

Form M1: Milestones



ADC ID: Subject ID: Form Date: / / Examiner's initials:

Please submit a new Milestones Form as soon as possible after each milestone event has occurred.

INSTRUCTIONS: Review the types of milestone at right and complete the appropriate box below. Use only one box (A or B) per form submitted. For more information, see flow chart on reverse.

What milestone are you reporting?	Complete:
1. Data-collection status CHANGE followed by CONTINUED CONTACT with subject. <i>The subject's status in the UDS or FTL D Module has changed, such that s/he will continue to be followed (at least minimally) by ADC.</i>	Box A only
2. Change followed by NO FURTHER CONTACT with subject. <i>Subject has DIED or been DROPPED FROM ADC with no further telephone contact and no minimal contact (such as to obtain autopsy).</i>	Box B only

BOX A — CHANGE WITH CONTINUED CONTACT

1. Date of status change (Unknown = 99/99/YEAR REQUIRED): / /

Complete the UDS and FTL D sections below, as appropriate.

UDS STATUS

2a. UDS data collection status changed; subject's new status is (CHECK ONE):

1 Annual UDS follow-up by telephone (CONTINUE TO QUESTION 2a1)

2 Minimal contact (CONTINUE TO QUESTION 2a1)
NOTE: Minimal contact status is reserved for subjects who can no longer participate for one of the reasons listed in Question 2b, below.

2a1. Autopsy consent on file? 0 No (CONTINUE TO QUESTION 2b) 1 Yes (CONTINUE TO QUESTION 2b)

3 Annual in-person UDS follow-up

2b. Reason(s) for change indicated in Question 2a (CHECK AT LEAST ONE):

1 Subject is too cognitively impaired

2 Subject is too ill or physically impaired

3 Subject refuses neuropsychological testing or clinical exam

4 Subject or co-participant unreachable, not available, or moved away

5 Subject has permanently entered nursing home

2b5a. Date permanently moved to nursing home:
 / / (Unknown = 99/99/YEAR REQUIRED)

6 Subject is REJOINING ADC

FTLD MODULE STATUS

3. 1 **Subject will no longer receive FTL D Module follow-up, but annual in-person UDS visits will continue**

3a. Reason (CHECK ONE): 1 ADC decision 2 Subject/informant refused 3 Informant not available 4 Other, specify below:

3a1. _____

BOX B — NO FURTHER CONTACT

4a. Subject has DIED
(COMPLETE DEATH SECTION, BELOW)

4b. Subject has been DROPPED from ADC
(COMPLETE DROPPED SECTION, BELOW)

DEATH

5a. Date of death (Unknown = 99/99/YEAR REQUIRED):
 / /

5b. ADC autopsy:

0 No ADC autopsy expected

1 An ADC autopsy has been done; data submitted or pending

END FORM HERE

DROPPED

DO NOT fill out this section if the subject has consented to autopsy or if you will maintain minimal contact. Instead, fill out Box A, UDS STATUS section.

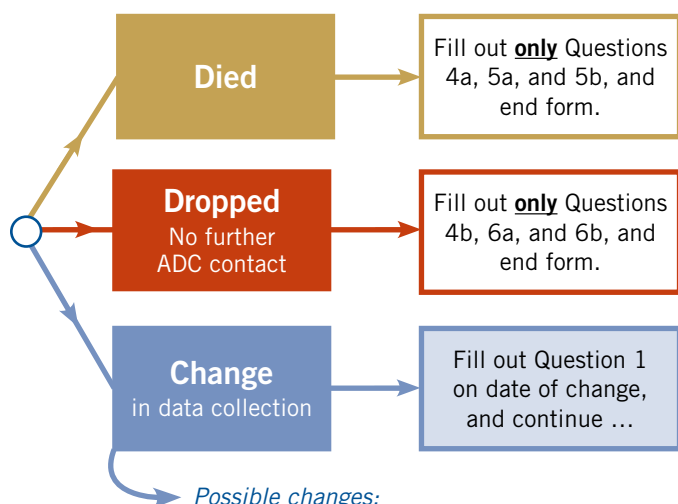
6a. Date dropped from ADC
(Unknown = 99/99/YEAR REQUIRED):
 / /

6b. Main reason for being dropped from ADC (CHECK ONE):

1 ADC decision or protocol

2 Subject or co-participant asked to be dropped

Completing the NACC Milestones Form



Possible changes:

- Rejoined ADC
- Changing to in-person visits
- Changing to telephone visits
- Changing to minimal contact
- No longer receiving FTLD Module
- Moved to nursing home**

Rejoining ADC after being discontinued (dropped):

FILL OUT:

- Question 2a
 - Question 2b
Select "6 = Subject is rejoining ADC"
- ... and end form.

Changing from telephone visits or minimal contact to annual in-person visits:

FILL OUT:

- Question 2a
Select "3 = Annual in-person UDS follow-up"
- ... and end form.

Changing to annual telephone follow-up:

FILL OUT:

- Question 2a
Select "1 = Annual UDS follow-up by telephone"
- Question 2a1
- Question 2b
- Question 2b5a (if applicable)

Subject will automatically be discontinued from the FTLD Module; no need to answer Questions 3 and 3a.

Changing to minimal contact (i.e., infrequent contact or followed to autopsy):

FILL OUT:

- Question 2a Select "2 = Minimal contact"
- Question 2a1
- Question 2b
- Question 2b5a (if applicable)

Subject will automatically be discontinued from the FTLD Module; no need to answer Questions 3 and 3a.

Subject will still be seen for annual in-person visits, but **will no longer receive FTLD Module**

FTLD Module status*

Subject previously received FTLD Module and will be discontinuing follow-up with the FTLD Module

- FILL OUT:
- Question 3
 - Question 3a

*FTLD MODULE STATUS

The only time NACC needs notification of FTLD Module follow-up status is when a subject is **continuing with annual in-person UDS visits but is discontinuing FTLD Module follow-up**. In other cases (dropped with no further ADC contact, changing to telephone follow-up, or changing to minimal contact), NACC will automatically discontinue the subject from FTLD Module follow-up. In the case where the subject is rejoining the ADC after being dropped, there is no need to provide the subject's FTLD Module status on the Milestones Form.

**PERMANENTLY ENTERED NURSING HOME

If the subject has moved to a nursing home but will continue to be followed by the Center, indicate in Question 2a how the subject will be followed (annual in-person visits, annual telephone follow-up, or minimal contact), and then in Question 2b, select "5 = Subject has permanently entered nursing home," along with any other reason for the change in data-collection status.