

Approved: 04/18/97
OMB No.: 0920-0411
Exp. Date: 10/31/98

SECOND LONGITUDINAL STUDY OF AGING

WAVE 2

Decedent Questionnaire (Computer Assisted Telephone Interview)

Version DF 1.1

July 2002

Study conducted by the National Center for Health Statistics, with funding from the National Institute on Aging and the Centers for Disease Control and Prevention.

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INTRODUCTION
AND SCREENING QUESTIONS

These questions are about the place (SP) lived prior to his/her death.

1. Was the place where (SP) was living a -- (*Read all categories.*)

Code (X) only one.

If SP was in the hospital code permanent residence.

- 01 Single family house or townhouse that was not part of a retirement community
- 02 Single family house, townhouse, or apartment that was part of a retirement community
- 03 Regular apartment
- 04 Nursing home
- 05 Convalescent or rest home
- 06 Retirement home
- 07 Supervised apartment
- 08 Personal care or board and care home
- 09 Assisted living facility
- 10 Some other type of group residence or facility
- 11 Something else
- 97 Refused
- 99 Don't know

These first questions are about the circumstances surrounding (SP)'s death.

2. On what date did (SP) die?

Month_____ Day_____ Year19__

999997 Refused

999999 Don't know

3. a. Did (SP) die at home, in a hospital, a nursing home, a hospice, or some other place? (If "other place" probe for type of place and circle appropriate response.)

Note: If SP died at someone else's home, circle 1 below.

- 01 Home (Skip to 8)
- 02 Hospital
- 03 Nursing home
- 04 Hospice
- 05 Convalescent or rest home
- 06 Retirement home
- 07 Supervised apartment
- 08 Personal care or board and care home
- 09 Assisted living facility
- 10 Some other type of group residence or facility
- 11 Something else (Specify:) _____
- 97 Refused (Skip to 8)
- 99 Don't know (Skip to 8)

- b. How long had (he/she) been in the (facility) prior to his/her death?

____ number

____ days

____ weeks

____ months

999997 Refused

999999 Don't know

4. In what city, county, and state did (he/she) die?

City

County/Parish

State

7 Refused

9 Don't know

5. a. Was there a major illness or injury that led to (his/her) death?

1 Yes

2 No (Skip to Section A)

7 Refused (Skip to Section A)

9 Don't know (Skip to Section A)

b. About how long was it between the start of the final illness or injury and (SP)'s death?

1 No warning (1 or 2 hours)

2 One day or less

3 More than one day but less than or equal to one week

4 More than one week but less than or equal to one month

5 More than one month but less than or equal to one year

6 More than one year

7 Refused

9 Don't know

SECTION A

HOUSING, MIGRATION, AND LONG-TERM CARE

These questions are about the place (SP) lived prior to his/her death.

1. Did (SP) move to that place since (month/year of last interview)?

1 Yes

2 No (Skip to 4)

7 Refused

9 Don't know (Skip to 4)

2. In what month and year did (he/she) move there?

Month: _____ Year 19__

9997 Refused

9999 Don't know

3. a. Why did (he/she) move at that time?

Code (X) all that apply.

- 01 SP's health deteriorated
- 02 SP's health improved
- 03 Spouse's health deteriorated
- 04 Spouse's health improved
- 05 To move to different climate (better weather)
- 06 SP moved to a nursing home or other institution
- 07 Spouse moved to a nursing home or other institution
- 08 Spouse died
- 09 Divorced or separated from spouse or remarried
- 10 To live CLOSER to child/children
- 11 To live WITH child/children
- 12 To live with or closer to other relatives
- 13 Change in the people or availability of people who helped or lived with SP
- 14 To move to smaller house/apartment
- 15 Financial reasons; moved to a place that was less expensive to maintain
- 16 Because of structural limitations of the previous house
- 17 To move to a better or safer neighborhood
- 18 To move to a retirement home or retirement community
- 19 To move closer to a health facility
- 20 Other reasons
- 97 Refused
- 99 Don't know

If more than one reason given in a, ask b. Otherwise, skip to 4.

- b. What was the main reason? (Record number from a)

4. Who was (SP) living with (just prior to his/her death/prior to entering the [facility in 7])?

Code (X) all that apply.

- 01 Spouse
- 02 Daughter
- 03 Son
- 04 Daughter-in-law
- 05 Son-in-law
- 06 Grandchild
- 07 Sibling
- 08 Parent
- 09 Other relative
- 10 Non-relative
- 11 Lived alone
- 97 Refused
- 99 Don't know

Ask 6a-f immediately following each "yes" in 5a&b. If SP was in any of these facilities at the time of death, skip question 5 for that facility and ask 6a-f as appropriate (omitting question on discharge date for final stay).

5. Since the last time we talked with (SP), that is (month/year), was (he/she) a resident or patient in any of these types of places--

- a. A nursing home?

- 1 Yes (Go to 6a)
- 2 No
- 3 Yes response changed to "no" when asked question 5b
- 7 Refused
- 9 Don't know

- b. A convalescent home, rest home, or any other residential care facility?

(Make sure to record if answer in "a" is changed in response to question b.)

- 1 Yes
- 2 No (Skip to next section)
- 7 Refused (Skip to next section)
- 9 Don't know (Skip to next section)

6. a. How many DIFFERENT TIMES had (he/she) been a resident or patient in (type of facility) since (month/year)?

_____ number of times

997 Refused

999 Don't know

- b. In what month and year was (he/she) admitted (the FIRST time)?

___ mo / ___ yr

9997 Refused

9999 Don't know

Do not ask 6c if SP died in a nursing home or convalescent or rest home.

- c. In what month and year was (he/she) discharged (the LAST time)?

___ mo / ___ yr

9997 Refused

9999 Don't know

If more than one stay during interval, ask d. Otherwise, skip to e.

- d. Since (month/year of last interview), how many months altogether did (he/she) spend in a (type of facility)?

_____ months

97 Refused

99 Don't know

- e. Who paid or will pay for (his/her) stay(s) in the (type of facility) since (month/year of last interview)?

Code (X) all that apply.

- 01 Decedent or family in household
- 02 Family NOT in household
- 03 Private health insurance
- 04 Medicare
- 05 Medicaid
- 06 VA program, or other military
- 07 Other private source
- 08 Other public source
- 09 No one/Free
- 97 Refused
- 99 Don't know

Ask f if more than one source given in e.

- f. Who paid or will pay the MOST for (his/her) stay(s) in the (type of facility) since (month/year of last interview)?

- 01 Decedent or family in household
- 02 Family NOT in household
- 03 Private health insurance
- 04 Medicare
- 05 Medicaid
- 06 VA program, or other military
- 07 Other private source
- 08 Other public source
- 97 Refused
- 99 Don't know

SECTION B

FAMILY STRUCTURE, RELATIONSHIPS AND LIVING ARRANGEMENTS

If decedent was married at baseline, ask question 1. Otherwise, skip to 2.

1. a. Our records indicate that (SP) was married when we last spoke with (him/her) in (month/year). Was (he/she) still married at the time of death?
 - 1 Yes
 - 2 No (Skip to 1c)
 - 3 Discrepancy, SP wasn't married at last interview (Skip to 2)
 - 7 Refused
 - 9 Don't know (Skip to 3)

- b. Was (SP) married to the same person as in (month/year)?
 - 1 Yes (Skip to 3)
 - 2 No
 - 7 Refused (Skip to 3)
 - 9 Don't know (Skip to 3)

- c. (Ask if necessary:) Did (his/her) (previous) spouse die, or was (he/she) divorced or separated?
 - 1 Spouse died
 - 2 Divorced
 - 3 Separated
 - 4 Other
 - 7 Refused
 - 9 Don't know (Skip to 3)

- d. In what month and year [was (he/she) (widowed/divorced/separated)/did (his/her) previous marriage end]?

____ mo/ ____ yr

9997 Refused
9999 Don't know

If decedent was remarried since last interview, ask 1e. Otherwise, skip to 3.

e. In what month and year was (he/she) remarried?

____mo/____yr

9997 Refused

9999 Don't know

If decedent was married at baseline, skip to question 3. Otherwise, continue with 2.

2. a. Our records indicate that (SP) was NOT married when we last spoke with (him/her) in (month/year). Had (he/she) gotten married since that time?

1 Yes

2 No (Skip to 3)

7 Refused

9 Don't know (Skip to 3)

b. In what month and year did (SP) get married?

____mo/____yr

9997 Refused

9999 Don't know

c. Was (SP) still married at the time of (his/her) death?

1 Yes (Skip to 3)

2 No

7 Refused (Skip to 3)

9 Don't know (Skip to 3)

d. (Ask if necessary:) Did that spouse die, or was (he/she) divorced or separated?

1 Spouse died

2 Divorced

3 Separated

4 Other

7 Refused

9 Don't know

- e. In what month and year [was (he/she) (widowed/divorced/separated)/did (his/her) marriage end]?

___ mo/ ___ yr

9997 Refused

9999 Don't know

If SP's spouse is the proxy respondent, skip to Section C.

3. Was (SP)'s spouse a resident in a nursing home or other long-term care facility at the time of (SP)'s death ?

1 Yes

2 No

7 Refused

9 Don't know

--->

How long had (his/her) spouse been a resident of this facility?

__ Number

__ Weeks

__ Months

__ Years

97 Refused

99 Don't know

SECTION C

ASSISTANCE WITH KEY ACTIVITIES

For this next set of questions, I'd like you to think about (SP's) condition approximately 6 months before (his/her) death, that is (month/year). These first questions are about how well (SP) was able to do certain activities by (himself/herself) and without using special equipment at that time.

Ask questions 1 A-C before continuing with question 2.

1. Because of a health or physical problem, did (he/she) have ANY difficulty -

Ask if "Didn't do": Was this because of a HEALTH or PHYSICAL problem? If "Yes", mark box 1; if "No" mark box 3.

- A. Eating?
- B. Getting in and out of bed or chairs?
- C. Walking?

Ask question 2 for each activity A-C recorded "yes" in 1. If all "no" in 1, skip to Item C1.

2. By (himself/herself) and without using special equipment, how much difficulty did he/she have (activity) [in (month/year)/approximately 6 months before his/her death] would you say some, a lot, or was (he/she) unable to do it.

- 1 Some
- 2 A lot
- 3 Unable
- 7 Refused
- 9 Don't know

If SP "unable" on all ADLs, skip to 7.

- ITEM C1 *Refer to question 1 for each activity in turn.*
- 1 Box 3 marked (Go to C1 for next activity)
 - 2 All other (Go to 3)

3. a. [In (month/year)/ approximately 6 months before (his/her) death], did (SP) use any special equipment or aids in (activity)?

- 1 Yes
- 2 No (Go to C1 for next activity)
- 7 Refused (Go to C1 for next activity)
- 9 Don't know (Go to C1 for next activity)

- b. What special equipment or aids did (he/she) use?

Anything else?

Code (X) all that apply.

For: Eating

- Special or oversized eating equipment
- Bed or lap tray
- Covered cup / modified bowl or cup
- Tube feeding / IV feeding equipment
- Pureed or liquified food
- Other (Specify:) _____
- Refused
- Don't know

For: Getting in and out of bed or chairs

- Cane or walking stick
- Walker
- Extra / special cushions
- Special "raising seat" chair / lift chair
- Hospital bed
- Trapeze / sling / lift / Hoyer lift
- Ramp
- Bed rails
- Hand rails
- Furniture (e.g., night stand, bed post, chair arms)
- Wheelchair / stay in wheelchair all day
- Other (Specify:) _____
- Refused
- Don't know

For: Walking

- Cane or walking stick
- Walker
- Crutch or crutches
- Wheelchair
- Artificial leg
- Brace
- Guide dog
- Oxygen / special breathing equipment
- Ramp
- Hand rail
- Furniture (walls, tables, chairs)
- Chair lift
- Scooter
- Other (Specify:) _____
- Refused
- Don't know

ITEM C2 *Refer to question 1 for each activity.*

- 1 Box 3 marked (Go to C2 for next activity)
- 2 All other (Go to 4)

Ask question 4 as appropriate for each activity before continuing to C2 for next activity.

4. [In (month/year)/approximately 6 months before his/her death], did (he/she) receive help from another person in (activity)?

- 1 Yes
- 2 No (Go to 5b)
- 7 Refused (Go to 5b)
- 9 Don't know (Go to 5b)

5. a. [In (month/year)/.....], did (he/she) need MORE help with (activity)?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

(Go to C2 for next activity)

b. [In month/year)/.....], did (SP) NEED help with (activity)?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

(Go to C2 for next activity)

ITEM C3 *Refer to questions 1, 3a, 4 for each activity.*

- 1 If "no" marked in 1 and any "yes" in 3a or 4 (Go to 6a)
- 2 All other (Go to C3 for next activity)

6. a. You mentioned earlier that (SP) had no difficulty (activity) [In (month/year)/.....]. If (he/she) did not (have help and/or use equipment) while (activity), would (he/she) have had ANY difficulty doing it?

- 1 Yes
- 2 No (Go to C3 for next activity)
- 3 Couldn't do it without help or equipment (Go to C3 for next activity)
- 7 Refused
- 9 Don't know (Go to C3 for next activity)

b. How much difficulty would (he/she) have had (activity) without (help and/or using equipment), would you say some, a lot, or would (he/she) have been unable to do it?

- 1 Some
- 2 A lot
- 3 Unable
- 7 Refused
- 9 Don't know

(Go to C3 for next activity)

ITEM C4 *Refer to question 1 for each activity.*

- 1 Box 3 marked in question 1 (go to C4 for next activity)
- 2. All other (Continue)

Read only if 2 in Item C4 for one or more activities. Otherwise skip to instruction before question 9.

Part of this study is concerned with the changes that occur as people age and reach the end of their lives. We just talked about (SP)'s ability to do different activities in (6 month date), 6 months prior to (his/her) death. Now I would like you to think about (SP)'s ability to do these same activities approximately one month prior to (his/her) death, that is in (month/year).

7. Between (6 month date) and (1 month date) was there a noticeable change in (SP)'s ability to (activity)?

- 1 Yes
- 2 No (Go to C4 for next activity)
- 7 Refused (Go to C4 for next activity)
- 9 Don't know (Go to C4 for next activity)

8. Did (his/her) ability to (activity) improve or get worse?

- 1 Improved (Go to C4 for next activity)
- 2 Got worse (Go to C4 for next activity)
- 7 Refused (Go to C4 for next activity)
- 9 Don't know (Go to C4 for next activity)

If any "yes" in question 7, continue as instructed below, otherwise skip to question 14.

Ask question 9 for each activity A-C recorded "no difficulty" in 1 or "improved" in 8 before continuing with 10. If none skip to 10.

9. Because of a health or physical problem [in (1 month date)/approximately 1 month before death], did (he/she) have ANY difficulty -

Ask if "Didn't do": Was this because of a HEALTH or PHYSICAL problem? If "Yes", mark box 1; if "No" mark box 3.

- A. Eating?
- B. Getting in and out of bed or chairs?
- C. Walking?

Ask question 10 if 2 was “some”, “a lot” or for each activity A-C recorded “yes” in 9. If all “no” in 9, go to 11.

10. By (himself/herself) and without using special equipment, how much difficulty did he/she have (activity) [in (1 month date)/approximately 1 month before death], would you say some, a lot, or was he/she unable to do it?

- 1 Some
- 2 A lot
- 3 Unable
- 7 Refused
- 9 Don't know

If SP “unable” on all ADLs, skip to 14.

ITEM C5 Refer to question 9 for each activity in turn.

- 1 Box 3 marked (Go to C5 for next activity)
- 2 All other (Go to 11)

11. a. [In (1 month date)/approximately 1 month before death], did (SP) use any special equipment or aids in (activity)?

- 1 Yes
- 2 No (Go to C5 for next activity)
- 7 Refused (Go to C5 for next activity)
- 9 Don't know (Go to C5 for next activity)

- b. What special equipment or aids did (he/she) use?

Anything else?

Code (X) all that apply.

For: Eating

- Special or oversized eating equipment
- Bed or lap tray
- Covered cup / modified bowl or cup
- Tube feeding / IV feeding equipment
- Pureed or liquified food
- Other (Specify:) _____
- Refused
- Don't know

For: Getting in and out of bed or chairs

Cane or walking stick
Walker
Extra / special cushions
Special "raising seat" chair / lift chair
Hospital bed
Trapeze / sling / lift / Hoyer lift
Ramp
Bed rails
Hand rails
Furniture (e.g., night stand, bed post, chair arms)
Wheelchair / stay in wheelchair all day
Other (Specify:) _____
Refused
Don't know

For: Walking

Cane or walking stick
Walker
Crutch or crutches
Wheelchair
Artificial leg
Brace
Guide dog
Oxygen / special breathing equipment
Ramp
Hand rail
Furniture (walls, tables, chairs)
Chair lift
Scooter
Other (Specify:) _____
Refused
Don't know

- ITEM C6 *Refer to question 9 for each activity in turn.*
1 Box 3 marked (Go to C6 for next activity)
2 All other (Go to 12)

Ask question 12 as appropriate for each activity before continuing to next activity.

12. [In (1 month date)/approximately 1 month before death], did (he/she) receive help from another person in (activity)?

- 1 Yes
- 2 No (Go to 13b)
- 7 Refused (Go to 13b)
- 9 Don't know (Go to 13b)

13. a. [In (1 month date)/approximately 1 month before death], did (he/she) need MORE help with (activity)?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

(Go to C6 for next activity)

- b. [In (1 month date)/approximately 1 month before death], did (SP) NEED help with (activity)? *(If yes, probe for type needed.)*

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

(Go to C6 for next activity)

14. a. Since the last time we spoke with (SP), that is since (month/year of last interview) and the time of death, did (he/she) fall?

- 1 Yes
- 2 No (Skip to Section D)
- 7 Refused (Skip to Section D)
- 9 Don't know (Skip to Section D)

b. Did (he/she) fall more than once between (month/year of last interview) and the time of death?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

c. Was (he/she) injured as a result of the fall(s)?

- 1 Yes
- 2 No (Skip to Section D)
- 7 Refused (Skip to Section D)
- 9 Don't know (Skip to Section D)

d. What kind of injuries did (he/she) have - a fracture, bruise, scrape or cut; did (he/she) lose consciousness, or did (he/she) have some other injury?

Code (X) all that apply.

- 1 Fracture
- 2 Bruise, cut, or scrape
- 3 Lost consciousness
- 4 Other
- 7 Refused
- 9 Don't know

SECTION D

CONDITIONS AND IMPAIRMENTS

Now I'm going to ask some questions about vision, hearing, and dental problems. Please tell me if (SP) had any of the following conditions, even if you have mentioned them before.

1. At the time of death did (SP) have:

a. Cataracts in one or both eyes?

1 Yes -----> Is that in one or both eyes?	1 One
2 No	2 Both
7 Refused	7 Refused
9 Don't know	9 Don't know

b. Glaucoma?

1 Yes
2 No
7 Refused
9 Don't know

c. Blindness in one or both eyes?

1 Yes -----> Is that in one or both eyes?	1 One
2 No	2 Both (Skip to 4)
7 Refused	7 Refused
9 Don't know	9 Don't know

If decedent used eyeglasses or contact lenses at last interview, skip to 3. Otherwise, continue with question 2.

2. Did (SP) use eyeglasses or contact lenses? Include eyeglasses that just magnify.

1 Yes
2 No
7 Refused
9 Don't know

3. Did (he/she) have any other trouble seeing with one or both eyes, EVEN when wearing glasses or contact lenses?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

4. At the time of death did (SP) have:

Deafness in one or both ears?

- | | |
|-------------------------------------------|--------------------|
| 1 Yes -----> Is that in one or both ears? | 1 One |
| 2 No | 2 Both (Skip to 6) |
| 7 Refused | 7 Refused |
| 9 Don't know | 9 Don't know |

5. Did (he/she) have any (other) trouble hearing with one or both ears?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

6. Did (he/she) use a hearing aid?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

7. Did (SP) have tooth or mouth problems that made it hard for (him/her) to eat EVEN when wearing dentures or partial plates?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

Now I'm going to ask about some other conditions. Again, please tell me if (SP) had had any of these conditions, even if you mentioned them before.

8. Since the last time we talked with (SP), that is since (month/year), did (he/she) break (his/her) hip?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

9. At the time of death did (SP) have osteoporosis?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

10. Did (SP) have diabetes?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

11. Did (SP) have arthritis?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

12. At the time of death did (SP) have chronic bronchitis or emphysema?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

13. Did (SP) have asthma?
- 1 Yes
 - 2 No
 - 7 Refused
 - 9 Don't know
14. At the time of death did (SP) have hypertension, sometimes called high blood pressure?
- 1 Yes
 - 2 No
 - 7 Refused
 - 9 Don't know
15. a. At the time of death did (SP) have any type of heart disease, including coronary heart disease, angina, or congestive heart failure?
- 1 Yes
 - 2 No (Skip to 16)
 - 7 Refused (Skip to 16)
 - 9 Don't know (Skip to 16)
- b. Did (SP) have a heart attack since (month/year of last interview) ?
- 1 Yes
 - 2 No
 - 7 Refused
 - 9 Don't know
16. Since the last time we spoke with (SP), that is since (month/year), did (he/she) have a stroke or cerebrovascular accident?
- 1 Yes
 - 2 No
 - 7 Refused
 - 9 Don't know
17. a. At the time of death did (SP) have cancer of any kind?
- 1 Yes
 - 2 No (Go to next section)
 - 7 Refused (Go to next section)
 - 9 Don't know (Go to next section)

b. What kind of cancer was this?

- | | |
|-----------------------|---------------|
| 1 Colon/rectal/bowel | 10 Cervical |
| 2 Skin - melanoma | 11 Lung |
| 3 Skin - nonmelanoma | 12 Liver |
| 4 Skin - unknown type | 13 Pancreatic |
| 5 Uterine/ovarian | 14 Kidney |
| 6 Prostate | 15 Lymphoma |
| 7 Stomach | 16 Other |
| 8 Leukemia | 97 Refused |
| 9 Breast | 99 Don't know |

SECTION E

HEALTH OPINIONS

For these next two questions I'd like you to think about (SP)'s health in general during the last half year of (his/her) life.

1. Approximately 6 months before (SP)'s death, that is (6 month date) would you say (his/her) health in general was excellent, very good, good, fair, or poor?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 7 Refused
- 9 Don't know

2. Between (6 month date) and (1 month date) was there a noticeable change in (SP's) health in general?

- 1 Yes
- 2 No (Go to Section F)
- 7 Refused (Go to Section F)
- 9 Don't know (Go to Section F)

3. Was (his/her) health in general better or worse?

- 1 Better
- 2 Worse
- 7 Refused (Go to Section F)
- 9 Don't know (Go to Section F)

(If 1 is "excellent" and 3 is "better" or if 1 is "poor" and 3 is "worse" go to Section F, else continue)

4. Approximately 1 month before (SP's death), that is (month/year) would you say (his/her) health in general was excellent, very good, good, fair, or poor?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 7 Refused
- 9 Don't know

SECTION F

COGNITIVE FUNCTIONING

1. Part of this study is concerned with people's memory, and ability to think about things. For the next few questions, I want you to think about (SP) as of one month before (his/her) death, that is (month/year). First, how would you rate (SP)'s memory at that time? Would you say it was excellent, very good, good, fair, or poor?

- 1 Excellent
- 2 Very good
- 3 Good
- 4 Fair
- 5 Poor
- 7 Refused
- 9 Don't know

Now we want you to remember what (NAME) was like when we interviewed (Him/Her) in (MM/DD/YY of last interview) and to compare it with what (He/She) was like toward the end of (His/Her) life, but leaving out the last month or so of (His/Her) life. I will read situations where (NAME) had to use (His/Her) memory or intelligence and we would like you to indicate whether this had improved, stayed the same, or gotten worse in that situation over the past two years. Note the importance of comparing (His/Her) performance toward the end of (His/Her) life with when we interviewed (Him/Her) in (MM/DD/YY of last interview). So if in (MM/DD/YY of last interview) (NAME) always forgot where (He/She) had left things, and (He/She) still did a month or so prior to death, then this would be considered "not much change".

- 2a. Compared with when we interviewed (Him/Her) in (MM/YY/DD), how was (NAME) at: Remembering things about family and friends, such as occupations, birthdays, and addresses. Had this improved, not much changed, or gotten worse?

- 1 Improved
- 2 Not much changed (Skip to 3a)
- 3 Gotten worse (Skip to 2c)
- 7 Refused (Skip to 3a)
- 9 Don't know (Skip to 3a)

2b. Was it much improved or a bit improved?

- 1 Much improved
- 2 A bit improved
- 7 Refused
- 9 Don't know

If proxy answers 1 to question 2a, skip to question 3a.

2c. Was it much worse or a bit worse?

- 4 A bit worse
- 5 Much worse
- 7 Refused
- 9 Don't know

3a. Compared with when we interviewed (Him/Her) in (MM/DD/YY), how was (NAME) at: Remembering things that had happened recently? (Had this improved, not much changed, or gotten worse?)

- 1 Improved
- 2 Not much changed (Skip to 4a)
- 3 Gotten worse (Skip to 3c)
- 7 Refused (Skip to 4a)
- 9 Don't know (Skip to 4a)

3b. Was it much improved or a bit improved?

- 1 Much improved
- 2 A bit improved
- 7 Refused
- 9 Don't know

If proxy answers 1 to question 3a, skip to question 4a.

3c. Was it much worse or a bit worse?

- 4 A bit worse
- 5 Much worse
- 7 Refused
- 9 Don't know

4a. (Compared with when we interviewed (Him/Her) in (MM/DD/YY), how was (NAME) at:)

Recalling conversations a few days later?

(Had this improved, not much changed, or gotten worse?)

- 1 Improved
- 2 Not much changed (Skip to 5a)
- 3 Gotten worse (Skip to 4c)
- 7 Refused (Skip to 5a)
- 9 Don't know (Skip to 5a)

4b. Was it much improved or a bit improved?

- 1 Much improved
- 2 A bit improved
- 7 Refused
- 9 Don't know

If proxy answers 1 to question 4a, skip to question 5a.

4c. Was it much worse or a bit worse?

- 4 A bit worse
- 5 Much worse
- 7 Refused
- 9 Don't know

5a. (Compared with when we interviewed (Him/Her) in (MM/DD/YY), how was (NAME) at:)

Remembering (His/Her) address and telephone number?

(Had this improved, not much changed, or gotten worse?)

- 1 Improved
- 2 Not much changed (Skip to 6a)
- 3 Gotten worse (Skip to 5c)
- 7 Refused (Skip to 6a)
- 9 Don't know (Skip to 6a)

5b. Was it much improved or a bit improved?

- 1 Much improved
- 2 A bit improved
- 7 Refused
- 9 Don't know

If proxy answers 1 to question 5a, skip to question 6a.

5c. Was it much worse or a bit worse?

- 4 A bit worse
- 5 Much worse
- 7 Refused
- 9 Don't know

6a. (Compared with when we interviewed (Him/Her) in (MM/DD/YY), how was (NAME) at:)

Remembering what day and month it is?

(Had this improved, not much changed, or gotten worse?)

- 1 Improved
- 2 Not much changed (Skip to 7a)
- 3 Gotten worse (Skip to 6c)
- 7 Refused (Skip to 7a)
- 9 Don't know (Skip to 7a)

6b. Was it much improved or a bit improved?

- 1 Much improved
- 2 A bit improved
- 7 Refused
- 9 Don't know

If proxy answers 1 to question 6a, skip to question 7a.

6c. Was it much worse or a bit worse?

- 4 A bit worse
- 5 Much worse
- 7 Refused
- 9 Don't know

7a. (Compared with when we interviewed (Him/Her) in (MM/DD/YY), how was (NAME) at:)

Remembering where things were usually kept?

(Had this improved, not much changed, or gotten worse?)

- 1 Improved
- 2 Not much changed (Skip to 8a)
- 3 Gotten worse (Skip to 7c)
- 7 Refused (Skip to 8a)
- 9 Don't know (Skip to 8a)

7b. Was it much improved or a bit improved?

- 1 Much improved
- 2 A bit improved
- 7 Refused
- 9 Don't know

If proxy answers 1 to question 7a, skip to question 8a.

7c. Was it much worse or a bit worse?

- 4 A bit worse
- 5 Much worse
- 7 Refused
- 9 Don't know

8a. (Compared with two years ago, how was (NAME) at:)

Making decisions on everyday matters?

(Had this improved, not much changed, or gotten worse?)

- 1 Improved
- 2 Not much changed (Skip to 9a)
- 3 Gotten worse (Skip to 8c)
- 7 Refused (Skip to 9a)
- 9 Don't know (Skip to 9a)

8b. Was it much improved or a bit improved?

- 1 Much improved
- 2 A bit improved
- 7 Refused
- 9 Don't know

If proxy answers 1 to question 8a, skip to question 9a.

8c. Was it much worse or a bit worse?

- 4 A bit worse
- 5 Much worse
- 7 Refused
- 9 Don't know

9a. (Compared with two years ago, how was (NAME) at:)
Handling money for shopping?
(Had this improved, not much changed, or gotten worse?)

- 1 Improved
- 2 Not much changed (Skip to 10a)
- 3 Gotten worse (Skip to 9c)
- 7 Refused (Skip to 10a)
- 9 Don't know (Skip to 10a)

9b. Was it much improved or a bit improved?

- 1 Much improved
- 2 A bit improved
- 7 Refused
- 9 Don't know

If proxy answers 1 to question 9a, skip to question 10a.

9c. Was it much worse or a bit worse?

- 4 A bit worse
- 5 Much worse
- 7 Refused
- 9 Don't know

10a. (Compared with two years ago, how was (NAME) at:
Handling financial matters, that is, the pension or dealing with the bank?
(Had this improved, not much changed, or gotten worse?)

- 1 Improved
- 2 Not much changed (Skip to 11a)
- 3 Gotten worse (Skip to 10c)
- 7 Refused (Skip to 11a)
- 9 Don't know (Skip to 11a)

10b. Was it much improved or a bit improved?

- 1 Much improved
- 2 A bit improved
- 7 Refused
- 9 Don't know

If proxy answers 1 to question 10a, skip to question 11a.

10c. Was it much worse or a bit worse?

- 4 A bit worse
- 5 Much worse
- 7 Refused
- 9 Don't know

11a. Now, thinking about some other behaviors, did (SP), between (month/year of interview)
and a month before death, ever get lost in a familiar environment?

- 1 Yes
- 5 No
- 7 Refused
- 9 Don't know

11b. Did (He/She) ever wander off and not return by (Himself/Herself)?

- 1 Yes
- 5 No
- 7 Refused
- 9 Don't know

11c. Could (He/She) be left alone for an hour or so?

- 1 Yes
- 5 No
- 7 Refused
- 9 Don't know

11d. Did (NAME) ever see or hear things that were not really there?

- 1 Yes
- 5 No
- 7 Refused
- 9 Don't know

SECTION G

HEALTH CARE UTILIZATION

These next questions are about hospital stays.

[If SP died in hospital, use lead in then skip to 1b:

Earlier you told me that (SP) died while in the hospital]

1. a. Since (month/year), had (SP) been a patient in a hospital overnight?

1 Yes

2 No (Skip to 2)

7 Refused (Skip to 2)

9 Don't know (Skip to 2)

b. (Including that last visit to the hospital) How many different times had (he/she) been a patient in a hospital overnight since (month/year)?

Number of times _____

97 Refused

99 Don't know

c. (Altogether) how many nights had (he/she) been a patient in a hospital since (month/year)?

Number of nights _____

997 Refused

999 Don't know

These next questions are about other services (SP) may have received since we last talked with (him/her).

2. a. Since (month/year of last interview) did (SP) receive any health care services IN (HIS/HER) HOME? This would include skilled nursing care, physical or occupational therapy, assistance with medications or personal care needs, and any other services provided IN (HIS/HER) HOME by a visiting nurse, nursing assistant, home health aide, personal assistant, therapist, or homemaker.

- 1 Yes
- 2 No (Skip to 3)
- 7 Refused (Skip to 3)
- 9 Don't know (Skip to 3)

- b. Which of the following services did (he/she) receive?

Skilled nursing care

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

Physical therapy
Occupational therapy
Speech therapy
Dialysis
Tube feeding
Personal assistant services
Homemaker/companion services
Oxygen / respiratory therapy
Hospice care
Other (Specify:) _____

- c. Did (he/she) receive any of these services during the last 3 months of life, that is from (3 month date) until the time of death?

- 1 Yes
- 2 No (Skip to e)
- 7 Refused (Skip to e)
- 9 Don't know (Skip to e)

- d. What was the total number of times (he/she) received any of these services during the last 3 months of life, that is from (3 month date) until the time of death?

_____ number of times

997 Refused

999 Don't know

- e. Thinking about the home health services received since (month/year of last interview), who paid or will pay for those services?

Code (X) all that apply.

(Anyone else?)

01 Decedent or family in household

02 Family NOT in household

03 Private health insurance

04 Medicare

05 Medicaid

06 VA program, or other military

07 Administration on Aging

08 Other private source

09 Other public source

10 No one/Free (Skip to h)

97 Refused

99 Don't know

If more than one source in 2e, ask f. Otherwise, skip to 2g.

- f. Who paid or will pay most of the cost for the home health services that (SP) received since (month/year of last interview)?

01 Decedent or family in household
02 Family NOT in household
03 Private health insurance
04 Medicare
05 Medicaid
06 VA program, or other military
07 Administration on Aging
08 Other private source
09 Other public source
97 Refused
99 Don't know

Ask 2g only if Medicare was not mentioned in 2e. Otherwise, skip to 2h.

- g. Did Medicare pay for all or part of these services?

1 Yes
2 No
7 Refused
9 Don't know

- h. Did (he/she) need more home health services than was received?

1 Yes
2 No (Skip to 4)
7 Refused (Skip to 4)
9 Don't know (Skip to 4)

- i. Why didn't (he/she) receive all of the home health services needed?

Code (X) all that apply.

- 01 Provider thought no longer needed
- 02 Did not receive referral/recommendation for continuation of service
- 03 Too expensive/could not afford
- 04 Not covered by Medicare/Medicaid/other insurance
- 05 Medicare/other insurance no longer covered; coverage ran out
- 06 No longer on Medicaid
- 07 No provider available
- 08 Did not like provider
- 09 Other
- 97 Refused
- 99 Don't know

Ask 3a-b only if decedent did not receive home health services during interval. Otherwise skip to 4.

3. a. Did (SP) NEED any home health services since (month/year of last interview)?

- 1 Yes
- 2 No (Skip to 4)
- 7 Refused (Skip to 4)
- 9 Don't know (Skip to 4)

- b. Why didn't (he/she) receive home health services since (month/year of last interview)?

Code (X) all that apply.

- 01 Did not know how to find a provider
- 02 Received services before, and provider thought no longer needed
- 03 Did not receive referral/recommendation for service
- 04 Too expensive/could not afford
- 05 Not covered by Medicare/Medicaid/other insurance
- 06 Medicare/other insurance no longer covered; coverage ran out
- 07 No longer on Medicaid
- 08 No home health services available
- 09 Received services before, but did not like provider
- 10 Institutionalized
- 11 Other
- 97 Refused
- 99 Don't know

The next questions are about different types of surgeries and examinations that (SP) may have had at some time during (his/her) life. Please tell me if (he/she) EVER had the following surgeries or tests, even if you have mentioned them before.

4. Had (SP) EVER had:

Ask a-e only if decedent had ever had any type of heart disease:

- a. Heart surgery or coronary bypass surgery
 - 1 Yes
 - 2 No
 - 7 Refused
 - 9 Don't know
- b. Coronary or balloon angioplasty
- c. Coronary catheterization, also known as a cardiac catheterization test
- d. Surgery to insert a pacemaker
- e. Surgery to insert an artificial heart valve

Ask f-h only if decedent had ever had cancer:

- f. Chemotherapy
- g. Radiation therapy
- h. Surgery for cancer

Ask i-p about all decedents:

- i. Hip replacement surgery?
- j. Knee replacement surgery?
- k. Foot surgery?
- l. A hernia operation?
- m. Kidney dialysis?
- n. A kidney transplant?
- o. A stress test?
- p. Cataract surgery? 1 Yes ----> Is that in one or both eyes?
 - 1 One
 - 2 Both
 - 7 Refused
 - 9 Don't know

Ask q for females only:

- q. A hysterectomy?

For each "Yes" in 4a-p above, ask question 5. Do not ask for item q. If all "No," skip to next section.

- 5. a. Had (he/she) had (a/an) (fill in type of operation/procedure/test) since the last time we talked with (him/her) that is since (month/year)?
 - 1 Yes
 - 2 No
 - 7 Refused
 - 9 Don't know

If "yes" 4a, 4b, 4i, 4j, or 4p, continue with question 6 as appropriate. Otherwise, skip to next section.

6. a. (If “yes” in 4a or 4b:) As a result of the (heart surgery/angioplasty) did the pain or discomfort in (SP)’s chest improve, stay the same, or get worse?

1 Improved
2 Stayed the same
3 Got worse
7 Refused
9 Don’t know

- b. (If “yes” in 4a or 4b:) As a result of the (heart surgery/angioplasty) did (SP)’s ability to do physical activities, such as walking, improve, stay the same, or get worse?

1 Improved
2 Stayed the same
3 Got worse
7 Refused
9 Don’t know

- c. (If “yes” in 4i or 4j:) As a result of the (knee/hip replacement) did (SP)’s ability to perform activities such as walking and getting in and out of bed or chairs improve, stay the same, or get worse?

1 Improved
2 Stayed the same
3 Got worse
7 Refused
9 Don’t know

- d. (If “yes” in 4p:) As a result of the cataract surgery, did (SP)’s vision (in that eye) improve, stay the same or get worse?

1 Improved
2 Stayed the same
3 Got worse
7 Refused
9 Don’t know

These next questions are about important health care decisions (SP) may have made prior to death

7. a. Did (SP) provide written instructions about the treatment or care (he/she) wanted to receive during the final days of (his/her) life?

1 Yes
2 No (Skip to 8)
7 Refused (Skip to 8)
9 Don't know (Skip to 8)

- b. Did these instructions express a desire to receive all care possible under any circumstances in order to prolong life?

1 Yes (skip to 7e)
2 No
7 Refused
9 Don't know

- c. Did these instructions express a desire to limit care in certain situations?

1 Yes
2 No
7 Refused
9 Don't know

- d. Did these instructions express a desire to keep (him/her) comfortable and pain free but to forego extensive measures to prolong life?

1 Yes
2 No
7 Refused
9 Don't know

- e. Were these written instructions followed at the time of death?

1 Yes
2 No
7 Refused
9 Don't know

8. Did (SP) make any legal arrangements for a specific person or persons to make decisions about (his/her) care or medical treatment if (he/she) could not make these decisions (him/her)self? This is sometimes called a “Durable Power of Attorney for Health Care.”

1 Yes

2 No

7 Refused

9 Don't know

SECTION H

HEALTH INSURANCE

These next questions are about (SP)'s health insurance.

Medicare coverage will be pre-loaded from baseline. Respondents who were covered by Medicare at baseline will skip to Item H1. All others will start with question 1a.

1. a. There are several government programs that provide medical care or help pay medical bills. Medicare is the Social Security health insurance program for people 65 years of age or older and for certain persons with disabilities. Was (SP) covered by Medicare at the time of (his/her) death?

- 1 Yes
- 2 No (Go to 3)
- 7 Refused (Go to 3)
- 9 Don't know (Go to 3)

- b. In what month and year did (his/her) Medicare coverage start?

_____ month/ _____ year

- 9997 Refused
- 9999 Don't know

- ITEM H1 1 Medicare number obtained at baseline (Skip to introduction before 3)
2 Medicare number not obtained at baseline (Continue with 2)

Read if covered by Medicare at baseline: When we talked with (SP) in (month/year of last interview, (he/she) mentioned that (he/she) was covered by Medicare.

2. May I please have the Health Insurance Claim Number on (his/her) Medicare card? This number is needed to allow Medicare records of the Health Care Financing Administration to be easily and accurately located and identified for statistical or research purposes. Except for this purpose, NCHS will not release the Health Insurance Claim Number to anyone including any other government agency. Providing the Health Insurance Claim Number is voluntary and collected under the authority of the Public Health Service Act.

Whether the number is given or not, there will be no effect on benefits. This number will be held in strict confidence.

Read if necessary: The Public Health Service Act is Title 42, United States Code, Section 242k.

H.I.C. number ____-____-____-__

99999999997 Refused

99999999999 Don't know

Read if Medicare number was obtained at baseline: When we talked with (SP) in (month/year of last interview, (he/she) mentioned that (he/she) was covered by Medicare.

3. In addition to Medicare, there are several other government health insurance programs. Please tell me if (SP) was covered by any of the following programs.

- a. Medicaid

1 Yes

2 No

7 Refused

9 Don't know

- b. Military health care, including VA, CHAMPUS, or CHAMP-VA

- c. Any other public assistance program

If decedent was covered by Medicaid in 3a, continue with 3d. Otherwise go to Item H2.

d. In what month and year did (his/her) Medicaid coverage start?

_____ month/ _____ year

9997 Refused

9999 Don't know

ITEM H2 1 Covered by Medicare or Medicaid at the time of death (Skip to question 5)
2 All others (Continue with question 4)

4. a. Not counting the government health programs we just mentioned, did (SP) have any private health insurance? This could include insurance for dental care, but does not include not long-term care insurance.

1 Yes

2 No (Go to ITEM H3)

7 Refused (Go to ITEM H3)

9 Don't know (Go to ITEM H3)

b. It's important that we have the complete and accurate name of each health insurance plan. What is the COMPLETE name of (each of these/this) plan(s)?

ENTER NAME(S):

1. _____

2. _____

3. _____

Etc.

97 Refused

99 Don't know

(Read intro only if decedent was covered by Medicare or Medicaid at the time of death: This next question is about how Medicare and/or Medicaid worked for non-emergency care.)

5. a. Was (SP) signed up with an HMO, that is a Health Maintenance Organization or some other type of managed care organization at the time of (his/her)death?

(Read if R hesitates or is uncertain: With an HMO or other managed care plan you generally receive care through the plan's own doctors and other health professionals and their own network of hospitals. Plans usually charge enrollees a monthly premium and may charge a small copayment for each appointment or drug prescription. Usually there are no additional charges by the plan no matter how many times you visit the doctor, go to the hospital or use other covered services.)

- 1 Yes (Go to 5c)
- 2 No
- 7 Refused
- 9 Don't know

- b. Was (SP) required to sign up with a certain primary care doctor, group of doctors, or with a certain clinic that (he/she) had to go to for all of (his/her) routine care? Do not include emergency care or care from a specialist.

- 1 Yes
- 2 No (Go to ITEM H3)
- 7 Refused (Go to ITEM H3)
- 9 Don't know (Go to ITEM H3)

- c. What was the name of this (managed care organization/HMO/health insurance plan)?

-
- 97 Refused
 - 99 Don't know

- ITEM H3 1 Not covered by Medicare or Medicaid at the time of death (Skip to question 7)
2 Covered by Medicare or Medicaid at time of death (Continue with question 6)

6. a. Besides government programs, people also get health insurance through their jobs or union, through other private groups, or directly from an insurance company.

Not counting (his/her Medicare/Medicaid/military/other public coverage and/or the HMO mentioned in 5c), did (SP) have any private health insurance? This could include insurance for dental care, Medicare supplements or medi-gap plans, but does not include long-term care insurance.

Read if necessary:

Medigap insurance is private insurance that pays for Medicare's deductibles and copayments or services such as prescription drugs that Medicare does not cover.

- 1 Yes
- 2 No (Skip to question 7)
- 7 Refused (Skip to question 7)
- 9 Don't know (Skip to question 7)

- b. It's important that we have the complete and accurate name of each health insurance plan. What is the COMPLETE name of (each of these/this) plan(s)?

ENTER NAME(S):

- 1. _____
- 2. _____
- 3. _____
- Etc.

- 97 Refused (Skip to 7)
- 99 Don't know (Skip to 7)

Ask c for each plan mentioned in 6b.

- c. Were any of these plans obtained in order to supplement (his/her) Medicare coverage?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

7. (Aside from Medicaid/other government programs,) was (SP) covered by a health insurance policy which paid any part of a nursing home stay or long term care services in (his/her) home?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

8. During the last 12 months of life, about how much did [SP/(his/her) family] spend for his/her own medical care? Do NOT include the cost of health insurance premiums, over-the-counter remedies, or any costs for which SP/(his/her) family was reimbursed.

- 01 Less than \$500
- 02 \$500-999
- 03 \$1,000-2,999
- 04 \$3,000 or more
- 97 Refused
- 99 Don't know

INTERVIEWER OBSERVATIONS

Ask or verify questions 1a-b below with the proxy respondent as necessary.

1. a. How are you related to (sample person)?

- 00 Parent
- 01 Spouse
- 02 Son/daughter
- 03 Son-in-law/daughter-in-law
- 04 Grandchild/great grandchild
- 05 Brother/sister
- 06 Brother-in-law/sister-in-law
- 07 Aunt/uncle/cousin
- 08 Niece/nephew
- 09 Other relative
- 10 Roommate/friend/neighbor
- 11 Other non-relative

b. Did you live with (sample person) at the time of his/her death?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

If necessary: Correct or confirm proxy name, address, and telephone number.

Thank you for your cooperation! We understand that these questions are sensitive and may have been difficult to answer. We appreciate your answering them.

2. Code each to indicate why a proxy/assistant was needed.

a. Sample person was hospitalized

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

b. Sample person institutionalized

c. Sample person's hearing problem

d. Sample person's speech problem

e. Sample person's language problem

f. Sample person's poor memory, senility, or confusion

g. Sample person's Alzheimer's disease

h. Sample person's other mental condition

i. Sample person's other physical illness and/or disability

j. Other non-health related reason

k. Sample person deceased

The "respondent" in the following items refers to the proxy. "You" refers to the interviewer.

3. Do you feel the --

a. Respondent was intellectually capable of responding?

- 1 Yes
- 2 No
- 7 Refused
- 9 Don't know

b. Respondent's answers were reasonably accurate?

c. Respondent understood the questions?

4. How cooperative was the respondent in answering the questions?

- 1 Very cooperative
- 2 Somewhat cooperative
- 3 Not cooperative
- 7 Refused
- 9 Don't know

5. How interested did the respondent seem to be in the content of the interview?

- 1 Very interested
- 2 Somewhat interested
- 3 Not interested
- 7 Refused
- 9 Don't know

If very interested, indicate sections that were of most interest: _____

6. How tiring did the interview seem to be for the respondent?

- 1 Very tiring
- 2 A little tiring
- 3 Not tiring
- 7 Refused
- 9 Don't know

7. Did the respondent have difficulty hearing you during the interview?

1 Yes

2 No (Skip to 8)

7 Refused (Skip to 8)

9 Don't know (Skip to 8)

8. Did you feel the respondent's hearing difficulty affected the interview?

1 Yes

2 No

7 Refused

9 Don't know

9. In what language was the interview conducted?

1 English

2 Spanish

3 Other