

**FOLLOW-UP 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 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

## Section II: Clinician

First predominant symptom	
13. Indicate the first predominant symptom to appear during the participant's lifetime.	
<input type="checkbox"/> 0 Provided at previous visit	
<input type="checkbox"/> 1 Disturbed nighttime sleep	
<input type="checkbox"/> 2 Excessive daytime sleepiness	
<input type="checkbox"/> 8 Not applicable — never experienced disturbed nighttime sleep or excessive daytime sleepiness <i>If not applicable, SKIP TO QUESTION 16</i>	
14. At what age did the disturbed nighttime sleep first appear? ____	(777= Provided at previous visit; 888=Not applicable; 999=Unknown)
15. At what age did the excessive daytime sleepiness first appear? ____	(777= Provided at previous visit; 888=Not applicable; 999=Unknown)
16. WAS A STANDARDIZED SCALE OF DAYTIME SLEEPINESS COMPLETED AT THIS VISIT?	
<input type="checkbox"/> 0 No (END FORM HERE)	<input type="checkbox"/> 1 Yes (CONTINUE TO QUESTIONS 16a and 16b)
16a. Which version?	
<input type="checkbox"/> 1 Epworth	
<input type="checkbox"/> 2 Stanford	
<input type="checkbox"/> 3 Other (SPECIFY): _____	
16b. What was the score? _____ (999 = Unknown)	