# **SUPPLEMENTARY MATERIALS**

Supplement #1.
Cognitive Pretesting Manual for Round 1
(Verbal Probing)

Name of Interviewer	
/ /	

## Cognitive Pretesting Manual for UPDRS

Cognitive testing of data collection instruments involves the use of techniques to elicit respondents' interpretations of the items/questions in the instrument being tested. It may test both usability and comprehension so that revisions can be made to enhance both before putting the instrument into practice for its intended purpose. For UPDRS, cognitive testing will involve indepth interviews with patients and data gathering from both raters and patients to understand any difficulties patients may have with understanding, as well as gathering responses from the raters administering the instrument related to ease of use.

Please review the entire testing manual before initiating a cognitive test to ensure you are familiar with the flow of cognitive testing questions interspersed with the shaded UPDRS segments.

All instructions and questions that are part of the standard UPDRS instrument (i.e., what is being tested) appear in areas that are lightly shaded gray in this cognitive testing manual. All non-shaded areas are part of the cognitive testing script.

In the non-shaded areas of the cognitive testing script throughout the manual, words that are boxed in are instructions to or questions for the rater only. Questions and instructions from UPDRS should be read/used verbatim. Please respond to all cognitive testing questions or mark them N/A if the question is not applicable for any reason. Your involvement and patience in conducting these in-depth interviews and recording the cognitive testing responses will be invaluable in making the UPDRS instrument as usable in a consistent manner for raters and correctly interpretable to patients as possible.

Words that are boxed in are questions to be asked of the patient. All cognitive testing responses from either the rater or the patient are to be recorded in the space provided. Patient responses should be captured in their own words whenever possible. In general, after each UPDRS question, there will be some cognitive testing questions addressed only to the rater related to ease of use. These will be interspersed with cognitive testing questions to be addressed to the patient by the rater about the patient's understanding of the question and the response options. These cognitive testing questions can be visibly distinguished by boxed questions for the rater and non-boxed questions for the patient.

#### Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)

Overview: This portion of the scale assesses the non-motor impact of Parkinson's disease (PD) on patients' experiences of daily living. These items include patient perceptions of aspects of both PD and its treatment and include behavioral as well as autonomic nervous system symptoms. Because the data source is subjective and historical in nature, the section is similar to Part II (see later, Motor Aspects of Experiences of Daily Living) in structure and rating guidelines, but Part I focuses on the **non-motor** consequences of living with PD.

In administering Part I of the UPDRS the examiner should comply with the following guidelines:

- 1. The response to each item on the scale should come primarily from the patient whenever possible and not the caregiver or examiner. If the patient is demented, confused or has an altered level of consciousness, the caregiver should then be consulted. Mark at the top of the form the primary data source as patient, caregiver, or patient and caregiver in equal proportion.
- 2. The response to each item should refer to a period encompassing the prior week including the day on which the information is collected.
- 3. This portion of the UPDRS is concerned only with disabilities due to PD. Patients should be instructed that physical or behavioral impairments due to other co-existent conditions should not be considered in their responses. Patients should respond to each item with the option that corresponds best to their CURRENT disabilities (slight, mild, moderate, severe). "Normal" should be marked if the item has not been affected by PD.
- 4. For this scale, use the following definition of ON and OFF:
  - **ON** is the typical functional state when patients are receiving medication and have a good response.
- **OFF** is the typical functional state when patients have a poor response in spite of taking medications or the typical functional response when patients are on NO treatment for parkinsonism
- 5. The response should represent typical or average function in the ON and OFF states during the past week. The examiner should instruct patients to avoid considering their very best or worst level of function by using phrases such as "in most circumstances" or "usually".
- 6. ON and OFF designations are provided next to each item of this Part of the UPDRS.
  - o In patients on symptomatic therapy for PD, without motor fluctuations, Part I is completed once in the ON column.
  - o If patients have motor fluctuations, each item should be completed twice, once for typical ON function and once for typical OFF function.
  - o For some experiences, (Sleep, Constipation and possibly others), the answers cannot be easily divided into separate ON and OFF responses. In such cases, the same answer should be entered into both ON and OFF columns for motor fluctuators.
  - o If patients are not on any symptomatic treatment for PD, scores should be entered once in the OFF column.

- 7. The nM-EDL section attempts to capture adaptations made for disabilities. Any adaptation that has been made in response to PD symptoms is an impairment, even if tasks are performed without difficulty once the adaptation has been made. These adaptive changes should be considered in scoring each item.
- 8. All items must have an integer rating (no half points, no missing scores). In the event that an item does not apply or cannot be rated (e.g., amputee who cannot walk), the item is marked **UR** for Unable to Rate.

Cognitive Test Question for Rater:
Were there any parts of the instructions on the previous page titled "Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)" that were difficult for you as rater to understand or that require clarification?
INCTRICTIONS TO SUINISAN ADMINISTEDING UPDDS
INSTRUCTIONS TO CLINICAN ADMINISTERING UPDRS
For Parts I, II and IV: Each question rates a specific item of interest. All questions have the following form:
On the average during the past week, have you experienced ' <u>item</u> ' as a result of your PD? By ' <u>item</u> ', I mean ' <u>'issues of focus</u> ''.
EXAMPLE OF NAVIGATING THROUGH THE RESPONSE OPTIONS FOR EACH QUESTION

Sample Instructions to Patient:

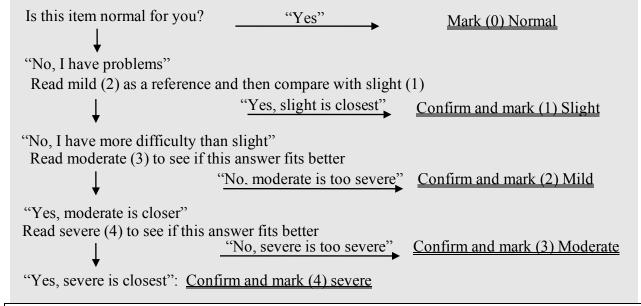
Normal vs not normal: The first response option is normal, used when no aspect of the disability described in <u>item</u> is present. If your response is 'normal', then let's move on to the next question category. {Record 0}

Establish an anchor: Mild: If your response is not 'normal', let's jump into a mid range or 'mild' impact just as an anchor of reference. By 'mild', we mean {read definition for mild}. With this definition in mind let's check to make sure the responses on either side of it do not sound like a better fit.

Slight vs. Mild: The response between 'normal' and 'mild' is 'slight' impact. By 'slight', we mean {read definition}. Does 'mild' or 'slight' fit your situation better? {If 'slight', record 1 and go to next question.}

Mild vs. Moderate: The first response that falls on the other side of 'mild' is 'moderate' impact. By 'moderate', we mean {read definition}. Does 'mild' or 'moderate' fit your situation better? {If 'mild', record 2 and go to next question.}

Moderate vs. Severe: The final response option that falls on the far side of 'moderate' is 'severe' impact. By 'severe', we mean {read definition}. Does 'moderate' or 'severe' fit your situation better? {Record response 3 or 4 and go to next question.}



#### **Cognitive Test Question for Rater:**

Were there any parts of the instructions on the previous page titled "INSTRUCTIONS TO CLINICAN ADMINISTERING UPDRS" that were difficult for you as rater to understand or that require clarification?

Y/N If yes, please circle those segments on the previous page and explain below what clarifications are needed.

### **Instructions to Patient about Cognitive Testing:**

The UPDRS assessment questionnaire is a tool used to help clinicians understand the impact of PD on the daily life activities of persons with PD. Thank you for participating with us in this test of the UPDRS assessment tool. It is very important to us that you describe any difficulties you have responding to particular questions as truthfully as possible. This is not a test of your intelligence but of how good we have been at developing an assessment tool that people with Parkinson's disease can understand easily. If you have difficulty in understanding anything I say to you, you are probably not alone and other people would also have the same difficulty. It is important for us to know this so that we can change the wording and make it easier for everyone to understand and answer consistently. Please do not hesitate to tell me when anything — instructions or questions - I say is confusing to you, including any medical terms.

We will do the test together by my reading each instruction or question to you the way it would be done in a regular assessment. After each question, we will then stop and talk about any parts of the instruction or question that were confusing to you.

#### INSTRUCTIONS TO PATIENT

#### [Sample script to read to patient]

I am going to ask you a series of questions about how your PD affects your daily life. The focus is on what you consider to be problems with daily experiences related to PD, not other health issues. It may be hard to differentiate, but try to exclude impacts you may have on your daily life from other health problems.

In answering all of the questions, I would like you to think about the past week including today and about a typical or usual effect, not the worst or the best effect.

The first response option to each question will be 'no problem' or 'normal'. If your answer is not normal, then there are different choices and we will explore the choices until we get the best answer.

#### **Cognitive Test Question for patient:**

Were there any parts of the instructions I just gave you that were difficult to understand or require clarification?

\_\_\_\_Y/N If yes, please circle those segments above and explain below what clarifications are needed.

(If a quota have in muca out)							
{ <i>If caretaker is present</i> }  Do you need to have your caretaker participate in helping you evaluate which response option							
fits best to describe the impact of PD on your daily living? {Record response below}							
Primary source of information:PatientCaregiverPatient and Caregiver in Equal Proportion							
Are you currently receiving medication to treat the symptoms of your Parkinson's disease? If you are receiving medicine for your PD, some people will have a different effect or impact when the medicine works from when it doesn't. Others just have a steady response. I will try to determine whether we need two responses or one. In general, would you say that you have a good response to your medication at the beginning of the dose and then a worse response toward the end of the dose or are you by-and-large stable? {Record response below} Patient not on symptomatic medication: complete Part I in OFF column onlyPatient has both ON and OFF Responses: complete Part I in ON and OFF columnsPatient on symptomatic medication has only one stable response: complete Part I in ON column							
Cognitive Test Question for patient:							
Were any parts of the instructions I just gave you about responding when you are on symptomatic medication difficult to understand or needing clarification?  Y/N If yes, please circle those segments above and explain below what clarifications are needed.							
Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)							
1.1 COGNITIVE IMPAIRMENT * - On the average during the past week, have you experienced cognitive or thinking impairment as a result of your PD? By "cognitive impairment", I mean cognitive or thinking deficits including overall intellectual function, attention, memory, mental flexibility or ability to juggle multiple mental tasks simultaneously and speed of thinking. I want to know if you have any problems and if so the extent of interference with your daily life.	ON	OFF					
0: Normal. No mental impairment.							
1: <u>Slight.</u> Impairment only recognized by you with no concrete interference with your ability							
to carry out normal activities and interactions.							
2: <u>Mild</u> . Cognitive impairment recognized by caregiver or others, but it causes no or only minimal interference with your ability to carry out daily activities and interactions.							
3: Moderate. Cognitive deficits interfere with but do not preclude your ability to carry out							

\*see Appendix for more detailed rating scales on this item

daily activities and interactions.

interactions.

4: Severe. Cognitive dysfunction precludes your ability to carry out daily activities and

Ra	Rater Experience Posing UPDRS Question (no patient involvement):									
1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)										
	Very difficult	1	2	3	4	5	6	Very Easy		
2.	2. Rater notes difficulties using the question below (Mark each item Y or N):									
_ Rater experienced difficulty reading question (Underline problematic parts above. Explain difficulty below)										
	Rater asked to repeat				on (Br	acket	repea	ated parts above)		
_	Rater had difficulty ex Other rater issue (pleas		-							

3.	How easy or	difficult is t	his question	for you to u	understand? (	(Circle choice)	į
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Very difficult 1 2 3 4 5 6 Very Easy

4.	What parts of the question were difficult to understand? What was the difficulty? (Circle these on form and explain why they were difficult)
5.	What do you understand by the following words?
	<ul> <li>"impairments or deficits"         Understood correctly? (Y/N)         What words would be easier to understand to capture the meaning? (Record suggestions)     </li> </ul>
	<ul> <li>"preclude"         Understood correctly? (Y/N)         What words would be easier to understand to capture the meaning? (Record suggestions)     </li> </ul>
Qι	nestions for the patient after they have decided on a rating:
6.	How easy or difficult was it for you to rate your answer to that question?
	Very difficult 1 2 3 4 5 6 Very Easy
	What made it difficult to rate?
	Suggested solution?
7.	Who answered this item? Patient primarily Caregiver primarily Both

1.2 HALLUCINATIONS * - On the average during the past week, have you experienced hallucinations as a result of your PD? By "hallucinations", I include misinterpretations of real stimuli, like thinking a lamp is a person, and spontaneous false sensations, whether those are visions, sounds, smells, tastes, or feelings of things touching your body. These problems may be vague feelings like a sense of something in the room or beside you that you cannot completely make out or highly formed and detailed. It is also important for me to understand whether you retain insight and recognize these hallucinations as not real or if insight is lost and you become convinced that they are real. Finally, you must rate if these problems are associated with convictions that are illogical or outside reality, termed delusions, and if they are associated with suspicious or fearful feelings, termed paranoia.	ON	OFF			
<ol> <li>Normal. No misinterpretations or hallucinations</li> <li>Slight. Misinterpretations of real stimuli or poorly-formed hallucinations, but you recognize them as unreal and they have no impact on daily activities or interactions.</li> <li>Mild. Formed hallucinations, but you recognize them as unreal and they have no or minimal impact on daily activities or interactions.</li> <li>Moderate. Misinterpretations or hallucinations of any type with loss of insight, affecting activities or interactions. No delusions, no paranoia.</li> <li>Severe. Misinterpretations or hallucinations with psychotic thinking, delusions or paranoia.</li> </ol>					
Rater Experience Posing UPDRS Question (no patient involvement):  1. Rater reads the question to the patient. How easy or difficult is it for you as the rater to use the current wording of the question verbatim? (Circle choice)  Very difficult 1 2 3 4 5 6 Very Easy  2. Rater notes difficulties using the question below (Mark each item Y or N):  Rater experienced difficulty reading question (Underline problematic parts above. Explain difficulty below)  Rater asked to repeat all or part of question (Bracket repeated parts above)  Rater had difficulty explaining question  Other rater issue (please specify)					

	<b>3.</b> How easy or difficult is this question for you to understand? (Circle choice)										
	Ve	ery difficult	1	2	3	4	5	6	Very Easy		
		What parts of th	-						rstand? What was the difficulty?		
	<b>5.</b> °	What do you und "hallucinations" Understood cor What words word	rectly	/? (Y	/N) _		_		eture the meaning? (Record suggestions)		
	0	"misinterpretati Understood cor What words woo	rectly				stand	to cap	oture the meaning? (Record suggestions)		
	0	"psychotic think Understood cor What words woo	rectly			under	stand	to cap	oture the meaning? (Record suggestions)		
Qu	ıest	ions for the pation	ent aft	er th	ey h	ave d	ecide	ed on a	a rating:		
	6.	How easy or diff	ficult	was i	t for	you to	o rate	your	answer to that question?		
Very difficult 1 2 3 4 5 6 Very Easy What made it difficult to rate?											
	Su	uggested solution	?								
	7.	Who answered Both	this it	tem?		Patie	nt pr	imari	ly Caregiver primarily		

de	B DEPRESSED MOOD * - On the average during the past week, have you experienced pressed mood as a result of your PD? By "depressed mood", I mean low mood, sadness loss of enjoyment, and if so, I am interested in how these feelings affect normal
	tivities and interactions.
0:	Normal. No depressed mood.
1:	Slight. Depressed mood occurs, but causes no interference with you ability to carry out
	daily activities and interactions.
2:	Mild. Depressed mood occurs, but with minimal impact on your ability to carry out daily
	activities and interactions.
3:	Moderate. Depressed mood considerably interferes with, but does not preclude, your ability
	to carry out daily activities and interactions.
4:	Severe. Depressed mood precludes your ability to carry out daily activities and interactions.

. Rater reads the quise the current wording			•				or difficult is it for you <u>as the rater</u> to e choice)
Very difficult	1	2	3	4	5	6	Very Easy
Explain difficulty	below) peat all lty expl	) l or p lainii	art o 1g qu	of quo	estio n	ı (Bra	nderline problematic parts above.

3.	How easy or diffi	cult is	this	quest	tion f	or yo	u to und	lerstand? (Circle choice)
Ve	ry difficult	1	2	3	4	5	6	Very Easy

	. How easy or d	ifficult	was i	t for	you t	o rate	your an	nswer to that question?
What made it difficult to rate?  Suggested solution?	Very difficult	1	2	3	4	5	6	Very Easy
Suggested solution?	What made it diffi	cult to	rate?					
Suggested solution?								
	Suggested solution	n?						

4. What parts of the question were difficult to understand? What was the difficulty? (Circle these on form and explain why they were difficult)

- 1.4 ANXIOUS MOOD On the average during the past week, have you experienced anxious mood as a result of your PD? By "anxious mood", I mean nervous, worried, tense and anxious feelings as well as episodes of sudden panic, called panic attacks. If these problems occur, I am interested in the extent to which they interfere with your ability to carry out daily activities and interactions.
- 0: Normal. No anxious feelings and no panic attacks.
- 1: <u>Slight</u>. Anxious feelings occur, but there is no interference with your ability to carry out daily activities and interactions. No panic attacks.
- 2: <u>Mild</u>. Anxious feelings occur and cause minimal interference with your ability to carry out daily activities and interactions. No panic attacks.
- 3: <u>Moderate</u>. Anxious feelings (that may include panic attacks) considerably interfere with, but do not preclude, your ability to carry out daily activities and interactions.
- 4: <u>Severe.</u> Anxious feelings (that may include panic attacks) preclude your ability to carry out daily activities and interactions.

\*see Appendix for more detailed rating scales on this item

Rater reads the questions the questions current wording			•			·	or difficult is it for you <u>as the rater</u> to ele choice)
Very difficult	1	2	3	4	5	6	Very Easy
 Rater experience Explain difficulty Rater asked to re Rater had difficu	d diffic below) peat all	ulty       or p   ainii	readi part o	ing q of que	uesti estio on	on (U n (Bra	(Mark each item Y or N):  Inderline problematic parts above.  Acket repeated parts above)

	3.	How easy or di	fficult	is this	s que	stion	for y	ou to	o understand? (Circle choice)
	Ve	ry difficult	1	2	3	4	5	6	Very Easy
		nat parts of the q ircle these on fo							tand? What was the difficulty? e difficult)
	4.	What do you ur	ndersta	nd by	the	follov	wing	word	ds?
	0	"episodes" Understood co What words wo				under	- rstanc	l to ca	apture the meaning? (Record suggestions)
	0	"panic attacks" Understood co What words wo	rrectly				- rstanc	l to c	apture the meaning? (Record suggestions)
Qι	ıesti	ions for the pati	ent aft	<u>ter th</u>	ey h	ave d	lecid	ed on	ı a rating:
	6.	How easy or dif	ficult v	vas it	for y	you to	rate	your	answer to that question?
	Ve	ry difficult	1	2	3	4	5	6	Very Easy
	Wl	nat made it diffic	cult to r	rate?					
	Su	ggested solution	?						
	7.	Who answered Both	this it	em?	1	Patie	nt pr	imar	rily Caregiver primarily

result of your PD? I initiative within the o	By "apathy",	I mean los	s or lack	κ, have you experienced ap κ of assertiveness, motivati	-	
): Normal. No apath		<b>J</b>				
: Slight. Reduced a activities and inter		motivation of	or initiati	ive, but no interference with	daily	
: Mild. Reduced as and interactions.	sertiveness, n	notivation or	· initiativ	ve that interferes with isolate	ed activities	
: Moderate. Reduce activities and inter				tiative that interferes with n	nost	
	n, loss of asse		-	on or initiative that preclude	s daily	
ater Experience Pos	ing UPDRS (	Question (n	o patien	nt involvement):		
	e question to	the patient	. How ea	asy or difficult is it for you	ı <u>as the</u>	
1. Rater reads the rater to use the current wordin  Very difficult	e question to g of the ques 1 2	the patient tion verbat	. How eadim? (Cin	asy or difficult is it for your		
1. Rater reads the rater to use the current wordin  Very difficult  2. Rater notes diff	e question to g of the ques 1 2 iculties using	the patient tion verbat 3 4 5 g the questi	. How eadim? (Cin 6 on below	asy or difficult is it for you rcle choice) Very Easy w (Mark each item Y or N	):	
rater to use the current wordin  Very difficult  2. Rater notes diff	e question to g of the ques 1 2 iculties using	the patient tion verbat 3 4 5 g the questi	. How eadim? (Cin 6 on below	asy or difficult is it for you rcle choice) Very Easy	):	

3 . How easy or difficult is this question for you to understand? (Circle choice)

	Very difficult	1	2 3	3 4	5	6	Very Easy
	4. What parts of th (Circle these on for						stand? What was the difficulty?  ifficult)
	5. What do you un  o "assertiveness"  Understood con What words wo	rrectly?	(Y/N)	)	_		ure the meaning? (Record suggestions)
<u>Qu</u>	<b>6.</b> How easy or dif						rating:  nswer to that question?
	Very difficult	1	2 3	3 4	5	6	Very Easy
	What made it diffic	ult to rat	re?				
	Suggested solution?	,					
	7. Who answered Both	this ite	m?	_ Patie	ent pr	rimarily	Caregiver primarily

# 1.6 SLEEP PROBLEMS \* - On the average during the past week, have you experienced sleep problems as a result of your PD? By "sleep problems", I mean frequent awakening as a result of your PD.

- 0: Normal. No sleep problems.
- 1: <u>Slight</u>. Minor interference with sleep with occasional awakenings but you easily fall back asleep.
- 2: <u>Mild</u>. Interference with sleep causes awakening 1-3 times per night with difficulty returning to sleep.
- 3: <u>Moderate</u>. Frequent awakenings and sleep interruptions. You are awakening more than 3 times per night with difficulty returning to sleep.
- 4: <u>Severe</u>. Infrequent sleeping. You are awake for more than 4 hours during the usual sleeping hours.

#### **Rater Experience Posing UPDRS Question (no patient involvement):**

	1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)									
	Very difficult	1	2	3	4	5	6	Very Easy		
2.	Rater notes dif	ficultie	es usi	ng th	e qu	estio	n belo	ow (Mark each item Y or N):		
	xplain difficulty below	) repeat culty ex	all oi xplaii	r par	t of q	quest tion	ion (B	(Underline problematic parts above.  Bracket repeated parts above)		
_										
_										

#### Questions for the patient after they have heard the UPDRS question:

3. How easy or difficult is this question for you to understand? (Circle choice)

	Very	difficult	1	2	3	4	5	6	Very Easy
		What parts of the	-						erstand? What was the difficulty?  difficult)
Qu	estio	ns for the patier	nt aft	er the	ey ha	ave d	ecide	ed on	a rating:
	<b>5.</b> 1	How easy or diff	icult	was i	t for	you t	o rate	e you	r answer to that question?
	Very	difficult	1	2	3	4	5	6	Very Easy
	V	Vhat made it diff	ficult	to rat	e?				
	S	uggested solutio	on?						
	6. V	Vho answered t Both	his it	em?	]	Patie	nt pr	imar	ily Caregiver primarily

1.7 DAYTIME SLEEPINESS \* - On the average during the past week, have you experienced daytime sleepiness as a result of your PD? By "daytime sleepiness", I mean difficulty staying awake interferes with your social or individual activities.

- 0: Normal. No daytime sleepiness.
- 1: Slight. Sleepiness occurs but you can resist it and stay awake.
- 2: <u>Mild</u>. You occasionally fall asleep when alone in a relaxing situation such as reading or watching television.
- 3: <u>Moderate</u>. You regularly fall asleep when alone in a relaxing situation such as reading or watching television **or** occasionally fall asleep in inappropriate social circumstances such as eating or conversing with others.
- 4: Severe. Regular falling asleep in socially inappropriate settings.

#### **Rater Experience Posing UPDRS Question (no patient involvement):**

1. Rater reads the question to the patient. How easy or difficult is it for you as the rater to use the current wording of the question verbatim? (Circle choice)								
Very difficult	1	2	3	4	5	6	Very Easy	
2. Rater notes diffic	cultie	s usii	ng th	e qu	estio	n belo	w (Mark each item Y or N):	
Explain difficulty below) Rater asked to re Rater had difficulty	peat :	all or	par	t of q	uest tion	ion (B	Underline problematic parts above. racket repeated parts above)	

#### Questions for the patient after they have heard the UPDRS question:

3. How easy or difficult is this question for you to understand? (Circ	rle choice)	le choice)
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Very difficult 1 2 3 4 5 6 Very Easy

	What parts of the question were difficult to understand? What was the difficulty? ircle these on form and explain why they were difficult)
5.	What do you understand by the following words?
0	"socially inappropriate settings"  Understood correctly? (Y/N)  What words would be easier to understand to capture the meaning? (Record suggestions)
uesti	ons for the patient after they have decided on a rating:
6.	How easy or difficult was it for you to rate your answer to that question?
Ve	ry difficult 1 2 3 4 5 6 Very Easy
	What made it difficult to rate?
	Suggested solution?
7.	Who answered this item? Patient primarily Caregiver primarily
	Both

1.8 PAIN AND ABNORMAL SENSORY SENSATIONS * - On the average during the
past week, have you experienced pain and abnormal sensory sensations as a result of your
PD? By "pain and abnormal sensory sensations", I mean aching, cramping or other
discomfort perceived by you to relate to PD and not to other medical conditions.

- 0: None. No pain or abnormal sensations.
- 1: Slight. Aching, cramping or discomfort, but without effect on daily activities.
- 2: Mild. Aching, cramping or discomfort occasionally interferes with daily activities.
- 3: Moderate. Aching, cramping or discomfort often interferes with daily activities.
- 4: <u>Severe</u>. Aching, cramping or discomfort interferes with daily activities to the point that it is a major contributor to overall disability.

## **Rater Experience Posing UPDRS Question (no patient involvement):**

1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)									
Very difficult	1	2	3	4	5	6	Very Easy		
2. Rater notes diff	ficultie	s usi	ng th	e qu	estio	n belo	w (Mark each item Y or N):		
Explain difficulty below Rater asked to r Rater had diffic	) epeat a ulty ex	all or plair	· par	t of q	ıuest tion	ion (B	Underline problematic parts above. racket repeated parts above)		

#### Questions for the patient after they have heard the UPDRS question:

3. How easy or difficult is this question for you to understand? (Circle choice)

<sup>\*</sup>see Appendix for more detailed rating scales on this item

	What parts of the rcle these on for							erstand? What was the difficulty? e difficult)	
Questio	ons for the patie	nt aft	er th	ey ha	ave d	ecide	ed on a	a rating:	
5.	How easy or diff	icult v	was i	t for	you to	o rate	your	r answer to that question?	
Ver	y difficult	1	2	3	4	5	6	Very Easy	
	What made it dif	ficult	to ra	te?					
	Suggested solution	on?							
6.	Who answered Both	this it	tem?	]	Patie	nt pr	imari	rily Caregiver primarily	

Very difficult 1 2 3 4 5 6 Very Easy

<ol> <li>URINARY PROBLEMS - On the average during the past week, have you experienced urinary problems as a result of your PD? By "urinary problems," I m bothersome urinary frequency, urgency or incontinence.</li> <li>Normal. No urinary problems</li> <li>Slight. Occasional urinary frequency or urgency but no major inconveniences to norma activities.</li> <li>Mild. Urinary frequency or urgency sufficient to cause inconvenience and requiring so adaptations in daily function, although no incontinence.</li> <li>Moderate. Urinary frequency, urgency with occasional incontinence; significantly interferes with daily activities such as social functions.</li> <li>Severe. Frequent urinary incontinence, may need to use catheter.</li> </ol>	nean	OFF
1. Rater reads the question to the patient. How easy or difficult is it for you as the rater to use the current wording of the question verbatim? (Circle choice)  Very difficult 1 2 3 4 5 6 Very Easy  2. Rater notes difficulties using the question below (Mark each item Y or N):  Rater experienced difficulty reading question (Underline problematic parts above Explain difficulty below)  Rater asked to repeat all or part of question (Bracket repeated parts above)  Rater had difficulty explaining question  Other rater issue (please specify)	e	
Questions for the patient after they have heard the UPDRS question:  3. How easy or difficult is this question for you to understand? (Circle choice)  Very difficult 1 2 3 4 5 6 Very Easy		

		What parts of the question were difficult to understand? What was the difficulty? ircle these on form and explain why they were difficult)							
	2.	What do you understand by the following words?							
	0	"urinary urgency"  Understood correctly? (Y/N)  What words would be easier to understand to capture the meaning? (Record suggestions)							
	0	"urinary incontinence"  Understood correctly? (Y/N)  What words would be easier to understand to capture the meaning? (Record suggestions)							
	<ul> <li>"catheter"         Understood correctly? (Y/N)         What words would be easier to understand to capture the meaning? (Record suggestions)     </li> </ul>								
<u>Qu</u>	esti	ions for the patient after they have decided on a rating:							
	6.	How easy or difficult was it for you to rate your answer to that question?							
	Ve	ery difficult 1 2 3 4 5 6 Very Easy							
		What made it difficult to rate?							
		Suggested solution?							
	7.	Who answered this item? Patient primarily Caregiver primarily Both							

1.10 CONSTIPATION IMPACT ON DAILY ACTIVITIES - On the average during the past week, have you experienced an impact from constipation on your daily activities as a result of your PD? By "an impact from constipation", I mean a bothersome change in bowel habits, discomfort, and preoccupation with bowel movements and their impact on independence in daily activities.

- 0: Normal. No constipation.
- 1: <u>Slight</u>. Constipation present, but without impact on daily activities.
- 2: Mild. Constipation has mild impact on daily activities.
- 3: <u>Moderate</u>. Constipation causes significant discomfort or inconvenience that markedly impacts on daily activities
- 4: <u>Severe</u>. Constipation dominates your concerns or you need physical disimpaction for handling constipation.

#### **Rater Experience Posing UPDRS Question (no patient involvement):**

ery difficult		-				`	rcle choice)
•							·
. Rater notes diff	ficultie	es usii	ng th	e qu	estio	n belo	w (Mark each item Y or N):
Explain difficulty below Rater asked to r Rater had diffic	) repeat culty ex	all or	par	t of q	uest tion	ion (B	Underline problematic parts above. racket repeated parts above)
Other rater issu	e (plea	ise sp	ecify	/)			

## Questions for the patient after they have heard the UPDRS question:

3. How easy or difficult is this question for you to understand? (Circle choice)

	Very difficult 1 2 3 4 5 6 Very Easy
	4. What parts of the question were difficult to understand? What was the difficulty? (Circle these on form and explain why they were difficult)
	5. What do you understand by the following words?
	<ul> <li>"physical disimpaction"</li> <li>Understood correctly? (Y/N)</li> <li>What words would be easier to understand to capture the meaning? (Record suggestions)</li> </ul>
<u>Q</u> ı	uestions for the patient after they have decided on a rating:
	6. How easy or difficult was it for you to rate your answer to that question?
	Very difficult 1 2 3 4 5 6 Very Easy
	What made it difficult to rate?
	Suggested solution?
	7. Who answered this item? Patient primarily Caregiver primarily Both

1.11 LIGHTHEADEDNESS ON STANDING - On the average during the past week, have you experienced lightheadedness on standing as a result of your PD? By "lightheadedness", I mean the impact of dizziness on your balance and safety when changing position from lying to sitting and sitting to standing.

- 0: Normal. No lightheadedness.
- 1: <u>Slight</u>. Lightheadedness occurs with changes in posture but has no impact on performance of daily activities.
- 2: <u>Mild.</u> Lightheadedness occurs with changes in posture so that you return to a sitting or lying position to manage symptoms. No falls and no loss of consciousness.
- 3: <u>Moderate</u>. Lightheadedness occurs with changes in position and has been associated with at least one fall in the past week, but without loss of consciousness.
- 4: <u>Severe.</u> Lightheadedness occurs with changes in posture and has been associated with at least one episode of loss of consciousness over the past week.

#### **Rater Experience Posing UPDRS Question:**

1. Rater reads the rater to use the current wording	-			-			easy or difficult is it for you <u>as the</u> Circle choice)
Very difficult	1	2	3	4	5	6	Very Easy
2. Rater notes diff	icultie	es usi	ng th	e qu	estio	n belo	ow (Mark each item Y or N):
Explain difficulty below) Rater asked to r Rater had difficulty	epeat ulty ex	all or xplair	r par	t of q	quest tion	tion (B	(Underline problematic parts above.  Bracket repeated parts above)

<sup>\*</sup>see Appendix for more detailed rating scales on this item

Ve	ry difficult	1	2	3	4	5	6	Very Easy
	What parts of tircle these on fo							rstand? What was the difficulty?
	ions for the pat							n rating: nnswer to that question?
Ve	ry difficult	1	2	3	4	5	6	Very Easy
	What made it o	lifficult	to ra	te?				
	Suggested solu	ution?						

#### UPDRS PART I PATIENT DEBRIEFING

For questions 1-2, the rater summarizes patient's answers to the questions below using patient's own words whenever possible.

Overall, did you find the assessment questions difficult? \_\_\_ (Y/N)
 If so, what made them difficult?
 Did you find any of the assessment questions upsetting? \_\_\_ (Y/N)
 If so, what made them upsetting?

[Note: At this point, the cognitive test of this UPDRS Part is complete for this patient.]

	R	ATE:	R'S	DE	EBF	RIEF	ING
3. How easy or difficult is it for you <u>as the rater</u> to explain the rating options to the patient using the navigation instructions (page 5)?							
Very difficult		1 2	3	4	5	6	Very Easy
What made th	ese options dif	ficult	for y	you	<u>as t</u>	<u>he ra</u>	<u>ter</u> to explain?
4. Which, if any,	of the question	ıs seei	med	to 1	nak	e the	patient uncomfortable? Why?
5. Which question	ons were the mo	ost un	com	fort	tabl	e or a	wkward for you to ask? Why?
6. Have you com Why?	e to dislike any	speci	ific o	ques	stio	ıs in t	this UPDRS Part? Which ones?
7. Please note yo (Mark Y/N) _ Interrupt		ervati	ons	of t	he i	ntera	ction between proxy/patient.
_ Contradio	eting						
_ Sharing							
_ Confirmi	ng						

Other/Please specify\_\_\_\_\_

8.	Did you sense that any of the following factors influenced answers? (Check appropriate factor and provide concrete examples)
	_ Social desirability?
	_ Minimization of PD impact?
	_ Defensiveness regarding disability?
	_ Protectiveness?
	_ Other/please specify?
	Example:

## Part II: Motor Aspects of Experiences of Daily Living (M-EDL)

Overview: This portion of the scale assesses the motor impact of PD on patients' experiences of daily living. These items include patient perceptions of aspects of PD (tremor, freezing) and also specific activities that are usually routine components of daily life. Because the data source is subjective and historical in nature, the section is similar to Part I in structure and rating guidelines, but focuses on the motor consequences of living with PD. In administering Part II of the UPDRS the examiner should follow exactly the same interview procedures outlined in Part I and comply with the following guidelines:

- 1. The response to each item on the scale should come primarily from the patient whenever possible and not the caregiver or examiner. If the patient is demented, confused or has an altered level of consciousness, the caregiver should then be consulted. Mark at the top of the form the primary data source as patient, caregiver, or patient and caregiver in equal proportion.
- 2. The response to each item should refer to a period encompassing the prior week including the day on which the information is collected.
- 3. This portion of the UPDRS is concerned only with disabilities due to PD. Patients should be instructed that physical or behavioral impairments due to other co-existent conditions should not be considered in their responses. Patients should respond to each item with the option that corresponds best to their CURRENT disabilities (slight, mild, moderate, severe). "Normal" should be marked if the item has not been affected by PD.
- 4. For this scale, use the following definition of ON and OFF:

**ON** is the typical functional state when patients are receiving medication and have a good response. **OFF** is the typical functional state when patients have a poor response in spite of taking medications or the typical functional response when patients are on NO treatment for parkinsonism.

- 5. The response should represent typical or average function in the ON and OFF states during the past week. The examiner should instruct patients to avoid considering their very best or worst level of function by using phrases such as "in most circumstances" or "usually".
- 6. ON and OFF designations are provided next to each item of this Part of the UPDRS.
  - o In patients on symptomatic therapy for PD, without motor fluctuations, Part I is completed once in the ON column.
  - If patients have motor fluctuations, each item should be completed twice, once for typical ON function and once for typical OFF function.
  - o For some experiences, (Sleep, Constipation and possibly others), the answers cannot be easily divided into separate ON and OFF responses. In such cases, the same answer should be entered into both ON and OFF columns for motor fluctuators.
- 7. If patients are not on any symptomatic treatment for PD, scores should be entered once in the OFF column. The nM-EDL section attempts to capture adaptations made for disabilities. Any adaptation that has been made in response to PD symptoms is an impairment, even if tasks are

- performed without difficulty once the adaptation has been made. These adaptive changes should be considered in scoring each item.
- 8. All items must have an integer rating (no half points, no missing scores). In the event that an item does not apply or cannot be rated (e.g., amputee who cannot walk), the item is marked **UR** for Unable to Rate.

### INSTRUCTIONS TO PATIENT

### [Sample script to read to patient]

I am now going to ask a series of similar questions about your PD but will focus on more physical problems than the prior questions addressed. Again, I am interested in how these problems affect your daily life and the focus is on what you consider to be problems related to PD, not other health issues. It may be hard to differentiate, but try to exclude impacts you may have on your daily life from other health problems.

In answering all of the questions, I would like you to think about the past week including today and about a typical or usual effect, not the worst or the best effect.

The first response option to each question will be 'no problem' or 'normal'. If your answer is not normal, then there are different choices and we will explore the choices until we get the best answer.

{*If caretaker is present*}

Do you need to have your caretaker participate in helping you evaluate which response option fits best to describe the impact of PD on your daily living? {Record response below}.

### **UPDRS PART II: EXPERIENCES OF DAILY LIVING**

Primary source of information:Patient Equal Proportion	Caregiver	Patient and Caregiver in
Follow ON/OFF designations utilized in Par Patient not on symptomatic medication Patient has both ON and OFF Response Patient on symptomatic medication has ON column	: complete Part es: complete Par	t I in ON and OFF columns

ON

### **OFF**

- 2.1. SPEECH On the average during the past week, have you experienced problems with speech as a result of your PD? By 'speech problems', I mean the volume, clarity, and efficiency of your verbal communication without needing to repeat.
- 0: Normal. No problems.
- 1: Slight. Minimal loss of volume or diction. No difficulty being understood.
- 2: Mild. Sometimes asked to repeat statements.
- 3: Moderate. Speech intelligible most of the time. Frequently asked to repeat statements.
- 4: Severe. Unintelligible most of the time.

### **Rater Experience Posing UPDRS Question:**

ratei	1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)											
V	ery difficult	1	2	3	4	5	6	Very Easy				
2. R	2. Rater notes difficulties using the question below (Mark each item Y or N):											
Expl dir Ra _ Ra	_ Rater experienced difficulty reading question (Underline problematic parts above.  Explain     difficulty below) _ Rater asked to repeat all or part of question (Bracket repeated parts above) _ Rater had difficulty explaining question _ Other rater issue (please specify)											

### Questions for the patient after they have heard the UPDRS question:

4. What parts of the question were difficult to understand? What was the difficulty? (Circle these on form and explain why they were difficult)											
Questions for the patient after they have decided on a rating:											
5. How easy or di	5. How easy or difficult was it for you to rate your answer to that question?										
Very difficult	1	2	3	4	5	6	Very Easy				
What made it o	difficult	to ra	te?								
Suggested solu	ition?										
6. Who answered Both	this ite	m? _	P	atien	t pri	marily	ly Caregiver primarily				

Very difficult 1 2 3 4 5 6 Very Easy

- 2.2. HANDLING SALIVA On the average during the past week, have you experienced problems with handling saliva as a result of your PD? By 'problems with handling saliva', I mean the presence of excess saliva during the day and night and the dependence on handkerchiefs or tissues.
- 0: Normal. No problem
- 1: Slight. Excess saliva with nighttime drooling.
- 2: Mild. Excess saliva with minimal drooling during the day.
- 3: <u>Moderate</u>. Excess saliva that causes daytime drooling, requiring frequent use of a tissue or handkerchief, specifically more than two times daily.
- 4: Severe. Drooling requires constant use of tissue or handkerchief.

1. Rater reads the question to the patient. How easy or difficult is it for you as the											
rater to use the current wording of the question verbatim? (Circle choice)											
Very difficult 1 2 3 4 5 6 Very Easy											
2. Rater notes difficulties using the question below (Mark each item Y or N):											
_ Rater experienced difficulty reading question (Underline problematic parts above.  Explain difficulty below) _ Rater asked to repeat all or part of question (Bracket repeated parts above) _ Rater had difficulty explaining question Other rater issue (please specify)											

# **Questions for the patient after they have heard the UPDRS question:**

4. What parts of th (Circle these on fo						stand? What was the difficulty? difficult)
estions for the pati	ent after th	ey ha	ve d	<u>ecide</u>	d on a	a rating:
5. How easy or diff	ficult was it	for ye	ou to	rate	your a	inswer to that question?
Very difficult	1 2	3	4	5	6	Very Easy
What made it d	ifficult to ra	te?				
Suggested solut	tion?					
6. Who answered Both	this item?	P	atier	ıt pri	maril	y Caregiver primarily

Very difficult 1 2 3 4 5 6 Very Easy

2.3. SWALLOWING and CHEWING/MANIPULATING FOOD IN MOUTH - On the average during the past week, have you experienced problems with swallowing and chewing or manipulating food in your mouth as a result of your PD? By 'problems with swallowing and chewing or manipulating food in your mouth', I mean ease of swallowing, presence of choking, time required to chew and swallow, and adaptations in food preparation in order to avoid choking.

ON OFF

- 0: Normal. No problems
- 1: <u>Slight</u>. Some difficulty with swallowing but no choking **or** extra time needed to chew food. However, food is not cut or prepared in a special way for you to chew or swallow.
- 2: <u>Mild.</u> Chokes but not daily, **or** expends considerable time and effort to chew food, but food is not cut or prepared in a special way for you to chew or swallow.
- 3: <u>Moderate</u>. Daily choking **or** food needs to be cut or prepared in a special manner because of difficulty chewing or swallowing.
- 4: <u>Severe</u>. Unable to obtain adequate nutrition without an alternative route for nutritional support (i.e. nasogastric tube or gastrostomy).

1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)											
Very difficult 1 2 3 4 5 6 Very Easy											
2. Rater notes difficulties using the question below (Mark each item Y or N):											
_ Rater experienced difficulty reading question (Underline problematic parts above.  Explain     difficulty below)     Rater asked to repeat all or part of question (Bracket repeated parts above)     Rater had difficulty explaining question     Other rater issue (please specify)											

# Questions for the patient after they have heard the UPDRS question: 3. How easy or difficult is this question for you to understand? (Circle choice) Very difficult 1 2 3 4 5 6 Very Easy

4. What parts of the question were difficult to understand? What was the difficulty? (Circle these on form and explain why they were difficult)5. What do you understand by the following words?

"adaptations"
 Understood correctly? (Y/N) \_\_\_\_
 What words would be easier to understand to capture the meaning? (Record suggestions)

# Questions for the patient after they have decided on a rating:

6. How easy or difficult was it for you to rate your answer to that question?

Very difficult 1 2 3 4 5 6 Very Easy

What made it difficult to rate?

Suggested solution?

7. Who answered this item? \_\_\_ Patient primarily \_\_\_ Caregiver primarily \_\_\_ Both

- 2.4. EATING TASKS This question on eating focuses on handling food and feeding yourself, not on swallowing or chewing. On the average during the past week, have you experienced problems with eating as a result of your PD? By 'eating problems', I mean slowness, clumsiness, adaptive changes like new eating utensils, new ways of handling food, or changes in the size of food portions to allow proper handling of food.
- 0: Normal. No problems
- 1: <u>Slight</u>. Slow or clumsy eating, but no adaptive changes or help needed to eat. No spills or accidents related to eating.
- 2: <u>Mild</u>. Slow or clumsy eating with some adaptive changes needed to eat. Occasional accidents (i.e. dropping food from fingers or utensils, spilling beverages) may occur but you remain independent for all eating.
- 3: Moderate. Cannot manage without some assistance but able to perform some eating tasks.
- 4: Severe. Needs to be fed completely.

								<u> </u>					
		ques	tion t	to the	pati	ient.	How	easy or difficult is it for you <u>as the</u>					
ra	<u>ter</u> to use the												
	current wording of the question verbatim? (Circle choice)												
	Very difficult	1	2	3	4	5	6	Very Easy					
2.	2. Rater notes difficulties using the question below (Mark each item Y or N):												
_	_ Rater experienced difficulty reading question (Underline problematic parts above.												
Ex	<b>xplain</b>												
	difficulty below)												
	Rater asked to r	eneat	all or	r nar	t of c	mest	ion (F	Bracket repeated parts above)					
_	Rater had diffici	ultv ev	enlaii	ning .	UNESI	tion	1011 (12	ruence repeated parts as over					
_		•	_	_	_								
_ '	Other rater issue	(piea	se sp	ecny	<i></i>								

# Questions for the patient after they have heard the UPDRS question:

	Very difficult	1	2	3	4	5	6	Vory Fosy					
	very unincum	1	<b>L</b>	3	4	3	U	very Easy					
	4. What parts of the (Circle these on for	-						erstand? What was the difficulty? e difficult)					
Qι	Questions for the patient after they have decided on a rating:												
	2. How easy or d	ifficult	was i	t for	you to	o rate	youı	answer to that question?					
	Very difficult	1	2	3	4	5	6	Very Easy					
	What made it o	lifficult	to ra	te?									
	Suggested solu	ition?											
	3. Who answered Both	this ite	m? _	Pa	atient	prim	arily	Caregiver primarily					

- 2.5. DRESSING On the average during the past week, have you experienced problems with dressing as a result of your PD? By 'dressing problems', I mean slowness, difficulties with large body movements (such as getting arms into sleeves) and small body movements such as buttoning), as well as the use of special adaptations (such as looser clothes, larger buttons, different clasps or fasteners) and the need for assistance.
- 0: Normal. No problems
- 1: <u>Slight.</u> Dresses slowly without adaptations **or** dresses at a normal speed only because adaptive measures are utilized. No assistance needed.
- 2: <u>Mild</u>. Assistance used for isolated tasks like buttons, getting arms in sleeves, tying knots or bows.
- 3: Moderate. Considerable help required, but can do some things alone.
- 4: Severe. Needs to be dressed fully.

	1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)											
	Very difficult	1	2	3	4	5	6	Very Easy				
2.	2. Rater notes difficulties using the question below (Mark each item Y or N):											
_ _ _ _	plain difficulty below) Rater asked to re Rater had difficul	peat a lty ex	all or plain	part	t of q	uesti tion	ion (B	(Underline problematic parts above.  Bracket repeated parts above)				

	_	2	3	4	5	6	Very Easy
							erstand? What was the difficulty? e difficult)
estions for the patien	t aft	er th	ey ha	ave d	ecide	ed on	a rating:
5. How easy or diffic	ult w	as it	for y	ou to	rate	your a	answer to that question?
Very difficult	1	2	3	4	5	6	Very Easy
What made it diff	icult	to rat	te?				
Suggested solution	n?						
6. Who answered th Both	is ite	em? _	P	Patier	nt pri	mari	ily Caregiver primarily
	estions for the patien  5. How easy or diffic  Very difficult  What made it diff  Suggested solution	estions for the patient after 5. How easy or difficult where the way of the patient after 1.  What made it difficult Suggested solution?  6. Who answered this items.	estions for the patient after the sections of the patient after the sections of the section sections and sections are sections of the section section section sections and section se	Circle these on form and explain  estions for the patient after they have  How easy or difficult was it for y  Very difficult 1 2 3  What made it difficult to rate?  Suggested solution?  6. Who answered this item?F	estions for the patient after they have destions for the patient after they have destined the state of the patient after they have described by the state of the patient after they have destined to the state of the patient after they have destined to the state of the patient after they have destined to the state of the patient after they have destined to the state of the patient after they have destined to the state of the patient after they have destined to the state of the patient after they have destined to the patient after they have destined the patient after the patient	estions for the patient after they have decide  5. How easy or difficult was it for you to rate  Very difficult 1 2 3 4 5  What made it difficult to rate?  Suggested solution?  6. Who answered this item? Patient pri	estions for the patient after they have decided on  5. How easy or difficult was it for you to rate your  Very difficult 1 2 3 4 5 6  What made it difficult to rate?  Suggested solution?  Patient primaria

2.6. HYGIENE - On the average during the past week, have you experienced problems with hygiene as a result of your PD? By 'hygiene problems', I mean speed and efficiency of bathing, brushing teeth, combing hair, with attention to adaptive measures (i.e. switching to an electric razor, switching to the non-dominant hand, reliance on shower bars) and the need for assistance. This item relates to the motor task of personal hygiene and not to lack of concern or interest.

ON OFF

- 0: Normal. No problems
- 1: <u>Slight</u>. Slowed or impaired hygienic care without adaptation **or** performs tasks at a normal speed only because adaptive measures are utilized. No help needed.
- 2: Mild. Slow in hygienic care with assistance needed for some tasks.
- 3: Moderate. Considerable help required, but can do some things alone.
- 4: Severe. Full care required.

1. Rater reads the question to the patient. How easy or difficult is it for you as the												
rater to use the												
current wording of the question verbatim? (Circle choice)												
Very difficult	1	2	3	4	5	6	Very Easy					
2. Rater notes diffi	2. Rater notes difficulties using the question below (Mark each item Y or N):											
_ Rater experienced difficulty reading question (Underline problematic parts above. Explain difficulty below)												
<ul> <li>Rater asked to re Rater had difficult</li> </ul>	-		-		-	ion (B	Bracket repeated parts above)					
Other rater issue	•	-	_	-								
_ Other rater issue	(pica	вс вр	cerry	<i>,</i>								

# **Questions for the patient after they have heard the UPDRS question:**

3.	How easy or diffic	cult is	s this	ques	stion	for yo	ou to 1	understand? (Circle choice)
Ve	ery difficult	1	2	3	4	5	6	Very Easy
	What parts of the circle these on for							estand? What was the difficulty?  difficult)
5.	Do you understar	nd by	the f	ollov	ving v	words	s?	
0	"non-dominant had Understood corr What words would	ectly				stand	to ca	pture the meaning? (Record suggestions)
0	"motor task"  Understood corr  What words would					- rstand	to ca	pture the meaning? (Record suggestions)
Quest	ions for the patier	nt aft	er th	ey h	ave d	lecide	ed on	a rating:
7.	How easy or diffi	icult v	was it	t for	you t	o rate	your	answer to that question?
Ve	ery difficult	1	2	3	4	5	6	Very Easy
	What made it diff	ficult	to rai	te?				
	Suggested solution	on?						

8.	Who answered this item? _ Both	Patient primarily	Caregiver primarily	
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- 2.7. HANDWRITING AND WRITTEN COMMUNICATION On the average during the past week, have you experienced problems with handwriting and written communication as a result of your PD? By 'handwriting and written communication problems', I mean size and legibility of handwriting.
- 0: Normal. No problems
- 1: <u>Slight</u>. Slightly slow or small handwriting, but all words are clear.
- 2: <u>Mild.</u> Mildly slow or small handwriting; all words and figures are legible but some are difficult to decipher.
- 3: Moderate. Some words or figures cannot be deciphered, but most are still legible.
- 4: Severe. The majority of words and figures are illegible.

<u>rater</u> to	use the	•			•			easy or difficult is it for you <u>as the</u> Fircle choice)
Very	difficult	1	2	3	4	5	6	Very Easy
2. Rate	r notes diffi	icultie	es usi	ng th	e qu	estio	n belo	w (Mark each item Y or N):
Explain diffic Rater Rater	ulty below) asked to re had diffice	epeat ilty ex	all oı xplaiı	r par	t of q	uest tion	ion (B	Underline problematic parts above.  Bracket repeated parts above)

Questions for the patient after they have heard the UPDRS question:

3.	How easy or dif	ficult	is thi	s que	stion	for y	ou to	understand? (Circle choice)
Ve	ery difficult	1	2	3	4	5	6	Very Easy
	What parts of th							erstand? What was the difficulty? difficult)
5.	What do you un	ıdersta	ınd b	y the	follo	wing	words	s?
0	"decipher" Understood con What words wor					- rstanc	l to ca	pture the meaning? (Record suggestions)
esti	"legibility"  Understood con  What words words	ould be	e easie	er to i	under			pture the meaning? (Record suggestions)  a rating:
								answer to that question?
Ve	ery difficult	1	2	3	4	5	6	Very Easy
	What made it di	fficult	t to ra	ate?				
	Suggested soluti	ion?						
7.	Who answered Both		tem?		Patie	ent pi	 rimari	ily Caregiver primarily

- 2.8. OTHER FINE MOTOR TASKS On the average during the past week, have you experienced problems with other fine motor tasks as a result of your PD? By 'other fine motor tasks, I mean your ability to perform activities and hobbies (such as playing musical instruments, gardening, using tools, handling a computer) that involve fine coordination. The focus is on speed, efficiency and your need to use special adaptive techniques or tools to complete these activities.
- 0: Normal. No problems
- 1: <u>Slight</u>. Minimally slow but able to perform tasks efficiently and completely **or** normal function because adaptations have been used.
- 2: Mild. Slow or less efficient performance with occasional errors.
- 3: Moderate. Performance impaired with frequent errors or problems.
- 4: Severe. Unable to perform tasks.

1. Rater reads the question to the patient. How easy or difficult is it for you as the rater to use the current wording of the question verbatim? (Circle choice)  Very difficult 1 2 3 4 5 6 Very Easy  2. Rater notes difficulties using the question below (Mark each item Y or N):  Rater experienced difficulty reading question (Underline problematic parts above. Explain difficulty below)  Rater asked to repeat all or part of question (Bracket repeated parts above)  Rater had difficulty explaining question  Other rater issue (please specify)	•								<u> </u>
Current wording of the question verbatim? (Circle choice)  Very difficult 1 2 3 4 5 6 Very Easy  2. Rater notes difficulties using the question below (Mark each item Y or N):  Rater experienced difficulty reading question (Underline problematic parts above. Explain difficulty below)  Rater asked to repeat all or part of question (Bracket repeated parts above)  Rater had difficulty explaining question		quest	ion t	o the	pati	ent. l	How e	asy	or difficult is it for you as the
Very difficult 1 2 3 4 5 6 Very Easy  2. Rater notes difficulties using the question below (Mark each item Y or N):  Rater experienced difficulty reading question (Underline problematic parts above. Explain difficulty below) Rater asked to repeat all or part of question (Bracket repeated parts above) Rater had difficulty explaining question	<u>rater</u> to use the								
Very difficult 1 2 3 4 5 6 Very Easy  2. Rater notes difficulties using the question below (Mark each item Y or N):  Rater experienced difficulty reading question (Underline problematic parts above. Explain difficulty below) Rater asked to repeat all or part of question (Bracket repeated parts above) Rater had difficulty explaining question	current wording	of th	e qu	estioi	n ver	batir	n? (Ci	ircl	e choice)
2. Rater notes difficulties using the question below (Mark each item Y or N):  _ Rater experienced difficulty reading question (Underline problematic parts above. Explain difficulty below) _ Rater asked to repeat all or part of question (Bracket repeated parts above) _ Rater had difficulty explaining question			-				`		,
<ul> <li>Rater experienced difficulty reading question (Underline problematic parts above.</li> <li>Explain         difficulty below)         <ul> <li>Rater asked to repeat all or part of question (Bracket repeated parts above)</li> <li>Rater had difficulty explaining question</li> </ul> </li> </ul>	Very difficult	1	2	3	4	5	6	,	Very Easy
Explain difficulty below) Rater asked to repeat all or part of question (Bracket repeated parts above) Rater had difficulty explaining question	2. Rater notes diffic	culties	usir	ng the	e que	estior	belov	w (N	Mark each item Y or N):
<ul> <li>Rater asked to repeat all or part of question (Bracket repeated parts above)</li> <li>Rater had difficulty explaining question</li> </ul>	_ Rater experienced Explain	l diffi	culty	y reac	ding	ques	tion (l	Und	lerline problematic parts above.
Rater had difficulty explaining question	• /						_		
_ , , , , , , , , , , , , , , , , , , ,							on (Bi	racl	ket repeated parts above)
_ Other rater issue (please specify)	_	•	•		_				
	_ Other rater issue (	pleas	e spe	ecify)					

# **Questions for the patient after they have heard the UPDRS question:**

3.	How easy or diffic	cult is	this	ques	stion f	for yo	ou to un	nderstand? (Circle choice)
V	ery difficult	1	2	3	4	5	6	Very Easy
	What parts of the Circle these on form							stand? What was the difficulty?
5.	What do you undo	erstar	ıd by	the!	follov	ving	words?	
0	"performance impuderstood corr What words would	rectly	? (Y				l to cap	ture the meaning? (Record suggestions)
Quest	tions for the patien	<u>nt aft</u>	<u>er th</u>	<u>iey h</u>	ave d	<u>lecid</u>	ed on a	rating:
6.	How easy or diffi	cult v	vas i	t for	you to	o rate	your a	inswer to that question?
V	ery difficult	1	2	3	4	5	6	Very Easy
	What made it diff	icult	to ra	te?				
	Suggested solutio	n?						
7.	Who answered t	his it	em?		<b>Patie</b>	nt pi		y Caregiver primarily

- 2.9. TREMOR IMPACT ON ACTIVITIES On the average during the past week, have you experienced problems with tremor having an impact on your activities as a result of your PD? By 'tremor impact on your activities', I mean your emotional and motor consequences of tremor.
- 0: Normal. No tremor.
- 1: <u>Slight</u>. Tremor present, but not bothersome or embarrassing. May have internal tremor without noticeable tremor. No interference with activities.
- 2: Mild. Bothersome or embarrassing tremor that does not interfere with activities.
- 3: Moderate. Tremor interferes with some activities.
- 4: Severe. Tremor interferes with most or all activities.

	Rater reads the ter to use the current wording	-			-			easy or difficult is it for you <u>as the</u> Circle choice)
	Very difficult	1	2	3	4	5	6	Very Easy
2.	Rater notes diffi	cultic	es usi	ng th	e qu	estio	n belo	w (Mark each item Y or N):
1 1	xplain difficulty below)	peat lty e	all oi xplaii	r par	t of q	quest tion	ion (B	Underline problematic parts above.  Bracket repeated parts above)

# **Questions for the patient after they have heard the UPDRS question:**

,	Ve	ery difficult	1	2	3	4	5	6	Very Easy
		What parts of the ircle these on form							erstand? What was the difficulty? e difficult)
,	5.	What do you unde	erstar	nd by	/ the	follo	wing	words	s?
(	0	"emotional and m Understood corr What words woul	rectly	? (Y	/N) _		_		apture the meaning? (Record suggestions)
Que	<u>esti</u>	ions for the patien	<u>nt aft</u>	er th	iey h	ave d	lecid	ed on	a rating:
(	6.	How easy or diffi	cult v	vas i	t for	you t	o rate	e your	answer to that question?
,	Ve	ery difficult	1	2	3	4	5	6	Very Easy
		What made it diff	ñcult	to ra	te?				
		Suggested solutio	n?						
,	7.	Who answered the Both	his it	em?	·	Patie	ent pi	rimar	rily Caregiver primarily

- 2.10. TURNING IN BED AND ADJUSTING BEDCLOTHES On the average during the past week, have you experienced problems with turning in bed and adjusting bedclothes as a result of your PD? By 'problems with turning in bed and adjusting bedclothes', I mean slowness, efficiency, and independence.
- 0: Normal. No problems
- 1: <u>Slight</u>. Slow or clumsy, but turns independently and adjusts bedclothes without considerable difficulty **or** normal function because adaptations are used (special sheets, bedclothes).
- 2: Mild. Can turn alone or adjust sheets, but with considerable difficulty.
- 3: Moderate. Can initiate, but not turn or adjust sheets alone.
- 4: Severe. Unable to initiate movement in bed.

1. Rater reads the rater to use the	ques	tion t	to the	pati	ient.	How e	easy or difficult is it for you <u>as the</u>
current wording	g of tl	ne qu	estio	n vei	rbati	m? (C	ircle choice)
Very difficult	1	2	3	4	5	6	Very Easy
2. Rater notes diffi	cultie	es usi	ng th	e qu	estio	n belo	w (Mark each item Y or N):
_ Rater experience Explain difficulty below)	d dif	ficult	y rea	ding	que	stion (	Underline problematic parts above.
• /	_		_		_	ion (B	racket repeated parts above)
Other rater issue	•	-	_	-			

# Questions for the patient after they have heard the UPDRS question:

3. How easy of di	fficult	is this	s que	stion	for y	ou to ı	understand? (Circle choice)
Very difficult	1	2	3	4	5	6	Very Easy
4. What parts of the (Circle these on for							rstand? What was the difficulty?  difficult)
uestions for the pat	ient aft	er th	iey h	ave d	lecide	ed on a	a rating:
5. How easy or diff	ficult w	as it	for y	ou to	rate :	your a	nswer to that question?
Very difficult	1	2	3	4	5	6	Very Easy
What made it d	ifficult	to ra	te?				
Suggested solu	ıtion?						
6. Who answered							

- 2.11. GETTING IN AND OUT OF BED, A CAR OR DEEP CHAIR On the average during the past week, have you experienced problems with getting in and out of bed, a car or a deep chair as a result of your PD? By 'problems with getting in and out of bed, a car or a deep chair', I mean speed, ease, and independence of these activities.
- 0: Normal. No problems
- 1: Slight. Slow but always independent.
- 2: Mild. Very slow, needing multiple attempts to rise, but remains independent.
- 3: Moderate. Sometimes needs assistance from others.
- 4: Severe. Regularly needs help to arise.

1. Rater reads the rater to use the	ques	tion t	to the	pati	ient.	How e	easy or difficult is it for you <u>as the</u>
current wording	g of tl	he qu	estio	n vei	rbati	m? (C	ircle choice)
Very difficult	1	2	3	4	5	6	Very Easy
2. Rater notes diffi	cultie	es usi	ng th	e qu	estio	n belo	w (Mark each item Y or N):
Explain difficulty below)	epeat ilty ex	all oi xplaii	r par	t of q	quest tion	ion (B	Underline problematic parts above. racket repeated parts above)

### Questions for the patient after they have heard the UPDRS question:

	ow easy or diff							nrating:  nnswer to that question?
Very o	difficult	1	2	3	4	5	6	Very Easy
W	hat made it dif	ficult	to rat	te?				
Su	ggested solution	on?						

Very difficult 1 2 3 4 5 6 Very Easy

- 2.12. BALANCE AND WALKING On the average during the past week, have you experienced problems with balance and walking as a result of your PD? By 'balance and walking problems', I mean steadiness and speed of walking, dragging a leg, catching a toe, level of independence and the need for walking assistance devices or caregiver involvement in walking.
- 0: Normal. No problems
- 1: <u>Slight</u>. Some slowing, may drag a leg or catch toe, but no balance problems.
- 2: <u>Mild.</u> Occasional unsteadiness or shuffling; may have perception of poor balance, but no falls and no assistance or walking aids needed.
- 3: <u>Moderate.</u> Walking speed significantly altered or balance impaired, causing need for walking aids, but without need for caregiver assistance. May have occasional falls.
- 4: Severe. Does not walk at all or requires assistance of a caregiver.

1. Rater reads the question to the patient. How easy or difficult is it for you as the
<u>rater</u> to use the current wording of the question verbatim? (Circle choice)
Very difficult 1 2 3 4 5 6 Very Easy
2. Rater notes difficulties using the question below (Mark each item Y or N):
_ Rater experienced difficulty reading question (Underline problematic parts above.  Explain     difficulty below) _ Rater asked to repeat all or part of question (Bracket repeated parts above) _ Rater had difficulty explaining question _ Other rater issue (please specify)

# **Questions for the patient after they have heard the UPDRS question:**

Very difficult	1	2	3	4	5	6	Very Easy
4. What parts of th (Circle these on for	-						erstand? What was the difficulty?  difficult)
Questions for the patients  5. How easy or disconnections.							a rating: answer to that question?
Very difficult	1	2	3	4	5	6	Very Easy
What made it di	fficult	to ra	te?				
Suggested soluti	ion?						
6. Who answered Both	this i	tem?		Patie	ent pr	rimar	ily Caregiver primarily
Dotti							

- 2.13. GAIT FREEZING On the average during the past week, have you experienced problems with gait freezing as a result of your PD? By 'gait freezing', I mean sudden episodes of halted movement while starting to walk, turning or walking, the frequency of freezing and its impact on your safety.
- 0: Normal. No problems.
- 1: <u>Slight.</u> Freezing occurs when starting to walk, turning or pivoting, but does not compromise your independent walking.
- 2: <u>Mild.</u> Freezing occurs in the midst of walking, but does not induce you to use assistance from a walking aid or another person.
- 3: <u>Moderate</u>. Freezing causes occasional falls or near-falls (less than once daily) **or** freezing induces you to use a walking aid or person for assistance.
- 4: <u>Severe</u>. Frequent freezing that causes daily falls or near-falls **or** freezing precludes you from walking even with assistance.

1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)								
Very difficult	1	2	3	4	5	6	Very Easy	
2. Rater notes difficulties using the question below (Mark each item Y or N):								
Rater experienced difficulty reading question (Underline problematic parts above. Explain difficulty below) Rater asked to repeat all or part of question (Bracket repeated parts above) Rater had difficulty explaining question Other rater issue (please specify)								

# Questions for the patient after they have heard the UPDRS question: 3. How easy or difficult is this question for you to understand? (Circle choice) Very difficult 1 2 3 4 5 6 Very Easy 4. What parts of the question were difficult to understand? What was the difficulty? (Circle these on form and explain why they were difficult) 5. What do you understand by the following words? o "pivoting" Understood correctly? (Y/N) What words would be easier to understand to capture the meaning? (Record suggestions) Questions for the patient after they have decided on a rating: 6. How easy or difficult was it for you to rate your answer to that question?

ıest	ions for the patie	nt aftei	r they	have d	lecido	ed on a r	rating:
6.	How easy or diff	icult wa	as it fo	r you t	o rate	e your an	nswer to that question?
Ve	ery difficult	1	2 3	4	5	6	Very Easy
	What made it diff	ficult to	o rate?				
	Suggested solution	on?					
7.	Who answered t	this ite	m?	_ Patie	ent pi	rimarily	Caregiver primarily
					64	,	

### UPDRS PART II PATIENT DEBRIEFING

For questions 1-2, the rater summarizes patient's answers to the questions below using patient's own words whenever possible.

1.	Overall, did you find the assessment questions difficult? $\_$ (Y/N) If so, what made them difficult?
2.	Did you find any of the assessment questions upsetting? $(Y/N)$ If so, what made them upsetting?
oto.	At this point, the aganitive test of this UDDDS Dout is complete for this potient

RATER'S DEBRIEFING						
3. How easy or difficult is it for you <u>as the rater</u> to explain to the patient the rating options using the navigation instructions (page 5)?						
Very difficult 1 2 3 4 5 6 Very Easy						
What made these options difficult for you as the rater to explain?						
4. Which, if any, of the questions seemed to make the patient uncomforta	ble? Why?					
	,					
5. Which questions were the most uncomfortable or awkward for you to	ask? Why?					
6. Have you come to dislike any specific questions in this UPDRS Part? V Why?	Vhich ones?					
7. Please note your general observations of the interaction between proxy (Mark Y/N)  _ Interrupting	//patient.					
_ Contradicting						

Sharing

Confirming

Other/Please specify\_

8.	Did you sense that any of the following factors influenced answers? (Check appropriate factor and provide concrete examples)
	_ Social desirability?
	_ Minimization of PD impact?
	_ Defensiveness regarding disability?
	_ Protectiveness?
	_ Other/please specify?
	Example:

### Part III: Motor Examination

Overview: This portion of the scale assesses the motor signs of PD. In administering Part III of the UPDRS the examiner should comply with the following guidelines:

- 1. At the top of the form, mark whether the patient is on medication for treating the symptoms of Parkinson's disease and, if on levodopa, the time since the last dose.
- For this scale, use the following definition of ON and OFF:
   ON is the typical functional state when patients are receiving medication and have a good response.
   OFF is the typical functional state when patients have a poor response in spite of taking medications or the typical functional response when patients are on NO treatment for parkinsonism
- 3. Complete whether the patient is ON or OFF during the examination. For patients not on symptomatic treatment mark OFF. For patients on symptomatic medication and without fluctuations, mark ON. For patients with motor fluctuations, record the ON or OFF status of the patient during *this* examination.
- 4. In contrast to the EDL sections (Part I and II) where patients were asked to evaluate only the deficits due to PD, in this part, the investigator should "rate what you see". Admittedly, concurrent medical problems such as stroke, paralysis, arthritis, contracture, and orthopedic problems such as hip or knee replacement and scoliosis may interfere with individual items in the motor examination. In situations where it is absolutely impossible to test (e.g., amputations, plegia, limb in a cast), use the notation "UR" for Unable to Rate. Otherwise, rate the performance of each task as the patient performs in the context of co-morbidities.
- 5. All items must have an integer rating (no half points, no missing ratings).
- 6. Specific instructions are provided for the testing of each item. These should be followed in all instances.
- 7. At the end of the rating, indicate if dyskinesia (chorea or dystonia) was present at the time of the examination, and if so, whether these movements interfered with the motor examination.
- 8. The investigator has the patient perform a number of tasks and rates function immediately thereafter. For Global Spontaneous Movement and Rest Tremor items (3.17 and 3.18), these items have been placed purposefully at the end of the scale because clinical information pertinent to the score will be obtained throughout the entire examination.

### **Cognitive Test Question:**

Examination" that were difficult for you as the rater to und	erstand or that require						
clarification?							
Y/N If yes, please circle those segments on the previous page and explain below							
what clarifications are needed.							
Part III: Motor Examination							
ON and OFF designations (Check 1):							
OFF							
No symptomatic treatment (OFF)							
Symptomatic treatment with motor fluctuations and is curr	ently OFF.						
ON							
On symptomatic treatment and has no motor fluctuations							
On symptomatic treatment with motor fluctuations but is c	urrently ON.						
Minutes since last levodopa dose Not	t on Levodopa						

Were there any parts of the instructions on the page above titled "Part III: Motor

### **3.1. SPEECH**

<u>Instructions to examiner</u>: Listen to the patient's spontaneous speech. If the patient tends to talk too little, engage the patient in conversation. Evaluate volume, modulation (prosody) and clarity.

<u>Instructions to patient</u>: As part of this assessment, I need to have you talk briefly about whatever comes to mind such as your daily activities or your work.

- 0: Normal. No speech problems
- 1: Slight. Any of the following: a) slight loss of modulation, b) diction or c) volume.
- 2: <u>Mild</u>. Any of the following: a) mild loss of modulation, b) diction, or c) volume. Speech may be monotone or slurred, but it is understandable.
- 3: Moderate. Difficult to understand.
- 4: Severe. Unintelligible.

### Rater Experience with Instructions and Ratings (no patient involvement):

1. How easy or difficult is it for you <u>as the rater</u> to understand and carry out the "Instructions to examiner"? (Circle choice)								
Very difficult	1	2	3	4	5	6	Very Easy	
Circle areas of the "Instructions to examiner" that were difficult above. What would make the "Instructions to examiner" easier to understand or carry out?								
the		•				·	difficult is it for you <u>as the rater</u> to use at"? (Circle choice)	
Very difficult	1	2	3	4	5	6	Very Easy	
<ul> <li>3. Rater notes difficulties giving the instructions to patient below (Mark each item Y or N):</li> <li>Rater experienced difficulty reading instructions to patients</li> </ul>								
_ Rater asked to repeat all or part of instruction to patients								

<ul><li>Rater had difficulty explaining instruction to patie</li><li>Other rater issue (please specify)</li></ul>	
4. What would make it easier for the rater to articul	late the instructions to the patient?
5. How easy or difficult was it for you to rate the par	tient using the ratings provided?
Very difficult 1 2 3 4 5 6	Very Easy
What made it difficult to rate?	
Conservated and officer 9	
Suggested solution?	

### **Questions for the patient regarding the instructions:**

**6.** How easy or difficult are the instructions for you to understand? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

7. What parts of the instructions were difficult to understand or follow? (Circle these on form and explain why they were difficult)

### 3.2. FACIAL EXPRESSION

<u>Instructions to examiner</u>: Observe the patient sitting at rest, without talking and also while talking. Observe eye-blink frequency, hypomimia or loss of facial expression, spontaneous smiling and parting of lips.

<u>Instructions to patient</u>: Now sit quietly for ten seconds and then, I will need to have you talk briefly about whatever comes to mind such as your family or your best friend.

- 0: Normal Normal facial expression
- 1: Slight. Minimal hypomimia manifested only by decreased frequency of blinking.
- 2: <u>Mild</u>. In addition to decreased eye-blink frequency, hypomimia present in the lower face as well, namely fewer movements around the mouth, such as less spontaneous smiling, but lips not parted.
- 3: <u>Moderate</u>. Hypomimia with lips parted some of the time when the mouth is at rest.
- 4: Severe. Masked facies with lips parted most of the time when the mouth is at rest.

1. How easy or di "Instructions to examiner"?				ou <u>as</u>	s the	<u>rater</u>	to understand and carry out the
Very difficult	1	2	3	4	5	6	Very Easy
							nt were difficult above. What would derstand or carry out?
the		•				·	difficult is it for you as the rater to use at"? (Circle choice)
Very difficult	1	2	3	4	5	6	Very Easy
3. Rater notes diffor N):  _ Rater experience _ Rater asked to r	ed dif	ficult	ty rea	ıding	inst	ructio	•

What would n	nake it	easie	er <u>for</u>	the	<u>rater</u>	to art	iculate the instructions to the patient
How easy or d	lifficult	was	it fo	r you	to ra	ate the	patient using the ratings provided?
v difficult	1	2	3	4	5	6	Very Easy
v							v
What made it	difficu	lt to	rate?	•			
Suggested solu	ıtion?						
one for the not	iont ro	rardi	ina tl	na inc	struc	tions:	
							10 (9) 1 1 1
How easy or di	ifficult	are th	ie ins	tructi	ons f	or you	to understand? (Circle choice)
y difficult	1	2	3	4	5	6	Very Easy
	How easy or day difficult  What made it  Suggested solutions for the pate	How easy or difficult  y difficult 1  What made it difficult  Suggested solution?  Ons for the patient res	How easy or difficult was y difficult 1 2  What made it difficult to Suggested solution?  Ons for the patient regarding the say or difficult are the say of the say or difficult are the say of the say or difficult are the say of the	How easy or difficult was it for y difficult 1 2 3  What made it difficult to rate?  Suggested solution?  Ons for the patient regarding the solution of the patient are the insertion of the solution.	How easy or difficult was it for you y difficult 1 2 3 4  What made it difficult to rate?  Suggested solution?  How easy or difficult are the instruction	How easy or difficult was it for you to ray difficult 1 2 3 4 5  What made it difficult to rate?  Suggested solution?  How easy or difficult are the instructions for the patient are the instructions are the patient are the instructions are the patient ar	Suggested solution?  Ons for the patient regarding the instructions:  How easy or difficult are the instructions for you

### 3.3. RIGIDITY

<u>Instructions to examiner</u>: Rigidity is judged on slow passive movement of major joints with the patient in a relaxed position and the examiner manipulating the limbs and neck. First, test without an activation maneuver. Test and rate neck and each limb separately. If no rigidity is detected, use an activation maneuver as tapping fingers, fist opening/closing, or heel tapping in a limb not being tested.

<u>Instructions to patient</u>: Relax completely and I will move your limbs and neck. (If needed): I want you to perform a simple action that I can observe (e.g., tapping fingers, fist opening/closing, or heel tapping) on the other side of your body while I continue testing this side.

- 0: Normal. No rigidity.
- 1: Slight. Rigidity only detected with activation maneuver.
- 2: Mild. Mild rigidity detected without the activation maneuver, but full range of motion is easily achieved.
- 3: <u>Moderate</u>. Moderate rigidity detected without the activation maneuver, but full range of motion is achieved.

Neck

RUE LUE

RLE LLE

4: <u>Severe</u>. Marked rigidity detected without the activation maneuver and full range of motion is achieved with much difficulty or not at all.

1. How easy or di "Instructions to examiner"?				ou <u>as</u>	the	<u>rater</u> t	o understand and carry out the
Very difficult	1	2	3	4	5	6	Very Easy
							t were difficult above. What would derstand or carry out?
the		-				•	difficult is it for you <u>as the rater</u> to use t"? (Circle choice)
Very difficult	1	2	3	4	5	6	Very Easy

3. Rater notes diffi or N):	culties gi	iving the i	instruction	s to patient below (Mark each i	tem Y
_ Rater experienced _ Rater asked to rep _ Rater had difficul _ Other rater issue (	oeat all o ty explai	r part of i ning instr	nstructions ructions to	s to patient patient	
4. What would ma	ke it easi	er for the	rater to ar	ticulate the instructions to the	oatient?
5. How easy or diff	ficult was	s it for yo	u to rate th	e patient using the ratings prov	ided?
Very difficult	1 2	3 4	5 6	Very Easy	
What made it di	fficult to	rate?			
Suggested soluti	on?				

6. How easy or difficult are the instructions for you to understand? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

### 3.4 FINGER TAPPING

<u>Instructions to examiner</u>: Each hand is tested separately. You may demonstrate the task, but do not continue to perform the task while the patient is tested. Once the task is understood so that patient taps as quickly AND as fully as possible, have the patient carry out 10 finger taps. Rate each side separately. Investigator will rate the number of halts or hesitations, the speed and ability to maintain a full open and close motion without fatigue or decrement.

<u>Instructions to Patient</u>: Please flex your right (left) elbow with the palm facing me. Spread apart your fingers and thumb on this hand. Tap your thumb with the tip of your index finger in rapid succession, using BOTH the largest amplitude possible and the fastest speed possible.

- 0: Normal. No problems.
- 1: <u>Slight.</u> Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the tapping movement; b) there is slight slowing; c) the amplitude slightly decrements with or after the 5th tap.
- 2: <u>Mild</u>. Any of the following: a) 3 to 5 interruptions during tapping; b) mild slowing; c) the amplitude starts decrementing between the 3rd and 5th tap.
- 3: <u>Moderate</u>. Any of the following: a) more than 5 interruptions during tapping or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) the amplitude decrements starting after the 1st tap.
- 4: <u>Severe</u>. Cannot or can only barely perform the task because of slowing, interruptions or decrements.

1. How easy or difficult is it for you <u>as the rater</u> to understand and carry out the "Instructions to examiner"? (Circle choice)													
Very difficult	1	2	3	4	5	6	Very Easy						
							at were difficult above. What would derstand or carry out?						

the		-				•	difficult is it for you as the rater to use at"? (Circle choice)
Very difficult	1	2	3	4	5	6	Very Easy
3. Rater notes difficultie	es givi	ng the	instr	uction	is to p	atient l	below (Mark each item Y or N):
_ Rater experience							
<ul><li>Rater asked to re</li><li>Rater had difficu</li></ul>							
	-	_	_			_	
4. What would ma	ke it	easie	r <u>for</u>	the 1	<u>rater</u>	to art	ticulate the instructions to the patient?
5. How easy or dif	ficult	was	it for	· you	to ra	ate the	e patient using the ratings provided?
Very difficult	1	2	3	4	5	6	Very Easy
What made it di	ifficu	lt to 1	rate?				
Suggested soluti	ion?						

6.	How easy or dif	ficult	are th	e ins	truct	ions f	or you	to understand? (Circle choice)
Ve	ery difficult	1	2	3	4	5	6	Very Easy
7.	What parts of to (Circle these or							o understand or follow? ere difficult)
8.	What do you u	nders	tand	by th	ne fol	llowi	ng woi	·ds?
0	"flex" Understood cor What words wo		,			- rstanc	l to cap	oture the meaning? (Record suggestions)
0	"amplitude" Understood con What words wo		,			- rstanc	l to cap	oture the meaning? (Record suggestions)

### 3.5 HAND MOVEMENTS

<u>Instructions to examiner:</u> Test each hand separately. If patients fail to make a tight fist or to open the hand fully, remind them to do so. You may demonstrate the task, but do not continue to perform the task while the patient is tested. Once the task is understood so that the patient opens and closes the fist as fully as possible and as quickly as possible simultaneously, have the patient complete 10 open-and-close movements with the right, then the left hand. Observe the number of haltings and hesitations, the speed and the ability to maintain the full open-and-close movements without decrements.

<u>Instructions patient</u>: Please extend your right (left) arm out in front of your body with your palm down. Open and close your hand in rapid succession, paying attention to open and close completely AND at the same time perform the task as fast as possible.

- 0: Normal. No problems
- 1: <u>Slight.</u> Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) there is slight slowing; c) the amplitude slightly decrements with or after the 5th open-and-close sequence.

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- 2: <u>Mild</u>. Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowing; c) the amplitude starts decrementing between the 3rd and 5th open-and-close sequence.
- 3: <u>Moderate.</u> Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) the amplitude decrements starting after the 1st open-and-close sequence.
- 4: <u>Severe.</u> Cannot or can only barely perform the task because of slowing, interruptions or decrements.

## Rater Experience with Instructions and Ratings (no patient involvement):

1.	How easy or	difficult is it	for you as	the rater	to understand	and carry	out the
"Ir	structions						

to examiner"? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

Circle areas of the "Instructions to examiner" that were difficult above. What would make the "Instructions to examiner" easier to understand or carry out?

2. Read instructions to the patient. How easy or difficult is it for you as the rater to use

current wording of the "Instructions to patient"? (Circle choice)

Very difficult	1	2	3	4	5	6	Very Easy
3. Rater notes diffic N):	culties	s givi	ing tl	he in	struc	ctions t	o patient below (Mark each item Y or
_ Rater experienced _ Rater asked to rep	eat a	ll or	part	of in	ıstru	ctions	to patient
<ul><li>Rater had difficult</li><li>Other rater issue (</li></ul>							
	ртенз	с эр	cerry,	,			<u> </u>
[							
_							
4. What would mak	ke it e	asier	for	the r	ater	to arti	culate the instructions to the patient?
5. How easy or diffi	icult v	vas i	t for	you	to ra	te the	patient using the ratings provided?
Very difficult	1	2	3	4	5	6	Very Easy
What made it di	fficul	t to 1	rate?				
Suggested solution	on?						

6. How easy or difficult are the instructions for you to understand? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

### 3.6 PRONATION-SUPINATION MOVEMENTS OF HANDS

<u>Instructions to examiner</u>: Test each hand separately. You may demonstrate the task, but do not continue to perform the task while the patient is tested. Once the task is understood, so that the patient pays attention to a full pronation-supination movements as well as speed of movement, have the patient complete 10 pronation-supination sets with the right, then the left hand. Observe for the number of haltings or hesitations, speed and amplitude of movements and the ability to execute the task without fatigue or decrements.

<u>Instructions to patient:</u> Please extend your right (left) arm out in front of your body with your palm down. Turn your palm up and down alternately, paying attention to turn the arm back and forth fully AND at the same time as quickly as possible.

- 0: Normal. No problems
- 1: <u>Slight</u>. Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) there is slight slowing; c) the amplitude slightly decrements with or after the 5th supination-pronation sequence.

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- 2: <u>Mild.</u> Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowing; c) the amplitude starts decrementing between the 3rd and 5th supination-pronation sequence.
- 3: <u>Moderate.</u> Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing c) the amplitude decrements starting after the 1st supination-pronation sequence.
- 4: <u>Severe</u>. Cannot or can only barely perform the task because of slowing, interruptions or decrements.

1. How easy or o "Instructions			•				to understand and carry out the
Very difficult	1	2	3	4	5	6	Very Easy
							at were difficult above. What would derstand or carry out?
		-					difficult is it for you <u>as the rater</u> to use tient"? (Circle choice)

_ R	Rater notes di Rater experie Rater asked to	nced dif	ficulty	y rea	ding	instr	uction	ıs to	
_ R	Rater had dif	ficulty ex	xplain	ing i	nstru				
_ C	Other rater is	sue (ple	ase sp	ecify	)				
_									
4	XX/I 4 I J	1		C.	. 41	4	4	·•	1-4-41
4.	wnat would	make ii	t easte	er <u>10r</u>	tne	<u>rater</u>	to art	ııcu	late the instructions to the patien
5	How easy or	· difficul	t was	it fo	r vou	to re	ate the	na	atient using the ratings provided?
J.	110W casy of	umcui	i was	10 10	ı you	1017	ite tiit	, pa	ment using the ratings provided.
Vei	ry difficult	1	2	3	4	5	6		Very Easy
	What made	it diffici	ılt to	rate?	•				
	Suggested so	olution?							
esti	ions for the p	atient re	egardi	ing tl	ne ins	struc	tions:		
6.	How easy or	difficult	are th	ne ins	tructi	ons f	or you	ı to	understand? (Circle choice)
	-						-		, , , , , , , , , , , , , , , , , , ,
Vei	ry difficult	1	2	3	4	5	6		Very Easy

### 3.7 TOE TAPPING

<u>Instructions to examiner</u>: Test each foot separately. You may demonstrate the task, but do not continue to perform the task while the patient is tested. Once the task is understood, the patient performs 10 toe taps on each side. Instructions are repeated for left foot. Observe for number of haltings or hesitations, speed and amplitude of toe taps, and the patient's ability to maintain the task without fatigue or decrements.

<u>Instructions to patient</u>: Please sit in the chair with your knees bent and your feet flat on the ground. Bring your right [left] foot forward about 5 cm [2 inches] forward so I can observe it during the tapping task. With your heel resting on the ground, tap the toes of your right (left) foot and don't stop until I tell you to; keep the tapping smooth and regular, and be attentive to make the toe taps as large AND as fast as you can.

- 0: Normal. No problems
- 1: <u>Slight</u>. Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the tapping movement; b) there is slight slowing; c) there is slight reduction in amplitude.
- 2: <u>Mild.</u> Any of the following: a) 3 to 5 interruptions during the tapping movements; b) mild slowing; c) mild decrementing of amplitude.
- 3: <u>Moderate.</u> Any of the following: a) more than 5 interruptions during the tapping movements or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) pronounced decrementing of amplitude. The amplitude never achieved a height of 2.5 cm.
- 4: <u>Severe.</u> Cannot or can only barely perform the task because of slowing, interruptions or decrements.

1. How easy or difficult is it for you <u>as the rater</u> to understand and carry out the "Instructions to examiner"? (Circle choice)												
Very difficult	1	2	3	4	5	6	Very Easy					
							at were difficult above. What would derstand or carry out?					

		_				•	difficult is it for you <u>as the rater</u> to use tient"? (Circle choice)
Very difficult	1	2	3	4	5	6	Very Easy
3. Rater notes diffior N):	iculti	es giv	ing 1	the ir	ıstru	ctions	to patient below (Mark each item Y
_ Rater experience			•	_			<del>-</del>
_ Rater asked to re							
_ Rater had difficu					uctio	ns to p	patient
_ Other rater issue	(plea	se sp	ecify	)			
4. What would ma	ke it	easie	r <u>for</u>	the	rater	to art	iculate the instructions to the patient?
5. How easy or dif	ficult	was	it for	r you	to ra	ate the	patient using the ratings provided?
Very difficult	1	2	3	4	5	6	Very Easy
What made it di	ifficu	lt to 1	rate?				
VVIIII IIIII II III		10 00 1					
Suggested soluti	ion?						

**6.** How easy or difficult are the instructions for you to understand? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

### 3.8 LEG AGILITY

<u>Instructions to examiner</u>: Test each leg separately. You may demonstrate the task, but do not continue to perform the task while the patient is tested. Once the task is understood, so that the patient knows to move the leg as quickly as possible but also to keep the amplitude of tapping maintained, you will test each leg for 10 taps and rate each independently. Observe for number of haltings or hesitations, speed and amplitude of heel taps, and the patient's ability to maintain the task without fatigue or decrements.

<u>Instructions to patient</u>: Please sit in the chair with both feet on the floor. Your knees should be flexed and your feet on the floor. Tap your right (left) heel or your entire right (left) foot on the ground flexing your hip and picking up your knee so that the foot or heel bounces up about  $10 \text{ cm } (6 \frac{1}{2} \text{ inches})$ . Do this 10 times making sure you tap as quickly as possible but without loosing the height of the first tap.

- 0: Normal. No problems
- 1: <u>Slight</u>. Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) there is slight slowing; c) there is slight reduction in amplitude.
- 2: <u>Mild</u>. Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowness; c) mild decrementing of amplitude.
- 3: <u>Moderate</u>. Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing in speed; c) pronounced decrementing of amplitude.
- 4: <u>Severe</u>. Cannot or can only barely perform the task because of slowing, interruptions or decrements.

"Instructions			•				to understand and carry out the
Very difficult	1	2	3	4	5	6	Very Easy
							at were difficult above. What would
make the Histiati	ctions t	U CAZ		ei e	asier	to une	derstand or carry out?

_ ;	Rater experien Rater asked to Rater had diffi Other rater issu	repeat culty ex	all oi xplaii	r par ning	t of i	nstru uctio	ictions ns to j	s to patient
4.	What would r	nake it	easie	er <u>for</u>	the	rater	to ar	ticulate the instructions to the patien
5.	How easy or o	lifficult	was	it fo	r you	to ra	ate the	e patient using the ratings provided?
Ve	ery difficult	1	2	3	4	5	6	Very Easy
		11.00	14 4a s	roto?	,			
	What made it	difficu	11 10	i att!				
	What made it			i ate!				
est		ution?				struc	tions:	
	Suggested sol	ution?	gardi	ing th	ne ins			to understand? (Circle choice)

### 3.9 ARISING FROM CHAIR

<u>Instructions to examiner</u>: Select a straight-backed chair with arm rests and ask the patient to cross the arms of the body across the chest and rise independently. If the patient is not successful, repeat this attempt a maximum of two more times. If still unsuccessful, allow the patient to move forward in the chair to arise with arms folded across the chest. Allow only one attempt in this situation. If unsuccessful, allow the patient to use his/her hands on the arm of the chair in order to push off the chair to arise independently. Allow a maximum of three trials of pushing off. If still not successful after several trials, the patient can be given assistance to arise. After the patient stands up, observe the posture for item 3.13

<u>Instructions to patient:</u> Please sit in this chair. Sit back in the chair, touching the back of the chair. Make sure both feet are touching the floor. If you are too short to sit this way, move forward in the chair until your feet are touching the floor. Fold your arms across your chest and stand up with your arms folded. (After 3 unsuccessful attempts) Please move forward in the chair and try to arise with arms folded again. (If again unsuccessful after one try) This time try to use your hands on the arm of the chair to arise. (No more than 3 trials pushing off)

- 0: Normal. No problems
- 1: <u>Slight.</u> Arising is slower than normal; or may need more than one attempt; or may need to move forward in the chair to arise. No need to use the arms of the chair.
- 2: Mild. Pushes self up from arms of chair without difficulty.
- 3: <u>Moderate</u>. Needs to push off, but tends to fall back; or may have to try more than one time using arms of chair, but can get up without help.
- 4: Severe. Unable to arise without help.

1. How easy or di "Instructions to			•				to understand and carry out the
Very difficult	1	2	3	4	5	6	Very Easy
							t were difficult above. What would derstand or carry out?

3. Rater notes diffic	ulties givin	ισ the ins	tructio	ons to	natien	t below (Mark each item Y or N):
	_					
<ul><li>Rater experience</li><li>Rater asked to 1</li></ul>						
_ Rater had diffic	ulty expl	laining	instrı			
_ Other rater issu	e (please	specify	)			
4. What would m	ake it ea	sier <u>for</u>	the r	ater	to art	ticulate the instructions to the patient?
						•
5. How easy or d	ifficult w	as it for	r you	to ra	ate the	e patient using the ratings provided?
Very difficult	1	2 3	4	5	6	Very Easy
What made it	difficult	to rate?				
Suggested solu	tion?					

**6.** How easy or difficult are the instructions for you to understand? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

#### 3.10 GAIT

<u>Instructions to examiner.</u> Testing gait is best performed by having the patient walking away from and towards the examiner so that both right and left sides of the body can be easily observed simultaneously. The patient should walk at least 10 meters (30 feet) in an open hallway, then turn around and return to the examiner. Setting up a start point and stop point is recommended, because patients are not likely to know 10 meters. This item measures multiple behaviors: stride amplitude, stride speed, height of foot lift, heel strike during walking, and arm swing, but not freezing. Assess also for "freezing of gait" (next item 3.11) while patient is walking. Observe posture for item 3.11

<u>Instructions to patient</u>: Please walk at least 10 meters (30 feet) away from me down this hallway. Start here and walk down to the marker in the hall and walk back.

- 0: Normal. No problems
- 1: Slight. Independent walking with minor abnormalities.
- 2: Mild. Independent walking but with substantial abnormalities.
- 3: Moderate. Requires an assistance device for safe walking (walking stick, walker) but not a person.
- 4: Severe. Cannot walk at all or only with assistance by a caregiver.

1.	How easy or dit "Instructions to			•				to understand and carry out the
Ve	ery difficult	1	2	3	4	5	6	Very Easy
								nt were difficult above. What would derstand or carry out?
2.			_				•	difficult is it for you <u>as the rater</u> to use tient"? (Circle choice)
	Very difficult	1	2	3	4	5	6	Very Easy

<b>3.</b> ]	Rater notes diffi	culties gi	ving t	he ins	structi	ons to	patien	t below (Mark each item Y or N):	
	Rater experien								
_	Rater asked to							±	
	Rater had diffi ther rater issi							patient	
	ther rater issu	ic (pica	se sp	ccity	,				
4.	What would i	nake it	easie	er <u>for</u>	the	<u>rater</u>	to ar	ticulate the instructions to the pa	ıtient?
5	How easy or a	lifficult	was	it fo	r vou	to r	ate the	e patient using the ratings provid	led?
J. 1	110W casy of V	annicun	was	10 10	ı you		acc cm	patient using the ratings provid	icu.
Ver	y difficult	1	2	3	4	5	6	Very Easy	
,	What made it	difficu	lt to	rate?	)				
1	Suggested sol	ution?							
<u>iestio</u>	ons for the pa	tient reg	gardi	ing tl	he ins	<u>struc</u>	<u>tions:</u>		
<b>6.</b> !	How easy or d	ifficult a	are th	ne ins	tructi	ons f	or you	to understand? (Circle choice)	
Ver	y difficult	1	2	3	4	5	6	Very Easy	
	-							nderstand or follow? ere difficult)	

### 3.11 FREEZING OF GAIT

<u>Instructions to examiner</u>. While assessing gait, also assess for the presence of any gait freezing episodes. Observe for start hesitation and stuttering movements especially when turning and reaching the end of the task. Patients may NOT use sensory tricks.

<u>Instructions to patient:</u> Just walk and then turn and walk back to me. You are not permitted to use any assistance devices for this test.

- 0: Normal. No freezing of gait.
- 1: Slight. One short (1 to 2 seconds) episode of freezing.
- 2: Mild. 2 to 3 short (1 to 2 seconds) episodes of freezing; or one longer episode lasting 3 to 5 seconds.
- 3: <u>Moderate</u>. More than three short (1 to 2 seconds) episodes of freezing; or two episodes lasting 3 to 5 seconds each.
- 4: <u>Severe.</u> At least one episode of prolonged freezing (>5 seconds); or more than three short episodes (1 to 2 seconds).

Instructions	to exam	iner"?	Circl	e cho	ice)	
Very difficult	1	2 3	4	5	6	Very Easy
						t were difficult above. What would derstand or carry out?
		-			•	difficult is it for you <u>as the rater</u> to u tient"? (Circle choice)
	ording o	of the "I	nstru	ctions	s to pa	tient"? (Circle choice)

•	What would mak	ke it	easie	r <u>for</u>	the	rater	to art	iculate the inst	ructions to t	he patient
	How easy or diff	icult	was	it fo	r you	to r	ate the	patient using	the ratings p	rovided?
	Very difficult	1	2	3	4	5	6	Very Easy		
	Suggested solution	on?								

Very difficult Very Easy 1 2 3 4 5 6

#### 3.12 POSTURAL STABILITY

Instructions to examiner: The test examines the response to sudden body displacement produced by a quick, forceful pull on shoulders while the patient is standing erect with eyes open and feet comfortably apart and parallel to each other. Test retropulsion. Stand behind the patient and instruct the patient on what is about to happen. The first pull is an instructional demonstration and is not rated. The second time the shoulders are pulled briskly and forcefully towards the examiner with enough force to displace the center of gravity so that patient MUST take a step backwards. The examiner needs to be ready to catch the patient, but must stand sufficiently back so as to allow enough room for the patient to take several steps to recover independently. Do not allow the patient to flex the body abnormally forward in anticipation of the pull. Observe for the number of steps backwards or falling. Up to and including two steps for recovery is considered normal, so abnormal ratings begin with three steps. If the patient fails to understand the test, the examiner can repeat the test so that the rating is based on an assessment that the examiner feels reflects the patient's limitations rather than misunderstanding or lack of preparedness. Observe ambient posture for item 3.11

<u>Instructions to patient:</u> Please stand erect with your eyes open and feet comfortably apart and parallel to each other. I am going to try to pull you off balance, but you are not to let me. You need to recover on your own. You are allowed to take steps in the direction of my pull to maintain balance. The first pull is an instructional demonstration and is not rated. The next pull will be harder.

- 0: Normal. No problems
- 1: <u>Slight.</u> Three or more steps, but subject recovers unaided.
- 2: Mild. Absence of postural response; would fall if not caught by examiner.
- 3: <u>Moderate</u>. Very unstable, tends to lose balance spontaneously or with just a gentle pull on the shoulders.
- 4: Severe. Unable to stand without assistance.

1. How easy or dis			•				to understand and carry out the
Very difficult	1	2	3	4	5	6	Very Easy
							at were difficult above. What would derstand or carry out?
		_				•	difficult is it for you <u>as the rater</u> to use tient"? (Circle choice)

Very difficult	1	2	3	4	5	6	Very Easy
3. Rater notes difficul  Rater experienced dif Rater asked to repeat Rater had difficulty e Other rater issue (ple	ficulty all or xplain	read part o	ing in of ins	ıstruc tructi	tions to	to patie	
							_
4. What would make i	t easie	er for t	the ra	iter to	artic	ulate tl	ne instructions to the patient?
5. How easy or diff	ïcult	was i	it for	you	to ra	te the	e patient using the ratings provided?
Very difficult	1	2	3	4	5	6	Very Easy
What made it di	fficul	t to r	ate?				
Suggested soluti	on?						

**6.** How easy or difficult are the instructions for you to understand? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

### 3.13 POSTURE

<u>Instructions to examiner</u>: Posture is assessed with the patient standing erect 1) after arising, 1) while walking and 3) while being tested for postural reflexes. Rate the worst posture seen in these three tasks. Observe for flexion and side-to-side leaning.

*Instructions to the patient: None, since this rating is obtained from other item instructions.* 

- 0: Normal. No problems
- 1: Slight. Not quite erect, but posture could be normal for older person.
- 2: <u>Mild.</u> Definite flexion, scoliosis or leaning to one side, but patient can correct posture to normal posture when asked to do so.
- 3: <u>Moderate.</u> Stooped posture, scoliosis or leaning to one side that cannot be corrected volitionally to a normal posture by the patient.
- 4: Severe. Flexion, scoliosis or leaning with extreme abnormality of posture.

1. How easy or dif "Instructions to			•				to understand and carry out the
Very difficult	1	2	3	4	5	6	Very Easy
							nt were difficult above. What would derstand or carry out?
2. How easy or dif	ficult	was	it foi	r you	to r	ate the	e patient using the ratings provided?
Very difficult	1	2	3	4	5	6	Very Easy
What made it d	ifficu	lt to	rate?	ı			
Suggested solut	ion?						

### 3.14 GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)

<u>Instructions to examiner</u>: This global rating combines all observations on slowness, hesitancy, and small amplitude and poverty of movement in general, including a reduction of gesturing and of crossing the legs. This assessment is based on the examiner's global impression after observing for spontaneous gestures while sitting, and the nature of arising and walking.

Instructions to patient: None, since this rating is obtained from the entire examination.

- 0: Normal. No problems
- 1: <u>Slight.</u> Minimal global slowness and poverty of spontaneous movements.
- 2: Mild. Mild global slowness and poverty of spontaneous movements.
- 3: Moderate. Moderate global slowness and poverty of spontaneous movements.
- 4: Severe. Severe global slowness and poverty of spontaneous movements.

1. How easy or dif "Instructions to				•			r to understand and carry out the
Very difficult	1	2	3	4	5	6	Very Easy
							at were difficult above. What would derstand or carry out?
2. How easy or dif	ficul	t was	s it fo	r yo	u to 1	rate tl	ne patient using the ratings provided?
Very difficult	1	2	3	4	5	6	Very Easy
What made it di	fficul	lt to 1	rate?				
Suggested solution	on?						

### 3.15 POSTURAL TREMOR OF THE HANDS

<u>Instructions to examiner</u>: All tremor, including re-emergent rest tremor, that is present in this posture is to be included in this rating. Rate each hand separately. Rate the highest amplitude seen.

<u>Instructions to patient</u>: Please extend your arms out in front of your body with your palms down. Make sure your arms are in a position horizontal to the ground and parallel to each other. Your wrist should be straight and the fingers comfortably extended and slightly separated so that they do not touch each other. Hold this posture for 10 seconds.

R

- 0: Normal. No tremor.
- 1: Slight. Tremor is present but less than 1 cm in amplitude.
- 2: Mild. Tremor is at least 1 but less than 3 cm in amplitude.
- 3: Moderate. Tremor is at least 3 but less than 10 cm in amplitude.
- 4: Severe. Tremor is at least 10 cm in amplitude.

1. How easy or di			•		s the	rater	to understand and carry out the
Very difficult	1	2	3	4	5	6	Very Easy
							at were difficult above. What would derstand or carry out?
the current wo	rding	of the	e "In	struc	ction	s to pa	difficult is it for you <u>as the rater</u> to use tient"? (Circle choice)
Very difficult	1	2	3	4	5	6	Very Easy
3. Rater notes difficu Rater experienced d Rater asked to repe Rater had difficulty	lifficult at all o	ty read r part	ling ir of ins	ıstruc tructi	tions ons to	to patie	

_ C	Other rater issue (p	lease sp	ecify)					
	-							
4.	What would m	ake it	easie	r <u>for</u>	the	rater	to art	ticulate the instructions to the patient?
5.	How easy or di	fficult	was	it foi	you	to ra	ate the	e patient using the ratings provided?
Ve	ery difficult	1	2	3	4	5	6	Very Easy
	What made it o	lifficu	lt to	rate?	ı			
	Suggested solu	tion?						

**6.** How easy or difficult are the instructions for you to understand? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

### 3.16 KINETIC TREMOR OF THE HANDS

<u>Instructions to examiner</u>: This is tested by the finger-to-nose maneuver. Rate each hand separately. Force the subject to reach as far as possible to touch your finger with one hand. Repeat with the other hand, rating each hand separately. The tremor can be present throughout the movement or as the tremor reaches either target (nose or finger). Rate the highest amplitude seen.

<u>Instructions to patient</u>: Please use your right (left) hand to move slowly and smoothly and reach out to touch my finger, then touch your nose and repeat this over again until you have completed five backand-forth motions.

- 0: Normal. No tremor.
- 1: Slight. Tremor is present but less than 1 cm in amplitude.
- 2: Mild. Tremor is at least 1 but less than 3 cm in amplitude.
- 3: Moderate. Tremor is at least 3 but less than 10 cm in amplitude.
- 4: Severe. Tremor is at least 10 cm in amplitude.

						•	atient involvement).
1. How easy or diffe "Instructions to			•				o understand and carry out the
Very difficult	1	2	3	4	5	6	Very Easy
							t were difficult above. What would lerstand or carry out?
							lifficult is it for you <u>as the rater</u> to use tient"? (Circle choice)
Very difficult	1	2	3	4	5	6	Very Easy
3. Rater notes difficult	ies giv	ving th	ie ins	tructio	ons to	patient	below (Mark each item Y or N):

_ Other	r rater issue (pl	ease sp	ecify)					
4. Wł	nat would ma	ake it	easie	r <u>for</u>	the	<u>rater</u>	to art	rticulate the instructions to the patient?
5. Но	w easy or di	fficult	was	it foi	r you	to ra	ate the	e patient using the ratings provided?
Very d	lifficult	1	2	3	4	5	6	Very Easy
Wł	nat made it d	lifficu	lt to 1	rate?	•			
Suş	ggested solut	ion?						

**6.** How easy or difficult are the instructions for you to understand? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

7. What parts of the instructions were difficult to understand or follow? (Circle these on form and explain why they were difficult)

#### 3.17 REST TREMOR AMPLITUDE

<u>Instructions to examiner</u>: This item has been placed purposefully at the end of the examination to allow the rater to gather observations on rest tremor over several minutes when quietly sitting, during walking and during activities when some body parts are moving but others are at rest. In addition to the observations made during the rest of the examination, the rater should have the patient sit quietly in a chair with the hands placed on the arms of the chair (not in the lap) and the feet comfortably supported on the floor for 10 seconds with no other directives. Rest tremor is assessed separately for all four limbs and also for the lip/jaw. Rate only the maximum amplitude that is seen at any time as the final rating.

<u>Instructions to patient</u>: Please sit quietly in this chair with your hands placed on the arms of the chair (not in your lap) and your feet comfortably supported on the floor for 10 seconds while I observe you.

(not in your lap) and your feet comfortably support	ed on the floor for 10 seconds while I observe you.
Extremity ratings	Lip/Jaw ratings
0: <u>Normal.</u> No tremor.	0: Normal. No tremor
1: <u>Slight.</u> < 1 cm in maximal amplitude.	1: Slight. <1 cm in maximal amplitude.
2: Mild. $\geq$ 1 cm but <3 cm in maximal amplitude	2: Mild. $\geq 1$ cm but $\leq 2$ cm in maximal amplitude
3: Moderate. 3-10 cm in maximal amplitude.	3: Moderate. >2 cm but <3 cm in maximal
	amplitude.
4: Severe. >10 cm in maximal amplitude.	4: <u>Severe</u> . ≥3 cm in maximal amplitude.

Lip/Jaw

RUE LUE

RLE LLE

## Rater Experience with Instructions and Ratings (no patient involvement):

1. How easy or di			•				to understand and carry out the			
Very difficult	1	2	3	4	5	6	Very Easy			
							at were difficult above. What would derstand or carry out?			
	2. Read instructions to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the "Instructions to patient"? (Circle choice)									
Very difficult	1	2	3	4	5	6	Very Easy			

3. Rater notes difficult	ties gi	ving t	he ins	tructi	ions to	patier	t below (Mark each item Y or N):
Rater experienced difficulty reading instructions to patient Rater asked to repeat all or part of instructions to patient Rater had difficulty explaining instructions to patient Other rater issue (please specify)							
4. What would ma	ke it	easie	r <u>for</u>	the	<u>rater</u>	to ar	ticulate the instructions to the patient?
5. How easy or dif	ficult	was	it fo	r you	to r	ate the	e patient using the ratings provided?
Very difficult	1	2	3	4	5	6	Very Easy
What made it dif	ficult	to ra	te?				
Suggested soluti	on?						

## **Questions for the patient regarding the instructions:**

**6.** How easy or difficult are the instructions for you to understand? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

7. What parts of the instructions were difficult to understand or follow? (Circle these on form and explain why they were difficult)

### 3.18 CONSTANCY OF REST TREMOR

<u>Instructions to examiner</u>: This item receives one rating for all rest tremor and focuses on the constancy of rest tremor during the examination period when different body parts are variously at rest. It is rated purposefully at the end of the examination so that several minutes of information can be coalesced into the rating.

Instruction to patient: No instructions.

- 0: Normal. No tremor.
- 1: Slight. Tremor at rest is present <25% of the entire examination period.
- 2: Mild. Tremor at rest is present 26-50% of the entire examination period.
- 3: Moderate. Tremor at rest is present 51-75% of the entire examination period.
- 4: Severe. Tremor at rest is present >75% of the entire examination period.

## Rater Experience with Instructions and Ratings (no patient involvement):

Very difficult	1 2	) 3	4	5	6	Very Facy	
very unineum	1 4	2 3	7	3	U	very Easy	
						were difficult above. Werstand or carry out?	hat would
•					•	patient using the ratings	s provided
•					•	patient using the ratings Very Easy	s provided
Very difficult	1 2	2 3			•		s provided
Very difficult What made it diff	1 2	2 3			•		s provided'
2. How easy or delegated whet made it differential solutions of the second sol	1 2	2 3			•		s provided'
Very difficult  What made it diff	1 2	2 3			•		s provided'
Very difficult  What made it diff	1 2	2 3			•		s provided'

# **UPDRS PART III PATIENT DEBRIEFING**

For questions1-2, rater summarizes patient's answers to the questions below using patient's own words whenever possible.

1.	Overall, did you find the instructions for this section difficult? $\underline{\hspace{1cm}}$ (Y/N) If so, what made them difficult?
2.	Overall, did you find the instruction or tasks upsetting? $\_$ (Y/N) If so, what made them upsetting?
[Note:	At this point, the cognitive test of this UPDRS Part is complete for this patient.]
	RATER'S DEBRIEFING
3.	Which, if any, of the instructions or tasks seemed to make the patient uncomfortable? Why?
4.	Which instructions were the most difficult or awkward for you to give? Why
5.	Have you come to dislike any specific instructions in this UPDRS Part? Which ones? Why

	Interrupting
_	Contracdicting
_	Sharing
_	Confirming
_0	ther/Please specify
-	
	Did you sense that any of the following factors influenced answer? (Check
	appropriate factor and provide concrete examples)
	Social desirability
-	
-	_ Minimization of PD impact?
-	_ Defensiveness regarding disability?
-	Protectiveness?
_	_ Other/please specify?
	Example:

## **Part IV: Motor Complications**

**Overview and Instructions:** In this section, the rater uses historical and objective information to provide information on two motor complications, dyskinesias and motor fluctuations that include OFF-state dystonia. Use all information from patient, caregiver, and the examination to answer the six questions that summarize function over the past week including today. As in the other sections, rate using only integers (no half points allowed) and leave no missing ratings. If the item cannot be rated, place UR for Unable to Rate.

### **Operational definitions:**

**Dyskinesias:** Involuntary random movements

**Dystonia:** contorted posture, often with a twisting component

**Motor fluctuation:** Variable response to medication

**OFF:** Typical functional state when patients have a poor response in spite of taking medications

or the typical functional response when patients are on NO treatment for parkinsonism.

**ON:** is the typical functional state when patients are receiving medication and have a good

response.

#### **Cognitive Test Question:**

Were there any parts of the instructions on the page above titled "<u>Part IV: Motor Complications</u>" that were difficult for you <u>as the rater</u> to understand or that require clarification?

Y/N If yes, please circle those segments on the previous page and explain below what clarifications are needed.

## A. DYSKINESIAS [exclusive of OFF-state dystonia]

- 4.1 TIME SPENT WITH DYSKINESIAS In the past week, on average, including today what proportion of the waking day were dyskinesias present?
- 0: Normal No dyskinesia
- 1: Slight. 1-25% of waking day
- 2: Mild. 26-50% of waking day
- 3: Moderate: 51-75% of waking day
- 4: Severe: 76-100% of waking day

### **Rater Experience Posing UPDRS Question (no patient involvement):**

1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

	2.	Rater notes difficu	ılties u	sing tl	he que	estion	below	(Mar	rk each item Y or N):	
	_	-	lifficult	y reac	ding q	uestio	n (Un	derlin	ne problematic parts above. Explain difficulty	
		below) Rater asked to repe	at all o	r part	of qu	estion	(Brac	eket re	epeated parts above)	
		Rater had difficulty							· · · · · · · · · · · · · · · · · · ·	
	- '	Other rater issue (p.	iease sį	jecny,	,					
										_
		-								
										_
		-								
										_
		-								
Q	uest	tions for the pation	ent af	ter th	ney h	ave h	<u>eard</u>	the l	UPDRS question:	
	3.	How easy or dif	ficult	is the	ques	stion	for yo	ou to	understand? (Circle choice)	
	<b>X</b> 7	1.00		•	2		_		W. F	
	V	ery difficult	1	2	3	4	5	6	Very Easy	
	4	What parts of th	e ques	stion	were	diffic	cult to	o unde	lerstand? What was the difficulty?	
		Circle these on for							The state of the s	
	5.	What do you un	dersta	nd by	the the	follov	wing	words	ls?	
		Ž		J	,		υ			
	0	"dyskinesia" Understood con	rrooth	7 <b>9 (V</b>	/NI)					
							stand	to ca	apture the meaning? (Record suggestions	)
Q	uest	tions for the patio	ent af	ter th	ney h	ave d	lecide	ed on	n a rating:	
	6	How easy or dif	ficult	wac i	t for	vou t	o rate	VOUT	r answer to that question?	
	υ.	110w casy of ull	ncuit	was 1	ι 101	you t	o raic	your	i answer to that question?	
	V	ery difficult	1	2	3	4	5	6	Very Easy	
	V	ery difficult	1	2	3	4	5	6	Very Easy	

7.	Who answered this item?	_ Patient primarily	Caregiver primarily
	Suggested solution?		
	What made it difficult to rate?		

# 4.2 FUNCTIONAL IMPACT OF DYSKINESIAS - How do dyskinesias influence the performance of activities? [Note: If there are no dyskinesias, this rating will be 0, but patients with dyskinesia can also be rated 0 if there is no impact on activities.]

- 0: Normal. No dyskinesias or no impact by dyskinesias on performance of activities.
- 1: <u>Slight.</u> Dyskinesias impact on the performance of a few activities, but you perform all activities during dyskinetic periods.
- 2: <u>Mild</u>. Dyskinesias impact on the performance of many activities, but you perform all activities during dyskinetic periods.
- 3: <u>Moderate</u>. Dyskinesias impact on the performance of activities to the point that you do not perform some activities during dyskinetic episodes.
- 4: <u>Severe</u>. Dyskinesias impact on function to the point that you do not perform most activities during dyskinetic episodes.

## **Rater Experience Posing UPDRS Question (no patient involvement):**

	-			-			easy or difficult is it for you <u>as the</u> on verbatim? (Circle choice)
Very difficult	1	2	3	4	5	6	Very Easy
2. Rater notes difficu	lties us	sing th	ie que	estion	below	(Mark	c each item Y or N):
Explain difficulty below)	peat a	all or plain	part	t of q	uesti ion	ion (B	Underline problematic parts above. racket repeated parts above)

## **Questions for the patient after they have heard the UPDRS question:**

<b>3.</b> H	How easy or	difficult is th	e question	for you to	understand?	(Circle choice)
-------------	-------------	-----------------	------------	------------	-------------	-----------------

Very difficult 1 2 3 4 5 6 Very Easy

Very difficult	1	2	3	4	5	6	Very Easy
What made it o	difficult	to ra	te?				
Suggested solu	ition?						

4. What parts of the question were difficult to understand? What was the difficulty?

(Circle these on form and explain why they were difficult)

В	. MOTOR	FLUCTUATIONS
4	3.3 TIME S	PENT IN THE OFF STATE - In the past week including today, on average, what
ŗ	roportion o	of the waking day were you in the OFF-state?
(	: Normal.	No OFF time
1	: Slight.	1-25% of waking day
2	: Mild	26-50% of waking day
3	: Moderate	2 51-75% of waking day
4	: <u>Severe</u>	76-100% of waking day

# **Rater Experience Posing UPDRS Question (no patient involvement):**

1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)											
Very difficult	1	2	3	4	5	6	Very Easy				
2. Rater notes difficul	ties u	sing th	ie que	stion	below	(Mark	each item Y or N):				
Explain difficulty below)	ı v										
Rater asked to rep Rater had difficul Other rater issue	ty ex	plain	ing o	quest	ion	юп (ві	cacket repeated parts above)				
	(P										

# **Questions for the patient after they have heard the UPDRS question:**

3.	How easy or diff	icult	is the	ques	tion 1	for yo	ou to u	nderstand? (Circle cho	ice)
Ve	ry difficult	1	2	3	4	5	6	Very Easy	

4. What parts of the question were difficult to understand? What was the difficulty? (Circle these on form and explain why they were difficult)

Questions for the patient after they have decided on a rating:
--

5.	How easy or diff	icult v	was it	t for	you to	o rate	your a	answer to that question?
Ve	ry difficult	1	2	3	4	5	6	Very Easy
	What made it dif	ficult	to rat	te?				
	Suggested solution	on?						
6.	Who answered	this it	em?		Patie	nt pr	rimaril	y Caregiver primarily

- 4.4 FUNCTIONAL IMPACT OF FLUCTUATIONS How do fluctuations impact on your performance of activities? [Note: This question concentrates on the difference between the ON state and the OFF state as opposed to the functional impact of just the OFF state (already assessed in the EDL section). If the patient has no OFF time, the rating must be 0, but if patients have very mild fluctuations, it is still possible to be rated 0 on this item if no impact on activities occurs.]
- 0: Normal No fluctuations or No impact by fluctuations on performance of activities.
- 1: <u>Slight</u>. Fluctuations impact on the performance of a few activities, but, during OFF, you perform all activities performed during the ON state.
- 2: <u>Mild.</u> Fluctuations impact on the performance of many activities, but, during OFF, you still perform all activities performed during the ON state.
- 3: <u>Moderate</u>. Fluctuations impact on the performance of activities during OFF to the point that you do not perform some activities that are performed during ON periods.
- 4: <u>Severe</u>. Fluctuations impact on function to the point that, during OFF, you do not perform most activities that are performed during ON periods.

## **Rater Experience Posing UPDRS Question (no patient involvement):**

1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)										
Very difficult 1 2 3 4 5 6 Ver	y Easy									
2. Rater notes difficulties using the question below (Mark each iter	n Y or N):									
_ Rater experienced difficulty reading question (Underline problematic parts above.  Explain difficulty below) _ Rater asked to repeat all or part of question (Bracket repeated parts above) _ Rater had difficulty explaining question										
_ Other rater issue (please specify)										

# Questions for the patient after they have heard the UPDRS question:

Ve	ery difficult	1	2	3	4	5	6	Very Easy
	What parts of t							rstand? What was the difficulty?
5.	What do you u	ndersta	nd by	y the	follov	ving	words?	)
0	"fluctuations" Understood co What words wo					stand	l to cap	oture the meaning? (Record suggestions
ıost	ions for the not	iont off	tor th	nov h	avo d	ocida	nd an a	a rating:
	<b>ions for the pat</b> How easy or di							a rating: answer to that question?
6.		fficult	was i	it for	you to	o rate	your a	answer to that question?
6.	How easy or di	fficult	was i	it for	you to	o rate	your a	answer to that question?
6.	How easy or di	ifficult y	was i	it for	you to	o rate	your a	answer to that question?

	5 COMPLEXITY OF MOTOR FLUCTUATIONS - What is the predictability of OFF function
ac	cording to dose, time of day, food intake or other factors that allow you to plan activities?
0:	Normal. No motor fluctuations or, if present, they are entirely predictable.
1:	Slight. OFF episodes are predictable more than 75% of the time.
2:	Mild. OFF episodes are predictable 50-75% of the time.
3:	Moderate. Most OFF episodes are NOT predictable, but at least some are.
4:	Severe. OFF episodes are random and completely unpredictable.

# **Rater Experience Posing UPDRS Question (no patient involvement):**

1. Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)										
Very difficult	1	2	3	4	5	6	Very Easy			
2. Rater notes difficult	lties us	sing th	1e que	estion	below	(Mark	each item Y or N):			
_ Rater experienced difficulty reading question (Underline problematic parts above.  Explain difficulty below)  Rater asked to repeat all or part of question (Bracket repeated parts above)										
Rater had difficult Other rater issue	•	_	_	-						

## Questions for the patient after they have heard the UPDRS question:

<b>3.</b> How easy or difficult is the question for you to understand? (Circle choice)									
Very difficult	1	2	3	4	5	6	Very Easy		
4. What parts of the (Circle these on for							rstand? What was the difficult	y?	

	5.	What do you u	nderstai	nd by	the	follov	wing	words	s?					
	0	"predictability Understood co What words wo	rrectly	? (Y	/N) _		- rstanc	l to ca	ıpture	the meani	ing? (Re	ecord su	ggestion	ıs)
Que	esti	ions for the pat	ient aft	er th	ey h	ave d	lecid	ed on	a rat	ing:				
	6.	How easy or di	fficult v	was i	t for	you t	o rate	e your	answ	er to that	question	1?		
	Ve	ry difficult	1	2	3	4	5	6	1	Very Easy	,			
		What made it d	ifficult	to ra	te?									
		Suggested solu	tion?											
	7.	Who answered Both	l this it	em?		Patie	ent p	rimar	rily	Ca	regiver	primai	ily	

	PAINFUL OFF-STATE DYSTONIA {For patients with fluctuations and OFF time} - What portion of the OFF episodes include painful dystonia?	
-	Normal: No dystonia	
	Slight. 1-25% of OFF episodes	
	Mild. 26-50% of OFF episodes	
	Moderate 51-75% of OFF episodes	
	Severe 76-100% of OFF episodes	
	·	
Ra	r Experience Posing UPDRS Question (no patient involvement):	
	Rater reads the question to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)	
	Tery difficult 1 2 3 4 5 6 Very Easy	
	Rater notes difficulties using the question below (Mark each item Y or N):	
	Rater experienced difficulty reading question (Underline problematic parts above. xplain difficulty below) Rater asked to repeat all or part of question (Bracket repeated parts above) Rater had difficulty explaining question Other rater issue (please specify)	
Qu	tions for the patient after they have heard the UPDRS question:  How easy or difficult is the question for you to understand? (Circle choice)	
	·	
	fery difficult 1 2 3 4 5 6 Very Easy	
	What parts of the question were difficult to understand? What was the difficulty? Circle these on form and explain why they were difficult)	

5.	What do you und	derstand l	by the	follov	wing	words	?	
0	"dystonia"  Understood cor  What words wor					I to ca	pture the meaning? (Reco	ord suggestions
	tions for the pation						a rating: answer to that question?	
Ve	ery difficult	1 2	3	4	5	6	Very Easy	
	What made it di	fficult to	rate?					
	Suggested soluti	on?						
7.	Who answered Both	this item	?	Patie	ent pi	rimari	ily Caregiver p	rimarily

## UPDRS PART IV PATIENT DEBRIEFING

For questions 1-2, the rater summarizes patient's answers to the questions below using patient's own words whenever possible.

8. Overall, did you find the assessment questions difficult?  $\underline{\hspace{1cm}}$  (Y/N)

If so, what made them difficult?

	9.	Did you find any of the assessment questions upsetting? $\_$ (Y/N) If so, what made them upsetting?						
[N	[Note: At this point, the cognitive test of this UPDRS Part is complete for this patient.]							
R	1 <i>TEI</i>	R'S DEBRIEFING						
	10	. How easy or difficult is it for you <u>as the rater</u> to explain to the patient the rating options using the navigation instructions (page 5)?						
		Very difficult 1 2 3 4 5 6 Very Easy						
	What made these options difficult for you as the rater to explain?							
	11.	. Which, if any, of the questions seemed to make the patient uncomfortable? Why?						
	12.	Which questions were the most uncomfortable or awkward for you to ask? Why?						

Have you come to dislike any specific questions in this UPDRS Part? Which ones? Why?
14. Please note your general observations of the interaction between proxy/patient. (Mark $Y/N$ )
_ Interrupting
_ Contradicting
_ Sharing
_ Confirming
_ Other/Please specify
15. Did you sense that any of the following factors influenced answers? (Check appropriate factor and provide concrete examples)
_ Social desirability?
_ Minimization of PD impact?
_ Defensiveness regarding disability?
_ Protectiveness?
_ Other/please specify?
Example:

Appendix-More detailed rating scales for use with the UPDRS
Summary of the conclusions – Recommended and Suggested scales/topic
(Dr. Sampaio and group working on re-updating on an ongoing basis)

## Operative Definitions:

Recommended: Acceptable scale that has been studied clinimetrically and considered valid, reliable and sensitive; and it has been used in PD in reports other than just the group that originally described it.

Suggested: Scale meets at least part of the above criteria, but falls short of meeting all.

TOPIC	Scales	Scales	Scales
10110		12 2 2 2	
HRQoL	identified  Sickness Impact Profile (SIP), the Nottingham Health Profile (NHP Short-Form Health Survey (SF-36] EQ-5D PDQ-39 Parkinson's disease summary index; PDSI PDQ-8 PDQL The simple comprehensive evaluation of quality of life. The Parkinson's disease symptom inventory (PDSI): the Functional Status Questionnaire Parkinson's Impact Scale (PIMS) Kuehleret al 2003 Welsh et al 2003	RECOMMENDED  Generic instrument: SF-36, EQ-5D Disease-specific instrument: PDQ-39 Index Instrument: EQ-5D	SUGGESTED
	<ul><li>Spliethoff-Kamminga et al 2003</li><li>SCOPA-PS</li></ul>		
Cognitive Impairment	Mini-Mental Parkinson     The SCOPA-COG     Brief assessment of executive control dysfunction     Frontal assessment battery at bedside.	None	The SCOPA-COG     Brief assessment of executive control dysfunction
Dementia	<ul> <li>MMSE</li> <li>ADAS-cog</li> <li>VADAS</li> <li>The Mattis' Dementia Ratings Scale.</li> <li>The Neuropsychiatric Inventory (NPI).</li> </ul>	None	ADAS-cog     The Mattis' Dementia Ratings Scale.
Insomnia (Quality nighttime sleep)	<ul> <li>the Pittsburgh Sleep Quality Index (PSQI)</li> <li>SCOPA-SLEEP nighttime sleep subscale</li> <li>Inappropriate Sleep Composite Score</li> <li>Sleep Disorders Questionnaire (SDQ)</li> <li>National Sleep Foundation sleep survey</li> <li>Parkinson's disease sleep scale</li> </ul>	• the Pittsburgh Sleep Quality Index (PSQI)	SCOPA-SLEEP nighttime sleep     sub-scale     Parkinson's disease sleep scale

Daytime sleepiness	Epworth Sleepiness Scale (ESS)     SCOPA-SLEEP daytime sleepiness sub-scale     Parkinson's disease sleep scale     The Stanford sleepiness scale     The Karolinska sleepiness scale  Hamilton Depression scale	Epworth Sleepiness Scale (ESS)      Hamilton Depression	SCOPA-SLEEP daytime sleepiness sub-scale     Parkinson's disease sleep scale      Montgomery-Asberg
	<ul> <li>Beck Inventory (self-administered questionnaire)</li> <li>Montgomery-Asberg Depression Rating Scale</li> <li>Zung Depression scale</li> <li>Hospital Anxiety and Depression scale</li> </ul>	scale • Hospital Anxiety and Depression scale	Depression Rating Scale
Psychosis	Rush Hallucinatory inventory     Structure Interview for hallucinations in PD     Positive and Negative Syndrome Scale (PANS)     Brief psychiatric Rating scale     Scale for the Assessment of negative symptoms (SANS).     Scale for the Assessment of positive symptoms (SAPS).     Clinical global impression (severity, improvement).     Brief Psychiatric scale.     Modified UPDRS item on thought disorder.     Parkinson Psychosis rating scale (PPRS)	None	• PPRS • BPRS
Non motor signs and symptoms	Global scale: -motor symptom assessment scale for Parkinson's disease	NONE	NONE
Dysphagia	Modified Rehabilitation Institute of Chicago Dysphagia Rating Scale,     Dysphagia Outcome and Severity Scale     Swallowing Ability Scale     Dysphagia Outcome and Severity Scale     Functional outcome swallowing scale	NONE	NONE
Fatigue	Multidimensional Fatigue Inventory,     Fatigue Severity Scale, 7-point scale to evaluate fatigue	Fatigue Severity Scale, 7- point scale to evaluate fatigue	Multidimensional Fatigue Inventory     Fatigue Severity Scale, 7-point scale to evaluate fatigue ??
Pain intensity Pain "Quality"	<ul> <li>VAS intensity of pain.</li> <li>Numerical scale for intensity of pain</li> <li>Eg: Mc Gill questionnaire</li> </ul>	<ul> <li>VAS intensity of pain.</li> <li>Numerical scale for intensity of pain</li> </ul> NONE	NONE
Dyskinesias	AIMS     Modified AIMS     OBESO Dyskinesias rating scale     RUSK Dyskinesias scale     Dyskinesia rating scale     Salpetriere Scale     Lang and Fahn Scale     Unified Dyskinesias Rating scale (UDRS) [ under development]	Dyskinesia rating scale	

# **SUPPLEMENT #2.** Cognitive Pretesting

Manual for Round 2

(Verbal Probing and "Think aloud"

Interviewing for a Sub-set of Items)

Name of Interviewer

\_\_\_/\_\_\_\_
Date

## Cognitive Pretesting Manual for UPDRS (Round 2)

Cognitive testing of data collection instruments involves the use of techniques to elicit respondents' interpretations of the items/questions in the instrument being tested. It may test both usability and comprehension so that revisions can be made to enhance both before putting the instrument into practice for its intended purpose. For UPDRS, cognitive testing will involve indepth interviews with patients and data gathering from both raters and patients to understand any difficulties patients may have with understanding, as well as gathering responses from the raters administering the instrument related to ease of use. Your involvement and patience in conducting these in-depth interviews and recording the cognitive testing responses will be invaluable in making the UPDRS instrument as usable in a consistent manner for raters and correctly interpretable to patients as possible.

Please review the entire testing manual before initiating a cognitive test to ensure you are familiar with the flow of cognitive testing questions interspersed with the shaded UPDRS segments.

All instructions and questions that are part of the standard UPDRS instrument (i.e., what is being tested) appear in areas that are lightly shaded gray in this cognitive testing manual. Questions and instructions from UPDRS should be read/used verbatim. All non-shaded areas are part of the cognitive testing script.

In general, after each UPDRS question, there will be some cognitive testing questions addressed only to the rater related to ease of use. These will be followed by cognitive testing questions to be addressed to the patient by the rater about the patient's understanding of the question and the response options. These cognitive testing questions can be visibly distinguished by boxed questions for the rater and non-boxed questions for the patient.

In the non-shaded areas of the cognitive testing script throughout the manual, words that are boxed in are instructions to or questions for the rater only. Please respond to all cognitive testing questions or mark them N/A if the question is not applicable for any reason.

Words that are **not boxed in** are questions to be **asked of the patient**. All cognitive testing responses from either the rater or the patient are to be recorded in the space provided. Patient responses should be captured in their own words whenever possible.

## New MDS-UPDRS working document

The Movement Disorder Society (MDS)-sponsored new version of the UDPRS is founded on the critique that was formulated by the Task Force for Rating Scales in Parkinson's disease (*Mov Disord* 2003; 18:738-750). Thereafter, the MDS recruited a Chairperson to organize a program to provide the Movement Disorder community with a new version of the UDPRS that would maintain the overall format of the original UPDRS, but address issues identified in the critique as weaknesses and ambiguities. The Chairperson identified subcommittees with chairs and members. Each part was written by the appropriate subcommittee members and then reviewed and ratified by the entire group. These members are listed below.

This new version of the UPDRS has been presented to the Movement Disorder Society and is in the process of being tested clinimetrically. The final version of the scale is anticipated for 2007, at which time it will be published. Researchers and clinicians are welcome to utilize the new version, but should understand that it has not yet been validated and has not been specifically tested against the original UPDRS. These projects are underway. Data from colleagues using both scales will be useful to the overall clinimetric testing program and contact with Dr. Goetz will facilitate participation.

The new UPDRS has four parts: Part I (non-motor experiences of daily living), Part II (motor experiences of daily living, Part III (motor examination) and Part IV (motor complications). Part I has two components: IA concerning a number of behaviors that are assessed by the investigator with all pertinent information from patients and caregivers and IB that is completed by the patient with or without the aid of the caregiver, but independently of the investigator. It can, however, be reviewed by the rater to ensure that all questions are answered clearly and the rater can help explain any perceived ambiguities. Part II is designed to be a self-administered questionnaire like Part IB, but can be reviewed by the investigator to ensure completeness and clarity. Of note, the official versions of Part1A, Part1B and Part2 of the MDS-UPDRS do not have separate on or off ratings. However, for individual programs or protocols the same questions can be used separately for on and off. Part III has instructions for the rater to give or demonstrate to the patient; it is completed by the rater. Part IV has instructions for the rater and also instructions to be read to the patient. This part integrates patient-derived information with the rater's clinical observations and judgments and is completed by the rater.

The authors of this new version are: Chairperson: Christopher G. Goetz

Part I: Werner Poewe (chair), Bruno Dubois, Anette Schrag

Part II: Matthew B. Stern (chair), Anthony E. Lang, Peter A. LeWitt Part III: Stanley Fahn (chair), Joseph Jankovic, C. Warren Olanow

Part IV: Pablo Martinez-Martin (chair), Andrew Lees, Olivier Rascol, Bob van Hilten Development Standards: Glenn T. Stebbins (chair), Robert Holloway, David Nyenhuis

Appendices: Cristina Sampaio (chair), Richard Dodel, Jaime Kulisevsky Statistical Testing: Barbara Tilley (chair), Sue Leurgans, Jean Teresi,

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#### Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)

Overview: This portion of the scale assesses the non-motor impact of Parkinson's disease (PD) on patients' experiences of daily living. There are 12 questions. Part 1A is administered by the rater (six questions) and focuses on complex behaviors. Part 1B is a component of the Patient Questionnaire that covers six questions on non-motor experiences of daily living. These questions gather an overall assessment of general experiences of daily living. The investigator can use such words as "usually", "generally", "most of the time" when interviewing patients.

Part 1A: In administering Part IA, the examiner should comply with the following guidelines:

- 1. Mark at the top of the form the primary data source as patient, caregiver, or patient and caregiver in equal proportion.
- 2. The response to each item should refer to a period encompassing the prior week including the day on which the information is collected.
- 3. All items must have an integer rating (no half points, no missing scores). In the event that an item does not apply or cannot be rated (e.g., amputee who cannot walk), the item is marked **UR** for Unable to Rate.

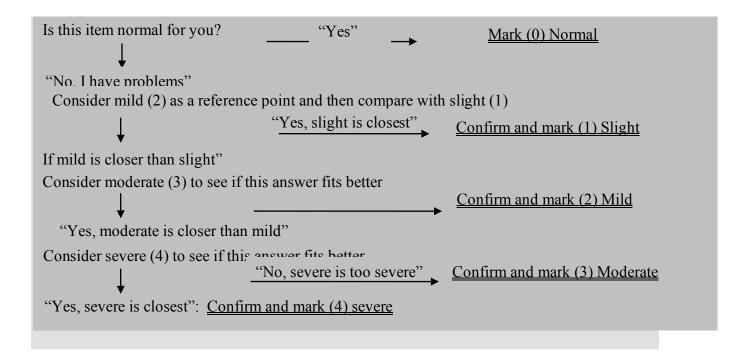
#### EXAMPLE OF NAVIGATING THROUGH THE RESPONSE OPTIONS FOR PART 1A

Suggested strategies for obtaining the most accurate answer:

After reading the instructions to the patient, you will need to probe the entire domain under discussion to determine Normal vs problematic: If your questions do not identify any problem in this domain, record 0 and move on to the next question.

If your questions identify a problem in this domain, you should work next with a reference anchor at the mid-range (option 2 or Mild) to find out if the patient functions at this level, better or worse. You will not be reading the choices of responses to the patient as the responses use clinical terminology. You will be asking enough probing questions to determine the response that should be coded.

Work up and down the options with the patient to identify the most accurate response, giving a final check by excluding the options above and below the selected response



## **Instructions to Patient about Cognitive Testing:**

The UPDRS assessment questionnaire is a tool used to help clinicians understand the impact of PD on the daily life activities of persons with PD. Thank you for participating with us in this test of the UPDRS assessment tool. It is very important to us that you describe any difficulties you have responding to particular questions as truthfully as possible. This is not a test of your intelligence but of how good we have been at developing an assessment tool that people with Parkinson's disease can understand easily. If you have difficulty in understanding anything I say to you, you are probably not alone and other people would also have the same difficulty. It is important for us to know this so that we can change the wording and make it easier for everyone to understand and answer consistently. Please do not hesitate to tell me when anything I say – instructions, questions, or response options - is confusing to you, including any medical terms.

We will do the first part of the test together by my reading each instruction or question to you the way it would be done in a regular assessment. After each question, we will then stop and talk about any parts of the instruction or question and response options that were confusing to you.

Primary source of information:PatientCaregiverPatient and Caregiver in Equal Proportion  1.1 COGNITIVE IMPAIRMENT: Instructions to examiner: Consider all types of altered level of cognitive function including cognitive slowing, impaired abstract reasoning, memory loss, deficits in attention and orientation. Rate their impact on activities of daily living as perceived by the patient and/or caregiver. Instructions to patients [and caregiver]: Over the past week have you had problems remembering things, following conversations, paying attention, thinking clearly, or finding your way around the house or in town? [If yes, examin patient or caregiver to elaborate and probes for information.] 0: Normal. 1: Slight: Impairment appreciated by patient or caregiver with no concrete interference with the patient's ability to carry out normal activities and social interactions. 2: Mild: Clinically evident cognitive dysfunction, but only minimal interference with the patient's ability to carry out normal activities and social interactions. 3: Moderate: Cognitive deficits interfere with but do not preclude the patient's ability to carry out normal activities and social interactions. 4: Severe. Cognitive dysfunction precludes the patient's ability to carry out normal activities and social interactions.  *see Appendix for more detailed rating scales on this item  Rater Observations Posing UPDRS Questions and Response Options:							
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Rater Observations Posing UPDRS Questions and Response Options:							
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1.0 How helpful are the "Instructions to examiner"? (Circle choice)							
Not helpful 1 2 3 4 5 6 Very Helpful							
Not helpful 1 2 3 4 5 6 Very Helpful							
1.1 Circle areas of the "Instructions to examiner" that that were not helpful.							
1.2 What would make the "Instructions to examiner" easier to understand?							
Questions 2 and 3 relate to the Instructions to Patients and questions 4 and 5 relate to the response							
options.							
2.0 Rater reads the Instructions to Patient to the patient. How easy or difficult is it for you as the rater							
to use the current wording of the <u>question</u> verbatim? (Circle choice)							
Very difficult 1 2 3 4 5 6 Very Easy							

3.1								tion. <u>Underline</u> problematic parts of the question. What to <u>read</u> easily?
3.2								the question. Bracket problematic parts of the uestion were difficult to explain?
3.3			Oth	er ra	ter is	sue (	pleas	se specify)
								nt and hearing responses, how difficult was it for use option? (Circle choice)
					-			·
Very di	ifficult	1	2	3	4	5	6	Very Easy
5.0 If you had	difficu	lty <u>sele</u>	cting	g a r	espoi	ise o	ption	n, explain why this selection was difficult?
Questions for t	he patio	ent afte	er th	ey ha	ıve h	eard	the l	UPDRS question:
6.0 How easy o	r diffici	ilt is th	nis q	uesti	on to	r yo	u to u	understand? (Circle choice)
Very di	fficult	1	2	3	4	5	6	Very Easy
								erstand? What was the difficulty? ficult in the space below.
		•					•-	
8.0 Who answe Both	ered this	item?		Pati	ent p	rima	arily	Caregiver primarily

<u>Instructions to examiner:</u> Consider both illusions (misinterpretations of real stimuli) and hallucinations (spontaneous false sensations). Consider all major sensory domains (visual, auditory, tactile, olfactory and								
gustatory). Determine presence of unformed (for example sense of presence or fleeting false impressions) as well as formed (fully developed and detailed) sensations. Rate the patient's insight into hallucinations and identify								
delusions and psychotic thinking.								
	<u>Instructions to patients [and caregiver]:</u> Over the past week have you seen, heard, smelled or felt things that were not really there? [If yes, examiner asks patient or caregiver to elaborate and probes for information].							
0: Normal.								
1: Slight:	Illusions of insight.		formed	l halluc	cinatio	ons, bu	ut patient recognizes them without loss	
2: Mild:	Formed ha	allucin	ations	indepe	ndent	of env	vironmental stimuli. No loss of insight.	
3: Moderate:	Formed h	alluci	nation	s with	loss o	f insig	ght.	
4: Severe:	Patient ha	s delus	sions or	r paran	oia.		_	
*see Appendi	x for more	e detai	led rat	ing sca	ales o	n this	item	
Rater Observ	zations Pos	sing II	PDRS	Ouesti	ions a	nd Re	esponse Options:	
Kater Observ	ations 1 os	ong O	DKS	Questi	ons a	ilu ix	esponse Options.	
1.0 How help	ful are the	"Inst	ructior	is to ex	kamin	er"?	(Circle choice)	
Not helpf	al	1	2 3	4	5	6	Very Helpful	
1.1 <u>Ci</u>	<u>rcle</u> areas	of the	"Instr	uctions	s to ex	xamin	er" that that were not helpful.	
1.2 W	hat would	make	the "Iı	nstruct	tions	to exa	miner" easier to understand?	
Questions 2 and 3 relate to the Instructions to Patients and questions 4 and 5 relate to the								
resnon					io i u	tients	and questions 4 and 5 relate to the	
respon	se options.				10 T u	nents	and questions 4 and 5 relate to the	
2.0 Rater read	ise options. Is the Instr	uction	s to Pa	itient to	o the j	patien	and questions 4 and 5 relate to the  at. How easy or difficult is it for you stion verbatim? (Circle choice)	
2.0 Rater read as the rate	ise options. Is the Instr	ruction ne cur	es to Pa	<i>itient to</i> ording	o the j	<i>patien</i> e <u>que</u>	at. How easy or difficult is it for you stion verbatim? (Circle choice)	
2.0 Rater read as the rate Very d	<i>ise options.</i> Is the Instream of use the standard of the st	<i>uction</i> ne cur	es to Parent we	<i>itient to</i> ording 4	o the j of th	<i>patien</i> e <u>que</u> 6	at. How easy or difficult is it for you stion verbatim? (Circle choice)	
2.0 Rater read as the rate Very d	ise options.  Is the Instrect of use the difficult  Rater exp	ne curi 1 ies <u>usi</u>	es to Parent we 2 3 ing the	ording  4  questi	o the property of the following of the f	patien e <u>que</u> 6 elow (	et. How easy or difficult is it for you stion verbatim? (Circle choice)  Very Easy	

**SCORE** 

1.2 HALLUCINATIONS AND PSYCHOSIS:

3.2	Rater had difficulty <u>explaining</u> the question. <u>Bracket</u> problematic parts of the question. What parts of the question were difficult to explain?								
3.3	Other rater issue (please specify)								
was it for	Ing Instructions to Patient to the patient and hearing responses, how difficult you as the rater to select the appropriate response option? (Circle choice) cult 1 2 3 4 5 6 Very Easy								
If you had dif	ficulty <u>coding</u> response options. <u>Underline</u> problematic parts of the ons. Why were these parts of the response options difficult to code?								
6. Who answe Both	red this item? Patient primarily Caregiver primarily								

	<u>patient (and caregiver)</u> : Over the past week have you felt low, sad, hopeless and unable to enjoy at this feeling for longer than one day at a time? Did it make it difficult for you carry out your							
usual activities or	sual activities or to be with people? [If yes, examiner asks patient or caregiver to elaborate and probes for SCORE							
information].								
): Normal: No depressed mood.								
1: Slight:	Slight: Episodes of depressed mood that are not sustained for more than one day at a time. No interference with patient's ability to carry out normal activities and social interactions.							
2: Mild:								
	normal activities and social interactions.							
3: Moderate:	Depressed mood that interferes with, but does not preclude, the patient's							
	ability to carry out normal activities and social interactions							
4: Severe:	Depressed mood precludes patient's ability to carry out normal activities and							
	social interactions.							
*see Appendix	for more detailed rating scales on this item							
Datam Obsamy	otions Desing LIDDDS Overtions and Despense Ontions							
Kater Observ	ations Posing UPDRS Questions and Response Options:							
1.0 Here helpful and the "Instrumetical to examine 222 (Cincle sheige)								
1.0 How helpful are the "Instructions to examiner"? (Circle choice)								
1.0 flow helpi	ur are the "instructions to examiner"? (Circle choice)							
•								
Not helpfu								
Not helpfu 1.1 <u>Cir</u>	l 1 2 3 4 5 6 Very Helpful							
Not helpfu 1.1 <u>Cir</u>	l 1 2 3 4 5 6 Very Helpful cle areas of the "Instructions to examiner" that that were not							
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Not helpfu 1.1 <u>Cir</u> helj 1.2 Wh	1 1 2 3 4 5 6 Very Helpful cle areas of the "Instructions to examiner" that that were not oful.  at would make the "Instructions to examiner" easier to understand?  and 3 relate to the Instructions to Patients and questions 4 and 5 relate to the respect	onse						
Not helpfu 1.1 Cir help 1.2 Wh Questions 2 ar options 2.0 Rater read.	1 1 2 3 4 5 6 Very Helpful cle areas of the "Instructions to examiner" that that were not oful.  at would make the "Instructions to examiner" easier to understand?  and 3 relate to the Instructions to Patients and questions 4 and 5 relate to the respect							
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Not helpfu 1.1 Cir help 1.2 Wh Questions 2 ar options 2.0 Rater read rater to us Very di	1 2 3 4 5 6 Very Helpful cle areas of the "Instructions to examiner" that that were not oful.  at would make the "Instructions to examiner" easier to understand?  at 3 relate to the Instructions to Patients and questions 4 and 5 relate to the response.  at the Instructions to Patient to the patient. How easy or difficult is it for you as the current wording of the question verbatim? (Circle choice)							
Not helpfu 1.1 Cir help 1.2 Wh Questions 2 ar options 2.0 Rater read rater to us Very di 3.0 Rater note	1 2 3 4 5 6 Very Helpful cle areas of the "Instructions to examiner" that that were not oful.  at would make the "Instructions to examiner" easier to understand?  at a relate to the Instructions to Patients and questions 4 and 5 relate to the response.  at the Instructions to Patient to the patient. How easy or difficult is it for you as the current wording of the question verbatim? (Circle choice)  at the Instructions to Patient to the patient. How easy or difficult is it for you as the current wording of the question verbatim? (Circle choice)	the						

Instructions to examiner: Consider low mood, sadness, hopelessness, and feelings of emptiness or loss of

ability to carry out daily routines and engage in social interactions.

enjoyment. Determine their presence and duration over the past week and rate their interference with the patient's

1.3 DEPRESSED MOOD:

3.2								ne question. <u>Bracket</u> problematic parts of the stion were difficult to explain?
3.3		(	Othe	r rate	er is	sue (	please	specify)
								and hearing responses, how difficult was it onse option? (Circle choice)
Very di	fficult	1	2	3	4	5	6	Very Easy
•	hy were	these	part	s of t	the r	espo	nse opt	lerline problematic parts of the response ions difficult to code?  DRS question:
								lerstand? (Circle choice)
·			-					Very Easy
-	_							tand? What was the difficulty? ult in the space below.
8.0 Who answe Both	- red this	item?	]	Patie	nt p	rima	rily	Caregiver primarily

	le? [If yes, examiner asks patient or caregiver to elaborate and probes for information].								
0: Normal:	No anxious feelings.								
1: Slight:	Anxious feelings present but not sustained for more than one day at a time.								
	No interference with patient's ability to carry out normal activities and								
	social interactions.								
2: Mild:	Anxious feelings are sustained over more than one day at a time, but								
	without interference with patient's ability to carry out normal activities and								
2. Madamata	social interactions.								
3: Moderate:	: Anxious feelings interfere with, but do not preclude, the patient's ability to carry out normal activities and social interactions.								
4: Severe:	Anxious feelings preclude patient's ability to carry out normal activities and								
4. Severe.	social interactions.								
*see Append	ix for more detailed rating scales on this item								
Rater Obser	vations Posing UPDRS Questions and Response Options:								
	······································								
1.0 How help	oful are the "Instructions to examiner"? (Circle choice)								
Not helpf	ful 1 2 3 4 5 6 Very Helpful								
1.1 <u>C</u> i	ircle areas of the "Instructions to examiner" that that were not helpful.								
1.2 W	hat would make the "Instructions to examiner" easier to understand?								
~	and 3 relate to the Instructions to Patients and questions 4 and 5 relate to the nse options.								
	ds the Instructions to Patient to the patient. How easy or difficult is it for you ter to use the current wording of the question verbatim? (Circle choice)								
Very o	difficult 1 2 3 4 5 6 Very Easy								
3.0 Rater not	tes difficulties <u>using</u> the question below (Mark each item Y or N):								
3.1	Rater experienced difficulty <u>reading</u> question. <u>Underline</u> problematic parts of the question. What parts of the question were difficult to <u>read</u> easily?								

<u>Instructions to examiner:</u> Determine nervous, tense, worried or anxious feelings (including panic attacks) over the past week and rate their duration and interference with the patient's ability to carry out daily routines and engage in

Instructions to patients [and caregiver]: Over the past week have you felt nervous, worried or tense? If yes, was this

**SCORE** 

1.4 ANXIOUS MOOD:

social interactions.

3.2	Rater had difficulty <u>explaining</u> the question. <u>Bracket</u> problematic parts of the question. What parts of the question were difficult to explain?
3.3	Other rater issue (please specify)
was it	ding Instructions to Patient to the patient and hearing responses, how difficult the rater to select the appropriate response option? (Circle choice)
5.0 If you had	d difficulty <u>coding</u> response options. <u>Underline</u> problematic parts of the options. Why were these parts of the response options difficult to code?
	the patient after they have heard the UPDRS question: or difficult is this question for you to understand? (Circle choice)
Very d 7.0 What part	ifficult 1 2 3 4 5 6 Very Easy s of the question were difficult to understand? What was the difficulty? se on form. Explain why they were difficult in the space below.
8.0 Who answ Both	ered this item? Patient primarily Caregiver primarily

<b>1.5 APATHY:</b>													
<u>Instructions to examiner:</u> Consider level of spontaneous activity, assertiveness, motivation and initiative and rate													
the impact of reduced levels on performance of daily routines and social interactions. Here the examiner should													
attempt to distinguish between apathy and similar symptoms that are best explained by depression.													
<u>Instructions to patients (and caregiver):</u> Over the past week have you felt a lack of interest in doing things or had													
problems making decisions? Did this feeling cause difficulties carrying out your daily routines or being with													
	s, examiner asks patient or caregiver to elaborate and probes for information].												
0: Normal:	No apathy												
1: Slight:	Reduced	assei	rtiver	iess, i	moti	vatio	n and	l ini	tiative appreciated by patient				
	and/or ca	ıregiv	ver, b	ut no	o inte	erfer	ence v	with	daily activities and social				
	interaction	ons.											
2: Mild:	Reduced	asser	rtiver	iess, i	moti	vatio	n and	l ini	tiative that interferes with isolated				
	activities												
3. Moderate.							or ma	ntive	ation that interferes with most				
o. Moderate.	activities			-			OI III	) (1 Y C	tion that interiores with most				
4: Severe:	Passive a						locc	of ir	nitiativa				
4. Severe.	1 assive a	iiu w	Itmui	awn,	, com	ipieu	1033	OI II	muauve.				
Rater Observ	ations Po	sing l	IPDI	2S ()	nesti	ons s	and R	esno	onse Options:				
Ratel Observ	ations i o	mg (		TD Q	ucsti	ons a	illu IX	cspt	onse Options.				
1 A Hovy holm	ful ava tha	. 66Tms	4	iona	40.0		n 01129	(C:	vala abajaa)				
1.0 How helps	iui are tiie	; 1115	struct	10118	to ex	(allilli	ner":	(CII	rcie choice)				
NT / N N O	•	_	_	•		_	_		Y. Y. A.				
Not helpfu	ul	1	2	3	4	5	6		Very Helpful				
1.1 <u>Ci</u>	<u>rcle</u> areas	of th	e "In	struc	ctions	s to e	xamiı	ner'	' that that were not helpful.				
1.2 W	hat would	mak	e the	"Ins	truci	tions	to exa	amiı	ner" easier to understand?				
Ouestions 2 a	nd 3 relate	e to th	ie Ins	truct	ions	to Pa	itients	s and	d questions 4 and 5 relate to the respo	nse			
option								,	a questions i una e retate to the respo				
option	J.												
2.0. D	J., 41 T., -4.	4.9 .	4 -	D4:	44	- 41	49	T1	I	1			
							-		low easy or difficult is it for you <u>as the same as th</u>	<u>ne</u>			
<u>rater</u> to us	se the curi	cent v	word	ing o	t the	ques	stion v	verb	eatim? (Circle choice)				
Very d	ifficult	1	2	3	4	5	6		Very Easy				
3.0 Rater not	es difficul	ties u	sing	the q	uesti	ion b	elow (	(Ma	rk each item Y or N):				
				-				`	,				
3.1	Rater exp	erien-	ced di	fficult	y rea	ding q	uestio	n. Ur	nderline problematic parts of the question.				
	w w	hat pa	rts of	the qu	uestio	n wer	e diffic	cult t	o read easily?				
	-												
3.2	Das	ton h.	.d 4:4	ffiaul	tx/ ^=	nlai-	ning 4	h^ ~	quastion Regalizat analysmatic names	of			
3.4					_			_	uestion. Bracket problematic parts	J1			
	th	e que	estion	ı. W li	ıat p	arts (	vi tne	que	estion were difficult to explain?				

3.3	-		Othe	er rat		\.		e specify)
								t and hearing responses, how difficult was it bonse option? (Circle choice)
5.0 If you had	difficul	ty <u>cod</u>	ing r	espo	nse o	ptior	ıs. <u>Ur</u>	Very Easy <u>aderline</u> problematic parts of the response otions difficult to code?
	-							PDRS question: nderstand? (Circle choice)
Very dif	ficult	1	2	3	4	5	6	Very Easy
-		-						rstand? What was the difficulty? cult in the space below.
8.0 Who answe	red this	item?	·	Patio	ent p	rima	rily	Caregiver primarily

gambling (e.g. ca interest in pornog dismantling obje medication for nactivities/behavio	caminer: Considering considering camines or lottery graphy, masturbects, sorting or oon-physical reasons on the patier other financial	er invo tickets ation, s rganizin sons (i.e at's pers difficu	lvemen ), atypic exual d ng), or t e., addic sonal lif lties lik	t in a veal or e emand aking tive be e and e with	excession pextra rehavion his	of act ive sex artner) non-pro r). Rat family	tivities including atypical or excessive xual drive or interests (e.g., unusual c), other repetitive activities (e.g. hobbies, rescribed dopaminergic antiparkinson te the impact of such abnormal cy and social relations (including need to edit cards, major family conflicts, lost		
Instructions to pa	ntients [and care	giver]:							
gambled too mud	ch? Have you p	ut thing	s togetl	ner or	taken 1	things	hard to control? For example, have you apart over and over again? Do you o elaborate and probes for information].	CORE	
<ul><li>0: Normal:</li><li>1: Slight:</li><li>2: Mild:</li><li>3: Moderate:</li><li>4: Severe:</li></ul>	<ul> <li>0: Normal: No problems present Problems are present but usually do not cause any concerns or difficulties for the patient or family/caregiver</li> <li>2: Mild: Problems are present and usually cause a few difficulties in the patient's personal and family life.</li> <li>3: Moderate: Problems are present and usually cause a lot of difficulties in the patient's personal and family life.</li> </ul>								
	in personal				eracti	ons o	or to maintain previous standards		
Rater Observations Posing UPDRS Questions and Response Options:  1.0 How helpful are the "Instructions to examiner"? (Circle choice)									
Not helpf	<b>ul</b> 1	2	3	4	5	6	Very Helpful		
1.1 Circle areas of the "Instructions to examiner" that that were not helpful.									
1.2 W	hat would m	ake tł	ne "In	struc	tions	to ex	xaminer" easier to understand?		
_	Questions 2 and 3 relate to the Instructions to Patients and questions 4 and 5 relate to the response options.								
						_	ent. How easy or difficult is it for you <u>as the</u> verbatim? (Circle choice)	2	

3

3.0 Rater notes difficulties  $\underline{using}$  the question below (Mark each item Y or N):

**Very Easy** 

Very difficult 1

3.1					g questio ifficult to			olematic part	ts of the qu	estion. What
3.2								racket pro ficult to ex		parts of the
3.3		O	ther rat	er issue	(please	spe	cify)			
4.0 <u>After read</u> for you as the <u>select</u> the a	rater to							<i>esponses</i> , h	ow diffict	ult was it
Very di 5.0 If you had options. W	difficult	y <u>codin</u>	g respo	nse opti	ions. <u>Un</u>	derl		matic part	s of the re	sponse
Questions for t								_	)	
Very di	fficult	1 2	3	4 5	6	1	Very Easy			
7.0 What parts <u>Circle</u> these	of the q	uestion			o under	stan	id? What v		ficulty?	
	_									
8.0 Who ans	wered th	is item?	Pa	_	imarily oth		Careş	giver prima	arily	_

## UPDRS PART 1A PATIENT DEBRIEFING

For questions 1-2, the rater summarizes patient's answers to the questions below using patient's own words whenever possible.

- 1.0 Overall, did you find the assessment questions difficult?\_\_\_\_\_(Y/N)
  - 1.1 If so, which questions and what made them difficult?
- 2.0 Did you find any of the assessment questions upsetting? \_\_\_\_\_ (Y/N)
  - 2.1 If so, which questions and what made them upsetting?

[Note: At this point, the cognitive test of this UPDRS Part is complete for this patient.]

R	ATER	'S	DE	BR	IE	FINC	j
3.0 How helpful were the gene overall for administering p						_	tion instructions on page 4
Not helpful	1	2	3	4	5	6	Very helpful
3.1 What areas for imp on page 4)	oroveme	nt o	do y	ou s	sugg	gest? (	Please circle problem areas
3.2 How often did you most of the time"							"usually", "generally",
Not at all	1	2	3	4	5	6	In every case
4.0 What problems did you ha for information" at the e							
5.0 How easy or difficult is it f patient's responses? (Circl			he r	<u>atei</u>	<u>r</u> to	use th	e rating options to code the
Very difficult	1	2	3	4	5	6	Very Easy
5.1 What made these op	otions di	iffic	ult	for	you	as the	e rater to explain?
Which, if any, of the ques Why?	stions se	em	ed t	o m	ake	the p	atient uncomfortable?
6.0 Which questions were the Why?	e most u	nco	mfo	orta	ble	or aw	kward for you to ask?
8.0 Have you come to dislike ones? Why?	any spe	ecifi	c qı	iest	ions	s in th	is UPDRS Part? Which

The remaining questions in Part I (Non-motor Experiences of Daily Living) [Sleep, Daytime Sleepiness, Pain and Other Sensation, Urinary Problems, Constipation Problems, and Lightheadedness on Standing] are in the **Patient Questionnaire** along with all questions in Part II [Motor Experiences of Daily Living]. The **APPENDIX** includes scales for guiding raters to additional, more detailed scales for some of these items.

#### **Cognitive Testing Instructions for rater:**

Give patients a copy of the Patient Questionnaire in the APPENDIX of this document that includes UPDRS parts 1B and 2 items. Questions regarding these items are also included in this cognitive test booklet followed by the cognitive test questions for each item.

For the cognitive test of the UPDRS instrument, for Parts 1B and Part 2, raters will have patients (and caregivers) complete only one question at a time on the Patient Questionnaire. After each question, raters will then pose the cognitive testing questions for that question on the pages that follow this one before having the patient complete the subsequent UPDRS question on the Patient Questionnaire.

## **Cognitive Testing Instructions to Patient:**

Please read the instructions on Page 1 of the Patient Questionnaire and then I will give you further instructions about the cognitive test before you start completing the patient questionnaire.

Patient Questionnaire
Instructions:
This questionnaire will ask you about your experiences of daily living.
There are 20 questions. Please read each one carefully and read all answers before selecting the one that best applies to you.
We are interested in your average or usual function over the past week including today. Some patients can do things better at one time of the day than at others. However, only one answer is allowed for each question, so please mark the answer that best describes what you can do most on the time.
Use only 0, 1, 2, 3, 4 for answers, nothing else. Do not leave any blanks.
Your doctor or nurse can review the questions with you, but this questionnaire is for patients to complete, either alone or with their caregivers.
Who is filling out this questionnaire? (check the best answer)

#### **Cognitive Testing Instructions for patient:**

Caregiver

**Patient** 

Usually, you would fill out the entire Patient Questionnaire by yourself or with your caregiver before reviewing it with your doctor or nurse. However, today, I am going to stop you after you have completed each question to ask you how easy the question was for you to understand and select an appropriate response. While you are completing the question, please talk over the question with your caregiver, if needed, or say out loud any problems you may be having with the question or response selection. I will not provide you with any additional information until after you have completed it. Then I will ask you how easy or difficult it was to complete that question and why.

**Patient and Caregiver** 

Questions 1.7-1.12
<ol> <li>1.7 SLEEP: Over the past week, have you had trouble going to sleep at night or staying asleep through the night? Consider how rested you felt after waking up in the morning.</li> <li>0: Normal: No problems</li> <li>1: Slight: Problems are present but usually do not cause trouble getting a full night of sleep.</li> <li>2: Mild: Problems usually cause some trouble getting a full night of sleep.</li> <li>3: Moderate: Problems cause a lot of trouble getting a full night of sleep, but I still usually sleep for more than half the night.</li> <li>4: Severe: I usually do not sleep for most of the night.</li> </ol>
Rater is to complete all answers to cognitive test questions.
Rater's observations while the patient is reading/responding to the question:
1.0 What issues with the question did you observe while the patient or caregiver was reading or interpreting the question?
2.0 What issues with the response options did you observe while the patient or caregiver was reading or interpreting the response options?
Questions for the patient after they have read and responded to the UPDRS question:
3.0 How easy or difficult is this question for you to understand? (Circle choice)
Very difficult 1 2 3 4 5 6 Very Easy
4.0 What parts of the question were difficult to understand?
4.1 Circle these on form.
4.2 Explain why they were difficult in the space below.
5.0 How easy or difficult was it for you to select a response choice to that question?
Very difficult 1 2 3 4 5 6 Very Easy

**SCORE** 

Part IB: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)

5.1 What made it difficult to select a response?	
5.2 Suggested solution?	
6.0 Who answered this item? Patient primarily Caregiver primarily Both	
<ol> <li>1.8 DAYTIME SLEEPINESS: Over the past week, have you had trouble staying awake during the daytime?</li> <li>0: Normal: No daytime sleepiness.</li> <li>1: Slight: Daytime sleepiness occurs but I can resist and I stay awake.</li> <li>2: Mild: Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV.</li> <li>3: Moderate: I sometimes fall asleep when I should not. For example, while eating or talking with other people.</li> <li>4: Severe: I often fall asleep when I should not. For example, while eating or talking with other people.</li> </ol>	SCORE —
Rater is to complete all answers to cognitive test questions.  Rater's observations while the patient is reading/responding to the question:  1.0 What issues with the question did you observe while the patient or caregiver was reading or interpreting the question?  2.0 What issues with the response options did you observe while the patient or caregiver was reading or interpreting the response options?	
Questions for the patient after they have read and responded to the UPDRS question:  3.0 How easy or difficult is this question for you to understand? (Circle choice)	
Very difficult 1 2 3 4 5 6 Very Easy	
4.0 What parts of the question were difficult to understand?	
4.1 <u>Circle</u> these on form.	
4.2 Explain why they were difficult in the space below.	

0 How easy or difficu	lt wa	s it fo	or yo	u to	selec	t a res	ponse choice to that question?
Very difficult	1	2	3	4	5	6	Very Easy
5.1 What made	it dif	ficult	to se	elect	a res	ponse'	?
5.2 Suggested so	olutio	n?					
0 Who answered this	item	?	_Pati	ient p	orima	arily	Caregiver primarily

	O OTHER SENSATIONS: Over the past week, have you had uncomfortable ur body like pain, aches and cramps?	SCORE
0: Normal:	No uncomfortable feelings.	
1: Slight:	I have these feelings. However, I can do things and be with other people without difficulty.	
2: Mild:	These feelings cause a few problems when I do things or am with other people.	
3: Moderate:	These feelings cause a lot of problems, but they do not stop me from doing	
	things or being with other people.	
4: Severe:	These feelings stop me from doing things or being with other people.	
Rater is to con	mplete all answers to cognitive test questions.	
Rater's obser	rvations while the patient is reading/responding to the question:	
	nes with the question did you observe while the patient or caregiver was r interpreting the question?	
	nes with the response options did you observe while the patient or caregivering or interpreting the response options?	
Questions for	the patient after they have read and responded to the UPDRS question:	
3.0 How easy o	or difficult is this question for you to understand? (Circle choice)	
Very di	ifficult 1 2 3 4 5 6 Very Easy	
4.0 What part	s of the question were difficult to understand?	
4.1 <u>Cir</u>	<u>cle</u> these on form.	
4.2 <u>Exp</u>	<u>plain</u> why they were difficult in the space below.	
	<u> </u>	
5.0 How easy o	or difficult was it for you to select a response choice to that question?	
Very di	ifficult 1 2 3 4 5 6 Very Easy	
5 1 Wh	at made it difficult to select a response?	

5.2 Suggested solution?			
6.0 Who answered this item? Both	_ Patient primarily	Caregiver primarily	

<ol> <li>1.10 URINARY PROBLEMS: Over the past week, have you had trouble with urine control?         For example, an urgent need to urinate, a need to urinate too often, or urine accidents?     </li> <li>O: Normal: No urine control problems         1: Slight: I need to urinate often or urgently. However, these problems do not cause difficulties with my daily routine.     </li> <li>Mild: Urine problems cause a few difficulties with my daily routine. However, I do not have urine accidents.</li> <li>Moderate: Urine problems cause a lot of difficulties with my daily routine, including urine accidents.</li> <li>Severe: I cannot control my urine and use a diaper or have a bladder tube.</li> </ol>	SCORE —
Rater is to complete all answers to cognitive test questions.	
Rater's observations while the patient is reading/responding to the question:	
1.0 What issues with the question did you observe while the patient or caregiver was reading or interpreting the question?	
2.0 What issues with the response options did you observe while the patient or caregiver was reading or interpreting the response options?	
Questions for the patient after they have read and responded to the UPDRS question:	
3.0 How easy or difficult is this question for you to understand? (Circle choice)	
Very difficult 1 2 3 4 5 6 Very Easy	
4.0 What parts of the question were difficult to understand?	
4.1 Circle these on form.	
4.2 Explain why they were difficult in the space below.	
5.0 How easy or difficult was it for you to select a response choice to that question?	
Very difficult 1 2 3 4 5 6 Very Easy	

5.1 What made it diffi	cult	to sel	ect a	resp	onse'	?	
5.2 Suggested solution	?						
How do you feel about the us	e of 1	the w	ord '	'diap	er" i	n resp	onse option 4?
Very uncomfortable	1	2	3	4	5	6	Very Comfortable
6.1 If uncomfortable,	what	tothe	r wo	rds v	ould	be mo	ore comfortable for you?
7.0 Who answered this item? Both		Patie	nt pr	imaı	ily		Caregiver primarily

# 1.11 CONSTIPATION PROBLEMS: Over the past week have you had constipation troubles that cause you difficulty moving your bowels? **SCORE** 0: Normal: No constipation. 1: Slight: I have been constipated. I use extra effort to move my bowels. However, this problem does not disturb my activities or my being comfortable. 2. Mild. Constipation causes me to have a few troubles doing things or being comfortable. 3: Moderate: Constipation causes me to have a lot of trouble doing things or being comfortable. However, it does not stop me from doing anything. I usually need physical help from someone else to empty my bowels. 4: Severe: Rater is to complete all answers to cognitive test questions. Rater's observations while the patient is reading/responding to the question: 1.0 What issues with the question did you observe while the patient or caregiver was reading or interpreting the question? 2.0 What issues with the response options did you observe while the patient or caregiver was reading or interpreting the response options? Questions for the patient after they have read and responded to the UPDRS question: 3.0 How easy or difficult is this question for you to understand? (Circle choice) Very difficult 5 6 **Very Easy** 1 2 3 4.0 What parts of the question were difficult to understand? 4.1 Circle these on form. 4.2 Explain why they were difficult in the space below.

5.0 How easy or difficult was it for you to select a response choice to that question?

V	ery difficult	1	2	3	4	5	6	Very Easy	
5.	1 What made	it dif	ficult	to se	elect	a res	ponse	?	
5.2	2 Suggested so	olutio	n?						
6.0 Who	answered this	item	?	Pati	ient p	orim	arily	Caregiver primarily	

<ol> <li>1.12 LIGHTHEADEDNESS ON STANDING: Over the past week, have you usually fel dizzy or foggy when you stand up after sitting or lying down?</li> <li>0: Normal: No dizzy or foggy feelings.</li> <li>1: Slight: Dizzy or foggy feelings occur. However, they do not cause me trouble things or being with people.</li> <li>2: Mild: Dizzy or foggy feelings cause me to hold on to something, but I do not to sit or lie back down.</li> </ol>	SCORE
3: Moderate: Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling.	•
4: Severe: Dizzy and foggy feelings cause me to fall or faint.	
Rater is to complete all answers to cognitive test questions.	
Kaler is to complete an answers to cognitive lest questions.	
Rater's observations while the patient is reading/responding to the question:	
1.0 What issues with the question did you observe while the patient or caregiver wa reading or interpreting the question?	s
2.0 What issues with the response options did you observe while the patient or care was reading or interpreting the response options?	giver
Questions for the patient after they have read and responded to the UPDRS question	<u>ı</u> :
3.0 How easy or difficult is this question for you to understand? (Circle choice)	
Very difficult 1 2 3 4 5 6 Very Easy	
4.0 What parts of the question were difficult to understand?	
4.1 Circle these on form.	
4.2 Explain why they were difficult in the space below.	
5.0 How easy or difficult was it for you to select a response choice to that question?	
Very difficult 1 2 3 4 5 6 Very Easy	

5.1 What made it difficult to select a response?				
5.2 Suggested solution?				
6.0 Who answered this item? Both	Patient primarily	Caregiver primarily		

1.13 TIRED	DNESS (FATIGUE): Over the past week, have you usually fe	lt tiredness or	SCORE
	fatigue)? This feeling is not part of being sleepy or sad.	it til culicis of	SCORE
0: Normal:	No tiredness		
1: Slight:	Tiredness occurs. However it does not cause me trouble	es doing things or	
10 ~1.g	being with people.	• • • • • • • • • • • • • • • • • • •	
2: Mild:	Tiredness causes me a few troubles doing things or being	g with people.	
	: Tiredness causes me a lot of troubles doing things or b		
	However, it does not stop me from doing anything.	<b>8 FF</b>	
4: Severe:	Tiredness stops me from doing things or being with people		
	omplete all answers to cognitive test questions.		
Rater's obser	ervations while the patient is reading/responding to the qu	estion:	
	ues with the question did you observe while the patient or ting the question?	caregiver was reading	g or
	ues with the response options did you observe while the por interpreting the response options?	atient or caregiver was	S
Questions for	the patient after they have read and responded to the UI	PDRS question:	
3.0 How easy	or difficult is this question for you to understand? (Circle	e choice)	
Very d	difficult 1 2 3 4 5 6 Very Easy		
4.0 What part	ts of the question were difficult to understand?		
4.1 <u>Cir</u>	rcle these on form.		
4.2 <u>Exp</u>	plain why they were difficult in the space below.		
	<u> </u>		
5.0 How easy	or difficult was it for you to select a response choice to th	at question?	
Very diffic	cult 1 2 3 4 5 6 Very Easy		
5.1 Wh	hat made it difficult to select a response?		

5.2 Suggested solution?			
6.0 Who answered this item? Both	_ Patient primarily	Caregiver primarily	

## UPDRS PART 1B PATIENT DEBRIEFING

For questions 1-3, the rater summarizes patient's answers to the questions below using the	
patient's own words whenever possible.	
1.0 Looking at page 1 of the Patient Questionnaire handout, how easy were the instruction	18

(page 29 of the cognitive test book) to understand in helping you complete it?

Very difficult 1 2 3 4 5 6 Very Easy

1.1 What would make the instructions easier to understand?

2.0 Overall, did you find the questions in this part of the assessment difficult? \_\_\_\_\_\_(Y/N)

2.1 If so, what made the questions difficult?

3.0 Did you find any of the questions in this part of the assessment upsetting? \_\_\_\_\_\_(Y/N)

3.1 If so, what made these questions upsetting?

[Note: At this point, the cognitive test of this UPDRS Part is complete for this patient.]

## **RATER DEBRIEFING**

4.0 Which, if any, of the questions seemed to make the patient uncomfortable? Why?

Part	II: Mot	tor Aspects of Experiences of Daily Living (M-EDL)
2.1 SP	PEECH: O	ver the past week, have you had problems with your speech?
0: N 1: S		Not at all (no problems)  My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself.
2: N	1ild:	My speech causes people to ask me to occasionally repeat myself, but less than daily.
		My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood.
4: S	evere:	Most or all of my speech cannot be understood.
Rate	r is to con	nplete all answers to cognitive test questions.
Rate	r's obser	vations while the patient is reading/responding to the question:
		es with the question did you observe while the patient or caregiver was interpreting the question?
		es with the response options did you observe while the patient or caregiver ng or interpreting the response options?
Quest	ions for t	the patient after they have read and responded to the UPDRS question:
3.0 Ho	ow easy o	r difficult is this question for you to understand? (Circle choice)
	Very di	fficult 1 2 3 4 5 6 Very Easy
4.0 W	hat parts	of the question were difficult to understand?
	4.1 <u>Circ</u>	ele these on form.
	4.2 <u>Exp</u>	lain why they were difficult in the space below.
5.0 Ho	ow easy o	r difficult was it for you to select a response choice to that question?
	Very di	fficult 1 2 3 4 5 6 Very Easy

**SCORE** 

5.1 What made it difficult to select a response?		
5.2 Suggested solution?		
6.0 Who answered this item? Patient primarily Both	Caregiver primarily	

22 Sarry & Droot No. Over the past week have you usually had too much selive	
2.2. SALIVA & DROOLING: Over the past week, have you usually had too much saliva during the day or night?	SCORE
0: Normal: Not at all (no problems)	SCORE
1: Slight: I have too much saliva, but do not drool during the day or at night.	
2: Mild: I have some nighttime drooling, but none during the day.	
3: Moderate: I have some drooling during the day, but I usually do not need tissues or a	
handkerchief.	
4: Severe: I have so much drooling that I regularly need to use tissues or a handkerchief to	
protect my clothes.	
	$\neg$
Rater is to complete all answers to cognitive test questions.	
Rater's observations while the patient is reading/responding to the question:	
Mater's observations while the patient is reading/responding to the question.	
1.0 What issues with the question did you observe while the patient or caregiver was	
reading or interpreting the question?	
2.0 What issues with the response options did you observe while the patient or caregiver	
was reading or interpreting the response options?	
Questions for the patient after they have read and responded to the UPDRS question:	
Questions for the patient after they have read and responded to the of DRS question.	
3.0 How easy or difficult is this question for you to understand? (Circle choice)	
Very difficult 1 2 3 4 5 6 Very Easy	
10 1111	
4.0 What parts of the question were difficult to understand?	
4.1 Circle these on form.	
4.1 Circle these on form.	
4.2 Explain why they were difficult in the space below.	
<u> </u>	
	<del>_</del>
	_
5.0 How easy or difficult was it for you to select a response choice to that question?	
V1:6614 1 2 2 4 5 6 V E	
Very difficult 1 2 3 4 5 6 Very Easy	
5.1 What made it difficult to select a response?	

5.2 Suggested solution?			
6.0 Who answered this item? Both	_ Patient primarily	Caregiver primarily	

	SAND SWALLOWING FOOD: Over the past week, have you usually had problems eating a mealing the way it needs to be fixed? For example, do you need meals to be made soft, chopped or dischoking?	SCOR
0: Normal:	Not at all (no problems and no changes have been made in the way my food is	
1. (1:-1.4.	prepared because of such concerns).	
1: Slight:	I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared to avoid such problems.	
2: Mild:	I need to have my food prepared differently because of chewing or swallowing	
	problems. In addition, I choke occasionally but not every day.	
	I choke on food at least once daily.	
4: Severe:	Because of chewing and swallowing problems, I need a feeding tube.	
Rater is to co	mplete all answers to cognitive test questions.	
Rater's obser	rvations while the patient is reading/responding to the question:	
	nes with the question did you observe while the patient or caregiver was or interpreting the question?	
	nes with the response options did you observe while the patient or caregiver ing or interpreting the response options?	
Questions for	the patient after they have read and responded to the UPDRS question:	
3.0 How easy	or difficult is this question for you to understand? (Circle choice)	
Very d	ifficult 1 2 3 4 5 6 Very Easy	
4.0 What part	s of the question were difficult to understand?	
4.1 Cir	cle these on form.	
4.1 <u>CII</u>	these on form.	
4.2 <u>Exp</u>	plain why they were difficult in the space below.	
5.0 How easy	or difficult was it for you to select a response choice to that question?	
Very d	ifficult 1 2 3 4 5 6 Very Easy	

5.1 What made it difficult to so	elect a response	?	
5.2 Suggested solution?			
6.0 Who answered this item? Path	ient primarily	Caregiver primarily	

food and usin	TASKS: Over the past week, have you usually had troubles handling your ag eating utensils? For example, do you have trouble using forks, knifes, sticks, or fingers to eat?  Not at all (No problems)  I am slow or clumsy, but I do not need any help handling my food and have not	SCORE
2. M:14.	had food spills while eating.	
2: Mild:	I am slow or clumsy with my eating and have occasional food spills. I may need help with a few tasks such as cutting meat.	
<ul><li>3: Moderate:</li><li>4: Severe:</li></ul>	I need help with many eating tasks but can manage some alone.  I need help for most or all eating tasks.	
Rater is to co	mplete all answers to cognitive test questions.	
	rvations while the patient is reading/responding to the question:	
	nes with the question did you observe while the patient or caregiver was r interpreting the question?	
	nes with the response options did you observe while the patient or caregiver ing or interpreting the response options?	
<b>Questions for</b>	the patient after they have read and responded to the UPDRS question:	
3.0 How easy	or difficult is this question for you to understand? (Circle choice)	
Very d	ifficult 1 2 3 4 5 6 Very Easy	
4.0 What part	s of the question were difficult to understand?	
4.1 <u>Cir</u>	<u>cle</u> these on form.	
4.2 <u>Ex</u> I	plain why they were difficult in the space below.	
5.0 How easy	or difficult was it for you to select a response choice to that question?	
·	ifficult 1 2 3 4 5 6 Very Easy	

5.1 What made it difficult	t to select a response?		
5.2 Suggested solution?			
6.0 Who answered this item? Both	_ Patient primarily	Caregiver primarily	

2.5. DRESSING: Over the past week, have you example, do you have trouble buttoning, using clothes?		CORE
0: Normal: Not at all (no problems)		
1: Slight: I am slow or clumsy but I do not no		
2: Mild: I am slow or clumsy and need help		
3: Moderate: I need help for many dressing tasks		
4: Severe: I need help for most or all dressing	tasks	
Rater is to complete all answers to cognitive test	questions.	
Rater's observations while the patient is reading	g/responding to the question:	
1.0 What issues with the question did you observeding or interpreting the question?	ve while the patient or caregiver was	
2.0 What issues with the response options did y was reading or interpreting the response op	•	
Questions for the patient after they have read an	nd responded to the UPDRS question:	
3.0 How easy or difficult is this question for you	to understand? (Circle choice)	
Very difficult 1 2 3 4 5	6 Very Easy	
4.0 What parts of the question were difficult to u	inderstand?	
4.2 Explain why they were difficult in the	space below.	
5.0 How easy or difficult was it for you to select	a response choice to that question?	
Very difficult 1 2 3 4 5	6 Very Easy	
5.1 What made it difficult to select a resp	onse?	
5.2 Suggested solution?		

6.0 Who answered this item?	Patient primarily	Caregiver primarily	
Both			

<ul> <li>2.6. HYGIENE: Over the past week, have you usually had problems with personal hygiene? For example, do you have trouble with washing, bathing, brushing teeth, or combing your hair?</li> <li>0: Normal: Not at all (no problems)</li> <li>1: Slight: I am slow or clumsy but I do not need any help.</li> <li>2: Mild: I need someone else to help me with a few tasks.</li> <li>3: Moderate: I need help for many tasks.</li> <li>4: Severe: I need help for most or all of my hygiene needs.</li> </ul>	SCORE
Rater is to complete all answers to cognitive test questions.	
Rater's observations while the patient is reading/responding to the question:	
1.0 What issues with the question did you observe while the patient or caregiver was reading or interpreting the question?	
2.0 What issues with the response options did you observe while the patient or caregiver was reading or interpreting the response options?	
Questions for the patient after they have read and responded to the UPDRS question:	
3.0 How easy or difficult is this question for you to understand? (Circle choice)	
Very difficult 1 2 3 4 5 6 Very Easy	
4.0 What parts of the question were difficult to understand?	
4.1 <u>Circle</u> these on form.	
4.2 Explain why they were difficult in the space below.	
5.0 How easy or difficult was it for you to select a response choice to that question?	
Very difficult 1 2 3 4 5 6 Very Easy	
5.1 What made it difficult to select a response?	

5.2 Suggested solution?			
6.0 Who answered this item? Both	_ Patient primarily	Caregiver primarily	

2.7. HANDWE handwriting?		ver the p	ast wee	k, hav	e peop	le usually had trouble reading your	SCORE		
0: Normal: 1: Slight: 2: Mild:	<ul><li>Normal: Not at all (no problems)</li><li>Slight: My writing is slow, clumsy or uneven, but all words are clear.</li></ul>								
<ul><li>3: Moderate:</li><li>4: Severe:</li></ul>	Many wo					l.			
Rater is to con	mplete all	answers	to cogni	itive te	st ques	tions.			
Rater's obser	vations w	hile the	patient	is reac	ling/re	sponding to the question:			
1.0 What issureading o					serve w	while the patient or caregiver was			
2.0 What issu was readi		_	_		•	bserve while the patient or caregiver s?			
						esponded to the UPDRS question:			
Very di	ifficult	1 2	3	4 5	6	Very Easy			
4.0 What parts	s of the qu	uestion w	ere diff	icult t	o unde	rstand?			
4.1 <u>Cir</u>	<u>cle</u> these o	on form.							
4.2 <u>Exp</u>	olain why	they wer	e diffic	ult in t	the spa	ce below.			
5.0 How easy	or difficu	lt was it	for you	to sele	ect a re	sponse choice to that question?			
Very di	ifficult	1 2	3	4 5	6	Very Easy			
5.1 Wh	at made i	t difficul	t to sele	ct a re	sponse	?			

5.2 Suggested solution?			
6.0 Who answered this item? Both	_ Patient primarily	Caregiver primarily	

2.8. Doing H trouble doing							ne past week, have you usually had like to do?	SCORE
<ul><li>0: Normal:</li><li>1: Slight:</li><li>2: Mild:</li><li>3: Moderate:</li></ul>	1: Slight: I am a bit slow or clumsy but do these activities easily.							
4: Severe:	I am unal	ble to do	o most o	or all	of th	ese ac	tivities.	
Rater is to co	mplete all	answer	rs to cog	nitiv	e test	quest	tions.	
Rater's obser	rvations w	while the	e patier	ıt is r	eadi	ng/res	sponding to the question:	
	ies with the r interpre	-		•	obse	erve w	hile the patient or caregiver was	
	ies with th ing or inte						bserve while the patient or caregiver s?	
<b>Questions for</b>	the patier	ıt after	they ha	ive re	ead a	nd re	sponded to the UPDRS question:	'
3.0 How easy	or difficu	lt is this	s questi	ion fo	or yo	u to u	nderstand? (Circle choice)	
Very d	ifficult	1 2	2 3	4	5	6	Very Easy	
4.0 What part	s of the qu	uestion	were d	ifficu	lt to	under	rstand?	
4.1 <u>Cir</u>	cle these o	on form	ı <b>.</b>					
4.2 <u>Ex</u> I	olain why	they wo	ere diff	icult i	in th	e spac	ce below.	
								- -
5.0 How easy	or difficu	lt was i	t for yo	ou to s	selec	t a res	sponse choice to that question?	
Very d	ifficult	1 2	2 3	4	5	6	Very Easy	
5.1 Wh	at made i	t difficı	ult to se	elect a	ı resi	onse'	?	

5.2 Suggested solution?			
6.0 Who answered this item? Both	_ Patient primarily	Caregiver primarily	

2.9. TURNING bed?	S IN BED: C	ver the p	ast week,	do y	ou usu	ally ha	ve troul	ble turnin	g over iı		SCORE
0: Normal: 1: Slight: 2: Mild 3: Moderate: 4: Severe:	I have a le	oit of troub ot of troub ver I ofter	ole turning ole turning n need help	and and fron	need oo n some	ecasiona one else	al help f e.	rom some	one else.		
Datavis to an	municato all			a 4as4	an agti						
Rater is to con	-		J		•						
Rater's obser	<u>vations w</u>	hile the p	<u>atient is r</u>	<u>eadir</u>	ıg/resp	onding	g to the	question:			
1.0 What issu interpreti		_	n did you	obse	rve wh	ile the	patient	or caregiv	ver was	reading	or
2.0 What issureading o		_	_	-		serve w	hile the	e patient o	r caregi	ver was	
Questions for	the patien	t after the	ey have re	ead a	nd resj	<u>ponded</u>	to the	UPDRS qı	uestion:		
3.0 How easy	or difficul	t is this q	uestion fo	or you	ı to un	derstar	nd? (Ciı	rcle choice	e)		
Very di	ifficult	1 2	3 4	5	6	Very	y Easy				
4.0 What part	s of the qu	estion we	ere difficu	lt to	unders	stand?					
4.1 <u>Cir</u>	<u>cle</u> these o	n form.									
4.2 <u>Exp</u>	olain why	they were	difficult	in the	e space	below.	•				
5.0 How easy	or difficul	t was it fo	or you to	select	a resp	onse cl	hoice to	that ques	tion?		
Very di	ifficult	1 2	3 4	5	6	Very	Easy				
5.1 Wh	at made it	difficult	to select a	a resp	onse?						

5.2 Suggested solution?			
6.0 Who answered this item? Both	_ Patient primarily	Caregiver primarily	

2.10. TREMOR: Over the past week, have you usually had shaking or tremor?	SCORE
<ol> <li>Normal: Not at all. I have no tremor.</li> <li>Slight: Tremor occurs but does not cause problems with any activities.</li> <li>Mild: Tremor causes problems with only a few activities.</li> <li>Moderate: Tremor causes problems with many of my daily activities.</li> <li>Severe: Tremor causes problems with most or all activities.</li> </ol>	
Rater is to complete all answers to cognitive test questions.	
Rater's observations while the patient is reading/responding to the question:	
1.0 What issues with the question did you observe while the patient or caregiver was reading or interpreting the question?	
2.0 What issues with the response options did you observe while the patient or caregiver was reading or interpreting the response options?	
Questions for the patient after they have read and responded to the UPDRS question:	1
3.0 How easy or difficult is this question for you to understand? (Circle choice)	
Very difficult 1 2 3 4 5 6 Very Easy	
4.0 What parts of the question were difficult to understand?	
4.1 Circle these on form.	
4.2 Explain why they were difficult in the space below.	_
	<b>-</b> -
5.0 How easy or difficult was it for you to select a response choice to that question?	
Very difficult 1 2 3 4 5 6 Very Easy	
5.1 What made it difficult to select a response?	
5.2 Suggested solution?	

6.0 Who answered this item?	_ Patient primarily	Caregiver primarily	
Both			

<ul> <li>2.11. GETTING OUT OF BED, A CAR, OR A DEEP CHAIR: Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair?</li> <li>0: Normal: Not at all (no problems)</li> <li>1: Slight: I am slow or awkward, but I usually can do it on my first try.</li> <li>2: Mild: I need more than one try to get up or need occasional help.</li> <li>3: Moderate: I frequently need help to get up, but most times can do it on my own.</li> <li>4: Severe: I need help at most or all of the time.</li> </ul>							
Rater is to complete all answers to cognitive test questions.							
Rater's observations while the patient is reading/responding to the question:							
Nater's observations while the patient is reading/responding to the question.							
1.0 What issues with the question did you observe while the patient or caregiver was reading or interpreting the question?							
2.0 What issues with the response options did you observe while the patient or caregiver was reading or interpreting the response options?							
Questions for the patient after they have read and responded to the UPDRS question:							
3.0 How easy or difficult is this question for you to understand? (Circle choice)							
Very difficult 1 2 3 4 5 6 Very Easy							
4.0 What parts of the question were difficult to understand?							
4.1 <u>Circle</u> these on form.							
4.2 Explain why they were difficult in the space below.							

**SCORE** 

5.0 How easy or diffic	ult wa	as it f	or yo	ou to	selec	et a res	sponse choice to that question?
Very difficult	1	2	3	4	5	6	Very Easy
5.1 What made	it dif	ficult	to so	elect	a res	ponse	?
5.2 Suggested so	olutio	n?					
6.0 Who answered this Both	item	?	Pati	ient p	orim	arily	Caregiver primarily

2.12. WALKING AND BALANCE: Over the past week, have you usually had problems with balance and walking.	SCORE									
0: Normal: Not at all (no problems).										
I: Slight: I am slightly slow or may drag a leg. I have no balance problems. I never use a walking aid.										
2: Mild: I occasionally use a walking aid, but I do not need any help from another person.										
Moderate: I usually use a walking aid (cane, walker) to walk safely without falling.  However, I do not usually need the support of another person.										
4: Severe: I usually use the support of another person to walk safely without falling.										
4. Severe. I usually use the support of another person to wark safety without failing.										
Rater is to complete all answers to cognitive test questions.										
Rater's observations while the patient is reading/responding to the question:										
1.0 What issues with the question did you observe while the patient or caregiver was reading or interpreting the question?										
2.0 What issues with the response options did you observe while the patient or caregiver										
was reading or interpreting the response options?										
Questions for the patient after they have read and responded to the UPDRS question:										
3.0 How easy or difficult is this question for you to understand? (Circle choice)										
Very difficult 1 2 3 4 5 6 Very Easy										
4.0 What parts of the question were difficult to understand?										
4.1 <u>Circle</u> these on form.										
4.2 Explain why they were difficult in the space below.										
-	-									
	=									
	_									

5.0	How easy or diffic	ult wa	as it f	or yo	ou to	selec	et a res	sponse choice to that question?
	Very difficult	1	2	3	4	5	6	Very Easy
	5.1 What made	it dif	ficult	to se	elect	a res	ponse	?
	5.2 Suggested so	olutio	n?					
6.0 Bot		item	?	Pati	ient p	orim	arily	Caregiver primarily

		NG - Over the past week, on your usual day when walking, do you suddenly e as if you feet are stuck to the floor.	CCORE							
0	NT 1	N. ( 11 / 11 )	SCORE							
1:	<ol> <li>Normal: Not at all (no problems).</li> <li>Slight: I briefly freeze up to three times daily, but I can easily start walking again.</li> <li>Mild: I freeze more than three times per day but I don't have trouble starting to walk again and I don't need help or a walking aid (i.e. cane, walker) because of freezing.</li> <li>Moderate: When I freeze I have a lot of trouble starting to walk again and, because of freezing, I may fall sometimes. I sometimes need to use a walking aid or need help to walk.</li> <li>Severe: Because of freezing, I need to use a walking aid or need help most or all the time.</li> </ol>									
3:										
4:										
R/	iter is to co	mplete all answers to cognitive test questions.								
	15 10 00.	imprese the till streets to cognitive test questions.								
Ra	iter's obsei	rvations while the patient is reading/responding to the question:								
		<u> </u>								
1.0		nes with the question did you observe while the patient or caregiver was r interpreting the question?								
2.0	) What issu	ies with the response options did you observe while the patient or caregiver								
		ing or interpreting the response options?								
Qu	estions for	the patient after they have read and responded to the UPDRS question:								
3.0	How easy	or difficult is this question for you to understand? (Circle choice)								
	Very di	ifficult 1 2 3 4 5 6 Very Easy								
4.0	What part	s of the question were difficult to understand?								
	4.1 <u>Cir</u>	cle these on form.								
	4.2 <u>Exp</u>	plain why they were difficult in the space below.								
			<del>_</del>							

	Very difficult	1 2	3	4	5	6	Very Easy				
	5.1 What made i	t difficu	lt to se	elect :	a res	ponse?					
	5.2 Suggested solution?										
6.0 W Both	6.0 Who answered this item? Patient primarily Caregiver primarily Both										
and mall the	This completes the questionnaire. We may have asked about problems you do not even have, and may have mentioned problems that you may never develop at all. Not all patients develop all these problems, but because they can occur, it is important to ask all the questions to every patient. Thank you for your time and attention in completing this questionnaire.										
-											
Cont	Continue with debriefing questions for Part 2										

### **UPDRS PART 2 PATIENT DEBRIEFING**

For questions 1-2, the rater summarizes patient's answers to the questions below using the patient's own words whenever possible.

1.0 What do you think about the statement you just read regarding the fact that not all patients have experienced all the problems we have been assessing?
2.0 Overall, did you find the assessment questions in Part 2 difficult?(Y/N)
2.1 If so, what made them difficult?
3.0 Did you find any of the Part 2 assessment questions upsetting? (Y/N)
3.1 If so, what made them upsetting?
4.0 Did you find the questions or the answers hard to read? (Y/N)
If yes, check all reasons.
☐ Print was too small to read easily
☐ Lines were too close together
☐ Words were difficult to understand
[Note: At this point, the cognitive test of this UPDRS Part is complete for this patient.]
RATER DEBRIEFING
3. Which, if any, of the questions seemed to make the patient uncomfortable? Why?

#### Part III: Motor Examination

Overview: This portion of the scale assesses the motor signs of PD. In administering Part III of the UPDRS the examiner should comply with the following guidelines:

- 9. At the top of the form, mark whether the patient is on medication for treating the symptoms of Parkinson's disease and, if on levodopa, the time since the last dose.
- 10.Also, if the patient is receiving medication for treating the symptoms of Parkinson's Disease, mark the patient's clinical state using the following definitions:

**ON** is the typical functional state when patients are receiving medication and have a good response.

**OFF** is the typical functional state when patients have a poor response in spite of taking medications.

- 11. The investigator should "rate what you see". Admittedly, concurrent medical problems such as stroke, paralysis, arthritis, contracture, and orthopedic problems such as hip or knee replacement and scoliosis may interfere with individual items in the motor examination. In situations where it is absolutely impossible to test (e.g., amputations, plegia, limb in a cast), use the notation "UR" for Unable to Rate. Otherwise, rate the performance of each task as the patient performs in the context of co-morbidities.
- 12. All items must have an integer rating (no half points, no missing ratings).
- 13. Specific instructions are provided for the testing of each item. These should be followed in all instances. The investigator demonstrates while describing tasks the patient is to perform and rates function immediately thereafter. For Global Spontaneous Movement and Rest Tremor items (3.17 and 3.18), these items have been placed purposefully at the end of the scale because clinical information pertinent to the score will be obtained throughout the entire examination.
- 14. At the end of the rating, indicate if dyskinesia (chorea or dystonia) was present at the time of the examination, and if so, whether these movements interfered with the motor examination.

Part III: Motor Examination
Is the patient on medication for treating the symptoms of Parkinson's Disease?
Yes
No
If the patient is receiving medication for treating the symptoms of Parkinson's Disease, mark the
patient's clinical state using the following definitions:
ON: On is the typical functional state when patients are receiving medication and have a
good
response.
<b>OFF:</b> Off is the typical functional state when patients have a poor response in spite of
taking
medications.
Minutes since last levodopa dose Not on Levodopa

3.1	. SPEECH								
Inst	tructions to ex	aminer: Listen to the patient's free-flowing speech and engage in conversation if necessary.							
	Suggested topics: ask about the patient's work, hobbies, exercise, or how he got to the doctor's office. Evaluate volume, modulation (prosody) and clarity, including slurring, palilalia, and tachyphemia.								
0:	Normal.	No speech problems							
1:	Slight.	Loss of modulation, diction or volume, but still all words easy to understand.							
2:	Mild.	Loss of modulation, diction, or volume, with a few words unclear, but the overall sentences easy to follow.							
3:	Moderate.	Speech is difficult to understand to the point that some, but not most, sentences are poorly understood.							
4:	Severe.	Most speech is difficult to understand or unintelligible.							

Ra	Rater Observations regarding Use of Instructions and Ratings:										
1.0	1.0 How easy or difficult is it for you <u>as the rater</u> to understand the "Instructions to examiner"? (Circle choice)										
	Very difficult	1	2	3	4	5	6	Very Easy			
	1.1 Circle areas of the "Instructions to examiner" that were difficult above.										
	1.2 What would ma	ke th	ie "In	stru	ction	s to e	examii	ner" easier to understand?			
2.0	0 How easy or difficu	lt wa	s it fo	or yo	u to	rate 1	the pa	tient using the ratings provided?			
	Very difficult	1	2	3	4	5	6	Very Easy			
	2.1 What made it difficult to rate?										
	2.2 Suggested solution?										

Inst talk	tructions to exting. Observe	<b>EXPRESSION</b> aminer: Observe the patient sitting at rest for 10 seconds, without talking and also while eye-blink frequency, hypomimia or loss of facial expression, spontaneous smiling and										
-	parting of lips. ): Normal. Normal facial expression											
	Slight.	Minimal hypomimia manifested only by decreased frequency of blinking.										
2:	Mild.	In addition to decreased eye-blink frequency, hypomimia present in the										
		lower face as well, namely fewer movements around the mouth, such as										
2	M 1 4	less spontaneous smiling, but lips not parted.										
		Hypomimia with lips parted some of the time when the mouth is at rest.										
4:	Severe.	Masked facies with lips parted most of the time when the mouth is at rest.										
	D. (											
	Kater	Observations regarding Use of Instructions and Ratings:										
		w easy or difficult is it for you <u>as the rater</u> to understand the "Instructions to miner"? (Circle choice)										
	Vei	ry difficult 1 2 3 4 5 6 Very Easy										
	1.1	<u>Circle</u> areas of the "Instructions to examiner" that were difficult above.										
	1.2	What would make the "Instructions to examiner" easier to understand?										
	2.0 Ho	w easy or difficult was it for you to rate the patient using the ratings provided?										
	Very difficult 1 2 3 4 5 6 Very Easy											
	2.1 What made it difficult to rate?											
		2.2 Suggested solution?										

3.3. RIGIDI	ГҮ	
Instructions to ex	<u>kaminer</u> : Rigidity is judged on slow passive movement of major joints with the patient	
in a relaxed posi	tion and the examiner manipulating the limbs and neck. First, test without an activation	
maneuver. Test	and rate neck and each limb separately. For <b>arms</b> , test the wrist and elbow joints	
simultaneously.	For <b>legs</b> , test the hip and knee joints simultaneously. If no rigidity is detected, use an	
activation maneu	iver such as tapping fingers, fist opening/closing, or heel tapping in a limb not being	
tested. Explain to	o the patient to go as limp as possible as you test for rigidity.	
0 N 1	NI ' '1'	
0: Normal.	No rigidity.	
1: Slight.	Rigidity only detected with activation maneuver.	Neck
2: Mild.	Rigidity detected without the activation maneuver, but full range of	
	motion is easily achieved.	
3: Moderate.	Rigidity detected without the activation maneuver; full range of motion	
. 1.10 <b></b>	is achieved with effort.	$\overline{\text{RUE}}$
4. C		LUE
4: Severe.	Rigidity detected without the activation maneuver and full range of	202
	motion not achieved.	RLE -
		LLE

Rater Observations 1	<u>regardiı</u>	ng Us	se of	Instr	<u>ructio</u>	ons an	d Ratings:			
1.0 How easy or diffiex examiner"? (Circ			you <u>:</u>	as the	<u>e rat</u>	<u>er</u> to u	inderstand the "Instructions to			
Very difficult	1	2	3	4	5	6	Very Easy			
1.1 <u>Circle</u> areas o	1.1 Circle areas of the "Instructions to examiner" that were difficult above.									
1.2 What would r	nake th	e "In	ıstru	ction	s to e	examii	ner" easier to understand?			
2.0 How easy or diffi	cult was	s it fo	or yo	u to	rate 1	the pa	tient using the ratings provided?			
Very difficult	1	2	3	4	5	6	Very Easy			
2.1 What mad	2.1 What made it difficult to rate?									
2.2 Suggested	solution	n?								

Question for the patient regarding the instruction:									
3.0 How easy or diffi	cult we	re th	e ins	truct	ions	for yo	u to understand? (Circle	choice)	
Very difficult	1	2	3	4	5	6	Very Easy		
4.0 What parts of the	e instru	ction	s we	re di	fficul	t to ur	iderstand?		
(Examiner ca	n <u>circle</u>	thes	e on	form	ı <b>).</b>				
4.1 Explain w	hy they	wer	e dif	ficult					

tas	k while the pa	atient is being teste	d. Instru	ict the	patien	it to ta	p the i	ndex fin	ask, but do not continue to perform the nger on the thumb 10 times as quickly tude, hesitations, halts and decrementing			
0:	Normal.	No problems.										
1:	Slight.	or hesitations	Any of the following: a) the regular rhythm is broken with one or two interruptions R or hesitations of the tapping movement; b) slight slowing; c) the amplitude decrements near the end of the 10 taps.									
2:	Mild.	Any of the following amplitude decrease.	_				-		ing tapping; b) mild slowing; c) the uence.			
	Moderate. Severe.	longer arrest (sidecrements sta	freeze) arting at	in ong	going ne 1st	g mov tap.	eme	nt; b) n	ns during tapping or at least one moderate slowing; c) the amplitude use of slowing, interruptions or			
	1.0 Ho		cult is i	it for					d Ratings: Inderstand the "Instructions to			
		aminer"? (Circ ery difficult		ce) 2	3	4	5	6	Very Easy			
									' that were difficult above. ner" easier to understand?			
		ow easy or diffi aminer" to the			•			<u>er</u> to d	lemonstrate the "Instructions to			
	Ve	ery difficult	1	2	3	4	5	6	Very Easy			
	2.1	What would r	nake th	ne "Ir	ıstru	ction	s to	examir	ner" easier to demonstrate?			
									tient using the ratings provided?			
	Ve	ery difficult	1	2	3	4	5	6	Very Easy			
	3.1	What made it	difficul	lt to 1	rate?							
		3.2 Suggested	solutio	n?								

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3.4 FINGER TAPPING

# $\underline{\textbf{Questions for the patient regarding the instructions}}\textbf{:}$

4.0	How easy or difficult were the instructions and demonstrations for you to understand? (Circle choice)										
	Very difficult	1	2	3	4	5	6	Very Easy			
5.0	What parts of the	instru	ction	s we	re di	fficul	t to u	nderstand?			
	(Examiner car	n <u>circle</u>	thes	e on	form	ı <b>).</b>					
	5.1 <u>Explain</u> wl	hy they	wer	e diff	ficult						

while the patient quickly as possib	examiner: Test each hand separately. Demonstrate the task, but do not continue to perform the task at is being tested. Instruct the patient to make a tight fist and open the hand 10 times as fully AND as tible. If the patient fails to make a tight fist or to open the hand fully, remind him/her to do so. Rate ately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.	
0: Normal.	No problems	
1: Slight.	Any of the following: a) the regular rhythm is broken with one or two interruptions or hesitations of the movement; b) slight slowing; c) the amplitude decrements near the end of the task.	
2: Mild.	Any of the following: a) 3 to 5 interruptions during the movements; b) mild	
<ul><li>3: Moderate.</li><li>4: Severe.</li></ul>	slowing; c) the amplitude decrements midway in the task.  Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing; c) the amplitude decrements starting after the 1st open-and-close sequence.  Cannot or can only barely perform the task because of slowing, interruptions or decrements.	
exa Ver 1.1 <u>.</u>	we easy or difficult is it for you as the rater to understand the "Instructions to aminer"? (Circle choice)  ry difficult 1 2 3 4 5 6 Very Easy  Circle areas of the "Instructions to examiner" that were difficult above. What would make the "Instructions to examiner" easier to understand?	
	ow easy or difficult is it for you <u>as the rater</u> to demonstrate the "Instructions to aminer" to the patient? (Circle choice)	
Ver	ry difficult 1 2 3 4 5 6 Very Easy	
2.1	What would make the "Instructions to examiner" easier to demonstrate?	
3.0 Hov	we easy or difficult was it for you to rate the patient using the ratings provided?	
Ver	ry difficult 1 2 3 4 5 6 Very Easy	
3.11	What made it difficult to rate?	
	3.2 Suggested solution?	

3.5 HAND MOVEMENTS

## **Questions for the patient regarding the instructions:**

4.0 How easy or difficunderstand? (Circ			e ins	truct	ions	(and d	lemonstrations) for you to
Very difficult	1	2	3	4	5	6	Very Easy
5.0 What parts of the	instru	ction	s we	re di	fficul	t to ur	nderstand?
(Examiner can	<u>circle</u>	thes	e on	form	).		
5.1 <u>Explain</u> wh	y they	wer	e diff	ficult			

pal	ms down; the	n to turn the paln	n up and	down	alterna	ately 1	0 time	es as fas	at and as fully as possible. Rate each enting amplitude.					
	Normal. Slight.		ollowing or hesit	ation	s of th	he mo	ovem	ent; b)	oroken with one or two ) slight slowing; c) the amplitude	R				
2:	Mild.	slowing; c) the amplitude decrements midway in the sequence.												
3:	Moderate. Any of the following: a) more than 5 interruptions during the movement or at least one longer arrest (freeze) in ongoing movement; b) moderate slowing c) the amplitude decrements starting after the 1st supination-pronation sequence.													
4:	Severe.	Cannot or car decrements.	a only b	arely	perfo	orm t	he tas	sk beca	ause of slowing, interruptions or					
	Rater C	<b>Observations</b>	<u> </u>	ng U	se of	Instr	netio	ons an	d Ratings:					
	1.1 <u>6</u> 1.2 V 2.0 How	miner"? (Circ y difficult <u>Circle</u> areas o What would i	tle choice  1  of the "I  make the	ce) 2 Instru ne "In	3 uction nstruc you <u>a</u>	4 ns to ction as the	5 exam s to 6	6 niner" examir	Very Easy that were difficult above. ner" easier to understand?					
		y difficult	1	2	3		5	6	Very Easy					
	•	v							ner" easier to demonstrate?					
	Hov	v easy or diffi	icult wa	s it fo	or yo	u to 1	rate 1	the pa	tient using the ratings provided	1?				
	Ver	y difficult	1	2	3	4	5	6	Very Easy					
	3.1V	What made it	difficul	lt to r	ate?									
		3 2 Suggested	colutio	n?										

**3.6 PRONATION-SUPINATION MOVEMENTS OF HANDS**<u>Instructions to examiner</u>: Test each hand separately. Demonstrate the task, but do not continue to perform the

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## **Questions for the patient regarding the instructions:**

3.0 How easy or difficunderstand? (Cir			e ins	truct	ions	(and d	lemonstrations) for you	0
Very difficult	1	2	3	4	5	6	Very Easy	
4.0 What parts of the	instru	ction	s we	re di	fficul	t to ur	nderstand?	
(Examiner car	ı <u>circle</u>	thes	e on	form	).			
4.1 Explain w	hy they	wer	e diff	ficult				

Instru each f tested as big	foot separa . Instruct t	xaminer: Have the tely. Demonstrate the patient to place the possible. Ra	e the task, te the heel	but do	o not c	ontinund in a	e to p	erform ortable	th arms, both feet on the floor. the task while the patient is be position and then tap the toes amplitude, hesitations, halts an	eing 10 times			
0: N	ormal.	No problems											
1: S	light.	interruptions	or hesita	ations	s of th	ne tap	ping	move	oroken with one or two ement; b) slight slowing; c	R e)			
2: N	Iild.												
3: M	Ioderate	mild slowing; c) amplitude decrements midway in the task.											
4: S	evere.	Cannot or ca decrements.	n only ba	arely	perfo	orm tł	ne tas	sk beca	ause of slowing, interrupt	ions or			
	Ver		1 of the "I	2 nstru		ns to	exan	niner"	Very Easy ' that were difficult above  ner" easier to understan				
		v easy or diff miner" to the			•			<u>er</u> to d	lemonstrate the "Instruc	ctions to			
	Ver	y difficult	1	2	3	4	5	6	Very Easy				
	2.1	What would	make th	e "In	struc	ctions	s to e	exami	ner" easier to demonstra	ıte?			

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Very difficult	1	2	3	4	5	6	Very Easy
3.1What m	ade it dif	ficult	to ra	ite?			
3.2 Suggest	ed solution	n?					
88							
estions for the patie	nt regard	ling tl	he ins	struc	tions	<u> </u>	
estions for the patie							
estions for the patie	ılt were tl						nstrations) for you to
How easy or difficuently understand? (Circle)	ilt were tl e choice)	ne ins	truct	ions	(and	demo	, ·
estions for the patie	ilt were tl e choice)	ne ins	truct	ions	(and	demo	, ·

	8 LEG AGI		ent sit in	a strai	oht_ha	icked i	chair v	with arm	ns, both feet on the floor. Test each leg	
sep to j	parately. Demo	nstrate the task, but do n the ground in a con	o not con nfortable	tinue t positio	o perf	orm th	ne task raise a	while t	the patient is being tested. Instruct the patient up the foot on the ground 10 times as high and	
	_		rately, eva	aluatin	ig spe	ed, am	plitud	le, hesita	ations, halts and decrementing amplitude.	
	Normal.	No problems		.1			.1 .			_
1:	Slight.	•			_	-			en with one or two interruptions or	
			movem	ient; l	b) sli	ght si	owin	ig; c) a	mplitude decrements near the end of	
2.	Mild.	the task.	rina: a)	2 to 6	into			durina	the maxements; h) mild slaveness; a)	
۷.	MIII.	amplitude decren				_		uuring	the movements; b) mild slowness; c)	
2.	Moderate	*		-				otions o	during the movement or at least one	
٦.	Wiodciate.	•					-		derate slowing in speed; c) amplitude	
		decrements after		_	<sub>5</sub>	0 1 611	iciit,	<i>o)</i> 1110 <b>c</b>	derate slowing in speed, e) unipittude	
4:	Severe.			-	form	the ta	ask b	ecause	of slowing, interruptions or	
		decrements.		<i>J</i> 1					<i>3</i> , 1	
	D (	01 4	1.	**		Ŧ ,			ID (	
	Rate	er Observations r	egaran	ng Us	se oi	Instr	uctio	ons and	a Ratings:	
	101	Jow open or diffi	oult is i	t for	vou.	ac th	o rot	or to u	nderstand the "Instructions to	
		examiner"? (Circ			you <u>a</u>	as tiii	erau	<u>er</u> to u	inderstand the Thstructions to	
	`	xammer . (enc	ic choic	ccj						
	•	Very difficult	1	2	3	4	5	6	Very Easy	
	1	l 1 Circle areas o	f the "I	nstri	ıctio	ns to	evan	niner"	that were difficult above.	
									ner" easier to understand?	
		•			-			<u>er</u> to d	emonstrate the "Instructions to	
	•	examiner" to the	patient	? (Ci	rcle	choic	e)			
		Very difficult	1	2	3	4	5	6	Very Easy	
		very unincum	1	4	3	7	3	v		
		•							very Easy	
	2	2.1 What would n	nake th	e "In	stru	ction	s to e	examin	ner" easier to demonstrate?	
									· ·	

3.1What made it difficult to rate?

3.2 Suggested solution?

## **Questions for the patient regarding the instructions:**

4.0 How easy or difficunderstand? (Circ			e ins	truct	ions	(and d	lemonstrations) for you to
Very difficult	1	2	3	4	5	6	Very Easy
5.0 What parts of the	instru	ction	s we	re di	fficul	t to ur	nderstand?
(Examiner can	<u>circle</u>	thes	e on	form	).		
5.1 Explain wh	y they	wer	e diff	ficult			

#### 3.9 ARISING FROM CHAIR

Very difficult

1

3

0: Normal.

<u>Instructions to examiner</u>: Have the patient sit in a straight-backed chair with arms, with both feet on the floor and sitting back in the chair (if the patient is not too short). Ask the patient to cross his/her arms across the chest and then to stand up. If the patient is not successful, repeat this attempt a maximum up to two more times. If still unsuccessful, allow the patient to move forward in the chair to arise with arms folded across the chest. Allow only one attempt in this situation. If unsuccessful, allow the patient to push off using his/her hands on the arms of the chair. Allow a maximum of three trials of pushing off. If still not successful, assist the patient to arise. After the patient stands up, observe the posture for item 3.13

No problems. Able to arise quickly without hesitation.

1: Slight.	Arising is slower forward in the ch			-	~			nan one attempt; or may need to meed to	iove
2: Mild.	Pushes self up fro								
3: Moderate								ve to try more than one time using	3
	arms of chair, bu						-	·	
4: Severe.	Unable to arise w	vithout l	help.						
D.	oton Ohaanvationa		II	~ ~ <b>. .</b>	T4-	4:		d Dodings	$\overline{}$
<u>K</u>	ater Observations	regarai	ing U	se oi	Insti	ructio	ons an	a Ratings:	
1.0				you	as th	e rat	<u>er</u> to u	nderstand the "Instructions to	
	examiner"? (Circ	cle choi	ice)						
	Very difficult	1	2	3	4	5	6	Very Easy	
	1.1 <u>Circle</u> areas o	of the "	Instr	uctio	ns to	exan	niner"	that were difficult above.	
	1.2 What would i	make tl	he "Iı	nstru	ction	s to o	examir	ner" easier to understand?	
2.0	0 How easy or diffi	icult wa	as it f	or yo	u to	rate	the pa	tient using the ratings provided	?
	Very difficult	1	2	3	4	5	6	Very Easy	
	2.1 What mad	de it dif	fficul	t to r	ate?				
	2.2 Suggested	solutio	on?						
Ouest	ons for the patient	magand	lina 4	ha in	atmira	tions			
Questi	ons for the patient	regaru	ınıg t	ne m	struc	HUIIS	<u>.</u> •		
3.0 Ho	w easy or difficult	were th	ie ins	truct	tions	for v	ou to 1	understand? (Circle choice)	

**Very Easy** 

4.0 What parts of the instructions were difficult to understand?

(Examiner can circle these on form).

4.1 Explain why they were difficult

so that both r (30 feet), the height of foo	T to examiner. Testing right and left sides of to turn around and retut lift, heel strike durin hile patient is walking	the body arn to the g walkin	can be exar	oe easi niner. rning,	ily obs This i and ar	erved tem m m swi	simul easure ing, bu	taneous es multi	ly. The ple beha	patient sl	hould w ide amp	alk at lea olitude, st	st 10 mete ride speed
0: Normal. 1: Slight. 2: Mild. 3: Modera 4: Severe.	Independent v Independent v	walking ssistan	g but	with evice	subs for s	tantia afe w	al abr alkin	normal 1g (wa	lking st		lker) b	out not a	person.
П	Rater Observatio	ns reg	ardi	ng U	se of	Instr	uctio	ons an	d Rati	ngs:			
	1.0 How easy or c examiner"? (0	lifficul	lt is i	t for							e "Ins	truction	ıs to
	Very difficult		1	2	3	4	5	6	Ve	ry Easy	V		
	1.1 <u>Circle</u> are	as of tl	he "I	nstrı	uctio	ns to	exan	niner"					
	2.0 How easy or o												vided?
	Very difficult		1	2	3	4	5	6	Ve	ry Easy	y		
	2.1 What	made i	t dif	ficult	to ra	ite?							
	2.2 Sugges	ted so	lutio	n?									
	tions for the pati							•					
3.0 H	low easy or diffic	ult we	re th	e ins	truct	ions	for y	ou to	unders	stand? (	(Circle	e choice	e)
V	ery difficult	1	2	3	4	5	6	V	Very E	asy			
4.0 V	What parts of the	instru	ction	s we	re dif	ficul	t to ı	ınders	stand?				
	(Examiner can	circle	thes	e on	form	).							

4.1 Explain why they were difficult

3 11 FDFF7	ING OF GAIT	
Instructions to exhesitation and stu	<u>caminer</u> . While assessing gait, also assess for the presence of any gait freezing episodes. Observe for start attering movements especially when turning and reaching the end of the task. To the extent that safety may NOT use sensory tricks during the assessment.	
0: Normal.	No freezing	
1: Slight.	Freezes on starting, turning or walking through doorway with a single halt during any of these events, but then continues smoothly without freezing during straight walking.	
2: Mild	Freezes on starting, turning or walking through doorway with more than one halt during any of these activities, but continues smoothly without freezing during straight walking	
3: Moderate	Freezes once during straight walking	
4: Severe	Freezes multiple times during straight walking	
	ter Observations regarding Use of Instructions and Ratings:  How easy or difficult is it for you as the rater to understand the "Instructions to	

regardi	ng U	se of	Insti	ructio	ons an	d Ratings:
		you <u>s</u>	as th	<u>e rat</u>	<u>er</u> to u	understand the "Instructions to
1	2	3	4	5	6	Very Easy
f the "I	nstr	uctio	ns to	exan	niner"	' that were difficult above.
	_					
1	2	3	4	5	6	Very Easy
le it dif	ficult	to r	ate?			
solutio	n?					
	cult is i ele choic 1 of the "I nake th lifficult 1	cult is it for ele choice)  1 2  of the "Instrumake the "Indifficult was  1 2	cult is it for you gele choice)  1 2 3  of the "Instruction make the "Instruction lifficult was it for the difficult to refer to the difficult to the diff	cult is it for you as the cle choice)  1 2 3 4  If the "Instructions to make the "Instruction difficult was it for you  1 2 3 4  It it difficult to rate?	cult is it for you as the rate ele choice)  1 2 3 4 5  If the "Instructions to exammake the "Instructions to exammake the "Instructions to elifficult was it for you to rate?  1 2 3 4 5  It it difficult to rate?	1 2 3 4 5 6  If the "Instructions to examiner"  make the "Instructions to examilifficult was it for you to rate the  1 2 3 4 5 6  It difficult to rate?

#### 3.12 POSTURAL STABILITY

Instructions to examiner: The test examines the response to sudden body displacement produced by a quick, forceful pull on shoulders while the patient is standing erect with eyes open and feet comfortably apart and parallel to each other. Test retropulsion. Stand behind the patient and instruct the patient on what is about to happen. Explain that s/he is allowed to take a step backwards to avoid falling. There should be a solid wall behind the examiner, at least 1-2 meters away to allow for the observation of the number of retropulsive steps. The first pull is an instructional demonstration and is purposely milder and not rated. The second time the shoulders are pulled briskly and forcefully towards the examiner with enough force to displace the center of gravity so that patient MUST take a step backwards. The examiner needs to be ready to catch the patient, but must stand sufficiently back so as to allow enough room for the patient to take several steps to recover independently. Do not allow the patient to flex the body abnormally forward in anticipation of the pull. Observe for the number of steps backwards or falling. Up to and including two steps for recovery is considered normal, so abnormal ratings begin with three steps. If the patient fails to understand the test, the examiner can repeat the test so that the rating is based on an assessment that the examiner feels reflects the patient's limitations rather than misunderstanding or lack of preparedness. Observe ambient posture for item 3.13

0: Normal. No problems: Recovers with one or two steps. 1: Slight. 3-5 steps, but subject recovers unaided.

2: Mild. More than 5 steps, but subject recovers unaided

Stands safely, but with absence of postural response; falls if not caught by examiner. 3: Moderate. 4: Severe.

Very unstable, tends to lose balance spontaneously or with just a gentle pull on the

shoulders

Rater Observations regarding Use of Instructions and Ratings:							
1.0 How easy or difficult is it for you <u>as the rater</u> to understand the "Instructions to examiner"? (Circle choice)							
Very difficult	1	2	3	4	5	6	Very Easy
1.1 Circle areas of the "Instructions to examiner" that were difficult above.							
1.2 What would make the "Instructions to examiner" easier to understand?							
2.0 How easy or difficult was it for you to rate the patient using the ratings provided?							
Very difficult	1	2	3	4	5	6	Very Easy
2.1 What made it difficult to rate?							
2.2 Suggested solution?							

# Questions for the patient regarding the instructions: 3.0 How easy or difficult were the instructions for you to understand? (Circle choice) Very difficult 1 2 3 4 5 6 Very Easy 4.0 What parts of the instructions were difficult to understand? (Examiner can circle these on form). 4.1 Explain why they were difficult

2 12 DOCTI	
while being teste improves (see op to-side leaning.  0: Normal.  1: Slight.  2: Mild.	RE  taminer: Posture is assessed with the patient standing erect after arising from a chair, during walking, and d for postural reflexes. If you notice poor posture, tell the patient to stand up straight and see if the posture pation 2 below). Rate the worst posture seen in these three observation points. Observe for flexion and side-  No problems  Not quite erect, but posture could be normal for older person.  Definite flexion, scoliosis or leaning to one side, but patient can correct posture to normal posture when asked to do so.  Stooped posture, scoliosis or leaning to one side that cannot be corrected volitionally to a normal posture by the patient.  Flexion, scoliosis or leaning with extreme abnormality of posture.
4. Severe	riexion, sconosis of leaning with extreme abhormanty of posture.
1.0	How easy or difficult is it for you <u>as the rater</u> to understand the "Instructions to examiner"? (Circle choice)  Very difficult 1 2 3 4 5 6 Very Easy  1.1 <u>Circle</u> areas of the "Instructions to examiner" that were difficult above.
2.0	1.2 What would make the "Instructions to examiner" easier to understand?  How easy or difficult was it for you to rate the patient using the ratings provided?

									ing the legs. This assessment ting, and the nature of arising			
): Norr	_	No problems	υ	1		U			ζ,	S		
1: Slight.		Slight global slowness and poverty of spontaneous movements. Less spontaneous										
J		gesturing or cross		-	-	-			1			
2: Mild	<b>l</b> .	Mild global slowr	ness an	d pov	erty	of spo	ontan	eous m	novements, including dec	reased		
		gesturing.		-	-	-			,			
3: Mod	lerate.	Moderate global s	lowne	ss and	d pov	erty o	of spo	ntaneo	ous movements. Lack of	gesturing in		
		both arms.										
4: Seve	ere.	Severe global slov	vness a	and p	overt	y of s	ponta	aneous	movements.			
	Rat	er Observations r	egardi	ing U	se of	Instr	uctio	ons an	d Ratings:			
					you 2	as the	<u>e rate</u>	<u>er</u> to u	nderstand the "Instruct	tions to		
		examiner"? (Circ	le choi	ce)								
	·	Very difficult	1	2	3	4	5	6	Very Easy			
		4.4.69	<b>9</b> . <b>9</b>									
		.1 <u>Circle</u> areas of the "Instructions to examiner" that were difficult above.										
		103371 / 11	1 41	<b>66</b> ▼	4	ructions to examiner" easier to understand?						
		1.2 What would n	iake ti	ie "Ii	nstru	ction	s to e	examın	ier" easier to understan	a?		
	2.0	Havy aggy an diffic	]4	: 4 f		40	t.a. 1	tha nat	tiont using the vetings n	marridad9		
	2.0	now easy or uninc	cuit wa	is it i	or yo	u to i	rate	me pai	tient using the ratings p	rovided:		
		Very difficult	1	2	3	1	5	6	Very Easy			
		very unificult	1	2	3	7	3	U	very Lasy			
		2.1 What mad	e it dif	ficul	t to r	ate?						
		2.1 What mau	c it uii	iicui	1 10 1	att.						
		2.2 Suggested	solutio	m?								
		2.2 Suggested	Solutio	,11 •								

**3.14 GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)**<u>Instructions to examiner</u>: This global rating combines all observations on slowness, hesitancy, and small amplitude and

Instruction rating. Rabody with	te each hand separat	emor, <u>includ</u> ely. Rate the rist should b	ling re highe e strai	e-emei	gent r	e seen	. Inst	ruct th	present in this posture is to be ince e patient to stretch the arms out in ly separated so that they do not to	front of the
0: Norm 1: Sligh 2: Mild 3: Mode 4: Seve	t. Tremor is Tremor is erate. Tremor is	present bu at least 1 t at least 3 t	out le	ss tha	an 3 c an 10	cm in	amp	litud		
	Rater Observa  1.0 How easy of examiner"	or difficul	t is it	for					nd Ratings: understand the "Instructio	ons to
		areas of th	ie "Ir	nstru	ction	is to	exan	niner	Very Easy " that were difficult above.	
1.2 What would make the "Instructions to exami 2.0 How easy or difficult was it for you to rate the pa							ntient using the ratings pro			
Very difficult 1 2 3 4 5 6 Very Easy  2.1 What made it difficult to rate?  2.2 Suggested solution?										
	estions for the p						_		understand? (Circle choic	e)
	Very difficult		2						Very Easy	,
4.0	What parts of t						t to u	nder	stand?	

 $\overline{R}$   $\overline{L}$ 

4.1 Explain why they were difficult

8.16 KINETIC TREMOR OF THE HANDS  Instructions to examiner: This is tested by the finger-to-nose maneuver. With the arm starting from the outstretched position have the patient perform at least three finger-to-nose maneuvers with each hand reaching as far as possible to touch the examiner's finger. The finger-to-nose maneuver should be performed slowly enough not to hide any tremor that could occur with very fast arm movements. Repeat with the other hand, rating each hand separately. The tremor can be present hroughout the movement or as the tremor reaches either target (nose or finger). Rate the highest amplitude seen.
<ol> <li>Normal. No tremor.</li> <li>Slight. Tremor is present but less than 1 cm in amplitude.</li> <li>Mild. Tremor is at least 1 but less than 3 cm in amplitude.</li> <li>Moderate. Tremor is at least 3 but less than 10 cm in amplitude.</li> <li>Severe Tremor is at least 10 cm in amplitude.</li> </ol>
Rater Observations regarding Use of Instructions and Ratings:
1.0 How easy or difficult is it for you as the rater to understand the "Instructions to examiner"? (Circle choice)  Very difficult 1 2 3 4 5 6 Very Easy  1.1 Circle areas of the "Instructions to examiner" that were difficult above.
1.2 What would make the "Instructions to examiner" easier to understand?
2.0 How easy or difficult was it for you to rate the patient using the ratings provided?
Very difficult 1 2 3 4 5 6 Very Easy
2.1 What made it difficult to rate?
2.2 Suggested solution?
Questions for the patient regarding the instructions:

 $\overline{R}$   $\overline{L}$ 

3.0 How easy or difficult were the instructions for you to understand? (Circle choice)

Very Easy

Very difficult

4.0 What parts of the instructions were difficult to understand?

(Examiner can circle these on form).

4.1 Explain why they were difficult

### 3.17 REST TREMOR AMPLITUDE

Instructions to examiner: This and the next item have been placed purposefully at the end of the examination to allow the rater to gather observations on rest tremor that may appear at any time during the exam, including when quietly sitting, during walking and during activities when some body parts are moving but others are at rest. Score the maximum amplitude that is seen at any time as the final score. Rate only the amplitude and not the persistence or the intermittency of the tremor. As part of this rating, the patient should sit quietly in a chair with the hands placed on the arms of the chair (not in the lap) and the feet comfortably supported on the floor for 10 seconds with no other directives. Rest tremor is assessed separately for all four limbs and also for the lip/jaw. Rate only the maximum amplitude that is seen at any time as the final rating.

Ex	tremity rat	ings	Lij	p/Jaw ratin	gs	
0:	Normal.	No tremor.	0:	Normal.	No tremor	Lip/Jaw
1:	Slight.	< 1 cm in maximal amplitude.	1:	Slight.	<1 cm in maximal amplitude.	
2:	Mild.	> 1 cm but <3 cm in maximal	2:	Mild.	>1 cm but <2 cm in maximal	
		amplitude			amplitude	RUE LUE
3:	Moderate.	3-10 cm in maximal amplitude.	3:	Moderate.	>2 cm but <3 cm in maximal	
	amplitude			amplitude.		RLE LLE
4:	Severe.	>10 cm in maximal amplitude.	4:	Severe.	>3 cm in maximal amplitude.	REL EEL

Rate	Rater Observations regarding Use of Instructions and Ratings:									
1.0 How easy or difficult is it for you as the rater to understand the "Instructions to examiner"? (Circle choice)										
V	ery difficult	1	2	3	4	5	6	Very Easy		
1.	.1 <u>Circle</u> areas of t	he "I	nstru	ıctio	ns to	exan	niner'	' that were difficult above.		
1.	.2 What would ma	ke th	e "In	stru	ction	s to e	exami	ner" easier to understand?		
2.0 H	low easy or difficu	lt wa	s it fo	or yo	u to 1	rate 1	the pa	tient using the ratings provided?		
V	ery difficult	1	2	3	4	5	6	Very Easy		
	2.1 What made it difficult to rate?									
	2.2 Suggested solution?									

Instruction the examin	ns to ex nation p		eives one oody part	rating s are v	g for al various	sly at 1	rest. I		ocuses on the constancy of rest ed purposefully at the end of th		
2: Mild	Slight. Tremor at rest is present <25% of the entire examination period.  Mild. Tremor at rest is present 26-50% of the entire examination period.  Moderate. Tremor at rest is present 51-75% of the entire examination period.										
	Were dyskinesias (chorea or dystonia) present during examination?YESNO										
пу	_	these movements inter Observations 1					uctio	ons ai	YESNO nd Ratings:		
		How easy or difficexaminer"? (Circ			you <u>z</u>	is the	e rate	er to	understand the "Instruct	tions to	
	,	Very difficult	1	2	3	4	5	6	Very Easy		
		1.1 <u>Circle</u> areas o	f the "I	nstru	ıctior	is to	exan	niner	" that were difficult abov	ve.	
	1.2 What would make the "Instructions to examiner" easier to understand?										
	2.0 How easy or difficult was it for you to rate the patient using the ratings provided?										
	,	Very difficult	1	2	3	4	5	6	Very Easy		
		2.1 What mad	e it diff	ficult	to ra	te?					
	2.2 Suggested solution?										

### RATER DEBRIEFING

- 1.0 What issue, if any, did you have with the Instructions on page 72 of Part 3?
- 2.0 What difficulties, if any, did you have with the instructions to mark the patient as ON or OFF during the examination?
- 3.0 Which, if any, of the instructions or tasks seemed to make the patient uncomfortable? Why?
- 4.0 Which instructions were the most difficult or awkward for you to give? Why?
- 5.0 Have you come to dislike any specific instructions in this UPDRS Part? Which ones? Why?

### **Part IV: Motor Complications**

Overview and Instructions: In this section, the rater uses historical and objective information to assess two motor complications, dyskinesias and motor fluctuations that include OFF-state dystonia. Use all information from patient, caregiver, and the examination to answer the six questions that summarize function over the past week including today. As in the other sections, rate using only integers (no half points allowed) and leave no missing ratings. If the item cannot be rated, place UR for Unable to Rate. You will need to choose some answers based on percentages, and therefore you will need to establish how many hours generally are awake hours and use this figure as the denominator for "OFF" time and Dyskinesias. For "OFF dystonia", the total "Off" time will be the denominator.

Operational definitions for examiner's use.

### **Dyskinesias:** Involuntary random movements

Words that patients often recognize for dyskinesias include "irregular jerking", "wiggling", "twitching". It is essential to stress to the patient the difference between dyskinesias and tremor, a common error when patients are assessing dyskinesias.

**Dystonia:** contorted posture, often with a twisting component:

Words that patients often recognize for dystonia include "spasms", "cramps", "posture".

### **Motor fluctuation:** Variable response to medication:

Words that patients often recognize for motor fluctuation include "wearing out", "wearing off", "roller-coaster effect", "on-off", "uneven medication effects".

**OFF:** Typical functional state when patients have a poor response in spite of taking mediation or the typical functional response when patients are on NO treatment for parkinsonism. *Words that patients often recognize include "low time"*, "bad time", "shaking time", "slow time", "time when my medications don't work."

**ON:** Typical functional state when patients are receiving medication and have a good response: Words that patients often recognize include "good time", "walking time", "time when my medications work."

# A. DYSKINESIAS [exclusive of OFF-state dystonia] 4.1 TIME SPENT WITH DYSKINESIAS

Instructions to examiner: Determine the hours in the usual waking day and then the hours of dyskinesias. Calculate	the							
percentage. If the patient has dyskinesias in the office, you can point them out as a reference to ensure that patients	and							
caregivers understand what they are rating. You may also use your own acting skills to enact the dyskinetic movement								
ou have seen in the patient before or show them dyskinetic movements typical of other patients. Exclude from this uestion early morning and nighttime painful dystonia								
question early morning and nighttime painful dystonia.								
Instructions to patient [and caregiver]. Over the past week, how many hours do you usually sleep on a daily basis,								
including nighttime sleep and daytime napping? Alright, if you sleep hrs, you are awake hrs. Out of those								
awake hours, how many hours in total do you have wiggling, twitching or jerking movements? Do not count the tin								
when you have tremor, which is a regular back and forth shaking or times when you have painful foot cramps or spain the early morning or at nighttime. I will ask about those later. Concentrate only on these types of wiggling, jerki								
and irregular movements. Add up all the time during the waking day when these usually occur. How many hours _								
(use this number for your calculation).								
(abo and name).								
0: Normal: No dyskinesias								
1: Slight: <25% of waking day								
2: Mild: 26-50% of waking day								
3: Moderate: 51-75% of waking day								
4: Severe: > 75% of waking day								
1.0 How helpful are the "Instructions to examiner"? (Circle choice)								
Not helpful 1 2 3 4 5 6 Very Helpful								
1.1 Circle areas of the "Instructions to examiner" that that were not helpful.								
1.2 What would make the "Instructions to examiner" easier to understand or								
carry out?								
carry out.								
On retirement 2 and 2 and retained to the Landau etimes to Dation to and I am retirement and 5 and retained to								
Questions 2 and 3 relate to the <u>Instructions to Patients</u> and questions 4 and 5 relate to the								
<u>response options.</u>								
2.0 Rater reads the <u>Instructions to Patient</u> to the patient. How easy or difficult is it for								
you <u>as the rater</u> to use the current wording of the question verbatim? (Circle choice)								
Very difficult 1 2 3 4 5 6 Very Easy								
3.0 Rater notes difficulties using the question below (Mark each item Y or N):								
3.0 Ratel notes unificulties using the question below (Mark each item 1 of 14).								
2.1 Pater experienced difficulty reading question. Underline problematic parts, of the								
3.1Rater experienced difficulty <u>reading</u> question. <u>Underline</u> problematic parts of the								
3.1Rater experienced difficulty <u>reading</u> question. <u>Underline</u> problematic parts of the question. What parts of the question were difficult to <u>read</u> easily?								

3.2	Rater had difficulty <u>explaining</u> the question. <u>Bracket</u> problematic parts of the question. What parts of the question were difficult to explain?
3.3	Other rater issue with instructions to patient (please specify)
	ing Instructions to Patient to the patient and hearing responses, how difficult you as the rater to select the appropriate response option? (Circle choice)
Very di	fficult 1 2 3 4 5 6 Very Easy
5.0 If you had difficult?	difficulty <u>selecting</u> a response option, <u>explain</u> why this selection was
Questions for th	e patient after they have heard the UPDRS question:
6.0 How easy or	difficult is this question for you to understand? (Circle choice)
Very diff	icult 1 2 3 4 5 6 Very Easy
	of the question were difficult to understand? What was the difficulty? on form. Explain why they were difficult in the space below.
	-
8.0 Who answer	red this item? Patient primarily Caregiver primarily

Instructions to e activities and so during the office Instructions to p	IONAL IMPACT OF DYSKINESIAS  Examiner: Determine the degree to which dyskinesias impact on the patient's daily function in terms of interactions. Use the patient's and caregiver's response to your question and your own observations is evisit to arrive at the best answer.  Installed I and Caregiver: Over the past week, did you usually have trouble doing things or being with people ing movements occurred? Did they stop you from doing things or from being with people?										
0: Normal.	No dyskinesias or no impact by dyskinesias on activities or social interactions.										
1: Slight.	Dyskinesias impact on a few activities, but the patient usually performs all activities and participates in all social interactions during dyskinetic periods.										
2: Mild.	Dyskinesias impact on many activities, but the patient usually performs all activities										
3: Moderate.	some activities or does not usually participate in some social activities during										
4: Severe.	dyskinetic episodes.  Dyskinesias impact on function to the point that the patient usually does not perform most activities or participate in most social interactions during dyskinetic episodes.										
1.0 How he	lpful are the "Instructions to examiner"? (Circle choice)										
1.2 V	oful 1 2 3 4 5 6 Very Helpful  Circle areas of the "Instructions to examiner" that that were not helpful.  What would make the "Instructions to examiner" easier to understand or yout?										
	and 3 relate to the <u>Instructions to Patients</u> and questions 4 and 5 relate to the <u>onse options</u> .										
	he rater to use the current wording of the question verbatim? (Circle choice)										
Very	difficult 1 2 3 4 5 6 Very Easy										
3.0 Rater n	otes difficulties <u>using</u> the question below (Mark each item Y or N): Rater experienced difficulty <u>reading</u> question. <u>Underline</u> problematic parts of the question. What parts of the question were difficult to <u>read</u> easily?										

3.2	Rater had difficulty <u>explaining</u> the question. <u>Bracket</u> problematic parts of the question. What parts of the question were difficult to explain?
3.3	Other rater issue with instructions to patient (please specify)
	ing Instructions to Patient to the patient and hearing responses, how difficult you as the rater to select the appropriate response option? (Circle choice)
Very di	fficult 1 2 3 4 5 6 Very Easy
8.0 If you had difficult?	difficulty <u>selecting</u> a response option, <u>explain</u> why this selection was
_	
Questions for th	e patient after they have heard the UPDRS question:
9.0 How easy or	difficult is this question for you to understand? (Circle choice)
Very diff	icult 1 2 3 4 5 6 Very Easy
	rts of the question were difficult to understand? What was the difficulty? on form. Explain why they were difficult in the space below.
8.0 Who answer Both	red this item? Patient primarily Caregiver primarily

### **B. MOTOR FLUCTUATIONS**

13	TIME	CDENT	IN THE	OFF	VT2	TE
4.3		OF UNI		UFF	$\mathbf{D} \mathbf{I} \mathbf{A}$	T D

Instructions to examiner: Use the number of waking hours derived from 4.1 and determine the hours spent in the "OFI state. Calculate the percentage. If the patient has an OFF period in the office, you can point to this state as a reference You may also use your knowledge of the patient to describe a typical OFF period. Additionally you may use your own acting skills to enact an OFF period you have seen in the patient before or show them OFF function typical of other patients. Mark down the typical number of OFF hours, because you will need this number for completing 4.6 Instructions to patient [and caregiver]. Some patients with Parkinson's disease have a good effect from their medications throughout all their awake hours and we call that "ON" time. Other patients take their medications but st have some hours of low time, bad time, slow time or shaking time. Doctors call these low periods "OFF" time. Over the past week, you told me before that you are generally awake hrs each day. Out of these awake hours, how many hours in total do you usually have this type of low level or OFF function (Use this number for your calculations)  1. Slight. < 25% of waking day  2. Mild
4: Severe > 75 of waking day
1.0 How helpful are the "Instructions to examiner"? (Circle choice)
Not helpful 1 2 3 4 5 6 Very Helpful
1.1 Circle areas of the "Instructions to examiner" that that were not helpful.
1.2 What would make the "Instructions to examiner" easier to understand or carry out?
Questions 2 and 3 relate to the <u>Instructions to Patients</u> and questions 4 and 5 relate to the <u>response options</u> .
2.0 Rater reads the <u>Instructions to Patient</u> to the patient. How easy or difficult is it for you <u>as the rater</u> to use the current wording of the <u>question</u> verbatim? (Circle choice)
Very difficult 1 2 3 4 5 6 Very Easy
3.0 Rater notes difficulties <u>using</u> the question below (Mark each item Y or N):
3.1Rater experienced difficulty <u>reading</u> question. <u>Underline</u> problematic parts of the question. What parts of the question were difficult to <u>read</u> easily?

3.2	Ra	ter had	diffic	ulty	expl	aini	ng tl	he question. <u>Bracket</u> problematic	
	parts of the question. What parts of the question were difficult to explain?								
3.3	_	Oth	ier ra	iter i	ssue	wit	h ins	structions to patient (please specify)	
								and hearing responses, how difficult te response option? (Circle choice)	
Very di	ifficult	1 2	3	4	. 5	;	6	Very Easy	
5.0 If you had difficult?	difficulty	y <u>selectir</u>	<u>1g</u> a r	espo	onse (	opti	on, <u>e</u>	explain why this selection was	
Questions for th	e patient	after th	ey ha	ve h	<u>eard</u>	the	UPI	DRS question:	
6.0 How easy or	difficult	is this q	uestio	n fo	r you	ı to	und	erstand? (Circle choice)	
Very diff	ficult [	1 2	3	4	5	6		Very Easy	
_	-							tand? What was the difficulty?  Alt in the space below.	
	_								
8.0 Who answer Both	ed this it	em?	Patio	ent p	rima	rily		Caregiver primarily	

### 4.4 FUNCTIONAL IMPACT OF FLUCTUATIONS

<u>Instructions to examiner:</u> Determine the degree to which motor fluctuations impact on the patient's daily function in terms of activities and social interactions. This question concentrates on the <u>difference</u> between the ON state and the OFF state. If the patient has no OFF time, the rating must be 0, but if patients have very mild fluctuations, it is still possible to be rated 0 on this item if no impact on activities occurs. Use the patient's and caregiver's response to your question and your own observations during the office visit to arrive at the best answer.

Instructions to patient [and caregiver]: Think about when those low or "OFF" periods have occurred over the past week. Do you usually have more problems doing things or being with people then compared to the rest of the day when you feel your medications working? Are there some things you usually do during a good period that you have trouble with or stop doing during a low period?

0: Normal No fluctuations or No impact by fluctuations on performance of activities or social

interactions.

1: Slight. Fluctuations impact on a few activities, but during OFF, the patient usually performs

all activities and participates in all social interactions that typically occur during the

ON state.

2: Mild. Fluctuations impact many activities, but during OFF, the patient still usually performs

all activities and participates in all social interactions that typically occur during the

ON state.

3: Moderate Fluctuations impact on the performance of activities during OFF to the point that the

patient usually does not perform some activities or participate in some social

interactions that are performed during ON periods.

4: Severe Fluctuations impact on function to the point that, during OFF, the patient usually does

not perform most activities or participate in most social interactions that are performed

during ON periods.

1.0 J	How helpful	are the	"Instructions t	o examiner"?	(Circle choice)
-------	-------------	---------	-----------------	--------------	-----------------

Not helpful 1 2 3 4 5 6 Very Helpful

1.1 Circle areas of the "Instructions to examiner" that that were not helpful.

1.2 What would make the "Instructions to examiner" easier to understand or carry out?

Questions 2 and 3 relate to the <u>Instructions to Patients</u> and questions 4 and 5 relate to the response options.

2.0 Rater reads the <u>Instructions to Patient</u> to the patient. How easy or difficult is it for you as the rater to use the current wording of the question verbatim? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

3.0 Rater notes difficulties using the question below (Mark each item Y or N):

3.1	Rater experienced difficulty <u>reading</u> question. <u>Underline</u> problematic parts of the question. What parts of the question were difficult to <u>read</u> easily?
3.2	Rater had difficulty <u>explaining</u> the question. <u>Bracket</u> problematic parts of the question. What parts of the question were difficult to explain?
3.3	Other rater issue with instructions to patient (please specify)
was it for Very d	ding Instructions to Patient to the patient and hearing responses, how difficult you as the rater to select the appropriate response option? (Circle choice)  difficult 1 2 3 4 5 6 Very Easy  difficulty selecting a response option, explain why this selection was
	he patient after they have heard the UPDRS question: r difficult is this question for you to understand? (Circle choice)
7.0 What parts	of the question were difficult to understand? What was the difficulty? on form. Explain why they were difficult in the space below.

0 0 W/L 1 41	D-44	C	
8.0 Who answered this item? Both	Patient primarily	Caregiver primarily	

intake or other factors. Usobservations. You will as time (in which case you withey totally unpredictable Instructions to patient [and or when they do activities occur? In other words, do they only sometimes composed or Normal. No model: Slight. OFF to 2: Mild. OFF to 3: Moderate. OFF to	Determine se the infor k if the pati vill probe fu? Narrowing discaregiver so like eating to your low pe at a certain otor fluctuimes are primes are prime	the use mation ent can arther teng down in time artions or executations or edicoredi	ual proving proving the country of separation of separatio	edictal ided by it on the irate sl perce patien g. Ove ys con your  all of most some	bility of the property the property of the pro	of OFF patients ways or rom m will all e low of past we certain eriods ost all he time	F function whether due to dose, time of day, food hats and caregiver and supplement with your own a coming at a special time, mostly coming at a special time, mostly coming at a special time or allow you to find the correct answer.  or "OFF" periods happen at certain times during doweek, do you usually know when your low periods an time? Do they mostly come at a certain time? It is stotally unpredictable?"  all of the time (> 75%)  me (51-75%).  me (26-50%).	are day will
1.0 How helpful ar	e the "In	struct	tions	to ex	amii	ner"?	?? (Circle choice)	
Not helpful	1	2			5		Very Helpful	
1.1 <u>Circle</u> a	reas of th	e "In	struc	ctions	s to e	xami	niner" that that were not helpful.	
carry out?  Questions 2 and 3 r	elate to ti						examiner" easier to understand or  outs and questions 4 and 5 relate to the	
	Instructio						tient. How easy or difficult is it for he question verbatim? (Circle choice)	
Very difficu	lt 1	2	3	4	5	6	Very Easy	
3.0 Rater notes diff	ficulties <u>u</u>	ising 1	the q	uesti	ion b	elow	v (Mark each item Y or N):	
3.1Rat							ion. <u>Underline</u> problematic parts of the n were difficult to <u>read</u> easily?	
3.2		of the		-			the question. Bracket problematic arts of the question were difficult to	

3.3		Other r	ater issu	e with in	structions to patient (	please specify)		
40.46	T44	: 4- D-4	: 4 4 - 41.	4!		- l 1:6614		
					tand hearing response to response option?			
Was it is	ou us the i	<u> </u>	eee the up	proprie	response option.	on ele enoice)		
Very di	fficult	1 2 3	3 4	5 6	Very Easy			
5.0 If you had difficult?	difficulty <u>s</u>	electing a	response	option,	explain why this selec	tion was		
unitedit.								
<b>Questions for th</b>	e patient af	fter they h	ave heard	l the UP	DRS question:			
6.0 How easy or	difficult is	this questi	on for yo	u to unc	lerstand? (Circle choi	ce)		
Very diff	icult 1	2 3	4 5	6	Very Easy			
	7.0 What parts of the question were difficult to understand? What was the difficulty? <u>Circle</u> these on form. <u>Explain</u> why they were difficult in the space below.							
<u>en ere</u> these (	JII 101 III. <u>122</u>	<u>хріаін</u>	they we	ic ullific	art in the space below	•		
		<u>-</u>						
	-							
8.0 Who answer Both	ed this iten	1? Pati	ient prim	arily	Caregiver prim	arily		
<del>-</del>								

C. "OFF" DYST 4.6 PAINFUL O	FF-STATE I					_		
<u>nstructions to examiner</u> : For patients who have motor fluctuations, determine what proportion of the OFF pisodes usually includes painful dystonia? You have already determined the number of hours of "OFF" time								
(4.3). Of these hours	, determine how			-		nia and calculate the percentage. If there		
s no OFF time, mark 0.  In one of the questions I asked earlier, you said you generally have								
hours of low or "OFF" time when your Parkinson's disease is under poor control. During these low or OFF" periods, do you usually have painful cramps or spasms? Out of the total hrs of this low time, if								
						of the total hrs of this low time, if we many hours would this make?		
	o dystonia							
1: Slight. < :								
2: Mild. 26 3: Moderate 51	5-50% of time							
	-75% of time i							
1.0 How helpfu	l are the "Ins	struction	is to ex	amiı	1er"? (	(Circle choice)		
Not helpful	1	2 3	4	5	6	Very Helpful		
1.1 Circ	le areas of th	e "Instr	uctions	to e	xamin	er" that that were not helpful.		
1.2 Wha		e the "I	ıstruct	ions	to exa	miner" easier to understand or		
	l 3 relate to the options.	he <u>Instru</u>	ctions	to Pa	<u>itients</u>	and questions 4 and 5 relate to the		
					-	nt. How easy or difficult is it for question verbatim? (Circle choice)		
Very diff	ficult 1	2 3	4	5	6	Very Easy		
3.0 Rater notes difficulties <u>using</u> the question below (Mark each item Y or N):								
3.1Rater experienced difficulty <u>reading</u> question. <u>Underline</u> problematic parts of the question. What parts of the question were difficult to <u>read</u> easily?								
_								
3.2		f the qu				e question. Bracket problematic s of the question were difficult to		

3.3		Other	rator issue	a with in	structions to patient (please spec	ifv)
3.3		Other i	atti issut	WILL III	isti uctions to patient (picase spec	
					and hearing responses, how diffi	
was it for	you as the i	rater to <u>sel</u>	lect the ap	propria	te <u>response option</u> ? (Circle choice	e)
Very di	ifficult	1 2	3 4	5 6	Very Easy	
5.0 If you had	difficulty s	selecting a	response	option,	explain why this selection was	
difficult?	-			1 /	<u> </u>	
_						
		C4 41 1-	ave heard	l the IIP	DRS question:	
Questions for th	e patient a	iter they n	ave neare	i the OI	DIAS question.	
					<u> </u>	
6.0 How easy or	difficult is	this quest	ion for yo	u to unc	lerstand? (Circle choice)	
6.0 How easy or	difficult is	this quest	ion for yo	u to unc	<u> </u>	
6.0 How easy or  Very diff 7.0 What parts	difficult is ficult 1	this quest  2 3  ion were o	ion for yo 4 5	ou to und 6 o unders	lerstand? (Circle choice)	
6.0 How easy or  Very diff 7.0 What parts	difficult is ficult 1	this quest  2 3  ion were o	ion for yo 4 5	ou to und 6 o unders	derstand? (Circle choice)  Very Easy  tand? What was the difficulty?	
6.0 How easy or  Very diff 7.0 What parts	difficult is ficult 1	this quest  2 3  ion were o	ion for yo 4 5	ou to und 6 o unders	derstand? (Circle choice)  Very Easy  tand? What was the difficulty?	
6.0 How easy or  Very diff 7.0 What parts	difficult is ficult 1	this quest  2 3  ion were o	ion for yo 4 5	ou to und 6 o unders	derstand? (Circle choice)  Very Easy  tand? What was the difficulty?	

### Summary statement to patient: READ TO PATIENT

This completes my rating of your Parkinson's disease. I know the questions and tasks have taken several minutes, but I wanted to be complete and cover all possibilities. In doing so, I may have asked about problems you do not even have, and I may have mentioned problems that you may never develop at all. Not all patients develop all these problems, but because they can occur, it is important to ask all the questions to every patient. Thank you for your time and attention in completing this scale with me.

### RATER DEBRIEFING

- 1.0 What issue, if any, did you have with the Instructions on page 104 for Part 4?
- 2.0 What difficulties, if any, did you have with the calculations needed to select a response option?
- 3.0 Which, if any, of the instructions seemed to make the patient uncomfortable? Why?
- 4.0 Which instructions were the most difficult or awkward for you to give? Why?
- 5.0 Have you come to dislike any specific instructions in this UPDRS Part? Which ones? Why?

Appendix-More detailed rating scales for use with the UPDRS
Summary of the conclusions – Recommended and Suggested scales/topic
(Dr. Sampaio and group working on re-updating on an ongoing basis)

### Operative Definitions:

Recommended: Acceptable scale that has been studied clinimetrically and considered valid, reliable and sensitive; and it has been used in PD in reports other than just the group that originally described it.

Suggested: Scale meets at least part of the above criteria, but falls short of meeting all. .

TOPIC	Scales	Scales	Scales
10110	identified	RECOMMENDED	SUGGESTED
HRQ <sub>0</sub> L	Sickness Impact Profile (SIP), the Nottingham Health Profile (NHP) Short-Form Health Survey (SF-36] EQ-5D PDQ-39 Parkinson's disease summary index; PDSI PDQ-8 PDQL The simple comprehensive evaluation of quality of life. The Parkinson's disease symptom inventory (PDSI): the Functional Status Questionnaire Parkinson's Impact Scale (PIMS) Kuehleret al 2003 Welsh et al 2003 Spliethoff-Kamminga et al 2003	Generic instrument: SF-36, EQ-5D     Disease-specific instrument: PDQ-39     Index Instrument: EQ-5D	THE STATE OF THE S
Cognitive	Mini-Mental Parkinson	None	• The SCOPA-COG
Impairment	<ul> <li>The SCOPA-COG</li> <li>Brief assessment of executive control dysfunction</li> <li>Frontal assessment battery at bedside.</li> </ul>		Brief assessment of executive control dysfunction
Dementia	<ul> <li>MMSE</li> <li>ADAS-cog</li> <li>VADAS</li> <li>The Mattis' Dementia Ratings Scale.</li> <li>The Neuropsychiatric Inventory (NPI).</li> </ul>	None	ADAS-cog     The Mattis' Dementia Ratings Scale.
Insomnia (Quality nighttime sleep)	the Pittsburgh Sleep Quality Index (PSQI)     SCOPA-SLEEP nighttime sleep subscale     Inappropriate Sleep Composite Score     Sleep Disorders Questionnaire (SDQ)     National Sleep Foundation sleep survey     Parkinson's disease sleep scale	the Pittsburgh Sleep Quality Index (PSQI)	SCOPA-SLEEP nighttime sleep sub-scale     Parkinson's disease sleep scale
Daytime sleepiness	Epworth Sleepiness Scale (ESS)     SCOPA-SLEEP daytime sleepiness subscale     Parkinson's disease sleep scale     The Stanford sleepiness scale     The Karolinska sleepiness scale	Epworth Sleepiness Scale (ESS)	SCOPA-SLEEP daytime sleepiness sub-scale     Parkinson's disease sleep scale

	•		
Depression	Hamilton Depression scale     Beck Inventory (self-administered questionnaire)     Montgomery-Asberg Depression Rating Scale     Zung Depression scale     Hospital Anxiety and Depression scale	Hamilton Depression scale     Hospital Anxiety and Depression scale	Montgomery-Asberg     Depression Rating Scale
Psychosis	<ul> <li>Rush Hallucinatory inventory</li> <li>Structure Interview for hallucinations in PD</li> <li>Positive and Negative Syndrome Scale (PANSS)</li> <li>Brief psychiatric Rating scale</li> <li>Scale for the Assessment of negative symptoms (SANS).</li> <li>Scale for the Assessment of positive symptoms (SAPS).</li> <li>Clinical global impression (severity, improvement).</li> <li>Brief Psychiatric scale.</li> <li>Modified UPDRS item on thought disorder.</li> <li>Parkinson Psychosis rating scale (PPRS)</li> </ul>	None	• PPRS • BPRS
Non motor signs and symptoms	Global scale: -motor symptom assessment scale for Parkinson's disease	NONE	NONE
Dysphagia	Modified Rehabilitation Institute of Chicago Dysphagia Rating Scale,     Dysphagia Outcome and Severity Scale     Swallowing Ability Scale     Dysphagia Outcome and Severity Scale     Functional outcome swallowing scale	NONE	NONE
Fatigue	Multidimensional Fatigue Inventory,     Fatigue Severity Scale, 7-point scale to     evaluate fatigue	Fatigue Severity Scale, 7- point scale to evaluate fatigue	Multidimensional Fatigue Inventory     Fatigue Severity Scale, 7-point scale to evaluate fatigue ??
Pain intensity Pain "Quality"	VAS intensity of pain.     Numerical scale for intensity of pain     Eg: Mc Gill questionnaire	VAS intensity of pain. Numerical scale for intensity of pain  NONE	NONE
Dyskinesias	<ul> <li>AIMS</li> <li>Modified AIMS</li> <li>OBESO Dyskinesias rating scale</li> <li>RUSK Dyskinesias scale</li> <li>Dyskinesia rating scale</li> <li>Salpetriere Scale</li> <li>Lang and Fahn Scale</li> <li>Unified Dyskinesias Rating scale (UDRS) [ under development]</li> </ul>	Dyskinesia rating scale	

### **APPENDIX**

# **Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)** Questions 1.7-1.12

asleep throug 0: Normal: 1: Slight: 2: Mild:	Over the past week, have you had trouble going to sleep at night or staying gh the night? Consider how rested you felt after waking up in the morning.  No problems Problems are present but usually do not cause trouble getting a full night of sleep.  Problems usually cause some trouble getting a full night of sleep.  Problems cause a lot of trouble getting a full night of sleep, but I still usually sleep for more than half the night.  I usually do not sleep for most of the night.	SCORE —	
1.8 DAYTIME SLEEPINESS: Over the past week, have you had trouble staying awake			
during the da		<b>SCORE</b>	
0: Normal:	No daytime sleepiness.		
1: Slight:	Daytime sleepiness occurs but I can resist and I stay awake.		
2: Mild:	Sometimes I fall asleep when alone and relaxing. For example, while reading or watching TV.		
3: Moderate:	I sometimes fall asleep when I should not. For example, while eating or talking with other people.		
4: Severe:	I often fall asleep when I should not. For example, while eating or talking with other people.		
	O OTHER SENSATIONS: Over the past week, have you had uncomfortable	SCORE	
feelings in your body like pain, aches and cramps?			
0: Normal:	No uncomfortable feelings.		
1: Slight:	I have these feelings. However, I can do things and be with other people without difficulty.		
2: Mild:	These feelings cause a few problems when I do things or am with other people.		
3: Moderate:	These feelings cause a lot of problems, but they do not stop me from doing things or being with other people.		
4: Severe:	These feelings stop me from doing things or being with other people.		
1.10 URINARY PROBLEMS: Over the past week, have you had trouble with urine control? For example, an urgent need to urinate, a need to urinate too often, or urine accidents?			
ror example,	, an urgent need to urmate, a need to urmate too often, or urine accidents?	SCORE	

	IPATION PROBLEMS: Over the past week have you had constipation cause you difficulty moving your bowels?	SCORE
0: Normal:	No constipation.	SCORE
1: Slight:	I have been constipated. I use extra effort to move my bowels. However, this problem does not disturb my activities or my being comfortable.	
2: Mild:	Constipation causes me to have a few troubles doing things or being comfortable.	
3: Moderate:	Constipation causes me to have a lot of trouble doing things or being comfortable. However, it does not stop me from doing anything.	
4: Severe:	I usually need physical help from someone else to empty my bowels.	
	HEADEDNESS ON STANDING: Over the past week, have you usually felt faint, y when you stand up after sitting or lying down?	SCORE
0: Normal:	No dizzy or foggy feelings.	
1: Slight:	Dizzy or foggy feelings occur. However, they do not cause me troubles doing	
	things or being with people.	
2: Mild:	Dizzy or foggy feelings cause me to hold on to something, but I do not need to sit or lie back down.	
3: Moderate:	Dizzy or foggy feelings cause me to sit or lie down to avoid fainting or falling.	
4: Severe:	Dizzy and foggy feelings cause me to fall or faint.	
1.14 TIREDNESS (FATIGUE): Over the past week, have you usually felt tiredness or exhaustion (fatigue)? This feeling is <u>not</u> part of being sleepy or sad.		
0: Normal:	No tiredness	
1: Slight:	Tiredness occurs. However it does not cause me troubles doing things or being with people.	
2: Mild:	Tiredness causes me a few troubles doing things or being with people.	
	Tiredness causes me a lot of troubles doing things or being with people.	
5. 1.15de1 ate	However, it does not stop me from doing anything.	
4: Severe:	Tiredness stops me from doing things or being with people.	

## Part II: Motor Aspects of Experiences of Daily Living (M-EDL)

2.1 SPEECH: Over the past week, have you had problems with your speech?		
0: Normal:	Not at all (no problems)	
1: Slight:	My speech is soft, slurred or uneven, but it does not cause others to ask me to repeat myself.	
2: Mild:	My speech causes people to ask me to occasionally repeat myself, but less than daily.	
3: Moderate	: My speech is unclear enough that others ask me to repeat myself every day even though most of my speech is understood.	
4: Severe:	Most or all of my speech cannot be understood.	
2.2. SALIVA & DROOLING: Over the past week, have you usually had too much saliva during the day or night?		SCORE
0: Normal:	Not at all (no problems)	
1: Slight:	I have too much saliva, but do not drool during the day or at night.	
2: Mild:	I have some nighttime drooling, but none during the day.	
3: Moderate	: I have some drooling during the day, but I usually do not need tissues or a handkerchief.	
4: Severe:	I have so much drooling that I regularly need to use tissues or a handkerchief to protect my clothes.	
2.3. CHEWING AND SWALLOWING FOOD: Over the past week, have you usually had problems eating a meal without changing the way it needs to be fixed? For example, do you need meals to be made soft, chopped or blended to avoid choking?		
0: Normal:	Not at all (no problems and no changes have been made in the way my food is prepared because of such concerns).	
1: Slight:	I am aware of slowness in my chewing or increased effort at swallowing, but I do not choke or need to have my food specially prepared to avoid such problems.	
2: Mild:	I need to have my food prepared differently because of chewing or swallowing problems. In addition, I choke occasionally but not every day.	
3: Moderate.	I choke on food at least once daily.	
4: Severe:	Because of chewing and swallowing problems, I need a feeding tube.	

2.4. EATING TASKS: Over the past week, have you usually had troubles handling your food and using eating utensils? For example, do you have trouble using forks, knifes, **SCORE** spoons, chopsticks, or fingers to eat? 0: Normal: Not at all (No problems) 1: Slight: I am slow or clumsy, but I do not need any help handling my food and have not had food spills while eating. 2: Mild: I am slow or clumsy with my eating and have occasional food spills. I may need help with a few tasks such as cutting meat. 3: Moderate: I need help with many eating tasks but can manage some alone. I need help for most or all eating tasks. 4: Severe: 2.5. DRESSING: Over the past week, have you usually had problems dressing? For example, do you have trouble buttoning, using zippers, putting on or taking off your **SCORE** clothes? 0: Normal: Not at all (no problems) I am slow or clumsy but I do not need help. 1: Slight: I am slow or clumsy and need help for a few dressing tasks. 2: Mild: 3: Moderate: I need help for many dressing tasks. I need help for most or all dressing tasks.. 4: Severe: 2.6. HYGIENE: Over the past week, have you usually had problems with personal hygiene? **SCORE** For example, do you have trouble with washing, bathing, brushing teeth, or combing your hair? 0: Normal: Not at all (no problems) I am slow or clumsy but I do not need any help. 1: Slight: 2. Mild. I need someone else to help me with a few tasks. 3: Moderate: I need help for many tasks. 4: Severe: I need help for most or all of my hygiene needs. 2.7. HANDWRITING: Over the past week, have people usually had trouble reading your handwriting? **SCORE** 0: Normal: Not at all (no problems) 1: Slight: My writing is slow, clumsy or uneven, but all words are clear. 2: Mild: Some words are unclear and difficult to read, but everything can still be understood. 3: Moderate: Many words cannot be understood at all. Most or all words cannot be read 4. Severe:

# 2.8. Doing hobbies and other activities: Over the past week, have you usually had trouble doing your hobbies or other things that you like to do?

**SCORE** 

**SCORE** 

- 0: Normal: Not at all (no problems)
- 1: Slight: I am a bit slow or clumsy but do these activities easily.
- 2: Mild: I have some difficulty doing these activities.
- 3: Moderate: I make frequent mistakes or have major problems doing these activities, but still

do most.

4: Severe: I am unable to do most or all of these activities.

# 2.9. TURNING IN BED: Over the past week, do you usually have trouble turning over in bed?

0: Normal: Not at all (no problems).

1: Slight: I have a bit of trouble turning, but I do not need any help.

2: Mild I have a lot of trouble turning and need occasional help from someone else.

3: Moderate: To turn over I often need help from someone else.

4: Severe: I am unable to turn over without help from someone else.

### 2.10. TREMOR: Over the past week, have you usually had shaking or tremor?

**SCORE** 

- 0: Normal: Not at all. I have no tremor.
- 1: Slight: Tremor occurs but does not cause problems with any activities.
- 2: Mild: Tremor causes problems with only a few activities.
- 3: Moderate: Tremor causes problems with many of my daily activities.
- 4: Severe: Tremor causes problems with most or all activities.

# 2.11. GETTING OUT OF BED, A CAR, OR A DEEP CHAIR: Over the past week, have you usually had trouble getting out of bed, a car seat, or a deep chair?

**SCORE** 

- 0: Normal: Not at all (no problems)
- 1: Slight: I am slow or awkward, but I usually can do it on my first try.
- 2: Mild: I need more than one try to get up or need occasional help.
- 3: Moderate: I frequently need help to get up, but most times can do it on my own.
- 4: Severe: I need help at most or all of the time.

### 2.12. WALKING AND BALANCE: Over the past week, have you usually had problems with balance and walking.

0: Normal: Not at all (no problems).

1: Slight: I am slightly slow or may drag a leg. I have no balance problems. I never use a

walking aid.

I occasionally use a walking aid, but I do not need any help from another person. 2: Mild:

3: Moderate: I usually use a walking aid (cane, walker) to walk safely without falling.

However, I do not usually need the support of another person.

4: Severe: I usually use the support of another person to walk safely without falling.

### 2.13. Freezing - Over the past week, on your usual day when walking, do you suddenly stop or freeze as if you feet are stuck to the floor.

0: Normal: Not at all (no problems).

1: Slight: I briefly freeze up to three times daily, but I can easily start walking again.

2: Mild: I freeze more than three times per day but I don't have trouble starting to walk

again and I don't need help or a walking aid (i.e. cane, walker) because of

freezing.

3: Moderate: When I freeze I have a lot of trouble starting to walk again and, because of

freezing, I may fall sometimes. I sometimes need to use a walking aid or need

help to walk.

4: Severe: Because of freezing. I need to use a walking aid or need help most or all the

time

This completes the questionnaire. We may have asked about problems you do not even have, and may have mentioned problems that you may never develop at all. Not all patients develop all these problems, but because they can occur, it is important to ask all the questions to every patient. Thank you for your time and attention in completing this questionnaire.

**SCORE** 

**SCORE**