
Next of Kin CATI SPECIFICATIONS:

<SECTION A: INTRODUCTION>

Hello, this is _____ calling on behalf of Duke University. We are conducting a followup to the 1999 National Long-Term Care Survey to study the health conditions and physical activities of persons who live in the United States.

Is this the right number for [#fill NOK LASTNAME]?

- 0 = YES
 - 2 = NO, BUT PERSON ON THE PHONE KNOWS THE SELECTED NOK SAMPLE MEMBER
 - 3 = NO, DOES NOT KNOW THE SELECTED NOK SAMPLE MEMBER
 - 4 = LANGUAGE BARRIER
 - 5 = REFUSED
 - 9 = MORE CODES
-

IF NOT ALREADY SPEAKING WITH NOK SAMPLE MEMBER, ASK:

May I speak with <NOK NAME>?

- 1 = YES, SUBJECT IS AVAILABLE
 - 2 = SUBJECT WILL CALL RTI
 - 3 = SUBJECT NOT AVAILABLE - SET APPT.
 - 5 = LANGUAGE BARRIER
 - 6 = REFUSED
 - 9 = MORE CODES
-

(Hello, this is _____. I am calling on behalf of Duke University. We are conducting a followup to the 1999 National Long-Term Care Survey to study the health conditions and physical activities of persons who live in the United States.)

Included in this survey are 450 persons who are recently deceased. I have some questions about [#fill MR./MS.] [#fill DECEASED'S FULL NAME]'s general care. Do you know about [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s general care?

- 1 = YES [#GO TO LETTER ADDRESS SCREEN]
 - 2 = NO [#GO TO TRACING SCREEN A]
 - 5 = LANGUAGE BARRIER
 - 6 = REFUSED
 - 9 = MORE CODES
-

<TRACING SCREEN A>

Do you have a name, address, and/or telephone number of the person who would be most knowledgeable about [#fill MR./MS.] [#fill DECEASED'S FULL NAME]'s general care?

- 1 = YES [#ENTER NEW CONTACT INFORMATION; THANK RESPONDENT]

2 = NO [#GO TO TRACING SCREEN B]

<TRACING SCREEN B>

Do you have a name, address, and/or telephone number of someone who could tell us who the most knowledgeable person would be concerning [#fill MR./MS.] [#fill DECEASED'S FULL NAME]'s general care?

1 = YES [#ENTER NEW CONTACT INFORMATION; THANK RESPONDENT]

2 = NO [#GO TO TRACING QUEUE; THANK RESPONDENT]

<HELP SCREEN>

If you have any questions about the study, please contact Ms. Jackie Teague, at RTI's toll-free number, 1-877-226-1192, during normal business hours (Monday through Friday, 8:30 am - 4:30 pm EST).

If you have any questions about your rights as a subject in a research study, please call Duke University's Office of Risk Management at 919-684-3277.

<LETTER ADDRESS SCREEN>

Did you receive our letter describing the study?

LETTER WAS MAILED TO : [#fill NOK STREET ADDRESS]

[#fill NOK CITY, STATE, ZIP CODE]

IF THE RESPONDENT REFUSES, USE ESC KEY FOR A BREAKOFF.

1 = YES [#GO TO LETTER SUMMARY A]

2 = NO [#GO TO LETTER SUMMARY B]

-1 = DK [#GO TO LETTER SUMMARY B]

<LETTER SUMMARY A>

As the letter mentioned, the study is being sponsored by the National Institute on Aging. The purpose of the study is to help us understand the long-term health care needs of our growing elderly population.

Included in this survey are the next of kin to 450 persons who participated in the National Long Term Care Survey. You were selected to participate in the study based on your relationship with [#fill MR./MS.] [#fill DECEASED'S FULL NAME]. We would like for you to assist us by answering a few questions about [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s general care.

The interview should take 15 to 25 minutes. Participation in this survey is voluntary and your federal assistance benefits will not be affected in any way by your decision about participating in this survey.

All information you provide will be kept strictly confidential. You may refuse to answer any individual items I ask you. If you're ready, we can start the interview.

NEED TO RESCHEDULE OR THE RESPONDENT REFUSES, USE ESC KEY FOR BREAKOFF
1 = CONTINUE

<LETTER SUMMARY B>

Since you have not seen the letter, let me briefly review the information that was provided. The study is sponsored by the National Institute on Aging. The purpose of the study is to help us understand the long-term health care needs of our growing elderly population.

Included in this survey are the next of kin to 450 persons who participated in the National Long Term Care Survey. You were selected to participate in the study based on your relationship with [#fill MR./MS.] [#fill DECEASED'S FULL NAME]. We would like for you to assist us by answering a few questions about [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s general care. Duke University will combine the information we collect with data that was collected in similar surveys in 1982, 1984, 1989, 1994, and 1999 to determine how the health care needs of the Nation have been changing.

The interview should take 15 to 25 minutes. Participation in this survey is voluntary and your federal assistance benefits will not be affected in any way by your decision about participating in this survey.

All information you provide will be kept strictly confidential. You may refuse to answer any individual items I ask you. If you're ready, we can start the interview.

NEED TO RESCHEDULE OR THE RESPONDENT REFUSES, USE ESC KEY FOR BREAKOFF
1 = CONTINUE

<HELP SCREEN>

IF R BECOMES UPSET OR ANXIOUS SPEAK PATIENTLY AND ASSURINGLY, FOR EXAMPLE:
"I'm sorry if I upset you." "Are you doing okay?" "Would you like to take a break?" "Would you like to reschedule this for another time?" "Do you want to continue the interview?"

IF R IS TOO UPSET AND DOES NOT RESPOND, IS SUICIDAL, OR IN CRISIS:

Signal Supervisor that R is suicidal or in crisis

Remain on the line with the respondent and calmly state, "Please hold on a moment while I transfer the line to someone who can help you."

When the supervisor takes over the call, the TI disconnects.

If the supervisor determines the R is ready, the R may return to the TI.

<SUPERVISOR HELP SCREEN>

SUPERVISORS OR TEAM LEADERS FOLLOW EMERGENCY PLAN:

Supervisor will keep R talking and ask whether R would like us to call a friend, family member, neighbor, the R's doctor or therapist. Meanwhile, a second supervisor or team leader will make the call to the desired person, if requested. If the supervisor determines the R is ready, the R may return to the TI.

If R repeats they are suicidal or is unable to answer, the second supervisor or team leader will make a call to the National Suicide Hotline 1-800-784-2433 and patch them in as a three-way call. Once the Hotline staff is on the line with the R, TSU personnel will disconnect from the call. There will be no further follow-up with R.

The supervisor will document the CASE ID of the R, the actions taken, the date and time of the call, the parties involved, and the outcome. This information will be e-mailed immediately to Jackie Teague (jlt@rti.org) and Rebecca Martin (rdm@rti.org).

<1a.> What is your relationship to [#fill MR./MS.] [#fill DECEASED'S FULL NAME]?

1 = PARENT

2 = SPOUSE

3 = SON OR DAUGHTER

4 = BROTHER OR SISTER

5 = OTHER RELATIVE

6 = OTHER NON-RELATIVE

-2 = RE

<1b.> Let me verify your name and address [#FILL AND ALLOW CORRECTIONS].

NAME: _____

STREET ADDRESS: _____

CITY: _____

STATE: _____

ZIP: _____

Now I have a few questions I need to ask concerning information found on [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s death certificate. As mentioned in the letter, it would be helpful if you had a copy of the death certificate to answer the next few questions.

<2a.> Do you have a copy of [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s death certificate?

1 = YES
2 = NO [#GO TO Q.2e]
-1 = DK [#GO TO Q.2e]
-2 = RE [#GO TO Q.2e]

[#PROGRAMMERS: If Q.2a = 1, CAPI instructions to FIs should say: WAIT FOR R TO GET A COPY, IF THEY HAVE ONE; CATI instructions to TIs should say: TELL R YOU WILL HOLD FOR THEM WHILE THEY GET THEIR COPY]

<2b.> Could you please tell me what is filled in on the death certificate to describe the immediate cause of death? [#PROVIDE MENU OF LEADING CAUSES SUCH AS]

ASTHMA, BRONCHITIS, EMPHYSEMA
CEREBROVASCULAR
DIABETES
HEART DISEASE
HIV/AIDS
LIVER DISEASE
CANCER
PNEUMONIA AND INFLUENZA
SUICIDE
UNINTENTIONAL INJURIES
OTHER- SPECIFY [#1 LINE - 35 CHARACTERS]

[#PROBE: IF NOT LEGIBLE, ASK THEM TO READ AS MUCH AS THEY CAN TO YOU.]

-1 = DK/NOT FILLED IN
-2 = RE

<2c.> Could you please tell me what is filled in on the death certificate to describe the underlying cause of death?

[#PROVIDE MENU OF LEADING CAUSES SUCH AS]
ASTHMA, BRONCHITIS, EMPHYSEMA
CEREBROVASCULAR
DIABETES
HEART DISEASE
HIV/AIDS
LIVER DISEASE
CANCER
PNEUMONIA AND INFLUENZA
SUICIDE
UNINTENTIONAL INJURIES
OTHER- SPECIFY [#3 LINES - 35 CHARACTERS EACH]

[#PROBE: IF NOT LEGIBLE, ASK THEM TO READ AS MUCH AS THEY CAN TO YOU.]

-1 = DK/NOT FILLED IN
-2 = RE

<2d.> Could you please tell me what is filled in on the death certificate to describe the associated cause of death? [#PROVIDE MENU OF LEADING CAUSES SUCH AS]

ASTHMA, BRONCHITIS, EMPHYSEMA

CEREBROVASCULAR

DIABETES

HEART DISEASE

HIV/AIDS

LIVER DISEASE

CANCER

PNEUMONIA AND INFLUENZA

SUICIDE

UNINTENTIONAL INJURIES

OTHER- SPECIFY [5 LINES - 35 CHARACTERS EACH]

[#GO TO Q.3a]

[#PROBE: IF NOT LEGIBLE, ASK THEM TO READ AS MUCH AS THEY CAN TO YOU.]

-1 = DK/NOT FILLED IN

-2 = RE

<2e.> What was [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s cause of death ?

[#PROVIDE MENU OF LEADING CAUSES SUCH AS]

ASTHMA, BRONCHITIS, EMPHYSEMA

CEREBROVASCULAR

DIABETES

HEART DISEASE

HIV/AIDS

LIVER DISEASE

CANCER

PNEUMONIA AND INFLUENZA

SUICIDE

UNINTENTIONAL INJURIES

OTHER- SPECIFY _____

-1 = DK

-2 = RE

<2f.>What other chronic conditions did [#fill HE/SHE] have, if any? [#SELECT ALL THAT APPLY]

[#PROVIDE MENU OF LEADING CONDITIONS SUCH AS]

ALZHEIMER'S DISEASE

ASTHMA, BRONCHITIS, EMPHYSEMA

DIABETES

HEART DISEASE

HIV/AIDS

LIVER DISEASE

LUPUS

CANCER

OSTEOPOROSIS, OSTEOARTHRITIS

PNEUMONIA AND INFLUENZA

SUICIDE

OTHER - SPECIFY [RECORD VERBATIM] _____

0 = NONE

-1 = DK

-2 = RE

<SECTION B: HEALTH CARE>

<3a.> Our records indicate that [#fill MR./MS.] [#fill DECEASED'S LAST NAME] died in [#fill MONTH] of [#fill YEAR]. Is that correct?

1 = YES [#GO TO 4a] [#PROGRAMMERS: Use pre-loaded dates if response is either Yes, DK, or RE)

2 = NO

-1 = DK [#GO TO 4a]

-2 = RE [#GO TO 4a]

<3b.> In what month and year did [#fill MR./MS.] [#fill DECEASED'S LAST NAME] die?

MONTH _____ [#ENTER MONTH 1-12]

-1 = DK

-2 = RE

YEAR _____ [#ENTER 4 DIGITS FOR YEAR, 1998-2001]

-1 = DK

-2 = RE

<4a.> What was [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s height during [#fill HIS/HER] adult life?

FEET _____ [#ENTER 3-7] INCHES _____ [#ENTER 0-11]

-1 = DK

-2 = RE

<4b.> What was [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s average weight during [#fill HIS/HER] adult life?

POUNDS _____ [#ENTER 60-500]

-1 = DK

-2 = RE

<5a.> Was [#fill MR./MS.] [#fill DECEASED'S LAST NAME] very sick in the last year before [#fill HIS/HER] death?

1 = YES

2 = NO [#GO TO 6a]

-1 = DK

-2 = RE

<5b.> How long had [#fill HE/SHE] been sick? [#ONLY READ PROMPTS IF NEEDED]

1 = LESS THAN A MONTH

2 = 1 - 5 MONTHS

3 = 6 - 11 MONTHS

4 = 1 YEAR TO LESS THAN 2 YEARS

5 = 2 OR MORE YEARS

-1 = DK

-2 = RE

<6a.> Did a physician or other health care provider make a diagnosis for [#fill MR./MS.] [#fill DECEASED'S LAST NAME]?

1 = YES

2 = NO [#GO TO 7a]

-1 = DK [#GO TO 7a]

-2 = RE [#GO TO 7a]

<6b.> What was the diagnosis? [#SELECT ALL THAT APPLY]

[#PROVIDE MENU OF LEADING CONDITIONS SUCH AS]

ALZHEIMER'S DISEASE

ASTHMA, BRONCHITIS, EMPHYSEMA

DIABETES

HEART DISEASE

HIV/AIDS

LIVER DISEASE

LUPUS

CANCER

OSTEOPOROSIS, OSTEOARTHRITIS

PNEUMONIA AND INFLUENZA

SUICIDE

OTHER - SPECIFY [RECORD VERBATIM] _____

-1 = DK

-2 = RE

<7a.> Where did [#fill MR./MS.] [#fill DECEASED'S LAST NAME] die? Was [#fill HE/SHE]?

1 = Alone or with others in a house or apartment (independent living) [#GO TO 8a]

2 = In a retirement home [#GO TO 8a]

3 = In a boarding house, rooming house, or rented room [#GO TO 8a]

4 = In a foster or family care house [#GO TO 8a]

5 = In a group home or community residential facility [#GO TO 8a]

6 = In a nursing or convalescent facility [#GO TO 7d]

7 = In an assisted living setting with board and/or personal care service available [#GO TO 7d]

8 = In a memory care or Alzheimer's care setting [#GO TO 7d]

9 = In a hospital [#GO TO 7b]

10 = In another place?

SPECIFY OTHER PLACE: _____ [#GO TO 8b]

-1 = DK [#GO TO 8b]

-2 = RE [#GO TO 8b]

<7b.> Was this a short-stay general hospital or was it a long-stay hospital such as a rehabilitation center or a mental hospital?

[IF NEEDED: "Short-stay" general hospital is defined as a hospital that has an average length of stay of less than 30 days. "Long-stay" hospital is defined as a hospital that has an average length of stay of 30 days or longer.]

1 = SHORT-STAY

2 = LONG-STAY

-1 = DK

-2 = RE

<7c.> In what month and year was [#fill MR./MS.] [#fill DECEASED'S LAST NAME] admitted to the hospital? [#IF NEEDED, "right before he/she died"]

MONTH _____ [#ENTER MONTH 1-12]

-1 = DK

-2 = RE

YEAR _____ [#ENTER 4 DIGITS FOR YEAR, 1950-2001] [#GO TO 7f]

-1 = DK [#GO TO 7f]

-2 = RE [#GO TO 7f]

<7d.> In what month and year was [#fill MR./MS.] [#fill DECEASED'S LAST NAME] admitted to the nursing home, convalescent home, memory care or assisted living setting? [#IF NEEDED, "right before he/she died"]

MONTH _____ [#ENTER MONTH 1-12]

-1 = DK

-2 = RE

YEAR _____ [#ENTER 4 DIGITS FOR YEAR, 1950-2001]

-1 = DK

-2 = RE

<7e.> About how long was [#fill HE/SHE] in the nursing home, convalescent home, memory care or assisted living setting? [#IF NEEDED, "right before he/she died"]

1 = 1 DAY OR LESS

2 = 2 DAYS OR LESS THAN 1 WEEK

3 = 1 WEEK TO LESS THAN 2 WEEKS

4 = 2 WEEKS TO LESS THAN 1 MONTH

5 = 1 MONTH TO LESS THAN 3 MONTHS

6 = 3 MONTHS TO LESS THAN 6 MONTHS

7 = 6 MONTHS TO LESS THAN 1 YEAR

8 = 1 YEAR TO LESS THAN 2 YEARS

9 = 2 YEARS AND OVER

-1 = DK

-2 = RE

<7f.> Who paid for [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s stay [#fill ENTRY IN 7a] ?

Was it? [#SELECT ALL THAT APPLY].

- 1 = Medicaid
- 2 = Medicare
- 3 = Private health insurance
- 4 = Veteran's benefits
- 5 = Himself/Herself
- 6 = His/Her spouse
- 7 = His/Her child(ren)
- 8 = Other relative(s)
- 9 = Other nonrelative(s)
- 10 = Any other source?

SPECIFY OTHER SOURCE: _____

- 1 = DK
- 2 = RE

[#NOTE TO PROGRAMMERS: If medicaid is marked in Q.7f, continue with Q.7g; if not, skip to Q.7h.]

<7g.> About how long did Medicaid pay for [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s stay [#fill ENTRY IN 7a]?

- 1 = 1 DAY OR LESS
- 2 = 2 DAYS OR LESS THAN 1 WEEK
- 3 = 1 WEEK TO LESS THAN 2 WEEKS
- 4 = 2 WEEKS TO LESS THAN 1 MONTH
- 5 = 1 MONTH TO LESS THAN 3 MONTHS
- 6 = 3 MONTHS TO LESS THAN 6 MONTHS
- 7 = 6 MONTHS TO LESS THAN 1 YEAR
- 8 = 1 YEAR TO LESS THAN 2 YEARS
- 9 = 2 YEARS AND OVER
- 1 = DK
- 2 = RE

<7h.> You said [#fill MR./MS.] [#fill DECEASED'S LAST NAME] died [#fill ENTRY IN 7a]. Where was [#fill HE/SHE] living prior to that time? Was it...?

- 1 = Alone or with others in a house or apartment (independent living) [#GO TO 10a]
- 2 = In a retirement home [#GO TO 10a]
- 3 = In a boarding house, rooming house, or rented room [#GO TO 10a]
- 4 = In a foster or family care house [#GO TO 10a]
- 5 = In a group home or community residential facility [#GO TO 10a]
- 6 = In a nursing or convalescent facility [#GO TO 8e]

7 = In an assisted living setting with board and/or personal care service available [#GO TO 8e]

8 = In a memory care or Alzheimer's care setting [#GO TO 8e]

9 = In a hospital [#GO TO 8c]

10 = In another place?

SPECIFY OTHER PLACE: _____ [#GO TO

10a]

-1 = DK [#GO TO 10a]

-2 = RE [#GO TO 10a]

<8a.> You said [#fill MR./MS.] [#fill DECEASED'S LAST NAME] died [#fill ENTRY IN 7a]. Is this where [#fill HE/SHE] lived prior to [#fill HIS/HER] death?

1 = YES [#GO TO 10a]

2 = NO

-1 = DK

-2 = RE

<8b.> Where was [#fill MR./MS.] [#fill DECEASED'S LAST NAME] living prior to [#fill HIS/HER] death? Was [#fill HE/SHE]....?

1 = Alone or with others in a house or apartment (independent living) [#GO TO 10a]

2 = In a retirement home [#GO TO 10a]

3 = In a boarding house, rooming house, or rented room [#GO TO 10a]

4 = In a foster or family care house [#GO TO 10a]

5 = In a group home or community residential facility [#GO TO 10a]

6 = In a nursing or convalescent facility [#GO TO 8e]

7 = In an assisted living setting with board and/or personal care service available [#GO TO 8e]

8 = In a memory care or Alzheimer's care setting [#GO TO 8e]

9 = In a hospital [#GO TO 8c]

10 = In another place?

SPECIFY OTHER PLACE: _____ [#GO TO

10a]

-1 = DK [#GO TO 10a]

-2 = RE [#GO TO 10a]

<8c.> Was this a short-stay general hospital or was it a long-stay hospital such as a rehabilitation center or a mental hospital?

[#IF NEEDED: "Short-stay" general hospital is defined as a hospital that has an average length of stay of less than 30 days. "Long-stay" hospital is defined as a hospital that has an average length of stay of 30 days or longer.]

1 = SHORT-STAY

2 = LONG-STAY

-1 = DK

-2 = RE

<8d.> In what month and year was [#fill MR./MS.] [#fill DECEASED'S LAST NAME] admitted to the hospital? [#IF NEEDED, THE TIME PERIOD TO FOCUS ON IS 'since 1999' OR 'the period leading to the last year before death']

MONTH _____ [#ENTER MONTH 1-12]

-1 = DK

-2 = RE

YEAR _____ [#ENTER 4 DIGITS FOR YEAR, 1950-2001] [#GO TO 8g]

-1 = DK [#GO TO 8g]

-2 = RE [#GO TO 8g]

<8e.> In what month and year was [#fill MR./MS.] [#fill DECEASED'S LAST NAME] admitted to the nursing home, convalescent home, memory care or assisted living setting? [#IF NEEDED, THE TIME PERIOD TO FOCUS ON IS 'since 1999' OR 'the period leading to the last year before death']

MONTH _____ [#ENTER MONTH 1-12]

-1 = DK

-2 = RE

YEAR _____ [#ENTER 4 DIGITS FOR YEAR, 1950-2001]

-1 = DK

-2 = RE

<8f.> About how long was [#fill HE/SHE] in the nursing home, convalescent home, memory care or assisted living setting?

1 = LESS THAN 1 WEEK

2 = 1 WEEK TO LESS THAN 2 WEEKS

3 = 2 WEEKS TO LESS THAN 1 MONTH

4 = 1 MONTH TO LESS THAN 3 MONTHS

5 = 3 MONTHS TO LESS THAN 6 MONTHS

6 = 6 MONTHS TO LESS THAN 1 YEAR

7 = 1 YEAR TO LESS THAN 2 YEARS

8 = 2 YEARS AND OVER

-1 = DK

-2 = RE

<8g.> Who paid for [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s stay [#fill ENTRY IN 7h or 8b]? Was it.....? [#SELECT ALL THAT APPLY].

- 1 = Medicaid
 - 2 = Medicare
 - 3 = Private health insurance
 - 4 = Veteran's benefits
 - 5 = Himself/Herself
 - 6 = His/Her spouse
 - 7 = His/Her child(ren)
 - 8 = Other relative(s)
 - 9 = Other nonrelative(s)
 - 10 = OTHER SPECIFY
- What was the other source? _____
- 1 = DK
 - 2 = RE

PROGRAMMERS: *If medicaid is marked in Q.8g, continue with Q.8h; if not, skip to Q. 9a.]*

<8h.> About how long did Medicaid pay for [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s stay [#fill ENTRY IN 7h or 8b]?

- 1 = LESS THAN 1 WEEK
- 2 = 1 WEEK TO LESS THAN 2 WEEKS
- 3 = 2 WEEKS TO LESS THAN 1 MONTH
- 4 = 1 MONTH TO LESS THAN 3 MONTHS
- 5 = 3 MONTHS TO LESS THAN 6 MONTHS
- 6 = 6 MONTHS TO LESS THAN 1 YEAR
- 7 = 1 YEAR TO LESS THAN 2 YEARS
- 8 = 2 YEARS AND OVER
- 1 = DK
- 2 = RE

NOTE TO PROGRAMMERS: *For the fill-in marked ,<ENTRY IN 8b>, in Q. 9a, please change the fill-ins in your program to these shortened versions:*

- 1 = In a house or apartment
- 3 = In a boarding house or rooming house
- 5 = In a group home
- 7 = In an assisted living setting
- 8 = In a memory care setting]

<9a.> Just before [#fill HE/SHE] was [#fill ENTRY IN 8b], where was [#fill MR./MS.] [#fill DECEASED'S LAST NAME] living? Was [#fill HE/SHE]....? [#IF NEEDED, THE TIME PERIOD TO FOCUS ON IS 'since 1999' OR 'the period of the last year before death']

- 1 = Alone or with others in a house or apartment (independent living) [#GO TO 10a]

- 2 = In a retirement home [#GO TO 10a]
- 3 = In a boarding house, rooming house, or rented room [#GO TO 10a]
- 4 = In a foster or family care house [#GO TO 10a]
- 5 = In a group home or community residential facility [#GO TO 10a]
- 6 = In a nursing or convalescent facility [#GO TO 9d]
- 7 = In an assisted living setting with board and/or personal care service available [#GO TO 9d]
- 8 = In a memory care or Alzheimer's care setting [#GO TO 9d]
- 9 = In a hospital [#GO TO 9b]
- 10 = In another place?
SPECIFY OTHER PLACE: _____ [#GO TO 10a]
- 1 = DK [#GO TO 10a]
- 2 = RE [#GO TO 10a]

<9b.> Was this a short-stay general hospital or was it a long-stay hospital such as a rehabilitation center or a mental hospital?

[#IF NEEDED: "Short-stay" general hospital is defined as a hospital that has an average length of stay of less than 30 days. "Long-stay" hospital is defined as a hospital that has an average length of stay of 30 days or longer.]

- 1 = SHORT-STAY
- 2 = LONG-STAY
- 1 = DK
- 2 = RE

<9c.> In what month and year was [#fill MR./MS.] [#fill DECEASED'S LAST NAME] admitted to the hospital? [#IF NEEDED, THE TIME PERIOD TO FOCUS ON IS 'since 1999' OR 'the period of the last year before death']

- MONTH _____ [#ENTER MONTH 1-12]
- 1 = DK
- 2 = RE

- YEAR _____ [#ENTER 4 DIGITS FOR YEAR, 1950-2001][#GO TO 9f]
- 1 = DK [#GO TO 9f]
- 2 = RE [#GO TO 9f]

<9d.> In what month and year was [#fill MR./MS.] [#fill DECEASED'S LAST NAME] admitted to the nursing home, convalescent home, memory care or assisted living setting? [#IF NEEDED, THE TIME PERIOD TO FOCUS ON IS 'since 1999' OR 'the period of the last year before death']

- MONTH _____ [#ENTER MONTH 1-12]
- 1 = DK
- 2 = RE

- YEAR _____ [#ENTER 4 DIGITS FOR YEAR, 1950-2001]
- 1 = DK

-2 = RE

<9e.> About how long was [#fill HE/SHE] in the nursing home, convalescent home, memory care or assisted living setting?

- 1 = LESS THAN 1 WEEK
- 2 = 1 WEEK TO LESS THAN 2 WEEKS
- 3 = 2 WEEKS TO LESS THAN 1 MONTH
- 4 = 1 MONTH TO LESS THAN 3 MONTHS
- 5 = 3 MONTHS TO LESS THAN 6 MONTHS
- 6 = 6 MONTHS TO LESS THAN 1 YEAR
- 7 = 1 YEAR TO LESS THAN 2 YEARS
- 8 = 2 YEARS AND OVER
- 1 = DK
- 2 = RE

<9f.> Who paid for [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s stay [#fill ENTRY IN 9a]? Was it.....? [#SELECT ALL THAT APPLY].

- 1 = Medicaid
 - 2 = Medicare
 - 3 = Private health insurance
 - 4 = Veteran's benefits
 - 5 = Himself/Herself
 - 6 = His/Her spouse
 - 7 = His/Her child(ren)
 - 8 = Other relative(s)
 - 9 = Other nonrelative(s)
 - 10 = OTHER SPECIFY
- What was the other source? _____
- 1 = DK
 - 2 = RE

[O PROGRAMMER: If medicaid is marked in Q.9f, continue with Q.9g; if not, skip to Q.10a.]

<9g.> About how long did Medicaid pay for [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s stay [#fill ENTRY IN 9a]?

- 1 = LESS THAN A WEEK
- 2 = 1 WEEK TO LESS THAN 2 WEEKS
- 3 = 2 WEEKS TO LESS THAN 1 MONTH
- 4 = 1 MONTH TO LESS THAN 3 MONTHS
- 5 = 3 MONTHS TO LESS THAN 6 MONTHS
- 6 = 6 MONTHS TO LESS THAN 1 YEAR
- 7 = 1 YEAR TO LESS THAN 2 YEARS
- 8 = 2 YEARS AND OVER
- 1 = DK
- 2 = RE

<10a.> [#fill Besides the times you have already told me about was/Was] [#fill MR./MS.] [#fill DECEASED'S LAST NAME] ever a patient in a nursing or convalescent home? [#IF NEEDED, THE TIME PERIOD TO FOCUS ON IS 'since 1999' OR 'the period of the last year before death']

1 = YES

2 = NO [#GO TO 11]

-1 = DK [#GO TO 11]

-2 = RE [#GO TO 11]

<10b.> How many times was [#fill he/she] admitted as a patient in a nursing or convalescent home? [#IF NEEDED, THE TIME PERIOD TO FOCUS ON IS 'since 1999' OR 'the period of the last year before death']

_____ TIME(S) [#ENTER 1-99]

-1 = DK [#GO TO 11]

-2 = RE [#GO TO 11]

[#ASK 10c AND 10d FOR EACH TIME NOTED IN Q.10b.]

<10c.> In what month and year was [#fill MR./MS.] [#fill DECEASED'S LAST NAME] admitted [#fill the first time/the second time.../the last time]? [#IF NEEDED, THE TIME PERIOD TO FOCUS ON IS 'since 1999' OR 'the period of the last year before death']

MONTH _____ [#ENTER MONTH 1-12]

-1 = DK

-2 = RE

YEAR _____ [#ENTER 4 DIGITS FOR YEAR, 1950-2001]

-1 = DK

-2 = RE

<10d.> How long was [#fill HE/SHE] in the nursing or convalescent home? [#IF NEEDED, THE TIME PERIOD TO FOCUS ON IS 'since 1999' OR 'the period of the last year before death']

YEARS _____ [#ENTER 0-50]

MONTHS _____ [#ENTER 0-23]

WEEKS _____ [#ENTER 0-12]

DAYS _____ [#ENTER 0-90]

-1 = DK

-2 = RE

<11.> "Hospice" is a service for the terminally ill. During the last 6 months before [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s death, that is from [#fill 6 MONTHS PRIOR TO ENTRY IN Q.3a or Q.3b] to [#fill ENTRY IN Q.3a or 3b], did [#fill HE/SHE] receive hospice care either at home, in a hospital, or in a hospice facility?

1 = YES

2 = NO

-1 = DK

-2 = RE

<12a.> During the last month before [#fill MR./MS.] [#fill DECEASED'S LAST NAME] died, that is from [#fill MONTH PRIOR TO ENTRY IN Q.3a or Q.3b] to [#fill ENTRY IN Q.3a or 3b] was anyone being **paid** (outside of the facilities you have told me about) to take care of [#fill HIM/HER] because of poor health?

1 = YES

2 = NO [#GO TO 13a]

-1 = DK [#GO TO 13a]

-2 = RE [#GO TO 13a]

<12b.> Who was this person? Was it.... [#SELECT ALL THAT APPLY]

- 1 = a health care provider
- 2 = a housekeeper
- 3 = a relative
- 4 = a neighbor or friend
- 5 = or someone else?

SPECIFY WHO WAS PAID TO TAKE CARE OF SUBJECT:

-
- 1 = DK
 - 2 = RE

<12c.> What kind of assistance was given? Was it help with.....? [SELECT ALL THAT APPLY]

- 1 = personal care, such as bathing or dressing
- 2 = things like cooking or housework
- 3 = nursing care, such as giving injections
- 1 = DK
- 2 = RE

<13a.> Did you or anyone else such as a relative, (spouse), or friend help to take care of [#fill MR./MS.] [#fill DECEASED'S LAST NAME] because of [HIS/HER] poor health? [#DO NOT INCLUDE PAID SERVICES.]

- 1 = YES
- 2 = NO [#GO TO 14a]
- 1 = DK [#GO TO 14a]
- 2 = RE [#GO TO 14a]

<13b.> Who helped to take care of [#fill HIM/HER]? Was it.....? [#SELECT ALL THAT APPLY]

- 1 = <HIS/HER> spouse
- 2 = a son or daughter who lived with <HIM/HER>
- 3 = another relative who lived with <HIM/HER>
- 4 = a nonrelative who lived with <HIM/HER>
- 5 = a son or daughter who did not live with <HIM/HER>
- 6 = another relative who did not live with <HIM/HER>
- 7 = a nonrelative who did not live with <HIM/HER>
- 1 = DK
- 2 = RE

<13c.> What kind of assistance was given? Was it assistance with.....? [#SELECT ALL THAT APPLY]

- 1 = personal care, such as bathing or dressing
 - 2 = things like cooking or housework
 - 3 = OTHER - SPECIFY
-

- 1 = DK
- 2 = RE

<14a.> Toward the end of [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s life, did [#fill HE/SHE] need any special foods, have any special dietary needs, or special nutritional help, such as.....? [#SELECT ALL THAT APPLY]

- 1 = a diet modified in texture (such as pureed)
- 2 = needing a person to assist in feeding
- 3 = using special feeding devices or equipment (such as special cups, spoons, or dishes)
- 4 = needing assistance with swallowing (such as with a liquid, holding head, sitting up)
- 5 = a specially modified diet (such as a low sodium, low protein, diabetes diet, etc.)
- 6 = using oral nutrition supplements (such as Ensure, Sustacal)
- 7 = needing tube feeding (such as a tube inserted into the throat, or, directly into the stomach)
- 8 = needing intravenous feeding
- 9 = Anything else?

SPECIFY OTHER SPECIAL FOOD, DIETARY NEEDS, OR NUTRITIONAL HELP: _____

- 1 = DK
- 2 = RE

<14b.> In the 12 months prior to [#fill HIS/HER] death from <MONTH AND YEAR PRIOR TO ENTRY IN Q.3a or Q.3b> to <ENTRY IN Q.3a or Q.3b>, did [#fill MR./MS.] [#fill DECEASED'S LAST NAME] receive any meal programs such as.....? [#SELECT ALL THAT APPLY]

- 1 = Meals on Wheels
- 2 = Homemaker Services
- 3 = Any other meal programs?

SPECIFY OTHER MEAL PROGRAM: _____

- 4 = NONE
- 1 = DK
- 2 = RE

<SECTION C: DEMOGRAPHIC INFORMATION>

Now I have some demographic questions about [#fill MR./MS.] [#fill DECEASED'S LAST NAME]. These questions are for statistical purposes only to help us analyze the results of the study.

<15.> At the time of [#fill HIS/HER] death, was [#fill MR./MS.] [#fill DECEASED'S LAST NAME].....?

- 1 = married
- 2 = widowed
- 3 = separated
- 4 = divorced
- 5 = never married
- 1 = DK
- 2 = RE

<16a.> In the year prior to [#fill HIS/HER] death, that is in [#fill YEAR PRIOR TO YEAR ENTRY IN Q.3a or Q.3b, i.e., 1995] was [#fill MR./MS.] [#fill DECEASED'S LAST NAME]'s [#fill and your/and [#fill HIS/HER] spouse's] annual income \$15,000 or more?

- 1 = YES [#GO TO 16c]
- 2 = NO [#GO TO 16b]
- 1 = DK [IF R SAYS, DK PROBE FOR BEST GUESS AND FILL IN APPROPRIATE
- 2 = RE [#GO TO 17a]

<16b.> Was it.....?

- 1 = under 3,000 [#GO TO 17a]
- 2 = between \$3,000 and \$4,999 [#GO TO 17a]
- 3 = between \$5,000 and \$5,999 [#GO TO 17a]
- 4 = between \$6,000 and \$9,999 [#GO TO 17a]
- 5 = between \$10,000 and \$14,999 [#GO TO 17a]
- 1 = DK [#GO TO 17a]
- 2 = RE [#GO TO 17a]

<16c.> Was it?

- 1 = between \$15,000 and \$24,999
- 2 = between \$25,000 and \$49,999
- 3 = between \$50,000 and \$59,999
- 4 = between \$60,000 and \$99,999
- 5 = \$100,000 and over
- 1 = DK
- 2 = RE

<17a.> Did [#fill MR./MS.] [#fill DECEASED'S LAST NAME] leave an estate?

- 1 = YES
- 2 = NO [#GO TO Q.19]
- 1= DK [#GO TO Q.19]
- 2 = RE [#GO TO Q.19]

<17b.> What was the value of the estate?

\$_____ [#GO TO 18a] [#CATI/CAPI fill in the commas]
[#UP TO 7 DIGITS]

- 1 = DK [#GO TO 17c]
- 2 = RE [#GO TO 18a]

<17c.> Do you know if it was.....?

- 1 = under \$50,000
- 2 = between \$50,000 and \$149,999
- 3 = between \$150,000 and \$599,999
- 4 = \$600,000 or more
- 1 = DK
- 2 = RE

<18a.> Did the beneficiaries of the estate include.....? [#SELECT ALL THAT APPLY]

[#IF Q.15 =1 or 3, ASK:]

1 = His/Her spouse

[#OTHERWISE, ASK:]

2 = His/Her child(ren)

3 = Other relatives

4 = Any nonrelatives

-1 = DK [#GO TO 19]

-2 = RE [#GO TO 19]

[#IF YES TO ANY OR ALL OF Q.18a, ASK:]

<18b.> What percentage of the estate did (the/each) beneficiary receive?

[#NOTE: SHOW TOTAL % FOR ALL CHILDREN, OTHER RELATIVES, AND OTHER NONRELATIVES; TOTAL SHOULD EQUAL 100%]

His/Her spouse	_____%
His/Her child(ren)	_____%
Other relatives	_____%
Any nonrelatives	_____%
TOTAL	<u>100</u> %

-1 = DK
-2 = RE

[#NOTE TO INTERVIEWERS: +10 OR -10% ACCEPTABLE IF R IS UNSURE OF EXACT PERCENTAGES.]

<19.> Those are all the questions I have.

Thank you for taking the time to answer these questions for this very important study.