

10/66 Dementia Research Group

LIFE2YEARS

January 2017 (VERSION 3.0)

INFORMANT INTERVIEW (Data Coding Sheet)

IDENTIFICATION

date Interview dd/mm/yy _____
interid ID Interviewer _____ [1-2 digits]
houseno Household No. _____ [1-5 digits]
particno Participant No. _____ [1 digit]

MODULE I - BACKGROUND MODULE

carerage _____ (B1.1)
carersex _____ (B1.2) - Female(1) Male(2)
carerrel _____ (B1.3) - 1 2 3 4 5 6 7 8
carelive _____ (B1.4) - No(0) Yes(1)
caremar _____ (B1.5) - Never(1) Married(2) Divorced(3) Widowed(4)
careeduc _____ (B1.6) - 1 2 3 4 5

INFORMANT EMPLOYMENT AND INCOME

cjob _____ (B1.8.1) - 1 2 3 4 5 6 - XXX - IF not employed (3-6), SKIP to B1.8.3.
cjobcat _____ (B1.8.2) - 1 2 3 4 5 6 7 8 9, unknown(99)

B1.8.3 Benefit type Monthly income
MV=9 MV=999999

cbntype1 _____ cben1 _____ (1-6 digits)
cbntype2 _____ cben2 _____ (1-6 digits)
cbntype3 _____ cben3 _____ (1-6 digits)
cbntype4 _____ cben4 _____ (1-6 digits)

TIME SPENT WITH THE OLDER PERSON

7AM-12PM	12PM-5PM	5PM-10PM	10PM-7AM
Morning	Afternoon	Evening	Night

B1.9.1 YESTERDAY

am1 _____	pm1 _____	eve1 _____	nite1 _____
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B1.9.2 DAY BEFORE

YESTERDAY

am2 _____	pm2 _____	eve2 _____	nite2 _____
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SELF-REPORTING QUESTIONNAIRE (SRQ)

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srq1 ☐ (B1.10.1) - No(0) Yes(1)
 srq2 ☐ (B1.10.2) - 0 1
 srq3 ☐ (B1.10.3) - 0 1
 srq4 ☐ (B1.10.4) - 0 1
 srq5 ☐ (B1.10.5) - 0 1
 srq6 ☐ (B1.10.6) - 0 1
 srq7 ☐ (B1.10.7) - 0 1
 srq8 ☐ (B1.10.8) - 0 1
 srq9 ☐ (B1.10.9) - 0 1
 srq10 ☐ (B1.10.10) - 0 1
 srq11 ☐ (B1.10.11) - 0 1
 srq12 ☐ (B1.10.12) - 0 1
 srq13 ☐ (B1.10.13) - 0 1
 srq14 ☐ (B1.10.14) - 0 1
 srq15 ☐ (B1.10.15) - 0 1
 srq16 ☐ (B1.10.16) - 0 1
 srq17 ☐ (B1.10.17) - 0 1
 srq18 ☐ (B1.10.18) - 0 1
 srq19 ☐ (B1.10.19) - 0 1
 srq20 ☐ (B1.10.20) - 0 1

MODULE II - CARE MODULE

CARE ARRANGEMENTS

careneed ☐ (C1.1) 1 2 3 - XXX - If 3 then skip to MODULE III

carewho1 ☐ (C1.2) 1 2 3 4

carewho2 ☐ (C1.3) 1 2 3 4

cutback ☐ (C1.4) - XXX - If 2 (yes, cut down) - SKIP to C1.6
 - XXX - If 3 (No) - SKIP to C1.7

cutwhen ☐ (C1.5) - months

cuthour ☐ (C1.6) - hours

carehelp ☐ (C1.7) - No(0) Yes(1) - XXX - If no, SKIP to C1.12

helphour ☐ (C1.8) - hours

helpcut ☐ (C1.9) - No(0) Yes(1) - XXX - If no, SKIP to C1.12

helpweek ☐ (C1.10) - weeks

helpjob ☐ (C1.11) - 1 2 3 4 5 6 7 8 9, unknown(99)

daypaid ☐ (C1.12) - None(1) Occasional(2) Regular(3) Constant(4)

ntpaid ☐ (C1.13) - None(1) Sleep-in(2) Waking(3)

17. CARE INPUTS

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cashrs1 communicate - Hours (C2.1) - unknown(99)
 cashrs2 transport (C2.2) - 0 1 2 3
 cashrs3 dressing (C2.3) - 0 1 2 3
 cashrs4 eating (C2.4) - 0 1 2 3
 cashrs5 appearance (C2.5) - 0 1 2 3
 cashrs6 supervise - Hours (C2.6) - unknown(99)
 cashrs7 toileting (C2.7) - 0 1 2 3
 cashrs8 bathing (C2.8) - 0 1 2 3

18. ZARIT CAREGIVER BURDEN INTERVIEW

zb1 (C3.1) - Never(0) Rarely(1) Sometimes(2) Q. frequently(3) Nearly always(4)
 zb2 (C3.2) - 0 1 2 3 4
 zb3 (C3.3) - 0 1 2 3 4
 zb4 (C3.4) - 0 1 2 3 4
 zb5 (C3.5) - 0 1 2 3 4

 zb6 (C3.6) - 0 1 2 3 4
 zb7 (C3.7) - 0 1 2 3 4
 zb8 (C3.8) - 0 1 2 3 4
 zb9 (C3.9) - 0 1 2 3 4
 zb10 (C3.10) - 0 1 2 3 4

 zb11 (C3.11) - 0 1 2 3 4
 zb12 (C3.12) - 0 1 2 3 4
 zb13 (C3.13) - 0 1 2 3 4
 zb14 (C3.14) - 0 1 2 3 4
 zb15 (C3.15) - 0 1 2 3 4

 zb16 (C3.16) - 0 1 2 3 4
 zb17 (C3.17) - 0 1 2 3 4
 zb18 (C3.18) - 0 1 2 3 4
 zb19 (C3.19) - 0 1 2 3 4
 zb20 (C3.20) - 0 1 2 3 4

 zb21 (C3.21) - 0 1 2 3 4
 zb22 (C3.22) - Not at all(0) A little(1) Fairly(2) Quite a bit(3) Very(4)

MODULE III - INFORMANT MODULE

COGNITIVE AND FUNCTIONAL IMPAIRMENT

activ	I.CSID.1	<input type="checkbox"/>	- no change(0) dimunition/reduced abilty(1)
mental	I.CSID.2	<input type="checkbox"/>	- no change(0) general decline(1)
memory	I.CSID.3	<input type="checkbox"/>	- no(0) yes(1)
put	I.CSID.4	<input type="checkbox"/>	- no(0) yes, sometimes(1) yes, regularly(2)
kept	I.CSID.5	<input type="checkbox"/>	- 0 1 2
frdname	I.CSID.6	<input type="checkbox"/>	- 0 1 2
famname	I.CSID.7	<input type="checkbox"/>	- 0 1 2
convers	I.CSID.8	<input type="checkbox"/>	- 0 1 2
wordfind	I.CSID.9	<input type="checkbox"/>	- 0 1 2
wordwrg	I.CSID.10	<input type="checkbox"/>	- 0 1 2
past	I.CSID.11	<input type="checkbox"/>	- 0 1 2
lastsee	I.CSID.12	<input type="checkbox"/>	- no(0) yes, sometimes(1) yes, regularly(2)
lastday	I.CSID.13	<input type="checkbox"/>	- 0 1 2
orient	I.CSID.14	<input type="checkbox"/>	- 0 1 2
lostout	I.CSID.15	<input type="checkbox"/>	- 0 1 2
lostin	I.CSID.16	<input type="checkbox"/>	- 0 1 2
chores	I.CSID.17	<input type="checkbox"/>	- 0 1 2
choredis	I.CSID.17a	<input type="checkbox"/>	- Not due to disability(0) Due to disability(1)
hobby	I.CSID.18	<input type="checkbox"/>	- no(0) yes(1)
money	I.CSID.19	<input type="checkbox"/>	- no difficulty(0) some(1) cannot handle money(2)
change	I.CSID.20	<input type="checkbox"/>	- no(0) yes, sometimes(1) yes, regularly(2)
reason	I.CSID.21	<input type="checkbox"/>	- no(0) yes(1)
feed	I.CSID.22a	<input type="checkbox"/>	- eats cleanly(0) messily(1) simple solids(2) fed(3)
feeddis	I.CSID.22b	<input type="checkbox"/>	- Not due to disability(0) Due to disability(1)
dress	I.CSID.23a	<input type="checkbox"/>	- dresses self(0) misplaces(1) forgets(2) Unable(3)
dressdis	I.CSID.23b	<input type="checkbox"/>	- Not due to disability(0) Due to disability(1)
toilet	I.CSID.24a	<input type="checkbox"/>	- no(0) occasionally(1) frequently(2) incontinence(3)
toildis	I.CSID.24b	<input type="checkbox"/>	- Not due to disability(0) Due to disability(1)
mistake	I.CSID.25	<input type="checkbox"/>	- no(0) yes(1)
decide	I.CSID.26	<input type="checkbox"/>	- no(0) yes(1)
muddled	I.CSID.27	<input type="checkbox"/>	- no(0) yes(1)

ENDIF I.CSID.28 ☐ - no(0) yes(1)

- XXX - If total score is 2 or less, SKIP to NEUROPSYCHIATRIC INVENTORY (NPI-Q)

- XXX - If total score is 3 or more, proceed to HISTORY AND AETIOLOGY SCHEDULE

HISTORY AND AETIOLOGY SCHEDULE - DEMENTIA DIAGNOSIS AND SUBTYPE

TIMEONS I.HAS1 ☐ - months, unknown(999)

HELP A.1 ☐ - no(0) yes(1) - XXX - If No, SKIP to I.HAS2

HELPTIME A.1.1 ☐ - months, unknown(99)

ADVICE A.1.2 ☐ - no(0) yes(1) - XXX - If No, SKIP to A.1.4

ADVHELP A.1.3 ☐ - not at all(0) slightly(1) very helpful(2)

MED A.1.4 ☐ - no(0) yes(1) - XXX - If No, SKIP to I.HAS2

MEDHELP A.1.5 ☐ - not at all(0) slightly(1) very helpful(2)

typeons I.HAS2 ☐ - rapid 1-3 days(1) rapid >3 days(2) gradual(3)

ONS1 I.HAS3.1 ☐ - no(0) yes(1)

ONS11 I.HAS.3.11 ☐ - 0 1

ONS13 I.HAS.3.13 ☐ - 0 1

ONS14 I.HAS.3.14 ☐ - 0 1

ONS16 I.HAS.3.16 ☐ - 0 1

ONS22 I.HAS.3.22 ☐ - deterioration(1) improvement(2) no change(3)

COURSE OF ILLNESS

FLUCT I.HAS.4 ☐ - fluctuate(1) No(0) - XXX - If No, SKIP to I.HAS.6

FLUCTCOG I.HAS.5.1 ☐ - return to normal (1) No(0) - XXX - If No, SKIP to I.HAS.6

GRADDEC I.HAS.6 ☐ - no(0) yes(1)

STEPWISE I.HAS.7.1 ☐ - no(0) yes(1) - XXX - If No, SKIP to I.HAS.10

OTHER MENTAL PHENOMENA - DELIRIUM

CLOUDING I.HAS.10 ☐ - no(0) yes(1)

CONFNITE I.HAS.11 ☐ - no(0) yes(1)

CONFDAY I.HAS.12 ☐ - XXX - If No for I.HAS.10, I.HAS.11, I.HAS.12, SKIP to I.HAS.14

NOCTURN I.HAS.13 ☐ - no(0) yes(1)

BEHAVIOURAL AND PERCEPTUAL DISTURBANCE

BCHANGE I.HAS.14.1 ☐ - no(0) yes(1)

BIRRIT I.HAS.15 ☐ - no(0) yes(1)

BUPSET I.HAS.17 ☐ - no(0) yes(1) - XXX - If 0 (No), SKIP to I.HAS.47

BFIRST I.HAS.18 ☐ - only recently(0) One of the first things noticed(1)

OTHER FACTORS FOR SECONDARY DEMENTIA

HI I.HAS.47 ☐ - no(0) probably(1) definitely(2)

HILL I.HAS.48 ☐ - XXX - If 0 (No) for I.HAS.47 and I.HAS.48, SKIP to I.HAS.52

LOC I.HAS.49 ☐ - no(0) few mins to an hour(1) longer than an hour(2)

BEHCHANG I.HAS.50 ☐ - permanent change(1) no change(0)

INTERVIEWER OBSERVATION

EARLYCHG I.HAS.52 ☐ - no(0) yes(1)

NEUROPSYCHIATRIC INVENTORY (NPI-Q)

NPI1	delusions	<input type="checkbox"/>	- no(0) yes(1) - XXX - If No, SKIP to NPI2
	NPI1SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI1DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI2	hallucinate	<input type="checkbox"/>	- no(0) yes(1) - XXX - If No, SKIP to NPI3
	NPI2SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI2DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI3	agitated	<input type="checkbox"/>	- XXX - If No, SKIP to NPI4
	NPI3SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI3DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI4	dep	<input type="checkbox"/>	- XXX - If No, SKIP to NPI5
	NPI4SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI4DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI5	anxiety	<input type="checkbox"/>	- no(0) yes(1) - XXX - If No, SKIP to NPI6
	NPI5SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI5DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI6	euphoria	<input type="checkbox"/>	- XXX - If No, SKIP to NPI7
	NPI6SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI6DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI7	apathy	<input type="checkbox"/>	- XXX - If No, SKIP to NPI8
	NPI7SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI7DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI8	disinhibited	<input type="checkbox"/>	- XXX - If No, SKIP to NPI9
	NPI8SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI8DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI9	irritable	<input type="checkbox"/>	- XXX - If No, SKIP to NPI10
	NPI9SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI9DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI10	motor	<input type="checkbox"/>	- XXX - If No, SKIP to NPI11
	NPI10SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI10DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI11	nighttime	<input type="checkbox"/>	- XXX - If No, SKIP to NPI12
	NPI11SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI11DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)
NPI12	appetite	<input type="checkbox"/>	- XXX - If No, SKIP to Q.0
	NPI12SEV	<input type="checkbox"/>	- mild(1) moderate(2) severe(3)
	NPI12DIS	<input type="checkbox"/>	- none (0) minimal(1) mild(2) mod(3) sev(4) extreme(5)

NPIHELP Q.0 ☐ - no(0) yes(1) - XXX - If No, SKIP to Q.7.21
NPITIME Q.1 ☐ - month, unknown(999)
NPIADV Q.2 ☐ - no(0) yes(1) - XXX - If No, SKIP to Q.4
NPIAHLQ Q.3 ☐ - not at all(0) slightly(1) very helpful(2)
NPIMED Q.4 ☐ - no(0) yes(1) - XXX - If No, SKIP to I.HAS.54
NPIMHLQ Q.5 ☐ - not at all(0) slightly(1) very helpful(2)

iptoldd Q.7.21 ☐ - no(0) yes(1) - XXX - If No, SKIP to I.HAS.54
ipdyear Q.7.21.1 ☐ - 0-5yrs(1) 5-10yrs(2) 10yrs or more(3)
ipdmed1 Q.7.21.2 ☐ - no(0) yes(1) - XXX - If No, SKIP to I.HAS.54
ipdmed2 Q.7.21.3 ☐ - AChE(1) Antipsychotic(2) Benzo(3)

HASCONF I.HAS.54 ☐ - 0 1 2 3 4