



NACC UNIFORM DATA SET

LBD MODULE V3.1 — SHORT VERSION

Follow-up Visit Packet

LBD Module v3.1, February 2020

UDS Version 3.0, March 2015

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Form Z1X: Form Checklist

ADC name: _____ Subject ID: _____ Form date: ____/____/____
 Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: This form is to be completed by clinic personnel.

NACC expects and intends that all UDS forms will be attempted on all subjects, but we realize this may be impossible when the patient is terminally ill, or when there is no co-participant, or for other reasons. An explanation is required below for forms that are not submitted.

UDS

Form	Language:		Description	Submitted:		If not submitted, specify reason (see KEY):
	English	Spanish		Yes	No	
A1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Demographics	Required		
A2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Co-participant Demographics	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
A3	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Family History	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
A4	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject Medications	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	EVALUATION FORM Physical	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B4	<input type="checkbox"/> 1	<input type="checkbox"/> 2	CDR® Plus NACC FTLD	Required		
B5	<input type="checkbox"/> 1	<input type="checkbox"/> 2	BEHAVIORAL ASSESSMENT NPI-Q	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B6	<input type="checkbox"/> 1	<input type="checkbox"/> 2	BEHAVIORAL ASSESSMENT GDS	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B7	<input type="checkbox"/> 1	<input type="checkbox"/> 2	FUNCTIONAL ASSESSMENT NACC FAS	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B8	<input type="checkbox"/> 1	<input type="checkbox"/> 2	EVALUATION FORM Neurological Examination Findings	Required		
B9	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician Judgment of Symptoms	Required		
C1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Neuropsychological Battery Summary Scores	Either C1 or C2 is required		
C2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Neuropsychological Battery Scores			
D1	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician Diagnosis	Required		
D2	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinician-assessed Medical Conditions	Required		

FTLD MODULE

Form	Language:		Description	Submitted:		If not submitted, specify reason (see KEY*):
	English	Spanish		Yes	No	
A3a	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Record of Consent for Biologic Specimen Use	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B3F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Supplemental UPDRS	Required		
B9F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Clinical PPA and bvFTD Features	Required		
C1F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Neuropsychological Battery Summary Scores	Required		
C2F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Social Norms Questionnaire	Required		
C3F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Social Behavior Observer Checklist	Required		
C4F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Behavioral Inhibition Scale	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
C5F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Interpersonal Reactivity Index	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
C6F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Revised Self-monitoring Scale	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
E2F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Imaging Available	Required		
E3F	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Imaging in Diagnosis	Required		

CLS FORM

Form	Language:		Description	Submitted:		
	English	Spanish		Yes	No	
CLS	<input type="checkbox"/> 1	<input type="checkbox"/> 2	Subject's Language History	<input type="checkbox"/> 1	<input type="checkbox"/> 0	Submit only once

KEY: If the specified form was not completed, please enter one of the following codes: 95=Physical problem 96=Cognitive or behavioral problem 97=Other problem 98=Verbal refusal
 *KEY FOR FTLD MODULE ONLY: Allowable codes are 95 – 98 as above, as well as 99=Unknown or inadequate information.

LBD MODULE V3.0 — ORIGINAL VERSION

Form	Description	Submitted:	
		Yes	No
B1L	Clinical Symptoms and Exam	Required	
B2L	UPDRS II: Activities of Daily Living	Required	
B3L	UPDRS III: Motor Examination	Required	
B4L	Neuropsychiatric Inventory (NPI)	Required	
B5L	Mayo Fluctuations Scale	Required	
B6L	Mayo Sleep Questionnaire — Participant	Required	
B7L	Mayo Sleep Questionnaire — Co-participant	Required	
B8L	Scopa Sleep — Participant	Required	
B9L	Scopa Sleep — Co-participant	Required	
C1L	Neuropsychological Battery Summary Scores	Required	
E1L	Genetics	Required	
E2L	Neuroimaging Available and Findings	Required	
E3L	Other Labs and Findings	Required	
D1L	Clinical DLB and PD Features	Required	

LBD MODULE V3.1 — SHORT VERSION

Form	Description	Submitted:		If not submitted, specify reason (see KEY)*:
		Yes	No	
B1L	Clinical Symptoms and Exam	Required		
B2L	UPDRS II: Activities of Daily Living	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B3L	UPDRS III: Motor Examination	Required		
B4L	Neuropsychiatric Inventory (NPI)	Required		
B5L	Mayo Fluctuations Scale	Required		
B6L	Mayo Sleep Questionnaire — Participant	<input type="checkbox"/> 1	<input type="checkbox"/> 0	— —
B7L	Mayo Sleep Questionnaire — Co-participant	Required		
B9L	Scopa Sleep — Co-participant	Required		
C1L	Neuropsychological Battery Summary Scores	Required		
E1L	Genetics	Required		
E2L	Neuroimaging Available and Findings	Required		
E3L	Other Labs and Findings	Required		
D1L	Clinical DLB and PD Features	Required		

KEY: If the specified form was not completed, please enter one of the following codes: 95=Physical problem 96=Cognitive or behavioral problem 97=Other problem 98=Verbal refusal
***KEY FOR FTLD MODULE ONLY:** Allowable codes are 95 – 98 as above, as well as 99=Unknown or inadequate information.

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) LBD MODULE V3.1 SHORT VERSION

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

21. At what age did the first predominant symptom appear? ____ ____ ____ (777=Provided at a previous visit; 888=Not applicable; 999=Unknown)

MEASUREMENTS	Standing position	Sitting position
Systolic blood pressure:	25a. ____ ____ ____ (888=Not assessed)	25b. ____ ____ ____ (888=Not assessed)
Diastolic blood pressure:	26a. ____ ____ ____ (888=Not assessed)	26b. ____ ____ ____ (888=Not assessed)
Heart rate:	27a. ____ ____ ____ (888=Not assessed)	27b. ____ ____ ____ (888=Not assessed)

AGE OF ONSET OF NON-MOTOR SYMPTOMS

28. Age of onset of probable REM sleep behavior disorder:	____ ____ ____ (777=Provided at a previous visit; 888=Not applicable; 999=Unknown)
29. Age of onset of impaired smell:	____ ____ ____ (777=Provided at a previous visit; 888=Not applicable; 999=Unknown)

AGE OF ONSET OF MOTOR SYMPTOMS	
30. Age of onset of gait disorder:	___ ___ ___ (777=Provided at a previous visit; 888=Not applicable; 999=Unknown)
31. Age of onset of falls:	___ ___ ___ (777=Provided at a previous visit; 888=Not applicable; 999=Unknown)
32. Age of onset of tremor:	___ ___ ___ (777=Provided at a previous visit; 888=Not applicable; 999=Unknown)
33. Age of onset of bradykinesia:	___ ___ ___ (777=Provided at a previous visit; 888=Not applicable; 999=Unknown)

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) LBD MODULE **V3.1 SHORT VERSION**

Form B2L: UPDRS Part II — Activities of Daily Living (Determine for “On/Off”)¹

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____

Visit #: _____ Examiner's initials: _____

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 B2L. Check only one box per question.

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.

¹Fahn S, Elton RL, UPDRS Development Committee. The Unified Parkinson's Disease Rating Scale. In Fahn S, Marsden CD, Calne DB, Goldstein M, eds. Recent developments in Parkinson's disease, Vol. 2. Florham Park, NJ: Macmillan Healthcare Information, 1987:153-163, 293-304. Reproduced by permission of the author.

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.

12. Tremor

- 0 Absent.
- 1 Slight and infrequently present.
- 2 Moderate; bothersome to participant.
- 3 Severe; interferes with many activities.
- 4 Marked; interferes with most activities.
- 8 Not applicable.
- 9 Unknown.

13. 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.
- 8 Not applicable.
- 9 Unknown.

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) LBD MODULE V3.1 SHORT VERSION

Form B3L: UPDRS Part III — Motor Examination¹

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____
 Visit #: _____ Examiner's initials: _____

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.

<p>1. Speech</p>
<p><input type="checkbox"/>₀ Normal.</p> <p><input type="checkbox"/>₁ Slight loss of expression, diction, and/or volume.</p> <p><input type="checkbox"/>₂ Monotone, slurred but understandable; moderately impaired.</p> <p><input type="checkbox"/>₃ Marked impairment, difficult to understand.</p> <p><input type="checkbox"/>₄ Unintelligible.</p> <p><input type="checkbox"/>₈ Untestable. (SPECIFY REASON): _____</p>
<p>2. Facial expression</p>
<p><input type="checkbox"/>₀ Normal.</p> <p><input type="checkbox"/>₁ Minimal hypomimia, could be normal “poker face.”</p> <p><input type="checkbox"/>₂ Slight but definitely abnormal diminution of facial expression.</p> <p><input type="checkbox"/>₃ Moderate hypomimia; lips parted some of the time.</p> <p><input type="checkbox"/>₄ Masked or fixed facies with severe or complete loss of facial expression; lips parted 1/4 inch or more.</p> <p><input type="checkbox"/>₈ Untestable. (SPECIFY REASON): _____</p>
<p>3. Tremor at rest</p>
<p>3a. Face, lips, chin</p> <p><input type="checkbox"/>₀ Absent.</p> <p><input type="checkbox"/>₁ Slight and infrequently present.</p> <p><input type="checkbox"/>₂ Mild in amplitude and persistent. Or moderate in amplitude, but only intermittently present.</p> <p><input type="checkbox"/>₃ Moderate in amplitude and present most of the time.</p> <p><input type="checkbox"/>₄ Marked in amplitude and present most of the time.</p> <p><input type="checkbox"/>₈ Untestable. (SPECIFY REASON): _____</p>

¹Fahn S, Elton RL, UPDRS Development Committee. The Unified Parkinson's Disease Rating Scale. In Fahn S, Marsden CD, Calne DB, Goldstein M, eds. Recent developments in Parkinson's disease, Vol. 2. Florham Park, NJ: Macmillan Healthcare Information, 1987:153-163, 293-304. Reproduced by permission of the author.

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): _____

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): _____

7. 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): _____

8. 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

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

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) LBD MODULE V3.1 SHORT VERSION

Form B4L: Neuropsychiatric Inventory (NPI)¹

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 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.	<p>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 <u>convinced</u> that these things are happening to him/her.</p> <p><input type="checkbox"/> 0 No (SKIP TO QUESTION 2)</p> <p><input type="checkbox"/> 1 Yes (COMPLETE QUESTIONS 1a – 1i)</p> <p><input type="checkbox"/> 8 Not applicable (SKIP TO QUESTION 2)</p>		
1a.	Does the participant believe that he/she is in danger — that others are planning to hurt him/her?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
1b.	Does the participant believe that others are stealing from him/her?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
1c.	Does the participant believe that his/her spouse is having an affair?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
1d.	Does the participant believe that unwelcome guests are living in his/her house?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
1e.	Does the participant believe that his/her spouse or others are not who they claim to be?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
1f.	Does the participant believe that his/her house is not his/her home?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
1g.	Does the participant believe that family members plan to abandon him/her?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 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?]	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
1i.	Does the participant believe any other unusual things that I haven't asked about?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes

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HALLUCINATIONS			
2.	<p>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.</p> <p><input type="checkbox"/> 0 No (SKIP TO QUESTION 3)</p> <p><input type="checkbox"/> 1 Yes (COMPLETE QUESTIONS 2a – 2g)</p> <p><input type="checkbox"/> 8 Not applicable (SKIP TO QUESTION 3)</p>		
2a.	Does the participant describe hearing voices or acts if he/she hears voices?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2b.	Does the participant talk to people who are not there?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2c.	Does the participant describe seeing things not seen by others or behave as if he/she is seeing things not seen by others?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2d.	Does the participant report smelling odors not smelled by others?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2e.	Does the participant describe feeling things on his/her skin or otherwise appear to be feeling things crawling or touching him/her?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2f.	Does the participant describe tastes that are without any known cause?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2g.	Does the participant describe any other unusual sensory experiences?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
ANXIETY			
3.	<p>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?</p> <p><input type="checkbox"/> 0 No (SKIP TO QUESTION 4)</p> <p><input type="checkbox"/> 1 Yes (COMPLETE QUESTIONS 3a – 3g)</p> <p><input type="checkbox"/> 8 Not applicable (SKIP TO QUESTION 4)</p>		
3a.	Does the participant say that he/she is worried about planned events?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
3b.	Does the participant have periods of feeling shaky, unable to relax, or feeling excessively tense?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
3c.	Does the participant have periods of (or complain of) shortness of breath, gasping, or sighing for no apparent reason other than nervousness?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
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)?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
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?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
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?]	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
3g.	Does the participant show any other signs of anxiety?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes

APATHY / INDIFFERENCE			
4.	<p>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?</p> <p><input type="checkbox"/> 0 No (END FORM HERE)</p> <p><input type="checkbox"/> 1 Yes (COMPLETE QUESTIONS 4a – 4h)</p> <p><input type="checkbox"/> 8 Not applicable (END FORM HERE)</p>		
4a.	Does the participant seem less spontaneous and less active than usual?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
4b.	Is the participant less likely to initiate a conversation?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
4c.	Is the participant less affectionate or lacking in emotions when compared to his/her usual self?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
4d.	Does the participant contribute less to household chores?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
4e.	Does the participant seem less interested in the activities and plans of others?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
4f.	Has the participant lost interest in friends and family members?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
4g.	Is the participant less enthusiastic about his/her usual interests?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
4h.	Does the participant show any other signs that he/she doesn't care about doing new things?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes

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.

<p>1. Is the participant drowsy and lethargic during the day, despite getting enough sleep the night before?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown</p>
<p>2. Does the participant sleep 2 or more hours during the day (before 7:00 p.m.)?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown</p>
<p>3. Are there times when the participant's flow of ideas is disorganized, unclear, or not logical?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown</p>
<p>4. Does the participant tend to stare into space for long periods of time?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown</p>

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) LBD MODULE V3.1 SHORT VERSION

Form B6L: Mayo Sleep Questionnaire — Participant

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 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)

1 Yes (END FORM HERE)

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

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)?	<input type="checkbox"/> 0 No (SKIP TO QUESTION 2) <input type="checkbox"/> 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)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
1c. Has a bedpartner ever been injured from these behaviors (bruises, blows, pulled hair)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 No bedpartner
1d. Have you had dreams of being chased or attacked, or that involve defending yourself?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
1e. Have you been told that you make movements while sleeping that seem to match the details of your dream?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

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<p>2. Have you been told that your legs repeatedly jerk or twitch <u>during</u> sleep (not just when falling asleep)?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes</p>
<p>3. Does a restless, nervous, tingly, or creepy-crawly feeling in your legs make it hard to fall or stay asleep?</p>	<p><input type="checkbox"/> 0 No (SKIP TO QUESTION 4) <input type="checkbox"/> 1 Yes (COMPLETE QUESTIONS 3a – 3c)</p>
<p>3a. Do you experience an irresistible urge to move the legs at those times?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes</p>
<p>3b. Do the uncomfortable leg sensations decrease when you move them or when you walk around?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes</p>
<p>3c. When do these sensations seem to be worse?</p>	<p><input type="checkbox"/> 1 Before 6:00 p.m. <input type="checkbox"/> 2 After 6:00 p.m.</p>
<p>4. Have you ever walked around the bedroom or house in your sleep?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes</p>
<p>5. Have you ever snorted or choked yourself awake?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes</p>
<p>6. Have you ever been told that you stop breathing in your sleep?</p>	<p><input type="checkbox"/> 0 No (SKIP TO QUESTION 7) <input type="checkbox"/> 1 Yes (COMPLETE QUESTION 6a)</p>
<p>6a. Are you currently being treated for this (e.g., CPAP)?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes</p>
<p>7. Do you experience leg cramps at night (e.g., also called a “charlie horse” with intense pain in certain muscles in the leg)?</p>	<p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes</p>
<p>8. Rate your general level of alertness for the past 3 weeks on a scale from 0 to 10: ____</p> <p style="text-align: center;"> 0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10 Sleep all day Fully and normally awake </p>	

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) LBD MODULE V3.1 SHORT VERSION

Form B7L: Mayo Sleep Questionnaire — Co-participant

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 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?	<input type="checkbox"/> 0 No (END FORM HERE) <input type="checkbox"/> 1 Yes (CONTINUE TO QUESTION 2)
2. Do you sleep in the same room as the participant?	<input type="checkbox"/> 0 No (CONTINUE TO QUESTION 2a) <input type="checkbox"/> 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.)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 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)?	<input type="checkbox"/> 0 No (SKIP TO QUESTION 4) <input type="checkbox"/> 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)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
3c.	Has a bedpartner ever been injured from these behaviors (bruises, blows, pulled hair)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 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?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 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?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Never told me about dreams
4.	Do the participant's legs repeatedly jerk or twitch <u>during</u> sleep (not just when falling asleep)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 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?	<input type="checkbox"/> 0 No (SKIP TO QUESTION 6) <input type="checkbox"/> 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?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
5b.	When do these sensations seem to be the worst?	<input type="checkbox"/> 1 Before 6:00 p.m. <input type="checkbox"/> 2 After 6:00 p.m.
6.	Has the participant ever walked around the bedroom or house while asleep?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
7.	Has the participant ever snorted or choked him/herself awake?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
8.	Does the participant ever seem to stop breathing during sleep?	<input type="checkbox"/> 0 No (SKIP TO QUESTION 9) <input type="checkbox"/> 1 Yes (COMPLETE QUESTION 8a)
8a.	Is the participant currently being treated for this (e.g., CPAP)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 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)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
10.	Rate the participant's general level of alertness for the past 3 weeks on a scale from 0 to 10: ____	
	<p>0 — 1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10</p> <p>Sleep all day Fully and normally awake</p>	

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) LBD MODULE V3.1 SHORT VERSION

Form B9L: SCOPA Sleep — Co-participant

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____
 Visit #: _____ Examiner's initials: _____

INSTRUCTIONS: Section I of this form is to be completed by the co-participant. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form B9L. Check only one box per question.

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				
In the past month, how often has the participant ...	Not at all	A little	Quite a bit	A lot
1. Had trouble falling asleep when they went to bed at night	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
2. Felt that they have woken too often	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
3. Felt that they have been lying awake for too long at night	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
4. Felt that they have woken too early in the morning	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
5. Felt they have had too little sleep at night	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
6. Overall, how well has the participant slept at night during the past month? (CHOOSE ONE):				
<input type="checkbox"/> 1 Very well				
<input type="checkbox"/> 2 Well				
<input type="checkbox"/> 3 Rather well				
<input type="checkbox"/> 4 Not well but not badly				
<input type="checkbox"/> 5 Rather badly				
<input type="checkbox"/> 6 Badly				
<input type="checkbox"/> 7 Very badly				

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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Daytime sleepiness				
In the past month, how often has the participant ...	Never	Sometimes	Regularly	Often
7. Fallen asleep unexpectedly during the day or in the evening	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
8. Fallen asleep while sitting peacefully	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
9. Fallen asleep while watching TV or reading	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
10. Fallen asleep while talking to someone	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
11. Had trouble staying awake during the day or in the evening	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3
12. Experienced falling asleep during the day as a problem	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) **LBD MODULE V3.1 SHORT VERSION**

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

2. Noise Pareidolia Task <i>If test not completed, enter reason code (95 – 98) for Question 2a, and END FORM HERE</i>	
2a. Correct YES Face Responses:	___ ___ (0 – 7, 95 – 98)
2b. Correct NO Noise Responses:	___ ___ (0 – 13)
2c. Total YES and NO Correct:	___ ___ (0 – 20)
2d. Pareidolia (Illusory) Responses:	___ ___ (0 – 13)

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)**

Does the participant have any of the following mutations (select only one answer per question):

Mutation	No	Yes	Unknown	If yes, information source (see KEY)			
2. LRRK2	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	2a. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
3. PARK2	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	3a. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
4. PARK7	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	4a. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
5. PINK1	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	5a. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
6. SNCA	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	6a. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
7. GBA	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	7a. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9
8. Other (SPECIFY): _____	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 9	8a. <input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 9

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?	<input type="checkbox"/> 0 No or unknown (SKIP TO QUESTION 2) <input type="checkbox"/> 1 Yes (CONTINUE)
1c. Was there an MRI finding of hippocampal atrophy, according to your Center's standards for positivity? (REPORT MOST RECENT)	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Results not available <input type="checkbox"/> 9 Unknown
1d. Is an MRI available for data sharing?	<input type="checkbox"/> 0 No or unknown <input type="checkbox"/> 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?	<input type="checkbox"/> 0 No or unknown (SKIP TO QUESTION 3) <input type="checkbox"/> 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?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Results not available <input type="checkbox"/> 9 Unknown
2d. Was there an FDG-PET finding of temporoparietal hypometabolism suggestive of AD, according to your Center's standards for positivity?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Results not available <input type="checkbox"/> 9 Unknown
2e. Was there an FDG-PET finding of cingulate island sign consistent with LBD, according to your Center's standards for positivity?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Results not available <input type="checkbox"/> 9 Unknown
2f. Is an FDG-PET available for data sharing?	<input type="checkbox"/> 0 No or unknown <input type="checkbox"/> 1 Yes

AMYLOID PET	
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?	<input type="checkbox"/> 0 No or unknown (SKIP TO QUESTION 4) <input type="checkbox"/> 1 Yes (CONTINUE)
3c. Is an amyloid PET available for data sharing?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
TAU PET	
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?	<input type="checkbox"/> 0 No or unknown (SKIP TO QUESTION 5) <input type="checkbox"/> 1 Yes (CONTINUE)
4c. Is a Tau PET available for data sharing?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown
DaTScan	
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?	<input type="checkbox"/> 0 No or unknown (END FORM HERE) <input type="checkbox"/> 1 Yes (CONTINUE)
5c. Were there abnormal DaTScan findings consistent with LBD, according to your Center's standards for positivity? (REPORT MOST RECENT)	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Results not available <input type="checkbox"/> 9 Unknown

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) LBD MODULE **V3.1 SHORT VERSION**

Form E3L: Other Labs and Findings

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____

Visit #: ____ Examiner's initials: ____

INSTRUCTIONS: This form is to be completed by the clinician or other laboratory specialist involved in interpreting the laboratory results. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form E3L. Check only one box per question.

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?	<input type="checkbox"/> 0 No or unknown (SKIP TO QUESTION 2) <input type="checkbox"/> 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)	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Results not available <input type="checkbox"/> 9 Unknown
1c. Is a polysomnography available for data sharing?	<input type="checkbox"/> 0 No or unknown <input type="checkbox"/> 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?	<input type="checkbox"/> 0 No or unknown (SKIP TO QUESTION 3) <input type="checkbox"/> 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)	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Results not available <input type="checkbox"/> 9 Unknown
2c. Is a cardiac-MIBG available for data sharing?	<input type="checkbox"/> 0 No or unknown <input type="checkbox"/> 1 Yes, raw data available <input type="checkbox"/> 2 Yes, processed data available <input type="checkbox"/> 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?	<input type="checkbox"/> 0 No or unknown (SKIP TO QUESTION 9) <input type="checkbox"/> 1 Yes (CONTINUE)
3b. Were the anosmia test results consistent with LBD, according to your Center's standards for positivity? (REPORT MOST RECENT)	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Results not available <input type="checkbox"/> 9 Unknown

3c. Are anosmia test data available for sharing?	<input type="checkbox"/> 0 No or unknown (SKIP TO QUESTION 9) <input type="checkbox"/> 1 Yes
3d. Which test was done (that is available for sharing)?	<input type="checkbox"/> 1 University of Pennsylvania Smell Identification Test (UPSIT) <input type="checkbox"/> 2 Brief-smell identification test (B-SIT) <input type="checkbox"/> 3 Sniffin Sticks <input type="checkbox"/> 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?	<input type="checkbox"/> 0 No or unknown (END FORM HERE) <input type="checkbox"/> 1 Yes (CONTINUE)
9b. Were the computerized gait testing results consistent with LBD, according to your Center's standards for positivity? (REPORT MOST RECENT)	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 8 Results not available <input type="checkbox"/> 9 Unknown
9c. Are computerized gait testing data available for sharing?	<input type="checkbox"/> 0 No or unknown <input type="checkbox"/> 1 Yes, raw data available <input type="checkbox"/> 2 Yes, processed data available <input type="checkbox"/> 3 Yes, both raw and processed data available

FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS) **LBD MODULE V3.1 SHORT VERSION**

Form D1L: Clinical DLB and PD Features

ADC name: _____ Subject ID: _____ Form date: ____ / ____ / _____

Visit #: _____ Examiner's initials: _____

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.	Absent	Questionably present	Definitely present	Not evaluated
1a. Episodic memory deficits	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
1b. Language deficits	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
1c. Attention deficits	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
1d. Executive deficits	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
1e. Visuo-perceptual deficits	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8

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.	Absent	Questionably present	Definitely present	Not evaluated
2a. Bradykinesia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
2b. Rigidity (with or without cogwheel characteristics)	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
2c. Rest tremor	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
2d. Postural tremor	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
2e. Action tremor	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8

	Absent	Questionably present	Definitely present	Not evaluated
2f. Myoclonus	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
2g. Gait abnormality	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
2h. Postural instability	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 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.	Absent	Questionably present	Definitely present	Not evaluated
3a. Depression	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
3b. Apathy	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
3c. Anxiety	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
3d. Hallucinations	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
3e. Delusions	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8

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.	Absent	Questionably present	Definitely present	Not evaluated
4a. REM sleep behavior disorder	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
4b. Obstructive sleep apnea	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
4c. Periodic leg movements of sleep	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
4d. Restless leg syndrome	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
4e. Excessive daytime sleepiness	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
4f. Cognitive fluctuations	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
4g. Orthostatic hypotension	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8

	Absent	Questionably present	Definitely present	Not evaluated
4h. Constipation	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
4i. Hyposmia	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
4j. Falls	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
4k. Syncope	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
4l. Severe sensitivity to anti-psychotic agents	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 8
Cognitive status and etiology				
5. What is the participant's cognitive status?	<input type="checkbox"/> 1 Normal cognition <input type="checkbox"/> 2 Cognitively impaired, not MCI <input type="checkbox"/> 3 MCI <input type="checkbox"/> 4 Dementia			
6. Which etiologic diagnosis best characterizes the participant?	<input type="checkbox"/> 1 Dementia with Lewy bodies <input type="checkbox"/> 2 Parkinson's disease <input type="checkbox"/> 3 Alzheimer's disease <input type="checkbox"/> 4 Vascular disease <input type="checkbox"/> 5 FTLD <input type="checkbox"/> 6 Other <input type="checkbox"/> 8 Not applicable — no neurodegenerative disease and no cognitive impairment			