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).

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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	☐ 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)*