(Affix Label Here)

Participant ID: _____

Participant Name Code: _____

Date Form Filled Out:

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐
d d M M M y y y y
(e.g., 10JUN2005)

Interviewer Code: ☐ ☐ ☐

Circle Field Center Location:
BU   CU   DK   UP

Circle Visit: **²Visit 1 Follow Up**   **⁵Visit 2 Follow Up**   **⁸Visit 3 Follow Up**

Form Version Date: _**22/11/2019**__

Decedent Proxy Interview
(Visit 3)

For Internal Use Only – **Please Mark the Appropriate Box Below:**

☐¹ ....This Form was Administered via a DFR/Proxy

Interviewer Script: "*Hello. My name is _____ from the University of (_____).*

Your (relationship) was a participant in the Long Life Family Study. We recently learned of (his/her) death, and we want to express our condolences to you and your family. Your (relationship) played an important role in helping us learn more about the factors involved in long life by being a participant in our study. It is also important that we learn about some of the details of (his/her) health since their last medical history update in [month/year]. Do you have a few minutes to answer some questions? (If no, ask when you can call back and arrange to talk.)"

Q1. What is your relationship to the Study Participant?

☐¹ ....Spouse
☐² ....Child (Daughter/Son)
☐³ ....Sibling (Brother/Sister)
☐⁴ ....Niece/Nephew
☐⁵ ....Other: _____

Q2. How often did you have contact with *[him/her]*?

☐¹ ....Lived together   **Go to Q4**
☐² ....Daily (but did not live together)
☐³ ....3 or more times per week
☐⁴ ....Less than 3 times per week
☐ᴰ ....Don't Know
☐ᴿ ....Refused

Q3. What was the most frequent type of contact?

☐¹ ....Mostly in-person
☐² ....Mostly by phone
☐³ ....Both in-person and by phone
☐⁴ ....Other
☐ᴰ ....Don't Know
☐ᴿ ....Refused

Interviewer Script: *Now I'm going to ask about some medical problems* [participant's name] *may have had since their last medical history update on* [insert date].

Q4a. Was *[he/she]* told by a doctor that *[he/she]* had a heart attack, angina, or chest pain due to heart disease?

☐¹ ....Yes   **Go to Q4b**
☐⁰ ....No   **Go to Q5a**
☐ᴰ ....Don't Know   **Go to Q5a**
☐ᴿ ....Refused   **Go to Q5a**

Q4b. Was *[he/she]* hospitalized overnight for this problem?

☐¹ ....Yes   **Go to Q4c**
☐⁰ ....No   **Go to Q5a**

Q4c. Date of Admission: ___ ___ / ___ ___ / ___ ___ ___ ___

Date of Discharge: ___ ___ / ___ ___ / ___ ___ ___ ___

Name of Hospital: _____

City, State: _____

Q5a. Was *[he/she]* told by a doctor that *[he/she]* had a stroke, mini-stroke or TIA?

☐¹ ....Yes   **Go to Q5b**
☐⁰ ....No   **Go to Q6a**
☐ᴰ ....Don't Know   **Go to Q6a**
☐ᴿ ....Refused   **Go to Q6a**

Q5b. Was *[he/she]* hospitalized overnight for this problem?

☐¹ ....Yes   **Go to Q5c**
☐⁰ ....No   **Go to Q6a**

Q5c. Date of Admission: ___ ___ / ___ ___ / ___ ___ ___ ___

Q5c1. Date of Discharge: ___ ___ / ___ ___ / ___ ___ ___ ___

Q5c2. Name of Hospital: _____

Q5c3. City, State: _____

Q6a. Was *[he/she]* told by a doctor that *[he/she]* had a congestive heart failure?

> ☐ 1 ....Yes   **Go to Q6b**
> ☐ 0 ....No   **Go to Q7a**
> ☐ D ....Don't Know   **Go to Q7a**
> ☐ R ....Refused   **Go to Q7a**

Q6b. Was *[he/she]* hospitalized overnight for this problem?

> ☐ 1 ....Yes   **Go to Q6c**
> ☐ 0 ....No   **Go to Q7a**

Q6c. Date of Admission: ___ ___ / ___ ___ / ___ ___ ___ ___

Q6c1. Date of Discharge: ___ ___ / ___ ___ / ___ ___ ___ ___

Q6c2. Name of Hospital: _____

Q6c3. City, State: _____

Q7a. Was *[he/she]* told by a doctor that *[he/she]* had cancer? We are specifically interested in hearing about a cancer that was diagnosed for the first time since the last medical update on *[month/year]*? [**_Interviewer Note:_** *A cancer recurrence is not considered a new cancer.]*

> ☐ 1 ....Yes   **Go to Q7b**
> ☐ 0 ....No   **Go to Q8a**
> ☐ D ....Don't Know   **Go to Q8a**
> ☐ R ....Refused   **Go to Q8a**

Q7b. Was *[he/she]* hospitalized overnight for this problem?

> ☐ 1 ....Yes   **Go to Q7c**
> ☐ 0 ....No   **Go to Q8a**

Q7c. Date of Admission: ___ ___ / ___ ___ / ___ ___ ___ ___

Q7c1. Date of Discharge: ___ ___ / ___ ___ / ___ ___ ___ ___

Q7c2. Name of Hospital: _____

Q7c3. City, State: _____

Q8a. Was *[he/she]* told by a doctor that *[he/she]* had pneumonia?

      ☐¹ ....Yes   **Go to Q8b**
      ☐⁰ ....No   **Go to Q9a**
      ☐ᴰ ....Don't Know   **Go to Q9a**
      ☐ᴿ ....Refused   **Go to Q9a**

Q8b. Was *[he/she]* hospitalized overnight for this problem?

      ☐¹ ....Yes   **Go to Q8c**
      ☐⁰ ....No   **Go to Q9a**

Q8c. Date of Admission: ___ ___ / ___ ___ / ___ ___ ___ ___

Q8c1. Date of Discharge: ___ ___ / ___ ___ / ___ ___ ___ ___

Q8c2. Name of Hospital: _____

Q8c3. City, State: _____

Q9a. Was *[he/she]* told by a doctor that *[he/she]* broke or fractured a bone(s)?

      ☐¹ ....Yes   **Go to Q9b**
      ☐⁰ ....No   **Go to Q10a**
      ☐ᴰ ....Don't Know   **Go to Q10a**
      ☐ᴿ ....Refused   **Go to Q10a**

Q9b. Was *[he/she]* hospitalized overnight for this problem?

      ☐¹ ....Yes   **Go to Q9c**
      ☐⁰ ....No   **Go to Q10a**

Q9c. Date of Admission: ___ ___ / ___ ___ / ___ ___ ___ ___

Q9c1. Date of Discharge: ___ ___ / ___ ___ / ___ ___ ___ ___

Q9c2. Name of Hospital: _____

Q9c3. City, State: _____

Q10a. Was *[participant's name]* hospitalized overnight <u>for any other reasons</u> since we last updated the medical history in *[month/year]*?

      ☐¹ ....Yes   **Go to Q10b**
      ☐⁰ ....No   **Go to Q11a**
      ☐ᴰ ....Don't Know   **Go to Q11a**
      ☐ᴿ ....Refused   **Go to Q11a**

Q10b. How many times was *[he/she]* hospitalized for any other reason since we last updated the medical history? _____

Q10c. For each hospitalization indicated in **Q10b**, please provide the following:

    (1)   Date of hospital admission: ___ ___ / ___ ___ / ___ ___ ___ ___   ___ ___

              Date of discharge: ___ ___ / ___ ___ / ___ ___ ___ ___

              Diagnosis at Discharge: _____

              Name of Hospital: _____

              City, State: _____

    (2)   Date of hospital admission: ___ ___ / ___ ___ / ___ ___ ___ ___

              Date of discharge: ___ ___ / ___ ___ / ___ ___ ___ ___

              Diagnosis at Discharge: _____

              Name of Hospital: _____

              City, State: _____

    (3)   Date of hospital admission: ___ ___ / ___ ___ / ___ ___ ___ ___

              Date of discharge: ___ ___ / ___ ___ / ___ ___ ___ ___

              Diagnosis at Discharge: _____

              Name of Hospital: _____

              City, State: _____

For more than three (3) hospitalizations, please list on a separate sheet.

<u>**Interviewer Script:**</u> "*Now I have some questions about his/her memory.*"

Q11a. Did *[participant's name]* have any problems with *[his/her]* memory that is out of the ordinary for him/her?

        ☐[1]................................Yes   **Go to Q11b**
        ☐[0]................................No   **Go to Q12a** [D]
        ☐................................Don't Know   **Go to Q12a** [R]
        ☐................................Refused   **Go to Q12a**

Q11b. How long before *[he/she]* died did *[he/she]* start having difficulty with *[his/her]* memory?

      _____ Days OR _____ Months OR _____ Years

        (If "Don't Know", Enter "D" in the space for Days)

Q11c. Did *[his/her]* trouble with *[his/her]* memory begin suddenly (OVERNIGHT) or slowly?

         ☐¹ ....Suddenly
         ☐⁰ ....Slowly
         ☐ᴰ ....Don't Know
         ☐ᴿ ....Refused

Q11d. Since *[month/year],* had the memory problems changed over time?

         ☐⁰ ....No change
         ☐¹ ....Yes, memory has improved
         ☐² ....Yes, steady decline over time
         ☐³ ....Yes, sudden decline(s)
         ☐ᴰ ....Don't know
         ☐ᴿ ....Refused

Q11e. Was a doctor aware of *[his/her]* memory problems?

         ☐¹ ....Yes   **Go to Q11f**
         ☐⁰ ....No   **Go to Q12a**
         ☐ᴰ ....Don't Know   **Go to Q12a**
         ☐ᴿ ....Refused   **Go to Q12a**

Q11f. What did the doctor believe was causing *[his/her]* memory problems?
      *[**Interviewer Note:** Please mark only one answer.]*

         ☐¹ ....Alzheimer's Disease
         ☐² ....Dementia
         ☐³ ....Confusion
         ☐⁴ ....Delierium
         ☐⁵ ....Depression
         ☐⁶ ....Multi-infarct
         ☐⁷ ....Parkinson's Disease
         ☐⁸ ....Stroke
         ☐⁹ ....Nothing Wrong
         ☐ ....Other; Please Specify: _____
         ☐ᴰ ....Don't Know
         ☐ᴿ ....Refused

Interviewer Script: *"Now I have some questions about his/her level of physical function."*

Q12a. Because of a health or physical problem, did *[participant's name]* have any difficulty walking a quarter of a mile (2-3 blocks)? *[**Interviewer Note:** If the proxy responds "Did not do", probe to determine whether this was because of a health or physical problem. If the participant didn't walk because of a health or physical problem, mark "Yes". If the participant did not walk for other reasons, mark "Did not do".]*

☐¹	................................Yes	**Go to Q12b**
☐²	................................Did Not Do	**Go to Q14a**
☐⁰	................................No	**Go to Q13a**
☐ᴰ	................................Don't Know	**Go to Q14a**
☐ᴿ	................................Refused	**Go to Q14a**

Q12b. How long before *[he/she]* died did *[he/she]* **start** having difficulty?

_____ Days   OR   _____ Months   OR   _____ Years

(If "Don't Know", Enter "D" in the space for Days)

Q12c. How much difficulty did *[he/she]* have? *[**Interviewer Note:** Read response options.]*

☐¹	................................A Little Difficulty
☐²	................................Some Difficulty
☐³	................................A Lot of Difficulty
☐⁰	................................Was unable to do it
☐ᴰ	................................Don't Know
☐ᴿ	................................Refused

Q13a. Because of a health or physical problem, did *[participant's name]* have any difficulty walking a distance of one mile, that is about 8 to 12 blocks? *[**Interviewer Note:** If the proxy responds "Did not do", probe to determine whether this was because of a health or physical problem. If the participant didn't walk because of a health or physical problem, mark "Yes". If the participant did not walk for other reasons, mark "Did not do".]*

☐¹	................................Yes	**Go to Q13b**
☐²	................................Did Not Do	**Go to Q14a**
☐⁰	................................No	**Go to Q14a**
☐ᴰ	................................Don't Know	**Go to Q14a**
☐ᴿ	................................Refused	**Go to Q14a**

Q13b. How long before *[he/she]* died did *[he/she]* **start** having difficulty?

_____ Days   OR   _____ Months   OR   _____ Years

(If "Don't Know", Enter "D" in the space for Days)

Q13c. How much difficulty did *[he/she]* have? [***Interviewer Note:*** *Read response options.]*

       ☐¹ ....A Little Difficulty
       ☐² ....Some Difficulty
       ☐³ ....A Lot of Difficulty
       ☐⁰ ....Wasere they unable to do it?
       ☐ᴰ ....Don't Know
       ☐ᴿ ....Refused

Q14a. Because of a health or physical problem, did *[participant's name]* have any difficulty walking up one flight of stairs (about 10 steps) without resting? [***Interviewer Note:*** *If the proxy responds "Did not do", probe to determine whether this was because of a health or physical problem. If the participant*
didn't walk up 10 steps because of a health or physical problem, mark "Yes". If the participant did not walk up steps for other reasons, such as there are simply no steps in the area, mark "Did not do".]

       ☐¹ ....Yes   **Go to Q14b**
       ☐² ....Did Not Do   **Go to Q16a**
       ☐⁰ ....No   **Go to Q15a**
       ☐ᴰ ....Don't Know   **Go to Q16a**
       ☐ᴿ ....Refused   **Go to Q16a**

Q14b. How long before *[he/she]* died did *[he/she]* **start** having difficulty?

      _____ Days   OR   _____Months   OR   _____Years

      (If "Don't Know", Enter "D" in the space for Days)

Q14c. How much difficulty did *[he/she]* have? [***Interviewer Note:*** *Read response options.]*

       ☐¹ ....A Little Difficulty
       ☐² ....Some Difficulty
       ☐³ ....A Lot of Difficulty
       ☐⁰ ....Wasere they unable to do it?
       ☐ᴰ ....Don't Know
       ☐ᴿ ....Refused

Q15a. Because of a health or physical problem, did *[participant's name]* have any difficulty walking up one two flights of stairs (about 20 steps) without resting? *[Interviewer Note: If the proxy responds "Did not do", probe to determine whether this was because of a health or physical problem. If the participant didn't walk up 10 steps because of a health or physical problem, mark "Yes". If the participant did not walk up steps for other reasons, such as there are simply no steps in the area, mark "Did not do".]*

☐¹ ....Yes   **Go to Q15b**
☐² ....Did Not Do   **Go to Q16a**
☐⁰ ....No   **Go to Q16a**
☐ᴰ ....Don't Know   **Go to Q16a**
☐ᴿ ....Refused   **Go to Q16a**

Q15b. How long before *[he/she]* died did *[he/she]* **start** having difficulty?

_____ Days   OR _____ Months   OR _____ Years

(If "Don't Know", Enter "D" in the space for Days)

Q15c. How much difficulty did *[he/she]* have? *[**Interviewer Note:** Read response options.]*

☐¹ ....A Little Difficulty
☐² ....Some Difficulty
☐³ ....A Lot of Difficulty
☐⁰ ....Wasere they unable to do it?
☐ᴰ ....Don't Know
☐ᴿ ....Refused

Q16a. Because of a health or physical problems, did *[participant's name]* have any difficulty getting in and out of bed or chairs?

☐¹ ....Yes   **Go to Q16b**
☐⁰ ....No   **Go to Q17a**
☐ᴰ ....Don't Know   **Go to Q17a**
☐ᴿ ....Refused   **Go to Q17a**

Q16b. How long before *[he/she]* died did *[he/she]* **start** having difficulty?

_____ Days   OR _____ Months   OR _____ Years

(If "Don't Know", Enter "D" in the space for Days)

Q16c. How much difficulty did *[he/she]* have? *[**Interviewer Note:** Read response options.]*

☐¹ ....A Little Difficulty
☐² ....Some Difficulty
☐³ ....A Lot of Difficulty
☐⁰ ....Wasere they unable to do it?
☐ᴰ ....Don't Know
☐ᴿ ....Refused

Q16d. Did *[he/she]* usually receive help from another person when *[he/she]* got in and out of bed or chairs?

☐¹ ....Yes
☐⁰ ....No
☐ᴰ ....Don't Know
☐ᴿ ....Refused

Q17a. Did *[participant's name]* have any difficulty bathing or showering?

☐¹ ....Yes   **Go to Q17b**
☐⁰ ....No   **Go to Q18a**
☐ᴰ ....Don't Know   **Go to Q18a**
☐ᴿ ....Refused   **Go to Q18a**

Q17b. How long before *[he/she]* died did *[he/she]* **start** having difficulty?

_____ Days   OR   _____ Months   OR   _____ Years

(If "Don't Know", Enter "D" in the space for Days)

Q17c. How much difficulty did *[he/she]* have? *[**Interviewer Note:** Read response options.]*

☐¹ ....A Little Difficulty
☐² ....Some Difficulty
☐³ ....A Lot of Difficulty
☐⁰ ....Wasere they unable to do it?
☐ᴰ ....Don't Know
☐ᴿ ....Refused

Q17d. Did *[he/she]* usually receive help from another person when *[he/she]* bathing or showering?

☐¹ ....Yes
☐⁰ ....No
☐ᴰ ....Don't Know
☐ᴿ ....Refused

Q18a. Did *[participant's name]* **have to** use a cane, walker, crutches, or other special equipment to help *[him/her]* get around?

    ☐¹ ....Yes   **Go to Q18b**
    ☐⁰ ....No   **Go to Q19**
    ☐ᴰ ....Don't Know   **Go to Q19**
    ☐ᴿ ....Refused   **Go to Q19**

Q18b. How long before *[he/she]* died did *[he/she]* **start** using equipment to help *[him/her]* get around?

    _____ Days OR _____Months OR _____Years

    (If "Don't Know", Enter "D" in the space for Days)

Q19. What was *[his/her]* housing situation before [*he/she*] passed away?

    ☐¹ ....House, including Townhouse or Farm
    ☐² ....Apartment/Co-op/Condominium
    ☐³ ....Assisted Living/Other Special Housing for Older Adults
    ☐⁴ ....Nursing Home
    ☐⁵ ....Other (Please Specify) _____

Q20a. Where did *[participant's name]* die?

    ☐¹ ....Hospital, inpatient   **Go to Q20b**
    ☐² ....Hospital, Emergency Room   **Go to Q20c**
    ☐³ ....Nursing Home/Rehabilitation Facility   **Go to Q20c**
    ☐⁴ ....Inpatient hospice facility   **Go to Q20c**
    ☐⁵ ....Home/Residence   **Go to Q20d**
    ☐⁶ ....Location not mentioned   **Go to Q20e**
    ☐ᴰ ....Don't Know   **Go to Q21a**
    ☐ᴿ ....Refused   **Go to Q21a**

Q20b. What was the date of admission for this hospitalization which resulted in death?

    ___ ___ / ___ ___ / ___ ___ ___ ___

Q20c. What is the name of the facility where *[participant's name]* died?

    Facility name: _____

Q20d. What city and state is this facility located in?

    City, State: _____   **Go to Q21a**

Q20e. Please describe this location, including city and state.

_____

Q21a. Do you know the main cause of your *[relationship]* death?

☐¹ ....Yes   **Go to Q21b**
☐⁰ ....No   **Go to Q21c**
☐ᴰ ....Don't Know   **Go to Q21c**
☐ᴿ ....Refused   **Go to Q21c**

Q21b. What was the cause of *[his/her]* death?

_____

Q21c. Please describe the circumstances surrounding {his/her} death. Was he/she in good health prior to death? For how long had he/she been ill? What were the symptoms? treatment? What did the doctor or healthcare provider discuss with you as the cause of his/her death?

_____

_____

_____

_____

_____

_____

_____

End Interview Script: *"Thank you for answering these important questions. This provides valuable study information. We really appreciate your help."*

*Interviewer: **Please answer the following question based on your judgment of the proxy's responses to the Decedent Proxy Interview.***

Q22. On the whole, how reliable do you think the proxy's responses to the Decedent Proxy Interview are?

☐¹ ....Very Reliable
☐² ....Fairly Reliable
☐⁰ ....Not Very Reliable
☐ᴰ ....Don't Know