NACC UNIFORM DATA SET **LBD MODULE**

Initial Visit Packet

LBD Module, August 2017
UDS Version 3.0, March 2015

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Revisions made to the Initial Visit Packet since LBD Module implementation (August 2017)

Date yyyy-mm-dd	Description	Form(s) affected	Question(s) affected	Data element(s) affected
2017-10-23	Item descriptions clarified and made consistent with Noise Pareidolia worksheet	C1L	2a – 2d	LBNPFACE, LBNPNOIS, LBNPTCOR, LBNPPARD

List of LBD Module Forms

To be included in the LBD database, each participant must have a co-participant. In addition, all of the LBD Module Forms, listed below, must be submitted.

Form	Description
B1L	Clinical Symptoms and Exam
B2L	UPDRS Part II — Activities of Daily Living
B3L	UPDRS Part III — Motor Examination
B4L	Neuropsychiatric Inventory (NPI)
B5L	Mayo Fluctuations Scale
B6L	Mayo Sleep Questionnaire — Participant
B7L	Mayo Sleep Questionnaire — Co-participant
B8L	SCOPA Sleep — Participant
B9L	SCOPA Sleep — Co-participant
C1L	Neuropsychological Battery Scores
E1L	Genetics
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D1L	Clinical DLB and PD Features

INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS) **LBD MODULE**

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 Initial 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?	☐ 0	☐ 1	☐ 9
2. Does the participant have difficulty swallowing?	☐ 0	☐ 1	☐ 9
3. Does the participant have altered interest in sex?	☐ 0	☐ 1	☐ 9
4. Does the participant have problems having sex?	☐ 0	☐ 1	☐ 9
5. Does the participant have a recent change in weight (not related to dieting)?	☐ 0	☐ 1	☐ 9
6. Does the participant report a change in the ability to taste or smell?	☐ 0	☐ 1	☐ 9
7. Does the participant experience excessive sweating (not related to hot weather)?	☐ 0	☐ 1	☐ 9
8. Does the participant report having difficulty tolerating cold weather?	☐ 0	☐ 1	☐ 9
9. Does the participant report having difficulty tolerating hot weather?	☐ 0	☐ 1	☐ 9
10. Does the participant experience double vision (two separate real objects, and not blurred vision)?	☐ 0	☐ 1	☐ 9
11. Does the participant have problems with constipation?	☐ 0	☐ 1	☐ 9
12. Does the participant have to strain to pass hard stools?	☐ 0	☐ 1	☐ 9
13. Has the participant had involuntary loss of stools?	☐ 0	☐ 1	☐ 9
14. Has the participant had the feeling that after passing urine, their bladder was not completely empty?	☐ 0	☐ 1	☐ 9
15. Has the participant's stream of urine been weak or reduced?	☐ 0	☐ 1	☐ 9
16. Has the participant had to pass urine within two hours of the previous urination?	☐ 0	☐ 1	☐ 9
17. Has the participant complained of feeling light-headed or dizzy when standing up?	☐ 0	☐ 1	☐ 9
18. Has the participant become light-headed after standing for some time?	☐ 0	☐ 1	☐ 9
19. Has the participant fainted?	☐ 0	☐ 1	☐ 9

20. Indicate the first predominant symptom to appear during the participant's lifetime: (SELECT ONLY ONE)

- ☐ 1 Dribbling saliva during the day
- ☐ 2 Difficulty swallowing
- ☐ 3 Altered interest in sex
- ☐ 4 Problems having sex
- ☐ 5 Recent change in weight not related to dieting
- ☐ 6 Change in the ability to taste or smell
- ☐ 7 Excessive sweating
- ☐ 8 Difficulty tolerating cold weather
- ☐ 9 Difficulty tolerating hot weather
- ☐ 10 Double vision
- ☐ 11 Constipation
- ☐ 12 Straining to pass hard stools
- ☐ 13 Involuntary loss of stools
- ☐ 14 Feeling after passing urine that bladder is not completely empty
- ☐ 15 Stream of urine weak or reduced
- ☐ 16 Passing urine within two hours of previous urination
- ☐ 17 Feeling light-headed or dizzy when standing up
- ☐ 18 Feeling light-headed after standing for some time
- ☐ 19 Fainting
- ☐ 88 Not applicable — never experienced any of these symptoms
- ☐ 99 Unknown

21. At what age did the first predominant symptom appear? ___ ___ ___ *(888=Not applicable; 999=Unknown)*

MEASUREMENTS		
Supine position	22. Systolic blood pressure:	___ ___ ___ *(888=Not assessed)*
	23. Diastolic blood pressure:	___ ___ ___ *(888=Not assessed)*
	24. Heart rate:	___ ___ ___ *(888=Not assessed)*
Standing position	25. Systolic blood pressure:	___ ___ ___ *(888=Not assessed)*
	26. Diastolic blood pressure:	___ ___ ___ *(888=Not assessed)*
	27. Heart rate:	___ ___ ___ *(888=Not assessed)*

AGE OF ONSET OF NON-MOTOR SYMPTOMS	
28. Age of onset of probable REM sleep behavior disorder:	___ ___ ___ *(888=Not applicable; 999=Unknown)*
29. Age of onset of impaired smell:	___ ___ ___ *(888=Not applicable; 999=Unknown)*

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

34. WAS A STANDARDIZED SCALE OF AUTONOMIC SYMPTOMS COMPLETED AT THIS VISIT?

☐ 0 No **(END FORM HERE)**

☐ 1 Yes **(CONTINUE TO QUESTIONS 34a and 34b)**

34a. If yes, which version?

☐ 1 NMSS

☐ 2 SCOPA-AUT

☐ 8 Other (SPECIFY): _____

34b. If yes, what was the score? _____ *(999 = Unknown)*

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 Initial 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 gastrotomy feeding.
- ☐ 8 Not applicable.
- ☐ 9 Unknown.

[1]Fahn 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.

Form B3L: UPDRS Part III — Motor Examination[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 Initial Visit Packet, Form B3L. Check only one box per question.

1. Speech

- ☐ 0 Normal.
- ☐ 1 Slight loss of expression, diction, and/or volume.
- ☐ 2 Monotone, slurred but understandable; moderately impaired.
- ☐ 3 Marked impairment, difficult to understand.
- ☐ 4 Unintelligible.
- ☐ 8 Untestable. (SPECIFY REASON): _____

2. Facial expression

- ☐ 0 Normal.
- ☐ 1 Minimal hypomimia, could be normal "poker face."
- ☐ 2 Slight but definitely abnormal diminution of facial expression.
- ☐ 3 Moderate hypomimia; lips parted some of the time.
- ☐ 4 Masked or fixed facies with severe or complete loss of facial expression; lips parted 1/4 inch or more.
- ☐ 8 Untestable. (SPECIFY REASON): _____

3. Tremor at rest

3a. Face, lips, chin

- ☐ 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): _____

[1]Fahn 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): _____

INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS) **LBD MODULE**

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 Initial 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 **(SKIP TO QUESTION 2)** ☐ 1 Yes **(COMPLETE QUESTIONS 1a – 1i)** ☐ 8 Not applicable **(SKIP 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

	1j.	If the screening question is confirmed, determine the frequency and severity of the delusions. FREQUENCY: ☐ 1 Occasionally — less than once per week ☐ 2 Often — about once per week ☐ 3 Frequently — several times per week but less than every day ☐ 4 Very frequently — once or more per day
	1k.	SEVERITY: ☐ 1 Mild — delusions present but seem harmless and produce little distress in the participant ☐ 2 Moderate — delusions are distressing and disruptive ☐ 3 Marked — delusions are very disruptive and are a major source of behavioral disruption (if PRN medications are prescribed, their use signals that the delusions are of marked severity)
	1l.	How emotionally distressing do you find this behavior? ☐ 0 Not at all ☐ 1 Minimally ☐ 2 Mildly ☐ 3 Moderately ☐ 4 Severely ☐ 5 Very severely or extremely

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 – 2j)**
☐ 8 Not applicable **(SKIP TO QUESTION 3)**

	2a.	Does the participant describe hearing voices or acts if he/she hears voices?	☐ 0 No	☐ 1 Yes
	2b.	Does the participant talk to people who are not there?	☐ 0 No	☐ 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?	☐ 0 No	☐ 1 Yes
	2d.	Does the participant report smelling odors not smelled by others?	☐ 0 No	☐ 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?	☐ 0 No	☐ 1 Yes
	2f.	Does the participant describe tastes that are without any known cause?	☐ 0 No	☐ 1 Yes
	2g.	Does the participant describe any other unusual sensory experiences?	☐ 0 No	☐ 1 Yes

	2h.	If the screening question is confirmed, determine the frequency and severity of the hallucinations. FREQUENCY: ☐ 1 Occasionally — less than once per week ☐ 2 Often — about once per week ☐ 3 Frequently — several times per week but less than every day ☐ 4 Very frequently — once or more per day
	2i.	SEVERITY: ☐ 1 Mild — hallucinations are present but seem harmless and cause little distress for the participant ☐ 2 Moderate — hallucinations are distressing and are disruptive to the participant ☐ 3 Marked — hallucinations are very disruptive and are a major source of behavioral disturbance. PRN medications may be required to control them.
	2j.	How emotionally distressing do you find this behavior? ☐ 0 Not at all ☐ 1 Minimally ☐ 2 Mildly ☐ 3 Moderately ☐ 4 Severely ☐ 5 Very severely or extremely

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 – 3j)** ☐ 8 Not applicable **(SKIP TO QUESTION 4)**			
	3a.	Does the participant say that he/she is worried about planned events?	☐ 0 No	☐ 1 Yes
	3b.	Does the participant have periods of feeling shaky, unable to relax, or feeling excessively tense?	☐ 0 No	☐ 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?	☐ 0 No	☐ 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)?	☐ 0 No	☐ 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?	☐ 0 No	☐ 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?]	☐ 0 No	☐ 1 Yes

	3g.	Does the participant show any other signs of anxiety?	☐ 0 No	☐ 1 Yes
	3h.	If the screening question is confirmed, determine the frequency and severity of the anxiety. FREQUENCY: ☐ 1 Occasionally — less than once per week ☐ 2 Often — about once per week ☐ 3 Frequently — several times per week but less than every day ☐ 4 Very frequently — once or more per day		
	3i.	SEVERITY: ☐ 1 Mild — anxiety is distressing but usually responds to redirection or reassurance ☐ 2 Moderate — anxiety is distressing, anxiety symptoms are spontaneously voiced by the participant and difficult to alleviate ☐ 3 Marked — anxiety is very distressing and a major source of suffering for the participant		
	3j.	How emotionally distressing do you find this behavior? ☐ 0 Not at all ☐ 1 Minimally ☐ 2 Mildly ☐ 3 Moderately ☐ 4 Severely ☐ 5 Very severely or extremely		
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 **(SKIP TO QUESTION 5)** ☐ 1 Yes **(COMPLETE QUESTIONS 4a – 4k)** ☐ 8 Not applicable **(SKIP TO QUESTION 5)**		
	4a.	Does the participant seem less spontaneous and less active than usual?	☐ 0 No	☐ 1 Yes
	4b.	Is the participant less likely to initiate a conversation?	☐ 0 No	☐ 1 Yes
	4c.	Is the participant less affectionate or lacking in emotions when compared to his/her usual self?	☐ 0 No	☐ 1 Yes
	4d.	Does the participant contribute less to household chores?	☐ 0 No	☐ 1 Yes
	4e.	Does the participant seem less interested in the activities and plans of others?	☐ 0 No	☐ 1 Yes
	4f.	Has the participant lost interest in friends and family members?	☐ 0 No	☐ 1 Yes
	4g.	Is the participant less enthusiastic about his/her usual interests?	☐ 0 No	☐ 1 Yes

	4h.	Does the participant show any other signs that he/she doesn't care about doing new things?	☐ 0 No	☐ 1 Yes

	4i.	If the screening question is confirmed, determine the frequency and severity of the apathy/indifference. FREQUENCY: ☐ 1 Occasionally — less than once per week ☐ 2 Often — about once per week ☐ 3 Frequently — several times per week but less than every day ☐ 4 Very frequently — nearly always present
	4j.	SEVERITY: ☐ 1 Mild — apathy is notable but produces little interference with daily routines; only mildly different from participant's usual behavior; participant responds to suggestions to engage in activities ☐ 2 Moderate — apathy is very evident; may be overcome by the caregiver with coaxing and encouragement; responds spontaeously only to powerful events such as visits from close relatives or family members ☐ 3 Marked — apathy is very evident and usually fails to respond to any encouragement or external events
	4k.	How emotionally distressing do you find this behavior? ☐ 0 Not at all ☐ 1 Minimally ☐ 2 Mildly ☐ 3 Moderately ☐ 4 Severely ☐ 5 Very severely or extremely

SUPPLEMENTAL INFORMATION*

**Items are not part of NPI*

For all questions related to medication use, determine the drugID by using the **drugID LookUp Tool** on the NACC website at http://www.alz.washington.edu/MEMBER/DrugCodeLookUp.html

5. Is the participant currently on **dopaminergic agents**?

☐ 0 No **(SKIP TO QUESTION 6)**

☐ 1 Yes **(CONTINUE TO QUESTION 5a)**

☐ 9 Unknown **(SKIP TO QUESTION 6)**

5a. Age at initiation of dopaminergic agents:

Age *(999=unknown)*	Drug code (drugID)	Dose
5a1. ___ ___ ___	5a2. d ___ ___ ___ ___ ___	5a3. _____
If not applicable, leave 5a4 – 5a6 blank:		
5a4. ___ ___ ___	5a5. d ___ ___ ___ ___ ___	5a6. _____

6. If the participant had no delusions, hallucinations, anxiety, or apathy reported in Questions 1 – 4, **END FORM HERE**.

Otherwise, if the participant has delusions (Question 1 is 1=Yes), then **ANSWER QUESTIONS 6a AND 6b**. If the participant does not have delusions or if the answer is not applicable (Question 1 is 0=No or 8=Not applicable), then enter 888=Not applicable for Question 6a and **SKIP TO QUESTION 7**.

6a. Age of onset of delusions: ___ ___ ___ *(888=Not applicable; 999=Unknown)*

6b. Delusions currently being treated with medication?

☐ 0 No **(SKIP TO QUESTION 7)**

☐ 1 Yes **(CONTINUE TO QUESTION 6c – 6d)**

☐ 9 Unknown **(SKIP TO QUESTION 7)**

6c. Medication 1: d ___ ___ ___ ___ ___

6d. Medication 2: d ___ ___ ___ ___ ___
Leave blank if not applicable

7. If the participant has hallucinations (Question 2 is 1=Yes), then **ANSWER QUESTIONS 7a AND 7b**. If the participant does not have hallucinations or if the answer is not applicable (Question 2 is 0=No or 8=Not applicable), then enter 888=Not applicable for Question 7a and **SKIP TO QUESTION 8**.

7a. Age of onset of hallucations: ___ ___ ___ *(888=Not applicable; 999=Unknown)*

7b. Hallucinations currently being treated with medication?

☐ 0 No **(SKIP TO QUESTION 8)**

☐ 1 Yes **(CONTINUE TO QUESTION 7c – 7d)**

☐ 9 Unknown **(SKIP TO QUESTION 8)**

7c. Medication 1: d ___ ___ ___ ___ ___

7d. Medication 2: d ___ ___ ___ ___ ___
Leave blank if not applicable

8. If the participant has anxiety (Question 3 is 1=Yes), then **ANSWER QUESTIONS 8a AND 8b**. If the participant does not have anxiety or if the answer is not applicable (Question 3 is 0=No or 8=Not applicable), then enter 888=Not applicable for Question 8a and **SKIP TO QUESTION 9**.

8a. Age of onset of anxiety: ___ ___ ___ *(888=Not applicable; 999=Unknown)*

8b. Anxiety currently being treated with medication?

☐ 0 No **(SKIP TO QUESTION 9)**

☐ 1 Yes **(CONTINUE TO QUESTION 8c – 8d)**

☐ 9 Unknown **(SKIP TO QUESTION 9)**

8c. Medication 1: d ___ ___ ___ ___ ___

8d. Medication 2: d ___ ___ ___ ___ ___
Leave blank if not applicable

9. If the participant is apathetic or indifferent (Question 4 is 1=Yes), then **ANSWER QUESTIONS 9a AND 9b**. If the participant is not apathetic or indifferent, or if the answer is not applicable (Question 4 is 0=No or 8=Not applicable), then enter 888=Not applicable for Question 9a and **END FORM HERE**.

9a. Age of onset of apathy/indifference: ___ ___ ___ *(888=Not applicable; 999=Unknown)*

9b. Apathy/indifference currently being treated with medication?

☐ 0 No **(END FORM HERE)**

☐ 1 Yes **(CONTINUE TO QUESTION 9c – 9d)**

☐ 9 Unknown **(END FORM HERE)**

9c.	Medication 1: d ___ ___ ___ ___ ___	9d. Medication 2: d ___ ___ ___ ___ ___ *Leave blank if not applicable*

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 Initial 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.

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

INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS) **LBD MODULE**

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 Initial 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 <u>at least 3 times</u>.

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)?**	☐ 0 No ☐ 1 Yes
3. **Does a restless, nervous, tingly, or creepy-crawly feeling in your legs make it hard to fall or stay asleep?**	☐ 0 No **(SKIP TO QUESTION 4)** ☐ 1 Yes **(COMPLETE QUESTIONS 3a – 3c)**
3a. **Do you experience an irresistible urge to move the legs at those times?**	☐ 0 No ☐ 1 Yes
3b. **Do the uncomfortable leg sensations decrease when you move them or when you walk around?**	☐ 0 No ☐ 1 Yes
3c. **When do these sensations seem to be worse?**	☐ 1 Before 6:00 p.m. ☐ 2 After 6:00 p.m.
4. **Have you ever walked around the bedroom or house in your sleep?**	☐ 0 No ☐ 1 Yes
5. **Have you ever snorted or choked yourself awake?**	☐ 0 No ☐ 1 Yes
6. **Have you ever been told that you stop breathing in your sleep?**	☐ 0 No **(SKIP TO QUESTION 7)** ☐ 1 Yes **(COMPLETE QUESTION 6a)**
6a. **Are you currently being treated for this (e.g., CPAP)?**	☐ 0 No ☐ 1 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)?**	☐ 0 No ☐ 1 Yes
8. **Rate your 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	

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 Initial 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 <u>at least 3 times</u>.

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

	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	

Form B8L: SCOPA Sleep — Participant

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

Visit #: _ _ _ Examiner's initials: _ _ _

INSTRUCTIONS: This form is to be completed by the participant. For additional clarification and examples, see LBD Module Coding Guidebook for Initial Visit Packet, Form B8L. 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)**

PARTICIPANT INSTRUCTIONS

By means of this questionnaire, we would like to find out to what extent *in the past month* you have 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 your situation. If you wish to change an answer, fill in the "wrong" box and place a cross in the correct one. If you have been using sleeping tablets, then the answer should reflect how you have slept while taking these tablets.

Nighttime sleep				
In the past month, how often have you …	**Not at all**	**A little**	**Quite a bit**	**A lot**
1. Had trouble falling asleep when you went to bed at night	☐ 0	☐ 1	☐ 2	☐ 3
2. Felt that you have woken too often	☐ 0	☐ 1	☐ 2	☐ 3
3. Felt that you have been lying awake for too long at night	☐ 0	☐ 1	☐ 2	☐ 3
4. Felt that you have woken too early in the morning	☐ 0	☐ 1	☐ 2	☐ 3
5. Felt you have had too little sleep at night	☐ 0	☐ 1	☐ 2	☐ 3

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).

Nighttime sleep, cont.

6. Overall, how well have you slept at night during the past month? (CHOOSE ONE):

- ☐ 1 Very well
- ☐ 2 Well
- ☐ 3 Rather well
- ☐ 4 Not well but not badly
- ☐ 5 Rather badly
- ☐ 6 Badly
- ☐ 7 Very badly

Daytime sleepiness

In the past month, how often have you …	Never	Sometimes	Regularly	Often
7. Fallen asleep unexpectedly during the day or in the evening	☐ 0	☐ 1	☐ 2	☐ 3
8. Fallen asleep while sitting peacefully	☐ 0	☐ 1	☐ 2	☐ 3
9. Fallen asleep while watching TV or reading	☐ 0	☐ 1	☐ 2	☐ 3
10. Fallen asleep while talking to someone	☐ 0	☐ 1	☐ 2	☐ 3
11. Had trouble staying awake during the day or in the evening	☐ 0	☐ 1	☐ 2	☐ 3
12. Experienced falling asleep during the day as a problem	☐ 0	☐ 1	☐ 2	☐ 3

INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS) **LBD MODULE**

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. Section II is to be completed by the clinician based on co-participant interview. For additional clarification and examples, see LBD Module Coding Guidebook for Initial 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	☐ 0	☐ 1	☐ 2	☐ 3
2. Felt that they have woken too often	☐ 0	☐ 1	☐ 2	☐ 3
3. Felt that they have been lying awake for too long at night	☐ 0	☐ 1	☐ 2	☐ 3
4. Felt that they have woken too early in the morning	☐ 0	☐ 1	☐ 2	☐ 3
5. Felt they have had too little sleep at night	☐ 0	☐ 1	☐ 2	☐ 3

6. Overall, how well has the participant slept at night during the past month? (CHOOSE ONE):

- ☐ 1 Very well
- ☐ 2 Well
- ☐ 3 Rather well
- ☐ 4 Not well but not badly
- ☐ 5 Rather badly
- ☐ 6 Badly
- ☐ 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).

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	☐ 0	☐ 1	☐ 2	☐ 3
8. Fallen asleep while sitting peacefully	☐ 0	☐ 1	☐ 2	☐ 3
9. Fallen asleep while watching TV or reading	☐ 0	☐ 1	☐ 2	☐ 3
10. Fallen asleep while talking to someone	☐ 0	☐ 1	☐ 2	☐ 3
11. Had trouble staying awake during the day or in the evening	☐ 0	☐ 1	☐ 2	☐ 3
12. Experienced falling asleep during the day as a problem	☐ 0	☐ 1	☐ 2	☐ 3

Section II: Clinician

First predominant symptom

13. Indicate the first predominant symptom to appear during the participant's lifetime.

☐ 1 Disturbed nighttime sleep

☐ 2 Excessive daytime sleepiness

☐ 8 Not applicable — never experienced disturbed nighttime sleep or excessive daytime sleepiness
If not applicable, **SKIP TO QUESTION 16**

14. At what age did the disturbed nighttime sleep first appear? ___ ___ ___ *(888=Not applicable; 999=Unknown)*

15. At what age did the excessive daytime sleepiness first appear? ___ ___ ___ *(888=Not applicable; 999=Unknown)*

16. WAS A STANDARDIZED SCALE OF DAYTIME SLEEPINESS COMPLETED AT THIS VISIT?

☐ 0 No **(END FORM HERE)** ☐ 1 Yes **(CONTINUE TO QUESTIONS 16a and 16b)**

16a. Which version?

☐ 1 Epworth

☐ 2 Stanford

☐ 3 Other (SPECIFY): _____

16b. What was the score? _____ *(999 = Unknown)*

INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS) **LBD MODULE**

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 Initial 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

1. Speeded Attention Task *If test not completed, enter reason code (995 – 998) for Question 1a, and* **SKIP TO QUESTION 2**	
1a. Raw Word Score:	___ ___ ___ *(0 – 150, 995 – 998)*
1b. Raw Color Score:	___ ___ ___ *(0 – 150)*
1c. Raw Color-word score:	___ ___ ___ *(0 – 150)*
2. Noise Pareidolia Task *If test not completed, enter reason code (95 – 98) for Question 2a, and* **END FORM HERE**	
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)*

INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS) **LBD MODULE**

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 Initial Visit Packet, Form E1L.

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)
1. LRRK2	☐ 0	☐ 1	☐ 9	1a. ☐ 1 ☐ 2 ☐ 3 ☐ 9
2. PARK2	☐ 0	☐ 1	☐ 9	2a. ☐ 1 ☐ 2 ☐ 3 ☐ 9
3. PARK7	☐ 0	☐ 1	☐ 9	3a. ☐ 1 ☐ 2 ☐ 3 ☐ 9
4. PINK1	☐ 0	☐ 1	☐ 9	4a. ☐ 1 ☐ 2 ☐ 3 ☐ 9
5. SNCA	☐ 0	☐ 1	☐ 9	5a. ☐ 1 ☐ 2 ☐ 3 ☐ 9
6. GBA	☐ 0	☐ 1	☐ 9	6a. ☐ 1 ☐ 2 ☐ 3 ☐ 9
7. Other (SPECIFY): _____	☐ 0	☐ 1	☐ 9	7a. ☐ 1 ☐ 2 ☐ 3 ☐ 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

INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS) **LBD MODULE**

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 Initial Visit Packet, Form E2L. Check only one box per question.

STRUCTURAL MRI	
1. Has the participant had at least one structural MRI scan, obtained as part of the current evaluation or a previous evaluation?	☐ 0 **No or unknown (SKIP TO QUESTION 2)** ☐ 1 **Yes (CONTINUE)**
1a. Date of most recent scan (MM/DD/YYYY): *NOTE: A value of 99 (unknown) is permissible for day only.*	_ _ / _ _ / _ _ _ _
1b. Are results of quantitative image analysis available?	☐ 0 No **(SKIP TO QUESTION 1d)** ☐ 1 Yes **(CONTINUE)** ☐ 9 Unknown **(SKIP TO QUESTION 1d)**
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 **(SKIP TO QUESTION 2)** ☐ 1 Yes **(COMPLETE QUESTIONS 1e – 1h)**
Questions 1e – 1h refer to MOST RECENT SCAN AVAILABLE:	
1e. Is it in DICOM format or other electronic format?	☐ 0 No ☐ 1 Yes (specify format): _____ ☐ 9 Unknown
1f. Was ADNI protocol used?	☐ 0 No ☐ 1 Yes; ADNI version: _____ ☐ 9 Unknown
1g. Scan manufacturer:	☐ 1 GE ☐ 2 Siemens ☐ 3 Philips ☐ 4 Other (SPECIFY): _____ ☐ 9 Unknown

1h. Field strength:	☐ 1 1.5T ☐ 2 3T ☐ 3 7T ☐ 4 Other (SPECIFY): _____ ☐ 9 Unknown
FDG-PET	
2. Has the participant had at least one FDG-PET scan, obtained as part of the current evaluation or a previous evaluation?	☐ 0 **No or unknown (SKIP TO QUESTION 3)** ☐ 1 **Yes (CONTINUE)**
2a. Date of most recent scan (MM/DD/YYYY): *NOTE: A value of 99 (unknown) is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
2b. Are results of quantitative image analysis available?	☐ 0 No **(SKIP TO QUESTION 2f)** ☐ 1 Yes **(CONTINUE)** ☐ 9 Unknown **(SKIP TO QUESTION 2f)**
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 **(SKIP TO QUESTION 3)** ☐ 1 Yes **(COMPLETE 2g – 2i)**
Questions 2g – 2i refer to MOST RECE2iNT SCAN AVAILABLE:	
2g. Is it in DICOM format or other electronic format?	☐ 0 No ☐ 1 Yes (specify format): _____ ☐ 9 Unknown
2h. Was ADNI protocol used?	☐ 0 No ☐ 1 Yes; ADNI version: _____ ☐ 9 Unknown
2i. Scan manufacturer:	☐ 1 GE ☐ 2 Siemens ☐ 3 Philips ☐ 4 Other (SPECIFY): _____ ☐ 9 Unknown

AMYLOID PET	
3. Has the participant had at least one amyloid PET scan, obtained as part of the current evaluation or a previous evaluation?	☐ 0 **No or unknown (SKIP TO QUESTION 4)** ☐ 1 **Yes (CONTINUE)**
3a. Date of most recent scan (MM/DD/YYYY): *NOTE: A value of 99 (unknown) is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
3b. Are results of quantitative image analysis available?	☐ 0 No ☐ 1 Yes ☐ 9 Unknown
3c. Is an amyloid PET available for data sharing?	☐ 0 No **(SKIP TO QUESTION 4)** ☐ 1 Yes **(COMPLETE QUESTIONS 3d – 3g)** ☐ 9 Unknown **(SKIP TO QUESTION 4)**
Questions 3d – 3g refer to MOST RECENT SCAN AVAILABLE:	
3d. Is it in DICOM format or other electronic format?	☐ 0 No ☐ 1 Yes (specify format): _____ ☐ 9 Unknown
3e. Ligand used:	☐ 1 11C-PIB ☐ 2 18F-AV45 ☐ 3 Flutametamol ☐ 4 Other (specify): _____ ☐ 9 Unknown
3f. Was ADNI protocol used?	☐ 0 No ☐ 1 Yes; ADNI version: _____ ☐ 9 Unknown
3g. Scan manufacturer:	☐ 1 GE ☐ 2 Siemens ☐ 3 Philips ☐ 4 Other (SPECIFY): _____ ☐ 9 Unknown
TAU PET	
4. Has the participant had at least one Tau PET scan, obtained as part of the current evaluation or a previous evaluation?	☐ 0 **No or unknown (SKIP TO QUESTION 5)** ☐ 1 **Yes (CONTINUE)**
4a. Date of scan (MM/DD/YYYY): *NOTE: A value of 99 (unknown) is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
4b. Are results of quantitative image analysis available?	☐ 0 No ☐ 1 Yes ☐ 9 Unknown
4c. Is a Tau PET available for data sharing?	☐ 0 No **(SKIP TO QUESTION 5)** ☐ 1 Yes **(COMPLETE QUESTIONS 4d – 4g)** ☐ 9 Unknown **(SKIP TO QUESTION 5)**

4d. Is it in DICOM format or other electronic format?	☐ 0 No ☐ 1 Yes (specify format): _____ ☐ 9 Unknown
4e. Ligand used:	☐ 1 18F-AV1451 (T807) ☐ 2 18F-THK5351 ☐ 3 Other, specify: _____
4f. Was ADNI protocol used?	☐ 0 No ☐ 1 Yes; ADNI version: _____ ☐ 9 Unknown
4g. Scan manufacturer:	☐ 1 GE ☐ 2 Siemens ☐ 3 Philips ☐ 4 Other (SPECIFY): _____ ☐ 9 Unknown
DaTScan	
5. Has the participant had at least one DaTScan scan, obtained as part of the current evaluation or a previous evaluation?	☐ 0 **No or unknown (END FORM HERE)** ☐ 1 **Yes (CONTINUE)**
5a. Date of scan (MM/DD/YYYY): *NOTE: A value of 99 (unknown) is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
5b. Are results of quantitative image analysis available?	☐ 0 No **(END FORM HERE)** ☐ 1 Yes **(CONTINUE)** ☐ 9 Unknown **(END FORM HERE)**
5c. Were there abnormal DaTScan findings consistent with LBD, according to your Center's standards for positivity? (REPORT MOST RECENT)	☐ 0 No ☐ 1 Yes ☐ 8 Results not available ☐ 9 Unknown

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 Initial Visit Packet, Form E3L. Check only one box per question.

Polysomnography	
1. Has the participant had at least one polysomnography, obtained as part of the current evaluation or a previous evaluation?	☐ 0 No or unknown **(SKIP TO QUESTION 2)** ☐ 1 Yes **(CONTINUE)**
1a. Date of most recent polysomnography (MM/DD/YYYY): *NOTE: A value of 99=Unknown is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
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, obtained as part of the current evaluation or a previous evaluation?	☐ 0 No or unknown **(SKIP TO QUESTION 3)** ☐ 1 Yes **(CONTINUE)**
2a. Date of most recent cardiac-MIBG scintigraphy (MM/DD/YYYY): *NOTE: A value of 99=Unknown is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
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, obtained as part of the current evaluation or a previous evaluation?	☐ 0 No or unknown **(SKIP TO QUESTION 4)** ☐ 1 Yes **(CONTINUE)**

3a. Date of most recent anosmia test (MM/DD/YYYY): *NOTE: A value of 99=Unknown is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
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 4)** ☐ 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): _____
Electroencephalogram (EEG)	
4. Has the participant had at least one electroencephalogram, obtained as part of the current evaluation or a previous evaluation?	☐ 0 No or unknown **(SKIP TO QUESTION 5)** ☐ 1 Yes **(CONTINUE)**
4a. Date of most recent electroencephalogram (MM/DD/YYYY): *NOTE: A value of 99=Unknown is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
4b. Was there prominent posterior slow wave activity on EEG with periodic fluctuations in the prealpha/theta range, consistent with LBD, according to your Center's standards for positivity? **(REPORT MOST RECENT)**	☐ 0 No ☐ 1 Yes ☐ 8 Results not available ☐ 9 Unknown
4c. Is an electroencephalogram 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
Multiple sleep latency test (MSLT)	
5. Has the participant had at least one MSLT, obtained as part of the current evaluation or a previous evaluation?	☐ 0 No or unknown **(SKIP TO QUESTION 6)** ☐ 1 Yes **(CONTINUE)**
5a. Date of most recent MSLT (MM/DD/YYYY): *NOTE: A value of 99=Unknown is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
5b. Were the MSLT 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

5c. Are MSLT data available for sharing?	☐ 0 No or unknown ☐ 1 Yes
Tilt table test	
6. Has the participant had at least one tilt table test, obtained as part of the current evaluation or a previous evaluation?	☐ 0 No or unknown **(SKIP TO QUESTION 7)** ☐ 1 Yes **(CONTINUE)**
6a. Date of most recent tilt table test (MM/DD/YYYY): *NOTE: A value of 99=Unknown is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
6b. Were the tilt table 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
6c. Are tilt table test data available for sharing?	☐ 0 No or unknown ☐ 1 Yes
Quantitative sudomotor axon reflex test (QSART)	
7. Has the participant had at least one QSART, obtained as part of the current evaluation or a previous evaluation?	☐ 0 No or unknown **(SKIP TO QUESTION 8)** ☐ 1 Yes **(CONTINUE)**
7a. Date of most recent QSART (MM/DD/YYYY): *NOTE: A value of 99=Unknown is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
7b. Were the QSART 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
7c. Are QSART data available for sharing?	☐ 0 No or unknown ☐ 1 Yes
Thermoregulatory sweat test	
8. Has the participant had at least one thermoregulatory sweat test, obtained as part of the current evaluation or a previous evaluation?	☐ 0 No or unknown **(SKIP TO QUESTION 9)** ☐ 1 Yes **(CONTINUE)**
8a. Date of most recent thermoregulatory sweat test (MM/DD/YYYY): *NOTE: A value of 99=Unknown is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
8b. Were the thermoregulatory sweat 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
8c. Are thermoregulatory sweat test data available for sharing?	☐ 0 No or unknown ☐ 1 Yes

Computerized gait testing	
9. Has the participant had at least one computerized gait testing, obtained as part of the current evaluation or a previous evaluation?	☐ 0 No or unknown **(END FORM HERE)** ☐ 1 Yes **(CONTINUE)**
9a. Date of most recent computerized gait testing (MM/DD/YYYY): *NOTE: A value of 99=Unknown is permissible for day only.*	___ ___ / ___ ___ / ___ ___ ___ ___
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

INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS) **LBD MODULE**

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 Initial 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	☐ 0	☐ 1	☐ 2	☐ 8
1b. Language deficits	☐ 0	☐ 1	☐ 2	☐ 8
1c. Attention deficits	☐ 0	☐ 1	☐ 2	☐ 8
1d. Executive deficits	☐ 0	☐ 1	☐ 2	☐ 8
1e. Visuoperceptual deficits	☐ 0	☐ 1	☐ 2	☐ 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	☐ 0	☐ 1	☐ 2	☐ 8
2b. Rigidity (with or without cogwheel characteristics)	☐ 0	☐ 1	☐ 2	☐ 8
2c. Rest tremor	☐ 0	☐ 1	☐ 2	☐ 8
2d. Postural tremor	☐ 0	☐ 1	☐ 2	☐ 8
2e. Action tremor	☐ 0	☐ 1	☐ 2	☐ 8

	Absent	Questionably present	Definitely present	Not evaluated
2f. Myoclonus	☐ 0	☐ 1	☐ 2	☐ 8
2g. Gait abnormality	☐ 0	☐ 1	☐ 2	☐ 8
2h. Postural instability	☐ 0	☐ 1	☐ 2	☐ 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	☐ 0	☐ 1	☐ 2	☐ 8
3b. Apathy	☐ 0	☐ 1	☐ 2	☐ 8
3c. Anxiety	☐ 0	☐ 1	☐ 2	☐ 8
3d. Hallucinations	☐ 0	☐ 1	☐ 2	☐ 8
3e. Delusions	☐ 0	☐ 1	☐ 2	☐ 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	☐ 0	☐ 1	☐ 2	☐ 8
4b. Obstructive sleep apnea	☐ 0	☐ 1	☐ 2	☐ 8
4c. Periodic leg movements of sleep	☐ 0	☐ 1	☐ 2	☐ 8
4d. Restless leg syndrome	☐ 0	☐ 1	☐ 2	☐ 8
4e. Excessive daytime sleepiness	☐ 0	☐ 1	☐ 2	☐ 8
4f. Cognitive fluctuations	☐ 0	☐ 1	☐ 2	☐ 8
4g. Orthostatic hypotension	☐ 0	☐ 1	☐ 2	☐ 8

	Absent	Questionably present	Definitely present	Not evaluated
4h. Constipation	☐ 0	☐ 1	☐ 2	☐ 8
4i. Hyposmia	☐ 0	☐ 1	☐ 2	☐ 8
4j. Falls	☐ 0	☐ 1	☐ 2	☐ 8
4k. Syncope	☐ 0	☐ 1	☐ 2	☐ 8
4l. Severe sensitivity to anti-psychotic agents	☐ 0	☐ 1	☐ 2	☐ 8

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