

CASE ID: |\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|\_|

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## **SECOND LONGITUDINAL STUDY OF AGING**

### **WAVE 3**

#### **Decedent Questionnaire (Self Administered)**

**Version DF 2.1**

**December 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.

NOTICE - Information collected on this form which would permit identification of any individual or establishment has been collected with a guarantee that it will be held in strict confidence, will be used only for purposes stated for this study, and will not be disclosed or released to others without the consent of the individual or the establishment in accordance with section 308(d) of the Public Health Service Act (42 USC 242m). Public reporting burden for this collection of information is estimated to vary from 40 to 50 minutes per response, with an average of 45 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS D-24, Atlanta, GA 30333, ATTN: PRA (0920-0411).

#### **ORIGINAL PARTICIPANT \_\_\_\_\_**

**Please record both the date you begin the questionnaire and the date you complete the questionnaire in the space provided below.**

Date Began: \_\_\_\_/\_\_\_\_/\_\_\_\_  
                  month day year

Date Completed: \_\_\_\_/\_\_\_\_/\_\_\_\_  
                    month day year

## Instructions for Completing the Second Longitudinal Study of Aging

**ORIGINAL PARTICIPANT** \_\_\_\_\_

We need you to function as a proxy for the original participant and fill out the questionnaire about that person's health before they died.

Please answer every question. Some questions may look like others, but each one is different. Please take the time to read and answer each question carefully by circling the appropriate number or by filling in the answer as requested. Instructions such as 'Go to' or arrows are sometimes used to direct you to the next question you should answer based on a particular response.

### Example Questions

1. Approximately six months before this person's death, would you say their health in general was excellent, very good, good, fair, or poor?

(circle one)

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

2. In what month and year was this person born?

\_\_\_\_\_/\_\_\_\_\_  
month year

If You Have Any Questions,  
Please Call Study Coordinator, Gwen Merker,  
Toll-Free At 1-800-720-0154.

Thank You for Taking Part in This Study.

## INTRODUCTION

**These first questions are about the circumstances surrounding the original participant's death.**

1. On what date did this person die?

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
month day year

2. a. Did this person die at home, in a hospital, a nursing home, a hospice, or some other place? *If died at someone else's home, circle 1 below.*

(circle one)

Home .....	1 (Go to 3)
Hospital .....	2
Nursing home .....	3
Hospice .....	4
Convalescent or rest home .....	5
Retirement home .....	6
Supervised apartment .....	7
Personal care or board and care home .....	8
Assisted living facility .....	9
Some other type of group residence or facility .....	10
Something else .....	11
Don't know .....	99

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

\_\_\_\_\_

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

\_\_\_\_\_

City                      County/Parish                      State

9999 Don't Know

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

- Yes ..... 1  
No ..... 2 (Go to 5)  
Don't know ..... 9 (Go to 5)

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

- (circle one)
- No warning (1 or 2 hours) ..... 1  
One day or less ..... 2  
More than one day but less than or equal to one week . 3  
More than one week but less than or equal  
to one month ..... 4  
More than one month but less than or equal  
to one year ..... 5  
More than one year ..... 6  
Don't know ..... 9

**These next questions are about the place the original participant lived prior to their death. If this person died in a hospital or hospice answer questions 5 and 6 about the place where this person was living prior to entering the facility.**

5. Was the place where this person was living prior to their death a...  
(circle one)

- Single family house or townhouse that **is not**  
part of a retirement community ..... 1
- Single family house, townhouse, or apartment that **is**  
part of a retirement community ..... 2
- Regular apartment ..... 3
- Nursing home ..... 4
- Convalescent or rest home ..... 5
- Retirement home ..... 6
- Supervised apartment ..... 7
- Personal care or board and care home ..... 8
- Assisted living facility ..... 9
- Some other type of group residence or facility ..... 10
- Something else ..... 11
- Don't know ..... 99

6. Who was this person living with just prior to their death?  
(circle all that apply)

- Lived alone ..... 0
- Spouse ..... 1
- Daughter ..... 2
- Son ..... 3
- Daughter-in-law ..... 4
- Son-in-law ..... 5
- Grandchild ..... 6
- Sibling ..... 7
- Parent ..... 8
- Other relative ..... 9
- Non-relative ..... 10
- Don't know ..... 99

7. a. Since September 1997, was the original participant a resident or patient in a nursing home?

(circle one)

Yes ..... 1 (Go to 7b)

No ..... 2 (Go to 8)

Don't know ..... 9 (Go to 8)

b. How many **different times** had (he/she) been a resident or patient in a nursing home since September 1997?

(write in number)

\_\_\_\_\_ Number of times

999 Don't know

c. Since September 1997, how many months altogether did (he/she) spend in a nursing home?

(write in number)

\_\_\_\_\_ Number of months

check if less than one month

9999 Don't know

8. a. Since September 1997, was the original participant a resident or patient in a convalescent home, rest home, or any other residential care facility?  
(circle one)

Yes ..... 1 (Go to 8b)

No ..... 2 (Go to 9)

Don't know ..... 9 (Go to 9)

b. How many **different times** had (he/she) been a resident or patient in a convalescent home, rest home, or any other residential care facility since September 1997?

(write in number)

\_\_\_\_\_ Number of times

999 Don't know

c. Since September 1997, how many months altogether did (he/she) spend in a convalescent home, rest home, or any other residential care facility?

(write in number)

\_\_\_\_\_ Number of months

check if less than one month

9999 Don't know

**FAMILY STRUCTURE, RELATIONSHIPS  
AND LIVING ARRANGEMENTS**

9. a. At the time of death, was this person married, widowed, divorced, separated, or had they never been married? (circle one)
- Married ..... 1
- Widowed ..... 2 (Go to 11)
- Divorced ..... 3 (Go to 11)
- Separated ..... 4 (Go to 11)
- Never married ..... 5 (Go to 11)

- b. If this person was married when (he/she) died, were they married to the same person that they were married to in September 1997? (circle one)
- Yes ..... 1
- No ..... 2
- Don't know ..... 9

10. a. At the time of this person's death, was their spouse a resident in a nursing home or other long-term care facility? (circle one)
- Yes ..... 1
- No ..... 2 (Go to 11a)
- Don't know ..... 9 (Go to 11a)

- b. How long had their spouse been a resident of a nursing home/long-term care facility?
- \_\_\_\_\_



## ASSISTANCE WITH KEY ACTIVITIES

For this next set of questions, I'd like you to think about the original participant's condition approximately 6 months before their death.

These first questions are about how well this person was able to do certain activities by himself/herself and without using special equipment at that time.

Please tell us if this person had **any** difficulty when they did the following.

11 a. Because of a health or physical problem, did this person have any difficulty eating?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

b. If yes, by himself/herself and without using special equipment, how much difficulty did this person have eating?

(circle one)

Some difficulty ..... 1

A lot of difficulty ..... 2

Unable to do it ..... 3

Don't know ..... 9

c. Because of a health or physical problem, did this person have any difficulty getting in and out of bed or chairs?

(circle one)

- Yes ..... 1
- No ..... 2
- Don't know ..... 9

d. If yes, by himself/herself and without using special equipment, how much difficulty did this person have getting in and out of bed or chairs?

(circle one)

- Some difficulty ..... 1
- A lot of difficulty ..... 2
- Unable to do it ..... 3
- Don't know ..... 9

e. Because of a health or physical problem, did this person have any difficulty walking?

(circle one)

- Yes ..... 1
- No ..... 2
- Don't know ..... 9

f. If yes, by himself/herself and without using special equipment, how much difficulty did this person have walking?

(circle one)

- Some difficulty ..... 1
- A lot of difficulty ..... 2
- Unable to do it ..... 3
- Don't know ..... 9

12 a. Did this person use any special equipment or aids in eating?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

If yes, what special equipment or aids did this person use?

---

b. Did this person use any special equipment or aids in getting in and out of bed or chairs?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

If yes, what special equipment or aids did this person use?

---

c. Did this person use any special equipment or aids in walking?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

If yes, what special equipment or aids did this person use?

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13 a. Did this person **receive** help from another person in eating?

(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

b. Did this person **need** help from another person in eating? If they received help, did they **need more** help?

(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

c. Did this person **receive** help from another person in getting in and out of bed or chairs?

(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

d. Did this person **need** help from another person in getting in and out of bed or chairs? If they received help, did they **need more** help?

(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

e. Did this person **receive** help from another person in walking?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

f. Did this person **need** help from another person in walking? If they received help, did they **need more** help?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

14. a. Between September 1997 and the time of death, did this person fall?  
(circle one)

- Yes ..... 1
- No ..... 2 (Go to 15)
- Don't know ..... 3 (Go to 15)

b. Did (he/she) fall more than once between September 1997 and the time of death?  
(circle one)

- Yes ..... 1
- No ..... 2
- Don't know ..... 3

c. Were they injured as a result of the fall(s)?  
(circle one)

- Yes ..... 1
- No ..... 2 (Go to 15)
- Don't know ..... 3 (Go to 15)

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

- Fracture ..... 1
- Bruise, cut, or scrape ..... 2
- Lost consciousness ..... 3
- Other ..... 4
- Don't know ..... 5

## CONDITIONS AND IMPAIRMENTS

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

15. At the time of death did this person have:

(circle one number on each line)

	YES	NO	DON'T KNOW
a. Cataracts in one eye	1	2	3
b. Cataracts in both eyes	1	2	3
c. Glaucoma	1	2	3
d. Blindness in one eye	1	2	3
e. Blindness in both eyes	1	2	3
f. Use eyeglasses or contact lenses? Include eyeglasses that magnify.	1	2	3
g. Other trouble seeing with one or both eyes, <b>even</b> when wearing glasses or contact lenses	1	2	3
h. Deafness in one ear	1	2	3
i. Deafness in both ears	1	2	3
j. Other trouble hearing with one or both ears	1	2	3
k. Use a hearing aid	1	2	3
l. Tooth or mouth problems that made it hard for this person to eat (even when wearing dentures or partial plates)	1	2	3

16. At the time of death did this person have:

(circle one number on each line)

	YES	NO	DON'T KNOW
a. Osteoporosis	1	2	3
b. Diabetes	1	2	3
c. Arthritis	1	2	3
d. Chronic bronchitis or emphysema	1	2	3
e. Asthma	1	2	3
f. Hypertension, sometimes called high blood pressure	1	2	3
g. Any type of heart disease including coronary heart disease, angina, or congestive heart failure	1	2	3

17. a. Between September 1997 and the time of death, did (he/she) break a hip?

(circle one)

Yes ..... 1  
 No ..... 2  
 Don't know ..... 9

b. Between September 1997 and the time of death, did (he/she) have a heart attack?

(circle one)

Yes ..... 1  
 No ..... 2  
 Don't know ..... 9

c. Between September 1997 and the time of death did (he/she) have a stroke or cerebrovascular accident?

(circle one)

Yes ..... 1  
 No ..... 2  
 Don't know ..... 9



18. a. At the time of death did this person have cancer of any kind?

(circle one)

- Yes ..... 1
- No ..... 2 (Go to 19)
- Don't know ..... 9 (Go to 19)

b. What kind of cancer was this?

(circle all that apply)

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

## HEALTH OPINIONS

**For these next two questions I'd like you to think about the original participant's health in general during the last half year of their life.**

19. Approximately 6 months before this person's death, would you say their health in general was excellent, very good, good, fair, or poor?

(circle one)

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

20. Between 6 months before they died and 1 month before they died was there a noticeable change in their health in general?

(circle one)

Yes .....	1
No .....	2 (Go to 23)
Don't know .....	9 (Go to 23)

21. Was their health in general better or worse?

(circle one)

Better .....	1
Worse .....	2
Don't know .....	9 (Go to 23)

22. Approximately 1 month before this person's death, would you say their health in general was excellent, very good, good, fair, or poor?

(circle one)

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

### COGNITIVE FUNCTIONING

23. Part of this study is concerned with people's memory, and ability to think about things. For the next question, I want you to think about this person as of one month before their death. First, how would you rate this person's memory at that time? Would you say it was excellent, very good, good, fair, or poor?

(circle one)

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

## HEALTH CARE UTILIZATION

These next questions are about hospital stays.

24. a. Since September 1997, had this person been a patient in a hospital overnight?

(circle one)

Yes ..... 1

No ..... 2 (Go to 25)

Don't know ..... 9 (Go to 25)

b. How many different times had (he/she) been a patient in a hospital overnight since September 1997? If this person died in a hospital, please include that visit.

(write in number)

\_\_\_\_\_ Number of times

99 Don't know

c. Altogether how many nights had (he/she) been a patient in a hospital since September 1997?

(write in number)

\_\_\_\_\_ Number of nights

999 Don't know

**These next questions are about other services the original participant may have received since September 1997.**

25. a. Since September 1997 did this person receive any health care services **in their home**? This would include skilled nursing care, physical or occupational therapy, assistance with medications or personal care needs, and any other services provided **in their home** by a visiting nurse, nursing assistant, home health aide, personal assistant, therapist, or homemaker.

(circle one)

- Yes ..... 1  
 No ..... 2 (Go to 26)  
 Don't know ..... 9 (Go to 26)

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

(circle one number on each line)

	YES	NO	DON'T KNOW
1. Skilled nursing care	1	2	3
2. Physical therapy	1	2	3
3. Occupational therapy	1	2	3
4. Speech therapy	1	2	3
5. Dialysis	1	2	3
6. Tube feeding	1	2	3
7. Personal assistant services	1	2	3
8. Homemaker/companion services	1	2	3
9. Nutritional counseling	1	2	3
10. Oxygen/respiratory therapy	1	2	3
11. Hospice care	1	2	3
12. Other	1	2	3
If yes, please specify: _____			
_____			

c. Did (he/she) receive any of these services during the last 3 months of life?

(circle one)

- Yes ..... 1
- No ..... 2 (Go to 25e)
- Don't know ..... 9 (Go to 25e)

d. What was the total number of times (he/she) received any of these services in the last 3 months?

(write in number)

\_\_\_\_\_ Number of times

999 Don't know

e. Thinking about the home health services received since September 1997, who paid or will pay for those services?

(circle all that apply)

- No one/Free ..... 0 (Go to 25g)
- Decedent or family in household ..... 1
- Family NOT in household ..... 2
- Private health insurance ..... 3
- Medicare ..... 4
- Medicaid ..... 5
- VA program, or other military ..... 6
- Administration on Aging ..... 7
- Other private source ..... 8
- Other public source ..... 9
- Don't know ..... 99

f. If more than one source paid, who paid the most of the cost for the home health services that this person received since September 1997?

(circle all that apply)

- Decedent or family in household ..... 1
- Family NOT in household ..... 2
- Private health insurance ..... 3
- Medicare ..... 4
- Medicaid ..... 5
- VA program, or other military ..... 6
- Administration on Aging ..... 7
- Other private source ..... 8
- Other public source ..... 9
- Don't know ..... 99

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

(circle one)

- Yes ..... 1
- No ..... 2 (Go to 27)
- Don't know ..... 9 (Go to 27)

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

(circle all that apply)

- Provider thought no longer needed . . . . . 1
- Didn't receive referral/recommendation for  
continuation of service . . . . . 2
- Too expensive/couldn't afford . . . . . 3
- Not covered by  
Medicare/Medicaid/other insurance . . . . . 4
  
- Medicare/other insurance no longer covered;  
coverage ran out . . . . . 5
- No longer on Medicaid . . . . . 6
- No provider available . . . . . 7
- Didn't like provider . . . . . 8
- Other . . . . . 9
- Don't know . . . . . 99

**Now go to question 27.**



Answer question 26 **only** if original participant did not receive any home health services.

26. a. Did this person NEED any home health services since September 1997?

(circle one)

Yes ..... 1  
No ..... 2 (Go to 27)  
Don't know ..... 9 (Go to 27)

b. Why didn't (he/she) receive home health services?

(circle all that apply)

Didn't know how to find a provider ..... 0  
Received services before, and provider thought  
no longer needed ..... 1  
Didn't receive referral/recommendation  
for service ..... 2  
Too expensive/couldn't afford ..... 3  
Not covered by  
Medicare/Medicaid/other insurance ..... 4  
Medicare/other insurance no longer covered;  
coverage ran out ..... 5  
No longer on Medicaid ..... 6  
No home health services available ..... 7  
Received services before,  
but didn't like provider ..... 8  
Institutionalized ..... 9  
Other ..... 10  
Don't know ..... 99

**The next questions are about different types of surgeries and examinations that the original participant may have had at some time during their life. Please tell me if they ever had the following surgeries or tests, even if you have mentioned them before.**

27. a. Had this person **ever** had heart surgery or coronary bypass surgery?

(circle one)

Yes ..... 1  
No ..... 2 (Go to 27e)  
Don't know ..... 9 (Go to 27e)

b. If yes, had (he/she) had a heart surgery or coronary bypass surgery since September 1997?

(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

c. As a result of the heart surgery did the pain or discomfort in this person's chest subside, was there no change, or did it get worse?

(circle one)

Improved ..... 1  
Stayed the same ..... 2  
Got worse ..... 3  
Don't know ..... 9

d. As a result of the heart surgery did this person's ability to do physical activities, such as walking, improve, stay the same, or get worse?

(circle one)

Improved ..... 1  
Stayed the same ..... 2  
Got worse ..... 3  
Don't know ..... 9

- e. Had this person **ever** had coronary or balloon angioplasty?  
(circle one)
- Yes ..... 1  
 No ..... 2 (Go to 27i)  
 Don't know ..... 9 (Go to 27i)
- f. If yes, had (he/she) had a coronary or balloon angioplasty since September 1997?  
(circle one)
- Yes ..... 1  
 No ..... 2  
 Don't know ..... 9
- g. As a result of the angioplasty did the pain or discomfort in this person's chest subside, was there no change, or did it get worse?  
(circle one)
- Improved ..... 1  
 Stayed the same ..... 2  
 Got worse ..... 3  
 Don't Know ..... 9
- h. As a result of the angioplasty did this person's ability to do physical activities, such as walking, improve, stay the same, or get worse?  
(circle one)
- Improved ..... 1  
 Stayed the same ..... 2  
 Got worse ..... 3  
 Don't know ..... 9

i. Had this person **ever** had coronary catheterization, also known as a cardiac catheterization test?

(circle one)

Yes ..... 1

No ..... 2 (Go to 27k)

Don't know ..... 9 (Go to 27k)

j. If yes, had (he/she) had a coronary catheterization since September 1997?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

k. Had this person **ever** had surgery to insert a pacemaker?

(circle one)

Yes ..... 1

No ..... 2 (Go to 27m)

Don't know ..... 9 (Go to 27m)

l. If yes, had (he/she) had a surgery to insert a pacemaker since September 1997?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

m. Had this person **ever** had surgery to insert an artificial heart valve?

(circle one)

Yes ..... 1

No ..... 2 (Go to 27o)

Don't know ..... 9 (Go to 27o)

n. If yes, had (he/she) had a surgery to insert an artificial heart valve since September 1997?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

o. Had this person **ever** had chemotherapy?

(circle one)

Yes ..... 1

No ..... 2 (Go to 27q)

Don't know ..... 9 (Go to 27q)

p. If yes, had (he/she) had chemotherapy since September 1997?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

- q. Had this person **ever** had radiation therapy?  
(circle one)  
 Yes ..... 1  
 No ..... 2 (Go to 27s)  
 Don't know ..... 9 (Go to 27s)
- r. If yes, had (he/she) had radiation therapy since September 1997?  
(circle one)  
 Yes ..... 1  
 No ..... 2  
 Don't know ..... 9
- s. Had this person **ever** had surgery for cancer?  
(circle one)  
 Yes ..... 1  
 No ..... 2 (Go to 27u)  
 Don't know ..... 9 (Go to 27u)
- t. If yes, had (he/she) had surgery for cancer since September 1997?  
(circle one)  
 Yes ..... 1  
 No ..... 2  
 Don't know ..... 9
- u. Had this person **ever** had hip replacement surgery?  
(circle one)  
 Yes ..... 1  
 No ..... 2 (Go to 27x)  
 Don't know ..... 9 (Go to 27x)

v. If yes, had (he/she) had a hip replacement surgery since September 1997?

(circle one)

- Yes ..... 1
- No ..... 2
- Don't know ..... 9

w. As a result of the hip replacement did this person's ability to perform activities such as walking and getting in and out of bed or chairs improve, stay the same, or get worse?

(circle one)

- Improved ..... 1
- Stayed the same ..... 2
- Got worse ..... 3
- Don't know ..... 9

x. Had this person **ever** had knee replacement surgery?

(circle one)

- Yes ..... 1
- No ..... 2 (Go to 27aa)
- Don't know ..... 9 (Go to 27aa)

y. If yes, had (he/she) had a knee replacement surgery since September 1997?

(circle one)

- Yes ..... 1
- No ..... 2
- Don't know ..... 9

z. As a result of the knee replacement did this person's ability to perform activities such as walking and getting in and out of bed or chairs improve, stay the same, or get worse?

(circle one)

Improved ..... 1  
Stayed the same ..... 2  
Got worse ..... 3  
Don't know ..... 9

aa. Had this person **ever** had foot surgery?

(circle one)

Yes ..... 1  
No ..... 2 (Go to 27cc)  
Don't know ..... 9 (Go to 27cc)

bb. If yes, had (he/she) had foot surgery since September 1997?

(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

cc. Had this person **ever** had a hernia operation?

(circle one)

Yes ..... 1  
No ..... 2 (Go to 27ee)  
Don't know ..... 9 (Go to 27ee)



dd. If yes, had (he/she) had a hernia operation since September 1997?  
(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

ee. Had this person **ever** had kidney dialysis?  
(circle one)

Yes ..... 1  
No ..... 2 (Go to 27gg)  
Don't know ..... 9 (Go to 27gg)

ff. If yes, had (he/she) had a kidney dialysis since September 1997?  
(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

gg. Had this person **ever** had a kidney transplant?  
(circle one)

Yes ..... 1  
No ..... 2 (Go to 27ii)  
Don't know ..... 9 (Go to 27ii)

hh. If yes, had (he/she) had a kidney transplant since September 1997?  
(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

- ii. Had this person **ever** had a stress test?  
(circle one)  
 Yes ..... 1  
 No ..... 2 (Go to 27kk)  
 Don't know ..... 9 (Go to 27kk)
- jj. If yes, had (he/she) had a stress test since September 1997?  
(circle one)  
 Yes ..... 1  
 No ..... 2  
 Don't know ..... 9
- kk. Had this person **ever** had cataract surgery on one eye?  
(circle one)  
 Yes ..... 1  
 No ..... 2 (Go to 27nn)  
 Don't know ..... 9 (Go to 27nn)
- ll. If yes, had (he/she) had cataract surgery on one eye since September 1997?  
(circle one)  
 Yes ..... 1  
 No ..... 2  
 Don't know ..... 9
- mm. As a result of the cataract surgery, did this person's vision improve, stay the same or get worse?  
(circle one)  
 Improved ..... 1  
 Stayed the same ..... 2  
 Got worse ..... 3  
 Don't know ..... 9

- nn. Had this person **ever** had cataract surgery on both eyes?  
(circle one)  
 Yes ..... 1  
 No ..... 2 (Go to 27qq)  
 Don't know ..... 9 (Go to 27qq)
- oo. If yes, had (he/she) had cataract surgery on both eyes since September 1997?  
(circle one)  
 Yes ..... 1  
 No ..... 2  
 Don't know ..... 9
- pp. As a result of the cataract surgery, did this person's vision improve, stay the same or get worse?  
(circle one)  
 Improved ..... 1  
 Stayed the same ..... 2  
 Got worse ..... 3  
 Don't know ..... 9
- qq. If the original participant was female, had she **ever** had a hysterectomy?  
(circle one)  
 Yes ..... 1  
 No ..... 2  
 Don't know ..... 9

**These next questions are about important health care decisions the original participant may have made prior to death.**

28. a. Did this person provide written instructions about the treatment or care they wanted to receive during the final days of their life?

(circle one)

Yes ..... 1

No ..... 2 (Go to 29)

Don't know ..... 9 (Go to 29)

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

(circle one)

Yes ..... 1 (Go to 28e)

No ..... 2

Don't know ..... 9

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

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

d. Did these instructions express a desire to keep them comfortable and pain free but to forego extensive measures to prolong life?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

- e. Were these written instructions followed at the time of death? (circle one)
- Yes ..... 1
- No ..... 2
- Don't know ..... 9

29. Did this person make any legal arrangements for a specific person or persons to make decisions about their care or medical treatment if they could not make these decisions himself/herself? This is sometimes called a "Durable Power of Attorney for Health Care."

- (circle one)
- Yes ..... 1
- No ..... 2
- Don't know ..... 9

## HEALTH INSURANCE

**These next questions are about the original participant's health insurance.**

30. a. There are several government programs that provide medical care or help pay medical bills. Medicare is the government health insurance program for people 65 years of age or older and for certain persons with disabilities. Was this person covered by Medicare at the time of their death?

(circle one)

Yes ..... 1

No ..... 2 (Go to 36)

Don't know ..... 9 (Go to 36)

- b. In what month and year did their Medicare coverage start?

\_\_\_\_\_/\_\_\_\_\_  
month year

9999 Don't know

31. What was their Health Insurance Claim Number on their 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 these purposes, NCHS will not release their 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 their benefits. This number will be held in strict confidence.

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

(write in numbers)

|\_|\_|\_|-|\_|\_|\_|-|\_|\_|\_|\_|\_|

32. Medicare now offers several different kinds of health insurance. We are interested in knowing more about the kind of Medicare health insurance (he/she) had and how it worked for non-emergency care.

a. As part of (his/her) Medicare coverage, did (he/she) have to sign up with a certain doctor or group of doctors or with a certain clinic for (his/her) routine care? Or was (he/she) allowed to see any doctor who accepted Medicare payment in (his/her) area?

(circle one)

Required to sign up with a certain doctor,  
group of doctors or clinic . . . . . 1

Allowed to see any doctor in area . . . . . 2

b. As part of (his/her) Medicare coverage, was (he/she) signed up with an HMO that is Health Maintenance Organization or other type of managed care plan?

With an HMO or managed care plan you generally must receive care from the plan's own doctors or their network of hospitals; otherwise the expense is not covered unless you were referred by the HMO or there was a medical emergency.

(circle one)

Yes . . . . . 1

No . . . . . 2 (Go to 33)

Don't know . . . . . 9 (Go to 33)

c. What is the complete name of this plan?

ENTER NAME: \_\_\_\_\_

33. Besides (his/her) Medicare plan, did (he/she) have any other health insurance plan that paid for some of the services that Medicare did not pay for? These plans are SOMETIMES called Medigap or Medicare supplements.

(circle one)

Yes . . . . . 1

No . . . . . 2 (Go to 35)

Don't know . . . . . 9 (Go to 35)

34. What (is/are) the complete name(s) of (each of these/this plan(s))?

ENTER NAME(S): \_\_\_\_\_

35. Thinking about (his/her) (Medicare/Medicare and Medigap/Medicare managed care plan/Medicare managed care and Medigap), please tell me did (his/her) employer help pay for (this/these) plan(s)?

(circle one)

Yes ..... 1

No ..... 2

Don't know ..... 9

36. In addition to Medicare, there are several other government health insurance programs. Please tell me if this person was covered by any of the following programs.

(circle one answer on each line)

	YES	NO
a. Medicaid	1	2
b. Military health care, including VA, CHAMPUS, or CHAMP-VA	1	2
c. Other public assistance program	1	2

37. a. Did (plan type from 36) require (him/her) to sign up with a certain doctor or group of doctors or with a certain clinic for (his/her) routine care? Or was (he/she) allowed to see any doctor in your area?

(circle one)

Required to sign up with a certain doctor,  
group of doctors or clinic ..... 1

Allowed to see any doctor in area ..... 2



- b. As part of (his/her) (plan type from 36) or (his/her) other non-Medicare coverage, was (he/she) signed up with an HMO that is Health Maintenance Organization or other type of managed care plan?

With an HMO or managed care plan you generally must receive care from the plan's own doctors or their network of hospitals; otherwise the expense is not covered unless you were referred by the HMO or there was a medical emergency.

(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

38. Aside from Medicaid and other government programs, was this person covered by a health insurance policy which paid any part of a nursing home stay or long term care services in their home?

(circle one)

Yes ..... 1  
No ..... 2  
Don't know ..... 9

39. During the last 12 months of life, about how much did this person and their family spend for this person's own medical care? Do **not** include the cost of health insurance premiums, over-the-counter remedies, or any costs for which this person or their family was reimbursed.

(circle one)

Zero ..... 0  
Less than \$500 ..... 1  
\$500-999 ..... 2  
\$1,000-2,999 ..... 3  
\$3,000 or more ..... 4  
Don't know ..... 9

The National Center for Health Statistics may wish to contact you again to obtain additional health related information. Please fill out **your** name, address and telephone number so we can keep our files up to date.

Name: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

City: \_\_\_\_\_ State: |\_\_||\_\_| Zip: |\_\_||\_\_||\_\_||\_\_||\_\_|

Telephone: (|\_\_||\_\_||\_\_|)|\_\_||\_\_||\_\_|-|\_\_||\_\_||\_\_||\_\_|

Check box if you do not have a telephone

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

Please return your completed questionnaire in the enclosed prepaid envelope addressed to:

NORC  
University of Chicago  
1525 E. 55th Street  
Chicago, IL 60615