



(Affix Label Here)

Participant ID: _____

Participant Name Code: _____

Date Form Filled Out:

d d M M M y y y y
(e.g., 10JUN2005)

Interviewer Code:

Circle Field Center Location:

BU CU DK UP

Circle Visit: ¹Visit 1 ²Visit 1 Follow-Up ³Visit 2 ⁴Visit 2 (New Participant)

⁵Visit 2 Follow-Up ⁶Visit 3 ⁷Visit 3 (New Participant) ⁸Visit 3 Follow Up

Form Version Date: 22/11/2019

Dementia Questionnaire (Visit 3)

Note to Interviewer: This form can only be administered via DFR/Proxy. For the first year this form is administered, omit using the phrasing in brackets [i.e., since date of last interview].

Note to Interviewer: If this is a follow-up DQ, then add: 'We are interested in any changes in [participant's name]'s memory and daily functioning since [insert date of last interview].'

What is the individual's relationship to the Study Participant?

- 1Spouse
- 2Child (Daughter/Son)
- 3Sibling (Brother/Sister)
- 4Niece/Nephew
- 5Other: _____

MEMORY/COGNITION: [Since [date of last interview],] does [participant name] have any problems with the following in a way that interferes with daily living and is out of the ordinary for him/her?

1. Memory problem (get specific examples and record below)

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ___ ___ / ___ ___ ___ ___ **OR** Age of Onset: ___ ___ ___
(If "Don't Know" = D; "Refused" = R)

Check box if date/age of onset has been previously recorded

Participant ID: _____

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2. Confusion (examples).

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

Check box if date/age of onset has been previously recorded

3. Trouble remembering people's names.

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

Check box if date/age of onset has been previously recorded

4. Trouble recognizing family members.

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

Check box if date/age of onset has been previously recorded

5. Trouble finding way on familiar streets

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

Check box if date/age of onset has been previously recorded

Participant ID: _____

Participant Name Code: _____

6. Trouble finding way about indoors.

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

Check box if date/age of onset has been previously recorded

7. Remembering a short list of items.

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

Check box if date/age of onset has been previously recorded

Interviewer: If the participant has answered "Yes" to any of **Q1-7** above, continue with **Q8**; otherwise, please skip to **Q10**.

8. Did the trouble begin suddenly (OVERNIGHT) or slowly?

- 1 Suddenly
- 0 Slowly
- D Don't Know
- R Refused

Check box if **Q8** has been previously recorded

9. [Since [date of last interview],] have the memory problems changed over time?

- 0 No change
- 1 Yes, memory has improved
- 2 Yes, steady decline over time
- 3 Yes, sudden decline(s)
- D Don't Know
- R Refused

NOTES AND EXAMPLES: _____

Participant ID: _____

Participant Name Code: _____

EXPRESSION: [Since *[date of last interview]*,] does *[participant name]* have any problems with the following that seems to be out of the ordinary for him/her:

10. Ever have trouble finding the right word or expressing self?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____
(If "Don't Know" = D; "Refused" = R)

Check box if date/age of onset has been previously recorded

11. Talking less than *[he/she]* used to?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____
(If "Don't Know" = D; "Refused" = R)

Check box if date/age of onset has been previously recorded

12. Have a tendency to dwell in the past?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____
(If "Don't Know" = D; "Refused" = R)

Check box if date/age of onset has been previously recorded

DAILY FUNCTIONING: [Since *[date of last interview]*,] does *[participant name]* have any problems with the following:

Note to Interviewer: Indicate "Yes" for problems due to physical, sensory, and/or cognitive impairments.

13. Trouble with household tasks (examples)?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____
(If "Don't Know" = D; "Refused" = R)

Participant ID: _____

Participant Name Code: _____

14. Trouble handling money (examples)?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

15. Trouble grasping situations or explanations?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

16a. Does [he/she] work for pay?

- 1 Yes **Skip to Q16c**
- 0 No **Skip to Q16b**
- D Don't Know **Skip to Q16b**
- R Refused **Skip to Q16b**

16b. Is [he/she] retired?

Check box if retirement has been previously recorded and proceed to Q17

- 1 Yes
- 0 No **Skip to Q17**
- 2 Retired, then volunteered for ____ years **Skip to Q17**
- W Never Worked **Skip to Q17**
- D Don't Know **Skip to Q17**
- R Refused **Skip to Q17**

Age: ____ (Convert Age to Code Year) **OR** Year: ____ **Skip to Q17**

(If "Don't Know" = D; "Refused" = R)

16c. Does [he/she] have difficulty at work?

- 1 Yes
- 0 No/Not Applicable
- D Don't Know
- R Refused

Year of Onset: ____ (If "Don't Know" = D; "Refused" = R)

Participant ID: _____

Participant Name Code: _____

17. Trouble with dressing or self-care (examples)?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

18. Trouble feeding self?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

19. Trouble controlling bladder and bowels?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

20. Agitation and nervousness?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____

(If "Don't Know" = D; "Refused" = R)

NOTES AND EXAMPLES: _____

Interviewer note: Indicate cause of deficits in daily function.

- 1 Sensorimotor
- 2 Cognitive
- 3 Both
- 4 Other: _____
- D Unknown

Participant ID: _____

Participant Name Code: _____

RECOGNITION OF PROBLEM:

Interviewer Note: If the informant has answered "YES" to any of Q1-12 above, ask Q21-25b below. If the informant has answered "NO" to Q1-12 and answered "YES" to Q13-15, 16c--20 above not due solely to sensory or physical impairment, ask Q21-25b below; otherwise, skip to Q26a.

Check box if Recognition of Problem questions have been previously recorded and proceed to **Q26a**

21. Who was the first person to notice something wrong?

- 1 Self
- 2 Spouse
- 3 Sibling
- 4 Child
- 5 Home Attendant
- 6 Physician
- 7 Other: _____
- D Don't Know
- R Refused

22. What was noticed? _____

23. When was the last time [he/she] seemed to be really well, [his/her] old self?

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____
(If "Don't Know" = D; "Refused" = R)

24a. Did [participant name] see a doctor for any of these problems [since [date of last interview]]?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

24b. If "Yes", what cause was given? _____

Participant ID: _____

Participant Name Code: _____

25a. Did [*participant name*] see a Neurologist for any of these problems [since [*date of last interview*]]?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

25b. If "Yes", was the diagnosis Alzheimer's disease?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

STROKE: [Since [*date of the last interview*],] did [*participant name*] have:

26a. A Stroke?

- 1 Yes
- 0 No **Skip to Q27a**
- D Don't Know **Skip to Q27a**
- R Refused **Skip to Q27a**

Date of Onset: ___ ___ / ___ ___ ___ ___ **OR** Age of Onset: ___ ___ ___
(If "Don't Know" = D; "Refused" = R)

Interviewer: If "Yes", ask the following:

26b. More than one (1) stroke?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ___ ___ / ___ ___ ___ ___ **OR** Age of Onset: ___ ___ ___
(If "Don't Know" = D; "Refused" = R)

26c. One side of body suddenly weaker than other side; paralysis?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ___ ___ / ___ ___ ___ ___ **OR** Age of Onset: ___ ___ ___
(If "Don't Know" = D; "Refused" = R)

Participant ID: _____

Participant Name Code: _____

26d. Sudden loss of sensation on one side of body?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____
(If "Don't Know" = D; "Refused" = R)

26e. Change in speech with slurring?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Date of Onset: ____ / ____ / ____ **OR** Age of Onset: ____
(If "Don't Know" = D; "Refused" = R)

26f. Which symptom was most prominent?

- 1 Weakness/Paralysis
- 2 Loss of Sensation
- 3 Slurred Speech
- 4 Other: _____
- D Don't Know
- R Refused

26g. Did the symptoms persist longer than a day?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

26h. Did the symptoms:

- 1 Become Worse
- 2 Improve
- 0 Stay Stable Over Time
- D Don't Know
- R Refused

Participant ID: _____

Participant Name Code: _____

26i. Did a doctor give a diagnosis of stroke?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

26j. Did a doctor say it was a hemorrhage or bleeding inside the brain?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Interviewer Note: *If there is both stroke (Q26a=Yes) and memory loss (Any of Q1-12=Yes or any of Q13-15, 16c-20=Yes and is not due only to sensory or physical impairment), explain that they are both common conditions and elderly people can get both without being related, we need to find out if the memory loss preceded the stroke, was caused by the stroke, or just occurred by itself; otherwise, skip to Q27a.*

Check box if **Q26k** and **Q26l** have been previously recorded and proceed to **Q27a**

26k. Did the memory loss you described occur before or after the stroke?

- 1 Before **Skip to Q27a**
- 2 After **Skip to Q27a**
- D Don't Know **Skip to Q27a**
- R Refused **Skip to Q27a**

Interviewer: If the memory loss occurred **after** the stroke, ask the following:

26l. How long after the stroke did [*participant name*] begin to show memory loss or have other problems with daily functioning?

- 1 Within the first 3 months
- 2 Between 3 and 6 months
- 3 After 6 months
- D Don't Know
- R Refused

Participant ID: _____

Participant Name Code: _____

27a. [Since [*date of last interview*],] does [*participant name*] have a drinking problem or a history of alcoholism?

Note to Interviewer: If this is a follow-up DQ, omit "history of".

- 1 Yes
- 0 No **Skip to Q28**
- D Don't Know **Skip to Q28**
- R Refused **Skip to Q28**

27b. Was this problem diagnosed by a doctor?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

27c. Did memory problems accompany drinking problems?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

27d. When did the drinking problem begin?

Date of Onset: ____ ____ / ____ ____ ____ **OR** Age of Onset: ____ ____ ____
(If "Don't Know" = D; "Refused" = R)

27e. How long (in years) did this problem continue? ____ ____ Years (*Don't Know*=D; *Refused*=R)

27f. Ever receive treatment for the drinking problem?

- 1 Yes
- 0 No **Skip to Q28**
- D Don't Know **Skip to Q28**
- R Refused **Skip to Q28**

27g. If "Yes", what [*was/were*] the treatment(s) given?

27g.1. Counseling?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Participant ID: _____

Participant Name Code: _____

27g.2. Medication?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

27g.3. Hospitalization?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

DEPRESSION: [Since [date of the last interview],] does [participant name] have:

28. Depression (e.g. sad, withdrawn, less talkative, unable to sleep, frequent crying)?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

29. A change in personality?

- 1 Yes
- 0 No
- D Don't Know
- R Refused

OTHER INFORMATION:

30. Does [he/she] drive?

Check box if driving cessation has been previously recorded and proceed to Q36

- 1 Yes
- 0 No
- D Don't Know
- R Refused

Skip to Q33

Skip to Q33

Skip to Q33

Participant ID: _____

Participant Name Code: _____

31. Is [*he/she*] having any problems driving?

- 1 Yes
- 0 No **Skip to Q36**
- D Don't Know **Skip to Q36**
- R Refused **Skip to Q36**

32. What type of problems?

- 1 Gets Lost/Confused
- 2 Poor Eyesight
- 3 Illness
- 4 Bad Coordination; Bad Reaction Time; Bad Reflexes
- 5 Frequent Accidents
- 6 Fear/Nervous Driving
- 7 Other Cognitive Problems: _____
- 8 Other: _____
- D Don't Know
- R Refused

33. Did [*he/she*] stop driving?

- 1 Yes
- 0 No/Not Applicable (never drove) **Skip to Q36**
- D Don't Know **Skip to Q36**
- R Refused **Skip to Q36**

34. Why did [*he/she*] stop driving?

- 1 Gets Lost/Confused
- 2 Poor Eyesight
- 3 Illness
- 4 Bad Coordination; Bad Reaction Time; Bad Reflexes
- 5 Frequent Accidents
- 6 Fear/Nervous Driving
- 7 Other Cognitive Problems: _____
- 8 Other: _____
- D Don't Know
- R Refused

35. When did [*he/she*] stop driving?

Month: ____ Year: ____ **OR** Age: ____

Participant ID: _____

Participant Name Code: _____

36. How often do you have contact with *[him/her]*?

- 1 Live Together
- 2 Daily
- 3 3 or More Times per Week
- 4 Less than 3 times per Week
- D Don't Know
- R Refused

Skip to Q38 (have REDCap code Q37 as 1)

37. Most frequent type of contact?

- 1 Mostly In-Person
- 2 Mostly Phone
- 3 Both
- 4 Other
- D Don't Know
- R Refused

Interviewer Note: Please answer the following question based on your judgment of the DFR's responses to this questionnaire.

38. On the whole, how reliable do you think the DFR's responses were to this interview?

- 1 Very Reliable
- 2 Fairly Reliable
- 3 Not Very Reliable
- D Don't Know

THANK YOU VERY MUCH!!