of the hospital stay.

catInpathH

Reason for hospital stay	Hospitalization related to Parkinson's disease?	Length of stay (e.g. 10 nights)
<input type="text"/> <span>strReasonHosp</span>	<input type="text"/> <span>catInpathH_rel</span>	<input type="text"/> <span>IngInpathH_dur</span>

1.8 Did you stay at an inpatient (overnight) rehabilitation facility during the past 3 months?

catInpatReha

1.9 Did you stay at an outpatient (dayhospital) rehabilitation facility during the past 3 months?

catOutpatReha

If 'yes', how many days in the last three months did you spend as an inpatient (at least one night) or as an outpatient in a rehabilitation facility? Please do also count the day of admittance and the day of discharge as a full day.

Outpatient in rehabilitaion facility (days)

IngOutpatReha

Inpatient in rehabilitaion facility (days)

IngInpatReha

1.10 What medication prescribed by a physician did you take during the past 3 months? (Please include all medications, for Parkinson's or not)

Name of the medication

strMedPres

1.11 Did you take any medication during the past 3 months without prescription (not prescribed by a physician and paid for by yourself)?

Name of the medication/vitamins

strMedNotPres

1.12 Did you receive any of the medical devices listed below during the past 3 months?

- ☐ No, I did not receive any medical devices/consumables during the past three months. catMedDevice  
☐ Yes, I did receive medical devices/consumables during the past 3 months.

Medical devices	Number	Did you have to pay some of it?	Amount of payment (EURO)
<input type="radio"/> Walking stick <span>catMedDev1</span>	<input type="text"/> <span>IngMedDev1</span>	<input type="text"/> <span>catMedDev1b</span>	<input type="text"/> <span>IngMedDev1b</span>
<input type="radio"/> Frame <span>catMedDev2</span>	<input type="text"/> <span>IngMedDev2</span>	<input type="text"/> <span>catMedDev2b</span>	<input type="text"/> <span>IngMedDev2b</span>
<input type="radio"/> Handrail in home <span>catMedDev3</span>	<input type="text"/> <span>IngMedDev3</span>	<input type="text"/> <span>catMedDev3b</span>	<input type="text"/> <span>IngMedDev3b</span>
<input type="radio"/> Ramp in home <span>catMedDev4</span>	<input type="text"/> <span>IngMedDev4</span>	<input type="text"/> <span>catMedDev4b</span>	<input type="text"/> <span>IngMedDev4b</span>
<input type="radio"/> Wheel chair <span>catMedDev5</span>	<input type="text"/> <span>IngMedDev5</span>	<input type="text"/> <span>catMedDev5b</span>	<input type="text"/> <span>IngMedDev5b</span>
<input type="radio"/> Special bed <span>catMedDev6</span>	<input type="text"/> <span>IngMedDev6</span>	<input type="text"/> <span>catMedDev6b</span>	<input type="text"/> <span>IngMedDev6b</span>

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
51	IngFurtTher6	IngFurtTher6	IngFurtTher6	Integer	99		
52	catFurtTher6	catFurtTher6	catFurtTher6	Category	10, Optional		1=Counseling
53	IngFurtTher7	IngFurtTher7	IngFurtTher7	Integer	99		
54	catFurtTher7	catFurtTher7	catFurtTher7	Category	18, Optional		1=Others, which ones
55	strFurtTher7	strFurtTher7	strFurtTher7	Text	100		
56	catInpatH	catInpatH	catInpatH	Category	3		1=Yes 0=No
Repeating Question Group: , Borders: Yes, RowStatus: Yes, RowNumbers: Yes, DisplayRows: 4, InitialRows: 3, Min Repeats: 1, Max Repeats: 10, Main Row Type: Single-Line, Sub Row Type: Multi-Line							
57	strReasonHosp	strReasonHosp	strReasonHosp	Text	100, Optional		
58	catInpatH_rel	catInpatH_rel	catInpatH_rel	Category	3, Optional		1=Yes 0=No
59	IngInpatH_dur	IngInpatH_dur	IngInpatH_dur	Integer	99, Optional		
60	catInpatReha	catInpatReha	catInpatReha	Category	3		0=No 1=Yes
61	catOutpatReha	catOutpatReha	catOutpatReha	Category	3		0=No 1=Yes
62	IngOutpatReha	IngOutpatReha	IngOutpatReha	Integer	99		
63	IngInpatReha	IngInpatReha	IngInpatReha	Integer	99		
64	strMedPres	strMedPres	strMedPres	Text	500, Optional		
65	strMedNotPres	strMedNotPres	strMedNotPres	Text	500, Optional		
66	catMedDevice	catMedDevice	catMedDevice	Category	83		See Appendix
67	catMedDev1	catMedDev1	catMedDev1	Category	13, Optional		1=Walking stick
68	IngMedDev1	IngMedDev1	IngMedDev1	Integer	99		
69	catMedDev1b	catMedDev1b	catMedDev1b	Category	9		1=Yes 0=No 9=Not known
70	IngMedDev1b	IngMedDev1b	IngMedDev1b	Real	99999.99		
71	catMedDev2	catMedDev2	catMedDev2	Category	5, Optional		1=Frame
72	IngMedDev2	IngMedDev2	IngMedDev2	Integer	99		
73	catMedDev2b	catMedDev2b	catMedDev2b	Category	9		1=Yes 0=No 9=Not known
74	IngMedDev2b	IngMedDev2b	IngMedDev2b	Real	99999.99		
75	catMedDev3	catMedDev3	catMedDev3	Category	16, Optional		1=Handrail in home
76	IngMedDev3	IngMedDev3	IngMedDev3	Integer	99		
77	catMedDev3b	catMedDev3b	catMedDev3b	Category	9		1=Yes 0=No 9=Not known
78	IngMedDev3b	IngMedDev3b	IngMedDev3b	Real	99999.99		
79	catMedDev4	catMedDev4	catMedDev4	Category	12, Optional		1=Ramp in home
80	IngMedDev4	IngMedDev4	IngMedDev4	Integer	99		
81	catMedDev4b	catMedDev4b	catMedDev4b	Category	9		1=Yes 0=No 9=Not known
82	IngMedDev4b	IngMedDev4b	IngMedDev4b	Real	99999.99		
83	catMedDev5	catMedDev5	catMedDev5	Category	11, Optional		1=Wheel chair
84	IngMedDev5	IngMedDev5	IngMedDev5	Integer	99		
85	catMedDev5b	catMedDev5b	catMedDev5b	Category	9		1=Yes 0=No 9=Not known
86	IngMedDev5b	IngMedDev5b	IngMedDev5b	Real	99999.99		
87	catMedDev6	catMedDev6	catMedDev6	Category	11, Optional		1=Special bed
88	IngMedDev6	IngMedDev6	IngMedDev6	Integer	99		
89	catMedDev6b	catMedDev6b	catMedDev6b	Category	9		1=Yes 0=No 9=Not known
90	IngMedDev6b	IngMedDev6b	IngMedDev6b	Real	99999.99		

Consumables

<input type="radio"/> Toilet seat	catMedDev7	<input type="text"/>	IngMedDev7	<input type="text"/>	catMedDev7b	<input type="text"/>	IngMedDev7b
<input type="radio"/> Incontinence pads	catMedDev8	<input type="text"/>	IngMedDev8	<input type="text"/>	catMedDev8b	<input type="text"/>	IngMedDev8b
<input type="radio"/> Catheter equipment	catMedDev9	<input type="text"/>	IngMedDev9	<input type="text"/>	catMedDev9b	<input type="text"/>	IngMedDev9b

Others	Number	Did you have to pay some of it?	Amount of payment (EURO)
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
strMedDev10	IngMedDev10	catMedDev10b	IngMedDev10b

1.13 Were there any other financial burdens due to Parkinson's disease within the past 3 months which were not covered by the questionnaire (e.g. paying for carers, having to take taxis to hospitals)?

Please feel free to use this space for your comments.

strFinBurden

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
91	catMedDev7	catMedDev7	catMedDev7	Category	11, Optional		1=Toilet seat
92	IngMedDev7	IngMedDev7	IngMedDev7	Integer	99		
93	catMedDev7b	catMedDev7b	catMedDev7b	Category	9		1=Yes 0=No 9=Not known
94	IngMedDev7b	IngMedDev7b	IngMedDev7b	Real	99999.99		
95	catMedDev8	catMedDev8	catMedDev8	Category	17, Optional		1=Incontinence pads
96	IngMedDev8	IngMedDev8	IngMedDev8	Integer	99		
97	catMedDev8b	catMedDev8b	catMedDev8b	Category	9		1=Yes 0=No 9=Not known
98	IngMedDev8b	IngMedDev8b	IngMedDev8b	Real	99999.99		
99	catMedDev9	catMedDev9	catMedDev9	Category	18, Optional		1=Catheter equipment
100	IngMedDev9	IngMedDev9	IngMedDev9	Integer	99		
101	catMedDev9b	catMedDev9b	catMedDev9b	Category	9		1=Yes 0=No 9=Not known
102	IngMedDev9b	IngMedDev9b	IngMedDev9b	Real	99999.99		
Repeating Question Group: , Borders: Yes, RowStatus: Yes, RowNumbers: Yes, DisplayRows: 3, InitialRows: 2, Min Repeats: 1, Max Repeats: 10, Main Row Type: Single-Line, Sub Row Type: Multi-Line							
103	strMedDev10	strMedDev10	strMedDev10	Text	50, Optional		
104	IngMedDev10	IngMedDev10	IngMedDev10	Integer	99, Optional		
105	catMedDev10b	catMedDev10b	catMedDev10b	Category	9, Optional		1=Yes 0=No 9=Not known
106	IngMedDev10b	IngMedDev10b	IngMedDev10b	Real	99999.99, Optional		
107	strFinBurden	strFinBurden	strFinBurden	Text	500, Optional		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



## RESOURCE UTILIZATION (Part 2)

Patient ID

IngPatID

### 2. Personal data of the informal PWP

#### 2.1 What is your current employment situation?

Please check only the most appropriate?

- ☐ Employee full time
- ☐ Employee part time
- ☐ Self-employed
- ☐ Volunteering
- ☐ Unemployed due to Parkinson's disease and its subsequent illnesses
- ☐ Unemployed due to other reasons
- ☐ Early retirement due to Parkinson's disease and its subsequent illnesses
- ☐ Early retirement due to other reasons
- ☐ Retired
- ☐ Housewife
- ☐ Not applicable (n/a)

catEmployment

If question 2.1 answered with 'Employee part time',  
please specify how many hours per week employed:

IngEmploymentPT

If question above is answered with one of these options:  
Volunteering, Unemployed ..., Early retirement ... or retirement',  
please specify start date of the status (MM/YYYY)

dtmEmployment

#### 2.2 If employed or self-employed have you been absent from work during the past 3 months due to Parkinson's disease?

If you were treated in hospital as an inpatient or were on a rehabilitation clinic  
please do NOT include these days.

- ☐ No
- ☐ Yes
- ☐ Not applicable (n/a)

catEmplAbsent

If question 2.2 answered with 'Yes':  
Number of days\* absent in the past three months

IngEmplAbsent

\* Please also include single hours over working day (e.g. 4 hours = 0.5 days).

#### 2.3 Did you have to change your employment situation due to Parkinson's disease during the last 3 months?

- ☐ No
- ☐ Yes, I had to stop working
- ☐ Yes, I had to get another job
- ☐ Yes, I had to reduce my work time (\* specify hours/time below)
- ☐ Yes, I had to get another job and to reduce my work time (\* specify below)
- ☐ Yes, I had to do an occupational re-training

catEmplChange

If question 2.3 is answered with 'reduced work time',  
please specify hours per week (from/to) and since work time reduced.

Work time in hours/week before reducing

IngEmplChange1

Work time in hours/week after reducing

IngEmplChange2

Work time reduced since (MM/YYYY)

dtmEmplChange

#### 2.4 Do you have private health insurance or compulsory health insurance?

catHealthIns

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catEmployment	catEmployment	catEmployment	Category	72		See Appendix
3	IngEmplomentPT	IngEmplomentPT	IngEmplomentPT	Real	99.9		
4	dtmEmployment	dtmEmployment	dtmEmployment	Date/Time	mm/yyyy		
5	catEmplAbsent	catEmplAbsCG	catEmplAbsCG	Category	20		0=No 1=Yes 9=Not applicable (n/a)
6	IngEmplAbsent	IngEmplAbsCG	IngEmplAbsCG	Real	99.9		
7	catEmplChange	catEmplChaCG	catEmplChaCG	Category	74		See Appendix
8	IngEmplChange1	IngEmplChaCG1	IngEmplChaCG1	Real	99.9		
9	IngEmplChange2	IngEmplChaCG2	IngEmplChaCG2	Real	99.9		
10	dtmEmplChange	dtmEmplChaCG	dtmEmplChaCG	Date/Time	mm/yyyy		
11	catHealthIns	catHealthIns	catHealthIns	Category	27		1=Private health insurance 2=Compulsory health insurance

2.5 Do you pay anything for your prescription medications?

--	--

catPayPresMed

2.6 Do you receive monthly payments e.g. from the compulsory long term care insurance or Disability Living allowance because of Parkinson's disease?

--	--

catReceivePay

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
12	catPayPresMed	catPayPresMed	catPayPresMed	Category	3		0=No 1=Yes
13	catReceivePay	catReceivePay	catReceivePay	Category	3		0=No 1=Yes



**CLaSP CRF**  
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## RESOURCE UTILIZATION (Part 3)

Patient ID

IngPatID

### 3. Personal data of the informal Caregiver

#### 3.1 What is your relationship to the PWP?

  catReltoPWP

Other relationship

 strReltoPWP

#### 3.2 Do you live with the PWP?

  catLivePWP

#### 3.3 If you don't live together with the PWP all of the time, how often do you visit the PWP?

  catNotVisit

#### 3.4 If you don't live together with the PWP, how often do you talk to the PWP on the phone?

  catNotTalk

#### 3.5 If you don't live together with the PWP, for how long are you in contact with the PWP in one week?

  catNotContact

#### 3.6 What is your current employment situation? Please check only the most appropriate.

  catEmployCG

If question 3.6 answered with 'Employee part time', please specify how many hours per week employed:

 IngEmploymentPT

If question above is answered with one of these options: Volunteering, Unemployed ..., Early retirement ... or retirement', please specify start date of the status (MM/YYYY)

 dtmEmployment

#### 3.7 If employed or self-employed have you been absent from work during the past 3 months due to care for the PWP?

If you were treated in hospital as an inpatient or were on a rehabilitation clinic please do NOT include these days

- ☐ No catEmplAbsent  
☐ Yes  
☐ Not applicable (n/a)

If question 3.7 answered with 'Yes':

Number of days\* absent in the past three months

 IngEmplAbsent

\* Please also include single hours over working day (e.g. 4 hours = 0.5 days).

#### 3.8 Did you have to change your employment situation due to the PWP's Parkinson's disease during the last 3 months?

- ☐ No catEmplChange  
☐ Yes, I had to stop working  
☐ Yes, I had to get another job  
☐ Yes, I had to reduce my work time (\* specify hours/time below)  
☐ Yes, I had to get another job and to reduce my work time (\* specify below)  
☐ Yes, I had to do an occupational re-training

If question 3.8 is answered with 'reduced work time', please specify hours per week (from/to) and since work time reduced.

Work time in hours/week before reducing

 IngEmplChange1

Work time in hours/week after reducing

 IngEmplChange2

Work time reduced since (MM/YYYY)

 dtmEmplChange

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catReltoPWP	catReltoPWP	catReltoPWP	Category	27		See Appendix
3	strReltoPWP	strReltoPWP	strReltoPWP	Text	40		
4	catLivePWP	catLivePWP	catLivePWP	Category	46		1=Yes (If Yes please continue with question 3.6) 2=Sometimes 0=No
5	catNotVisit	catNotVisit	catNotVisit	Category	24		See Appendix
6	catNotTalk	catNotTalk	catNotTalk	Category	36		See Appendix
7	catNotContact	catNotContact	catNotContact	Category	18		See Appendix
8	catEmployCG	catEmployCG	catEmployCG	Category	80		See Appendix
9	IngEmploymentPT	IngEmploymentPT	IngEmploymentPT	Real	99.9		
10	dtmEmployment	dtmEmployment	dtmEmployment	Date/Time	mm/yyyy		
11	catEmplAbsent	catEmplAbsCG	catEmplAbsCG	Category	20		0=No 1=Yes 9=Not applicable (n/a)
12	IngEmplAbsent	IngEmplAbsCG	IngEmplAbsCG	Real	99.9		
13	catEmplChange	catEmplChaCG	catEmplChaCG	Category	74		See Appendix
14	IngEmplChange1	IngEmplChaCG1	IngEmplChaCG1	Real	99.9		
15	IngEmplChange2	IngEmplChaCG2	IngEmplChaCG2	Real	99.9		
16	dtmEmplChange	dtmEmplChaCG	dtmEmplChaCG	Date/Time	mm/yyyy		



**CLaSP CRF**  
Care of Late Stage Parkinsonism



## RESOURCE UTILIZATION (Part 4)

Patient ID

IngPatID

### 4. PWP's Living and Care Situation

4.1 Please specify the PWP's current living accommodation.

catPWPAcc

Specify other

strPWPAcc

4.2 If the PWP lives in his/her own home, how many persons live in his/her household permanently? Please include all children living in his/her household.

IngPWPPerson

4.3 Does the PWP need help in his/her daily life from caregivers?

catNeedHelp

4.4 If the PWP needs help in his/her daily life from caregivers, please specify the assistance he/she needs (check all that apply)?

- ☐ Assistance with dressing catHelpFrCG1
- ☐ Assistance with personal hygiene catHelpFrCG2
- ☐ Assistance with preparing food catHelpFrCG3
- ☐ Assistance with eating catHelpFrCG4
- ☐ Assistance with preparation / intake / application of medication catHelpFrCG5
- ☐ Assistance with the household chores, catHelpFrCG6  
e.g. shopping, cleaning, DIY, looking after home
- ☐ Assistance with mobility catHelpFrCG7
- ☐ Others (please specify below) catHelpFrCG8

Specify other help

strHelpFrCG8

4.5 If the PWP lives in his/her own home, please specify the above care he/she has received during the last 3 months?

- ☐ Informal care catHelpRec1 (provided by e.g. family members, neighbours, friends)

since

dtmHelpRec1

- ☐ Professional care catHelpRec2 (provided by a professional care service)

since

dtmHelpRec2

If he/she received professional care:

How much professional care does he/she receive per week (hours/week)?

IngHelpRec2

- ☐ Financial assistance by state or insurance for home care catHelpRec3

Amount of financial assistance (EURO, no Cents)

IngHelpRec3

### INFORMAL CARE

4.6 Are there any people (other than yourself) helping with the care of the PWP?

catPeopHelp

If yes, who?

strPeopHelp

4.7 Among all professional and informal caregivers what proportion of the care do you provide?

catPropCare

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	catPWPAcc	catPWPAcc	catPWPAcc	Category	73		See Appendix
3	strPWPAcc	strPWPAcc	strPWPAcc	Text	100		
4	IngPWPPerson	IngPWPPerson	IngPWPPerson	Integer	99		
5	catNeedHelp	catNeedHelp	catNeedHelp	Category	51		0=No 1=Yes (if yes, please answer the following questions)
6	catHelpFrCG1	catHelpFrCG1	catHelpFrCG1	Category	24, Optional		1=Assistance with dressing
7	catHelpFrCG2	catHelpFrCG2	catHelpFrCG2	Category	32, Optional		1=Assistance with personal hygiene
8	catHelpFrCG3	catHelpFrCG3	catHelpFrCG3	Category	30, Optional		1=Assistance with preparing food
9	catHelpFrCG4	catHelpFrCG4	catHelpFrCG4	Category	22, Optional		1=Assistance with eating
10	catHelpFrCG5	catHelpFrCG5	catHelpFrCG5	Category	64, Optional		1=Assistance with preparation / intake / application of medication
11	catHelpFrCG6	catHelpFrCG6	catHelpFrCG6	Category	37, Optional		1=Assistance with the household chores,
12	catHelpFrCG7	catHelpFrCG7	catHelpFrCG7	Category	24, Optional		1=Assistance with mobility
13	catHelpFrCG8	catHelpFrCG8	catHelpFrCG8	Category	29, Optional		1=Others (please specify below)
Repeating Question Group: , Borders: Yes, RowStatus: Yes, RowNumbers: Yes, DisplayRows: 3, InitialRows: 2, Min Repeats: 1, Max Repeats: 5, Main Row Type: Single-Line, Sub Row Type: Multi-Line							
14	strHelpFrCG8	strHelpFrCG8	strHelpFrCG8	Text	150, Optional		
15	catHelpRec1	catHelpRec1	catHelpRec1	Category	13, Optional		1=Informal care
16	dtmHelpRec1	dtmHelpRec1	dtmHelpRec1	Date/Time	mm/yyyy		
17	catHelpRec2	catHelpRec2	catHelpRec2	Category	17, Optional		1=Professional care
18	dtmHelpRec2	dtmHelpRec2	dtmHelpRec2	Date/Time	mm/yyyy		
19	IngHelpRec2	IngHelpRec2	IngHelpRec2	Real	999.9		
20	catHelpRec3	catHelpRec3	catHelpRec3	Category	56, Optional		1=Financial assistance by state or insurance for home care
21	IngHelpRec3	IngHelpRec3	IngHelpRec3	Integer	999999		
22	catPeopHelp	catPeopHelp	catPeopHelp	Category	3		0=No 1=Yes
23	strPeopHelp	strPeopHelp	strPeopHelp	Text	100		
24	catPropCare	catPropCare	catPropCare	Category	8		1=< 20% 2=20 - 40% 3=41 - 60% 4=61 - 80% 5=> 80%

4.8 On a typical care day during the last 30 days, how much time per day did you assist the PWP with tasks such as shopping, food preparation, housekeeping, laundry, transportation, taking medication and managing financial matters?

hours / day  IngAssistPWP1 and minutes / day  IngAssistPWP2

4.9 During the last 30 days, how many days did you spend providing these services to the PWP?

Number of days  IngServicePWP

4.10 On a typical care day during the last 30 days, how much time per day did you spend supervising (that is, prevent dangerous events) the PWP?

hours / day  IngSupervPWP1 and minutes / day  IngSupervPWP2

## PROFESSIONAL SERVICES

4.11 For each service listed below, please specify the NUMBER OF DAYS the PWP received the service during the last 3 months.

- ☐ Day Care outside the home (e.g. day centre) catProfServD1  
 Number of days  IngProfServD1
- ☐ Day Care inside the home (carer coming to the home) catProfServD2  
 Number of days  IngProfServD2
- ☐ Night Care catProfServD3  
 Number of days  IngProfServD3
- ☐ Respite or Short-term Care admission catProfServD4  
 Number of days  IngProfServD4
- ☐ Nursing Home catProfServD5  
 Number of days  IngProfServD5
- ☐ Other catProfServD6  
 Specify other:  strProfServD6  
 Number of days  IngProfServD6

4.12 For each service listed below, please specify the NUMBER OF TIMES the service was used during the last 3 months.

- ☐ Food delivery (meals on wheels / food delivery by supermarkets) catProfServT1  
 Times / week  IngProfServT1
- ☐ Transportation (care related) catProfServT2  
 Times  IngProfServT2
- ☐ Support group / Self-help group catProfServT3  
 Times  IngProfServT3
- ☐ Other catProfServT4  
 Specify other:  strProfServT4  
 Times  IngProfServT4

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
25	IngAssistPWP1	IngAssistPWP1	IngAssistPWP1	Integer	99		
26	IngAssistPWP2	IngAssistPWP2	IngAssistPWP2	Integer	99		
27	IngServicePWP	IngServicePWP	IngServicePWP	Integer	99		
28	IngSupervPWP1	IngSupervPWP1	IngSupervPWP1	Integer	99		
29	IngSupervPWP2	IngSupervPWP2	IngSupervPWP2	Integer	99		
30	catProfServD1	catProfServD1	catProfServD1	Category	43, Optional		1=Day Care outside the home (e.g. day centre)
31	IngProfServD1	IngProfServD1	IngProfServD1	Integer	99		
32	catProfServD2	catProfServD2	catProfServD2	Category	51, Optional		1=Day Care Inside the home (carer coming to the home)
33	IngProfServD2	IngProfServD2	IngProfServD2	Integer	99		
34	catProfServD3	catProfServD3	catProfServD3	Category	10, Optional		1=Night Care
35	IngProfServD3	IngProfServD3	IngProfServD3	Integer	99		
36	catProfServD4	catProfServD4	catProfServD4	Category	36, Optional		1=Respite or Short-term Care admission
37	IngProfServD4	IngProfServD4	IngProfServD4	Integer	99		
38	catProfServD5	catProfServD5	catProfServD5	Category	12, Optional		1=Nursing Home
39	IngProfServD5	IngProfServD5	IngProfServD5	Integer	99		
40	catProfServD6	catProfServD6	catProfServD6	Category	5, Optional		1=Other
41	strProfServD6	strProfServD6	strProfServD6	Text	200		
42	IngProfServD6	IngProfServD6	IngProfServD6	Integer	99		
43	catProfServT1	catProfServT1	catProfServT1	Category	63, Optional		1=Food delivery (meals on wheels / food delivery by supermarkets)
44	IngProfServT1	IngProfServT1	IngProfServT1	Integer	99		
45	catProfServT2	catProfServT2	catProfServT2	Category	29, Optional		1=Transportation (care related)
46	IngProfServT2	IngProfServT2	IngProfServT2	Integer	999		
47	catProfServT3	catProfServT3	catProfServT3	Category	31, Optional		1=Support group / Self-help group
48	IngProfServT3	IngProfServT3	IngProfServT3	Integer	99		
49	catProfServT4	catProfServT4	catProfServT4	Category	5, Optional		1=Other
50	strProfServT4	strProfServT4	strProfServT4	Text	200		
51	IngProfServT4	IngProfServT4	IngProfServT4	Integer	99		



**CLaSP CRF**  
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## CLOCK DRAWING

Patient ID

IngPatID

Assessed: ☐ Yes catAssQ  
☐ No

Date of completing forms:

dtmExam

Duration of completing foms (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

Method for evaluating clock drawings decribed by  
Sunderland and colleagues (1989)

Criterion

catClockDraw1

**If criterion is 'GENERALLY intact' please score with 10 to 6**

IngClockDraw1

10=Hands are in correct position.

9=Slight errors in placement of the hands.

8=More noticeable errors in the placement of hour and minute hands.

7=Placement of hands is significantly of course.

6=Inappropriate use of clock hands (i.e., use of digital display or circling of numbers despite repeated instructions).

**If criterion is 'NOT intact' please score with 5 to 1**

IngClockDraw2

5=Crowding of numbers at one end of the clock or reversal of numbers.  
Hands may still be present in some fashion.

4=Further distortion of number sequence. Integrity of clock face is now gone (i.e., numbers missing or placed outside of the boundaries of the clock face).

3=Numbers and clock face no longer obviously connected in the drawing. Hands are not present.

2=Drawing reveals some evidence of instruction being received but only a vague representation of a clock.

1=Either no attempt or an uninterpretable effort is made

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	catClockDraw1	catClockDraw1	catClockDraw1	Category	72		See Appendix
8	IngClockDraw1	IngClockDraw1	IngClockDraw1	Integer	-99		
9	IngClockDraw2	IngClockDraw2	IngClockDraw2	Integer	-99		



**CLaSP CRF**  
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**LEXICAL FLUENCY**

Patient ID

IngPatID

Assessed:

- ☐ Yes  
☐ No

catAssQ

Date of completing forms:

dtmExam

Duration of completing foms (minutes):

Ing\_duration\_As

Reason, if not assessed:

catAss\_Test\_P

Other reason:

strAssessReas

**Ask for the number of words beginning with the letter S and count the number in 1 minute (exclude duplications, names).**

IngLexFluency

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmExam	dtmExam	dtmExam	Date/Time	dd/mm/yyyy		
3	catAssQ	catAssQ	catAssQ	Category	3, Mandatory		1=Yes 0=No
4	Ing_duration_As	Ing_duration_As	Ing_duration_As	Integer	999		
5	catAss_Test_P	catAss_Test_P	catAss_Test_P	Category	62		See Appendix
6	strAssessReas	strAssessReas	strAssessReas	Text	500		
7	IngLexFluency	IngLexFluency	IngLexFluency	Integer	-99		



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ASSESSMENT SUMMARY

Patient ID  IngPatID

How long did evaluation take (hours and minutes)?

Ing\_Ass\_eva\_h and  Ing\_Ass\_eva\_min  
(h) (min)

How many breaks?  IngAss\_breaks

Assessment done over how many days?  IngAss\_days

Assesment during assessment On or off?   catAss\_onoff

Last dose anti-parkinsonian medication taken (minutes before assessment)  Ing\_lastDose

Did the patient have fluctuations?   catAss\_Fluct

Please enter the percentage of fluctuations:  IngAss\_fluc\_per

Participant feedback:  
What were particular relevant or good or suggested modifications and what not?

strFeedback

Interviewers comments on the results given by the patient and the caregiver.

strIntervComm

When was the last dose of antiparkinsonian medication taken?

 dtmLastDose

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	Ing_Ass_eva_h	Ing_Ass_eva_h	Ing_Ass_eva_h	Integer	99		
3	Ing_Ass_eva_min	Ing_Ass_eva_min	Ing_Ass_eva_min	Integer	99		
4	IngAss_breaks	IngAss_breaks	IngAss_breaks	Integer	99		
5	IngAss_days	IngAss_days	IngAss_days	Integer	99		
6	catAss_onoff	catAss_onoff	catAss_onoff	Category	3		1=ON 2=OFF
7	Ing_lastDose	Ing_lastDose	Ing_lastDose	Integer	-9999		
8	catAss_Fluct	catAss_Fluct	catAss_Fluct	Category	3		1=Yes 0=No
9	IngAss_fluc_per	IngAss_fluc_per	IngAss_fluc_per	Integer	999		
10	strFeedback	strFeedback	strFeedback	Text	500, Optional		
11	strIntervComm	strIntervComm	strIntervComm	Text	1500, Optional		
12	dtmLastDose	dtmLastDose	dtmLastDose	Date/Time	mm/dd/yyyy, Optional, Hidden		



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AUTHORIZATION OF VISIT

Patient ID

IngPatID

Date of authorization

dtmAuthorize

Name of invesigator

strAuthorize

☐ Visit authorized by investigator

catAuthorize

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	dtmAuthorize	dtmAuthorize	dtmAuthorize	Date/Time	dd/mm/yyyy		
3	strAuthorize	strAuthorize	strAuthorize	Text	30		
4	catAuthorize	catAuthorize	catAuthorize	Category	32		1=Visit authorized by Investigator



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ADVERSE EVENT FORM



Patient ID

IngPatID

Adverse Event Description - Explanation of abbreviations and codes

INT = Intensity According to CTC-Grade  
(1=mild; 2=moderate; 3=severe; 4=live threatening; 5=death)

THE = Therapy for the event  
(0=none; 1=drug; 2=other; 3=1 and 2)

OUT = Outcome  
(1=recovered/resolved; 2=recovering/resolving; 3=not recovered/not resolved; 4=recovered/resolved with sequelae; 5=fatal; 6=unknown)

SER = Serious  
(0=No; 1=Yes; If Yes, please fill out SAE-Report Form)

AE - NUMBER (automatically completed)

IngAENumber

CTCAE Term

strCTCAEterm

Date of onset or change of AE properties (dd/mm/yyyy)	Date of resolution (dd/mm/yyyy)	INT	THE	OUT	SER
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
<input type="text"/> <input type="text"/>	dtmAEresolution	catINT	catTHE	catOUT	catSER
dtmAEonset					

Date of authorization of AE form by investigator

dtmAuthorizeAE

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	IngAEnumber	IngAEnumber	IngAEnumber	Integer	999	form:cycle	
3	strCTCAEterm	strCTCAEterm	strCTCAEterm	Text	255		
Repeating Question Group: , Borders: Yes, RowStatus: Yes, RowNumbers: Yes, DisplayRows: 10, InitialRows: 8, Min Repeats: 1, Max Repeats: 99, Main Row Type: Single-Line, Sub Row Type: Multi-Line							
4	dtmAEonset	dtmAEonset	dtmAEonset	Date/Time	dd/mm/yyyy		
5	dtmAEresolution	dtmAEresolution	dtmAEresolution	Date/Time	dd/mm/yyyy		
6	catINT	catINT	catINT	Category	1		1=1 2=2 3=3 4=4 5=5
7	catTHE	catTHE	catTHE	Category	1		0=0 1=1 2=2 3=3
8	catOUT	catOUT	catOUT	Category	1		1=1 2=2 3=3 4=4 5=5 6=6
9	catSER	catSER	catSER	Category	1		0=0 1=1
10	dtmAuthorizeAE	dtmAuthorizeAE	dtmAuthorizeAE	Date/Time	dd/mm/yyyy		



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## ALLIED HEALTH INTERVENTION

### E-Form REMOVED:

- redundant to **RECOMMENDATIONS**
- E-mail **Danny Hommel, 03-DEC-2015**
- Confirmed by **Joy Read 04-DEC-2015**
- Items set to hidden

	Done	Ongoing	Start date	Stop date	Referral criteria fulfilled	Patient ID	Aims
Physiotherapy:	<input type="text"/> <input type="text"/> <small>cat_AHI_a</small>	<input type="text"/> <input type="text"/> <small>catOnGo_AHI_a</small>	<input type="text"/> <input type="text"/> <small>dtmAHI_a</small>	<input type="text"/> <input type="text"/> <small>dtmAHI_aa</small>	<input type="text"/> <small>str_Ref_Crit_a</small>	<input type="text"/> <small>IngPatID</small>	<input type="text"/> <small>cat_AHI_Aim_a</small>
Speech and language:	<input type="text"/> <input type="text"/> <small>cat_AHI_b</small>	<input type="text"/> <input type="text"/> <small>catOnGo_AHI_b</small>	<input type="text"/> <input type="text"/> <small>dtmAHI_b</small>	<input type="text"/> <input type="text"/> <small>dtmAHI_bb</small>	<input type="text"/> <small>str_Ref_Crit_b</small>		<input type="text"/> <small>str_AHI_Aim_b</small>
Occupational therapy (OT):	<input type="text"/> <input type="text"/> <small>cat_AHI_c</small>	<input type="text"/> <input type="text"/> <small>catOnGo_AHI_c</small>	<input type="text"/> <input type="text"/> <small>dtmAHI_c</small>	<input type="text"/> <input type="text"/> <small>dtmAHI_cc</small>	<input type="text"/> <small>str_Ref_Crit_c</small>		<input type="text"/> <small>str_AHI_Aim_c</small>
Parkinson nurse:	<input type="text"/> <input type="text"/> <small>catAHIInurse</small>						
Psychosocial interventions:		<input type="text"/> <input type="text"/> <small>catAHIPsycho</small>					
Please choose Psychosocial intervention:			<input type="text"/> <input type="text"/> <small>catAHIIntervent</small>				
if other carer support please specify:			<input type="text"/> <small>str_AHI_OtCar</small>				

ID	CODE	NAME	EXP.CODE	TYPE	FMT/LEN	DERIVATION	CAT. VALUES
1	IngPatID	IngPatID	IngPatID	Integer	99999, Optional, Hidden	T1:Cover:IngSite*1000 + T1:Cover:IngPatNo	
2	cat_AHI_a	cat_AHI_a	cat_AHI_a	Category	3, Optional, Hidden		1=Yes 0=No
3	dtmAHI_a	dtmAHI_a	dtmAHI_a	Date/Time	dd/mm/yyyy, Optional, Hidden		
4	dtmAHI_aa	dtmAHI_aa	dtmAHI_aa	Date/Time	dd/mm/yyyy, Optional, Hidden		
5	str_Ref_Crit_a	cat_Ref_Crit_a	cat_Ref_Crit_a	Category	3, Optional, Hidden		1=Yes 0=No
6	catOnGo_AHI_a	catOnGo_AHI_a	catOnGo_AHI_a	Category	3, Optional, Hidden		1=Yes 0=No
7	cat_AHI_Aim_a	str_AHI_Aim_a	str_AHI_Aim_a	Text	255, Optional, Hidden		
8	cat_AHI_b	cat_AHI_b	cat_AHI_b	Category	3, Optional, Hidden		1=Yes 0=No
9	catOnGo_AHI_b	catOnGo_AHI_b	catOnGo_AHI_b	Category	3, Optional, Hidden		1=Yes 0=No
10	dtmAHI_b	dtmAHI_b	dtmAHI_b	Date/Time	dd/mm/yyyy, Optional, Hidden		
11	dtmAHI_bb	dtmAHI_bb	dtmAHI_bb	Date/Time	dd/mm/yyyy, Optional, Hidden		
12	str_Ref_Crit_b	cat_Ref_Crit_b	cat_Ref_Crit_b	Category	3, Optional, Hidden		1=Yes 0=No
13	str_AHI_Aim_b	str_AHI_Aim_b	str_AHI_Aim_b	Text	255, Optional, Hidden		
14	cat_AHI_c	cat_AHI_c	cat_AHI_c	Category	3, Optional, Hidden		1=Yes 0=No
15	catOnGo_AHI_c	catOnGo_AHI_c	catOnGo_AHI_c	Category	3, Optional, Hidden		1=Yes 0=No
16	dtmAHI_c	dtmAHI_c	dtmAHI_c	Date/Time	dd/mm/yyyy, Optional, Hidden		
17	dtmAHI_cc	dtmAHI_cc	dtmAHI_cc	Date/Time	dd/mm/yyyy, Optional, Hidden		
18	str_Ref_Crit_c	cat_Ref_Crit_c	cat_Ref_Crit_c	Category	3, Optional, Hidden		1=Yes 0=No
19	str_AHI_Aim_c	str_AHI_Aim_c	str_AHI_Aim_c	Text	255, Optional, Hidden		
20	catAHINurse	catAHINurse	catAHINurse	Category	3, Optional, Hidden		1=Yes 0=No
21	catAHIPsycho	catAHIPsycho	catAHIPsycho	Category	3, Optional, Hidden		1=Yes 0=No
22	catAHIIntervent	catAHIIntervent	catAHIIntervent	Category	19, Optional, Hidden		1=1 = Psychologist 2=2 = Respite 3=3 = Social services 9=9 = Other
23	str_AHI_OtCar	str_AHI_OtCar	str_AHI_OtCar	Text	255, Optional, Hidden		

CODE	NAME	TYPE	EXPRESSION
cat_EOT_c	cat_EOT_c	Category Values	1=Study treatment stopped by patient wish, but agrees in further data documentation
cat_NPI_NH_A	cat_NPI_NH_A	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_B	cat_NPI_NH_B	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_C	cat_NPI_NH_C	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_D	cat_NPI_NH_D	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_E	cat_NPI_NH_E	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_F	cat_NPI_NH_F	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_G	cat_NPI_NH_G	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_H	cat_NPI_NH_H	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_I	cat_NPI_NH_I	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_J	cat_NPI_NH_J	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_K	cat_NPI_NH_K	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_NPI_NH_L	cat_NPI_NH_L	Category Values	1=Yes (If yes, please proceed to subquestions) 0=No (If no, please proceed to next screening question) 2=N/A (Not Applicable)
cat_Q2_Rigid	cat_Q2_Rigid	Category Values	0=0 = Absent. 1=1 = Slight or detectable only when activated by mirror or other movements. 2=2 = Mild to moderate. 3=3 = Marked, but full range of motion easily achieved. 4=4 = Severe, range of motion achieved with difficulty.
cat_Q3_Rest	cat_Q3_Rest	Category Values	0=0 = Absent. 1=1 = Slight and infrequently present. 2=2 = Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present. 3=3 = Moderate in amplitude and present most of the time. 4=4 = Marked in amplitude and present most of the time.
cat_Q4_Post	cat_Q4_Post	Category Values	0=0 = Normal. 1=1 = Retropulsion, but recovers unaided. 2=2 = Absence of postural response; would fall if not caught by examiner. 3=3 = Very unstable, tends to lose balance spontaneously. 4=4 = Unable to stand without assistance.
cat01UPDRS	cat01UPDRS	Category Values	0=0 = Normal 1=1 = Somewhat slow, but no help needed. 2=2 = Occasional assistance with buttoning, getting arms in sleeves. 3=3 = Considerable help required, but can do some things alone. 4=4 = Helpless
cat01UPDRS	cat01UPDRS	Category Values	0=0 = Normal 1=1 = Somewhat slow, but no help needed. 2=2 = Needs help to shower or bathe, or very slow in hygienic care. 3=3 = Requires assistance for washing, brushing teeth, combing hair, going to bathroom. 4=4 = Foley catheter or other mechanical aids.
cat01UPDRS	cat01UPDRS	Category Values	0=0 = Normal 1=1 = Somewhat slow and clumsy, but no help needed. 2=2 = Can turn alone or adjust sheets, but with great difficulty. 3=3 = Can initiate, but not turn or adjust sheets alone. 4=4 = Helpless
cat01UPDRS	cat01UPDRS	Category Values	0=0 = None 1=1 = Rare falling. 2=2 = Occasionally falls, less than once per day. 3=3 = Falls an average of once daily. 4=4 = Falls more than once daily.

CODE	NAME	TYPE	EXPRESSION
cat01UPDRS	cat01UPDRS	Category Values	0=0 = None 1=1 = Rare freezing when walking; may have start-hesitation. 2=2 = Occasional freezing when walking. 3=3 = Frequent freezing. Occasionally falls from freezing. 4=4 = Frequent falls from freezing.
cat01UPDRS	cat01UPDRS	Category Values	0=0 = Normal 1=1 = Mild difficulty. May not swing arms or may tend to drag leg. 2=2 = Moderate difficulty, but requires little or no assistance. 3=3 = Severe disturbance of walking, requiring assistance. 4=4 = Cannot walk at all, even with assistance.
cat01UPDRS	cat01UPDRS	Category Values	0=0 = Absent 1=1 = Slight and infrequently present. 2=2 = Moderate; bothersome to patient. 3=3 = Severe; interferes with many activities. 4=4 = Marked; interferes with most activities.
cat01UPDRS	cat01UPDRS	Category Values	0=0 = None 1=1 = Occasionally has numbness, tingling, or mild aching. 2=2 = Frequently has numbness, tingling, or aching; not distressing. 3=3 = Frequent painful sensations. 4=4 = Excruciating pain.
cat01UPDRS	cat01UPDRS	Category Values	0=0 = Normal 1=1 = Mildly affected. No difficulty being understood. 2=2 = Moderately affected. Sometimes asked to repeat statements. 3=3 = Severely affected. Frequently asked to repeat statements. 4=4 = Unintelligible most of the time.
cat01UPDRS	cat01UPDRS	Category Values	0=0 = Normal 1=1 = Slight but definite excess of saliva in mouth; may have nighttime drooling. 2=2 = Moderately excessive saliva; may have minimal drooling. 3=3 = Marked excess of saliva with some drooling. 4=4 = Marked drooling, requires constant tissue or handkerchief.
cat01UPDRS	cat01UPDRS	Category Values	0=0 = Normal 1=1 = Rare choking. 2=2 = Occasional choking. 3=3 = Requires soft food. 4=4 = Requires NG tube or gastrotomy feeding.
cat01UPDRS	cat01UPDRS	Category Values	0=0 = Normal 1=1 = Slightly slow or small. 2=2 = Moderately slow or small; all words are legible. 3=3 = Severely affected; not all words are legible. 4=4 = The majority of words are not legible.
cat01UPDRS	cat01UPDRS	Category Values	0=0 = Normal 1=1 = Somewhat slow and clumsy, but no help needed. 2=2 = Can cut most foods, although clumsy and slow; some help needed. 3=3 = Food must be cut by someone, but can still feed slowly. 4=4 = Needs to be fed.
cat11UPDRS	cat11UPDRS	Category Values	0=0 = None 1=1 = Mild. Consistent forgetfulness with partial recollection of events and no other difficulties. 2=2 = Moderate memory loss, with disorientation and moderate difficulty handling complex problems. Mild but definite impairment of function at home with need of occasional prompting. 3=3 = Severe memory loss with disorientation for time and often to place. Severe impairment in handling problems. 4=4 = Severe memory loss with orientation preserved to person only. Unable to make judgments or solve problems. Requires much help with personal care. Cannot be left alone at all.
cat11UPDRS	cat11UPDRS	Category Values	0=0 = None 1=1 = Vivid dreaming. 2=2 = Benign hallucinations with insight retained. 3=3 = Occasional to frequent hallucinations or delusions; without insight; could interfere with daily activities. 4=4 = Persistent hallucinations, delusions, or florid psychosis. Not able to care for self.
cat11UPDRS	cat11UPDRS	Category Values	0=0 = Not present 1=1 = Periods of sadness or guilt greater than normal, never sustained for day or weeks. 2=2 = Sustained depression (1 week or more). 3=3 = Sustained depression with vegetative symptoms (insomnia, anorexia, weight loss, loss of interest). 4=4 = Sustained depression with vegetative symptoms and suicidal thoughts or intent.
cat11UPDRS	cat11UPDRS	Category Values	0=0 = Normal 1=1 = Less assertive than usual; more passive. 2=2 = Loss of initiative or disinterest in elective (non-routine) activities. 3=3 = Loss of initiative or disinterest in day to day (routine) activities. 4=4 = Withdrawn, complete loss of motivation.
catAge_CCI	catAge_CCI	Category Values	0=0 = Age <40 years 1=1 = Age 41-50 years 2=2 = Age 51-60 years 3=3 = Age 61-70 years 4=4 = Age 71-80 years
catArea1Imp	catArea1Imp	Category Values	0=0 = Not important+++ 1=1 = Not important++ 2=2 = Not important+ 3=3 = Important 4=4 = Very important+ 5=5 = Very important++ 6=6 = Very important+++ 7=7 = Extremely important
catArea1Sat	catArea1Sat	Category Values	0=-3 = Very unsatisfied+++ 1=-2 = Very unsatisfied++ 2=-1 = Very unsatisfied+ 3=0 = In between 4=1 = Very satisfied+ 5=2 = Very satisfied++ 6=3 = Very satisfied+++

Appendix

CODE	NAME	TYPE	EXPRESSION
catArea2Imp	catArea2Imp	Category Values	0=0 = Not important+++ 1=1 = Not important++ 2=2 = Not important+ 3=3 = Important 4=4 = Very important+ 5=5 = Very important++ 6=6 = Very important+++ 7=7 = Extremely important
catArea2Sat	catArea2Sat	Category Values	0=-3 = Very unsatisfied+++ 1=-2 = Very unsatisfied++ 2=-1 = Very unsatisfied+ 3=0 = In between 4=1 = Very satisfied+ 5=2 = Very satisfied++ 6=3 = Very satisfied+++
catArea3Imp	catArea3Imp	Category Values	0=0 = Not important+++ 1=1 = Not important++ 2=2 = Not important+ 3=3 = Important 4=4 = Very important+ 5=5 = Very important++ 6=6 = Very important+++ 7=7 = Extremely important
catArea3Sat	catArea3Sat	Category Values	0=-3 = Very unsatisfied+++ 1=-2 = Very unsatisfied++ 2=-1 = Very unsatisfied+ 3=0 = In between 4=1 = Very satisfied+ 5=2 = Very satisfied++ 6=3 = Very satisfied+++
catArea4Imp	catArea4Imp	Category Values	0=0 = Not important+++ 1=1 = Not important++ 2=2 = Not important+ 3=3 = Important 4=4 = Very important+ 5=5 = Very important++ 6=6 = Very important+++ 7=7 = Extremely important
catArea4Sat	catArea4Sat	Category Values	0=-3 = Very unsatisfied+++ 1=-2 = Very unsatisfied++ 2=-1 = Very unsatisfied+ 3=0 = In between 4=1 = Very satisfied+ 5=2 = Very satisfied++ 6=3 = Very satisfied+++
catArea5Imp	catArea5Imp	Category Values	0=0 = Not important+++ 1=1 = Not important++ 2=2 = Not important+ 3=3 = Important 4=4 = Very important+ 5=5 = Very important++ 6=6 = Very important+++ 7=7 = Extremely important
catArea5Sat	catArea5Sat	Category Values	0=-3 = Very unsatisfied+++ 1=-2 = Very unsatisfied++ 2=-1 = Very unsatisfied+ 3=0 = In between 4=1 = Very satisfied+ 5=2 = Very satisfied++ 6=3 = Very satisfied+++
catArea6Imp	catArea6Imp	Category Values	0=0 = Not important+++ 1=1 = Not important++ 2=2 = Not important+ 3=3 = Important 4=4 = Very important+ 5=5 = Very important++ 6=6 = Very important+++ 7=7 = Extremely important
catArea6Sat	catArea6Sat	Category Values	0=-3 = Very unsatisfied+++ 1=-2 = Very unsatisfied++ 2=-1 = Very unsatisfied+ 3=0 = In between 4=1 = Very satisfied+ 5=2 = Very satisfied++ 6=3 = Very satisfied+++
catArea7Imp	catArea7Imp	Category Values	0=0 = Not important+++ 1=1 = Not important++ 2=2 = Not important+ 3=3 = Important 4=4 = Very important+ 5=5 = Very important++ 6=6 = Very important+++ 7=7 = Extremely important
catArea7Sat	catArea7Sat	Category Values	0=-3 = Very unsatisfied+++ 1=-2 = Very unsatisfied++ 2=-1 = Very unsatisfied+ 3=0 = In between 4=1 = Very satisfied+ 5=2 = Very satisfied++ 6=3 = Very satisfied+++
catAss_Test_P	catAss_Test_P	Category Values	1=1 = Patients does not understand the scale\the question 2=2 = Patient refuses to collaborate\answer (excludes tiredness) 3=3 = Patient is too tired to proceed 4=4 = Patient is sleepy 5=5 = Attention deficit precludes assessment 6=6 = Bradykinesia precludes assessment 7=7 = Investigator does not understand answer due to anarthria 8=8 = Investigator does not understand answer due to dementia 9=9 = Other
catAss_Test_P	catAss_Test_P	Category Values	1=1 = Patients does not understand the scale\the question 2=2 = Patient refuses to collaborate\answer (excludes tiredness) 3=3 = Patient is too tired to proceed 4=4 = Patient is sleepy 5=5 = Attention deficit precludes assessment 6=6 = Bradykinesia precludes assessment 7=7 = Investigator does not understand answer due to anarthria 8=8 = Investigator does not understand answer due to dementia 9=9 = Other
catAssDBy	catAssDBy	Category Values	1=1 = Movement disorder specialist 2=2 = Neurologist 3=3 = Geriatrician 4=4 = Palliative care 5=5 = Rehab physician 6=6 = General Practitioner 7=7 = PD nurse 8=8 = Other nurse 9=9 = Social worker 10=10 = Psychologist 11=11 = researcher / research worker 99=99 = Other health care professional
catCareLik	catCareLik	Category Values	1=1 = Very satisfied 2=2 = satisfied 3=3 = neutral 4=4 = dissatisfied 5=5 = very dissatisfied
catCareLikP	catCareLikP	Category Values	1=1 = Very satisfied 2=2 = satisfied 3=3 = neutral 4=4 = dissatisfied 5=5 = very dissatisfied
catCareSup	catCareSup	Category Values	1=1 = Very satisfied 2=2 = satisfied 3=3 = neutral 4=4 = dissatisfied 5=5 = very dissatisfied
catCareSupP	catCareSupP	Category Values	1=1 = Very satisfied 2=2 = satisfied 3=3 = neutral 4=4 = dissatisfied 5=5 = very dissatisfied
catCGIchange	catCGIchange	Category Values	0=0 = Not assesed 1=1 = Marked improvement 2=2 = Moderate improvement 3=3 = Minimal improvement 4=4 = No change 5=5 = Minimal worsening 6=6 = Moderate worsening 7=7 = Marked worsening
catCGIseverity	catCGIseverity	Category Values	0=0 = Not assesed 1=1 = Normal, not at all ill 2=2 = Borderline ill 3=3 = Mildly ill 4=4 = Moderately ill 5=5 = Markedly ill 6=6 = Severely ill 7=7 = Extremely ill

Appendix

CODE	NAME	TYPE	EXPRESSION
catClockDraw1	catClockDraw1	Category Values	1=1=10-6: Drawing of clock face with circle and number is generally intact 2=2=5-1: Drawing of clock face with circle and number is not intact
catEmplChange	catEmplChange	Category Values	0=No 1=Yes, I had to stop working 2=Yes, I had to get another job 3=Yes, I had to reduce my work time (* specify hours/time below) 4=Yes, I had to get another job and to reduce my work time (* specify below) 5=Yes, I had to do an occupational re-training
catEmployCG	catEmployCG	Category Values	1=Employee full time 2=Employee part time 3=Self-employed 4=Volunteering 5=Unemployed due to the PWP's Parkinsons disease and its subsequent illnesses 6=Unemployed due to other reasons 7=Early retirement due to the PWP's Parkinsons disease and its subsequent illnesses 8=Early retirement due to other reasons 9=Retired 10=Housewife 11=Not applicable (n/a)
catEmployment	catEmployment	Category Values	1=Employee full time 2=Employee part time 3=Self-employed 4=Volunteering 5=Unemployed due to Parkinson's disease and its subsequent illnesses 6=Unemployed due to other reasons 7=Early retirement due to Parkinson's disease and its subsequent illnesses 8=Early retirement due to other reasons 9=Retired 10=Housewife 11=Not applicable (n/a)
catEQ5D3L_Q	catEQ5D3L_Q	Category Values	1=1 = I have no problems in walking about 2=2 = I have some problems in walking about 3=3 = I am confined to bed
catEQ5D3L_Q	catEQ5D3L_Q	Category Values	1=1 = I have no problems with self-care 2=2 = I have some problems washing or dressing myself 3=3 = I am unable to wash or dress myself
catEQ5D3L_Q	catEQ5D3L_Q	Category Values	1=1 = I have no problems with performing my usual activities 2=2 = I have some problems with performing my usual activities 3=3 = I am unable to perform my usual activities
catEQ5D3L_Q	catEQ5D3L_Q	Category Values	1=1 = I have no pain or discomfort 2=2 = I have moderate pain or discomfort 3=3 = I have extreme pain or discomfort
catEQ5D3L_Q	catEQ5D3L_Q	Category Values	1=1 = I am not anxious or depressed 2=2 = I am moderately anxious or depressed 3=3 = I am extremely anxious or depressed
catEQ5D3LC	catEQ5D3LC	Category Values	1=1 = I have no problems in walking about 2=2 = I have some problems in walking about 3=3 = I am confined to bed
catEQ5D3LC	catEQ5D3LC	Category Values	1=1 = I have no problems with self-care 2=2 = I have some problems washing or dressing myself 3=3 = I am unable to wash or dress myself
catEQ5D3LC	catEQ5D3LC	Category Values	1=1 = I have no problems with performing my usual activities 2=2 = I have some problems with performing my usual activities 3=3 = I am unable to perform my usual activities
catEQ5D3LC	catEQ5D3LC	Category Values	1=1 = I have no pain or discomfort 2=2 = I have moderate pain or discomfort 3=3 = I have extreme pain or discomfort
catEQ5D3LC	catEQ5D3LC	Category Values	1=1 = I am not anxious or depressed 2=2 = I am moderately anxious or depressed 3=3 = I am extremely anxious or depressed
catFinDiagCon	catFinDiagCon	Category Values	1=1 = Parkinson's disease 2=2 = MSA 3=3 = PSP 4=4 = DLB 5=5 = PDD 6=6 = Parkinsonism with dementia (PDD or DLB) 7=7 = CBD 8=8 = vascular parkinsonism 9=9 = other
catInterview1	catInterview1	Category Values	1=1 = Option A, Participants living at home 2=2 = Option B, Participants living in residential care facilities/nursing homes
catInterview2	catInterview2	Category Values	1=1 = Option A, Partner/family member/friend of participants living at home 2=2 = Option B, Partner/family member/friend of participants living in
catMartStat	catMartStat	Category Values	1=1 = single 2=2 = married 3=3 = Divorced 4=4 = widowed 5=5 = Living apart from Spouse 6=6 = Living in Staple partnership without marriage
catMedDevice	catMedDevice	Category Values	0=No, I did not receive any medical devices/consumables during the past three months. 1=Yes, I did receive medical devices/consumables during the past 3 months.
catMMSE_scal	catMMSE_scal	Category Values	1=1 = Backward counting (calculation) 2=2 = Backward spelling (word with five letters)
catNotContact	catNotContact	Category Values	1=less than 1 hour 2=less than 5 hours 3=5 to 10 hours 4=10 to 24 hours 5=more than 24 hours
catNotTalk	catNotTalk	Category Values	1=several times every day 2=once every day 3=at least once per week 4=at least once per month 5=less than once per month 6=I never talk to the PWP on the phone
catNotVisit	catNotVisit	Category Values	1=several times every day 2=once every day 3=at least once per week 4=at least once per month 5=less than once per month 6=I never visit the PWP

## Appendix

CODE	NAME	TYPE	EXPRESSION
catPatStatus	catPatStatus	Category Values	1=1 = Patient alive 2=2 = Patient died 3=3 = Patient is lost to follow up 4=4 = Patient has withdrawn informed consent
catPWPAcc	catPWPAcc	Category Values	1=Own home 2=With relatives 3=Intermediate forms of accommodation (e.g. Short term care / Respite care) 4=Assisted living (accommodation with on site support) 5=Long-term institutional care (care home with nursing) 9=Other
catRecoQ1_ty	catRecoQ1_ty	Category Values	1=Start treatment 2=Increase dose 3=Increase frequency 4=Increase dose and frequency 5=Decrease dose and frequency 6=Decrease dose 7=Decrease frequency 8=Stop treatment
catRecoQ2_ty	catRecoQ2_ty	Category Values	1=Start treatment 2=Increase dose 3=Increase frequency 4=Increase dose and frequency 5=Decrease dose and frequency 6=Decrease dose 7=Decrease frequency 8=Stop treatment
catRecoQ3_ty	catRecoQ3_ty	Category Values	1=Start treatment 2=Increase dose 3=Increase frequency 4=Increase dose and frequency 5=Decrease dose and frequency 6=Decrease dose 7=Decrease frequency 8=Stop treatment
catReltoPWP	catReltoPWP	Category Values	1=Spouse 2=Life partner 3=Daughter 4=Son 5=Daughter-in-law 6=Son-in-law 7=Friend 8=Other, please specify below
catSeenWhere	catSeenWhere	Category Values	1=1 = Patient's private home 2=2 = protected living 3=3 = nursing home 4=4 = hospital
catSource_Do	catSource_Do	Category Values	1=1 = Patient 2=2 = Informal carer 3=3 = Formal carer 4=4 = Medical file 5=5 = Treating physician 9=9 = Other
catSource_Mer	catSource_Mer	Category Values	1=1 = Patient 2=2 = Informal carer 3=3 = Formal carer 4=4 = Medical file 5=5 = Treating physician 9=9 = Other
catSource_ND	catSource_ND	Category Values	1=1 = Patient 2=2 = Informal carer 3=3 = Formal carer 4=4 = Medical file 5=5 = Treating physician 9=9 = Other
catSource_OT	catSource_OT	Category Values	1=1 = Primary care record at 3 months 2=2 = Patient and carer at 3 month 9=9 = Other
catUPDRS_3_	catUPDRS_3_	Category Values	0=0 = Normal 1=1 = Slight loss of expression, diction and/or volume. 2=2 = Monotone, slurred but understandable; moderately 3=3 = Marked impairment, difficult to understand. 4=4 = Unintelligible
catUPDRS_3_	catUPDRS_3_	Category Values	0=0 = Normal 1=1 = Minimal hypomimia, could be normal Poker Face. 2=2 = Slight but definitely abnormal diminution of facial expression 3=3 = Moderate hypomimia; lips parted some of the time. 4=4 = Masked or fixed facies with severe or complete loss of facial expression; lips parted 1/4 inch or more.
catUPDRS_3_	catUPDRS_3_	Category Values	0=0 = Absent 1=1 = Slight and infrequently present. 2=2 = Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present. 3=3 = Moderate in amplitude and present most of the time. 4=4 = Marked in amplitude and present most of the time.
catUPDRS_3_	catUPDRS_3_	Category Values	0=0 = Absent 1=1 = Slight and infrequently present. 2=2 = Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present. 3=3 = Moderate in amplitude and present most of the time. 4=4 = Marked in amplitude and present most of the time.
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catUPDRS_3_	catUPDRS_3_	Category Values	0=0 = Absent 1=1 = Slight and infrequently present. 2=2 = Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present. 3=3 = Moderate in amplitude and present most of the time. 4=4 = Marked in amplitude and present most of the time.
catUPDRS_3_	catUPDRS_3_	Category Values	0=0 = Absent 1=1 = Slight; present with action. 2=2 = Moderate in amplitude, present with action. 3=3 = Moderate in amplitude with posture holding as well as action. 4=4 = Marked in amplitude; interferes with feeding.

CODE	NAME	TYPE	EXPRESSION
catUPDRS_3	catUPDRS_3	Category Values	0=0 = Absent 1=1 = Slight; present with action. 2=2 = Moderate in amplitude, present with action. 3=3 = Moderate in amplitude with posture holding as well as action. 4=4 = Marked in amplitude; interferes with feeding.
catUPDRS_3	catUPDRS_3	Category Values	0=0 = Absent 1=1 = Slight or detectable only when activated by mirror or other movements. 2=2 = Mild to moderate. 3=3 = Marked, but full range of motion easily achieved. 4=4 = Severe, range of motion achieved with difficulty.
catUPDRS_3	catUPDRS_3	Category Values	0=0 = Absent 1=1 = Slight or detectable only when activated by mirror or other movements. 2=2 = Mild to moderate. 3=3 = Marked, but full range of motion easily achieved. 4=4 = Severe, range of motion achieved with difficulty.
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catUPDRS_3	catUPDRS_3	Category Values	0=0 = Absent 1=1 = Slight or detectable only when activated by mirror or other movements. 2=2 = Mild to moderate. 3=3 = Marked, but full range of motion easily achieved. 4=4 = Severe, range of motion achieved with difficulty.
catUPDRS_3	catUPDRS_3	Category Values	0=0 = Absent 1=1 = Slight or detectable only when activated by mirror or other movements. 2=2 = Mild to moderate. 3=3 = Marked, but full range of motion easily achieved. 4=4 = Severe, range of motion achieved with difficulty.
catUPDRS_3	catUPDRS_3	Category Values	0=0 = Normal 1=1 = Mild slowing and/or reduction in amplitude. 2=2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement. 3=3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement. 4=4 = Can barely perform the task.
catUPDRS_3	catUPDRS_3	Category Values	0=0 = Normal 1=1 = Mild slowing and/or reduction in amplitude. 2=2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement. 3=3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement. 4=4 = Can barely perform the task.
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catUPDRS_3	catUPDRS_3	Category Values	0=0 = Normal 1=1 = Mild slowing and/or reduction in amplitude. 2=2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement. 3=3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement. 4=4 = Can barely perform the task.

CODE	NAME	TYPE	EXPRESSION
catUPDRS_3	catUPDRS_3	Category Values	0=0 = Normal 1=1 = Slow; or may need more than one attempt. 2=2 = Pushes self up from arms of seat. 3=3 = Tends to fall back and may have to try more than one time, but can get up without help. 4=4 = Unable to arise without help.
catUPDRS_3	catUPDRS_3	Category Values	0=0 = Normal erect 1=1 = Not quite erect, slightly stooped posture; could be normal for older person. 2=2 = Moderately stooped posture, definitely abnormal; can be slightly leaning to one side. 3=3 = Severely stooped posture with kyphosis; can be moderately leaning to one side. 4=4 = Marked flexion with extreme abnormality of posture.
catUPDRS_3	catUPDRS_3	Category Values	0=0 = Normal 1=1 = Walks slowly, may shuffle with short steps, but no festination (hastening steps) or propulsion. 2=2 = Walks with difficulty, but requires little or no assistance; may have some festination, short steps, or propulsion. 3=3 = Severe disturbance of gait, requiring assistance. 4=4 = Cannot walk at all, even with assistance.
catUPDRS_3	catUPDRS_3	Category Values	0=0 = Normal 1=1 = Retropulsion, but recovers unaided. 2=2 = Absence of postural response; would fall if not caught by examiner. 3=3 = Very unstable, tends to lose balance spontaneously. 4=4 = Unable to stand without assistance.
catUPDRS_3	catUPDRS_3	Category Values	0=0 = None 1=1 = Minimal slowness, giving movement a deliberate character; could be normal for some persons. Possibly reduced amplitude. 2=2 = Mild degree of slowness and poverty of movement which is definitely abnormal. Alternatively, some reduced amplitude. 3=3 = Moderate slowness, poverty or small amplitude of movement. 4=4 = Marked slowness, poverty or small amplitude of movement.
catUPDRS_4	catUPDRS_4	Category Values	0=0 = None 1=1 = 1-25% of day. 2=2 = 26-50% of day. 3=3 = 51-75% of day. 4=4 = 76-100% of day.
catUPDRS_4	catUPDRS_4	Category Values	0=0 = Not disabling 1=1 = Mildly disabling. 2=2 = Moderately disabling. 3=3 = Severely disabling. 4=4 = Completely disabled.
catUPDRS_4	catUPDRS_4	Category Values	0=0 = No painful dyskinesias. 1=1 = Slight 2=2 = Moderate 3=3 = Severe 4=4 = Marked
catUPDRS_4	catUPDRS_4	Category Values	0=0 = None 1=1 = 1-25% of day. 2=2 = 26-50% of day. 3=3 = 51-75% of day. 4=4 = 76-100% of day.
catUPDRS5	catUPDRS5	Category Values	0=Stage 0 - No signs of disease 1=Stage 1 - Unilateral disease 2=Stage 1,5 - Unilateral plus axial involvement 3=Stage 2 - Bilateral disease, without impairment of balance 4=Stage 2,5 - Mild bilateral disease with recovery on pull test 5=Stage 3 - Mild to moderate bilateral disease; some postural instability; physically independent 6=Stage 4 - Severe disability; still able to walk or stand unassisted 7=Stage 5 - Wheelchair bound or bedridden unless aided
catUPDRSVI	catUPDRSVI	Category Values	100=100% = Completely independent. Able to do all chores without slowness, difficulty or impairment. Essentially normal. Unaware of any difficulty. 90=90% = Completely independent. Able to do all chores with some degree of slowness, difficulty, and impairment. Might take twice as long. Beginning to be aware of difficulty. 80=80% = Completely independent in most chores. Takes twice as long. Conscious of difficulty and slowness. 70=70% = Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores. 60=60% = Some dependency. Can do most chores, but exceedingly slowly and with much effort. Errors; some impossible. 50=50% = More dependent. Help with half, slower, etc. Difficulty with everything. 40=40% = Very dependent. Can assist with all chores, but few alone. 30=30% = With effort, now and then does a few chores alone or begins alone. Much help needed. 20=20% = Nothing alone. Can be a slight help with some chores. Severe invalid. 10=10% = Total dependent, helpless. Complete invalid. 0=0% = Vegetative functions such as swallowing, bladder and bowel functions are not functioning. Bedridden.
hid_Ing_Age_C	hid_Ing_Age_C	Derivation	case((Charlson_Index:catAge_CCI=0, 0), (Charlson_Index:catAge_CCI=1, 1), (Charlson_Index:catAge_CCI=2, 2), (Charlson_Index:catAge_CCI=3, 3), (Charlson_Index:catAge_CCI=4, 4))
hid_realnrCatA	hid_realnrCatA	Derivation	case(( SMiLE:catArea1Sat = 0 , 0 ) , ( SMiLE:catArea1Sat = 1 , '16, 7' ) , ( SMiLE:catArea1Sat = 2 , '33, 3' ) , ( SMiLE:catArea1Sat = 3 , 50 ) , ( SMiLE:catArea1Sat = 4 , '66, 7' ) , ( SMiLE:catArea1Sat = 5 , '83, 3' ) , ( SMiLE:catArea1Sat = 6 , 100 ) , ( else, 0 ) )

CODE	NAME	TYPE	EXPRESSION
hid_realnrCatA	hid_realnrCatA	Derivation	case(( SMiLE:catArea2Sat = 0 , 0 ) , ( SMiLE:catArea2Sat = 1 , '16, 7') , ( SMiLE:catArea2Sat = 2 , '33, 3' ) , ( SMiLE:catArea2Sat = 3 , 50 ) , ( SMiLE:catArea2Sat = 4 , '66, 7' ) , ( SMiLE:catArea2Sat = 5 , '83, 3' ) , ( SMiLE:catArea2Sat = 6 , 100 ) , ( else, 0 ) )
hid_realnrCatA	hid_realnrCatA	Derivation	case(( SMiLE:catArea3Sat = 0 , 0 ) , ( SMiLE:catArea3Sat = 1 , '16, 7') , ( SMiLE:catArea3Sat = 2 , '33, 3' ) , ( SMiLE:catArea3Sat = 3 , 50 ) , ( SMiLE:catArea3Sat = 4 , '66, 7' ) , ( SMiLE:catArea3Sat = 5 , '83, 3' ) , ( SMiLE:catArea3Sat = 6 , 100 ) , ( else, 0 ) )
hid_realnrCatA	hid_realnrCatA	Derivation	case(( SMiLE:catArea4Sat = 0 , 0 ) , ( SMiLE:catArea4Sat = 1 , '16, 7') , ( SMiLE:catArea4Sat = 2 , '33, 3' ) , ( SMiLE:catArea4Sat = 3 , 50 ) , ( SMiLE:catArea4Sat = 4 , '66, 7' ) , ( SMiLE:catArea4Sat = 5 , '83, 3' ) , ( SMiLE:catArea4Sat = 6 , 100 ) , ( else, 0 ) )
hid_realnrCatA	hid_realnrCatA	Derivation	case(( SMiLE:catArea5Sat = 0 , 0 ) , ( SMiLE:catArea5Sat = 1 , '16, 7') , ( SMiLE:catArea5Sat = 2 , '33, 3' ) , ( SMiLE:catArea5Sat = 3 , 50 ) , ( SMiLE:catArea5Sat = 4 , '66, 7' ) , ( SMiLE:catArea5Sat = 5 , '83, 3' ) , ( SMiLE:catArea5Sat = 6 , 100 ) , ( else, 0 ) )
hid_realnrCatA	hid_realnrCatA	Derivation	case(( SMiLE:catArea6Sat = 0 , 0 ) , ( SMiLE:catArea6Sat = 1 , '16, 7') , ( SMiLE:catArea6Sat = 2 , '33, 3' ) , ( SMiLE:catArea6Sat = 3 , 50 ) , ( SMiLE:catArea6Sat = 4 , '66, 7' ) , ( SMiLE:catArea6Sat = 5 , '83, 3' ) , ( SMiLE:catArea6Sat = 6 , 100 ) , ( else, 0 ) )
hid_realnrCatA	hid_realnrCatA	Derivation	case(( SMiLE:catArea7Sat = 0 , 0 ) , ( SMiLE:catArea7Sat = 1 , '16, 7') , ( SMiLE:catArea7Sat = 2 , '33, 3' ) , ( SMiLE:catArea7Sat = 3 , 50 ) , ( SMiLE:catArea7Sat = 4 , '66, 7' ) , ( SMiLE:catArea7Sat = 5 , '83, 3' ) , ( SMiLE:catArea7Sat = 6 , 100 ) , ( else, 0 ) )
hidIngImpoSum	hidIngImpoSum	Derivation	sum( [ SMiLE:hid_IngCatImA1, SMiLE:hid_IngCatImA2, SMiLE:hid_IngCatImA3, SMiLE:hid_IngCatImA4, SMiLE:hid_IngCatImA5, SMiLE:hid_IngCatImA6, SMiLE:hid_IngCatImA7] )
hidIngSMiLEsu	hidIngSMiLEsu	Derivation	sum( [ SMiLE:hidden_IngA1, SMiLE:hidden_IngA2, SMiLE:hidden_IngA3, SMiLE:hidden_IngA4, SMiLE:hidden_IngA5, SMiLE:hidden_IngA6, SMiLE:hidden_IngA7] )
hidIngZBI_Q1	hidIngZBI_Q1	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ1 ) , ZaritBurden:IngZaBulnQ1), (else, 0 ) )
hidIngZBI_Q10	hidIngZBI_Q10	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ10 ) , ZaritBurden:IngZaBulnQ10), (else, 0 ) )
hidIngZBI_Q11	hidIngZBI_Q11	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ11 ) , ZaritBurden:IngZaBulnQ11), (else, 0 ) )
hidIngZBI_Q12	hidIngZBI_Q12	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ12 ) , ZaritBurden:IngZaBulnQ12), (else, 0 ) )
hidIngZBI_Q13	hidIngZBI_Q13	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ13 ) , ZaritBurden:IngZaBulnQ13), (else, 0 ) )
hidIngZBI_Q14	hidIngZBI_Q14	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ14 ) , ZaritBurden:IngZaBulnQ14), (else, 0 ) )
hidIngZBI_Q15	hidIngZBI_Q15	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ15 ) , ZaritBurden:IngZaBulnQ15), (else, 0 ) )
hidIngZBI_Q16	hidIngZBI_Q16	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ16 ) , ZaritBurden:IngZaBulnQ16), (else, 0 ) )
hidIngZBI_Q17	hidIngZBI_Q17	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ17 ) , ZaritBurden:IngZaBulnQ17), (else, 0 ) )
hidIngZBI_Q18	hidIngZBI_Q18	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ18 ) , ZaritBurden:IngZaBulnQ18), (else, 0 ) )
hidIngZBI_Q19	hidIngZBI_Q19	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ19 ) , ZaritBurden:IngZaBulnQ19), (else, 0 ) )
hidIngZBI_Q2	hidIngZBI_Q2	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ2 ) , ZaritBurden:IngZaBulnQ2), (else, 0 ) )

CODE	NAME	TYPE	EXPRESSION
hidIngZBI_Q20	hidIngZBI_Q20	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ20 ) , ZaritBurden:IngZaBulnQ20), (else, 0 ) )
hidIngZBI_Q21	hidIngZBI_Q21	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ21 ) , ZaritBurden:IngZaBulnQ21), (else, 0 ) )
hidIngZBI_Q22	hidIngZBI_Q22	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ22 ) , ZaritBurden:IngZaBulnQ22), (else, 0 ) )
hidIngZBI_Q3	hidIngZBI_Q3	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ3 ) , ZaritBurden:IngZaBulnQ3), (else, 0 ) )
hidIngZBI_Q4	hidIngZBI_Q4	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ4 ) , ZaritBurden:IngZaBulnQ4), (else, 0 ) )
hidIngZBI_Q5	hidIngZBI_Q5	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ5 ) , ZaritBurden:IngZaBulnQ5), (else, 0 ) )
hidIngZBI_Q6	hidIngZBI_Q6	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ6 ) , ZaritBurden:IngZaBulnQ6), (else, 0 ) )
hidIngZBI_Q7	hidIngZBI_Q7	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ7 ) , ZaritBurden:IngZaBulnQ7), (else, 0 ) )
hidIngZBI_Q8	hidIngZBI_Q8	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ8 ) , ZaritBurden:IngZaBulnQ8), (else, 0 ) )
hidIngZBI_Q9	hidIngZBI_Q9	Derivation	case(( isknown( ZaritBurden:IngZaBulnQ9 ) , ZaritBurden:IngZaBulnQ9), (else, 0 ) )
hidRealRecSur	hidRealRecSur	Derivation	sum( [SMILE:hid_realnrCatA1, SMILE:hid_realnrCatA2, SMILE:hid_realnrCatA3, SMILE:hid_realnrCatA4, SMILE:hid_realnrCatA5, SMILE:hid_realnrCatA6, SMILE:hid_realnrCatA7] )
Ing_CCI_Score	Ing_CCI_Score	Derivation	sum( [ Charlson_Index:hid_Ing_Age_CCI , Charlson_Index:hid_Ing_CCI_Q1 , Charlson_Index:hid_Ing_CCI_Q2 , Charlson_Index:hid_Ing_CCI_Q3 , Charlson_Index:hid_Ing_CCI_Q4 , Charlson_Index:hid_Ing_CCI_Q5 , Charlson_Index:hid_Ing_CCI_Q6 , Charlson_Index:hid_Ing_CCI_Q7 , Charlson_Index:hid_Ing_CCI_Q8 , Charlson_Index:hid_Ing_CCI_Q9 , Charlson_Index:hid_Ing_CCI_Q10 , Charlson_Index:hid_Ing_CCI_Q11 , Charlson_Index:hid_Ing_CCI_Q12 , Charlson_Index:hid_Ing_CCI_Q13 , Charlson_Index:hid_Ing_CCI_Q14 , Charlson_Index:hid_Ing_CCI_Q15 , Charlson_Index:hid_Ing_CCI_Q16 , Charlson_Index:hid_Ing_CCI_Q17 , Charlson_Index:hid_Ing_CCI_Q18 , Charlson_Index:hid_Ing_CCI_Q19 ] )
Ing_GDS_total	Ing_GDS_total	Derivation	sum( [ GDS:hid_GDS_Q1, GDS:hid_GDS_Q2, GDS:hid_GDS_Q3, GDS:hid_GDS_Q4, GDS:hid_GDS_Q5, GDS:hid_GDS_Q6, GDS:hid_GDS_Q7, GDS:hid_GDS_Q8, GDS:hid_GDS_Q9, GDS:hid_GDS_Q10, GDS:hid_GDS_Q11, GDS:hid_GDS_Q12, GDS:hid_GDS_Q13, GDS:hid_GDS_Q14, GDS:hid_GDS_Q15 ] )
Ing_NMS_SEF	Ing_NMS_SEF	Derivation	case((( isknown( NMS_Scale:Ing_NMS_Sev_Q1 ) and isknown( NMS_Scale:Ing_NMS_FREQ_Q1 )), NMS_Scale:Ing_NMS_Sev_Q1*NMS_Scale:Ing_NMS_FREQ_Q1 ), ( else, 0 ))
Ing_NMS_SEF	Ing_NMS_SEF	Derivation	case((( isknown( NMS_Scale:Ing_NMS_Sev_Q2 ) and isknown( NMS_Scale:Ing_NMS_FREQ_Q2 )), NMS_Scale:Ing_NMS_Sev_Q2*NMS_Scale:Ing_NMS_FREQ_Q2 ), ( else, 0 ))
Ing_NMS_SEF	Ing_NMS_SEF	Derivation	case((( isknown( NMS_Scale:Ing_NMS_Sev_Q3 ) and isknown( NMS_Scale:Ing_NMS_FREQ_Q3 )), NMS_Scale:Ing_NMS_Sev_Q3*NMS_Scale:Ing_NMS_FREQ_Q3 ), ( else, 0 ))
Ing_NMS_SEF	Ing_NMS_SEF	Derivation	case((( isknown( NMS_Scale:Ing_NMS_Sev_Q4 ) and isknown( NMS_Scale:Ing_NMS_FREQ_Q4 )), NMS_Scale:Ing_NMS_Sev_Q4*NMS_Scale:Ing_NMS_FREQ_Q4 ), ( else, 0 ))
Ing_NMS_SEF	Ing_NMS_SEF	Derivation	case((( isknown( NMS_Scale:Ing_NMS_Sev_Q5 ) and isknown( NMS_Scale:Ing_NMS_FREQ_Q5 )), NMS_Scale:Ing_NMS_Sev_Q5*NMS_Scale:Ing_NMS_FREQ_Q5 ), ( else, 0 ))

CODE	NAME	TYPE	EXPRESSION
Ing_NMS_SEF	Ing_NMS_SEF	Derivation	case((( isknown( NMS_Scale:Ing_NMS_Sev_Q6 ) and isknown( NMS_Scale:Ing_NMS_FREQ_Q6 )), NMS_Scale:Ing_NMS_Sev_Q6*NMS_Scale:Ing_NMS_FREQ_Q6 ), ( else, 0 ))
Ing_NMS_SEF	Ing_NMS_SEF	Derivation	case((( isknown( NMS_Scale:Ing_NMS_Sev_Q7 ) and isknown( NMS_Scale:Ing_NMS_FREQ_Q7 )), NMS_Scale:Ing_NMS_Sev_Q7*NMS_Scale:Ing_NMS_FREQ_Q7 ), ( else, 0 ))
Ing_NMS_SEF	Ing_NMS_SEF	Derivation	case((( isknown( NMS_Scale:Ing_NMS_Sev_Q8 ) and isknown( NMS_Scale:Ing_NMS_FREQ_Q8 )), NMS_Scale:Ing_NMS_Sev_Q8*NMS_Scale:Ing_NMS_FREQ_Q8 ), ( else, 0 ))
Ing_NMS_SEF	Ing_NMS_SEF	Derivation	case((( isknown( NMS_Scale:Ing_NMS_Sev_Q9 ) and isknown( NMS_Scale:Ing_NMS_FREQ_Q9 )), NMS_Scale:Ing_NMS_Sev_Q9*NMS_Scale:Ing_NMS_FREQ_Q9 ), ( else, 0 ))
Ing_Score_D2	Ing_Score_D2	Derivation	sum( [ NMS_Scale:Ing_NMS_SEFR_Q3, NMS_Scale:Ing_NMS_SEFR_Q4, NMS_Scale:Ing_NMS_SEFR_Q5, NMS_Scale:Ing_NMS_SEFR_Q7 ] )
Ing_Score_D3	Ing_Score_D3	Derivation	sum( [ NMS_Scale:Ing_NMS_SEFR_Q8, NMS_Scale:Ing_NMS_SEFR_Q9, NMS_Scale:IngNMS_SEFR_Q11, NMS_Scale:IngNMS_SEFR_Q12, NMS_Scale:IngNMS_SEFR_Q13, NMS_Scale:IngNMS_SEFR_Q14 ] )
Ing_Score_D4	Ing_Score_D4	Derivation	sum( [ NMS_Scale:IngNMS_SEFR_Q15, NMS_Scale:IngNMS_SEFR_Q16, NMS_Scale:IngNMS_SEFR_Q17 ] )
Ing_Score_D5	Ing_Score_D5	Derivation	sum( [ NMS_Scale:IngNMS_SEFR_Q18, NMS_Scale:IngNMS_SEFR_Q19, NMS_Scale:IngNMS_SEFR_Q20 ] )
Ing_Score_D6	Ing_Score_D6	Derivation	sum( [ NMS_Scale:IngNMS_SEFR_Q21, NMS_Scale:IngNMS_SEFR_Q22, NMS_Scale:IngNMS_SEFR_Q23 ] )
Ing_Score_D7	Ing_Score_D7	Derivation	sum( [ NMS_Scale:IngNMS_SEFR_Q24, NMS_Scale:IngNMS_SEFR_Q25, NMS_Scale:IngNMS_SEFR_Q26 ] )
Ing_Score_D9	Ing_Score_D9	Derivation	sum( [ NMS_Scale:IngNMS_SEFR_Q29, NMS_Scale:IngNMS_SEFR_Q30, NMS_Scale:IngNMS_SEFR_Q31, NMS_Scale:IngNMS_SEFR_Q32 ] )
Ing_Total_Score	Ing_Total_Score	Derivation	sum( [ NMS_Scale:Ing_Score_D1, NMS_Scale:Ing_Score_D2, NMS_Scale:Ing_Score_D3, NMS_Scale:Ing_Score_D4, NMS_Scale:Ing_Score_D5, NMS_Scale:Ing_Score_D6, NMS_Scale:Ing_Score_D7, NMS_Scale:Ing_Score_D8, NMS_Scale:Ing_Score_D9 ] )
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q10) and isknown( NMS_Scale: IngNMS_FREQ_Q10)), NMS_Scale: Ing_NMS_Sev_Q10*NMS_Scale: IngNMS_FREQ_Q10), ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q11) and isknown( NMS_Scale: IngNMS_FREQ_Q11)), NMS_Scale: Ing_NMS_Sev_Q11*NMS_Scale: IngNMS_FREQ_Q11), ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q12) and isknown( NMS_Scale: IngNMS_FREQ_Q12)), NMS_Scale: Ing_NMS_Sev_Q12*NMS_Scale: IngNMS_FREQ_Q12), ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q13) and isknown( NMS_Scale: IngNMS_FREQ_Q13)), NMS_Scale: Ing_NMS_Sev_Q13*NMS_Scale: IngNMS_FREQ_Q13), ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q14) and isknown( NMS_Scale: IngNMS_FREQ_Q14)), NMS_Scale: Ing_NMS_Sev_Q14*NMS_Scale: IngNMS_FREQ_Q14), ( else, 0 ))

CODE	NAME	TYPE	EXPRESSION
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q15) and isknown( NMS_Scale: IngNMS_FREQ_Q15)), NMS_Scale: Ing_NMS_Sev_Q15*NMS_Scale: IngNMS_FREQ_Q15) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q16) and isknown( NMS_Scale: IngNMS_FREQ_Q16)), NMS_Scale: Ing_NMS_Sev_Q16*NMS_Scale: IngNMS_FREQ_Q16) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q17) and isknown( NMS_Scale: IngNMS_FREQ_Q17)), NMS_Scale: Ing_NMS_Sev_Q17*NMS_Scale: IngNMS_FREQ_Q17) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q18) and isknown( NMS_Scale: IngNMS_FREQ_Q18)), NMS_Scale: Ing_NMS_Sev_Q18*NMS_Scale: IngNMS_FREQ_Q18) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q19) and isknown( NMS_Scale: IngNMS_FREQ_Q19)), NMS_Scale: Ing_NMS_Sev_Q19*NMS_Scale: IngNMS_FREQ_Q19) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q20) and isknown( NMS_Scale: IngNMS_FREQ_Q20)), NMS_Scale: Ing_NMS_Sev_Q20*NMS_Scale: IngNMS_FREQ_Q20) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q21) and isknown( NMS_Scale: IngNMS_FREQ_Q21)), NMS_Scale: Ing_NMS_Sev_Q21*NMS_Scale: IngNMS_FREQ_Q21) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q22) and isknown( NMS_Scale: IngNMS_FREQ_Q22)), NMS_Scale: Ing_NMS_Sev_Q22*NMS_Scale: IngNMS_FREQ_Q22) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q23) and isknown( NMS_Scale: IngNMS_FREQ_Q23)), NMS_Scale: Ing_NMS_Sev_Q23*NMS_Scale: IngNMS_FREQ_Q23) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q24) and isknown( NMS_Scale: IngNMS_FREQ_Q24)), NMS_Scale: Ing_NMS_Sev_Q24*NMS_Scale: IngNMS_FREQ_Q24) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q25) and isknown( NMS_Scale: IngNMS_FREQ_Q25)), NMS_Scale: Ing_NMS_Sev_Q25*NMS_Scale: IngNMS_FREQ_Q25) , ( else, 0 ))
IngNMS_SEFR	IngNMS_SEFR	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q26) and isknown( NMS_Scale: IngNMS_FREQ_Q26)), NMS_Scale: Ing_NMS_Sev_Q26*NMS_Scale: IngNMS_FREQ_Q26) , ( else, 0 ))

CODE	NAME	TYPE	EXPRESSION
IngNMS_SEF	IngNMS_SEF	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q27) and isknown( NMS_Scale: IngNMS_FREQ_Q27)), NMS_Scale: Ing_NMS_Sev_Q27*NMS_Scale: IngNMS_FREQ_Q27) , ( else, 0 ))
IngNMS_SEF	IngNMS_SEF	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q28) and isknown( NMS_Scale: IngNMS_FREQ_Q28)), NMS_Scale: Ing_NMS_Sev_Q28*NMS_Scale: IngNMS_FREQ_Q28) , ( else, 0 ))
IngNMS_SEF	IngNMS_SEF	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q29) and isknown( NMS_Scale: IngNMS_FREQ_Q29)), NMS_Scale: Ing_NMS_Sev_Q29*NMS_Scale: IngNMS_FREQ_Q29) , ( else, 0 ))
IngNMS_SEF	IngNMS_SEF	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q30) and isknown( NMS_Scale: IngNMS_FREQ_Q30)), NMS_Scale: Ing_NMS_Sev_Q30*NMS_Scale: IngNMS_FREQ_Q30) , ( else, 0 ))
IngNMS_SEF	IngNMS_SEF	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q31) and isknown( NMS_Scale: IngNMS_FREQ_Q31)), NMS_Scale: Ing_NMS_Sev_Q31*NMS_Scale: IngNMS_FREQ_Q31) , ( else, 0 ))
IngNMS_SEF	IngNMS_SEF	Derivation	case((( isknown( NMS_Scale: Ing_NMS_Sev_Q32) and isknown( NMS_Scale: IngNMS_FREQ_Q32)), NMS_Scale: Ing_NMS_Sev_Q32*NMS_Scale: IngNMS_FREQ_Q32) , ( else, 0 ))
IngSUM_ZBI_a	IngSUM_ZBI_a	Derivation	sum( [ ZaritBurden:hidIngZBI_Q1, ZaritBurden:hidIngZBI_Q2, ZaritBurden:hidIngZBI_Q3, ZaritBurden:hidIngZBI_Q4, ZaritBurden:hidIngZBI_Q5, ZaritBurden:hidIngZBI_Q6, ZaritBurden:hidIngZBI_Q7, ZaritBurden:hidIngZBI_Q8, ZaritBurden:hidIngZBI_Q9, ZaritBurden:hidIngZBI_Q10, ZaritBurden:hidIngZBI_Q11, ZaritBurden:hidIngZBI_Q12, ZaritBurden:hidIngZBI_Q13, ZaritBurden:hidIngZBI_Q14, ZaritBurden:hidIngZBI_Q15, ZaritBurden:hidIngZBI_Q16, ZaritBurden:hidIngZBI_Q17, ZaritBurden:hidIngZBI_Q18, ZaritBurden:hidIngZBI_Q19, ZaritBurden:hidIngZBI_Q20, ZaritBurden:hidIngZBI_Q21, ZaritBurden:hidIngZBI_Q22] )
IngSUMall	IngSUMall	Derivation	sum( [ PDQ8:hidIngPDQ8_Q1, PDQ8:hidIngPDQ8_Q2, PDQ8:hidIngPDQ8_Q3, PDQ8:hidIngPDQ8_Q4, PDQ8:hidIngPDQ8_Q5, PDQ8:hidIngPDQ8_Q6, PDQ8:hidIngPDQ8_Q7, PDQ8:hidIngPDQ8_Q8] )
Ing01UPDRS_1	Ing01UPDRS_1	Derivation	UPDRSII_AD.L:IngADL5 + UPDRSII_AD.L:IngADL6 + UPDRSII_AD.L:IngADL7 + UPDRSII_AD.L:IngADL8 + UPDRSII_AD.L:IngADL9 + UPDRSII_AD.L:IngADL10 + UPDRSII_AD.L:IngADL11 + UPDRSII_AD.L:IngADL12 + UPDRSII_AD.L:IngADL13 + UPDRSII_AD.L:IngADL14 + UPDRSII_AD.L:IngADL15 + UPDRSII_AD.L:IngADL16 + UPDRSII_AD.L:IngADL17
IngADL10	IngADL10	Derivation	case((isknown( UPDRSII_AD.L:cat01UPDRS_2_10 ), UPDRSII_AD.L:cat01UPDRS_2_10), (else, 0))
IngADL11	IngADL11	Derivation	case((isknown( UPDRSII_AD.L:cat01UPDRS_2_11 ), UPDRSII_AD.L:cat01UPDRS_2_11), (else, 0))
IngADL12	IngADL12	Derivation	case((isknown( UPDRSII_AD.L:cat01UPDRS_2_12 ), UPDRSII_AD.L:cat01UPDRS_2_12), (else, 0))

CODE	NAME	TYPE	EXPRESSION
IngADL13	IngADL13	Derivation	case((isknown( UPDRSII_ADL:cat01UPDRS_2_13 ), UPDRSII_ADL:cat01UPDRS_2_13), (else, 0))
IngADL14	IngADL14	Derivation	case((isknown( UPDRSII_ADL:cat01UPDRS_2_14 ), UPDRSII_ADL:cat01UPDRS_2_14), (else, 0))
IngADL15	IngADL15	Derivation	case((isknown( UPDRSII_ADL:cat01UPDRS_2_15 ), UPDRSII_ADL:cat01UPDRS_2_15), (else, 0))
IngADL16	IngADL16	Derivation	case((isknown( UPDRSII_ADL:cat01UPDRS_2_16 ), UPDRSII_ADL:cat01UPDRS_2_16), (else, 0))
IngADL17	IngADL17	Derivation	case((isknown( UPDRSII_ADL:cat01UPDRS_2_17 ), UPDRSII_ADL:cat01UPDRS_2_17), (else, 0))
IngADL5	IngADL5	Derivation	case((isknown( UPDRSII_ADL:cat01UPDRS_2_5 ), UPDRSII_ADL:cat01UPDRS_2_5), (else, 0))
IngADL6	IngADL6	Derivation	case((isknown( UPDRSII_ADL:cat01UPDRS_2_6 ), UPDRSII_ADL:cat01UPDRS_2_6), (else, 0))
IngADL7	IngADL7	Derivation	case((isknown( UPDRSII_ADL:cat01UPDRS_2_7 ), UPDRSII_ADL:cat01UPDRS_2_7), (else, 0))
IngADL8	IngADL8	Derivation	case((isknown( UPDRSII_ADL:cat01UPDRS_2_8 ), UPDRSII_ADL:cat01UPDRS_2_8), (else, 0))
IngADL9	IngADL9	Derivation	case((isknown( UPDRSII_ADL:cat01UPDRS_2_9 ), UPDRSII_ADL:cat01UPDRS_2_9), (else, 0))
IngMMSE_tot	IngMMSE_tot	Derivation	IngMMSE1 + IngMMSE2 + IngMMSE3 + IngMMSE4 + IngMMSE5 + IngMMSE6 + IngMMSE7 + IngMMSE8 + IngMMSE9 + IngMMSE10 + IngMMSE11 + IngMMSE12 + IngMMSE13 + IngMMSE_scale3 + IngMMSE19 + IngMMSE20 + IngMMSE21 + IngMMSE22 + IngMMSE23 + IngMMSE24 + IngMMSE25 + IngMMSE26 + IngMMSE27 + IngMMSE28 + IngMMSE29 + IngMMSE30
IngSite	IngSite	Derivation	case((person:trialsite like 'clasp01', 1), (person:trialsite like 'clasp02', 2), (person:trialsite like 'clasp03', 3), (person:trialsite like 'clasp04', 4), (person:trialsite like 'clasp05', 5), (person:trialsite like 'clasp06', 6), (person:trialsite like 'clasp07', 7), (person:trialsite like 'clasp08', 8), (person:trialsite like 'training', 99))
IngUPDRSIII_tot	IngUPDRSIII_tot	Derivation	IngUPDRSIII_18 + IngUPDRSIII_19 + IngUPDRSIII_20 + IngUPDRSIII_20b + IngUPDRSIII_20c + IngUPDRSIII_20d + IngUPDRSIII_20e + IngUPDRSIII_21 + IngUPDRSIII_21b + IngUPDRSIII_22 + IngUPDRSIII_22b + IngUPDRSIII_22c + IngUPDRSIII_22d + IngUPDRSIII_22e + IngUPDRSIII_23 + IngUPDRSIII_23b + IngUPDRSIII_24 + IngUPDRSIII_24b + IngUPDRSIII_25 + IngUPDRSIII_25b + IngUPDRSIII_26 + IngUPDRSIII_26b + IngUPDRSIII_27 + IngUPDRSIII_28 + IngUPDRSIII_29 + IngUPDRSIII_30 + IngUPDRSIII_31
IngUPDRSIV_tot	IngUPDRSIV_tot	Derivation	IngUPDRSIV_32 + IngUPDRSIV_33 + IngUPDRSIV_34 + IngUPDRSIV_35 + IngUPDRSIV_36 + IngUPDRSIV_37 + IngUPDRSIV_38 + IngUPDRSIV_39 + IngUPDRSIV_40 + IngUPDRSIV_41 + IngUPDRSIV_42
RealNr_loWS	RealNr_loWS	Derivation	sum( [ (( SMILE:hid_IngCatImA1/SMILE:hidIngImpoSum )*SMILE:hid_realnrCatA1 )+(( SMILE:hid_IngCatImA2/SMILE:hidIngImpoSum )*SMILE:hid_realnrCatA2 )+(( SMILE:hid_IngCatImA3/SMILE:hidIngImpoSum )*SMILE:hid_realnrCatA3 )+(( SMILE:hid_IngCatImA4/SMILE:hidIngImpoSum )*SMILE:hid_realnrCatA4 )+(( SMILE:hid_IngCatImA5/SMILE:hidIngImpoSum )*SMILE:hid_realnrCatA5 )+(( SMILE:hid_IngCatImA6/SMILE:hidIngImpoSum )*SMILE:hid_realnrCatA6 )+(( SMILE:hid_IngCatImA7/SMILE:hidIngImpoSum )*SMILE:hid_realnrCatA7 ) ] )
strSite	strSite	Derivation	case((IngSite=1, '01 University College London'), (IngSite=2, '02 University of Marburg'), (IngSite=3, '03 University of Lisbon'), (IngSite=4, '04 University of Bordeaux'), (IngSite=5, '05 Lund University'), (IngSite=6, '06 University of Nijmegen'), (IngSite=7, '07 University of Munich'), (IngSite=8, '08 Geriatrie-Zentrum Essen'), (IngSite=99, '!!! TRAINING MODE!!!'), (else, '!!! PLEASE CONTACT KKS !!!'))

CODE	NAME	TYPE	EXPRESSION
strSite_check	strSite_check	Derivation	case((Cover:IngSite=99, 'ATTENTION: Study Centre is !!! TRAINING MODE !!! Please use training mode with dummy data before entering real trial subjects. After training done please use ACTIVATE ACCOUNT. The activation of your account for your center is accessible at the home area.'), (else, 'Site check OK. User account is activated for your site to document patients in productive environment.'))