



(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

Decedent Proxy Interview (Phase II Follow-Up)

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.)”

1. What is your relationship to the Study Participant?

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

2. 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

3. 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

Participant ID: _____

Participant Name Code: _____

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].*

4a. Was [he/she] told by a doctor that [he/she] had a heart attack, angina, or chest pain due to heart disease?

- | | | |
|---------------------------------------|-----------------|------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q4b |
| <input type="checkbox"/> ⁰ |No | Go to Q5a |
| <input type="checkbox"/> ^D |Don't Know | Go to Q5a |
| <input type="checkbox"/> ^R |Refused | Go to Q5a |

4b. Was [he/she] hospitalized overnight for this problem?

- | | | |
|---------------------------------------|----------|------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q4c |
| <input type="checkbox"/> ⁰ |No | Go to Q5a |

4c. Date of Hospitalization: ____ ____ / ____ ____ ____ / ____ ____ ____ ____

Code: _____

5a. Was [he/she] told by a doctor that [he/she] had a stroke, mini-stroke or TIA?

- | | | |
|---------------------------------------|-----------------|------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q5b |
| <input type="checkbox"/> ⁰ |No | Go to Q6a |
| <input type="checkbox"/> ^D |Don't Know | Go to Q6a |
| <input type="checkbox"/> ^R |Refused | Go to Q6a |

5b. Was [he/she] hospitalized overnight for this problem?

- | | | |
|---------------------------------------|----------|------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q5c |
| <input type="checkbox"/> ⁰ |No | Go to Q6a |

5c. Date of Hospitalization: ____ ____ / ____ ____ ____ / ____ ____ ____ ____

Code: _____

6a. Was [he/she] told by a doctor that [he/she] had a congestive heart failure?

- | | | |
|---------------------------------------|-----------------|------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q6b |
| <input type="checkbox"/> ⁰ |No | Go to Q7a |
| <input type="checkbox"/> ^D |Don't Know | Go to Q7a |
| <input type="checkbox"/> ^R |Refused | Go to Q7a |

6b. Was [he/she] hospitalized overnight for this problem?

- | | | |
|---------------------------------------|----------|------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q6c |
| <input type="checkbox"/> ⁰ |No | Go to Q7a |

Participant ID: _____

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6c. Date of Hospitalization: ____ ____ / ____ ____ ____ / ____ ____ ____ ____

Code: _____

7a. 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.*

- | | | |
|---------------------------------------|-----------------|------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q7b |
| <input type="checkbox"/> ⁰ |No | Go to Q8a |
| <input type="checkbox"/> ^D |Don't Know | Go to Q8a |
| <input type="checkbox"/> ^R |Refused | Go to Q8a |

7b. Was [he/she] hospitalized overnight for this problem?

- | | | |
|---------------------------------------|----------|------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q7c |
| <input type="checkbox"/> ⁰ |No | Go to Q8a |

7c. Date of Hospitalization: ____ ____ / ____ ____ ____ / ____ ____ ____ ____

Code: _____

8a. Was [he/she] told by a doctor that [he/she] had pneumonia?

- | | | |
|---------------------------------------|-----------------|------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q8b |
| <input type="checkbox"/> ⁰ |No | Go to Q9a |
| <input type="checkbox"/> ^D |Don't Know | Go to Q9a |
| <input type="checkbox"/> ^R |Refused | Go to Q9a |

8b. Was [he/she] hospitalized overnight for this problem?

- | | | |
|---------------------------------------|----------|------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q8c |
| <input type="checkbox"/> ⁰ |No | Go to Q9a |

8c. Date of Hospitalization: ____ ____ / ____ ____ ____ / ____ ____ ____ ____

Code: _____

9a. Was [he/she] told by a doctor that [he/she] broke or fractured a bone(s)?

- | | | |
|---------------------------------------|-----------------|-------------------|
| <input type="checkbox"/> ¹ |Yes | Go to Q9b |
| <input type="checkbox"/> ⁰ |No | Go to Q10a |
| <input type="checkbox"/> ^D |Don't Know | Go to Q10a |
| <input type="checkbox"/> ^R |Refused | Go to Q10a |

Participant ID: _____

Participant Name Code: _____

9b. Was [he/she] hospitalized overnight for this problem?

- ¹Yes
- ⁰No

Go to Q9c

Go to Q10a

9c. Date of Hospitalization: ____ ____ / ____ ____ ____ / ____ ____ ____ ____

Code: _____

10a. Was [participant's name] hospitalized overnight for any other reasons since we last updated the medical history in [month/year]?

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

Go to Q10b

Go to Q11a

Go to Q11a

Go to Q11a

10b. How many times was [he/she] hospitalized for any other reason since we last updated the medical history? _____

10c. For each hospitalization indicated in **Q10b**, please provide the following:

(1) Date of Hospitalization: ____ ____ / ____ ____ ____ / ____ ____ ____ ____

Reason for Hospitalization: _____

Code: _____

(2) Date of Hospitalization: ____ ____ / ____ ____ ____ / ____ ____ ____ ____

Reason for Hospitalization: _____

Code: _____

(3) Date of Hospitalization: ____ ____ / ____ ____ ____ / ____ ____ ____ ____

Reason for Hospitalization: _____

Code: _____

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

Interviewer Script: "Now I have some questions about his/her memory."

11a. Did [participant's name] have any problems with [his/her] memory that is out of the ordinary for him/her?

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

Go to Q11b

Go to Q12a

Go to Q12a

Go to Q12a

11b. 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)

11c. Did [his/her] trouble with memory begin suddenly (OVERNIGHT) or slowly?

- 1 Suddenly
- 0 Slowly
- D Don't Know
- R Refused

11d. 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

11e. 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**

11f. 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 Delerium
- 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."

12a. 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**

12b. 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)

12c. 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

13a. 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**

13b. 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)

13c. 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

14a. 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**

14b. 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)

14c. 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

15a. 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**

Participant ID: _____

Participant Name Code: _____

^RRefused

Go to Q16a

15b. 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)

15c. 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

16a. 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

16b. 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)

16c. 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

16d. 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

Participant ID: _____

Participant Name Code: _____

17a. 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**

17b. 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)

17c. 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

17d. Did [*he/she*] usually receive help from another person when [*he/she*] bathing or showering?

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

18a. 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**

18b. 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)

19. 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) _____

20. Did [participant's name] die in a hospital (**do not** include emergency room, hospice, nursing home, or rehabilitation facility)?

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

21a. Do you know the main cause of your [relationship] death?

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

Go to Q21b
End Interview – Interviewer answer Q22
End Interview – Interviewer answer Q22
End Interview – Interviewer answer Q22

21b. What was 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.*

22. 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