

**FOLLOW-UP VISIT PACKET** NACC UNIFORM DATA SET (UDS) LBD MODULE

**Form B4L: Neuropsychiatric Inventory (NPI)<sup>1</sup>**

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

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

*INSTRUCTIONS: This form is to be completed by a clinician or other trained health professional based on co-participant interview. For additional clarification and examples, see LBD Module Coding Guidebook for Follow-up Visit Packet, Form B4L. Check only one box per question.*

**Inquire about symptoms the last four weeks before visit.**

DELUSIONS			
<b>1.</b>		<p><b>Does the participant have beliefs that you know are not true (for example, insisting that people are trying to harm him/her or steal from him/her)? Has he/she said that family members are not who they say they are or that the house is not their home? I'm not asking about mere suspiciousness; I am interested if the participant is <u>convinced</u> that these things are happening to him/her.</b></p> <p><input type="checkbox"/> 0 No (SKIP TO QUESTION 2)</p> <p><input type="checkbox"/> 1 Yes (COMPLETE QUESTIONS 1a – 1i)</p> <p><input type="checkbox"/> 8 Not applicable (SKIP TO QUESTION 2)</p>	
	1a.	Does the participant believe that he/she is in danger — that others are planning to hurt him/her?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
	1b.	Does the participant believe that others are stealing from him/her?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
	1c.	Does the participant believe that his/her spouse is having an affair?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
	1d.	Does the participant believe that unwelcome guests are living in his/her house?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
	1e.	Does the participant believe that his/her spouse or others are not who they claim to be?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
	1f.	Does the participant believe that his/her house is not his/her home?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
	1g.	Does the participant believe that family members plan to abandon him/her?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
	1h.	Does the participant believe that television or magazine figures are actually present in the home? [Does he/she try to talk or interact with them?]	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
	1i.	Does the participant believe any other unusual things that I haven't asked about?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

<sup>1</sup>Copyright JL Cummings, 1994, all rights reserved; permission for commercial use required; npITEST.net. Reproduced by permission of the author, Jeffrey L Cummings NPITEST.NET; do not copy or distribute without author's permission. Form created as part of the Uniform Data Set of the National Alzheimer's Coordinating Center, copyright 2017 University of Washington.

1j.	If the screening question is confirmed, determine the frequency and severity of the delusions.		
	FREQUENCY:		
	<input type="checkbox"/> 1 Occasionally — less than once per week		
	<input type="checkbox"/> 2 Often — about once per week		
	<input type="checkbox"/> 3 Frequently — several times per week but less than every day		
	<input type="checkbox"/> 4 Very frequently — once or more per day		
1k.	SEVERITY:		
	<input type="checkbox"/> 1 Mild — delusions present but seem harmless and produce little distress in the participant		
	<input type="checkbox"/> 2 Moderate — delusions are distressing and disruptive		
	<input type="checkbox"/> 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?		
	<input type="checkbox"/> 0 Not at all		
	<input type="checkbox"/> 1 Minimally		
	<input type="checkbox"/> 2 Mildly		
	<input type="checkbox"/> 3 Moderately		
	<input type="checkbox"/> 4 Severely		
	<input type="checkbox"/> 5 Very severely or extremely		
<b>HALLUCINATIONS</b>			
<b>2.</b>	<b>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.</b>		
	<input type="checkbox"/> 0 No (SKIP TO QUESTION 3)		
	<input type="checkbox"/> 1 Yes (COMPLETE QUESTIONS 2a – 2j)		
	<input type="checkbox"/> 8 Not applicable (SKIP TO QUESTION 3)		
2a.	Does the participant describe hearing voices or acts if he/she hears voices?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2b.	Does the participant talk to people who are not there?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2c.	Does the participant describe seeing things not seen by others or behave as if he/she is seeing things not seen by others?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2d.	Does the participant report smelling odors not smelled by others?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2e.	Does the participant describe feeling things on his/her skin or otherwise appear to be feeling things crawling or touching him/her?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2f.	Does the participant describe tastes that are without any known cause?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
2g.	Does the participant describe any other unusual sensory experiences?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes

	<p>2h. If the screening question is confirmed, determine the frequency and severity of the hallucinations.</p> <p>FREQUENCY:</p> <p><input type="checkbox"/> 1 Occasionally — less than once per week</p> <p><input type="checkbox"/> 2 Often — about once per week</p> <p><input type="checkbox"/> 3 Frequently — several times per week but less than every day</p> <p><input type="checkbox"/> 4 Very frequently — once or more per day</p>	
	<p>2i. SEVERITY:</p> <p><input type="checkbox"/> 1 Mild — hallucinations are present but seem harmless and cause little distress for the participant</p> <p><input type="checkbox"/> 2 Moderate — hallucinations are distressing and are disruptive to the participant</p> <p><input type="checkbox"/> 3 Marked — hallucinations are very disruptive and are a major source of behavioral disturbance. PRN medications may be required to control them.</p>	
	<p>2j. How emotionally distressing do you find this behavior?</p> <p><input type="checkbox"/> 0 Not at all</p> <p><input type="checkbox"/> 1 Minimally</p> <p><input type="checkbox"/> 2 Mildly</p> <p><input type="checkbox"/> 3 Moderately</p> <p><input type="checkbox"/> 4 Severely</p> <p><input type="checkbox"/> 5 Very severely or extremely</p>	
<b>ANXIETY</b>		
<b>3.</b>	<p><b>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?</b></p> <p><input type="checkbox"/> 0 No (SKIP TO QUESTION 4)</p> <p><input type="checkbox"/> 1 Yes (COMPLETE QUESTIONS 3a – 3j)</p> <p><input type="checkbox"/> 8 Not applicable (SKIP TO QUESTION 4)</p>	
3a.	Does the participant say that he/she is worried about planned events?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
3b.	Does the participant have periods of feeling shaky, unable to relax, or feeling excessively tense?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
3c.	Does the participant have periods of (or complain of) shortness of breath, gasping, or sighing for no apparent reason other than nervousness?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
3d.	Does the participant complain of butterflies in his/her stomach, or of racing or pounding of the heart in association with nervousness (symptoms not explained by ill health)?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
3e.	Does the participant avoid certain places or situations that make him/her more nervous such as riding in the car, meeting with friends, or being in crowds?	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes
3f.	Does the participant become nervous and upset when separated from you [or his/her caregiver]? [Does he/she cling to you to keep from being separated?]	<input type="checkbox"/> 0 No <input type="checkbox"/> 1 Yes

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

	4h. Does the participant show any other signs that he/she doesn't care about doing new things?	<input type="checkbox"/> 0 No	<input type="checkbox"/> 1 Yes
	<p>4i. If the screening question is confirmed, determine the frequency and severity of the apathy/indifference.</p> <p>FREQUENCY:</p> <p><input type="checkbox"/> 1 Occasionally — less than once per week</p> <p><input type="checkbox"/> 2 Often — about once per week</p> <p><input type="checkbox"/> 3 Frequently — several times per week but less than every day</p> <p><input type="checkbox"/> 4 Very frequently — nearly always present</p>		
	<p>4j. SEVERITY:</p> <p><input type="checkbox"/> 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</p> <p><input type="checkbox"/> 2 Moderate — apathy is very evident; may be overcome by the caregiver with coaxing and encouragement; responds spontaneously only to powerful events such as visits from close relatives or family members</p> <p><input type="checkbox"/> 3 Marked — apathy is very evident and usually fails to respond to any encouragement or external events</p>		
	<p>4k. How emotionally distressing do you find this behavior?</p> <p><input type="checkbox"/> 0 Not at all</p> <p><input type="checkbox"/> 1 Minimally</p> <p><input type="checkbox"/> 2 Mildly</p> <p><input type="checkbox"/> 3 Moderately</p> <p><input type="checkbox"/> 4 Severely</p> <p><input type="checkbox"/> 5 Very severely or extremely</p>		

## SUPPLEMENTAL INFORMATION\*

*\*Items 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**)

<p>5a. Age at initiation of dopaminergic agents:  <i>(If provided at previous visit, enter 777 for Question 5a1 and SKIP TO QUESTION 6)</i></p> <table border="1" style="width: 100%; border-collapse: collapse; background-color: #0056b3; color: white;"> <thead> <tr> <th style="width: 33%;">Age (999=unknown)</th> <th style="width: 33%;">Drug code (drugID)</th> <th style="width: 33%;">Dose</th> </tr> </thead> <tbody> <tr> <td style="padding: 5px;">5a1. _____</td> <td style="padding: 5px;">5a2. d _____</td> <td style="padding: 5px;">5a3. _____</td> </tr> <tr> <td colspan="3" style="padding: 5px;"><i>If not applicable, leave 5a4 – 5a6 blank:</i></td> </tr> <tr> <td style="padding: 5px;">5a4. _____</td> <td style="padding: 5px;">5a5. d _____</td> <td style="padding: 5px;">5a6. _____</td> </tr> </tbody> </table>		Age (999=unknown)	Drug code (drugID)	Dose	5a1. _____	5a2. d _____	5a3. _____	<i>If not applicable, leave 5a4 – 5a6 blank:</i>			5a4. _____	5a5. d _____	5a6. _____
Age (999=unknown)	Drug code (drugID)	Dose											
5a1. _____	5a2. d _____	5a3. _____											
<i>If not applicable, leave 5a4 – 5a6 blank:</i>													
5a4. _____	5a5. d _____	5a6. _____											
<p>6. If the participant had no delusions, hallucinations, anxiety, or apathy reported in Questions 1 – 4, <b>END FORM HERE</b>.                  Otherwise, if the participant has delusions (Question 1 is 1=Yes), then <b>ANSWER QUESTIONS 6a AND 6b</b>. 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 <b>SKIP TO QUESTION 7</b>.</p>													
<p>6a. Age of onset of delusions: _____ <i>(777=Provided at previous visit; 888=Not applicable; 999=Unknown)</i></p>													
<p>6b. Delusions currently being treated with medication?</p> <p><input type="checkbox"/> 0 No (<b>SKIP TO QUESTION 7</b>)</p> <p><input type="checkbox"/> 1 Yes (<b>CONTINUE TO QUESTION 6c – 6d</b>)</p> <p><input type="checkbox"/> 9 Unknown (<b>SKIP TO QUESTION 7</b>)</p>													
<p>6c. Medication 1: d _____</p>	<p>6d. Medication 2: d _____  <i>Leave blank if not applicable</i></p>												
<p>7. If the participant has hallucinations (Question 2 is 1=Yes), then <b>ANSWER QUESTIONS 7a AND 7b</b>. 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 <b>SKIP TO QUESTION 8</b>.</p>													
<p>7a. Age of onset of hallucinations: _____ <i>(777=Provided at previous visit; 888=Not applicable; 999=Unknown)</i></p>													
<p>7b. Hallucinations currently being treated with medication?</p> <p><input type="checkbox"/> 0 No (<b>SKIP TO QUESTION 8</b>)</p> <p><input type="checkbox"/> 1 Yes (<b>CONTINUE TO QUESTION 7c – 7d</b>)</p> <p><input type="checkbox"/> 9 Unknown (<b>SKIP TO QUESTION 8</b>)</p>													
<p>7c. Medication 1: d _____</p>	<p>7d. Medication 2: d _____  <i>Leave blank if not applicable</i></p>												

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: \_\_\_\_ \_\_\_\_ \_\_\_\_ (777=Provided at previous visit; 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: \_\_\_\_ \_\_\_\_ \_\_\_\_ (777=Provided at previous visit; 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*