Dataset name: dmqu_v1.0

Participant ID pid D000000

Acrostic acrostic ZZZZZ

Interviewer compby

V.C. vc YYY

End Date vis_dat

Dementia Questionnaire (DQ)

CRF 1.0

PROXY INFORMATION		
	Proxy's Name:	proxy_name_dmqu
	Proxy Seems Reliable:	reliable_dmqu -9 1 Yes 2 No 3 DK/NR 4 NA
	Relationship to participant:	relationship_dmqu -9 1 Spouse 2 Son/Daughter 3 Son/Daughter-in-law 4 Sister/Brother 5 Neighbor/Friend 6 Paid Caregiver 7 Other
1.	How long have you known her/him?	howlong_dmqu -9 1 Less than a year 2 1-4 years 3 5-14 years 4 15 or more years 5 DK/NR
2.	How often did/do you have contact with her/him?	howoften_dmqu -9 1 Live together 2 Daily 3 3 or more times a week 4 Less than 3 times a week 5 DK/NR
3.	Most frequent type of contact?	frequent_dmqu -9 1 Mostly in-person 2 Mostly phone 3 Both 4 Other (specify)

		5 DK/NR Other: frequent_other_dmqu
I. MEMORY/ COGNITION		
4.	Memory	memory_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year memory_yr_dmqu
5.	Remembering people's names	names_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year names_yr_dmqu
6.	Recognizing familiar faces	faces_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year faces_yr_dmqu
7.	Finding way about indoors	indoors_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year indorrs_yr_dmqu
8.	Finding way on familiar streets	streets_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year streets_yr_dmqu
9.	Remembering a short list of items	shortlist_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year shortlist_yr_dmqu
10.	Trouble finding the right word or expressing self	exp_word_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year exp_word_yr_dmqu

11.	Trouble grasping situations or explanations	grasping_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year grasping_yr_dmqu
12.	Talking less over time	talkless_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year talkless_yr_dmqu
13.	Tendency to dwell in the past	past_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year **past_yr_dmqu**
II. ONSET AND COURSE		
14.	Did these problems begin suddenly or slowly	suddenly_dmqu -9 1 Suddenly 2 Slowly 3 DK/NR
15.	Have these problems stayed the same, been steadily getting worse, or have there been abrupt declines	steadily_dmqu -9 1 No Decline 2 Abrupt Decline 3 Steady downhill Progression 4 Got Better 5 Steady then abrupt 6 Fluctuations 7 Stepwise decline 8 DK/NR 9 NA
16.	Is a doctor aware of these problems	doc_aware_dmqu -9 1 Yes (go to Q17) 2 No (go to section III) 3 DK/NR (go to section III)
17.	What does the doctor believe is causing the problems	cause_dmqu -9 1 Alzheimer's Disease 2 Dementia 3 Confusion 4 Depression 5 Nothing wrong 6 Parkinson's Disease 7 Stroke 8 DK/NR 9 Other 10 Old age

		Other: cause_other_dmqu
18.	Name and address of first doctor seen for memory problems:	Name: doc_dmqu doc_address_dmqu
19.	Did (s)he receive medications for memory problems	meds_dmqu -9 1 Yes 2 No 3 DK/NR 4 NA
III. RECOGNITION OF PROBLEM		
20.	What was noticed (the first 3 symptoms noticed)	a. noticed_a_dmqu Year noticed_a_yr_dmqu
		b. noticed_b_dmqu Year noticed_b_yr_dmqu
		c. noticed_c_dmqu Year noticed_c_yr_dmqu
21.	When was the last time she/he seemed to be really well or her/his old self	Year lasttime_yr_dmqu
IV. CAREGIVING		
22.	Is an in-home paid caregiver ever utilized (full or part-time)	caregiver_dmqu -9 1 Yes (year) 2 No (go to Q23) 3 DK/NR (go to Q23) 4 NA Year caregiver_yr_dmqu
a)	How long was the caregiver utilized (in months)	Months caregiver_mnth_dmqu
b)	Why was caregiver utilized	caregiver_why_dmqu -9 1 Physical problems 2 Cognitive problems 3 Physical > cognitive 4 Cogntivie > physical 5 Other 6 DK/NR

		Other: caregiver_why_other_dmqu
23.	Did (s)he ever move in with relatives	relatives_dmqu -9 1 Yes (year) 2 No (go to Q24) 3 DK/NR (go to Q24) 4 NA Year relatives_yr_dmqu
a)	How long did (s)he live with relatives (in months)	Months relatives_mnth_dmqu
b)	Why did (s)he move in with relatives	relatives_why_dmqu -9 1 Physical problems 2 Cognitive problems 3 Physical > cognitive 4 Cogntivie > physical 5 Other 6 DK/NR Other: relatives_why_other_dmqu
24.	Did (s)he ever reside in assisted living and/or board & care home	assisted_dmqu -9 1 Yes (year) 2 No (go to Q25) 3 DK/NR (go to Q25) 4 NA Year assisted_yr_dmqu
a)	How long did (s)he reside in assisted living/board & care (in months)	Months assisted_mnth_dmqu
b)	Why did (s)he move to assisted living and/or board & care home	assisted_why_dmqu -9 1 Physical problems 2 Cognitive problems 3 Physical > cognitive 4 Cogntivie > physical 5 Other 6 DK/NR Other: assisted_why_other_dmqu
25.	Did (s)he ever reside in a nursing home	nursing_dmqu -9 1 Yes (year) 2 No (go to Q26) 3 DK/NR (go to Q26)

		4 NA Year nursing_yr_dmqu
a)	How long did (s)he reside in a nursing home (in months)	Months nursing_mnth_dmqu
b)	Why did (s)he move to a nursing	nursing_why_dmqu -9 1 Physical problems 2 Cognitive problems 3 Physical > cognitive 4 Cogntivie > physical 5 Other 6 DK/NR Other: nursing_why_other_dmqu
V. DAILY FUNCTIONING		
	Did (s)he ever have:	
26.	Trouble with household tasks: using microwave, light cleaning i.e. putting items away	tasks_dmqu -9 1 Yes, some trouble 2 Yes, needs help (year) 3 No 8 DK/NR Year tasks_yr_dmqu
27.	Trouble handling money: paying bills, making change, writing checks, balancing check book, taxes, investments	money_dmqu -9 1 Yes, some trouble 2 Yes, needs help (year) 3 No 8 DK/NR Year money_yr_dmqu
28.	Trouble dressing: choosing or changing clothes, tying shoes, using fasteners	dressing_dmqu -9 1 Yes, some trouble 2 Yes, needs help (year) 3 No 8 DK/NR Year dressing_yr_dmqu
29.	Trouble feeding self: using cups or utensils, cutting meat, buttering bread	feeding_dmqu -9 1 Yes, some trouble 2 Yes, needs help (year) 3 No 8 DK/NR Year feeding_yr_dmqu
30.	Trouble bathing: knowing what to do in the shower or tub,	bathing_dmqu -9 1 Yes, some trouble 2 Yes, needs help (year) 3 No

	knowing how to wash	8 DK/NR Year bathing_yr_dmqu
31.	Trouble controlling bladder or bowels	bladder_dmqu -9 1 Yes, some trouble 2 Yes, needs help (year) 3 No 8 DK/NR Year bladder_yr_dmqu
32.	Trouble remembering to take medications	take_meds_dmqu -9 1 Yes, some trouble 2 Yes, needs help (year) 3 No 8 DK/NR 9 NA Year take_meds_yr_dmqu
33.	Did (s)he ever drive	drive_dmqu -9 1 Yes 2 No (go to Q34) 8 DK/NR (go to Q34)
a)	Did (s)he ever stop driving	drive_stop_dmqu -9 1 Yes (year) 2 No (go to Q33c) 3 DK/NR Year drive_stop_yr_dmqu
b)	Why did (s)he stop driving	drive_stop_why_dmqu -9 1 Get lost/confused 2 Poor eyesight 3 Illness 4 Poor coordination/rsn. time/bad reflexes 5 Accidents 6 Fear/nervous driving 7 Other cognitive problems/ NOC 8 Other 9 DK/NR
c)	Is (did)(s)he having (have) any problems	drive_problems_dmqu -9 1 Yes (go to Q33d) 2 No 8 DK/NR

d)	What type of problems	drive_problems_type_dmqu -9 1 Get lost/confused 2 Poor eyesight 3 Illness 4 Poor coordination/rsn. time/bad reflexes 5 Accidents 6 Fear/nervous driving 7 Other cognitive problems/ NOC 8 Other 9 DK/NR
VI. MEDICAL PROBLEMS		
	Did (s)he ever have:	
34.	High blood pressure	highbp_dmqu -9 1 Yes (year) 2 No 3 DK/NR Year highbp_yr_dmqu
35.	Stroke (symptoms unresolved or >24 hrs)	stroke_dmqu -9 1 Yes (year) 2 No 3 DK/NR Year stroke_yr_dmqu
36.	TIA (symptoms resolved ≤ 24 hrs)	tia_dmqu -9 1 Yes (year) 2 No 3 DK/NR Year tia_yr_dmqu
37.	Is the one side of the body weaker than the other side	one_side_dmqu -9 1 Yes (year & why) 2 No 3 DK/NR Year one_side_yr_dmqu Why: one_side_why_dmqu
38.	Parkinson's disease (resting, tremor, shuffling gait, limb rigidity)	parkinsons_dmqu -9 1 Yes (year) 2 No 3 DK/NR Year parkinsons_yr_dmqu
39.	Epileptic seizures or fits	seizure_dmqu -9 1 Yes (year) 2 No 3 DK/NR Year seizure_yr_dmqu
40.	Drinking problem	drinking_dmqu -9 1 Yes

		2 No (go to Q41) 3 DK/NR (go to Q41)
a)	Does (s)he have memory/thinking problems that could be due to drinking	drinking_mem_dmqu -9 1 Yes 2 No 3 DK/NR
41.	Ever depressed or sad for two weeks or more	depressed_dmqu -9 1 Yes (year) 2 No (go to Q42) 3 DK/NR (go to Q42) Year depressed_yr_dmqu
a)	Ever seek treatment	dep_treat_dmqu -9 1 Yes 2 No 3 DK/NR
42.	Hallucinations (see or hear things/people not there)	hallucinations_dmqu -9 1 Yes (year) 2 No 3 DK/NR Year hallucinations_yr_dmqu
43.	Delusions (false beliefs, people stealing, wanting to harm, cheating)	delusions_dmqu -9 1 Yes (year) 2 No 3 DK/NR Year delusions_yr_dmqu
44.	Agitation and nervousness	agitation_dmqu -9 1 Yes (year) 2 No 3 DK/NR Year agitation_yr_dmqu
45.	Ever seek psychiatric help for any reason	psych_dmqu -9 1 Yes, (go to 45a) 2 No (go to Q46) 3 DK/NR (go to Q46)
a)	Ever hospitalized for psychiatric illness	psych_hosp_dmqu -9 1 Yes (year & where) 2 No 3 DK/NR Year psych_hosp_yr_dmqu Where: psych_hosp_where_dmqu

46.	Did (s)he ever have a neurological or psychiatric exam	psych_exam_dmqu -9 1 Yes (year, where & why) 2 No 3 DK/NR Date psych_exam_dt_dmqu Where: psych_exam_where_dmqu Why: psych_exam_why_dmqu
47.	Did (s)he ever have a CT scan or MRI of the head	ct_mri_dmqu -9 1 Yes (year, where & why) 2 No 3 DK/NR Date ct_mri_yr_dmqu Where: ct_mri_where_dmqu Why: ct_mri_why_dmqu

Source Form Language: lang

-9 -
1 English
2 Spanish

Participant ID (affix ID label here)	**L I F E** Acrostic ☐☐☐☐☐ Interviewer ☐☐☐☐☐ Visit Code ☐☐☐ Date of Visit ☐☐ ☐☐ ☐☐☐☐ month day year

Dementia Questionnaire

If answer is shaded, do not data enter

Proxy's Name:	_____		
Proxy Seems Reliable:	☐ Yes ☐ No		
Relationship to participant	☐ Spouse ☐ Son/Daughter ☐ Son/Daughter-in-law ☐ Sister/Brother ☐ Neighbor/Friend ☐ Paid Caregiver ☐ Other		
1) How long have you known her/him?	☐ Less than a year ☐ 1-4 years ☐ 5-14 years ☐ 15 or more years ☐ Don't Know/No Response		
2) How often did/do you have contact with her/him?	☐ Live together ☐ Daily ☐ 3 or more times a week ☐ Less than 3 times a week ☐ DK/NR		
3) Most frequent type of contact?	☐ Mostly in-person ☐ Mostly phone ☐ Both ☐ Other _____ ☐ DK/NR		
I.Memory/ Cognition	**If yes, complete year or check DK yr.**		
Does (did) (s)he have any problems with:	**Yes**	**No**	**DK/NR**
4) Memory	☐ → ☐☐☐☐ yyyy ☐ DK yr	☐	☐
5) Remembering people's names	☐ → ☐☐☐☐ yyyy ☐ DK yr	☐	☐
6) Recognizing familiar faces	☐ → ☐☐☐☐ yyyy ☐ DK yr	☐	☐

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	Yes	No	DK/NR
7) Finding way about indoors	☐ → ☐☐☐☐ yyyy ☐ DK yr	☐	☐
8) Finding way on familiar streets	☐ → ☐☐☐☐ yyyy ☐ DK yr	☐	☐
9) Remembering a short list of items	☐ → ☐☐☐☐ yyyy ☐ DK yr	☐	☐
10) Trouble finding the right word or expressing self	☐ → ☐☐☐☐ yyyy ☐ DK yr	☐	☐
11) Trouble grasping situations or explanations	☐ → ☐☐☐☐ yyyy ☐ DK yr	☐	☐
12) Talking less over time	☐ → ☐☐☐☐ yyyy ☐ DK yr	☐	☐
13) Tendency to dwell in the past	☐ → ☐☐☐☐ yyyy ☐ DK yr	☐	☐

Participant ID (affix ID label here)	***L I F E***	Acrostic ☐☐☐☐☐ Visit Code ☐☐☐

II. **Onset and Course**: Ask questions in this section <u>ONLY</u> if subject has/had cognitive problems i.e., responded 'YES' to any Question 4-13. Otherwise, skip to Section IV.	
"You mentioned (s)he has/ had problems with _____" (refer to Questions 4-13)	
14) Did these problems begin suddenly or slowly	☐ Suddenly ☐ Slowly ☐ DK/NR
15) Have these problems stayed the same, been steadily getting worse, or have there been abrupt declines	☐ No Decline ☐ Abrupt Decline ☐ Steady Downhill progression ☐ Got better ☐ Steady then abrupt ☐ Fluctuations ☐ Stepwise decline ☐ DK/NR
16) Is a doctor aware of these problems	☐ Yes, go to Q17 ☐ No, go to Section III ☐ DK/NR, go to Section III
17) What does the doctor believe is causing the problems	☐ Alzheimer's Disease ☐ Dementia ☐ Confusion ☐ Depression ☐ Nothing Wrong ☐ Parkinson's Disease ☐ Stroke ☐ DK/ NR ☐ Other _____ ☐ Old Age
18) Name and address of first doctor seen for memory problems:	_____ _____
19) Did (s)he receive medications for memory problems	☐ Yes ☐ No ☐ DK/NR

Participant ID (affix ID label here)	**L I F E**	Acrostic ☐☐☐☐☐ Visit Code ☐☐☐

III. Recognition of Problem: Ask questions in this section ONLY if subject has cognitive problems, i.e. said 'YES' to any Question 4-13. Otherwise skip to Section IV.	
20) What was first noticed (the first 3 symptoms noticed) 01 Forgets dates/to do things 02 Forgets names/people/faces 03 Forgets to eat/has eaten 04 Forgets things told 05 Forgets where things are/were put 06 Unspecified/other forgetfulness 07 Problems with job 08 Problems driving 09 Problems with money/banking 10 Confusion 11 Gets lost/disoriented 12 No interest in hobbies/usual activites 13 Less active 14 Seems different/not (her)himself 15 Can't use familar equipment/ appliances 16 Other 88 DK/DR	20a ☐☐ ☐☐☐☐ DK y y y y yr 20b ☐☐ ☐☐☐☐ DK y y y y yr 20c ☐☐ ☐☐☐☐ DK y y y y yr

	Year	DK/NR	No memory Problems
21) When was the last time she/he seemed to be really well or her/his old self?	☐☐☐☐	☐	☐

IV. Caregiving (Ask as open ended question, interviewer puts the story together)	
22) Is an in-home paid caregiver ever utilized (full or part- time)	22 ☐ Yes, year ☐☐☐☐ ☐ DK yr ☐ No, go to Q23 ☐ DK/NR, go to Q23
22a) How long was the caregiver utilized (in months)	22a months ☐☐☐
22b) Why was caregiver utilized	22b ☐ Physical problems ☐ Cognitive problems ☐ Physical > cognitive ☐ Cognitive> physical ☐ Other _____ ☐ DK/NR

23) Did (s)he ever move in with relatives	23 ☐ Yes, year ☐☐☐☐ ☐ DK yr ☐ No, go to Q24 ☐ DK/NR, go to Q24
23a) How long did (s)he live with relatives (in months)	23a months ☐☐☐
23b) Why did (s)he move in with relatives	23b ☐ Physical problems ☐ Cognitive problems ☐ Physical > cognitive ☐ Cognitive > physical ☐ Other _____ ☐ DK/NR
24) Did (s)he ever reside in assisted living and/or board & care home	24 ☐ Yes, year ☐☐☐☐ ☐ DK yr ☐ No, go to Q25 ☐ DK/NR, go to Q25
24a) How long did (s)he reside in assisted living/board & care (in months)	24a months ☐☐☐
24b) Why did (s)he move to assisted living and/or board & care home	24b ☐ Physical problems ☐ Cognitive problems ☐ Physical > cognitive ☐ Cognitive > physical ☐ Other _____ ☐ DK/NR
25) Did (s)he ever reside in a nursing home	25 ☐ Yes, year ☐☐☐☐ ☐ DK yr ☐ No, go to Q26 ☐ DK/NR, go to Q26
25a) How long did (s)he reside in a nursing home (in months)	25a months ☐☐☐
25b) Why did (s)he move to a nursing home (mark most prominent)	25b ☐ Physical problems ☐ Cognitive problems ☐ Physical > cognitive ☐ Cognitive > physical ☐ Other _____ ☐ DK/NR

Participant ID (affix ID label here)	***L I F E***	Acrostic ☐☐☐☐☐ Visit Code ☐☐☐

V. Daily Functioning (Mark as Yes only if trouble due to **COGNITIVE** problems)
Use the following interpretation for the codes
1= independent but more difficult or problems noticed
2= need prompting, supervision, assistance, or dependent
3= no problems or never did but could

Did (s)he ever have:	
26) Trouble with household tasks: using microwave, light cleaning i.e. putting items away	☐ 1-Yes, some trouble ☐ 2-Yes, needs help, year ☐☐☐☐ ☐ DK yr ☐ 3-No ☐ 8-DK/NR
27) Trouble handling money: paying bills, making change, writing checks, balancing check book, taxes, investments	☐ 1-Yes, some trouble ☐ 2-Yes, needs help, year ☐☐☐☐ ☐ DK yr ☐ 3-No ☐ 8-DK/NR
28) Trouble dressing: choosing or changing clothes, tying shoes, using fasteners	☐ 1-Yes, some trouble ☐ 2-Yes, needs help, year ☐☐☐☐ ☐ DK yr ☐ 3-No ☐ 8-DK/NR
29) Trouble feeding self: using cups or utensils, cutting meat, buttering bread	☐ 1-Yes, some trouble ☐ 2-Yes, needs help, year ☐☐☐☐ ☐ DK yr ☐ 3-No ☐ 8-DK/NR
30) Trouble bathing: knowing what to do in the shower or tub, knowing how to wash	☐ 1-Yes, some trouble ☐ 2-Yes, needs help, year ☐☐☐☐ ☐ DK yr ☐ 3-No ☐ 8-DK/NR
31) Trouble controlling bladder or bowels	☐ 1-Yes, some trouble (rare accidents) ☐ 2-Yes, needs help (frequent accidents, needs reminding, wears pads), year ☐☐☐☐ ☐ DK yr ☐ 3-No ☐ 8-DK/NR

32) Trouble remembering to take medications	☐ 1-Yes, some trouble ☐ 2-Yes, needs help, year ☐☐☐☐ ☐ DK yr ☐ 3-No ☐ 8-DK/NR ☐ 9-NA
33) Did (s)he ever drive	☐ Yes ☐ No, go to Q34 ☐ DK/NR, go to Q34
33a) Did (s)he ever stop driving	33a ☐ Yes, year ☐☐☐☐ ☐ DK yr ☐ No, go to 33c ☐ DK/NR
33b) Why did (s)he stop driving	33b ☐ Gets lost/ confused ☐ Poor eyesight ☐ Illness ☐ Poor coordination/rxn. time/ bad reflexes ☐ Accidents ☐ Fear/nervous driving ☐ Other cognitive problems/ Not Otherwise Classified ☐ Other ☐ DK/NR
33c) Is (did)(s)he having (have) any problems	33c ☐ Yes ☐ No ☐ DK/NR
33d) What type of problems	33d ☐ Gets lost/ confused ☐ Poor eyesight ☐ Illness ☐ Poor coordination/ rxn. time/ bad reflexes ☐ Accidents ☐ Fear/ nervous driving ☐ Other cognitive problems NOC ☐ Other ☐ DK/NR

Participant ID (affix ID label here)	**L I F E**	Acrostic ☐☐☐☐☐ Visit Code ☐☐☐

VI. Medical Problems- Did (s)he ever have:	Yes	No	DK/NR
34) High blood pressure	☐ ↓ ☐☐☐☐ (y y y y) ☐ DK year	☐	☐
35) Stroke (symptoms unresolved or >24 hrs)	☐ ↓ ☐☐☐☐ (y y y y) ☐ DK year	☐	☐
36) TIA (symptoms resolved ≤ 24 hrs)	☐ ↓ ☐☐☐☐ (y y y y) ☐ DK year	☐	☐

37) Is the one side of the body weaker than the other side	☐ Yes, year ☐☐☐☐ Why? _____ ☐ No ☐ DK/NR
38) Parkinson's disease (resting, tremor, shuffling gait, limb rigidity)	☐ Yes, year ☐☐☐☐ ☐ No ☐ DK/NR
39) Epileptic seizures or fits	☐ Yes, year ☐☐☐☐ ☐ No ☐ DK/NR
40) Drinking problem	40 ☐ Yes ☐ No, go to Q41 ☐ DK/NR, go to Q41
40a) Does (s)he have memory/thinking problems that could be due to drinking	40a ☐ Yes ☐ No ☐ DK/NR

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41) Ever depressed or sad for two weeks or more	41 ☐ Yes, year ☐☐☐☐ ☐ No, go to Q42 ☐ DK/NR, go to Q42
41a) Ever seek treatment	41a ☐ Yes ☐ No ☐ DK/NR
42) Hallucinations (see or hear things/people not there)	☐ Yes, year ☐☐☐☐ ☐ No ☐ DK/NR
43) Delusions (false beliefs, people stealing, wanting to harm, cheating)	☐ Yes, year ☐☐☐☐ ☐ No ☐ DK/NR
44) Agitation and nervousness	☐ Yes, year ☐☐☐☐ ☐ No ☐ DK/NR
45) Ever seek psychiatric help for any reason	45 ☐ Yes, go to 45a ☐ No, go to Q46 ☐ DK/DR, go to Q46
45a) Ever hospitalized for psychiatric illness	45a ☐ Yes, year ☐☐☐☐ Where _____ ☐ No ☐ DK/NR
46) Did (s)he ever have a neurological or psychiatric exam	☐ Yes Date _____ Where _____ Why _____ ☐ No ☐ DK/NR

47) Did (s)he ever have a CT scan or MRI of the head	☐ Yes Date _____ Where _____ Why _____ ☐ No ☐ DK/NR
Ask about any additional medical conditions not yet discussed. If answered YES to any Q45-47 mention to proxy that we may want to obtain medical records, then fax a medical records request.	