



(Affix Label Here)

Participant ID: _____

Participant Name Code: _____

Date Form Filled Out:

Grid for date entry: d d M M M y y y y (e.g., 10JUN2005)

Interviewer Code: [] [] []

Circle Field Center Location:

BU CU DK UP

Circle Visit: 1Visit 1 3Visit 2 4Visit 2 (New Participant) 5Visit 2 Follow Up

Form Version Date: 07/09/2016

Decedent Proxy Interview (Visit 2)

For Internal Use Only - Please Mark the Appropriate Box Below: [] 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
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

Go to Q4

Participant ID: _____

Participant Name Code: _____

Q3. What was the most frequent type of contact?

- 1Mostly in-person
- 2Mostly by phone
- 3Both in-person and by phone
- 4Other
- DDon't Know
- RRefused

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?

- 1Yes **Go to Q4b**
- 0No **Go to Q5a**
- DDon't Know **Go to Q5a**
- RRefused **Go to Q5a**

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

- 1Yes **Go to Q4c**
- 0No **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?

- 1Yes **Go to Q5b**
- 0No **Go to Q6a**
- DDon't Know **Go to Q6a**
- RRefused **Go to Q6a**

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

- 1Yes **Go to Q5c**
- 0No **Go to Q6a**

Participant ID: _____

Participant Name Code: _____

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?

- ¹Yes **Go to Q6b**
- ⁰No **Go to Q7a**
- ^DDon't Know **Go to Q7a**
- ^RRefused **Go to Q7a**

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

- ¹Yes **Go to Q6c**
- ⁰No **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.]

- ¹Yes **Go to Q7b**
- ⁰No **Go to Q8a**
- ^DDon't Know **Go to Q8a**
- ^RRefused **Go to Q8a**

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

- ¹Yes **Go to Q7c**
- ⁰No **Go to Q8a**

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

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

Q7c2. Name of Hospital: _____

Q7c3. City, State: _____

Participant ID: _____

Participant Name Code: _____

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

- ¹Yes **Go to Q8b**
- ⁰No **Go to Q9a**
- ^DDon't Know **Go to Q9a**
- ^RRefused **Go to Q9a**

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

- ¹Yes **Go to Q8c**
- ⁰No **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)?

- ¹Yes **Go to Q9b**
- ⁰No **Go to Q10a**
- ^DDon't Know **Go to Q10a**
- ^RRefused **Go to Q10a**

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

- ¹Yes **Go to Q9c**
- ⁰No **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 for any other reasons since we last updated the medical history in [month/year]?

- ¹Yes **Go to Q10b**
- ⁰No **Go to Q11a**
- ^DDon't Know **Go to Q11a**
- ^RRefused **Go to Q11a**

Participant ID: _____ Participant Name Code: _____

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.

Interviewer Script: "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?

¹Yes

Go to Q11b

⁰No

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)

Participant ID: _____

Participant Name Code: _____

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

- 1Suddenly
- 0Slowly
- DDon't Know
- RRefused

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

- 0No change
- 1Yes, memory has improved
- 2Yes, steady decline over time
- 3Yes, sudden decline(s)
- DDon't know
- RRefused

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

- 1Yes **Go to Q11f**
- 0No **Go to Q12a**
- DDon't Know **Go to Q12a**
- RRefused **Go to Q12a**

Q11f. What did the doctor believe was causing [his/her] memory problems?

[Interviewer Note: Please mark only one answer.]

- 1Alzheimer's Disease
- 2Dementia
- 3Confusion
- 4Delerium
- 5Depression
- 6Multi-infarct
- 7Parkinson's Disease
- 8Stroke
- 9Nothing Wrong
-Other; Please Specify: _____
- DDon't Know
- RRefused

Participant ID: _____

Participant Name Code: _____

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".]

- 1Yes **Go to Q12b**
- 2Did Not Do **Go to Q14a**
- 0No **Go to Q13a**
- DDon't Know **Go to Q14a**
- RRefused **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.]

- 1A Little Difficulty
- 2Some Difficulty
- 3A Lot of Difficulty
- 0Was unable to do it
- DDon't Know
- RRefused

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".]

- 1Yes **Go to Q13b**
- 2Did Not Do **Go to Q14a**
- 0No **Go to Q14a**
- DDon't Know **Go to Q14a**
- RRefused **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)

Participant ID: _____

Participant Name Code: _____

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

- 1A Little Difficulty
- 2Some Difficulty
- 3A Lot of Difficulty
- 0Were they unable to do it?
- DDon't Know
- RRefused

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".]

- 1Yes **Go to Q14b**
- 2Did Not Do **Go to Q16a**
- 0No **Go to Q15a**
- DDon't Know **Go to Q16a**
- RRefused **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.]

- 1A Little Difficulty
- 2Some Difficulty
- 3A Lot of Difficulty
- 0Were they unable to do it?
- DDon't Know
- RRefused

Participant ID: _____

Participant Name Code: _____

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".*]

- ¹Yes **Go to Q15b**
- ²Did Not Do **Go to Q16a**
- ⁰No **Go to Q16a**
- ^DDon't Know **Go to Q16a**
- ^RRefused **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.*]

- ¹A Little Difficulty
- ²Some Difficulty
- ³A Lot of Difficulty
- ⁰Were they unable to do it?
- ^DDon't Know
- ^RRefused

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

- ¹Yes **Go to Q16b**
- ⁰No **Go to Q17a**
- ^DDon't Know **Go to Q17a**
- ^RRefused **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)

Participant ID: _____

Participant Name Code: _____

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

- 1A Little Difficulty
- 2Some Difficulty
- 3A Lot of Difficulty
- 0Were they unable to do it?
- DDon't Know
- RRefused

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

- 1Yes
- 0No
- DDon't Know
- RRefused

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

- 1Yes **Go to Q17b**
- 0No **Go to Q18a**
- DDon't Know **Go to Q18a**
- RRefused **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.]

- 1A Little Difficulty
- 2Some Difficulty
- 3A Lot of Difficulty
- 0Were they unable to do it?
- DDon't Know
- RRefused

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

- 1Yes
- 0No
- DDon't Know
- RRefused

Participant ID: _____

Participant Name Code: _____

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

- ¹Yes **Go to Q18b**
- ⁰No **Go to Q19**
- ^DDon't Know **Go to Q19**
- ^RRefused **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?

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

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

- ¹Hospital, inpatient **Go to Q20b**
- ²Hospital, Emergency Room **Go to Q20c**
- ³Nursing Home/Rehabilitation Facility **Go to Q20c**
- ⁴Inpatient hospice facility **Go to Q20c**
- ⁵Home/Residence **Go to Q20d**
- ⁶Location not mentioned **Go to Q20e**
- ^DDon't Know **Go to Q21a**
- ^RRefused **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**

Participant ID: _____

Participant Name Code: _____

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

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

- ¹Yes **Go to Q21b**
- ⁰No **Go to Q21c**
- ^DDon't Know **Go to Q21c**
- ^RRefused **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?

- ¹Very Reliable
- ²Fairly Reliable
- ⁰Not Very Reliable
- ^DDon't Know