Dataset name: dmqu_v1.0

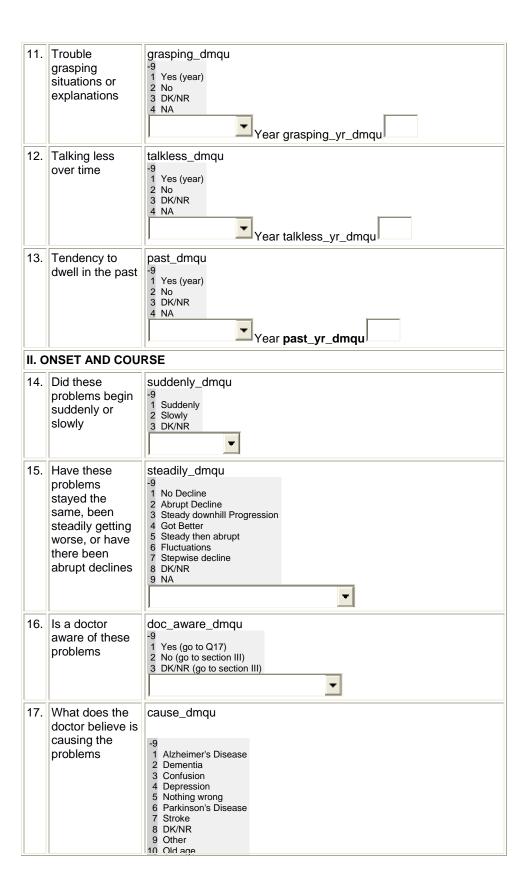


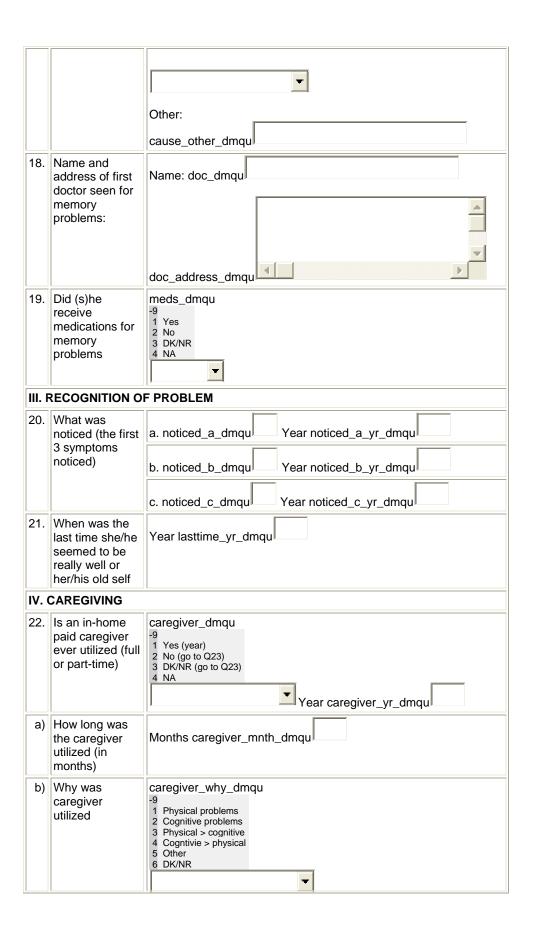
Dementia Questionnaire (DQ)

CRF 1.0

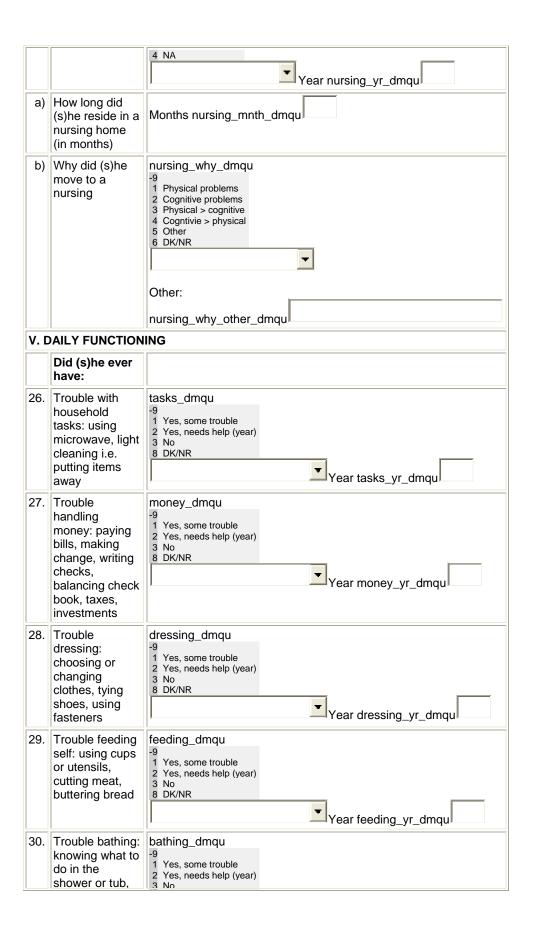
PR	OXY INFORMATION	N		
	Proxy's Name:	proxy_name_dmqu		
	Proxy Seems Reliable:	reliable_dmqu -9 1 Yes 2 No 3 DK/NR 4 NA		
	Relationship to participant:	relationship_dmqu -9 1 Spouse 2 Son/Daughter 3 Son/Daughter-in-law 4 Sister/Brother 5 Neighbor/Friend 6 Paid Caregiver 7 Other		
1.	How long have you 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)		

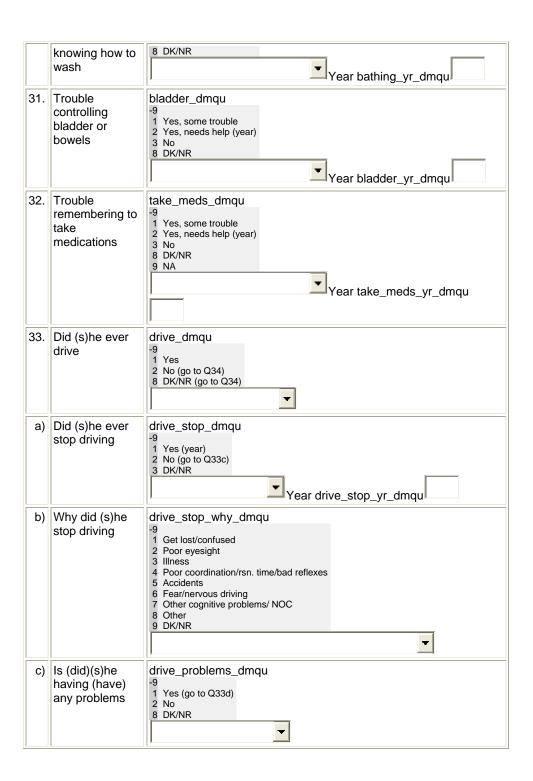
		5 DK/NR
		—
		Other:
		frequent_other_dmqu
	EMORY/ COGNIT	
4.	Memory	memory_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year memory_yr_dmqu
5.	Remembering people's names	names_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 NA Year names_yr_dmqu
6.	Recognizing familiar faces	faces_dmqu -9 1 Yes (year) 2 No 3 DK/NR 4 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

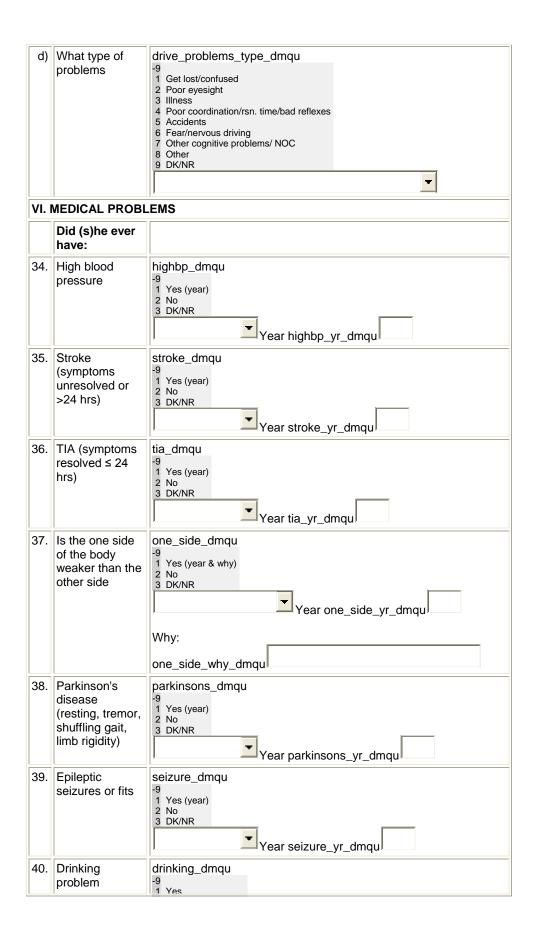


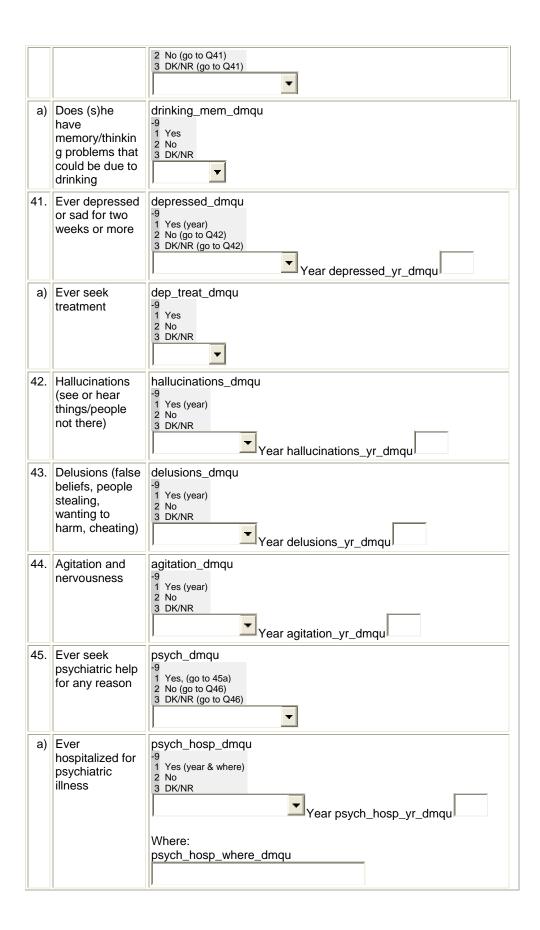


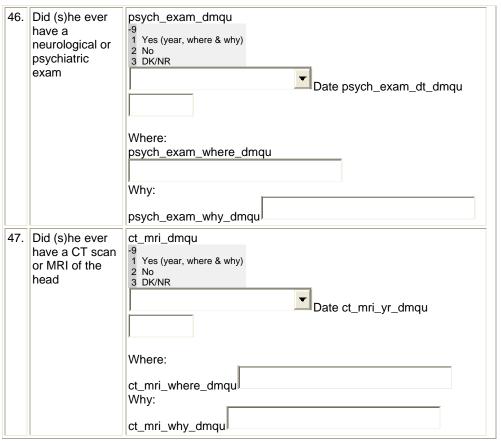
		Other: caregiver_why_other_dmqu
23.	Did (s)he ever move in with relatives	relatives_dmqu -9 1 Yes (year) 2 No (go to Q24) 3 DK/NR (go to Q24) 4 NA Year relatives_yr_dmqu
a)	How long did (s)he live with relatives (in months)	Months relatives_mnth_dmqu
b)	Why did (s)he move in with relatives	relatives_why_dmqu -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 (no to Q26)



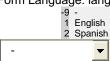








Source Form Language: lang



	LIFE	Acrostic			
Participant ID (affix ID label here)	Interviewer Date of Visit	month day	Visit Code	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 ☐ Live together □ Daily her/him? ☐ 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 If yes, complete year or check DK yr. I.Memory/ Cognition Does (did) (s)he have any problems with: Yes DK/NR No 4) Memory DK yr 5) Remembering people's names DK yr 6) Recognizing familiar faces DK

	LIFE		Acrostic		
Participant ID			Visi		
(affix ID label here)			Cod	ie	
		Ye	es	No	DK/NR
7) Finding way about indoors		—			
	у	y y y	DK yr		
8) Finding way on familiar streets		—			
	y	y y y	DK yr		
Remembering a short list of items					
	y	y y y	DK yr		
 Trouble finding the right word or expressing self 					
	y	y y y	DK yr		
11) Trouble grasping situations or explanations		\Box			
	y	y y y	DK yr		
12) Talking less over time					
	y	у у у	DK yr		
13) Tendency to dwell in the past					
			DK yr		

Participant ID (affix ID label here)	LIFE	Acrostic Visit Code	
	1		
II. Onset and Course: Ask questions in the subject has/had cognitive problems i.e., rough Question 4-13. Otherwise, skip to Section "You mentioned (s)he has/ had problem (refer to Questions 4-13)	esponded 'YES' to any n IV. ems with"	Cuddonly	
14) Did these problems begin sudden	☐ Suddenly☐ Slowly☐ DK/NR		
15) Have these problems stayed the s getting worse, or have there been		□ No Decline □ Abrupt Decline □ Steady Downh progression □ Got better □ Steady then at □ Fluctuations □ Stepwise decli □ DK/NR	orupt
16) Is a doctor aware of these probler	ns	☐ Yes, go to Q17☐ No, go to Section III	
17) What does the doctor believe is c	ausing the problems	Alzheimer's Di Dementia Confusion Depression Nothing Wrong Parkinson's Di Stroke DK/ NR Other Old Age	3
18) Name and address of first doctor problems:	seen for memory		
19) Did (s)he receive medications for	memory problems	☐ Yes ☐ No ☐ DK/NR	

Participant ID (affix ID label here)	FE 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
21) When was the last time she/he seemed to be really well or her/his old self?	Year DK/NR No memory Problems
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

Participant ID (affix ID label here)	FE Acrostic Visit Code
23) Did (s)he ever move in with relatives	23 Yes, year 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 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 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) V. Daily Functioning (Mark as Yes only		OGNITI	Acrostic Visit Code VE problems)
Use the following interpretation for the co 1= independent but more difficult 2= need prompting, supervision, a 3= no problems or never did but of Did (s)he ever have:	or problems notice assistance, or depe		
26) Trouble with household tasks: using light cleaning i.e. putting items aw	•		1-Yes, some trouble 2-Yes, needs help, year DK yr 3-No 8-DK/NR
27) Trouble handling money: paying be change, writing checks, balancing taxes, investments			1-Yes, some trouble 2-Yes, needs help, year DK yr 3-No 8-DK/NR
28) Trouble dressing: choosing or chatying shoes, using fasteners	anging clothes,		1-Yes, some trouble 2-Yes, needs help, year DK yr 3-No 8-DK/NR
29) Trouble feeding self: using cups o cutting meat, buttering bread	r utensils,		1-Yes, some trouble 2-Yes, needs help, year DK yr 3-No 8-DK/NR
30) Trouble bathing: knowing what to or tub, knowing how to wash	do in the shower		1-Yes, some trouble 2-Yes, needs help, year DK yr 3-No 8-DK/NR
31) Trouble controlling bladder or bow	/els		1-Yes, some trouble (rare accidents) 2-Yes, needs help (frequent accidents, needs reminding, wears pads), year DK yr 3-No

		LIFE	Acrostic
	Participant ID		Visit
	(affix ID label here)		Code L
3	32) Trouble remembering to take med	dications	1-Yes, some trouble 2-Yes, needs help, year DK yr 3-No 8-DK/NR 9-NA
3	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 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) a	ny problems	33c
	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 DK/NR

1	LIF	E		Acrostic		
Participant ID				Vis	it 🗀	
(affix ID label here)				Co		
VI. Medical Problems- Did (s)he ever	have:		Υ	es	No	DK/NR
34) High blood pressure						
			VV	DK year		
35) Stroke (symptoms unresolved or >	24 hrs)		7 /	,		
		l i		DK		
			$\overline{}$	year		
36) TIA (symptoms resolved ≤ 24 hrs)			7	•		
		IT		DK		
			уГу	year		
37) Is the one side of the body weaker	than the	other		Yes, year		
side						
				Why?		
				No		
38) Parkinson's disease (resting, tremo	or chuffl	ina aait		DK/NR Yes, year		
limb rigidity)	Ji, Silulli	ing gait,		Tes, year		
3 7/						
				No		
39) Epileptic seizures or fits				DK/NR		
39) Epileptic seizures of his				Yes, year		
				No		
40) Drinking problem			40	DK/NR		
40) Drinking problem			40	Yes		
				No, go to Q	41	
				DK/NR, go	to Q41	
40a) Does (s)he have memory/thin	kina nro	hleme	40a			
that could be due to drinking	iking pro	DICITIO	40a	Yes		
3				No		
				DK/NR		

	LIFE	A	Acrostic
Participant ID			Visit
(affix ID label here)			Code
(4)			
		T	
41) Ever depressed or sad for two we	eks or more	41 	∕es, year
			 No, go to Q42
			DK/NR, go to Q42
41a) Ever seek treatment		41a	
1.0, 2.0. 0000 000			⁄es
			No DK/NR
42) Hallucinations (see or hear things	/people not		∕es, year
there)			
			No
42) Dolusiano (falso baliato magnio at	taalina wantina		OK/NR
43) Delusions (false beliefs, people stoto harm, cheating)	tealing, wanting		∕es, year □
ζ,			
			No DK/NR
44) Agitation and nervousness			res, year
			No
45) Ever seek psychiatric help for any	, roason	45	DK/NR
40) Ever seek psychiatric help for any	1643011		∕es, go to 45a
			No, go to Q46 DK/DR, go to Q46
			DIVDIX, go to Q+0
45a) Ever hospitalized for psychia	atric illness	45a □	∕es, year
			C3, year
		\//ho	ro
		Whe	No
46) Did (a)ba ayar baya a nauralarias	al or povobiatria		OK/NR
46) Did (s)he ever have a neurologica exam	a or psychiatric		∕es ⊃ate
			Where
			Vhy No
		1 n	NK/NR

Participant ID (affix ID label here)	LIFE	Acrostic	Visit Code
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 conditional discussed. If answered YES to any Q45-47 mention may want to obtain medical records, ther records request.	to proxy that we		