

TELEPHONE FOLLOW-UP PACKET NACC UNIFORM DATA SET (UDS)

Form B9: Clinician Judgment of Symptoms

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 UDS Coding Guidebook for Telephone Follow-up Visit Packet, Form B9. Check only one box per question.

| Declines in memory reported by subject and co-participant | | | |
|---|--|----------------------------|----------------------------|
| 1. Does the subject report a decline in memory (relative to previously attained abilities)? | <input type="checkbox"/> 0 No | | |
| | <input type="checkbox"/> 1 Yes | | |
| | <input type="checkbox"/> 8 Could not be assessed/subject is too impaired | | |
| 2. Does the co-participant report a decline in the subject's memory (relative to previously attained abilities)? | <input type="checkbox"/> 0 No | | |
| | <input type="checkbox"/> 1 Yes | | |
| | <input type="checkbox"/> 8 There is no co-participant | | |
| Cognitive symptoms | | | |
| 3. Based on the clinician's judgment, is the subject currently experiencing meaningful impairment in cognition? | <input type="checkbox"/> 0 No (If No, SKIP TO QUESTION 8) | | |
| | <input type="checkbox"/> 1 Yes | | |
| 4. Indicate whether the subject currently is meaningfully impaired, <i>relative to previously attained abilities</i> , in the following cognitive domains, or has fluctuating cognition: | | No | Yes |
| | | Unknown | |
| 4a. Memory For example, does s/he forget conversations and/or dates, repeat questions and/or statements, misplace things more than usual, forget names of people s/he knows well? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 4b. Orientation For example, does s/he have trouble knowing the day, month, and year, or not recognize familiar locations, or get lost in familiar locations? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 4c. Executive function — judgment, planning, problem-solving Does s/he have trouble handling money (e.g., tips), paying bills, preparing meals, shopping, using appliances, handling medications, driving? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 4d. Language Does s/he have hesitant speech, have trouble finding words, use inappropriate words without self-correction? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 4e. Visuospatial function Does s/he have difficulty interpreting visual stimuli and finding his/her way around? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 4f. Attention, concentration Does the subject have a short attention span or limited ability to concentrate? Is s/he easily distracted? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 4g. Fluctuating cognition Does the subject exhibit pronounced variation in attention and alertness, noticeably over hours or days — for example, long lapses or periods of staring into space, or times when his/her ideas have a disorganized flow? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 4g1. If yes, at what age did the fluctuating cognition begin? _____ (777 = Age of onset provided at a previous UDS visit.) (The clinician must use his/her best judgment to estimate an age of onset.) | | | |
| 4h. Other (SPECIFY): _____ | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | |

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| | |
|---|---|
| <p>5. Indicate the predominant symptom that was first recognized as a decline in the subject's cognition: <i>NOTE: Enter 0 if this information was provided on a previously submitted Form B9.</i></p> | <p><input type="checkbox"/> 0 Assessed at a previous UDS visit</p> <p><input type="checkbox"/> 1 Memory</p> <p><input type="checkbox"/> 2 Orientation</p> <p><input type="checkbox"/> 3 Executive function — judgment, planning, problem-solving</p> <p><input type="checkbox"/> 4 Language</p> <p><input type="checkbox"/> 5 Visuospatial function</p> <p><input type="checkbox"/> 6 Attention/concentration</p> <p><input type="checkbox"/> 7 Fluctuating cognition</p> <p><input type="checkbox"/> 8 Other (SPECIFY): _____</p> <p><input type="checkbox"/> 99 Unknown</p> |
| <p>6. Mode of onset of cognitive symptoms</p> | <p><input type="checkbox"/> 1 Gradual</p> <p><input type="checkbox"/> 2 Subacute</p> <p><input type="checkbox"/> 3 Abrupt</p> <p><input type="checkbox"/> 4 Other (SPECIFY): _____</p> <p><input type="checkbox"/> 99 Unknown</p> |

7. Based on the clinician's assessment, at what age did the cognitive decline begin? _____
(777 = Age of cognitive decline entered at a previous UDS visit)
 (The clinician must use her/his best judgment to estimate an age of onset of cognitive decline.)

Behavioral symptoms

8. Based on the clinician's judgment, is the subject currently experiencing any kind of behavioral symptoms? 0 No (If No, **SKIP TO QUESTION 13**) 1 Yes

| <p>9. Indicate whether the subject currently manifests meaningful change in behavior in any of the following ways:</p> | <table border="1"> <thead> <tr> <th>No</th> <th>Yes</th> <th>Unknown</th> </tr> </thead> </table> | No | Yes | Unknown | | | | | | | | | |
|---|---|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| No | Yes | Unknown | | | | | | | | | | | |
| <p>9a. Apathy, withdrawal Has the subject lost interest in or displayed a reduced ability to initiate usual activities and social interaction, such as conversing with family and/or friends?</p> | <table border="1"> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </table> | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | |
| <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | | | |
| <p>9b. Depressed mood Has the subject seemed depressed for more than two weeks at a time, e.g., shown loss of interest or pleasure in nearly all activities, sadness, hopelessness, loss of appetite, fatigue?</p> | <table border="1"> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </table> | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | |
| <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | | | |
| <p>9c. Psychosis</p> <p>9c1. Visual hallucinations</p> <p>9c1a. If yes, are the hallucinations well formed and detailed?</p> <p>9c1b. If well formed and clear-cut, at what age did these visual hallucinations begin? _____ <i>(777 = Age of onset provided at a previous UDS visit; 888 = N/A, not well-formed)</i> (The clinician must use his/her best judgment to estimate age of onset)</p> <p>9c2. Auditory hallucinations</p> <p>9c3. Abnormal, false, or delusional beliefs</p> | <table border="1"> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </table> | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | | | |
| <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | | | |
| <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | | | |
| <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | | | |
| <p>9d. Disinhibition Does the subject use inappropriate coarse language or exhibit inappropriate speech or behaviors in public or in the home? Does s/he talk personally to strangers or have disregard for personal hygiene?</p> | <table border="1"> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </table> | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | |
| <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | | | |
| <p>9e. Irritability Does the subject overreact, e.g., by shouting at family members or others?</p> | <table border="1"> <tr> <td><input type="checkbox"/> 0</td> <td><input type="checkbox"/> 1</td> <td><input type="checkbox"/> 9</td> </tr> </table> | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | |
| <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 | | | | | | | | | | | |

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| 9f. Agitation Does the subject have trouble sitting still? Does s/he shout, hit, and/or kick? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 9g. Personality change Does the subject exhibit bizarre behavior or behavior uncharacteristic of the subject, such as unusual collecting, suspiciousness (without delusions), unusual dress, or dietary changes? Does the subject fail to take others' feelings into account? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 9h. REM sleep behavior disorder While sleeping, does the subject appear to act out his/her dreams (e.g., punch or flail their arms, shout, or scream)? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 9h1. If yes, at what age did the REM sleep behavior disorder begin? _____ (777 = Age of onset provided at a previous UDS visit.) (The clinician must use his/her best judgment to estimate an age of onset) | | | |
| 9i. Anxiety For example, does s/he show signs of nervousness (e.g., frequent sighing, anxious facial expressions, or hand-wringing) and/or excessive worrying? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 9j. Other (SPECIFY): _____ | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | |
| 10. Indicate the predominant symptom that was first recognized as a decline in the subject's behavior: <i>NOTE: Enter 0 if this information was provided on a previously submitted Form B9.</i> | <input type="checkbox"/> 0 Assessed at a previous UDS visit <input type="checkbox"/> 1 Apathy/withdrawal <input type="checkbox"/> 2 Depressed mood <input type="checkbox"/> 3 Psychosis <input type="checkbox"/> 4 Disinhibition <input type="checkbox"/> 5 Irritability <input type="checkbox"/> 6 Agitation <input type="checkbox"/> 7 Personality change <input type="checkbox"/> 8 REM sleep behavior disorder <input type="checkbox"/> 9 Anxiety <input type="checkbox"/> 10 Other (SPECIFY): _____ <input type="checkbox"/> 99 Unknown | | |
| 11. Mode of onset of behavioral symptoms: | <input type="checkbox"/> 1 Gradual <input type="checkbox"/> 2 Subacute <input type="checkbox"/> 3 Abrupt <input type="checkbox"/> 4 Other (SPECIFY): _____ <input type="checkbox"/> 99 Unknown | | |
| 12. Based on the clinician's assessment, at what age did the behavioral symptoms begin? (777 = Age of onset provided at a previous UDS visit.) (The clinician must use her/his best judgment to estimate age of onset of behavioral symptoms.) | | | _____ |
| Motor symptoms | | | |
| 13. Based on the clinician's judgment, is the subject currently experiencing any motor symptoms? | <input type="checkbox"/> 0 No (If No, SKIP TO QUESTION 20) <input type="checkbox"/> 1 Yes | | |
| 14. Indicate whether the subject currently has meaningful change in motor function in any of the following areas: | No | Yes | Unknown |
| 14a. Gait disorder Has subject's walking changed, not specifically due to arthritis or an injury? Is s/he unsteady, or does s/he shuffle when walking, have little or no arm-swing, or drag a foot? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 14b. Falls Does the subject fall more than usual? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 14c. Tremor Has the subject had rhythmic shaking, especially in the hands, arms, legs, head, mouth, or tongue? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |
| 14d. Slowness Has the subject noticeably slowed down in walking, moving, or writing by hand, other than due to an injury or illness? Has his/her facial expression changed or become more "wooden," or masked and unexpressive? | <input type="checkbox"/> 0 | <input type="checkbox"/> 1 | <input type="checkbox"/> 9 |

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| <p>15. Indicate the predominant symptom that was first recognized as a decline in the subject's motor function: <i>NOTE: Enter 0 if this information was provided on a previously submitted Form B9.</i></p> | <p><input type="checkbox"/> 0 Assessed at a previous UDS visit <input type="checkbox"/> 1 Gait disorder <input type="checkbox"/> 2 Falls <input type="checkbox"/> 3 Tremor <input type="checkbox"/> 4 Slowness <input type="checkbox"/> 99 Unknown</p> |
| <p>16. Mode of onset of motor symptoms:</p> | <p><input type="checkbox"/> 1 Gradual <input type="checkbox"/> 2 Subacute <input type="checkbox"/> 3 Abrupt <input type="checkbox"/> 4 Other (SPECIFY): _____ <input type="checkbox"/> 99 Unknown</p> |
| <p>17. Were changes in motor function suggestive of parkinsonism?</p> | <p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown If No or Unknown, SKIP TO QUESTION 18</p> |
| <p>17a. If yes, at what age did the motor changes suggestive of parkinsonism begin? (The clinician must use his/her best judgment to estimate an age of onset.)</p> <p style="text-align: right;">_____ (777 = Provided at a previous UDS visit)</p> | |
| <p>18. Were changes in motor function suggestive of amyotrophic lateral sclerosis?</p> | <p><input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes <input type="checkbox"/> 9 Unknown If No or Unknown, SKIP TO QUESTION 19</p> |
| <p>18a. If yes, at what age did the motor changes suggestive of ALS begin? (The clinician must use his/her best judgment to estimate an age of onset.)</p> <p style="text-align: right;">_____ (777 = Provided at a previous UDS visit)</p> | |
| <p>19. Based on the clinician's assessment, at what age did the motor changes begin? (The clinician must use her/his best judgment to estimate an age of onset.)</p> <p style="text-align: right;">_____ (777 = Provided at a previous UDS visit)</p> | |
| <p>Overall course of decline and predominant domain</p> | |
| <p>20. Overall course of decline of cognitive/behavioral/ motor syndrome:</p> | <p><input type="checkbox"/> 1 Gradually progressive <input type="checkbox"/> 2 Stepwise <input type="checkbox"/> 3 Static <input type="checkbox"/> 4 Fluctuating <input type="checkbox"/> 5 Improved <input type="checkbox"/> 8 N/A <input type="checkbox"/> 9 Unknown</p> |
| <p>21. Indicate the predominant domain that was first recognized as changed in the subject: <i>NOTE: Enter 0 if this information was provided on a previously submitted Form B9.</i></p> | <p><input type="checkbox"/> 0 Assessed at a previous UDS visit <input type="checkbox"/> 1 Cognition <input type="checkbox"/> 2 Behavior <input type="checkbox"/> 3 Motor function <input type="checkbox"/> 8 N/A <input type="checkbox"/> 9 Unknown</p> |

Candidate for further evaluation for Lewy body disease or frontotemporal lobar degeneration

| | |
|--|---|
| 22. Is the subject a potential candidate for further evaluation for Lewy body disease? | <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes |
| 23. Is the subject a potential candidate for further evaluation for frontotemporal lobar degeneration? | <input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes |