

Appendix C: CATI Questionnaire

Intro

Hello. My name is _____ and I am an interviewer with Princeton Data Source. We are conducting a public opinion survey about important issues facing us today. We are not selling anything or raising money. The survey is completely confidential. (IF NEEDED REASSURE RESPONDENT: This research company will never try to sell you anything. IF ASK: The survey takes about 20 minutes.)

May I please speak to the person 18 years old or older in your household who had a birthday most recently? (IF NECESSARY ARRANGE FOR A CALL BACK AND RECORD DATE AND TIME. REPEAT INTRO. AS NECESSARY)

Screen

S1. In the last 12 months, have you or anyone in your household provided unpaid care to a relative or friend 18 years or older to help them take care of themselves? Unpaid care may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you. (IF YES: Is that you or someone else?)

IF R. IS UNSURE, RE-READ QUESTION.

IF R. ASKS "DOES GIVING MONEY COUNT?", ASK: Aside from giving money, do you provide any other type of unpaid care to help them take care of themselves, such as help with personal needs, household chores, arranging for outside services, or other things? IF NOTHING OTHER THAN \$, CODE "NO"

YES -- PERSON ON PHONE IS CAREGIVER

YES -- ANOTHER PERSON IN HOUSEHOLD

NO

DK (TERMINATE)

REF (TERMINATE)

S2. Just to be sure I speak to people of all ages, how old were you on your last birthday?

____ (GO TO S2b)

DK

REF

S2b. IF DK/REFUSE: Well are you between:

18-24

25-34

35-44

45-54

55-64

65-74, or

75 or older?

DK (TERMINATE)

REF (TERMINATE)

S3. Are you of Hispanic origin or background?

YES

NO

DK

REF

S4. Would you say you are white, black or African American, Asian or Pacific Islander, or something else?

WHITE

BLACK

ASIAN

OTHER (SPECIFY____)

DK (TERMINATE)

REF (TERMINATE)

S5. RECORD GENDER

MALE

FEMALE

S6. How many people including children live in the household?

1 -- LIVES ALONE (GO TO S13a)

DK (TERMINATE)

REF (TERMINATE)

S7. Are you the person in the household who owns or rents the residence? [WE WANT THE PERSON WHO PAYS THE MORTGAGE OR WHOSE NAME IS ON THE LEASE]

YES

NO (GO TO S9)

DK (TERMINATE)

REF (TERMINATE)

S8. IF HOUSEHOLDER: Are you related by marriage, blood, or adoption to anyone in the household?

YES (GO TO S13a)

NO (GO TO S13a)

DK (TERMINATE)

REF (TERMINATE)

S9. Thinking about the person who owns/rents the house, please tell me if that person is related to anyone in the household by marriage, blood, or adoption? [IF MORE THAN ONE PERSON OWNS/RENTS WE WANT THE PERSON WHO PAYS THE MORTGAGE OR WHOSE NAME IS ON THE LEASE]

YES

NO

DK (TERMINATE)

REF (TERMINATE)

S10. Thinking about the person who owns/rents the house, please tell me how old they are? PROMPT: Your best estimate is fine.

DK (TERMINATE)

REF (TERMINATE)

S11. As far as you know, is the person of Hispanic origin or background?

YES
NO
DK
REF

S12. Would you say they are white, black or African American, Asian or Pacific Islander, or something else?

WHITE
BLACK
ASIAN
OTHER (_____)
DK (TERMINATE)
REF (TERMINATE)

S13a.

- IF "NO" CAREGIVER IN S1: END INTERVIEW - TERMINATE AND THANK YOU.
- IF "INITIAL RESPONDENT CAREGIVER": GO TO Q1a.
- IF "INITIAL RESPONDENT NOT CAREGIVER, BUT CAREGIVER IN HH":

S13. May I please speak to the person in your household who is providing unpaid care to a relative or friend 18 years or older? **IF MORE THAN ONE CAREGIVER ASK TO SPEAK TO THE ONE WITH THE LAST BIRTHDAY.**

YES
NOT AVAILABLE (ARRANGE CALLBACK)
NO (CALL BACK TO CONVERT)
DK (CALL BACK TO CONVERT)
REF (CALL BACK TO CONVERT)

CAREGIVER ON PHONE:

S14. Hello. We are conducting a survey about caregiving, by which I mean providing unpaid care to a relative or friend 18 years or older to help them take care of themselves. Caregiving may include help with personal needs or household chores. It might be managing a person's finances, arranging for outside services, or visiting regularly to see how they are doing. This person need not live with you.

S15. Just to confirm, in the last 12 months, have you provided this kind of unpaid help to a relative or friend who is 18 years or older – or are doing so currently?

YES

NO (Is there someone else in the household who is a caregiver? IF YES: ASK TO SPEAK TO THE PERSON, THEN RETURN TO S14. OTHERWISE TERMINATE.)

DK (CALL BACK TO CONVERT)

REF (CALL BACK TO CONVERT)

S16. Just to be sure I speak to people of all ages, how old were you on your last birthday?

DK

REF

S16b. IF DK/REFUSE: Well are you between:

18-24

25-34

35-44

45-54

55-64

65-74, or

75 or older?

DK (TERMINATE)

REF (TERMINATE)

S17. Are you of Hispanic origin or background?

YES

NO

DK

REF

S18. Would you say you are white, black or African American, Asian or Pacific Islander, or something else?

WHITE

BLACK

ASIAN
OTHER (SPECIFY____)
DK (TERMINATE)
REF (TERMINATE)

S19. RECORD GENDER
GO TO Q1a.

ALL CAREGIVERS:

Characteristics of relationship

This survey is part of an important national study conducted by AARP and the National Alliance for Caregiving. We really appreciate your participation.

IF HELPFUL, INTERVIEWER MAY TELL RESPONDENT: This is a national survey, and although individual answers are confidential, the results from the overall survey will be published. If you'd like, we could send you a copy of the final report.

1a. Are you currently providing unpaid help to a relative or friend 18 years or older, or, was this something you did in the past 12 months but are no longer doing?

CURRENTLY
PAST 12 MONTHS
DK
REF

IF CURRENTLY: USE PRESENT TENSE, FIRST VERB IN [BRACKETS]
IF PAST 12 MONTHS: USE PAST TENSE, SECOND VERB IN [BRACKETS]

1. How many adults do you provide this care for? / did you provide this care for in the past 12 months?]

1

DK
REF

IF ONE PERSON: Now, I'd like to ask you some questions about the adult for whom you [provide/provided] care.

IF MORE THAN ONE: Let's focus on the adult for whom you [provide/provided] the most assistance.

Q1b. What [is/was] this person's relationship to you? PRE-CODED OPEN END

SPOUSE
MOTHER
FATHER
MOTHER-IN-LAW
FATHER-IN-LAW
SON
DAUGHTER
BROTHER
SISTER
BROTHER-IN-LAW
SISTER-IN-LAW
GRANDMOTHER
GRANDFATHER
GRANDPARENT-IN-LAW
AUNT/UNCLE
OTHER RELATIVE (SPECIFY _____)
FRIEND/NON-RELATIVE/NEIGHBOR
COMPANION/PARTNER
DK
REFUSE

Q1c. IF "SPOUSE," "AUNT/UNCLE," "GRANDPARENT IN-LAW": RECORD GENDER OF THE RESPONDENT'S (Q1B CODE):

MALE
FEMALE
DK

Q1d. IF "OTHER RELATIVE", "FRIEND", "COMPANION": Would you mind telling me if your (Q1B CODE) is male or female?

MALE
FEMALE
REF

2. [Is your (Q1B CODE) currently/Was your (Q1B CODE)] widowed, married, living with a partner, separated, divorced, or single – that is never been married?

WIDOWED
MARRIED
LIVING WITH A PARTNER
SEPARATED
DIVORCED
SINGLE
DK
REF

3. How old [is/was] your (Q1B CODE)? PROMPT: Your best estimate is fine.

DK
REF

4. [Does/Did] your (Q1B CODE) live....

In your household, (GO TO Q9)
Within twenty minutes of your home,
Between 20 minutes and an hour from your home,
A one to two hour drive from your home, or
More than two hours away?
DK (GO TO Q7)
REF (GO TO Q7)

5. IF NOT IN HOUSEHOLD: On average, how often [do/did] you visit your (Q1B CODE)? More than once a week, once a week, few times a month, once a month, few times a year, or less often?

MORE THAN ONCE A WEEK
ONCE A WEEK
FEW TIMES A MONTH
ONCE A MONTH
FEW TIMES A YEAR
LESS OFTEN
DK
REF

6. IF NOT IN HOUSEHOLD: [Does/Did] your (Q1B CODE) live in:

His or her own home,
Someone else's home,
An independent living or retirement community,
In an assisted living facility where some care may be provided,
A nursing home or facility, (GO TO Q8)
Or somewhere else? (SPECIFY _____)
DK
REF

7. [Does/Did] your (Q1B CODE) live: MULTIPLE PUNCH

Alone,
With her/his spouse,
With her/his grown children,
With other family members,
With friends,
With an aide, housekeeper, or other staff,
Or with someone else? (SPECIFY _____)
DK
REF

8. [Does/Did] your (Q1B CODE) live in an urban, suburban, or rural area?

URBAN
SUBURBAN
RURAL AREA
DK
REF

9. And do you live in an urban, suburban, or rural area?

URBAN
SUBURBAN
RURAL AREA
DK
REF

Characteristics of recipient

10. [Is/Was] your (Q1B CODE) frail, sick, disabled, or none of these? (ACCEPT MULTIPLE RESPONSES)

FRAIL
SICK
DISABLED
NONE OF THESE
DK
REF

11. What would you say [is/was] the main problem or illness your (Q1B CODE) [has/had]? PRECODED OPEN END: ACCEPT ONE ANSWER
IF "DISABLED", PROBE: What kind of disability would that be?

AIDS
ALZHEIMER'S/CONFUSION/DEMENTIA/FORGETFULNESS (GO TO Q13)
AMPUTEE
ARTHRITIS
BLINDNESS/VISION LOSS, CAN'T SEE WELL
BLOOD PRESSURE/HYPERTENSION
BOREDOM, NOTHING TO DO
BROKEN BONES
CANCER
DEAFNESS/HEARING LOSS
DIABETES
FEEBLE, UNSTEADY, FALLING
HEART DISEASE
LUNG DISEASE, EMPHYSEMA
MENTAL RETARDATION
MENTAL ILLNESS, EMOTIONAL ILLNESS, DEPRESSION
MOBILITY (CAN'T GET AROUND)
OLD AGE, JUST OLD
OSTEOPOROSIS
PARAPLEGIA
PARKINSON'S
SPEAKING, CAN'T SPEAK
STROKE
OTHER (SPECIFY____)

DK

REF

12. IF ALZHEIMER'S/CONFUSION/DEMENTIA NOT MENTIONED:
[Does/Did] your (Q1B CODE) suffer from Alzheimer's or other mental
confusion?

YES—ALZHEIMER'S

YES--OTHER

NO

DK

REF

13. For how long [have you been providing/did you provide] help to your (Q1B
CODE)? PROMPT: Your best estimate is fine. PRE-CODED OPEN END

_____ YEARS

SIX MONTHS TO ONE YEAR

LESS THAN SIX MONTHS

OCCASIONALLY, ON AND OFF

DK

REF

I'm going to read a list of kinds of help, which might be provided to a person, if
the person cannot do this by him or herself. For each, just tell me if you
[provide/provided] this kind of help. [Do/Did] you help your (Q1B CODE)...

YES

NO

DK

REF

14. Get in and out of beds and chairs

15. Get dressed

16. Get to and from the toilet

17. Bathe or shower

18. Dealing with incontinence or diapers

19. By feeding him or her

20. Giving medicines, pills, or injections

[Do/Did] you provide help for your (Q1B CODE) with:

YES

NO

DK
REF

- 21. Managing finances, such as paying bills, or filling out insurance claims
- 22. Grocery shopping
- 24. Housework, such as doing dishes, laundry, or straightening up
- 24b. Preparing meals
- 25. Transportation, either by driving him or her, or helping your (Q1B CODE) get transportation
- 26. Arranging or supervising services from an agency, such as nurses or aides

IF NO/DK/REF TO ALL Q14-Q26: TERMINATE (TREAT AS NON CAREGIVER HOUSEHOLD)

- 27. Thinking now of all the kinds of help you [provide/provided] for your (Q1B CODE), about how many hours [do/did] you spend in an average week, doing these things?

LESS THAN 1 HOUR PER WEEK
____ HOURS PER WEEK
CONSTANT CARE (VOLUNTEERED)
DK
REF

Medications

- 28. [Does/Did] your (Q1B CODE) take any prescription medicine?

YES
NO - SKIP TO 31
DK- SKIP TO 31
REF- SKIP TO 31

- 29. Would you say your (Q1B CODE) [needs/needed] someone to oversee giving him/her medicine in the right amount and on time, or that he/she [manages/had managed] this well on his/her own?

NEEDS HELP
MANAGES ON OWN
DK
REF

30. Do you feel you [know/knew] as much as you [need/needed] to about the prescription medicine your (Q1B CODE) [takes/took], or that you [need/needed] to know more about it?

KNOW AS MUCH AS NEED TO KNOW
NEEDED TO KNOW MORE ABOUT IT
DK
REF

Other caregiver support

31. Has anyone else provided unpaid help to your (Q1B CODE) during the last 12 months?

YES
NO -SKIP TO 34
DK - SKIP TO 34
REF - SKIP TO 34

32a. What relationship [are/were] they to your (Q1B CODE)? CODE UP TO TWO

IF "CHILDREN", PROBE: Would that be (Q1B CODE)'s son or daughter or both?
CODE IN TWO SEPARATE COLUMNS.

SPOUSE
MOTHER
FATHER
SON
DAUGHTER
FATHER-IN-LAW/MOTHER-IN-LAW
BROTHER
SISTER
BROTHER-IN-LAW/SISTER-IN-LAW
GRANDSON/GRANDDAUGHTER
OTHER RELATIVE
ALL FAMILY
NON RELATIVE/FRIEND/COMPANION/NEIGHBOR
VOLUNTEER (E.G., RED CROSS)
NIECE/NEPHEW
SON-IN-LAW/DAUGHTER-IN-LAW
OTHER (SPECIFY____)
NO ONE ELSE (GO TO Q34)

DK (GO TO Q33)
REF(GO TO Q33)

Q32b. Just to be sure I have this down correctly, that would be your (Q1B CODE)'s (Q32b CODE) who also [provides/provided] care?

YES
NO
DK
REF

33. Who would you consider to be the person who [provides/provided] *most* of the unpaid care for your (Q1B CODE): you yourself, or someone else?

SELF
SOMEONE ELSE
WE SPLIT IT 50-50 (VOLUNTEERED)
DK
REF

(IF NURSING HOME IN 6, SKIP TO Q39)

During the last 12 months, did your (Q1B CODE) receive paid help from any of the following - regardless of who paid for it. First"
REPEAT STEM AS NECESSARY

YES
NO
DK
REF

34. An aide or nurses hired through an agency or service?

35. An aide or nurse hired *independently*- that is not through an agency or service?

36. A housekeeper hired to clean or cook?

37. Any other people who are paid to help her/him?

38. (IF YES TO ANY IN Q34-37 ABOVE): Who would you say [provides/provided] more of your (Q1B CODE)'s care: you, other unpaid helpers, or paid helpers such as nurses or aides?

YOU (THE RESPONDENT)
OTHER UNPAID HELPERS
PAID HELPERS

DK
REF

Stress on working caregivers

39. Now I have a few questions about you. Are you currently:

Working full time, (GO TO 41 IF Q1a = 1, CURRENTLY)
Working part time, (GO TO 41 IF Q1a = 1, CURRENTLY)
A student,
Disabled,
Retired,
A homemaker,
Unemployed and looking for work, or
Something else (SPECIFY _____)
DK
REF

40. [Have you been employed at any time since you began helping your (Q1B CODE)? / Were you employed at any time while you were helping your (Q1B CODE)]?

YES
NO (SKIP TO 52)
DK (SKIP TO 52)
REF (SKIP TO 52)

In your experience as both a worker and a caregiver, did you ever:

YES
NO
DK
REF

- 41. Have to go in late, leave early, or take time off during the day to provide care
- 42. Have to take a leave of absence
- 43. Have to go from working full-time to part-time, or taken a less demanding job
- 44. Have to turn down a promotion
- 45. Lose any of your job benefits
- 46. Have to give up working entirely
- 47. Choose early retirement

Physical, emotional and financial stress of caregiving

52. ONLY ASK IF CARE RECIPIENT IS NOT R's SPOUSE IN Q1b

How much of your money would you estimate you [spend/spent] in a typical month for groceries, medicines, or other kinds of cash support for your (Q1B CODE)'s care, if any? PROBE: Your best estimate is fine.

_____ RECORD AMOUNT TO NEAREST DOLLAR

DK

REF

There may have been other ways in which providing care to your (Q1B CODE) has affected your life. As a caregiver,

YES

NO

DK

REF

53. [Do/Did] you have less time for friends or other family members than before?

54. [Do/Did] you have to give up vacations, hobbies, or your own social activities?

55. [Do/Did] you have to get less exercise than before?

56. Think of a scale from 1 to 5, where 1 is not a strain at all and 5 is very much of a strain. How much of a physical strain would you say that caring for your (Q1B CODE) [is/was] for you?

1 NOT AT ALL A STRAIN

2

3

4

5 VERY MUCH OF A STRAIN

DK

REF

57. Using the same scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how emotionally stressful would you say that caring for your (Q1B CODE) [is/was] for you?

- 1 NOT AT ALL STRESSFUL
- 2
- 3
- 4
- 5 VERY STRESSFUL
- DK
- REF

58. Using the same scale from 1 to 5, where 1 is no hardship at all and 5 is a great deal of hardship, how much of a financial hardship would you say that caring for your (Q1B CODE) [is/was] for you?

- 1 NO FINANCIAL HARDSHIP AT ALL
- 2
- 3
- 4
- 5 GREAT DEAL OF FINANCIAL HARDSHIP
- DK
- REF

59. We have been talking about the help you [provide/provided] for your (Q1B CODE). Do you feel you had a choice in taking on this responsibility for caring for your (Q1B CODE)?

- YES
- NO
- DK
- REF

I'm going to read a list of ways that caregivers such as yourself have coped with the demands of caregiving. For each one, please tell me whether you have used any of these. [Have/Did] you ever [tried/try] to cope with caregiving stress by:
READ LIST

- YES
- NO
- DK
- REF

- 60. talking with or seeking advice from friends or relatives?
- 61. exercising or working out?
- 62. taking any kind of medication?
- 63. talking to a professional or spiritual counselor?
- 65. praying?
- 66. going on the Internet to find information?
- 67. reading about caregiving in books or other materials?

IF YES IN 66. ASK 68-70:

Which of the following things have you looked for on the Internet?

YES
NO
DK
REF

- 68. Information about your (Q1B CODE)'s condition and treatment?
- 69. Information about services available for people like your (Q1B CODE)?
- 70. Support or advice from people with similar caregiving experiences?

Information/Services

In your experience as a caregiver, [have/did] you ever...

YES
NO
DK
REF

PLEASE PROGRAM SO THAT Q71 AND Q72 COME LAST IN THE SERIES

- 71. [Requested/Request] information about how to get financial help for your (Q1B CODE)?
- 72. [Taken/Take] part in support groups for caregivers?
- 73. [Used/Use] a respite (**RESS - PIT**) service to take care of your (Q1B CODE) to free up your time?
- 74. [Helped/Help] enroll your (Q1B CODE) in Adult Day Care?
- 75. [Helped/Help] enroll your (Q1B CODE) in a recreation program or camp?
- 77. [Had/Have] an outside service such as Meals on Wheels deliver meals to your (Q1B CODE)'s home?
- 78. [Had/Have] an outside service provide transportation for your (Q1B CODE) instead of you providing the transportation?

Have you done or obtained any of these types of things to make it easier to care for your (Q1B CODE):

YES
NO
DK
REF

79. Had modifications made in the house or apartment where your (Q1B CODE) [lives/lived] to make things easier for your (Q1B CODE)?

80. Obtained formal training of some sort about how to care for a person with your (Q1B CODE)'s needs?

81. Obtained a bathing bench, magnifying lens for reading, or other helpful devices for your (Q1B CODE)?

As a caregiver, on which of the following do you feel you [need/needed] more help or information:

YES
NO
DK
REF

82a. Keeping the person I care for safe at home

82b. Managing challenging behaviors, such as wandering

82c. Easy activities I can do with the person I care for

82d. Managing incontinence or toileting problems

82e. Moving or lifting the person I care for

82f. Balancing my work and family responsibilities

82g. Finding time for myself

82h. Choosing an assisted living facility

82i. Choosing a nursing home

82j. Choosing a home care agency

82k. How to talk with doctors and other healthcare professionals

82l. Managing my emotional and physical stress

82m. Making end-of-life decisions

82n. Finding non-English language educational materials

83. If you were looking for information about some aspect of helping take care of your (Q1B CODE), where would you turn? DO NOT READ CODES MULTIPLE PUNCH IF THEY VOLUNTEER MORE THAN ONE

DOCTOR
NURSE, OTHER HEALTH PROFESSIONALS
INTERNET
BOOKS, MAGAZINES, LIBRARY
EMPLOYER
SENIOR CITIZEN'S CENTER
OTHER (SPECIFY _____)
DK
REF

Demographics

And finally, just a few questions for classification purposes only....

87. How would you describe your own health? Is it excellent, very good, good, fair, or poor?

EXCELLENT
VERY GOOD
GOOD
FAIR
POOR
DK
REF

88. How would you say taking care of your (Q1B CODE) has affected your health? Has it made it better, not affected it, or made it worse?

MADE IT BETTER
NOT AFFECTED IT
MADE IT WORSE
DK
REF

89. Are you currently: READ LIST

Married,
Living with a partner,
Widowed,
Separated,
Divorced,
Single, that is never been married
DK
REF

91. Did you ever serve on active duty in the US Armed Forces? PROBE: Army,
Navy, Air Force, Marines, Coast Guard or Women's Armed Forces

YES
NO
DK
REF

92. Did your (Q1B CODE) serve in the US Armed Forces?

YES
NO
DK
REF

93. Are there any children or grandchildren living in your household under 18
years of age?

YES
NO
DK
REF

94. What is the last grade of school you completed?

LESS THAN HS
HS GRAD/GED
SOME COLLEGE
TECHNICAL SCHOOL
COLLEGE GRAD
GRADUATE SCHOOL/GRAD WORK
DK

REF

95. Last year, was your total annual household income from all sources, before taxes over or under \$50,000?

IF UNDER \$50,000:

Over or under 30,000?

OVER (GO TO 96)

UNDER

DK (GO TO 96)

REF(GO TO 96)

If UNDER \$30,000:

Over or under 15,000?

OVER (GO TO 96)

UNDER (GO TO 96)

DK (GO TO 96)

REF(GO TO 96)

IF OVER 50,000:

Over or under 100,000?

OVER (GO TO 96)

UNDER

DK (GO TO 96)

REF(GO TO 96)

IF UNDER 100,000:

Over or under 75,000?

OVER (GO TO 96)

UNDER (GO TO 96)

DK (GO TO 96)

REF(GO TO 96)

96. Besides the telephone number I reached you on, how many other telephone numbers in your house, if any, could I have reached you on? Don't include fax or modem lines or cell phones.

RECORD SINGLE DIGIT NUMBER

—

NONE

REF

If the situation arose, would you be interested in participating in future research on caregivers?

YES (RESPONDENT'S NAME _____, PHONE _____)

NO

Also, the results of this survey are totally confidential. However if a reporter writing a story about the results of the overall survey wanted to ask you more questions or get a quote from you for a news story, would you like to get a call back or not? It is completely optional.

YES

NO (THANK AND TERMINATE)

DK (THANK AND TERMINATE)

REF (THANK AND TERMINATE)

IF YES, ASK: Who should the reporter ask for? _____ What is the best number to reach you during the day on weekdays? (____) _____

Thank you very much for your time. Your responses have been very helpful to this research.