### DEMOGRAPHICS

1. **Date of birth:**
   
2. **Gender at birth:** (1 = Female, 2 = Male)
   
3a. **Subject Education:** (number of years)
   
3b. **Highest Level of Education:**
   1 = elementary / middle school or equivalent
   2 = high school or equivalent
   3 = college / university or equivalent
   4 = Master’s level or equivalent
   5 = post graduate or equivalent
   
4. **Race:**
   
5. **Ethnicity:**
   
**NOTE:** Race and Ethnicity will be captured the way each site collects this information. If you have a code and codelist, please enter the code here and provide the codelist. Otherwise, please write the race/ethnicity responses.

### PD INFORMATION

6. **Enrollment Category:** (0 = No Parkinson disease, 1 = Parkinson disease)
   
7. **Age at Parkinson disease diagnosis:**
   
8. **Age at onset:**
<table>
<thead>
<tr>
<th>Subject Mutation</th>
<th>Family Mutation</th>
</tr>
</thead>
<tbody>
<tr>
<td>G2019S</td>
<td></td>
</tr>
<tr>
<td>G2385R</td>
<td></td>
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<tr>
<td>R1441G</td>
<td></td>
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<tr>
<td>R1441C</td>
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<tr>
<td>N1437H</td>
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<tr>
<td>R1628P</td>
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<tr>
<td>I2020T</td>
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<tr>
<td>Q930R</td>
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<tr>
<td>S1228T</td>
<td></td>
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<tr>
<td>L1114L</td>
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<tr>
<td>C228S</td>
<td></td>
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<tr>
<td>R1325Q</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

NOTE: If genotyping has not yet been done, or you are waiting for the results, please leave the response blank and update it when the results are available.

1. Is the subject biologically related to someone with PD? (0 = No, 1 = Yes)
2. Is pedegree available at your local site? (0 = No, 1 = Yes)
<table>
<thead>
<tr>
<th>NUMBER of FAMILY MEMBERS</th>
<th>NUMBER with PD or PARKINSONISM</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Biological Mother</td>
<td>4.1 1</td>
</tr>
<tr>
<td>5. Biological Father</td>
<td>5.1 1</td>
</tr>
<tr>
<td>6. Full Siblings</td>
<td>6.1 2</td>
</tr>
<tr>
<td>7. Half Siblings</td>
<td>7.1 2</td>
</tr>
<tr>
<td>8. Maternal Grandparents</td>
<td>8.1 2</td>
</tr>
<tr>
<td>9. Paternal Grandparents</td>
<td>9.1 2</td>
</tr>
<tr>
<td>10. Maternal Aunts and Uncles</td>
<td>10.1 2</td>
</tr>
<tr>
<td>11. Paternal Aunts and Uncles</td>
<td>11.1 2</td>
</tr>
<tr>
<td>12. Children</td>
<td>12.1</td>
</tr>
</tbody>
</table>
PART I MENTATION, BEHAVIOR AND MOOD (RATE ITEMS 1 TO 4 BY INTERVIEW)
When completing this section, indicate the subject’s level of function during the past week.

A. The subject’s PD symptoms during the past week were:
   1 = Non Fluctuator
   2 = Fluctuator

1. Intellectual Impairment:
   0 = None.
   1 = Mild. Consistent forgetfulness with partial recollection of events and no other
difficulties.
   2 = Moderate memory loss, with disorientation and moderate difficulty handling
   complex problems. Mild but definite impairment of function at home with need of
   occasional prompting.
   3 = Severe memory loss with disorientation for time and often to place. Severe
   impairment in handling problems.
   4 = Severe memory loss with orientation preserved to person only. Unable to make
   judgments or solve problems. Requires much help with personal care.
   Cannot be left alone at all.

2. Thought Disorder (DUE TO DEMENTIA OR DRUG INTOXICATION):
   0 = None.
   1 = Vivid dreaming.
   2 = “Benign” hallucinations with insight retained.
   3 = Occasional to frequent hallucinations or delusions; without insight; could
   interfere with daily activities.
   4 = Persistent hallucinations, delusions, or florid psychosis. Not able to care for self.

3. Depression:
   0 = Not present.
   1 = Periods of sadness or guilt greater than normal, never sustained for days or
   weeks.
   2 = Sustained depression (1 week or more).
   3 = Sustained depression with vegetative symptoms (insomnia, anorexia, weight
   loss, loss of interest).
   4 = Sustained depression with vegetative symptoms and suicidal thoughts or intent.

4. Motivation/Initiative:
   0 = Normal.
   1 = Less assertive than usual; more passive.
   2 = Loss of initiative or disinterest in elective (nonroutine) activities.
   3 = Loss of initiative or disinterest in day-to-day (routine) activities.
   4 = Withdrawn, complete loss of motivation.
PART II ACTIVITIES OF DAILY LIVING (RATE ITEMS 5 TO 17 BY INTERVIEW)
When completing this section, indicate the subject’s level of function during the past week.

A. The subject’s PD symptoms during the past week were:

1 = Non Fluctuator
2 = Fluctuator

5. **Speech:**
   - 0 = Normal.
   - 1 = Mildly affected. No difficulty being understood.
   - 2 = Moderately affected. Sometimes asked to repeat statements.
   - 3 = Severely affected. Frequently asked to repeat statements.
   - 4 = Unintelligible most of the time.

6. **Salivation:**
   - 0 = Normal.
   - 1 = Slight but definite excess of saliva in mouth; may have nighttime drooling.
   - 2 = Moderately excessive saliva; may have minimal drooling.
   - 3 = Marked excess of saliva with some drooling.
   - 4 = Marked drooling, requires constant tissue or handkerchief.

7. **Swallowing:**
   - 0 = Normal.
   - 1 = Rare choking.
   - 2 = Occasional choking.
   - 3 = Requires soft food.
   - 4 = Requires NG tube or gastrostomy feeding.

8. **Handwriting:**
   - 0 = Normal.
   - 1 = Slightly slow or small.
   - 2 = Moderately slow or small; all words are legible.
   - 3 = Severely affected; not all words are legible.
   - 4 = The majority of words are not legible.

9. **Cutting Food and Handling Utensils:**
   - 0 = Normal.
   - 1 = Somewhat slow and clumsy, but no help needed.
   - 2 = Can cut most foods, although clumsy and slow; some help needed.
   - 3 = Food must be cut by someone, but can still feed slowly.
   - 4 = Needs to be fed.

10. **Dressing:**
    - 0 = Normal.
    - 1 = Somewhat slow, but no help needed.
    - 2 = Occasional assistance with buttoning, getting arms in sleeves.
    - 3 = Considerable help required, but can do some things alone.
    - 4 = Helpless.
PART II ACTIVITIES OF DAILY LIVING
When completing this section, indicate the subject’s level of function during the past week.

11. **Hygiene:**

   0 = Normal.
   1 = Somewhat slow, but no help needed.
   2 = Needs help to shower or bathe; or very slow in hygienic care.
   3 = Requires assistance for washing, brushing teeth, combing hair, going to the bathroom.
   4 = Foley catheter or other mechanical aids.

12. **Turning in Bed and Adjusting Bedclothes:**

   0 = Normal.
   1 = Somewhat slow and clumsy, but no help needed.
   2 = Can turn alone or adjust sheets, but with great difficulty.
   3 = Can initiate, but not turn or adjust sheets alone.
   4 = Helpless.

13. **Falling (unrelated to freezing):**

   0 = None.
   1 = Rare falling.
   2 = Occasionally falls, less than once per day.
   3 = Falls an average of once daily.
   4 = Falls more than once daily.

14. **Freezing When Walking:**

   0 = None.
   1 = Rare freezing when walking; may have start-hesitation.
   2 = Occasional freezing when walking.
   3 = Frequent freezing. Occasionally falls from freezing.
   4 = Frequent falls from freezing.

15. **Walking:**

   0 = Normal.
   1 = Mild difficulty. May not swing arms or may tend to drag leg.
   2 = Moderate difficulty, but requires little or no assistance.
   3 = Severe disturbance of walking, requiring assistance.
   4 = Cannot walk at all, even with assistance.

16. **Tremor:**

   0 = Absent.
   1 = Slight and infrequently present.
   2 = Moderate; bothersome to patient.
   3 = Severe; interferes with many activities.
   4 = Marked; interferes with most activities.

17. **Sensory Complaints Related to Parkinsonism:**

   0 = None.
   1 = Occasionally has numbness, tingling, or mild aching.
   2 = Frequently has numbness, tingling, or aching; not distressing.
   3 = Frequent painful sensations.
   4 = Excruciating pain.
### PART III MOTOR EXAMINATION (Acceptable responses are 0, 1, 2, 3, 4)

**Instructions:** All efforts should be made to conduct the motor exam while the subject is in a stable state (e.g., “On” for the entire exam or “Off” for the entire exam). If unstable, re-examine the subject in a stable state if possible.

<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>18.</td>
<td><strong>Speech:</strong>&lt;br&gt;0 = Normal.&lt;br&gt;1 = Slight loss of expression, diction and/or volume.&lt;br&gt;2 = Monotone, slurred but understandable; moderately impaired.&lt;br&gt;3 = Marked impairment, difficult to understand.&lt;br&gt;4 = Unintelligible.</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td><strong>Facial Expression:</strong>&lt;br&gt;0 = Normal.&lt;br&gt;1 = Minimal hypomimia, could be normal “Poker Face”.&lt;br&gt;2 = Slight but definitely abnormal diminution of facial expression.&lt;br&gt;3 = Moderate hypomimia; lips parted some of the time.&lt;br&gt;4 = Masked or fixed facies with severe or complete loss of facial expression; lips parted 1/4 inch or more.</td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td><strong>Tremor at Rest:</strong>&lt;br&gt;0 = Absent.&lt;br&gt;1 = Slight and infrequently present.&lt;br&gt;2 = Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.&lt;br&gt;3 = Moderate in amplitude and present most of the time.&lt;br&gt;4 = Marked in amplitude and present most of the time.</td>
<td>20a. Face, lips+chin&lt;br&gt;20b. Right Hand&lt;br&gt;20c. Left Hand&lt;br&gt;20d. Right Foot&lt;br&gt;20e. Left Foot</td>
</tr>
<tr>
<td>21.</td>
<td><strong>Action or Postural Tremor of Hands:</strong>&lt;br&gt;0 = Absent.&lt;br&gt;1 = Slight; present with action.&lt;br&gt;2 = Moderate in amplitude, present with action.&lt;br&gt;3 = Moderate in amplitude with posture holding as well as action.&lt;br&gt;4 = Marked in amplitude; interferes with feeding.</td>
<td>21a. Right Hand&lt;br&gt;21b. Left Hand</td>
</tr>
</tbody>
</table>
PART III MOTOR EXAMINATION (CONT) (Acceptable responses are 0, 1, 2, 3, 4)

22. **Rigidity:** (Judged on passive movement of major joints with subject relaxed in sitting position. Cogwheeling to be ignored.)
   - 0 = Absent.
   - 1 = Slight or detectable only when activated by mirror or other movements.
   - 2 = Mild to moderate.
   - 3 = Marked, but full range of motion easily achieved.
   - 4 = Severe, range of motion achieved with difficulty.

22a. Neck
22b. RUE
22c. LUE
22d. RLE
22e. LLE

23. **Finger Taps:** (Subject taps thumb with index finger in rapid succession with widest amplitude possible, each hand separately.)
   - 0 = Normal.
   - 1 = Mild slowing and/or reduction in amplitude.
   - 2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
   - 3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
   - 4 = Can barely perform the task.

23a. Right Hand
23b. Left Hand

24. **Hand Movements:** (Subject opens and closes hands in rapid succession with widest amplitude possible, each hand separately.)
   - 0 = Normal.
   - 1 = Mild slowing and/or reduction in amplitude.
   - 2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
   - 3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
   - 4 = Can barely perform the task.

24a. Right Hand
24b. Left Hand

25. **Rapid Alternating Movements of Hands:** (Pronation-supination movements of hands, vertically or horizontally, with as large an amplitude as possible, both hands simultaneously.)
   - 0 = Normal.
   - 1 = Mild slowing and/or reduction in amplitude.
   - 2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
   - 3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
   - 4 = Can barely perform the task.

25a. Right Hand
25b. Left Hand

26. **Leg Agility:** (Subject taps heel on ground in rapid succession, picking up entire leg. Amplitude should be about 3 inches.)
   - 0 = Normal.
   - 1 = Mild slowing and/or reduction in amplitude.
   - 2 = Moderately impaired. Definite and early fatiguing. May have occasional arrests in movement.
   - 3 = Severely impaired. Frequent hesitation in initiating movements or arrests in ongoing movement.
   - 4 = Can barely perform the task.

26a. Right Leg
26b. Left Leg
PART III MOTOR EXAMINATION (CONT) (Acceptable responses are 0, 1, 2, 3, 4)

27. **Arising from Chair:** (Subject attempts to arise from a straight-back wood or metal chair with arms folded across chest.)
   - 0 = Normal.
   - 1 = Slow; or may need more than one attempt.
   - 2 = Pushes self up from arms of seat.
   - 3 = Tends to fall back and may have to try more than one time, but can get up without help.
   - 4 = Unable to arise without help.

28. **Posture:**
   - 0 = Normal erect.
   - 1 = Not quite erect, slightly stooped posture; could be normal for older person.
   - 2 = Moderately stooped posture, definitely abnormal; can be slightly leaning to one side.
   - 3 = Severely stooped posture with kyphosis; can be moderately leaning to one side.
   - 4 = Marked flexion with extreme abnormality of posture.

29. **Gait:**
   - 0 = Normal.
   - 1 = Walks slowly, may shuffle with short steps, but no festination or propulsion.
   - 2 = Walks with difficulty, but requires little or no assistance; may have some festination, short steps, or propulsion.
   - 3 = Severe disturbance of gait, requiring assistance.
   - 4 = Cannot walk at all, even with assistance.

30. **Postural Stability:** (Response to sudden posterior displacement produced by pull on shoulders while subject is erect, with eyes open and feet slightly apart. Subject is prepared.)
   - 0 = Normal.
   - 1 = Retropulsion, but recovers unaided.
   - 2 = Absence of postural response; would fall if not caught by examiner.
   - 3 = Very unstable, tends to lose balance spontaneously.
   - 4 = Unable to stand without assistance.

31. **Body Bradykinesia and Hypokinesia:** (Combining slowness, hesitancy, decreased arm swing, small amplitude, and poverty of movement in general.)
   - 0 = None.
   - 1 = Minimal slowness, giving movement a deliberate character; could be normal for some persons. Possibly reduced amplitude.
   - 2 = Mild degree of slowness and poverty of movement which is definitely abnormal. Alternatively, some reduced amplitude.
   - 3 = Moderate slowness, poverty or small amplitude of movement.
   - 4 = Marked slowness, poverty or small amplitude of movement.

A. Indicate the subject’s PD state during the examination:
   - 1 = Fluctuator - “On” during exam
   - 2 = Fluctuator - Fluctuated during the exam
   - 3 = Fluctuator - “Off” during exam
   - 4 = Non-fluctuator
PART IV COMPLICATIONS OF THERAPY (in the past week)

A. Dyskinesias

1. **Duration:** What proportion of the waking day are dyskinesias present? (Historical information):
   - 0 = None.
   - 1 = 1 - 25% of day.
   - 2 = 26 - 50% of day.
   - 3 = 51 - 75% of day.
   - 4 = 76 - 100% of day.

2. **Disability:** How disabling are the dyskinesias? (Historical information; may be modified by office examination):
   - 0 = Not disabling.
   - 1 = Mildly disabling.
   - 2 = Moderately disabling.
   - 3 = Severely disabling.
   - 4 = Completely disabled.

3. **Painful dyskinesias:** How painful are the dyskinesias?
   - 0 = No painful dyskinesias.
   - 1 = Slight.
   - 2 = Moderate.
   - 3 = Severe.
   - 4 = Marked.

4. **Presence of early morning dystonia:** (Historical information): (0 = No, 1 = Yes)

B. Clinical Fluctuations

5. Are any “off” periods **predictable** as to timing after a dose of medication? (0 = No, 1 = Yes)

6. Are any “off” periods **unpredictable** as to timing after a dose of medication? (0 = No, 1 = Yes)

7. Do any of the “off” periods **come on suddenly**, e.g. over a few seconds? (0 = No, 1 = Yes)

8. What proportion of the waking day is the subject “off” on average?
   - 0 = None.
   - 1 = 1 - 25% of day.
   - 2 = 26 - 50% of day.
   - 3 = 51 - 75% of day.
   - 4 = 76 - 100% of day.

C. Other Complications

9. Does the subject have anorexia, nausea, or vomiting? (0 = No, 1 = Yes)

10. Does the subject have any sleep disturbances, e.g., insomnia or hypersomnolence? (0 = No, 1 = Yes)

11. Does the subject have symptomatic orthostasis? (0 = No, 1 = Yes)
1. Hoehn and Yahr Stage (Acceptable responses are 0, 1, 1.5, 2, 2.5, 3, 4, 5)

Stage 0 = No signs of disease.
Stage 1 = Unilateral disease.
Stage 1.5 = Unilateral plus axial involvement.
Stage 2 = Bilateral disease, without impairment of balance.
Stage 2.5 = Mild bilateral disease, with recovery on pull test.
Stage 3 = Mild to moderate bilateral disease; some postural instability; physically independent.
Stage 4 = Severe disability; still able to walk or stand unassisted
Stage 5 = Wheelchair bound or bedridden unless aided.

A. Indicate the subject's PD state during the examination:
1 = Fluctuator - “On” during exam
2 = Fluctuator - Fluctuated during the exam
3 = Fluctuator - “Off” during exam
4 = Non-fluctuator
100% Completely independent. Able to do all chores without slowness, difficulty or impairment. Essentially normal. Unaware of any difficulty.

90% Completely independent. Able to do all chores with some degree of slowness, difficulty and impairment. Might take twice as long. Beginning to be aware of difficulty.

80% Completely independent in most chores. Takes twice as long. Conscious of difficulty and slowness.

70% Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores.

60% Some dependency. Can do most chores, but exceedingly slowly and with much effort. Errors; some impossible.

50% More dependent. Help with half, slower, etc. Difficulty with everything.

40% Very dependent. Can assist with all chores but few alone.

30% With effort, now and then does a few chores alone or begins alone. Much help needed.

20% Nothing alone. Can be a slight help with some chores. Severe invalid.

10% Totally dependent, helpless. Complete invalid.

0% Vegetative functions such as swallowing, bladder, and bowel functions are not functioning. Bedridden.

A. The subject's PD symptoms during the past week were:
   1 = Non Fluctuator
   2 = Fluctuator

Consensus rating
(Investigator, patient, other sources)
Record score for each item below. There is a 1 point maximum unless otherwise noted.

1. Alternating Trail Making

2. Visuoconstructional Skills (Cube)

3. Visuoconstructional Skills (Clock)
   3a. Contour
   3b. Numbers
   3c. Hands

4. Naming
   4a. Lion
   4b. Rhinoceros or rhino
   4c. Camel or dromedary

5. Attention
   5a. Forward Digit Span
   5b. Backward Digit Span
   5c. Vigilance
   5d. Serial 7s [3 point maximum]

6. Sentence Repetition (Language) [2 point maximum]

7. Verbal Fluency
Record score for each item below. There is a 1 point maximum unless otherwise noted.

8. Abstraction [2 point maximum]

9. Delayed Recall
   9a. Face
   9b. Velvet
   9c. Church
   9d. Daisy
   9e. Red

10. Orientation
    10a. Date
    10b. Month
    10c. Year
    10d. Day
    10e. Place
    10f. City

TOTAL SCORE: Sum all subscores listed (1-10f). Add 1 point for subject who has 12 years or fewer of formal education.
A. Source of Information: 1 = Patient, 2 = Caregiver, 3 = Patient and caregiver

SCOPA-AUT

By means of this questionnaire, we would like to find out to what extent in the past month you have had problems with various bodily functions, such as difficulty passing urine, or excessive sweating. Answer the questions by placing a cross in the box which best reflects your situation. If you wish to change an answer, fill in the ‘wrong’ box and place a cross in the correct one. If you have used medication in the past month in relation to one or more of the problems mentioned, then the question refers to how you were while taking this medication. You can note the use of medication on the last page.

1. In the past month have you had difficulty swallowing or have you choked?
   - never
   - sometimes
   - regularly
   - often

2. In the past month, has saliva dribbled out of your mouth?
   - never
   - sometimes
   - regularly
   - often

3. In the past month, has food ever become stuck in your throat?
   - never
   - sometimes
   - regularly
   - often

4. In the past month, did you ever have the feeling during a meal that you were full very quickly?
   - never
   - sometimes
   - regularly
   - often

5. Constipation is a blockage of the bowel, a condition in which someone has a bowel movement twice a week or less.
   In the past month, have you had problems with constipation?
   - never
   - sometimes
   - regularly
   - often

6. In the past month, did you have to strain hard to pass stools?
   - never
   - sometimes
   - regularly
   - often
7. In the past month, have you had involuntary loss of stools?
   | never | sometimes | regularly | often |

Questions 8 to 13 deal with problems with passing urine. If you use a catheter you can indicate this by placing a cross in the box “use catheter”.

8. In the past month, have you had difficulty retaining urine?
   | never | sometimes | regularly | often | use catheter

9. In the past month, have you had involuntary loss of urine?
   | never | sometimes | regularly | often | use catheter

10. In the past month, have you had the feeling that after passing urine your bladder was not completely empty?
    | never | sometimes | regularly | often | use catheter

11. In the past month, has the stream of urine been weak?
    | never | sometimes | regularly | often | use catheter

12. In the past month, have you had to pass urine again within 2 hours of the previous time?
    | never | sometimes | regularly | often | use catheter

13. In the past month, have you had to pass urine at night?
    | never | sometimes | regularly | often | use catheter
14. In the past month, when standing up have you had the feeling of either becoming light-headed, or no longer being able to see properly, or no longer being able to think clearly?

- never
- sometimes
- regularly
- often

15. In the past month, did you become light-headed after standing for some time?

- never
- sometimes
- regularly
- often

16. Have you fainted in the past 6 months?

- never
- sometimes
- regularly
- often

17. In the past month, have you ever perspired excessively during the day?

- never
- sometimes
- regularly
- often

18. In the past month, have you ever perspired excessively during the night?

- never
- sometimes
- regularly
- often

19. In the past month, have your eyes ever been over-sensitive to bright light?

- never
- sometimes
- regularly
- often

20. In the past month, how often have you had trouble tolerating cold?

- never
- sometimes
- regularly
- often

21. In the past month, how often have you had trouble tolerating heat?

- never
- sometimes
- regularly
- often
The following questions are about sexuality. Although we are aware that sexuality is a highly intimate subject, we would still like you to answer these questions. For the questions on sexual activity, consider every form of sexual contact with a partner or masturbation (self-gratification). An extra response option has been added to these questions. Here you can indicate that the situation described has not been applicable to you in the past month, for example because you have not been sexually active. Questions 22 and 23 are intended specifically for men, 24 and 25 for women.

**The following 3 questions are only for men**

22. In the past month, have you been impotent (unable to have or maintain an erection)?

   [ ] never
   [ ] sometimes
   [ ] regularly
   [ ] often
   [ ] not applicable

23. In the past month, how often have you been unable to ejaculate?

   [ ] never
   [ ] sometimes
   [ ] regularly
   [ ] often
   [ ] not applicable

23a. In the past month, have you taken medication for an erection disorder? (If so, which medication?)

   [ ] no
   [ ] yes: ________________________

**Proceed with question 26**

**The following 2 questions are only for women**

24. In the past month, was your vagina too dry during sexual activity?

   [ ] never
   [ ] Sometimes
   [ ] regularly
   [ ] often
   [ ] not applicable

25. In the past month, have you had difficulty reaching an orgasm?

   [ ] never
   [ ] Sometimes
   [ ] regularly
   [ ] often
   [ ] not applicable
The following questions are for everyone

26. In the past month, have you used medication for:

a. constipation?  
   - no  
   - yes: _____________________________

b. urinary problems?  
   - no  
   - yes: _____________________________

c. blood pressure?  
   - no  
   - yes: _____________________________

d. other symptoms  
   (not symptoms related to Parkinson’s disease)  
   - no  
   - yes: _____________________________

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For further information, please contact M.Visser, Leiden University Medical Center, Department of Neurology (K5Q), P.O. Box 9600, NL-2300 RC Leiden (email: m.visser@lumc.nl).
Choose the best answer for how you have felt over the past week. (0 = No, 1 = Yes)

1. Are you basically satisfied with your life?  
2. Have you dropped many of your activities and interests?  
3. Do you feel that your life is empty?  
4. Do you often get bored?  
5. Are you in good spirits most of the time?  
6. Are you afraid that something bad is going to happen to you?  
7. Do you feel happy most of the time?  
8. Do you often feel helpless?  
9. Do you prefer to stay at home, rather than going out and doing new things?  
10. Do you feel you have more problems with memory than most?  
11. Do you think it is wonderful to be alive now?  
12. Do you feel pretty worthless the way you are now?  
13. Do you feel full of energy?  
14. Do you feel that your situation is hopeless?  
15. Do you think that most people are better off than you are?
How likely are you to doze off or fall asleep in situations described below, in contrast to feeling just tired? This refers to your usual way of life in recent times. Even if you haven’t done some of these things recently try to work out how they would have affected you.

Use the following scale to choose the most appropriate number for each situation:

- 0 = would never doze
- 1 = slight chance of dozing
- 2 = moderate chance of dozing
- 3 = high chance of dozing

It is important that you answer each question as best you can.

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### A. Source of Information: 1 = Patient, 2 = Caregiver, 3 = Patient and caregiver

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1. Sitting and reading
2. Watching TV
3. Sitting, inactive in a public place (e.g., a theatre or a meeting)
4. As a passenger in a car for an hour without a break
5. Lying down to rest in the afternoon when circumstances permit
6. Sitting and talking to someone
7. Sitting quietly after a lunch without alcohol
8. In a car, while stopped for a few minutes in the traffic
1. I sometimes have very vivid dreams. (0 = No, 1 = Yes)

2. My dreams frequently have an aggressive or action-packed content. (0 = No, 1 = Yes)

3. The dream contents mostly match my nocturnal behaviour. (0 = No, 1 = Yes)

4. I know that my arms or legs move when I sleep. (0 = No, 1 = Yes)

5. It thereby happened that I (almost) hurt my bed partner or myself. (0 = No, 1 = Yes)

6. I have or had the following phenomena during my dreams:
   6.1 speaking, shouting, swearing, laughing loudly (0 = No, 1 = Yes)
   6.2 sudden limb movements, “fights” (0 = No, 1 = Yes)
   6.3 gestures, complex movements, that are useless during sleep, e.g., to wave, to salute, to frighten mosquitoes, falls off the bed (0 = No, 1 = Yes)
   6.4 things that fell down around the bed, e.g., bedside lamp, book, glasses (0 = No, 1 = Yes)

7. It happens that my movements awake me. (0 = No, 1 = Yes)

8. After awakening I mostly remember the content of my dreams well. (0 = No, 1 = Yes)

9. My sleep is frequently disturbed. (0 = No, 1 = Yes)
10. I have/had a disease of the nervous system: (0 = No, 1 = Yes)

10a. stroke

10b. head trauma

10c. parkinsonism

10d. RLS

10e. narcolepsy

10f. depression

10g. epilepsy

10h. inflammatory disease of the brain

10i. other, specify: ________________________________
### MJFF LRRK2 COHORT CONSORTIUM (LRRK2C)
### UNIVERSITY OF PENNSYLVANIA SMELL ID TEST

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**Record score from each booklet.**

1. **Score from booklet #1:**

2. **Score from booklet #2:**

3. **Score from booklet #3:**

4. **Score from booklet #4:**

5. **Comments:**

________________________________________________________________________

________________________________________________________________________

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11/23/11 Page 1 of 1
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**Please indicate which measures were performed. This may be the source of data for additional research questions.**

**IMAGING**

1. DatSCAN completed? (0 = No, 1 = Yes)
   1a. If Yes (1), date DatSCAN completed:
      MM DD YYYY

2. MRI scan completed? (0 = No, 1 = Yes)
   2a. If Yes (1), date MRI scan completed:
      MM DD YYYY

3. FDG PET completed? (0 = No, 1 = Yes)
   3a. If Yes (1), date FDG PET completed:
      MM DD YYYY

4. Transcranial ultrasound completed? (0 = No, 1 = Yes)
   4a. If Yes (1), date transcranial ultrasound completed:
      MM DD YYYY

**ADDITIONAL MEASURES**

5. Post Mortem Brain collected? (0 = No, 1 = Yes)

6. DNA collected? (0 = No, 1 = Yes)

7. Lymphocytes collected? (0 = No, 1 = Yes)

8. Skin fibroblasts collected? (0 = No, 1 = Yes)