## Form B1L: Clinical Symptoms and Exam

ADC name: ______________________  Subject ID: ____________  Form date: __ __/ __ __/ __ __

Visit #: __ __ __  Examiner’s initials: __ __ __

**INSTRUCTIONS:** This form is to be completed by a clinician or other trained health professional. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form B1L. Check only one box per question.

### AUTONOMIC SYMPTOMS CHECKLIST

**In the past six months …**

<table>
<thead>
<tr>
<th>Question</th>
<th>No</th>
<th>Yes</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Does the participant dribble saliva during the day?</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>2. Does the participant have difficulty swallowing?</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>6. Does the participant report a change in the ability to taste or smell?</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>7. Does the participant experience excessive sweating (not related to hot weather)?</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>11. Does the participant have problems with constipation?</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>14. Has the participant had the feeling that after passing urine, their bladder was not completely empty?</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>17. Has the participant complained of feeling light-headed or dizzy when standing up?</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>18. Has the participant become light-headed after standing for some time?</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>19. Has the participant fainted?</td>
<td>0</td>
<td>1</td>
<td>9</td>
</tr>
</tbody>
</table>

21. **At what age did the first predominant symptom appear?** __ __ __

(777=Provided at a previous visit; 888=Not applicable; 999=Unknown)

### MEASUREMENTS

<table>
<thead>
<tr>
<th>Measurement</th>
<th>Standing position</th>
<th>Sitting position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systolic blood pressure:</td>
<td>25a. ___ ___ (888=Not assessed)</td>
<td>25b. ___ ___ (888=Not assessed)</td>
</tr>
<tr>
<td>Diastolic blood pressure:</td>
<td>26a. ___ ___ (888=Not assessed)</td>
<td>26b. ___ ___ (888=Not assessed)</td>
</tr>
<tr>
<td>Heart rate:</td>
<td>27a. ___ ___ (888=Not assessed)</td>
<td>27b. ___ ___ (888=Not assessed)</td>
</tr>
</tbody>
</table>

### AGE OF ONSET OF NON-MOTOR SYMPTOMS

<table>
<thead>
<tr>
<th>Symptom</th>
<th>__ __ __</th>
</tr>
</thead>
<tbody>
<tr>
<td>28. Age of onset of probable REM sleep behavior disorder:</td>
<td>(777=Provided at a previous visit; 888=Not applicable; 999=Unknown)</td>
</tr>
<tr>
<td>29. Age of onset of impaired smell:</td>
<td>(777=Provided at a previous visit; 888=Not applicable; 999=Unknown)</td>
</tr>
</tbody>
</table>
## AGE OF ONSET OF MOTOR SYMPTOMS

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>30. Age of onset of gait disorder:</td>
<td></td>
<td></td>
<td>(777=Provided at a previous visit; 888=Not applicable; 999=Unknown)</td>
</tr>
<tr>
<td>31. Age of onset of falls:</td>
<td></td>
<td></td>
<td>(777=Provided at a previous visit; 888=Not applicable; 999=Unknown)</td>
</tr>
<tr>
<td>32. Age of onset of tremor:</td>
<td></td>
<td></td>
<td>(777=Provided at a previous visit; 888=Not applicable; 999=Unknown)</td>
</tr>
<tr>
<td>33. Age of onset of bradykinesia:</td>
<td></td>
<td></td>
<td>(777=Provided at a previous visit; 888=Not applicable; 999=Unknown)</td>
</tr>
</tbody>
</table>
1. **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.
- □ 8  Not applicable.
- □ 9  Unknown.

2. **Salivation**

- □ 0  Normal.
- □ 1  Slight but definite excess of saliva in mouth; may have night time 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.
- □ 8  Not applicable.
- □ 9  Unknown.

3. **Swallowing**

- □ 0  Normal.
- □ 1  Rare choking.
- □ 2  Occasional choking.
- □ 3  Requires soft food.
- □ 4  Requires NG tube or gastrostomy feeding.
- □ 8  Not applicable.
- □ 9  Unknown.

---

### 4. 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.
- **8** Not applicable.
- **9** Unknown.

### 5. 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.
- **8** Not applicable.
- **9** Unknown.

### 6. 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.
- **8** Not applicable.
- **9** Unknown.

### 7. 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 bathroom.
- **4** Foley catheter or other mechanical aids.
- **8** Not applicable.
- **9** Unknown.
### 8. 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.
- **8** Not applicable.
- **9** Unknown.

### 9. 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.
- **8** Not applicable.
- **9** Unknown.

### 10. 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.
- **8** Not applicable.
- **9** Unknown.

### 11. 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.
- **8** Not applicable.
- **9** Unknown.
<table>
<thead>
<tr>
<th></th>
<th>12. Tremor</th>
<th>13. Sensory complaints related to parkinsonism</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 Absent.</td>
<td>0 None.</td>
</tr>
<tr>
<td></td>
<td>1 Slight and infrequently present.</td>
<td>1 Occasionally has numbness, tingling, or mild aching.</td>
</tr>
<tr>
<td></td>
<td>2 Moderate; bothersome to participant.</td>
<td>2 Frequently has numbness, tingling, or aching; not distressing.</td>
</tr>
<tr>
<td></td>
<td>3 Severe; interferes with many activities.</td>
<td>3 Frequent painful sensations.</td>
</tr>
<tr>
<td></td>
<td>4 Marked; interferes with most activities.</td>
<td>4 Excruciating pain.</td>
</tr>
<tr>
<td></td>
<td>8 Not applicable.</td>
<td>8 Not applicable.</td>
</tr>
<tr>
<td></td>
<td>9 Unknown.</td>
<td>9 Unknown.</td>
</tr>
</tbody>
</table>
# Form B3L: UPDRS Part III — Motor Examination

INSTRUCTIONS: This form is to be completed by the clinician or other trained health professional. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form B3L. Check only one box per question.

<table>
<thead>
<tr>
<th>1. Speech</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 Normal.</td>
</tr>
<tr>
<td>1 Slight loss of expression, diction, and/or volume.</td>
</tr>
<tr>
<td>2 Monotone, slurred but understandable; moderately impaired.</td>
</tr>
<tr>
<td>3 Marked impairment, difficult to understand.</td>
</tr>
<tr>
<td>4 Unintelligible.</td>
</tr>
<tr>
<td>8 Untestable. (SPECIFY REASON):</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Facial expression</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 Normal.</td>
</tr>
<tr>
<td>1 Minimal hypomimia, could be normal “poker face.”</td>
</tr>
<tr>
<td>2 Slight but definitely abnormal diminution of facial expression.</td>
</tr>
<tr>
<td>3 Moderate hypomimia; lips parted some of the time.</td>
</tr>
<tr>
<td>4 Masked or fixed facies with severe or complete loss of facial expression; lips parted 1/4 inch or more.</td>
</tr>
<tr>
<td>8 Untestable. (SPECIFY REASON):</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3. Tremor at rest</th>
</tr>
</thead>
<tbody>
<tr>
<td>3a. Face, lips, chin</td>
</tr>
<tr>
<td>0 Absent.</td>
</tr>
<tr>
<td>1 Slight and infrequently present.</td>
</tr>
<tr>
<td>2 Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.</td>
</tr>
<tr>
<td>3 Moderate in amplitude and present most of the time.</td>
</tr>
<tr>
<td>4 Marked in amplitude and present most of the time.</td>
</tr>
<tr>
<td>8 Untestable. (SPECIFY REASON):</td>
</tr>
</tbody>
</table>

### Tremor at rest (CONTINUED)

#### 3b. Right hand
- □ 0 Absent.
- □ 1 Slight and infrequently present.
- □ 2 Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.
- □ 3 Moderate in amplitude and present most of the time.
- □ 4 Marked in amplitude and present most of the time.
- □ 8 Untestable. *(SPECIFY REASON): ________________________________*

#### 3c. Left hand
- □ 0 Absent.
- □ 1 Slight and infrequently present.
- □ 2 Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.
- □ 3 Moderate in amplitude and present most of the time.
- □ 4 Marked in amplitude and present most of the time.
- □ 8 Untestable. *(SPECIFY REASON): ________________________________*

#### 3d. Right foot
- □ 0 Absent.
- □ 1 Slight and infrequently present.
- □ 2 Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.
- □ 3 Moderate in amplitude and present most of the time.
- □ 4 Marked in amplitude and present most of the time.
- □ 8 Untestable. *(SPECIFY REASON): ________________________________*

#### 3e. Left foot
- □ 0 Absent.
- □ 1 Slight and infrequently present.
- □ 2 Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.
- □ 3 Moderate in amplitude and present most of the time.
- □ 4 Marked in amplitude and present most of the time.
- □ 8 Untestable. *(SPECIFY REASON): ________________________________*
<table>
<thead>
<tr>
<th>Subject ID:</th>
<th>Form date:</th>
<th>Visit #:</th>
</tr>
</thead>
</table>

### 4. Action or postural tremor of hands

#### 4a. Right hand

- **0** Absent.
- **1** Slight; present with action.
- **2** Moderate in amplitude, present with action.
- **3** Moderate in amplitude with posture holding as well as action.
- **4** Marked in amplitude; interferes with feeding.
- **8** Untestable. *(SPECIFY REASON):* 

#### 4b. Left hand

- **0** Absent.
- **1** Slight; present with action.
- **2** Moderate in amplitude, present with action.
- **3** Moderate in amplitude with posture holding as well as action.
- **4** Marked in amplitude; interferes with feeding.
- **8** Untestable. *(SPECIFY REASON):* 

### 5. Rigidity

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

#### 5a. Neck

- **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.
- **8** Untestable. *(SPECIFY REASON):* 

#### 5b. Right upper extremity

- **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.
- **8** Untestable. *(SPECIFY REASON):* 

## Rigidity (CONTINUED)

### 5c. Left upper extremity

- **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.
- **8** Untestable. *(SPECIFY REASON): ________________________________*

### 5d. Right lower extremity

- **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.
- **8** Untestable. *(SPECIFY REASON): ________________________________*

### 5e. Left lower extremity

- **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.
- **8** Untestable. *(SPECIFY REASON): ________________________________*

### 6. Finger taps

*(Participant taps thumb with index finger in rapid succession with widest amplitude possible, each hand separately.)*

#### 6a. Right hand

- **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.
- **8** Untestable. *(SPECIFY REASON): ________________________________*
### Finger taps (CONTINUED)

**6b. Left hand**

- □ 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.
- □ 8 Untestable. *(SPECIFY REASON): ____________________________*

### Hand movements

*(Participant opens and closes hands in rapid succession with widest amplitude possible, each hand separately.)*

**7a. Right hand**

- □ 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.
- □ 8 Untestable. *(SPECIFY REASON): ____________________________*

**7b. Left hand**

- □ 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.
- □ 8 Untestable. *(SPECIFY REASON): ____________________________*

### Rapid alternating movements of hands

*(Pronation-supination movements of hands, vertically or horizontally, with as large an amplitude as possible, both hands simultaneously.)*

**8a. Right hand**

- □ 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.
- □ 8 Untestable. *(SPECIFY REASON): ____________________________*
### Rapid alternating movements of hands (CONTINUED)

#### 8b. Left hand
- **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.
- **8** Untestable. *(SPECIFY REASON): ________________________________*

#### 9. Leg agility
*(Participant taps heel on ground in rapid succession, picking up entire leg. Amplitude should be about 3 inches.)*

#### 9a. Right leg
- **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.
- **8** Untestable. *(SPECIFY REASON): ________________________________*

#### 9b. Left leg
- **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.
- **8** Untestable. *(SPECIFY REASON): ________________________________*

#### 10. Arising from chair
*(Participant 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.
- **8** Untestable. *(SPECIFY REASON): ________________________________*
### 11. 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.
- **8** Untestable. *(SPECIFY REASON):* ____________________________________________________________________________

### 12. 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.
- **8** Untestable. *(SPECIFY REASON):* ____________________________________________________________________________

### 13. Postural stability

*(Response to sudden posterior displacement produced by pull on shoulders while participant erect with eyes open and feet slightly apart. Participant 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.
- **8** Untestable. *(SPECIFY REASON):* ____________________________________________________________________________

### 14. Body bradykinesia and hypokinesia

*(Combining slowness, hesitancy, decreased armswing, 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.
- **8** Untestable. *(SPECIFY REASON):* ____________________________________________________________________________
### 15. Modified Hoehn and Yahr staging

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>No signs of disease.</td>
</tr>
<tr>
<td>1</td>
<td>Unilateral disease.</td>
</tr>
<tr>
<td>1.5</td>
<td>Unilateral plus axial involvement.</td>
</tr>
<tr>
<td>2</td>
<td>Bilateral disease, without impairment of balance.</td>
</tr>
<tr>
<td>2.5</td>
<td>Mild bilateral disease, with recovery on pull test.</td>
</tr>
<tr>
<td>3</td>
<td>Mild to moderate bilateral disease; some postural instability; physically independent.</td>
</tr>
<tr>
<td>4</td>
<td>Severe disability; still able to walk or stand unassisted.</td>
</tr>
<tr>
<td>5</td>
<td>Wheelchair-bound or bedridden unless aided.</td>
</tr>
<tr>
<td>6</td>
<td>Untestable. (SPECIFY REASON):</td>
</tr>
</tbody>
</table>

SPECIFY REASON:
**NACC UNIFORM DATA SET (UDS) LBD MODULE V3.1 SHORT VERSION**

### **Form B4L: Neuropsychiatric Inventory (NPI)**

ADC name: __________________________  Subject ID: ____________  Form date: ___________/_________/__________

Visit #: __________  Examiner’s initials: __________

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**INSTRUCTIONS:** This form is to be completed by a clinician or other trained health professional based on co-participant interview. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form B4L. Check only one box per question.

**Inquire about symptoms the last four weeks before visit.**

#### **DELUSIONS**

1. Does the participant have beliefs that you know are not true (for example, insisting that people are trying to harm him/her or steal from him/her)? Has he/she said that family members are not who they say they are or that the house is not their home? I’m not asking about mere suspiciousness; I am interested if the participant is **convinced** that these things are happening to him/her.

   - [ ] 0  No (SKIPP TO QUESTION 2)
   - [ ] 1  Yes (COMPLETE QUESTIONS 1a – 1j)
   - [ ] 8  Not applicable (SKIPP TO QUESTION 2)

   | 1a.  | Does the participant believe that he/she is in danger — that others are planning to hurt him/her? | [ ] 0  No | [ ] 1  Yes |
   | 1b.  | Does the participant believe that others are stealing from him/her? | [ ] 0  No | [ ] 1  Yes |
   | 1c.  | Does the participant believe that his/her spouse is having an affair? | [ ] 0  No | [ ] 1  Yes |
   | 1d.  | Does the participant believe that unwelcome guests are living in his/her house? | [ ] 0  No | [ ] 1  Yes |
   | 1e.  | Does the participant believe that his/her spouse or others are not who they claim to be? | [ ] 0  No | [ ] 1  Yes |
   | 1f.  | Does the participant believe that his/her house is not his/her home? | [ ] 0  No | [ ] 1  Yes |
   | 1g.  | Does the participant believe that family members plan to abandon him/her? | [ ] 0  No | [ ] 1  Yes |
   | 1h.  | Does the participant believe that television or magazine figures are actually present in the home? [Does he/she try to talk or interact with them?] | [ ] 0  No | [ ] 1  Yes |
   | 1i.  | Does the participant believe any other unusual things that I haven’t asked about? | [ ] 0  No | [ ] 1  Yes |

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### HALLUCINATIONS

2. Does the participant have hallucinations such as seeing false visions or hearing imaginary voices? Does he/she seem to see, hear, or experience things that are not present? By this question, we do not mean just mistaken beliefs such as stating that someone who has died is still alive; rather we are asking if the participant actually has abnormal experiences of sounds or visions.

- **0** No (SKIP TO QUESTION 3)
- **1** Yes (COMPLETE QUESTIONS 2a – 2g)
- **8** Not applicable (SKIP TO QUESTION 3)

<table>
<thead>
<tr>
<th>Question</th>
<th>0 No</th>
<th>1 Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>2a. Does the participant describe hearing voices or acts if he/she hears voices?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2b. Does the participant talk to people who are not there?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2c. Does the participant describe seeing things not seen by others or behave as if he/she is seeing things not seen by others?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2d. Does the participant report smelling odors not smelled by others?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2e. Does the participant describe feeling things on his/her skin or otherwise appear to be feeling things crawling or touching him/her?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2f. Does the participant describe tastes that are without any known cause?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2g. Does the participant describe any other unusual sensory experiences?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### ANXIETY

3. Is the participant very nervous, worried, or frightened for no apparent reason? Does he/she seem very tense or fidgety? Is the participant afraid to be apart from you?

- **0** No (SKIP TO QUESTION 4)
- **1** Yes (COMPLETE QUESTIONS 3a – 3g)
- **8** Not applicable (SKIP TO QUESTION 4)

<table>
<thead>
<tr>
<th>Question</th>
<th>0 No</th>
<th>1 Yes</th>
</tr>
</thead>
<tbody>
<tr>
<td>3a. Does the participant say that he/she is worried about planned events?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3b. Does the participant have periods of feeling shaky, unable to relax, or feeling excessively tense?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3c. Does the participant have periods of (or complain of) shortness of breath, gasping, or sighing for no apparent reason other than nervousness?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3d. Does the participant complain of butterflies in his/her stomach, or of racing or pounding of the heart in association with nervousness (symptoms not explained by ill health)?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3e. Does the participant avoid certain places or situations that make him/her more nervous such as riding in the car, meeting with friends, or being in crowds?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3f. Does the participant become nervous and upset when separated from you [or his/her caregiver]? [Does he/she cling to you to keep from being separated?]</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3g. Does the participant show any other signs of anxiety?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## APATHY / INDIFFERENCE

4. Has the participant lost interest in the world around him/her? Has he/she lost interest in doing things or lack motivation for starting new activities? Is he/she more difficult to engage in conversation or in doing chores? Is the participant apathetic or indifferent?

- **0** No (END FORM HERE)
- **1** Yes (COMPLETE QUESTIONS 4a – 4h)
- **8** Not applicable (END FORM HERE)

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4a.</td>
<td>Does the participant seem less spontaneous and less active than usual?</td>
</tr>
<tr>
<td></td>
<td>□ 0 No  □ 1 Yes</td>
</tr>
<tr>
<td>4b.</td>
<td>Is the participant less likely to initiate a conversation?</td>
</tr>
<tr>
<td></td>
<td>□ 0 No  □ 1 Yes</td>
</tr>
<tr>
<td>4c.</td>
<td>Is the participant less affectionate or lacking in emotions when compared to his/her usual self?</td>
</tr>
<tr>
<td></td>
<td>□ 0 No  □ 1 Yes</td>
</tr>
<tr>
<td>4d.</td>
<td>Does the participant contribute less to household chores?</td>
</tr>
<tr>
<td></td>
<td>□ 0 No  □ 1 Yes</td>
</tr>
<tr>
<td>4e.</td>
<td>Does the participant seem less interested in the activities and plans of others?</td>
</tr>
<tr>
<td></td>
<td>□ 0 No  □ 1 Yes</td>
</tr>
<tr>
<td>4f.</td>
<td>Has the participant lost interest in friends and family members?</td>
</tr>
<tr>
<td></td>
<td>□ 0 No  □ 1 Yes</td>
</tr>
<tr>
<td>4g.</td>
<td>Is the participant less enthusiastic about his/her usual interests?</td>
</tr>
<tr>
<td></td>
<td>□ 0 No  □ 1 Yes</td>
</tr>
<tr>
<td>4h.</td>
<td>Does the participant show any other signs that he/she doesn’t care about doing new things?</td>
</tr>
<tr>
<td></td>
<td>□ 0 No  □ 1 Yes</td>
</tr>
</tbody>
</table>
**FOLLOW-UP VISIT PACKET**  
**NACC UNIFORM DATA SET (UDS) LBD MODULE V3.1 SHORT VERSION**

**Form B5L: Mayo Fluctuations Scale**

ADC name: ____________________  
Subject ID: ________________  
Form date: ___/___/____  
Visit #: __________  
Examiner's initials: ____________

INSTRUCTIONS: This form is to be completed by a clinician or other trained health professional, based on co-participant response. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form B5L. Check only one box per question.

**DIRECTIONS:** Please mark the answer that best describes the participant within the past 6 months.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 1. Is the participant drowsy and lethargic during the day, despite getting enough sleep the night before? | ☐ 0 No  
☐ 1 Yes  
☐ 9 Unknown |
| 2. Does the participant sleep 2 or more hours during the day (before 7:00 p.m.)? | ☐ 0 No  
☐ 1 Yes  
☐ 9 Unknown |
| 3. Are there times when the participant's flow of ideas is disorganized, unclear, or not logical? | ☐ 0 No  
☐ 1 Yes  
☐ 9 Unknown |
| 4. Does the participant tend to stare into space for long periods of time? | ☐ 0 No  
☐ 1 Yes  
☐ 9 Unknown |
# Follow-up Visit Packet
## NACC Uniform Data Set (UDS) LBD Module V3.1 Short Version

### Form B6L: Mayo Sleep Questionnaire — Participant

<table>
<thead>
<tr>
<th>ADC name:</th>
<th>Subject ID:</th>
<th>Form date:</th>
<th>Visit #:</th>
<th>Examiner’s initials:</th>
</tr>
</thead>
</table>

**INSTRUCTIONS:** This form is to be completed by a clinician or other trained health professional based on the participant’s response. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form B6L. Check only one box per question.

---

### For Clinician Use Only

0. Is the participant too cognitively impaired (e.g., CDR>1) to complete this form?

- [ ] 0 No (CONTINUE TO ADMINISTER QUESTIONNAIRE)
- [x] 1 Yes (END FORM HERE)

---

Please mark “Yes” if the described event has occurred at least 3 times.

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
</table>
| 1. Have you ever been told that you seem to “act out your dreams” while sleeping (punched or flailed arms in the air, shouted or screamed)? | [ ] 0 No (SKIP TO QUESTION 2)  
[ ] 1 Yes (COMPLETE QUESTIONS 1a – 1e) |
| 1a. How many months or years has this been going on? | [ ] ___ year(s)  
[ ] ___ month(s) |
| 1b. Have you ever been injured from these behaviors (bruises, cuts, broken bones)? | [ ] 0 No  
[ ] 1 Yes |
| 1c. Has a bedpartner ever been injured from these behaviors (bruises, blows, pulled hair)? | [ ] 0 No  
[ ] 1 Yes  
[ ] 8 No bedpartner |
| 1d. Have you had dreams of being chased or attacked, or that involve defending yourself? | [ ] 0 No  
[ ] 1 Yes |
| 1e. Have you been told that you make movements while sleeping that seem to match the details of your dream? | [ ] 0 No  
[ ] 1 Yes |
2. Have you been told that your legs repeatedly jerk or twitch during sleep (not just when falling asleep)?

| □ | No |
| □ | Yes |

3. Does a restless, nervous, tingly, or creepy-crawly feeling in your legs make it hard to fall or stay asleep?

| □ | No (SKIP TO QUESTION 4) |
| □ | Yes (COMPLETE QUESTIONS 3a – 3c) |

3a. Do you experience an irresistible urge to move the legs at those times?

| □ | No |
| □ | Yes |

3b. Do the uncomfortable leg sensations decrease when you move them or when you walk around?

| □ | No |
| □ | Yes |

3c. When do these sensations seem to be worse?

| □ | Before 6:00 p.m. |
| □ | After 6:00 p.m. |

4. Have you ever walked around the bedroom or house in your sleep?

| □ | No |
| □ | Yes |

5. Have you ever snorted or choked yourself awake?

| □ | No |
| □ | Yes |

6. Have you ever been told that you stop breathing in your sleep?

| □ | No (SKIP TO QUESTION 7) |
| □ | Yes (COMPLETE QUESTION 6a) |

6a. Are you currently being treated for this (e.g., CPAP)?

| □ | No |
| □ | Yes |

7. Do you experience leg cramps at night (e.g., also called a “charlie horse” with intense pain in certain muscles in the leg)?

| □ | No |
| □ | Yes |

8. Rate your general level of alertness for the past 3 weeks on a scale from 0 to 10: ___

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sleep all day</td>
<td>Fully and normally awake</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## Form B7L: Mayo Sleep Questionnaire — Co-participant

<table>
<thead>
<tr>
<th>ADC name:</th>
<th>Subject ID:</th>
<th>Form date:</th>
<th>Visit #:</th>
<th>Examiner’s initials:</th>
</tr>
</thead>
</table>

**INSTRUCTIONS:** This form is to be completed by a clinician or other trained health professional based on the co-participant’s response. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form B7L. Check only one box per question.

1. **Do you live with the participant?**
   - [ ] 0 No  (END FORM HERE)
   - [ ] 1 Yes  (CONTINUE TO QUESTION 2)

2. **Do you sleep in the same room as the participant?**
   - [ ] 0 No  (CONTINUE TO QUESTION 2a)
   - [ ] 1 Yes  (SKIP TO QUESTION 3)

2a. **If no, is it because of his/her sleep behaviors (i.e., snores too loud, acts out dreams, etc.)?**
   - [ ] 0 No
   - [ ] 1 Yes

Please mark “Yes” if the described event has occurred at least 3 times.

3. **Have you ever seen the participant appear to “act out his/her dreams” while sleeping (punched or flailed arms in the air, shouted, or screamed)?**
   - [ ] 0 No  (SKIP TO QUESTION 4)
   - [ ] 1 Yes  (COMPLETE QUESTIONS 3a – 3e)

3a. **How many months or years has this been going on?**
   - ______ year(s)
   - ______ month(s)

3b. **Has the participant ever been injured from these behaviors (bruises, cuts, broken bones)?**
   - [ ] 0 No
   - [ ] 1 Yes

3c. **Has a bedpartner ever been injured from these behaviors (bruises, blows, pulled hair)?**
   - [ ] 0 No
   - [ ] 1 Yes
   - [ ] 8 No bedpartner

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3d. Has the participant told you about dreams of being chased or attacked, or that involve defending himself/herself?

- **0** No
- **1** Yes
- **8** Never told me about dreams

3e. If the participant woke up and told you about a dream, did the details of the dream match the movements made while sleeping?

- **0** No
- **1** Yes
- **8** Never told me about dreams

4. Do the participant's legs repeatedly jerk or twitch during sleep (not just when falling asleep)?

- **0** No
- **1** Yes

5. Does the participant complain of a restless, nervous, tingly, or creepy-crawly feeling in his/her legs that disrupts his/her ability to fall or stay asleep?

- **0** No (SKIP TO QUESTION 6)
- **1** Yes (COMPLETE QUESTIONS 5a – 5b)

5a. Does the participant tell you that these leg sensations decrease when he/she moves them or walks around?

- **0** No
- **1** Yes

5b. When do these sensations seem to be the worst?

- **1** Before 6:00 p.m.
- **2** After 6:00 p.m.

6. Has the participant ever walked around the bedroom or house while asleep?

- **0** No
- **1** Yes

7. Has the participant ever snorted or choked him/herself awake?

- **0** No
- **1** Yes

8. Does the participant ever seem to stop breathing during sleep?

- **0** No (SKIP TO QUESTION 9)
- **1** Yes (COMPLETE QUESTION 8a)

8a. Is the participant currently being treated for this (e.g., CPAP)?

- **0** No
- **1** Yes

9. Does the participant have leg cramps at night (e.g., also called a “charlie horse” with intense pain in certain muscles in the leg)?

- **0** No
- **1** Yes

10. Rate the participant's general level of alertness for the past 3 weeks on a scale from 0 to 10: __ __

    0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10

    Sleep all day  Fully and normally awake
Section I: Co-participant

CO-PARTICIPANT INSTRUCTIONS

By means of this questionnaire, we would like to find out to what extent in the past month the participant has had problems with sleeping. Some of the questions are about problems with sleeping at night, such as, for example, not being able to fall asleep or not managing to sleep on. Another set of questions is about problems with sleeping during the day, such as dozing off (too) easily and having trouble staying awake.

First read these instructions before you answer the questions!

Place a cross in the box corresponding to the answer that best reflects the situation. If you wish to change an answer, fill in the “wrong” box and place a cross in the correct one. If the participant has been using sleeping tablets, then the answer should reflect how s/he has slept while taking these tablets.

**Nighttime sleep**

<table>
<thead>
<tr>
<th>In the past month, how often has the participant ...</th>
<th>Not at all</th>
<th>A little</th>
<th>Quite a bit</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Had trouble falling asleep when they went to bed at night</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Felt that they have woken too often</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Felt that they have been lying awake for too long at night</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Felt that they have woken too early in the morning</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Felt they have had too little sleep at night</td>
<td></td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Overall, how well has the participant slept at night during the past month? <em>(CHOOSE ONE)</em>:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 1 Very well</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 2 Well</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 3 Rather well</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 4 Not well but not badly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 5 Rather badly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 6 Badly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>□ 7 Very badly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Adapted from Marinus J, Visser M, van Hilten JJ, Lammers GJ, Stiggelbout AM. Assessment of sleep and sleepiness in Parkinson disease. SLEEP 2003;26:1049-1054. For further information, please contact Dr. J. Marinus, Leiden University Medical Center, Department of Neurology (K5Q), P.O. Box 9600, NL-2300 RC Leiden (email: j.marinus@lumc.nl).

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<table>
<thead>
<tr>
<th>Daytime sleepiness</th>
<th>Never</th>
<th>Sometimes</th>
<th>Regularly</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. Fallen asleep unexpectedly during the day or in the evening</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>8. Fallen asleep while sitting peacefully</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>9. Fallen asleep while watching TV or reading</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>10. Fallen asleep while talking to someone</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>11. Had trouble staying awake during the day or in the evening</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
<tr>
<td>12. Experienced falling asleep during the day as a problem</td>
<td>☐ 0</td>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
</tr>
</tbody>
</table>
### Form C1L: Neuropsychological Battery Scores

ADC name: ___________________________  Subject ID: ____________  Form date: ___ / ___ / ___

Visit #: __________  Examiner’s initials: __________

**INSTRUCTIONS:** This form is to be completed by ADC or clinic staff. For test administration and scoring, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form C1L.

**KEY:** If the participant cannot complete any of the following exams, please give the reason by entering one of the following codes:

- 95/995 = Physical problem
- 96/996 = Cognitive/behavior problem
- 97/997 = Other problem
- 98/998 = Verbal refusal

<table>
<thead>
<tr>
<th>Question</th>
<th>Score Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>2a. Correct <strong>YES</strong> Face Responses:</td>
<td>(0 – 7, 95 – 98)</td>
</tr>
<tr>
<td>2b. Correct <strong>NO</strong> Noise Responses:</td>
<td>(0 – 13)</td>
</tr>
<tr>
<td>2c. Total <strong>YES</strong> and <strong>NO</strong> Correct:</td>
<td>(0 – 20)</td>
</tr>
<tr>
<td>2d. Pareidolia (Illusory) Responses:</td>
<td>(0 – 13)</td>
</tr>
</tbody>
</table>
**FOLLOW-UP VISIT PACKET**  
**NACC UNIFORM DATA SET (UDS) LBD MODULE V3.1 SHORT VERSION**

**Form E1L: Genetics**

ADC name: ________________________  
Subject ID: ________________________  
Form date: __________ / __________ / __________

Visit #: __________  
Examiner’s initials: __________

**INSTRUCTIONS:** This form is to be completed by a clinician with experience in evaluating family history. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form E1L.

1. Since the last visit, is new information available concerning the genetic mutations listed below?
   - [ ] 0  No  **(END FORM HERE)**
   - [ ] 1  Yes  **(CONTINUE)**

<table>
<thead>
<tr>
<th>Mutation</th>
<th>No</th>
<th>Yes</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. LRRK2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. PARK2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. PARK7</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. PINK1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. SNCA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. GBA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Other (SPECIFY):</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>If yes, information source (see KEY)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2a. [ ] 1  [ ] 2  [ ] 3  [ ] 9</td>
</tr>
<tr>
<td>3a. [ ] 1  [ ] 2  [ ] 3  [ ] 9</td>
</tr>
<tr>
<td>4a. [ ] 1  [ ] 2  [ ] 3  [ ] 9</td>
</tr>
<tr>
<td>5a. [ ] 1  [ ] 2  [ ] 3  [ ] 9</td>
</tr>
<tr>
<td>6a. [ ] 1  [ ] 2  [ ] 3  [ ] 9</td>
</tr>
<tr>
<td>7a. [ ] 1  [ ] 2  [ ] 3  [ ] 9</td>
</tr>
<tr>
<td>8a. [ ] 1  [ ] 2  [ ] 3  [ ] 9</td>
</tr>
</tbody>
</table>

**KEY:**  
1 = Commercial laboratory test documentation  
2 = Research laboratory test documentation  
3 = Family report (select only if no laboratory test was done)  
9 = Unknown
**FOLLOW-UP VISIT PACKET**  
NACC UNIFORM DATA SET (UDS)  
**LBD MODULE V3.1 SHORT VERSION**  

**Form E2L: Neuroimaging Available and Findings**

ADC name: ______________ Subject ID: ____________ Form date: __ / __ / __________

Visit #: ___________ Examiner’s initials: ___________

**INSTRUCTIONS:** This form is to be completed by the clinician or imaging specialist involved in interpreting the scan. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form E2L. Check only one box per question.

### STRUCTURAL MRI

1. **Has the participant had at least one structural MRI scan that has not yet been recorded, obtained as part of the current evaluation or a previous evaluation?**
   - [ ] 0 No or unknown (SKIP TO QUESTION 2)
   - [ ] 1 Yes (CONTINUE)

   1c. **Was there an MRI finding of hippocampal atrophy, according to your Center’s standards for positivity? (REPORT MOST RECENT)**
   - [ ] 0 No
   - [ ] 1 Yes
   - [ ] 8 Results not available
   - [ ] 9 Unknown

   1d. **Is an MRI available for data sharing?**
   - [ ] 0 No or unknown
   - [ ] 1 Yes

### FDG-PET

2. **Has the participant had at least one FDG-PET scan that has not yet been recorded, obtained as part of the current evaluation or a previous evaluation?**
   - [ ] 0 No or unknown (SKIP TO QUESTION 3)
   - [ ] 1 Yes (CONTINUE)

   Questions 2c – 2e refer to MOST RECENT SCAN:

   2c. **Was there an FDG-PET finding of occipital hypometabolism consistent with LBD, according to your Center’s standards for positivity?**
   - [ ] 0 No
   - [ ] 1 Yes
   - [ ] 8 Results not available
   - [ ] 9 Unknown

   2d. **Was there an FDG-PET finding of temporoparietal hypometabolism suggestive of AD, according to your Center’s standards for positivity?**
   - [ ] 0 No
   - [ ] 1 Yes
   - [ ] 8 Results not available
   - [ ] 9 Unknown

   2e. **Was there an FDG-PET finding of cingulate island sign consistent with LBD, according to your Center’s standards for positivity?**
   - [ ] 0 No
   - [ ] 1 Yes
   - [ ] 8 Results not available
   - [ ] 9 Unknown

   2f. **Is an FDG-PET available for data sharing?**
   - [ ] 0 No or unknown
   - [ ] 1 Yes
### AMYLOID PET

<table>
<thead>
<tr>
<th>3. Has the participant had at least one amyloid PET scan that has not yet been recorded, obtained as part of the current evaluation or a previous evaluation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>3c. Is an amyloid PET available for data sharing?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>9</td>
</tr>
</tbody>
</table>

### TAU PET

<table>
<thead>
<tr>
<th>4. Has the participant had at least one Tau PET scan that has not yet been recorded, obtained as part of the current evaluation or a previous evaluation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>4c. Is a Tau PET available for data sharing?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>9</td>
</tr>
</tbody>
</table>

### DaTScan

<table>
<thead>
<tr>
<th>5. Has the participant had at least one DaTScan scan that has not yet been recorded, obtained as part of the current evaluation or a previous evaluation?</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5c. Were there abnormal DaTScan findings consistent with LBD, according to your Center's standards for positivity? (REPORT MOST RECENT)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
</tr>
<tr>
<td>1</td>
</tr>
<tr>
<td>8</td>
</tr>
<tr>
<td>9</td>
</tr>
</tbody>
</table>
### Polysomnography

1. Has the participant had at least one polysomnography that has not yet been recorded, obtained as part of the current evaluation or a previous evaluation?  
   - 0 No or unknown (SKIP TO QUESTION 2)  
   - 1 Yes (CONTINUE)

1b. Was there polysomnographic confirmation of REM sleep without atonia, +/- dream enactment behavior, consistent with LBD, according to your Center's standards for positivity? (REPORT MOST RECENT)  
   - 0 No  
   - 1 Yes  
   - 8 Results not available  
   - 9 Unknown

1c. Is a polysomnography available for data sharing?  
   - 0 No or unknown  
   - 1 Yes

### Cardiac-MIBG scintigraphy

2. Has the participant had at least one cardiac-MIBG scintigraphy that has not yet been recorded, obtained as part of the current evaluation or a previous evaluation?  
   - 0 No or unknown (SKIP TO QUESTION 3)  
   - 1 Yes (CONTINUE)

2b. Were there abnormal (low uptake) MIBG myocardial scintigraphy results consistent with LBD, according to your Center's standards for positivity? (REPORT MOST RECENT)  
   - 0 No  
   - 1 Yes  
   - 8 Results not available  
   - 9 Unknown

2c. Is a cardiac-MIBG available for data sharing?  
   - 0 No or unknown  
   - 1 Yes, raw data available  
   - 2 Yes, processed data available  
   - 3 Yes, both raw and processed data available

### Anosmia test (e.g., UPSIT)

3. Has the participant had at least one anosmia test that has not yet been recorded, obtained as part of the current evaluation or a previous evaluation?  
   - 0 No or unknown (SKIP TO QUESTION 9)  
   - 1 Yes (CONTINUE)

3b. Were the anosmia test results consistent with LBD, according to your Center's standards for positivity? (REPORT MOST RECENT)  
   - 0 No  
   - 1 Yes  
   - 8 Results not available  
   - 9 Unknown
### 3c. Are anosmia test data available for sharing?
- **0** No or unknown (**SKIP TO QUESTION 9**)
- **1** Yes

### 3d. Which test was done (that is available for sharing)?
- **1** University of Pennsylvania Smell Identification Test (UPSIT)
- **2** Brief-smell identification test (B-SIT)
- **3** Sniffin Sticks
- **4** Other (SPECIFY):

---

### Computerized gait testing

### 9. Has the participant had at least one computerized gait testing that has not yet been recorded, obtained as part of the current evaluation or a previous evaluation?
- **0** No or unknown (**END FORM HERE**)
- **1** Yes (CONTINUE)

### 9b. Were the computerized gait testing results consistent with LBD, according to your Center’s standards for positivity? (REPORT MOST RECENT)
- **0** No
- **1** Yes
- **8** Results not available
- **9** Unknown

### 9c. Are computerized gait testing data available for sharing?
- **0** No or unknown
- **1** Yes, raw data available
- **2** Yes, processed data available
- **3** Yes, both raw and processed data available
Form D1L: Clinical DLB and PD Features

INSTRUCTIONS: This form is to be completed by the clinician. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form D1L. Check only one box per question.

Gateway question for cognitive symptoms

1. Is an acquired disorder of cognition a prominent element of the clinical presentation of the participant? (i.e., at least one of the characteristics described in Questions 1a–1e is “Definitely present.”)
   
   □ 0 No (SKIP TO QUESTION 2)
   □ 1 Yes (CONTINUE)

Characterizing cognitive symptoms

Please indicate whether any of the features listed below are present during the current examination.

<table>
<thead>
<tr>
<th>Question</th>
<th>Absent</th>
<th>Questionably present</th>
<th>Definitely present</th>
<th>Not evaluated</th>
</tr>
</thead>
<tbody>
<tr>
<td>1a. Episodic memory deficits</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>1b. Language deficits</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>1c. Attention deficits</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>1d. Executive deficits</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>1e. Visuoperceptual deficits</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
</tbody>
</table>

Gateway question for motor symptoms

2. Is an acquired disorder of movement a prominent element of the clinical presentation of the participant? (i.e., at least one of the characteristics described in Questions 2a–2h is “Definitely present.”)
   
   □ 0 No (SKIP TO QUESTION 3)
   □ 1 Yes (CONTINUE)

Characterizing motor symptoms

Please indicate whether any of the features listed below are present during the current examination.

<table>
<thead>
<tr>
<th>Question</th>
<th>Absent</th>
<th>Questionably present</th>
<th>Definitely present</th>
<th>Not evaluated</th>
</tr>
</thead>
<tbody>
<tr>
<td>2a. Bradykinesia</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>2b. Rigidity (with or without cogwheel characteristics)</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>2c. Rest tremor</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>2d. Postural tremor</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>2e. Action tremor</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
</tbody>
</table>
### 2f. Myoclonus
- **Absent**: 0
- **Questionably present**: 1
- **Definitely present**: 2
- **Not evaluated**: 8

### 2g. Gait abnormality
- **Absent**: 0
- **Questionably present**: 1
- **Definitely present**: 2
- **Not evaluated**: 8

### 2h. Postural instability
- **Absent**: 0
- **Questionably present**: 1
- **Definitely present**: 2
- **Not evaluated**: 8

---

**Gateway question for behavioral symptoms**

3. Is an acquired disorder of behavior a prominent element of the clinical presentation of the participant? (i.e., at least one of the characteristics described in Questions 3a–3e is “Definitely present.”)

- [ ] 0 No (SKIP TO QUESTION 4)
- [ ] 1 Yes (CONTINUE)

---

**Characterizing behavioral symptoms**

Please indicate whether any of the features listed below are present during the current examination.

<table>
<thead>
<tr>
<th>Question</th>
<th>Absent</th>
<th>Questionably present</th>
<th>Definitely present</th>
<th>Not evaluated</th>
</tr>
</thead>
<tbody>
<tr>
<td>3a. Depression</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>3b. Apathy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>3c. Anxiety</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>3d. Hallucinations</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>3e. Delusions</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
</tbody>
</table>

---

**Gateway question for autonomic or constitutional symptoms**

4. Is an acquired disorder of autonomic or constitutional features a prominent element of the clinical presentation of the participant? (i.e., at least one of the characteristics described in Questions 4a–4l is “Definitely present.”)

- [ ] 0 No (SKIP TO QUESTION 5)
- [ ] 1 Yes (CONTINUE)

---

**Characterizing autonomic or constitutional symptoms**

Please indicate whether any of the features listed below are present during the current examination.

<table>
<thead>
<tr>
<th>Question</th>
<th>Absent</th>
<th>Questionably present</th>
<th>Definitely present</th>
<th>Not evaluated</th>
</tr>
</thead>
<tbody>
<tr>
<td>4a. REM sleep behavior disorder</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>4b. Obstructive sleep apnea</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>4c. Periodic leg movements of sleep</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>4d. Restless leg syndrome</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>4e. Excessive daytime sleepiness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>4f. Cognitive fluctuations</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>4g. Orthostatic hypotension</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Question</td>
<td>Absent</td>
<td>Questionably present</td>
<td>Definitely present</td>
<td>Not evaluated</td>
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<tr>
<td>--------------------------------</td>
<td>--------</td>
<td>----------------------</td>
<td>-------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>4h. Constipation</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>4i. Hyposmia</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>4j. Falls</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>4k. Syncope</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
<tr>
<td>4l. Severe sensitivity to anti-psychotic agents</td>
<td>□ 0</td>
<td>□ 1</td>
<td>□ 2</td>
<td>□ 8</td>
</tr>
</tbody>
</table>

**Cognitive status and etiology**

5. What is the participant’s cognitive status?
   - □ 1 Normal cognition
   - □ 2 Cognitively impaired, not MCI
   - □ 3 MCI
   - □ 4 Dementia

6. Which etiologic diagnosis best characterizes the participant?
   - □ 1 Dementia with Lewy bodies
   - □ 2 Parkinson’s disease
   - □ 3 Alzheimer’s disease
   - □ 4 Vascular disease
   - □ 5 FTLD
   - □ 6 Other
   - □ 8 Not applicable — no neurodegenerative disease and no cognitive impairment