SUPPLEMENTARY MATERIALS

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

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Name of Interviewer

__ __/__ __/__ __

Date

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 in-depth 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.

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

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 '*item*' as a result of your PD? By '*item*', I mean "*issues of focus*".

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 *item* 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.}*

Is this item normal for you? → "Yes" → Mark (0) Normal

↓

"No, I have problems"
Read mild (2) as a reference and then compare with slight (1)

↓ "Yes, slight is closest" → Confirm and mark (1) Slight

"No, I have more difficulty than slight"
Read moderate (3) to see if this answer fits better

↓ "No, moderate is too severe" → Confirm and mark (2) Mild

"Yes, moderate is closer"
Read severe (4) to see if this answer fits better

↓ "No, severe is too severe" → Confirm and mark (3) Moderate

"Yes, severe is closest": Confirm and mark (4) severe

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 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*}

Primary source of information: __Patient __Caregiver __Patient 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 only
____Patient has both ON and OFF Responses: complete Part I in ON and OFF columns
____Patient 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: Slight. Impairment only recognized by you with no concrete interference with your ability to carry out normal activities and interactions.		
2: Mild. 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 daily activities and interactions.		
4: Severe. Cognitive dysfunction precludes your ability to carry out daily activities and interactions.		
***see Appendix for more detailed rating scales on this item**		

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) _____**

_____

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?

   - "impairments or deficits"
     Understood correctly? (Y/N) _____
     What words would be easier to understand to capture the meaning? **(Record suggestions)**

   - "preclude"
     Understood correctly? (Y/N) _____
     What words would be easier to understand to capture the meaning? **(Record suggestions)**

<u>Questions for the patient after they have decided on a rating:</u>

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**
0: Normal. No misinterpretations or hallucinations	___	___
1: 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.		
2: Mild. Formed hallucinations, but you recognize them as unreal and they have no or minimal impact on daily activities or interactions.		
3: Moderate. Misinterpretations or hallucinations of any type with loss of insight, affecting activities or interactions. No delusions, no paranoia.		
4: Severe. Misinterpretations or hallucinations with psychotic thinking, delusions or paranoia.		

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) _____

_____

_____

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?

- "hallucinations"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

- "misinterpretations"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

- "psychotic thinking"
  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

1.3 DEPRESSED MOOD * - On the average during the past week, have you experienced depressed mood as a result of your PD? By "depressed mood", I mean low mood, sadness or loss of enjoyment, and if so, I am interested in how these feelings affect normal activities 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 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) _____**

_____

_____

_____

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)**

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

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 difficult to rate?

Suggested solution?

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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: Slight. Anxious feelings occur, but there is no interference with your ability to carry out daily activities and interactions. No panic attacks.
2: Mild. Anxious feelings occur and cause minimal interference with your ability to carry out daily activities and interactions. No panic attacks.
3: Moderate. Anxious feelings (that may include panic attacks) considerably interfere with, but do not preclude, your ability to carry out daily activities and interactions.
4: Severe. 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 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) _____

_____

_____

_____

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

4. What do you understand by the following words?

- "episodes"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

- "panic attacks"
  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

1.5 APATHY - On the average during the past week, have you experienced apathy as a result of your PD? By "apathy", I mean loss or lack of assertiveness, motivation, and initiative within the context of daily activities.	**ON**	**OFF**
0: Normal. No apathy.	___	___
1: Slight. Reduced assertiveness, motivation or initiative, but no interference with daily activities and interactions.		
2: Mild. Reduced assertiveness, motivation or initiative that interferes with isolated activities and interactions.		
3: Moderate. Reduced assertiveness, motivation or initiative that interferes with most activities and interactions, but does not preclude any.		
4: Severe. Withdrawn, loss of assertiveness, motivation or initiative that precludes daily activities and interactions.		

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) _____

_____

_____

_____

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?

- "assertiveness"
  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

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: Slight. Minor interference with sleep with occasional awakenings but you easily fall back asleep.
2: Mild. Interference with sleep causes awakening 1-3 times per night with difficulty returning to sleep.
3: Moderate. Frequent awakenings and sleep interruptions. You are awakening more than 3 times per night with difficulty returning to sleep.
4: Severe. 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 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:

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)**

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

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 difficult to rate?

Suggested solution?

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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: Mild. You occasionally fall asleep when alone in a relaxing situation such as reading or watching television.
3: Moderate. 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 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?

- "socially inappropriate settings"
  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

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: Severe. Aching, cramping or discomfort interferes with daily activities to the point that it is a major contributor to overall disability.

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

___ ___

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) _____

_____

_____

_____

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)**

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

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 difficult to rate?

Suggested solution?

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

1.9 URINARY PROBLEMS - On the average during the past week, have you experienced urinary problems as a result of your PD? By "urinary problems," I mean bothersome urinary frequency, urgency or incontinence.	**ON**	**OFF**
0: Normal. No urinary problems	___	___
1: Slight. Occasional urinary frequency or urgency but no major inconveniences to normal activities.		
2: Mild. Urinary frequency or urgency sufficient to cause inconvenience and requiring some adaptations in daily function, although no incontinence.		
3: Moderate. Urinary frequency, urgency with occasional incontinence; significantly interferes with daily activities such as social functions.		
4: Severe. Frequent urinary incontinence, may need to use catheter.		

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) _____

_____

_____

_____

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

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

2. What do you understand by the following words?

- "urinary urgency"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

- "urinary incontinence"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

- "catheter"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

<u>Questions for the patient after they have decided on a rating:</u>

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

1.10 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: Slight. Constipation present, but without impact on daily activities.
2: Mild. Constipation has mild impact on daily activities.
3: Moderate. Constipation causes significant discomfort or inconvenience that markedly impacts on daily activities
4: Severe. Constipation dominates your concerns or you need physical disimpaction for handling constipation.

___ ___

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) _____

_____

_____

_____

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?

- "physical disimpaction"
  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

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: Slight. Lightheadedness occurs with changes in posture but has no impact on performance of daily activities.
2: Mild. 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: Moderate. 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: Severe. Lightheadedness occurs with changes in posture and has been associated with at least one episode of loss of consciousness over the past week.

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

___ ___

Rater Experience Posing UPDRS Question:

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:

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)**

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

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 difficult to rate?

Suggested solution?

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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.

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?

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

RATER'S DEBRIEFING

3. How easy or difficult is it for you as the rater 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 these options difficult for you as the rater to explain?

4. Which, if any, of the questions seemed to make the patient uncomfortable? 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? Which ones? Why?

7. Please note your general observations of the interaction between proxy/patient. (Mark Y/N)

- **_ Interrupting**
- **_ 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 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.
    - 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.
    - 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 __Caregiver __Patient and Caregiver in Equal Proportion

Follow ON/OFF designations utilized in Part I:
____Patient not on symptomatic medication: complete Part I in OFF column only
____Patient has both ON and OFF Responses: complete Part I in ON and OFF columns
____Patient on symptomatic medication has only one stable response: complete Part I in ON column

	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:

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:

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)

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

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 difficult to rate?

Suggested solution?

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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: Moderate. 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.

___ ___

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) _____

_____

_____

_____

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)

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

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 difficult to rate?

Suggested solution?

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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: Slight. 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: Mild. 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: Moderate. Daily choking **or** food needs to be cut or prepared in a special manner because of difficulty chewing or swallowing.		
4: Severe. Unable to obtain adequate nutrition without an alternative route for nutritional support (i.e. nasogastric tube or gastrostomy).		

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) _____

_____

_____

_____

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: Slight. Slow or clumsy eating, but no adaptive changes or help needed to eat. No spills or accidents related to eating.
2: Mild. 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.

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) _____

_____

_____

_____

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)**

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

2. 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?

3. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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: Slight. Dresses slowly without adaptations **or** dresses at a normal speed only because adaptive measures are utilized. No assistance needed.
2: Mild. 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.

___ ___

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) _____

_____

_____

_____

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)

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

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 difficult to rate?

Suggested solution?

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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: Slight. 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.		

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) _____

_____

_____

_____

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. Do you understand by the following words?

- "non-dominant hand"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

- "motor task"
  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:

7. 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?

8. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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: Slight. Slightly slow or small handwriting, but all words are clear.
2: Mild. 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.

___ ___

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) _____

_____

_____

_____

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?

- "decipher"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

- "legibility"
  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

2.8. 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: Slight. 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.

___ ___

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) _____

_____

_____

_____

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?

- "performance impaired"
  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

2.9. 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: Slight. 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 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) _____

_____

_____

_____

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?

- "emotional and motor consequences of tremor"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

<u>Questions for the patient after they have decided on a rating:</u>

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

2.10. 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: Slight. 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.

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) _____

_____

_____

_____

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)**

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

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 difficult to rate?

Suggested solution?

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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.

___ ___

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) _____

_____

_____

_____

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)**

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

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 difficult to rate?

Suggested solution?

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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: Slight. Some slowing, may drag a leg or catch toe, but no balance problems.
2: Mild. Occasional unsteadiness or shuffling; may have perception of poor balance, but no falls and no assistance or walking aids needed.
3: Moderate. 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.

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) _____

_____

_____

_____

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)**

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

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 difficult to rate?

Suggested solution?

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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: Slight. Freezing occurs when starting to walk, turning or pivoting, but does not compromise your independent walking.
2: Mild. Freezing occurs in the midst of walking, but does not induce you to use assistance from a walking aid or another person.
3: Moderate. 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: Severe. Freezing that causes daily falls or near-falls **or** freezing precludes you from walking even with assistance.

___ ___

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) _____

_____

_____

_____

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?

- "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?

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

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?

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

RATER'S DEBRIEFING

3. How easy or difficult is it for you as the rater 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 uncomfortable? 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? Which ones? Why?

7. Please note your general observations of the interaction between proxy/patient. (Mark Y/N)

- **_ Interrupting**
- **_ 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.

2. 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:

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

<u>Part III: Motor Examination</u>

ON and OFF designations (Check 1):

OFF

____No symptomatic treatment (OFF)

___ Symptomatic treatment with motor fluctuations and is currently OFF.

ON

____On symptomatic treatment and has no motor fluctuations

____On symptomatic treatment with motor fluctuations but is currently ON.

Minutes since last levodopa dose _____ Not on Levodopa _____

3.1. SPEECH

Instructions to examiner: 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.

Instructions to patient: 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: Mild. 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 as the rater 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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient below (Mark each item Y or N):

_ Rater experienced difficulty reading instructions to patients
_ Rater asked to repeat all or part of instruction to patients

_ Rater had difficulty explaining instruction to patient
_ Other rater issue (please specify) _____

_____

_____

4. What would make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

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

Instructions to examiner: 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.

Instructions to patient: 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: Mild. 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: Moderate. 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.

_____

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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient below (Mark each item Y or N):

_ Rater experienced difficulty reading instructions to patients
_ Rater asked to repeat all or part of instruction to patients

_ Rater had difficulty explaining instruction to patient
_ Other rater issue (please specify) _____

_____

_____

4. What would make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

Suggested solution?

<u>Questions for the patient regarding the instructions:</u>

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)

3.3. RIGIDITY

Instructions to examiner: 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.

Instructions to patient: 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: Moderate. Moderate rigidity detected without the activation maneuver, but full range of motion is achieved.
4: Severe. Marked rigidity detected without the activation maneuver and full range of motion is achieved with much difficulty or not at all.

Neck

____ ____
RUE LUE

____ ____
RLE LLE

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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier for the rater to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

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)

3.4 FINGER TAPPING

Instructions to examiner: 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.

Instructions to Patient: 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: Slight. 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: Mild. 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: Moderate. 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: Severe. Cannot or can only barely perform the task because of slowing, interruptions or decrements.

___ ___
R L

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 "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?

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 difficulties giving the instructions to patient 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 make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

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)**

8. **What do you understand by the following words?**

- "flex"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

- "amplitude"
  Understood correctly? (Y/N) _____
  What words would be easier to understand to capture the meaning? **(Record suggestions)**

3.5 HAND MOVEMENTS

Instructions to examiner: 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.

Instructions patient: 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.

		R	L
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) there is slight slowing; c) the amplitude slightly decrements with or after the 5th open-and-close sequence.		
2:	Mild. 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:	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 open-and-close sequence.		
4:	Severe. 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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier for the rater to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

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)

3.6 PRONATION-SUPINATION MOVEMENTS OF HANDS

Instructions to examiner: 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.

Instructions to patient: 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: Slight. 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.
2: Mild. 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: 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 can only barely perform the task because of slowing, interruptions or decrements.

R	L
___	___

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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

Suggested solution?

<u>Questions for the patient regarding the instructions:</u>

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)

3.7 TOE TAPPING

Instructions to examiner: 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.

Instructions to patient: 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.

	R	L
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 tapping movement; b) there is slight slowing; c) there is slight reduction in amplitude.		
2: Mild. Any of the following: a) 3 to 5 interruptions during the tapping movements; b) mild slowing; c) mild decrementing of amplitude.		
3: Moderate. 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: Severe. 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 "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?

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 difficulties giving the instructions to patient 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 make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

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)

3.8 LEG AGILITY

Instructions to examiner: 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.

Instructions to patient: 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 cm (6 ½ 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: Slight. 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: Mild. Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowness; c) mild decrementing of amplitude.
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 in speed; c) pronounced decrementing of amplitude.
4: Severe. Cannot or can only barely perform the task because of slowing, interruptions or decrements.

R L

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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

Suggested solution?

<u>Questions for the patient regarding the instructions:</u>

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)

3.9 ARISING FROM CHAIR

Instructions to examiner: 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

Instructions to patient: 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: Slight. 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: Moderate. 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.

_____

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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

Suggested solution?

<u>Questions for the patient regarding the instructions:</u>

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)

3.10 GAIT

Instructions to examiner. 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

Instructions to patient: 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.

_____

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 "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?

2. **Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

Suggested solution?

<u>Questions for the patient regarding the instructions:</u>

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)

3.11 FREEZING OF GAIT

Instructions to examiner. 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.

Instructions to patient: 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: Moderate. More than three short (1 to 2 seconds) episodes of freezing; or two episodes lasting 3 to 5 seconds each.
4: Severe. At least one episode of prolonged freezing (>5 seconds); or more than three short episodes (1 to 2 seconds).

_____

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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier <u>for the rater</u> to articulate the instructions to the patient?

5.
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

Suggested solution?

<u>Questions for the patient regarding the instructions:</u>

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)

3.12 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

Instructions to patient: 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: Slight. Three or more steps, but subject recovers unaided.
2: Mild. Absence of postural response; would fall if not caught by examiner.
3: Moderate. Very unstable, tends to lose balance spontaneously or with just a gentle pull on the shoulders.
4: Severe. Unable to stand without assistance.

_____

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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier for the rater to articulate the instructions to the patient?**

5. 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

What made it difficult to rate?

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)

3.13 POSTURE

Instructions to examiner: 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: Mild. Definite flexion, scoliosis or leaning to one side, but patient can correct posture to normal posture when asked to do so.
3: Moderate. 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.

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 "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?

2. 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

What made it difficult to rate?

Suggested solution?

3.14 GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)

Instructions to examiner: 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: Slight. 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.

_____

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 "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?

2. 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

What made it difficult to rate?

Suggested solution?

3.15 POSTURAL TREMOR OF THE HANDS

Instructions to examiner: 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.

Instructions to patient: 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**.**

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.

R	L

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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

Suggested solution?

<u>Questions for the patient regarding the instructions:</u>

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)

3.16 KINETIC TREMOR OF THE HANDS

Instructions to examiner: 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.

Instructions to patient: 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 back-and-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.

___ ___
R L

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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

Suggested solution?

<u>Questions for the patient regarding the instructions:</u>

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

Instructions to examiner: 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.

Instructions to patient: 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.

Extremity ratings

0: Normal. No tremor.
1: Slight. < 1 cm in maximal amplitude.
2: Mild. ≥ 1 cm but <3 cm in maximal amplitude.
3: Moderate. 3-10 cm in maximal amplitude.
4: Severe. >10 cm in maximal amplitude.

Lip/Jaw ratings

0: Normal. No tremor
1: Slight. <1 cm in maximal amplitude.
2: Mild. ≥1 cm but <2 cm in maximal amplitude
3: Moderate. ≥2 cm but <3 cm in maximal amplitude.
4: Severe. ≥3 cm in maximal amplitude.

Lip/Jaw

___ ___
RUE LUE

___ ___
RLE LLE

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 "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?

2. Read instructions to the patient. How easy or difficult is it for you as the rater 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 difficulties giving the instructions to patient 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 make it easier <u>for the rater</u> to articulate the instructions to the patient?

5. 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

What made it difficult to rate?

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)

3.18 CONSTANCY OF REST TREMOR

Instructions to examiner: 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):

1. How easy or difficult is it for you as the rater 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?

2. 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

What made it difficult to rate?

Suggested solution?

Were dyskinesias (chorea or dystonia) present during examination? _____YES _____NO

If yes, did these movements interfere with your ratings? _____YES _____NO

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? ____ (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**

6. Please note your general observation of the interaction between proxy/patient. (Mark Y/N)

_ Interrupting

_ Contracdicting

_ Sharing

_ Confirming

_ Other/Please specify _____

7. 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 "Part IV: Motor Complications" that were difficult for you as the 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.

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 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:

3. 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 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?

- "dyskinesia"
  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**

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: Slight. Dyskinesias impact on the performance of a few activities, but you perform all activities during dyskinetic periods.
2: Mild. Dyskinesias impact on the performance of many activities, but you perform all activities during dyskinetic periods.
3: Moderate. Dyskinesias impact on the performance of activities to the point that you do not perform some activities during dyskinetic episodes.
4: Severe. 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):

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:

3. 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 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 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?

6. **Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both**

B . MOTOR FLUCTUATIONS

4.3 TIME SPENT IN THE OFF STATE - In the past week including today, on average, what proportion of the waking day were you in the OFF-state?

0: Normal. No OFF time
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 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:

3. 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 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 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?

6. **Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both**

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: Slight. Fluctuations impact on the performance of a few activities, but, during OFF, you perform all activities performed during the ON state.
2: Mild. Fluctuations impact on the performance of many activities, but, during OFF, you still perform all activities performed during the ON state.
3: Moderate. 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: Severe. 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 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:

3. 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 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?

- "fluctuations"
  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

4.5 COMPLEXITY OF MOTOR FLUCTUATIONS - What is the predictability of OFF function according 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 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:

3. 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 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?

- "predictability of OFF function"
  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**

4.6 PAINFUL OFF-STATE DYSTONIA {For patients with fluctuations and OFF time} - What proportion of the OFF episodes include painful dystonia?

0: Normal: No dystonia
1: Slight. 1-25% of OFF episodes
2: Mild. 26-50% of OFF episodes
3: Moderate 51-75% of OFF episodes
4: Severe 76-100% of OFF episodes

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) _____

_____

_____

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

3. 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 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?

- "dystonia"
  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**

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? ___ (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?

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

RATER'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 <u>as the rater</u> 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?**

13.

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 identified	Scales RECOMMENDED	Scales SUGGESTED
HRQoL	• **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** • **SCOPA-PS**	• **Generic instrument: SF-36, EQ-5D** • **Disease-specific instrument: PDQ-39** • **Index Instrument: EQ-5D**	**----**
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	• **MMSE** • **ADAS-cog** • **VADAS** • **The Mattis' Dementia Ratings Scale.** • **The Neuropsychiatric Inventory (NPI).**	**None**	• **ADAS-cog** • **The Mattis' Dementia Ratings Scale.**
Insomnia (Quality nighttime sleep)	• **the Pittsburgh Sleep Quality Index (PSQI)** • **SCOPA-SLEEP nighttime sleep sub-scale** • **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 sub-scale** • **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	• **Rush Hallucinatory inventory** • **Structure Interview for hallucinations in PD** • **Positive and Negative Syndrome Scale (PANSS)** • **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"**	• **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	• **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 in-depth 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,

Consultant: Nancy LaPelle

Contact person:

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September 19, 2005

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.

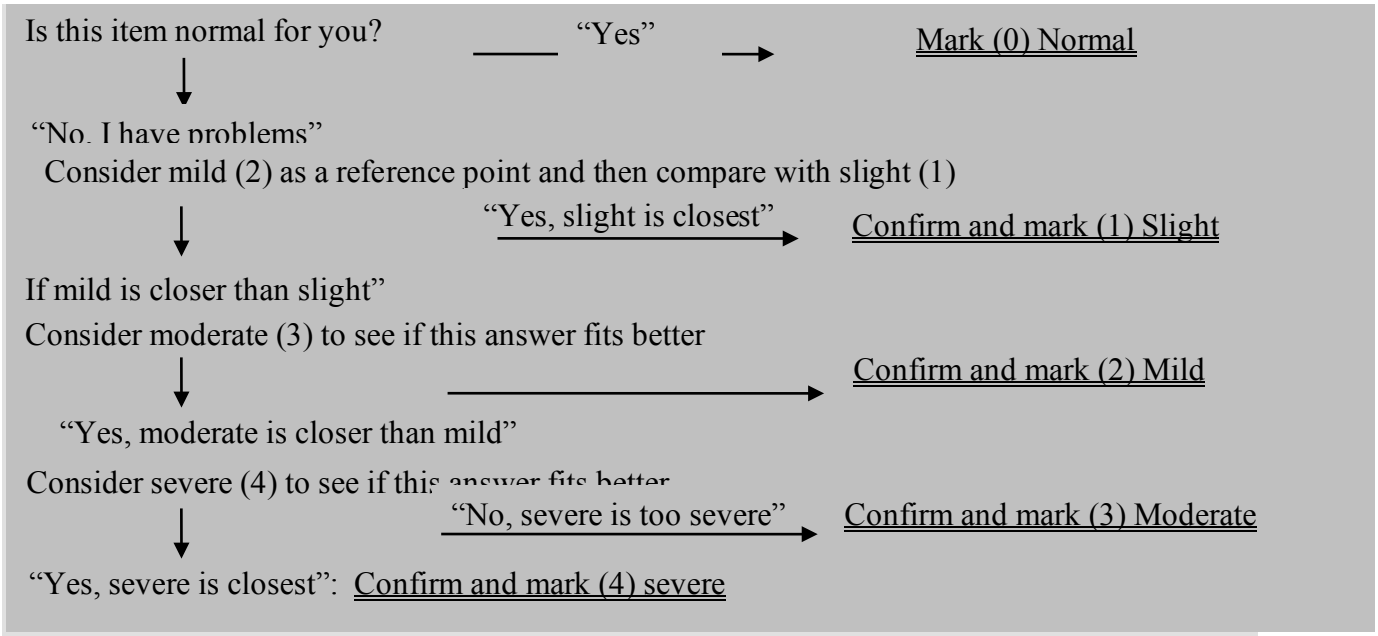
EXAMPLE OF NAVIGATING THROUGH THE RESPONSE OPTIONS FOR PART 1A

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.

Part I: Non-Motor Aspects of Experiences of Daily Living (nM-EDL)
Part 1A: Complex behaviors: [completed by rater]

Primary source of information:
__Patient __Caregiver __Patient 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.]

SCORE ___

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:

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?

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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

_____

3.2 _____ Rater had difficulty explaining the question. Bracket problematic parts of the question. What parts of the question were difficult to explain?

_____

_____

3.3 _____ Other rater issue (please specify)

_____

_____

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.0 If you had difficulty selecting a response option, explain why this selection was difficult?

_____

_____

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

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

Very difficult 1 2 3 4 5 6 Very Easy

7.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

_____

_____

_____

_____

8.0 Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

1.2 HALLUCINATIONS AND PSYCHOSIS:

Instructions to examiner: 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.

Instructions to patients [and caregiver]: 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].

SCORE

___

0: Normal.

1: Slight: Illusions or non-formed hallucinations, but patient recognizes them without loss of insight.

2: Mild: Formed hallucinations independent of environmental stimuli. No loss of insight.

3: Moderate: Formed hallucinations with loss of insight.

4: Severe: Patient has delusions or paranoia.

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

Rater Observations Posing UPDRS Questions and Response Options:

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?

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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

_____

3.2 _____ Rater had difficulty explaining the question. Bracket problematic parts of the question. What parts of the question were difficult to explain?

_____
_____

3.3 _____ Other rater issue (please specify)

_____

_____
_____

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

If you had difficulty coding response options. Underline problematic parts of the response options. Why were these parts of the response options difficult to code?

_____
_____

6. Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

1.3 DEPRESSED MOOD:

Instructions to examiner: Consider low mood, sadness, hopelessness, and feelings of emptiness or loss of enjoyment. Determine their presence and duration over the past week and rate their interference with the patient's ability to carry out daily routines and engage in social interactions.

Instruction to the patient (and caregiver): Over the past week have you felt low, sad, hopeless and unable to enjoy things? If yes, was this feeling for longer than one day at a time? Did it make it difficult for you carry out your usual activities or to be with people? [If yes, examiner asks patient or caregiver to elaborate and probes for information].

SCORE

0: Normal: No depressed mood. ___

1: 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: Depressed mood that is sustained over days, but without interference with 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**

Rater Observations Posing UPDRS Questions and Response Options:

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?

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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

3.2 _____ Rater had difficulty explaining the question. Bracket problematic parts of the question. What parts of the question were difficult to explain?

_____

_____

3.3 _____ Other rater issue (please specify)

_____

_____

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.0 If you had difficulty coding response options. Underline problematic parts of the response options. Why were these parts of the response options difficult to code?

_____

_____

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

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

Very difficult 1 2 3 4 5 6 Very Easy

7.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

_____

_____

_____

_____

8.0 Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

1.4 ANXIOUS MOOD:

Instructions to examiner: 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 social interactions.

Instructions to patients [and caregiver]: Over the past week have you felt nervous, worried or tense? If yes, was this feeling for longer than one day at a time? Did it make it difficult for you to follow your usual activities or to be with other people? [If yes, examiner asks patient or caregiver to elaborate and probes for information].

SCORE

___

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 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 social interactions.

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

Rater Observations Posing UPDRS Questions and Response Options:

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?

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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

_____

3.2 _____ Rater had difficulty explaining the question. Bracket problematic parts of the question. What parts of the question were difficult to explain?

_____

3.3 _____ Other rater issue (please specify)

_____

_____

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.0 If you had difficulty coding response options. Underline problematic parts of the response options. Why were these parts of the response options difficult to code?

_____

_____

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

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

Very difficult 1 2 3 4 5 6 Very Easy

7.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

_____

_____

8.0 Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

1.5 APATHY:

Instructions to examiner: 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.

Instructions to patients (and caregiver): 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 people? [If yes, examiner asks patient or caregiver to elaborate and probes for information].

SCORE

___

0: Normal: No apathy.

1: Slight: Reduced assertiveness, motivation and initiative appreciated by patient and/or caregiver, but no interference with daily activities and social interactions.

2: Mild: Reduced assertiveness, motivation and initiative that interferes with isolated activities and social interactions.

3: Moderate: Reduced assertiveness, initiative or motivation that interferes with most activities and social interactions.

4: Severe: Passive and withdrawn, complete loss of initiative.

Rater Observations Posing UPDRS Questions and Response Options:

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?

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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

_____

3.2 _____ Rater had difficulty explaining the question. Bracket problematic parts of the question. What parts of the question were difficult to explain?

_____

3.3 _____ Other rater issue (please specify)

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.0 If you had difficulty coding response options. Underline problematic parts of the response options. Why were these parts of the response options difficult to code?

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

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

Very difficult 1 2 3 4 5 6 Very Easy

7.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

8.0 Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

1.6 FEATURES OF DOPAMINE DYSREGULATION SYNDROME

Instructions to examiner: Consider involvement in a variety of activities including atypical or excessive gambling (e.g. casinos or lottery tickets), atypical or excessive sexual drive or interests (e.g., unusual interest in pornography, masturbation, sexual demands on partner), other repetitive activities (e.g. hobbies, dismantling objects, sorting or organizing), or taking extra non-prescribed dopaminergic antiparkinson medication for non-physical reasons (i.e., addictive behavior). Rate the impact of such abnormal activities/behaviors on the patient's personal life and on his family and social relations (including need to borrow money or other financial difficulties like withdrawal of credit cards, major family conflicts, lost time from work, or missed meals or sleep because of the activity).

Instructions to patients [and caregiver]:

Over the past week, have you had unusually strong urges that are hard to control? For example, have you gambled too much? Have you put things together or taken things apart over and over again? Do you think a lot about sex? [If yes, examiner asks patient or caregiver to elaborate and probes for information].

SCORE

___

0: Normal: No problems present

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

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

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

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

Rater Observations Posing UPDRS Questions and Response Options:

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?

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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

_____

3.2 _____ Rater had difficulty explaining the question. Bracket problematic parts of the question. What parts of the question were difficult to explain?

_____

_____

3.3 _____ Other rater issue (please specify)

_____

_____

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.0 If you had difficulty coding response options. Underline problematic parts of the response options. Why were these parts of the response options difficult to code?

_____

_____

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

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

Very difficult 1 2 3 4 5 6 Very Easy

7.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

_____

_____

_____

_____

8.0 Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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.]

RATER'S DEBRIEFING

3.0 How helpful were the general instructions and navigation instructions on page 4 overall for administering part 1A of the assessment?

Not helpful 1 2 3 4 5 6 Very helpful

3.1 What areas for improvement do you suggest? (Please circle problem areas on page 4)

3.2 How often did you remember to use the words "usually", "generally", "most of the time" when interviewing patients?

Not at all 1 2 3 4 5 6 In every case

4.0 What problems did you have, if any, with the instructions to "elaborate and probe for information" at the end of the Instructions to patients for each item?

5.0 How easy or difficult is it for you as the rater to use the rating options to code the patient's responses? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.1 What made these options difficult for you as the rater to explain?

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

6.0 Which questions were the most uncomfortable or awkward for you to ask? Why?

8.0 Have you come to dislike any specific questions in this UPDRS Part? Which ones? Why?

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 of 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)
__Patient __Caregiver __Patient and Caregiver

Cognitive Testing Instructions for 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.

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

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.

SCORE ___

0: Normal: No problems
1: Slight: Problems are present but usually do not cause trouble getting a full night of sleep.
2: Mild: Problems usually cause some trouble getting a full night of sleep.
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.
4: Severe: I usually do not sleep for most of the night.

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 difficult to select a response?

5.2 Suggested solution?

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

1.8 DAYTIME SLEEPINESS: Over the past week, have you had trouble staying awake during the daytime? **SCORE**

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.	

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 difficult to select a response?

5.2 Suggested solution?

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

1.9 PAIN AND OTHER SENSATIONS: Over the past week, have you had uncomfortable feelings in your 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 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 difficult to select a response?

5.2 Suggested solution?

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

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?

SCORE

___

0: 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.
2: Mild: Urine problems cause a few difficulties with my daily routine. However, I do not have urine accidents.
3: Moderate: Urine problems cause a lot of difficulties with my daily routine, including urine accidents.
4: Severe: I cannot control my urine and use a diaper or have a bladder tube.

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 difficult to select a response?

5.2 Suggested solution?

How do you feel about the use of the word "diaper" in response option 4?

Very uncomfortable 1 2 3 4 5 6 Very Comfortable

6.1 If uncomfortable, what other words would be more comfortable for you?

7.0 Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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.
4: Severe: I usually need physical help from someone else to empty my bowels.

___

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 difficult to select a response?

5.2 Suggested solution?

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

1.12 LIGHTHEADEDNESS ON STANDING: Over the past week, have you usually felt faint, dizzy or foggy 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.

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 difficult to select a response?

5.2 Suggested solution?

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

1.13 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. **SCORE**

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.

3: Moderate: Tiredness causes me a lot of troubles doing things or being with people. However, it does not stop me from doing anything.

4: Severe: Tiredness stops me from doing things or being with people.

___

Rater is to complete all answers to cognitive test questions.

<u>Rater's observations while the patient is reading/responding to the question:</u>

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?

<u>Questions for the patient after they have read and responded to the UPDRS question:</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 <u>Circle</u> these on form.

4.2 <u>Explain</u> 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? ___ Patient primarily ___ Caregiver primarily ___ Both

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 instructions (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: Motor Aspects of Experiences of Daily Living (M-EDL)

2.1 SPEECH: Over the past week, have you had problems with your speech? **SCORE** ___

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.

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 difficult to select a response?

5.2 Suggested solution?

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

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.

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 difficult to select a response?

5.2 Suggested solution?

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

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?

SCORE ___

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.

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 difficult to select a response?

5.2 Suggested solution?

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

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, spoons, chopsticks, or fingers to eat? **SCORE**

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.
4: Severe: I need help for most or all eating tasks.

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 difficult to select a response?

5.2 Suggested solution?

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

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 clothes? **SCORE**

0: Normal: Not at all (no problems) ___
1: Slight: I am slow or clumsy but I do not need help.
2: Mild: I am slow or clumsy and need help for a few dressing tasks.
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/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 difficult to select a response?

5.2 Suggested solution?

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

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? **SCORE**

0: Normal: Not at all (no problems) ___
1: Slight: I am slow or clumsy but I do not need any help.
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.

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 difficult to select a response?

5.2 Suggested solution?

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

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.
4: Severe: Most or all words cannot be read.
.

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 difficult to select a response?

5.2 Suggested solution?

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

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

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.

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 difficult to select a response?

5.2 Suggested solution?

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

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

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.

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 difficult to select a response?

5.2 Suggested solution?

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

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.

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 difficult to select a response?

5.2 Suggested solution?

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

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.

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 difficult to select a response?

5.2 Suggested solution?

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

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). ___
1: 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.
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.

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 difficult to select a response?

5.2 Suggested solution?

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

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.

SCORE

___

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.

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 difficult to select a response?

5.2 Suggested solution?

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

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.

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.
____ **OFF:** 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 _____

Instructions to examiner: 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.

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?

3.2. FACIAL EXPRESSION

Instructions to examiner: Observe the patient sitting at rest for 10 seconds, without talking and also while talking. Observe eye-blink frequency, hypomimia or loss of facial expression, spontaneous smiling and parting of lips.

0:	Normal.	Normal facial expression	_____
1:	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 less spontaneous smiling, but lips not parted.	
3:	Moderate.	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.	

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?

3.3. RIGIDITY

_____

Instructions to examiner: 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. For **arms**, test the wrist and elbow joints simultaneously. For **legs**, test the hip and knee joints simultaneously. If no rigidity is detected, use an activation maneuver such as tapping fingers, fist opening/closing, or heel tapping in a limb not being tested. Explain to the patient to go as limp as possible as you test for rigidity.

0: Normal. No rigidity.
1: Slight. Rigidity only detected with activation maneuver.
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 is achieved with effort.
4: Severe. Rigidity detected without the activation maneuver and full range of motion not achieved.

_____ Neck

___ RUE
___ LUE

___ RLE ___
___ LLE

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?

Question for the patient regarding the instruction:

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

3.4 FINGER TAPPING

Instructions to examiner: Each hand is tested separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to tap the index finger on the thumb 10 times as quickly AND as big as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.

			R	L
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 tapping movement; b) slight slowing; c) the amplitude decrements near the end of the 10 taps.		
2:	Mild.	Any of the following: a) 3 to 5 interruptions during tapping; b) mild slowing; c) the amplitude decrements midway in the 10-tap sequence.		
3:	Moderate.	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:	Severe.	Cannot or can only barely perform the task because of slowing, interruptions or decrements.		

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 is it for you as the rater to demonstrate the "Instructions to examiner" to the patient? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

2.1 What would make the "Instructions to examiner" easier to demonstrate?

3.0 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

3.1What made it difficult to rate?

3.2 Suggested solution?

Questions for the patient regarding the instructions:

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 instructions were difficult to understand?

(Examiner can circle these on form).

5.1 **Explain why they were difficult**

3.5 HAND MOVEMENTS

Instructions to examiner: Test each hand separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to make a tight fist and open the hand 10 times as fully AND as quickly as possible. If the patient fails to make a tight fist or to open the hand fully, remind him/her to do so. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.

		R	L
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 slowing; c) the amplitude decrements midway in the task.		
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 open-and-close sequence.		
4: Severe.	Cannot or can only barely perform the task because of slowing, interruptions or decrements.		

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 is it for you as the rater to demonstrate the "Instructions to examiner" to the patient? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

2.1 What would make the "Instructions to examiner" easier to demonstrate?

3.0 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

3.1What made it difficult to rate?

3.2 Suggested solution?

Questions for the patient regarding the instructions:

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 instructions were difficult to understand?

(Examiner can circle these on form).

5.1 **Explain why they were difficult**

3.6 PRONATION-SUPINATION MOVEMENTS OF HANDS

Instructions to examiner: Test each hand separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to extend the arm out in front of his/her body with the palms down; then to turn the palm up and down alternately 10 times as fast and as fully as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.

			R	L
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 sequence.		
2:	Mild.	Any of the following: a) 3 to 5 interruptions during the movements; b) 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 can only barely perform the task because of slowing, interruptions or decrements.		

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 is it for you as the rater to demonstrate the "Instructions to examiner" to the patient? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

2.1 What would make the "Instructions to examiner" easier to demonstrate?

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

3.1What made it difficult to rate?

3.2 Suggested solution?

Questions for the patient regarding the instructions:

3.0 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

4.0 What parts of the instructions were difficult to understand?

(Examiner can circle these on form).

4.1 **Explain why they were difficult**

3.7 TOE TAPPING

Instructions to examiner: Have the patient sit in a straight-backed chair with arms, both feet on the floor. Test each foot separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to place the heel on the ground in a comfortable position and then tap the toes 10 times as big and as fast as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.

			R	L
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 tapping movement; b) slight slowing; c) amplitude decrements near the end of the ten taps.		
2:	Mild.	Any of the following: a) 3 to 5 interruptions during the tapping movements; b) mild slowing; c) amplitude decrements midway in the task.		
3:	Moderate	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) amplitude decrements after the first tap.		
4:	Severe.	Cannot or can only barely perform the task because of slowing, interruptions or decrements.		

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 is it for you as the rater to demonstrate the "Instructions to examiner" to the patient? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

2.1 What would make the "Instructions to examiner" easier to demonstrate?

3.0 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

3.1What made it difficult to rate?

3.2 Suggested solution?

<u>Questions for the patient regarding the instructions</u>:

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 instructions were difficult to understand?

(Examiner can <u>circle</u> these on form).

5.1 **<u>Explain</u> why they were difficult**

3.8 LEG AGILITY

Instructions to examiner: Have the patient sit in a straight-backed chair with arms, both feet on the floor. Test each leg separately. Demonstrate the task, but do not continue to perform the task while the patient is being tested. Instruct the patient to place the foot on the ground in a comfortable position and then raise and stomp the foot on the ground 10 times as high and as fast as possible. Rate each side separately, evaluating speed, amplitude, hesitations, halts and decrementing amplitude.

			R	L
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) amplitude decrements near the end of the task.		
2:	Mild.	Any of the following: a) 3 to 5 interruptions during the movements; b) mild slowness; c) amplitude decrements midway in the task.		
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 in speed; c) amplitude decrements after the first tap.		
4:	Severe.	Cannot or can only barely perform the task because of slowing, interruptions or decrements.		

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 is it for you as the rater to demonstrate the "Instructions to examiner" to the patient? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

2.1 What would make the "Instructions to examiner" easier to demonstrate?

3.0 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

3.1What made it difficult to rate?

3.2 Suggested solution?

Questions for the patient regarding the instructions:

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 instructions were difficult to understand?

(Examiner can circle these on form).

5.1 **Explain why they were difficult**

3.9 ARISING FROM CHAIR

Instructions to examiner: 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

0: Normal. No problems. Able to arise quickly without hesitation. _____
1: Slight. 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: Moderate. 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.

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:

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

3.10 GAIT

Instructions to examiner. 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), then turn around and return to the examiner. This item measures multiple behaviors: stride amplitude, stride speed, height of foot lift, heel strike during walking, turning, and arm swing, but not freezing. Assess also for "freezing of gait" (next item 3.11) while patient is walking. Observe posture for item 3.13

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 another person's assistance.

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:

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

3.11 FREEZING OF GAIT

Instructions to examiner. 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. To the extent that safety permits, patients 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

_____

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? 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?

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

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

3.13 POSTURE

Instructions to examiner: Posture is assessed with the patient standing erect after arising from a chair, during walking , and while being tested for postural reflexes. If you notice poor posture, tell the patient to stand up straight and see if the posture improves (see option 2 below). Rate the worst posture seen in these three observation points. Observe for flexion and side-to-side leaning.

0: Normal. No problems _____
1: Slight. Not quite erect, but posture could be normal for older person.
2: Mild. Definite flexion, scoliosis or leaning to one side, but patient can correct posture to normal posture when asked to do so.
3: Moderate. 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.

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?

3.14 GLOBAL SPONTANEITY OF MOVEMENT (BODY BRADYKINESIA)

Instructions to examiner: 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.

0: Normal. No problems

1: Slight. Slight global slowness and poverty of spontaneous movements. Less spontaneous gesturing or crossing legs than normal.

2: Mild. Mild global slowness and poverty of spontaneous movements, including decreased gesturing.

3: Moderate. Moderate global slowness and poverty of spontaneous movements. Lack of gesturing in both arms.

4: Severe. Severe global slowness and poverty of spontaneous movements.

_____

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?

3.15 POSTURAL TREMOR OF THE HANDS

Instructions to examiner: 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. Instruct the patient to stretch the arms out in front of the body with palms down. The wrist should be straight and the fingers comfortably separated so that they do not touch each other. Observe this posture for 10 seconds.

			R	L
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.		

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:

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

3.16 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 throughout the movement or as the tremor reaches either target (nose or finger). Rate the highest amplitude seen.

			R	L
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.		

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:

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

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.

.

Extremity ratings

0: Normal. No tremor.
1: Slight. < 1 cm in maximal amplitude.
2: Mild. > 1 cm but <3 cm in maximal amplitude
3: Moderate. amplitude 3-10 cm in maximal amplitude.
4: Severe. >10 cm in maximal amplitude.

Lip/Jaw ratings

0: Normal. No tremor
1: Slight. <1 cm in maximal amplitude.
2: Mild. >1 cm but <2 cm in maximal amplitude
3: Moderate. amplitude. >2 cm but <3 cm in maximal amplitude.
4: Severe. >3 cm in maximal amplitude.

Lip/Jaw

___ ___
RUE LUE

___ ___
RLE LLE

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?

3.18 CONSTANCY OF REST TREMOR

Instructions to examiner: 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.

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.

Were dyskinesias (chorea or dystonia) present during examination? _____YES _____NO

If yes, did these movements interfere with your ratings? _____YES _____NO

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?

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 movements you have seen in the patient before or show them dyskinetic movements typical of other patients. Exclude from this 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 times when you have tremor, which is a regular back and forth shaking or times when you have painful foot cramps or spasms in the early morning or at nighttime. I will ask about those later. Concentrate only on these types of wiggling, jerking 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).

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?

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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

_____

3.2 _____ Rater had difficulty explaining the question. Bracket 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)

_____
_____
_____
_____

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.0 If you had difficulty selecting a response option, explain why this selection was difficult?

_____
_____
_____

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

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

Very difficult 1 2 3 4 5 6 Very Easy

7.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

_____
_____
_____
_____

8.0 Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

4.2 FUNCTIONAL IMPACT OF DYSKINESIAS ____

Instructions to examiner: Determine the degree to which dyskinesias impact on the patient's daily function in terms of activities and social interactions. 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]: Over the past week, did you usually have trouble doing things or being with people when these jerking 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 and participates in all social interactions during dyskinetic periods.

3: Moderate. Dyskinesias impact on activities to the point that the patient usually does not perform some activities or does not usually participate in some social activities during dyskinetic episodes.

4: Severe. 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 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 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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

_____

_____

3.2 _____ Rater had difficulty explaining the question. Bracket 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)

_____
_____
_____
_____

5.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

8.0 If you had difficulty selecting a response option, explain why this selection was difficult?

_____
_____
_____

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

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

Very difficult 1 2 3 4 5 6 Very Easy

10.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

_____
_____
_____
_____

8.0 Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

B . MOTOR FLUCTUATIONS

4.3 TIME SPENT IN THE OFF STATE ____

Instructions to examiner: Use the number of waking hours derived from 4.1 and determine the hours spent in the "OFF" 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 still 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).

0: Normal. No OFF time
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?

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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

_____

3.2 _____ Rater had difficulty explaining the question. Bracket 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)

_____
_____
_____
_____

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.0 If you had difficulty selecting a response option, explain why this selection was difficult?

_____
_____

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

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

Very difficult 1 2 3 4 5 6 Very Easy

7.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

_____
_____
_____
_____

8.0 Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

4.4 FUNCTIONAL IMPACT OF FLUCTUATIONS ____

Instructions to examiner: 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 **difference** 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 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 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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____
__

3.2 _____ Rater had difficulty explaining the question. Bracket 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)

_____
__
_____
__

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.0 If you had difficulty selecting a response option, explain why this selection was difficult?

_____
__

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

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

Very difficult 1 2 3 4 5 6 Very Easy

7.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

8.0 **Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both**

4.5 COMPLEXITY OF MOTOR FLUCTUATIONS ____

Instructions to examiner: Determine the usual predictability of OFF function whether due to dose, time of day, food intake or other factors. Use the information provided by the patients and caregiver and supplement with your own observations. You will ask if the patient can count on them always coming at a special time, mostly coming at a special time (in which case you will probe further to separate slight from mild), only sometimes coming at a special time or are they totally unpredictable? Narrowing down the percentage will allow you to find the correct answer.

Instructions to patient [and caregiver]: For some patients, the low or "OFF" periods happen at certain times during day or when they do activities like eating or exercising. Over the past week, do you usually know when your low periods will occur? In other words, do your low periods always come at a certain time? Do they mostly come at a certain time? Do they only sometimes come at a certain time? Are your low periods totally unpredictable?"

0: Normal. No motor fluctuations
1: Slight. OFF times are predictable all or almost all of the time (> 75%)
2: Mild. OFF times are predictable most of the time (51-75%).
3: Moderate. OFF times are predictable some of the time (26-50%).
4: Severe OFF episodes are rarely predictable. (≤ 25%).

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 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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

_____

3.2 _____ Rater had difficulty explaining the question. Bracket 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)

_____
_____
_____
_____

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.0 If you had difficulty selecting a response option, explain why this selection was difficult?

_____
_____
_____

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

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

Very difficult 1 2 3 4 5 6 Very Easy

7.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

_____
_____
_____
_____

8.0 **Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both**

C. "OFF" DYSTONIA

4.6 PAINFUL OFF-STATE DYSTONIA _____

Instructions to examiner: For patients who have motor fluctuations, determine what proportion of the OFF episodes usually includes painful dystonia? You have already determined the number of hours of "OFF" time (4.3). Of these hours, determine how many are associated with dystonia and calculate the percentage. If there is no OFF time, mark 0.

Instructions to patient [and caregiver]: 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 you add up all the time in a day when these painful cramps come, how many hours would this make?

0: Normal: No dystonia
1: Slight. < 25% of time in OFF state
2: Mild. 26-50% of time in OFF state
3: Moderate 51-75% of time in OFF state
4: Severe > 75% of time in OFF state

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 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 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 reading question. Underline problematic parts of the question. What parts of the question were difficult to read easily?

_____

_____

_____

3.2 _____ Rater had difficulty explaining the question. Bracket 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)

_____
_____
_____
_____

4.0 *After reading Instructions to Patient to the patient and hearing responses*, how difficult was it for you as the rater to select the appropriate response option? (Circle choice)

Very difficult 1 2 3 4 5 6 Very Easy

5.0 If you had difficulty selecting a response option, explain why this selection was difficult?

_____
_____
_____

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

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

Very difficult 1 2 3 4 5 6 Very Easy

7.0 What parts of the question were difficult to understand? What was the difficulty? Circle these on form. Explain why they were difficult in the space below.

_____
_____
_____
_____

8.0 Who answered this item? ___ Patient primarily ___ Caregiver primarily ___ Both

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 identified	Scales RECOMMENDED	Scales SUGGESTED
HRQoL	• **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** • **SCOPA-PS**	• **Generic instrument: SF-36, EQ-5D** • **Disease-specific instrument: PDQ-39** • **Index Instrument: EQ-5D**	**----**
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	• **MMSE** • **ADAS-cog** • **VADAS** • **The Mattis' Dementia Ratings Scale.** • **The Neuropsychiatric Inventory (NPI).**	**None**	• **ADAS-cog** • **The Mattis' Dementia Ratings Scale.**
Insomnia (Quality nighttime sleep)	• **the Pittsburgh Sleep Quality Index (PSQI)** • **SCOPA-SLEEP nighttime sleep sub-scale** • **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 sub-scale** • **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	• **Rush Hallucinatory inventory** • **Structure Interview for hallucinations in PD** • **Positive and Negative Syndrome Scale (PANSS)** • **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"**	• **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	• **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**	

APPENDIX

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 of 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)

__Patient __Caregiver __Patient and Caregiver

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

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. **SCORE**

0: Normal: No problems ___
1: Slight: Problems are present but usually do not cause trouble getting a full night of sleep.
2: Mild: Problems usually cause some trouble getting a full night of sleep.
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.
4: Severe: I usually do not sleep for most of the night.

1.8 DAYTIME SLEEPINESS: Over the past week, have you had trouble staying awake during the daytime? **SCORE**

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.

1.9 PAIN AND OTHER SENSATIONS: Over the past week, have you had uncomfortable feelings in your 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.

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?

SCORE

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.
4: Severe: I usually need physical help from someone else to empty my bowels.

1.12 LIGHTHEADEDNESS ON STANDING: Over the past week, have you usually felt faint, dizzy or foggy 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. **SCORE**

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.
3: Moderate: Tiredness causes me a lot of troubles doing things or being with people. 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? **SCORE**

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? **SCORE**

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, spoons, chopsticks, or fingers to eat? **SCORE**

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.
4: Severe: I need help for most or all eating tasks.

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 clothes? **SCORE**

0: Normal: Not at all (no problems) ___
1: Slight: I am slow or clumsy but I do not need help.
2: Mild: I am slow or clumsy and need help for a few dressing tasks.
3: Moderate: I need help for many dressing tasks.
4: Severe: I need help for most or all dressing tasks..

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? **SCORE**

0: Normal: Not at all (no problems) ___
1: Slight: I am slow or clumsy but I do not need any help.
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.
4: Severe: Most or all words cannot be read.

.

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

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?

SCORE

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. **SCORE**

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

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.