

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. There are many possible example scenarios one might be able to construct, where several milestone events could potentially be reported on a single Milestone Form; however, to avoid confusion and misinterpretation of data, please submit a new Milestones Form as soon as possible after each milestone event has occurred.

Complete only those items necessary to report current milestone events. For example, to illustrate this concept:

- If the subject has died and you are submitting a Milestones Form to report that event, no other entries are necessary on the rest of the form.
- If the subject has discontinued ADC participation because they have moved out of the area, complete only items associated with item 2 on the Milestones Form; no other entries are necessary on the rest of the form.
- If the subject has entered a nursing home with expectation of permanent residence and has changed from UDS in-person to UDS telephone follow-up, complete items 4 and 7 (as appropriate); no other entries are necessary on the rest of the form.

Enter all dates as completely as known in the format of mm/dd/yyyy. If either the month or day is unknown, enter "99" for that element only. The year must be entered; it cannot be coded as unknown.

1. Subject has died. Date of death: ___/___/_____

1a. ADC autopsy done (data pending or submitted).

Check the box for "ADC autopsy done" if an autopsy has been performed at your ADC or another site, following ADC protocol, you have a neuropathology report and data sufficient to complete a NACC NP Data form, and you have stored tissue at or available to your ADC directly.

Do NOT check the box if an autopsy has not been done or if it was a private or non-ADC autopsy and you have no reports or data sufficient to complete a NACC NP Data form nor timely easy access tissue specimens.

2. Subject has discontinued ADC participation. Date discontinued: ___/___/_____

2a. Primary reason (*check only one*):

- | | |
|---|--|
| <input type="checkbox"/> 1 Refused further participation in ADC | <input type="checkbox"/> 3 Discontinued by ADC decision/protocol |
| <input type="checkbox"/> 2 Moved out of area | <input type="checkbox"/> 4 Seeking care elsewhere |
| <input type="checkbox"/> 8 Other (<i>specify</i>): _____ | |

Select the primary reason to explain why the subject has discontinued. "Discontinued by ADC decision/protocol" includes any decisions made by the ADC regarding the inclusion, exclusion, and retention of subjects as ADC participants.

3. Subject has rejoined ADC participation after discontinuing.

Subjects who rejoin ADC participation after discontinuing are expected to resume in-person UDS data collection protocol unless otherwise specified.

4. Subject has entered nursing home with expectation of permanent residence.

Date: ___/___/_____

If the subject enters a nursing home with the expectation of permanent residence, check this box. In this context, nursing home reflects primarily skilled nursing facilities. It does not include adult family homes, retirement residences, or other similar facilities.

An "expectation of permanent residence" excludes 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.

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.

If the subject has 'entered a nursing home' (as defined above), please complete item 2 if the subject has discontinued; if the subject has not discontinued, complete applicable items 5–7 only if there has been a NACC data collection protocol change to UDS telephone follow-up or to minimal ADC contact and include the reasons as appropriate.

5. Subject's NACC data collection protocol has changed as indicated below (*check only one*):

- 1 To UDS telephone follow-up.
 2 To minimal ADC contact (e.g., followed only to obtain autopsy).
 3 To UDS in-person visit.

If the subject has been on UDS telephone follow-up or minimal ADC contact data collection protocol and is now re-joining in-person UDS data collection, check box 3 and leave questions 6 and 7 blank).

If there has been a change in the data collection protocol to UDS telephone follow-up or to minimal ADC contact, indicate the reason(s) below:

6. Unable to collect neuropsychological test data.

Due to (*check all that apply*):

- a. Too cognitively impaired.
b. Too physically impaired.
c. Homebound/nursing home/cannot travel.
d. Refused testing.
e. Other (*specify*): _____

7. Unable to collect physical/neurological data.

Due to (*check all that apply*):

- a. Too cognitively impaired.
b. Too physically impaired.
c. Homebound/nursing home/cannot travel.
d. Refused examination.
e. Other (*specify*): _____

During the course of follow-up, for both patients and controls, events causing substantial changes in physical and cognitive abilities can occur which require a change from the usual in-person UDS data collection protocol to the UDS telephone follow-up or to simply minimal ADC contact, especially for those subjects whose decline has caused them to enter a nursing home or to have only minimal ADC contact (e.g., followed for autopsy only). The decision to make the protocol change is based on the clinician's best judgment that the subject can no longer proceed at their current data collection level. Please check the reasons that describe the clinician's judgment for the protocol change; at least one reason must be checked.