

## Instructions for UDS Form M1: MILESTONES

The purpose of this form is to record important events or changes which may occur any time after the subject is enrolled in the ADC and which may affect the subject's continuing level of participation in the ADC. More than one Milestones form may be submitted per subject.

For continuing subjects who do not experience one of the listed events, this form is not required.

	Yes	No
1. Are you <u>unable</u> to collect neuropsychological test data on subject? If yes, indicate reason(s):	<input type="checkbox"/> 1	<input type="checkbox"/> 0
1a. Too cognitively impaired	<input type="checkbox"/> 1	<input type="checkbox"/> 0
1b. Too physically ill to travel/participate	<input type="checkbox"/> 1	<input type="checkbox"/> 0
1c. Homebound/entered nursing home for permanent care	<input type="checkbox"/> 1	<input type="checkbox"/> 0
1d. Other reason (specify): _____	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<p>During the course of follow-up or illness, among either subjects or normal controls, events can occur which make the collection of neuropsychological testing data impossible. These events may be the direct result of the subject's cognitive or physical condition, or other reasons. "Clinician's judgment" is the primary means of deciding whether the clinician is unable to collect neuropsychological data.</p> <p>Clinician judgment is also used to determine the <u>reason</u> the data cannot be collected, and should be specified in items 1a–1c. That judgment may be based on interviews with subject and/or informant, neurological exam, cognitive screening tests, medical records, study protocol, etc.</p> <p>If the subject is deceased, check number 1 for "Other reason" and specify 'dead' or 'deceased' in the space provided.</p>		
2. Are you <u>unable</u> to collect physical/neurological exam data on subject? If yes, indicate reason(s):	<input type="checkbox"/> 1	<input type="checkbox"/> 0
2a. Too cognitively impaired	<input type="checkbox"/> 1	<input type="checkbox"/> 0
2b. Too physically ill to travel/participate	<input type="checkbox"/> 1	<input type="checkbox"/> 0
2c. Homebound/entered nursing home for permanent care	<input type="checkbox"/> 1	<input type="checkbox"/> 0
2d. Other reason (specify): _____	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<p>During the course of follow-up or illness, among either subjects or normal controls, events can occur which make the collection of neuropsychological testing data impossible. These events may be the direct result of the subject's cognitive or physical condition, or other reasons. "Clinician's judgment" is the primary means of deciding whether the clinician is unable to collect these data.</p> <p>Clinician judgment is also used to determine the <u>reason</u> the data cannot be collected, and should be specified in items 1a–1c. That judgment may be based on interviews with subject and/or informant, neurological exam, cognitive screening tests, medical records, study protocol, etc.</p> <p>If the subject is deceased, check box 1 for "Other reason" and specify 'dead' or 'deceased' in the space provided.</p>		

	Yes	No
3. Has the subject entered a nursing home with expectation of permanent residence?	<input type="checkbox"/> 1	<input type="checkbox"/> 0
<p>If the subject enters a nursing home with the expectation of permanent residence, check number 1. In this context, nursing home reflects primarily skilled nursing facilities. It does <u>not</u> include adult family homes, retirement residences, or other similar facilities.</p> <p>An "expectation of permanent residence" <u>excludes</u> persons who enter a nursing home for short-term rehab resulting from an injury, surgery, or other medical condition where such rehab would be projected to last three months or less.</p>		
3a. If yes, date entered nursing home: ___/___/_____		
<p>If a subject enters the nursing home anticipating a short-term stay and the status is later determined to be permanent, without transferring or releasing the subject, then record the date the patient first entered the facility, rather than the date that the status was changed to permanent.</p>		
4. Has the subject discontinued?	<input type="checkbox"/> 1	<input type="checkbox"/> 0
4a. If yes, date discontinued: ___/___/_____		
<p>If the subject has discontinued participation as an enrollee in the ADC, check number 1 and record the date of occurrence.</p>		
4b. Reason discontinued: <ul style="list-style-type: none"> <li><input type="checkbox"/> 1 Refused to return</li> <li><input type="checkbox"/> 2 Moved out of area</li> <li><input type="checkbox"/> 3 Discontinued due to Center protocol</li> <li><input type="checkbox"/> 4 Seeking care elsewhere</li> <li><input type="checkbox"/> 8 Other (specify): _____</li> </ul>		
<p>Select the most appropriate reason to explain why the subject discontinued. "Discontinued due to Center protocol" includes any decisions made by the ADC regarding the inclusion, exclusion, and retention of subjects as ADC participants.</p> <p>If the subject is deceased, check number 8 and specify 'dead' or 'deceased' in the space provided.</p>		
5. Is the subject deceased?	<input type="checkbox"/> 1	<input type="checkbox"/> 0
5a. If yes, date of death: ___/___/_____		
<p>If the subject has died, check number 1 and record the date of death.</p>		
5b. If yes, was autopsy performed? <span style="float: right;"><input type="checkbox"/> 1 <input type="checkbox"/> 0</span>		
<p>If an autopsy was performed at your ADC or an affiliated ADC, such that neuropathological diagnosis, neuropathological features, and tissue specimens are/will be directly available to your ADC, check 1. Please ensure that the NACC Neuropathology Data forms are completed in a timely fashion.</p> <p>If an autopsy was performed at a non-ADC site and you have no specific information on neuropathological examination (gross and microscopic) nor direct access to tissue specimens, check 0.</p> <p>If no autopsy was performed or you do not know whether an autopsy was performed, check 0.</p>		

6. What is the subject's status following the milestone event(s) indicated above:

- 1 Active: further in-person visits expected
- 2 Active: telephone or other contact expected
- 3 Active: followed for autopsy only
- 4 Inactive: no further data expected

Check the most appropriate box for the subject's status following completion of this form. For discontinued and deceased subjects, check number 4.