

Attachment 1: Questions to be cognitively tested

Form Approved
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Proposed Questions:

Q1. During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?

- 1) Yes
- 2) No
- 3) Caregiving recipient died in past 30 days
- 4) Don't know
- 5) Refused

Q2. Do you consider yourself a caregiver for a friend or family member?

- 1) Yes
- 2) No [end]
- 3) Caregiving recipient died in past 30 days [end]
- 4) Don't know [end]
- 5) Refused [end]

Q3. How many people with a health care problem or disability did you provide care for in the past 30 days?

- 1) 1
- 2) 2
- 3) 3
- 4) 4 or more

Q4. For the next few questions, please only think about the person you care for the most. What is their relationship to you? For example, is this person your mother or daughter or father or son?

- 1) Parent, stepparent, or parent-in-law
- 2) Grandparent, step grandparent or grandparent-in-law
- 3) Spouse or partner
- 4) Child or stepchild
- 5) Grandchild or step grandchild
- 6) Sibling, stepsibling, or sibling-in-law
- 7) Other relative
- 8) Friend or non-relative
- 9) Don't know
- 10) Refused

Q5. How old is that person?

- 1) Under 18 years of age
- 2) Aged 18-44 years
- 3) Aged 45-64 years
- 4) Aged 65 years or older
- 5) Don't know
- 6) Refused

Q6. What is the main health problem or disability that the person you care for has?

- 1) Alzheimer's disease, dementia or other cognitive impairment [skip to question 8]
- 2) Heart disease, hypertension, or stroke
- 3) Cancer
- 4) Diabetes
- 5) Injuries including broken bones or traumatic brain injury
- 6) Mental illness such as depression, anxiety, or schizophrenia
- 7) Developmental disorders such as autism, Down syndrome, or spina bifida
- 8) Respiratory conditions such as asthma, emphysema, or chronic obstructive pulmonary disease
- 9) Arthritis/rheumatism
- 10) Hearing or vision loss
- 11) Movement disorders such as Parkinson's, spinal cord injury, or multiple sclerosis
- 12) Old age, infirmity, or frailty
- 13) Other

Q7. Does the person you care for also have Alzheimer's disease, dementia or other cognitive impairment?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q8. In the past 30 days, did you provide care for this person by helping with nursing or medical tasks such as injections, wound care, or tube feedings?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q9. In the past 30 days, did you provide care for this person by managing personal care such as bathing, getting to the bathroom, or helping to eat?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q10. In the past 30 days, did you provide care for this person by managing household tasks such as help with transportation, shopping, or managing money?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q11. In the past 30 days, did you provide care for this person by coordinating their care such as scheduling appointments, dealing with insurance, or filling out paperwork?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q12. In the past 30 days, did you provide care for this person through mental health support, emotional support, or companionship?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q13. In an average week, how many hours do you provide regular care or assistance? Would you say...

- 1) Up to 19 hours per week
- 2) 20 to 39 hours per week
- 3) 40 hours or more per week

Q14. How long have you provided regular care to this person? Would you say...

- 1) Less than 30 days
- 2) 1 month to less than 2 years

- 3) 2 years to less than 5 years
- 4) More than 5 years

Q15. Does this person receive any additional unpaid or paid care besides routine medical care?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q16. Do you get paid to provide care for this person?

- 1) Yes
- 2) No [go to question 17]
- 3) Don't know [go to question 17]
- 4) Refused [go to question 17]

Q17. What is the main source from which you are paid?

- 1) I am paid by the person I care for or their family directly.
- 2) I am paid through a state or community agency like an Area Agency on Aging
- 3) I am paid through a health care system like the VA
- 4) I am paid through an insurance provider like Medicaid or a private insurance plan
- 5) Other (can we get text responses from cognitive interviews to help inform categories?)
- 6) Don't know
- 7) Refused

Q18. Various services or supports may be available to assist you in providing care. Which of the following services or supports do you currently use that is most important caring for this person?

- 1) Out of home services for the care recipient
- 2) In home services for the care recipient
- 3) Caregiver support groups
- 4) Food and nutrition service for care recipient
- 5) Transportation services for care recipient
- 6) Financial planning for care recipient
- 7) Caregiving/caregiver skills-based training (e.g., The Savvy Caregiver)
- 8) Other
- 9) I don't use any services
- 10) Don't know
- 11) Refused

Q19. Do you have friends or family that help you out?

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

4) Refused

Q20. Has being a caregiver created financial difficulty for you?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused

Q21. Has being a caregiver provided you personal fulfillment, purpose, or satisfaction?

- 1) Yes
- 2) No
- 3) Don't know
- 4) Refused