Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA)

Wave 4 Questionnaire: Confidential

W	4				

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Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

IDS-TILDA

Working to Make Ireland the Best Place to Grow Old

Table of Contents

1. INTSTATUSW4 = 1 Existing PARTICIPANTS
2. INTSTATUSW4 =2 NEW PARTICIPANTS

ASK ALL PARTICIPANTS.

Demographics			
CS_IWER_4	**Interviewer Number**	**IDS_i for i = 1-3ii**	**Interviewer number IDS3ii**
CS_IWERName_4	**Interviewer Name Display FFIWERName and give option to confirm Yes (1) correct No (0) incorrect**	**Text Box**	**Interviewer name**
CS_IWERName1_4	**If no, ask to verify correct interviewer number**		
CS_Resp_4	**Respondant ID**	**W3XYZ**	
CS_Rname_4	**Display FFName and give option to confirm Yes (1) correct No (0) incorrect If no ask to verify respondant ID number is correct**		

Ask existing participants only. If INTSTATUSW4 = 1 Ask CS_AddressConf_3. If INTSTATUSW4 = 2 go to CS_ToR _B_4			
CS_AddressConf_4	Feedforward address from wave 3 and give option to confirm Yes (1) No (0) If no enter in correct Address	In month year of last interview, you lived at this address. Is that correct address for you at wave 3 (at that time)? Yes 1 No (0) if no enter in correct address at time of last interview	
CS_Address_4	If no enter in correct address for participant at wave 3.		
CS_TypeConf_4	Feedforward type of residence from wave 3 and give option to confirm Yes (1) No (0)	In month year of last interview, you lived at this type of residence Yes 1 No (0) if no enter in correct type of residence at time of last interview	
CS_ToR_4	If no enter in correct Type of residence		
CS_GenderConf_4ph_	Display Gender fed forward and give option to confirm Yes (1) correct No (0) incorrect		
CS_Gender_4	If no enter in correct gender		
CS_DOBConf_4	Display (DOB) DDMMYYYY fed forward and give option to confirm Yes (1) No (0) incorrect		
CS_DOB_4	If no enter in correct (DOB) DDMMYYYY		
CS_LOID_4	If MissingID = 1 then ask		

	What is your level of intellectual disability? Please tick one box only Not verified (1) Mild (2) Moderate (3) Severe (4) Profound (5) Don't know (98)		

CS_Marital Status_4	Are you…? Single (1) Living with a partner as if married (2) With a partner but not living with him/her (3) Married (4) Separated (5) Divorced (6) Widowed (7) Unclear response (97) Don't know (98) Refused to answer (99)		Go to CS_1_4

If INTSTATUSW4 = 2 ask CS_ToR_1B_4. Others go to CS_1_4

CS_ToR_1B_4

How many years have you lived in your current residence?

CS_ToR_2B_4

Which type of residence do you live in at the current time?

IWER: Select one only

Family/Independent (Drop Down Menu)	
At home with both parents	1
At home with one parent	2
At home with Sibling	3
At home with other relative	4
Foster care and boarding-out arrangements	5
Living independently	6
Living semi-independently	7
Home Sharing / Shared living	22
Community (Drop Down Menu)	
5-day community group home – (Dispersed setting)	8
5-day community group home – (Clustered setting)	20
7-day community group home – (Dispersed setting)	9
7-day community group home – (clustered setting)	10

Residential (Drop Down Menu)	
7-day residential setting	14
5-day residential setting (home at weekends)	12
Nursing home	15
Mental health community residence	16
Psychiatric hospital	17
Intensive placement (challenging behaviour)	18
Intensive placement (profound or multiple disability)	19
Different unit in same residence i.e. moved residence within the campus setting	21
OTHER (please specify, e.g. hostel) CS_ToR_Oth_4_New	95

Unclear response	97
Don't know	98
Refused to answer	99

CS_ToR_3B_4

If years < 3 years, ask what type of residence did you live in beforehand?

IWER: Select one only

Family/Independent (Drop Down Menu)	
At home with both parents	1
At home with one parent	2
At home with Sibling	3
At home with other relative	4
Foster care and boarding-out arrangements	5
Living independently	6
Living semi-independently	7
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Intensive placement (profound or multiple disability)	19
Different unit in same residence i.e. moved residence within the campus setting	21

OTHER (please specify, e.g. hostel) CS_ToR_Oth_4_New	95

Unclear response	97
Don't know	98
Refused to answer	99

1 Section 1: Cover screen & Demographics (CS)

IWER: Thank you for taking part in this fourth wave of the IDS-TILDA study. As you know, this study is interested in learning about the health and well-being of people aged 40 and over. This interview is completely voluntary and private. If we should come to any question you do not want to answer, just let me know and I will go on to the next question. The answers that you give will be kept private and will be used only for research purposes.

IWER: Verbal consent should be negotiated throughout the interview process.

PAT01:

IWER: Designate type of Interview for all participants

1. Self Respondent / Self Respondent with Proxy Support -   code 1

2. Proxy only - code 2

1.1   Residence and Moves

If INTSTATUSW4 = 1, then ask CS_1_4 others go to CS_35_4

Now I would like to ask some questions about where [you/Rname] [live/lives].

We have asked this question from you before, but we are interested in finding out if many people have moved house since the last interview in [month] [year].

CS_1_4: [Are/Is] [you/he/she] living at the same address that [you/he/she] lived in at the time of the last interview?

[**IWER:** State address participant gave at Wave 3 here CS_AddressFF_4 or corrected address if applicable]

1. Yes, **Go to CS_35 _4**
5. No record new current address **Go to CS_1b_4**
97. Unclear response **Go to CS_1b_4**
98. Don't know **Go to CS_1b_4**
99. Refused to answer **Go to CS_1b_4**

CS_1b_4: Please enter the current address at which the respondent is now resident

CS_1c_4: Which type of residence is this?

IWER: Select one only

Family/Independent (Drop Down Menu)

1. At home with both parents
2. At home with one parent
3. At home with Sibling
4. At home with other relative
5. Foster care and boarding-out arrangements
6. Living independently
7. Living semi-independently
22. Home Sharing / Shared living

Community (Drop Down Menu)

9. 5-day community group home – (Dispersed setting)
20. 5-day community group home – (Clustered setting)
10. 7-day community group home – (Dispersed setting)
11. 7-day community group home – (clustered setting)

Residential (Drop Down Menu)

12. 5-day residential setting (home at weekends)
15. Nursing home
16. Mental health community residence
17. Psychiatric hospital
18. Intensive placement (challenging behaviour)
19. Intensive placement (profound or multiple disability)
21. Different unit in same residence i.e. moved residence within the campus setting (new option wave 3)
95. Other (please specify, e.g. hostel) **Go to CS_1c_oth_4**
96. Unclear response
97. Don't know
98. Refused to answer

(Adapted from NIDD/IDS-TILDA)

CS_1c_oth_4: Text Up to 60 characters.

CS_35_4: To be completed by Interviewer. Probe for all relevant movements that may have occurred in the last three years

1. Participant has NOT moved in the last three years **Go to CS_5_4**
2. Participant has moved but has returned to the same address they had three years ago **Go to CS_5_4**
3. Participant has moved in the last three years **Go to CS_5 _4**

(IDS-TILDA)

If CS_35_4 = 1, **Go to CS_info1_4**

If CS_35_4 = 2 OR If CS_35_4 = 3, **Go to CS_5_4**

CS_5_4: What was the reason for this move?

IWER: Code All That Apply

CS_5_i_4 for i = 1-13, 95, oth, 97, 98, 99

1. Physical health changes/change in health status
1. Loss of primary carer e.g. death of a parent
1. Change in service policy
1. Moved to accommodate service
1. Not happy where [I/he/she] was living
1. Funding shortages/staff shortages
1. Supports, services, skill mix not in place to meet [my/his/her] needs
1. Lack of accessibility within the home/home not accessible
1. For [my/his/her/ changing needs (e.g. no downstairs facilities)
1. Lack of nursing support
1. Lack of 24hr care
1. As part of the transition process
1. Personal choice
95. Other (Please tell us): _____

97. Unclear Response
98. Don't Know
99. Refused to answer

(IDS-TILDA)

CS_6_4: Now, thinking about the reason(s) you chose, what was the most important reason for this move?

IWER: CODE THE ONE THAT APPLIES

1. Physical health changes/change in health status
2. Loss of primary carer e.g. death of a parent
3. Change in service policy
4. Moved to accommodate service
5. Not happy where [I/he/she] was living
6. Funding shortages/staff shortages
13. Supports, services, skill mix not in place to meet [my/his/her] needs
7. Lack of accessibility within the home/home not accessible for [my/his/her] changing needs (e.g. no downstairs facilities)
8. Lack of nursing support
9. Lack of 24hr care
10. As part of the transition process
11. Personal choice
12. [I/He/She] [don't/doesn't] know the reason for the move
95. Other (as given in CS_5_95_4)

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

CS_7_4: Who was involved in choosing [your/Rname's] new home/accommodation?

IWER: CODE ALL THAT APPLY

CS_7_i _4 for i = 1-5, 95, oth, 97, 98, 99

1. [Myself/Himself/Herself]
1. Family
1. Key worker
1. The staff
1. The service
95. Other (please tell us): _____

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

CS_36_4: Was the move of house talked about or/included in [your/his/her] personal plan

1. Yes
5. No
97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

CS_10_4: Did [you/he/she] view any alternative accommodation options? (e.g. bungalow, independent living house or flat, nursing home)

1. Yes
5. No
97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

CS_11_4: Did [you/he/she] want to move?

IWER: CODE ONE THAT APPLIES

1. Yes
5. No
97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

CS_47_4: Does [your/his/her] home/accommodation meet your needs?

IWER: CODE ONE THAT APPLIES

1. Yes
5. No
97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

CS_37_4: How [do/does] [you/he/she] feel now that [you/he/she] [have/has] moved?

IWER: CODE ONE THAT APPLIES

1. Happy with new home
2. Not happy with new home
3. Still getting used/adapting to the change

CS_37oth_4: Other

95. Other (Please specify): _____
97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

CS_38_4: How many times [have/has] [you/he/she] moved in the last three years?

INTERVIEWER: Please Note That a Move Includes a Change in Unit on The Same Campus.

IF ONLY ONE MOVE RECORD '1' IN THE BOX BELOW

NUMBER:_____   (Constrain from 1 to 96)

97. Unclear response **Go to CS_info1_4**
98. Don't know **Go to CS_info1_4**
99. Refused to answer **Go to CS_info1_4**

(IDS-TILDA)

CS_info1_4: Any other information (Residence and Moves)

1.2 Faith / Spirituality

CS_0_4: How will this section be completed?

1. Self-Report Only
2. Self-Report & Proxy
3. Proxy only

If CS_0_4 = 1 or CS_0_4 = 2 ask CS_43_4

IWER: (SELF-REPORT ONLY)

IWER: Now we would like to ask you some questions about the things that give you hope, peace or comfort

CS_43_4: What helps you and brings you hope during difficult times?

IWER: Tick all that apply

CS_43_i_4 for i = 1 to 9, 95, oth, 93, 97, 98, 99, 0.

1. Talking to Friends / family
1. Talking to staff
1. Praying
1. Going to a religious/faith-based service
1. Spending quiet time on my own
1. Listening to music
1. Going for a walk
1. Being in nature
1. Meditating/yoga/other practice
95. Other (Please Specify): _____

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – Proxy NOT to complete

CS_44_4: Which of these things would you do most often during the difficult times?

Difficult times may include death of a parent, loss of a pet, change of keyworker, victim of crime.

If CS_0_4 = 1 or CS_0_4 = 2 ask CS_44_4

IWER: Tick one only

1. Talking to friends / family
2. Talking to staff
3. Praying
4. Going to a religious / faith-based service
5. Spending quiet time on my own
6. Listening to music
7. Going for a walk
8. Being in nature
9. Meditating / yoga / other practice
95. Other (as given above in CS_43_95_3)

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – Proxy NOT to complete

CS_45_4: What helps you to feel peace and at ease in your life?

If CS_0_4 = 1 or CS_0_4 = 2 ask CS_45_4

IWER: (SELF-REPORT ONLY)

IWER prompt: Feel calm and relaxed

IWER: Code all that applies

CS_45_i_4 for i = 1 to 9, 95, oth, 93, 97, 98, 99, 0.

1. Talking to friends / family
1. Talking to staff
1. Praying
1. Going to a religious / faith-based service
1. Spending quiet time on my own
1. Listening to music
1. Going for a walk/
1. Being in nature
1. Meditating/yoga/other practice
95. Other (Please specify)

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – Proxy NOT to complete

CS_46_4: Which of these things would you do most often to help you feel peaceful and at ease?

If CS_0_4 = 1 or CS_0_4 = 2 ask CS_46_4

IWER: (SELF-REPORT ONLY)

IWER: Tick one only

1. Talking to friends/ family
2. Talking to staff
3. Praying
4. Going to a religious / faith-based service
5. Spending quiet time on my own
6. Listening to music
7. Going for a walk/
8. Being in nature
9. Meditating/yoga/other practice
95. Other (As given in CS_45_95_3): _____

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – Proxy NOT to complete

CS_30_4: About how often [do/does] [you/he/she] go to religious services?

IWER: CODE THE ONE THAT APPLIES

1. No religion **(Go to CS_33_4)**
2. Never / almost never **(Go to CS_31_4)**
3. About once or twice a year **(Go to CS_31_4)**
4. Every few months **(Go to CS_31_4)**
5. About once a month **(Go to CS_31_4)**
6. Twice a month **(Go to CS_31_4)**
7. About once a week **(Go to CS_31_4)**
8. More than once a week **(Go to CS_31_4)**

97. Unclear response
98. Don't know
99. Refused to answer

(SNI/IDS-TILDA)

CS_31_4: How important would you say religion is in your life?

If CS_0_4 = 1 or CS_0_4 = 2 ask CS_31_4

IWER: (SELF-REPORT ONLY)

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Very important
2. Somewhat important
3. Not too important

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – Proxy NOT to complete

(HRS)

CS_32_4: Do you find that you get comfort and strength from religion or not?

If CS_0_4 = 1 or CS_0_4 = 2 ask CS_32_4

IWER: (SELF-REPORT ONLY)

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Often/Always
2. Sometimes
3. Never

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – Proxy NOT to complete

(HRS)

CS_33_4: Any other information (Spirituality): Text Up to 60 characters.

2   Section 2: Cognitive Health (CH)

2.1   Memory

CH_0_4: TO BE COMPLETED BY THE INTERVIEWER

NOTE: This is a Proxy ONLY SECTION. Only the Proxy can answer the questions in this section. It cannot be answered by an SR.

IWER: Please indicate the status of completion.

IWER: CODE THE ONE THAT APPLIES

1.   SR is present
2.   SR is present (and supported by a PROXY)
0.   SR is not present, and proxy is invited to Complete CH_53_4

CH_53_4: How would your rate [Rname's] day to day memory at the present time?

(PROXY ONLY)
If CH_0_3= 0 then ask CH_53_4, OTHERS GO TO pCH_55_4

IWER: Would you say it is

1.   Excellent
2.   Very Good
3.   Good
4.   Fair
5.   Poor

97. Unclear Response
98. Don't Know
99. Refused to answer

CH_54_4: Compared to three years ago would you say [Rname's] memory is

(PROXY ONLY)
If CH_0_4= 0 then ask CH_54_4, OTHERS GO TO CH_55_4

NOTE: You may need to remind the proxy of the date of the last interview.

1. Much Better
2. A bit better
3. The same
4. A bit worse
5. Much worse

97. Unclear Response
98. Don't Know
99. Refused to answer

CH_55_4: Any other Information (Memory and Cognitive Domains): Text Up to 60 characters.

(PROXY ONLY)

If CH_0_4= 0 then ask CH_54_4 OTHERS GO TO Next section

3   Section 3: Social Participation (SP)

3.1   General Activities

SP_0_4:TO BE COMPLETED BY INTERVIEWER.

IWER: How will this section be completed?

1. Self Report ONLY
2. SR and PROXY
3. PROXY ONLY

SP_1_94_4SP_1_97_4

SP_1_98_4

SP_1_4:

INTRO: Now I would like to ask you some general questions about [your/Rname's] life.

Which of these statements apply to [you/Rname]?

IWER: READ OUT AND CODE ALL THAT APPLY

SP_1_i_4 from i = 1 to 4

1. Have voted in any recent election
1. Have taken a holiday in Ireland in the last 12 months
1. Have taken a holiday abroad in the last 12 months
1. Have gone on a daytrip or outing in the last 12 months

SP_1_94_4SP_1_97_4, SP_1_98_4, SP_1_99_4

94. Not applicable – none of these statements apply to [me/him/her]
97. Unclear response
98. Don't know
99. Refused to answer

(ELSA)

SP_3_4: [Are/Is] [you/he/she] an active member of any of these organisations, clubs or societies? (Have attended within the last six months)

Please ensure that all responses relate to when the SR is in attendance of these groups and not just a member by default e.g. in receipt of residential services from a charity organisation.

IWER: READ OUT AND CODE ALL THAT APPLY

Note: If yes for SP_3_i_4 for i = 1 to 95, go to SP_3A_4

Question SP_3_4			Question SP_3A_4											
			Within Community Setting		Within ID Service		Both within community & ID		Unclear response		Don't know		Refused to Answer	
Political party, trade union or environmental groups		1		1		2		3		97		98		99
Tenants groups, resident groups, Neighbourhood Watch		1		1		2		3		97		98		99
Church or religious groups		1		1		2		3		97		98		99
Charitable associations (e.g. St Vincent De Paul's)		1		1		2		3		97		98		99
Arts or music		1		1		2		3		97		98		99
Special Olympics Network		1		1		2		3		97		98		99
Arch Club		1		1		2		3		97		98		99
Advocacy Group		1		1		2		3		97		98		99
Social, Sports or Leisure club		1		1		2		3		97		98		99
Other (please specify)		1		1		2		3		97		98		99

Not applicable – Not a member or any specialized, club or society		1		1		2		3		97		98		99

SP_3_97_4	Unclear response		97	Go to SP_4_4
SP_3_98_4	Don't know		98	Go to SP_4_4
SP_3_99_4	Refused to answer		99	Go to SP_4_4

(ELSA/IDS-TILDA)

SP_4_4: Any other information (General Activities)

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SP_7_4: Are there particular activities you would like to do more?

IWER: (SELF-REPORT ONLY)

If SP_0__4 = 1 OR SP_0_4 = 2 then ask SP_7_4

1. Yes **(Go to SP 8_3)**
5. No **(Go to SP 9_3)**

93. Unable to understand **(Go to SP 9_4)**
97. Unclear response **(Go to SP 9_4)**
98. Don't know **(Go to SP 9_4)**
99. Refused to answer **(Go to SP 9_4)**
0. SR not present –Proxy NOT to complete **(Go to SP 9_4)**

(IDS-TILDA)

SP_8_4: What activities would you like to do?

IWER: (SELF-REPORT ONLY)

If SP_0__3 = 1 OR SP_0_4 = 2 then ask SP_8_4

What activities would you like to do?

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93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – proxy NOT to complete

(IDS-TILDA)

SP_9_4: [Do/Does] [you/he/she] experience any difficulties participating in social activities outside [your/his/her] home?

IWER: Ask All Participants

1. Yes **(Go to SP_10_4)**
5. No (**Go to SP_11_4)**

97. Unclear response **(Go to SP_11_4)**
98. Don't know **(Go to SP_11_4)**
99. Refused to answer **(Go to SP_11_4)**

(IDS-TILDA)

SP_10_4: What makes it difficult for [you/him/her] to participate in social activities outside [your/his/her] home?

IWER: CODE ALL THAT APPLY

1. Health considerations or physically unable
1. Need someone's assistance
1. Need specialized aids or equipment that [you/he/she] [do/does] not have
1. Transport services are inadequate or not accessible
1. Service facilities are not accessible
1. Not able to read signs and timetables
1. Not allowed to go
1. Have no one to go with
1. Lack of local facilities or suitable activities
1. Unfriendly or negative attitudes towards [you/him/her]
1. [You/He/She] [are/is] self-conscious of [your/his/her] intellectual disability
1. Don't have enough money
1. Don't have enough time
1. Don't like social activities
1. Getting too old
1. Family and friends' residence not accessible to [you/him/her]
1. Communication/language problems
1. Mental Health or Challenging Behaviour
95. Other (please specify): _____

97. Unclear response
98. Don't know
99. Refused to answer

(CSO NDS 2006/IDS-TILDA)

SP_11_4: [Do/Does] [you/he/she] experience any difficulty getting around [your/his/her] community (e.g. using zebra crossings, using traffic lights etc.)?

1. Yes **(Go to SP_10_4)**
5. No **(Go to SP_13_4)**
94. Not applicable **(Go to SP_13_4)**

97. Unclear response **(Go to SP_13_4)**
98. Don't know **(Go to SP_13_4)**
99. Refused to answer **(Go to SP_13_4)**

(IDS-TILDA)

SP_12_4: What causes [you/him/her] difficulty?

IWER: CODE ALL THAT APPLY

1. Footpaths design and surfaces
1. Lack of street crossings
1. Problems with signs (e.g. size and colour)
1. Getting access to recreational areas
1. Feeling unsafe
95. Other (Please specify)

SP_12_i_4 for i = 1 to 5, 95, oth, 97, 98, 99.

97. Unclear response
98. Don't know
99. Refused to answer

(Adapted from NDS)

SP_13_4: Any Other Information (Social Activities):

4   Section 4: Social Connectedness (SC)

SC_0_4:

IWER: How will this section be completed?

1. Self Report ONLY
2. SR and PROXY
3. PROXY ONLY

SC_1_4:

INTRO: Now I would like to ask you some questions about [your/Rname's] family and social networks

[Do/Does] [you/he/she] have family… please tell us

PLEASE CODE ALL THAT APPLY

SC_1_1_4	Spouse/Partner		1	Go to SC_2_4
SC_1_2_4	Mother		1	Go to SC_2_4
SC_1_3_4	Father		1	Go to SC_2_4
SC_1_4_4	Brother(s)		1	Go to SC_1_4a_4
SC_1_5_4	Sister(s)		1	Go to SC_1_5a_4
SC_1_6_4	Aunt/uncle		1	Go to SC_2_4
SC_1_7_4	Nieces/nephews		1	Go to SC_2_4
SC_1_8_4	Cousin		1	Go to SC_2_4
SC_1_9_4	Child		1	Go to SC_2_4
SC_1_95_4	Other		95	Go to SC_2_4

SC_1_94_4	Not applicable, [I/he/she] [don't/doesn't] have family		94	(Go to SC_28_4)
SC_1_97_4	Unclear response		97	(Go to SC_28_4)
SC_1_98_4	Don't know		98	(Go to SC_28_4)
SC_1_99_4	Refused to answer		99	(Go to SC_28_4)

SC_1_4a_4: If SC_1_4_4 = 1 then ask, **"How many brothers [do/does] [you/he/she] have?"**

(numerical response): _____

> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

SC_1_5a_4: SC_1_5a_4: If SC_1_5_4 = 1 then ask, **"How many sisters [do/does] [you/he/she] have?"**

(numerical response): _____

> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

SC_2_4: Please tell us where [your/his/her] family member lives in relation to [you/him/her]

If respondent has more than one brother or sister clarify that it is the one, they live closest to

SC_2_i_4 for i = 1 to 9, 95

	Lives with [me/him/her]	Lives in the same building	Lives in the same neighbourhood	Lives in different neighbourhood but same county	Lives in different county	Lives in different country	Unclear response	Don't Know	Refused to answer
Spouse/partner	1	2	3	4	5	6	97	98	99
Mother	1	2	3	4	5	6	97	98	99
Father	1	2	3	4	5	6	97	98	99
Brother(s)	1	2	3	4	5	6	97	98	99
Sister(s)	1	2	3	4	5	6	97	98	99
Aunt/Uncle	1	2	3	4	5	6	97	98	99
Nieces/Nephews	1	2	3	4	5	6	97	98	99
Cousin	1	2	3	4	5	6	97	98	99
Child	1	2	3	4	5	6	97	98	99
Other	1	2	3	4	5	6	97	98	99

(Adapted from TILDA)

SC_3_4: Spouse / Partner

IWER: On average, how often [do/does] [you/he/she] do each of the following with [your/his/her] spouse/partner?

IWER: READ OUT AND CODE ONE BOX ON EACH LIINE

If SC_2_i_4 = 1, 97 ,98, 99 then skip SC_3_ia_4 to SC_3_ic_4

SC_3_1a_4: On average, how often [do/does] [you/he/she] **meet up (both arrange and chance meeting)** with [your/his/her] spouse/partner?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_1b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** with [your/his/her] spouse/partner?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_1c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** with [your/his/her] spouse/partner?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4: Mother

IWER: On average, how often [do/does] [you/he/she] do each of the following with [your/his/her] mother?
IWER: READ OUT AND MARK EACH LINE

SC_3_2a_4: On average, how often [do/does] [you/he/she] **Meet up (both arranged and chance meeting**) with [your/his/her] mother?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_2b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** with [your/his/her] mother?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_2c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** with [your/his/her] mother?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4: Father

IWER: On average, how often [do/does] [you/he/she] do each of the following with [your/his/her] father?
IWER: READ OUT AND MARK EACH LINE

SC_3_3a_4: On average, how often [do/does] [you/he/she] **Meet up (both arranged and chance meeting**) with [your/his/her] father?

> 1. Three or more times a week
> 2. Once or twice a week
> 3. Once or twice a month
> 4. Every few months
> 5. Once or twice a year
> 6. Less than once a month
> 7. Never
>
> 94. Not Applicable
> 97. Unclear Response
> 98. Don't Know
> 99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_3b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** with [your/his/her] father?

> 1. Three or more times a week
> 2. Once or twice a week
> 3. Once or twice a month
> 4. Every few months
> 5. Once or twice a year
> 6. Less than once a month
> 7. Never
>
> 94. Not Applicable
> 97. Unclear Response
> 98. Don't Know
> 99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_3c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** with [your/his/her] father?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4: Brother

IWER: On average, how often [do/does] [you/he/she] do each of the following with [your/his/her] brother?
IWER: READ OUT AND MARK EACH LINE

IWER: If respondent has more than one brother or sister clarify that it is the one, they have most contact with

SC_3_4a_4: On average, how often [do/does] [you/he/she] **Meet up (both arranged and chance meeting**) with [your/his/her] brother?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** with [your/his/her] brother?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** with [your/his/her] brother?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4: Sister

IWER: On average, how often [do/does] [you/he/she] do each of the following with [your/his/her] sister?
IWER: READ OUT AND MARK EACH LINE

IWER: If respondent has more than one brother or sister clarify that it is the one, they have most contact with

SC_3_5a_4: On average, how often [do/does] [you/he/she] **Meet up (both arranged and chance meeting**) with [your/his/her] sister?

       1. Three or more times a week
       2. Once or twice a week
       3. Once or twice a month
       4. Every few months
       5. Once or twice a year
       6. Less than once a month
       7. Never

       94. Not Applicable
       97. Unclear Response
       98. Don't Know
       99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_5b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** with [your/his/her] sister?

       1. Three or more times a week
       2. Once or twice a week
       3. Once or twice a month
       4. Every few months
       5. Once or twice a year
       6. Less than once a month
       7. Never

       94. Not Applicable
       97. Unclear Response
       98. Don't Know
       99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_5c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** with [your/his/her] sister?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4: Aunt/ Uncle

IWER: On average, how often [do/does] [you/he/she] do each of the following with [your/his/her] aunt/uncle?
IWER: READ OUT AND MARK EACH LINE

SC_3_6a_4: On average, how often [do/does] [you/he/she] **Meet up (both arranged and chance meeting**) with [your/his/her] aunt/uncle?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_6b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** with [your/his/her] aunt/uncle?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_6c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** with [your/his/her] aunt/uncle?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4: Niece / Nephew

IWER: On average, how often [do/does] [you/he/she] do each of the following with [your/his/her] Niece **/** Nephew?

IWER: READ OUT AND MARK EACH LINE

SC_3_7a_4: On average, how often [do/does] [you/he/she] **Meet up (both arranged and chance meeting)** with [your/his/her] niece/nephew?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_7b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** with [your/his/her] niece/nephew?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_7c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** with [your/his/her] niece/nephew?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4: Cousin

IWER: On average, how often [do/does] [you/he/she] do each of the following with [your/his/her] cousin?
IWER: READ OUT AND MARK EACH LINE

SC_3_8a_4: On average, how often [do/does] [you/he/she] **Meet up (both arranged and chance meeting**) with [your/his/her] cousin?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_8b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** with [your/his/her] cousin?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_8c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** with [your/his/her] cousin?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4: Child

IWER: On average, how often [do/does] [you/he/she] do each of the following with [your/his/her] child?
IWER: READ OUT AND MARK EACH LINE

SC_3_9a_4: On average, how often [do/does] [you/he/she] **Meet up (both arranged and chance meeting**) with [your/his/her] child?

> 1. Three or more times a week
> 2. Once or twice a week
> 3. Once or twice a month
> 4. Every few months
> 5. Once or twice a year
> 6. Less than once a month
> 7. Never
>
> 94. Not Applicable
> 97. Unclear Response
> 98. Don't Know
> 99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_9b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** with [your/his/her] child?

> 1. Three or more times a week
> 2. Once or twice a week
> 3. Once or twice a month
> 4. Every few months
> 5. Once or twice a year
> 6. Less than once a month
> 7. Never
>
> 94. Not Applicable
> 97. Unclear Response
> 98. Don't Know
> 99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_9c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** with [your/his/her] child?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_4: Other

IWER: On average, how often [do/does] [you/he/she] do each of the following with [your/his/her] cousin?
IWER: READ OUT AND MARK EACH LINE

SC_3_95a_4: On average, how often [do/does] [you/he/she] **Meet up (both arranged and chance meeting**) with [your/his/her] other?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_95b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** with [your/his/her] other?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_3_95c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** with [your/his/her] other?

1. Three or more times a week
2. Once or twice a week
3. Once or twice a month
4. Every few months
5. Once or twice a year
6. Less than once a month
7. Never

94. Not Applicable
97. Unclear Response
98. Don't Know
99. Refused to answer

(ELSA/IDS-TILDA)

SC_28_4:

IWER: I am now going to ask you some questions about your friends. Friends can include family or staff as well as other types of friends

If SC_0_4 = 1 or SC_0_4 =2 skip SC_30_4 and SC_31_4

SC_28_1_4: [Do/Does] [you/Rname} have friends?

> 1. Yes
> 5. No
> 3. Sometimes

SC_28_2_4: [Do/Does] [you/Rname} have a best friend?

Skip if SC_28_1_4 = 5

> 1. Yes
> 5. No
> 3. Sometimes

SC_28_3_4: Can [you/he/she] see friends when [you/he/she] [want/wants]?

Skip if SC_28_1_4 = 5

> 1. Yes
> 5. No
> 3. Sometimes

SC_28_4_4: Can [you/he/she] go on a date if [you/he/she] [want/wants]?

> 1. Yes
> 5. No
> 3. Sometimes

SC_28_5_4: Do you ever feel lonely?

Ask only if SC_0_4 = 1 OR SC_0_4 = 2

> 1. Yes
> 5. No
> 3. Sometimes

SC_28_info_4:

IWER: Ask all participants

Any other information (Friendship scale):

IF SC_28_2_4 = 1 OR SC_28_2_4 = 3, then ask SC_29_4 - Others go to SC_4_4

SC_29_4: Who is [your/Rnames] best friend?

1. Family
2. Work colleague
3. Friend who has an intellectual disability
4. Other friend
5. Carer or person who provides a disability service

(National Disability Survey categories – Q8.2)

(Lead-in question about friendship: (Mehling & Tasse, 2014) [developed using data from National Core Indicators survey – these 5 questions were used as initial indicators of overall quality of social relationships])

IWER: IF SC_28_2_4 = 1 OR SC_28_2_4 = 3, then ask SC_29A_4

SC_29A_4: Is [your/Rnames] 'best friend' someone who lives with [you/him/her]?

1. Yes
5. No

4.1 Closeness Scale

SC_30_4 Closeness Scale (SC_30_01_4 + SC_30_02_4 +SC_30_03_4 + SC_30_04_04 +

SC_30_05_4)/5

 If SC_0_4 = 1 or SC_0_4=2 ASK SC_30_4 and SC_31_4

SC_30_4:

IWER: (SELF REPORT ONLY)

IF SC_28_2_4 = 1 OR SC_28_2_4 = 3, AND If SC_0_3 = 1 or SC_0_3 =2 THEN ASK SC_30_3 and
SC_31_3. Other go to SC_4_4

INTRO: The following questions are about your best friend and how you are with your friend

IWER: Please explain response options using these scales before asking the questions AND SELECT
WHAT IS APPLICABLE

IWER: Please explain response options using these scales before asking the questions

Bukowski et al (1994) – Closeness Sub-scale of the Friendship Qualities Scale:

SC_30_1_4: If _____ had to move away, I would miss him/her.

> 1. Not at all
> 2. A little
> 3. A lot
>
> 93. Unable to understand
> 97. Unclear response
> 98. Don't know
> 99. Refused to answer
> 0. SR not present – Proxy NOT to complete

SC_30_2_4: I feel happy when I am with _____.

> 1. Not at all
> 2. A little
> 3. A lot
>
> 93. Unable to understand
> 97. Unclear response
> 98. Don't know
> 99. Refused to answer
> 0. SR not present – Proxy NOT to complete

SC_30_3_4: I think about _____even when my friend is not around.

    1.   Not at all
    2.   A little
    3.   A lot

    93. Unable to understand
    97. Unclear response
    98. Don't know
    99. Refused to answer
    0.   SR not present – Proxy NOT to complete

SC_30_4_4: When I do a good job at something, _____is happy for me.

    1.   Not at all
    2.   A little
    3.   A lot

    93. Unable to understand
    97. Unclear response
    98. Don't know
    99. Refused to answer
    0.   SR not present – Proxy NOT to complete

SC_30_5_4: Sometimes _____does things for me or makes me feel special.

    1.   Not at all
    2.   A little
    3.   A lot

    93. Unable to understand
    97. Unclear response
    98. Don't know
    99. Refused to answer
    0.   SR not present – Proxy NOT to complete

Ref: Bukowski, W.M., Hoza, B. & Boivin, M. (1994) 'Measuring friendship quality during pre- and early adolescence: The development and psychometric properties of the Friendship Qualities scale', Journal of social and personal relationships 11(3), 471-84

SC_31_4:

SC_31_3 Intimacy Scale (SC_31_01_4 + SC_31_02_4 + SC_31_03_4 + SC_31_04_4 + SC_31_05_4)/5

If SC_0_4 = 1 or SC_0_4 =2 THEN ASK SC_30_4 and SC_31_4

IF SC_28_2_4 = 1 OR SC_28_2_4 = 3, then ask SC_31_4

IWER: (SELF-REPORT ONLY)

INTRO: The following questions are about your best friend and how you are with your friend

IWER: Please explain response options using these scales before asking the questions AND SELECT WHAT IS APPLICABLE

Intimacy Scale

(Responses on a 3-point scale from 1 Not at all to 3 A lot)

SC_31_1_4: _____is someone I can tell private things to.

1. Not at all
2. A little
3. A lot

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – Proxy NOT to complete

SC_31_2_4: _____knows when I'm upset.

1. Not at all
2. A little
3. A lot

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – Proxy NOT to complete

SC_31_3_4: _____is someone I can tell secrets to.

    1. Not at all
    2. A little
    3. A lot

    93. Unable to understand
    97. Unclear response
    98. Don't know
    99. Refused to answer
    0. SR not present – Proxy NOT to complete

SC_31_4_4: _____knows when something bothers me/

    1. Not at all
    2. A little
    3. A lot

    93. Unable to understand
    97. Unclear response
    98. Don't know
    99. Refused to answer
    0. SR not present – Proxy NOT to complete

SC_31_5_4: _____is easy to talk to about private things.

    1. Not at all
    2. A little
    3. A lot

    93. Unable to understand
    97. Unclear response
    98. Don't know
    99. Refused to answer
    0. SR not present – Proxy NOT to complete

Ref: Mendelson, M.J. & aboud, F.E. (1999) 'Measuring friendship quality in late adolescents and young adults: McGill Friendship Questionnaires', Canadian Journal of Behavioural Science/Revue can

SC_4_4: If SC_28_1_4 = 1 or SC_28_1_4 = 3, then ask SC_4_4 – Others go to SC_6_4

Are [your/his/her] friends…?

IWER: READ OUT AND CODE ALL THAT APPLY

SC_4_i_4 for i = 1,2,3,95,oth, 93, 97, 98, 99

      1. Friends within [your/his/her] house **Go to SC_6_4**
      1. Friends outside [your/his/her] house **Go to SC_5_4**
      1. Key worker/support staff **Go to SC_6_4**
      1. Other (Please specify) **Go to SC_6_4**

      93. Unable to understand **Go to SC_6_4**
      97. Unclear response **Go to SC_6_4**
      98. Don't know **Go to SC_6_4**
      99. Refused to answer **Go to SC_6_4**

(IDS-TILDA)

SC_5_4: IF **SC_4_2_4 = 1 then ask SC_5_4 – Others go to SC_6_4**

On average, how often [do/does] [you/he/she] do each of the following [your/his/her] friends, not counting any of [your/his/her] family members, staff or anyone who lives with [you/him/her]?

IWER: READ OUT AND CODE ONE

SC_5a_4: On average, how often [do/does] [you/he/she] **Meet up (both arranged and chance meeting)** [your/his/her] friends, not counting any of [your/his/her] family members, staff or anyone who lives with [you/him/her]?

      1. Three or more times a week
      2. Once or twice a week
      3. Once or twice a month
      4. Every few months
      5. Once or twice a year
      6. Less than once a month
      7. Never

      94. Not Applicable
      97. Unclear Response
      98. Don't Know
      99. Refused to answer

(ELSA/IDS-TILDA)

SC_5b_4: On average, how often [do/does] [you/he/she] **Speak on the phone** [your/his/her] friends, not counting any of [your/his/her] family members, staff or anyone who lives with [you/him/her]?

       1. Three or more times a week
       2. Once or twice a week
       3. Once or twice a month
       4. Every few months
       5. Once or twice a year
       6. Less than once a month
       7. Never

       94. Not Applicable
       97. Unclear Response
       98. Don't Know
       99. Refused to answer

(ELSA/IDS-TILDA)

SC_5c_4: On average, how often [do/does] [you/he/she] **Write, text, email or Facebook** [your/his/her] friends, not counting any of [your/his/her] family members, staff or anyone who lives with [you/him/her]?

       1. Three or more times a week
       2. Once or twice a week
       3. Once or twice a month
       4. Every few months
       5. Once or twice a year
       6. Less than once a month
       7. Never

       94. Not Applicable
       97. Unclear Response
       98. Don't Know
       99. Refused to answer

(ELSA/IDS-TILDA)

SC_6_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_6_4, OTHER GO TO SC_8A_4

IWER: (SELF-REPORT ONLY)

IWER: READ OUT AND CODE THE ONE THAT APPLIES

IWER: Now I would like to ask you some questions about happiness

IWER: Most of the time do you feel…?

1. Happy
2. Not Happy
3. Not Sure

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
93. SR not present – Proxy NOT to complete

(Adapted from the Oxford Happiness Questionnaire, Oxford happiness inventory, and from GDS Scale Brink TL, Yessavage JA Lum O, Heersema P, Adey MB, Rose TL)

SC_7_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_7_4

IWER: (SELF-REPORT ONLY)

IWER: What makes you happy?

Record SR response below

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93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – Proxy NOT to complete

(Adapted from ideas by Sonja Lyubomirsky, Ed Diener & Robert Biswas Diener)

SC_8_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_8_4

IWER: (SELF-REPORT ONLY)

INTRO: The next few questions are about how people sometimes feel.

IWER: Do you ever feel lonely?

IWER: PROBE IF NECESSARY 'Would you say Yes or No?

1. Yes, **Go to SC_9_4**
5. No **Go to SC_10_4**

93. Unable to understand **Go to SC_10_4**
97. Unclear response **Go to SC_10_4**
98. Don't know **Go to SC_10_4**
99. Refused to answer **Go to SC_10_4**
0. SR not present – Proxy NOT to complete **Go to SC_10_4**

(IDS-TILDA/UCLA Loneliness Scale)

SC_8a_4: If SC_0_4 = 3 then ask SC_8A_4. OTHERS GO TO SC_9_4

Do you think Rname ever feels lonely?

IWER: Proxy Only

1. Yes, **Go to SC_9a_4**
2. No **Go to SC_18_4**

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

SC_9a_4: If SC_0_4 = 3 then ask SC_8A_4

How often do you think Rname feels lonely?

IWER: Proxy Only

      1. Most of the time
      2. Some of the time
      3. Hardly ever, never

      97. Unclear response
      98. Don't know
      99. Refused to answer

(IDS-TILDA)

SC_9_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_9_4. OTHERS GO TO SC_18_4

How often do you feel lonely? Would you say…?

IWER: (SELF-REPORT ONLY)

IWER: READ OUT AND CODE THE ONE THAT APPLIES

      1. Most of the time
      2. Some of the time
      3. Hardly ever, never

      93. Unable to understand
      97. Unclear response
      98. Don't know
      99. Refused to answer
      0. SR not present - Proxy NOT to complete

(IDS-TILDA)

SC_10_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_10_4

IWER: (SELF-REPORT ONLY)

IWER: PROBE IF NECESSARY – 'WOULD YOU SAY YES OR NO?'

      1. Yes, **Go to SC_11_4**
      5. No **Go to SC_12_4**

      93. Unable to understand
      97. Unclear response
      98. Don't know
      99. Refused to answer
      0. SR not present - Proxy NOT to complete

(IDS-TILDA/UCLA Loneliness Scale)

SC_11_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_11_4

How often do you feel left out? Would you say…

IWER: (SELF-REPORT ONLY)

IWER: READ OUT AND CODE THE ONE THAT APPLIES

      1. Most of the time
      2. Some of the time
      3. Hardly ever, never

      93. Unable to understand
      97. Unclear response
      98. Don't know
      99. Refused to answer
      0. SR not present - Proxy NOT to complete

(IDS-TILDA)

SC_12_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_12_4

Do you find it difficult to make friends?

IWER: (SELF-REPORT ONLY)

IWER: PROBE IF NECESSARY – 'WOULD YOU SAY YES OR NO?'

    1. Yes
    5. No

    93. Unable to understand
    97. Unclear response
    98. Don't know
    99. Refused to answer
    0. SR not present - Proxy NOT to complete

(IDS-TILDA/UCLA Loneliness Scale)

SC_13_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_13_4

How often do you feel you lack friendship / friends?

IWER: (SELF-REPORT ONLY)

IWER: READ OUT AND CODE THE ONE THAT APPLIES

    1. Most of the time
    2. Some of the time
    3. Hardly ever, never

    93. Unable to understand
    97. Unclear response
    98. Don't know
    99. Refused to answer
    0. SR not present - Proxy NOT to complete

(IDS-TILDA)

SC_14a_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_14a_4

Do you ever feel isolated?

IWER: (SELF-REPORT ONLY)

PROMPT: (Never asked out to socialize e.g. out for coffee, I live very far away from other people)

IWER: READ OUT AND CODE THE ONE THAT APPLIES

      1. Yes, **Go to SC_14b_4**
      5. No **Go to SC_15_4**

      93. Unable to understand **Go to SC_15_4**
      97. Unclear response **Go to SC_15_4**
      98. Don't know **Go to SC_15_4**
      99. Refused to answer **Go to SC_15_4**
      0. SR not present - Proxy NOT to complete **Go to SC_15_4**

(UCLA/IDS-TILDA)

SC_14b_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_14b_4

How often do you feel isolated?

IWER: (SELF-REPORT ONLY)

      1. Most of the time
      2. Some of the time
      3. Hardly ever, never

      93. Unable to understand
      97. Unclear response
      98. Don't know
      99. Refused to answer
      0. SR not present - Proxy NOT to complete

(IDS-TILDA)

SC_15_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_15_4

Do you have someone with whom you can confide? (e.g. someone that you feel at ease with, can talk to about private matters, and can call on for help)

IWER: (SELF-REPORT ONLY)

IWER: PROBE IF NECESSARY – 'WOULD YOU SAY YES OR NO?'

    1. Yes, **Go to SC_16_4**
    5. No **Go to SC_17_4**

    93. Unable to understand **Go to SC_17_4**
    94. Not applicable (e.g. completely dependent on others to interpret needs and wants etc. **Go to SC_17_4**
    97. Unclear response **Go to SC_17_4**
    98. Don't know **Go to SC_17_4**
    99. Refused to answer **Go to SC_17_4**
    0. SR not present – Proxy NOT to complete **Go to SC_17_4**

(Adapted from Community Integration Questionnaire)

SC_16_4: If SC_0_4 = 1 or SC_0_4 = 2 then ask SC_16_4

Who do you confide in?

IWER: CODE All THAT APPLY
SC_16_i_4 from i = 1 to 10, 95,97,98,99

    1. Spouse / Partner / Boyfriend / Girlfriend
    1. Parent
    1. Sibling
    1. Grandparent
    1. Aunt / Uncle
    1. Cousin
    1. Friend
    1. Neighbor
    1. Key worker / Support worker
    1. Advocate
    95. Other (Please specify)

    0. SR not present – Proxy NOT to complete
    97. Unclear response
    98. Don't know
    99. Refused to answer

(IDS-TILDA)

SC_18_4:

INTRO: The next questions are about help [you/Rname] gave or received regularly in the last two years from friends and neighbors.

In the last 2 years, did [your/his/her] neighbors or friends give [you/him/her] any kind of help, such as:

- Household help: help with home repairs, gardening, transportation, shopping or household chores

- Help with paperwork, such as filling out forms, settling money matters

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

        1. Yes, **Go to SC_18_oth_4**
        5. No **Go to SC_18_oth_4**

        97. Unclear response **Go to SC_20_4**
        98. Don't know **Go to SC_20_4**
        99. Refused to answer **Go to SC_20_4**

SC_18_oth_4:

Please record any narrative information below

(SHARE/12months)

SC_19_4: About how much help did [you/he/she] receive from friends and neighbours over the last two years?

IWER: READ OUT AND CODE THE ONE THAT APPLES

      1. Daily
      2. Weekly
      3. Monthly
      4. Less often

      97. Unclear response
      98. Don't know
      99. Refused to answer

(IDS-TILDA)

SC_20_4:

IWER: ASK ALL PARTICIPANTS

INTRO: In the last 2 years, did [you/Rname] give any kind of help to [your/his/her] friends, and neighbours (who did not pay [you/him/her]) such as:

- Household help: help with home repairs, gardening, transportation, shopping or household chores

- Help with personal care, such as dressing, eating, getting into and out of bed, using the toilet

- Help with paperwork, such as filling out forms, settling money matters

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

      1. Yes, **Go to SC_20_oth_4**
      5. No **Go to SC_20_oth_4**

      97. Unclear response **Go to SC_22_4**
      98. Don't know **Go to SC_22_4**
      99. Refused to answer **Go to SC_22_4**

SC_20_oth_4:
Please record any narrative information below

(SHARE)

SC_21_4: If SC_20_4 =1 then ask SC_21_4. OTHERS GO TO SC_22_4

IWER: READ OUT AND CODE THE ONE THAT APPLES

1. Daily
2. Weekly
3. Monthly
4. Less often

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

SC_22_4:

IWER: Ask All Participants

[Do /Does] [you/he/she] provide support/help to a family member?

1. Yes, **Go to SC_23_4**
5. No **Go to SC_27_Comm_4**
94. N/A - Don't have a family member **Go to SC_27_Comm_4**

97. Unclear response **Go to SC_27_Comm_4**
98. Don't know **Go to SC_27_Comm_4**
99. Refused to answer **Go to SC_27_Comm_4**

(IDS-TILDA)

SC_23_4: Who [do/does] [you/he/she] provide support/help to…?

IWER: TICK ALL THAT APPLY

SC_23_i_4 for i = 1 to 5, 95, oth, 97,98,99

1. Mother
1. Father
1. Sibling
1. Aunt / Uncle
1. Cousin
95. Other: (Please tell us): _____

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

SC_24_4: What support [do/does] [you/he/she] provide?

IWER: TICK ALL THAT APPLY

SC_24_i_4 for i = 1 to 7, 95, oth,97,98,99

1. Day to day support i.e. washing, dressing, cooking
1. Help with shopping
1. Help with remembering day to day items and events
1. Support with mobility e.g going up and down stairs / from room to room
1. Emotional support i.e. companionship
1. Financial support
1. Full support – do everything for them
95. Other

Please tell us

| |
| |

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

SC_25_4: How satisfied [are/is] [you/he/she] with providing support/help to a family member?

1. Very satisfied **Go to SC_25_info_4**
2. Satisfied **Go to SC_25_info_4**
3. Not Satisfied **Go to SC_25_info_4**

97. Unclear response **Go to SC_27_4_comm**
98. Don't know **Go to SC_27_4_comm**
99. Refused to answer **Go to SC_27_4_comm**

SC_25_info_4:

Please tell us

| |
| |

(IDS-TILDA)

SC_27_Comm_4: Sense of belonging / Connection with community

IWER: Please state the specific name local community SC_27_info_3_____(e.g.) Clonsilla, Palmerstown) so the person refers to the general locality, rather than a service campus

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IWER: Sense of belonging refers to if the person feels like they are a part of their community (and interviewer should name the community e.g. Clonsilla, Blackrock, to clarify what is meant by community

SC_27_4: [Do/Does] [you/he/she] feel a part of the community of _ (SC_27_Comm_4)   _?

        1.   A Little
        2.   A lot
        3.   Not at all

        97. Unclear response
        98. Don't know
        99. Refused to answer

(Capriano & hystad, 2011 shields, 2008: Romans et al., 2010; Wister & Wanless, 2007; Ross, 2002)

SC_26_4:

Any Other Information (Social Connectedness):

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5   Section 5: Personal Choices

PC_0_4: TO BE COMPLETED THE BY INTERVIEWER

IWER: Who is completing this section

> 1. Self-report only
> 2. SR and Proxy
> 3. Proxy only

(TILDA)

PC_1_4:

INTRO: Now I would like to ask you some questions about personal choices.

NOTE: If the SR says it is **"someone else" then ask, "who does choose; is it a relative, friend, or support staff?"** Remember that friends may include neighbours, or non-relative residents, and support staff may include any paraprofessional or professional persons.

No choice should be used in situations where there are no options available to the individual and/or the staff that support the individual in choice-making. An example would be where an individual is not given option of searching/applying/having a job – employment is not considered an option or feasible for the individual and the decision as to whether the individual would like to have a job or not, and what job that would be, is not provided. In effect no choice opportunity is present.

PC_1_4:

IWER: ASK ALL PARTICIPANTS

IWER: In general, who chooses …?

IWER: READ OUT AND CODE ONE BOX ON EACH LINE

PC_1_i_4 for i = 1 to 1 to 14

		Supported Choice			Someone Else			No choice	Unclear Response	Don't Know	Refused to Answer	Not Applicable
	Self	**Relative**	**Friend**	**Support Staff**	**Relative**	**Friend**	**Support Staff / Services**	**No choice**	**Unclear Response**	**Don't Know**	**Refused to Answer**	**Not Applicable**
The food [you/he/she] [eat/eats]?	1	2	3	4	5	6	7	8	97	98	99	94
What food is cooked in [your/his/her] home?	1	2	3	4	5	6	7	8	97	98	99	94
The clothes [you/he/she] [wear/wears]?	1	2	3	4	5	6	7	8	97	98	99	94
Who [you/he/she] [spend/spends] [your/his/her] free time with?	1	2	3	4	5	6	7	8	97	98	99	94
Where [you/he/she] [go/goes] in [your/his/her] free time?	1	2	3	4	5	6	7	8	97	98	99	94
How [you/he/she] [spend/spends] [your/his/her] money	1	2	3	4	5	6	7	8	97	98	99	94
What time [you/he/she] [go/goes] to bed	1	2	3	4	5	6	7	8	97	98	99	94

What job [you/he/she] [have/has]	1		2	3	4		5	6	7		8	97	98	99	94
Where [you/he/she] [live/lives]	1		2	3	4		5	6	7		8	97	98	99	94
Who [you/he/she] [live/lives] with	1		2	3	4		5	6	7		8	97	98	99	94
What support [you/he/she] may receive	1		2	3	4		5	6	7		8	97	98	99	94
How [do/does] [you/he/she] decorate [your/his/her] room	1		2	3	4		5	6	7		8	97	98	99	94
Where [you/he/she] [keep/keeps] [your/his/her] money	1		2	3	4		5	6	7		8	97	98	99	94
What training/day activation[you/he/she] [have/has]	1		2	3	4		5	6	7		8	97	98	99	94

{Adapted from Heller et al (2000) adaption of a scale developed by Kishi et al (1980}

PC_SDS_4: Self Determination Scale

Instructions: Please read the following pairs of statements, one pair at a time, and think about which statement within the pair seems more true to you at this point in your life. If statement A feels completely true and statement B feels completely untrue, your response would be 1. If the two statements are equally true, your response would be a 3. If only statement B feels true, your response would be 5. And so, on

(Michael Weymeyer (2015) based on The Arc's Self-Determination Scale)

PC_39_4:

A. I always feel like I choose the things I do.   **B**. I sometimes feel that it's not really me choosing the things I do.

Only **A** feels true	1	2	3	4	5	Only **B** feels true

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to complete

PC_40_4:

A. My emotions sometimes seem alien to me.   **B**. My emotions always seem to belong to me.

Only **A** feels true	1	2	3	4	5	Only **B** feels true

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to complete

PC_41_4:

A. I choose to do what I have to do.

B. I do what I have to, but I do not feel like it is really my choice.

Only **A** feels true	1	2	3	4	5	Only **B** feels true

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to complete

PC_42_4:

A. I feel that I am rarely myself.

B. I feel like I am always completely myself.

Only **A** feels true	1	2	3	4	5	Only **B** feels true

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to complete

PC_43_4:

A. I do what I do because it interests me.

B. I do what I do because I have to.

Only **A** feels true	1	2	3	4	5	Only **B** feels true

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to complete

PC_44_4:

A. I am free to do whatever I decide to do.   **B**. What I do is often not what I'd choose to do.

Only **A** feels true	1	2	3	4	5	Only **B** feels true

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to complete

PC_45_4:

A. My body sometimes feels like a stranger to me.   **B**. My body always feels like me.

Only **A** feels true	1	2	3	4	5	Only **B** feels true

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to complete

PC_15_4:

IWER: Read the following statement to the participant:

How [do/does] [you/he/she] usually handle instructions from the doctor or nurse to do something for [your/his/her] health such as getting blood pressure checked or taking [your/his/her] medications?

IWER: TICK ONE ONLY

1. [I/He/She] [do/does] these things by [myself/himself/herself]
   IWER: Mostly independently (or "self-manage")
2. Other people help [me/him/her/] with these things
   IWER: Together with family members or close friends or staff (("co-manage")
3. Other people do these things for [me/him/her]
   IWER: Mostly managed by others (example family or staff)
4. It changes, sometimes [I/he/she] [get/gets] help, sometimes [I/he/she] [do/does] these thing [myself/himself/herself]
   IWER: It varied

97. Unclear response
98. Don't know
99. Refused to answer

(Wolff and Boyd, 2015 based on 2012 national health and aging trends study)

PC_22_4: [Do/Does] [you/he/she] have a formal written plan (decision agreement plan) in place that includes the support [you/he/she] may need to make decisions about [your/his/her] life?

IWER: By a decision agreement plan we mean is there a plan in place which highlights the individual need for support in making decisions (such as what clothes [you/he/she] wear, how [you/he/she] [spend/spends] [your/his/her] money, where [you/he/she] [live/lives], who [you/he/she] [live/lives] with), as well as specifying what type of support is needed to make decisions and who should provide this support.

IWER: This may be co-decision maker agreement, decision – making assistance agreement or other

1. Yes, In progress
2. Yes full / complete
3. No but have plans make a decision agreement plan
4. No
5. Not needed / did not want
6. No individual plan but organisational protocol in place

97. Unclear response
98. Don't know
99. Refused to answer

PC_23_4:

IWER: SELF REPORT ONLY

If PC_0_4 = 1 or PC_0_4 = 2, then ask PC_23_4. OTHERS GO TO PC_2_4

IWER: Thinking about the year ahead, are there any things you would like to do or achieve in the next year? These can be big or small goals you have.

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to PC _24_4**
5. No **Go to PC _2_4**

93. Unable to understand **Go to PC _2_4**
97. Unclear response **Go to PC _2_4**
98. Don't know **Go to PC _2_4**
99. Refused to answer **Go to PC _2_4**
0. SR not present Proxy NOT to answer question **Go to PC _2_4**

PC_24_4:

What are these things/goals? (open ended question) **(Please specify)**

PC_2_4:

IWER: Ask All Participants

IWER: [Do/Does] [you/he/she] have a personal plan?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

      1.   Yes, **Go to PC_3_4**
      5.   No Go **to PC_5_4**

      97. Unclear response **Go to PC_5_4**
      98. Don't know **Go to PC_5_4**
      99. Refused to answer **Go to PC_5_4**

(IDS-TILDA/National Quality Standards)

PC_3_4:

IWER: ASK ALL PARTICIPANTS

IWER: Does [your/his/her] plan include what support [you/he/she] will need to achieve [your/his/her] goals?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

97. Unclear response **Go to PC_25_4**
98. Don't know **Go to PC_25_4**
99. Refused to answer **Go to PC_25_4**

(IDS-TILDA/National Quality Standards)

PC_25_4:

If PC_0_4 = 1 or PC_0_4 = 2, then ask PC_25_4

Are these things/goals you would like to do, that you mentioned above included in your plan?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to PC_26_4**
5. No **Go to PC_26_4**

93. Unable to understand **Go to PC_26_4**
97. Unclear response **Go to PC_26_4**
98. Don't know **Go to PC_26_4**
99. Refused to answer **Go to PC_26_4**

PC_26_4: (To be completed by interviewer only)

If PC_0_4 = 1 or PC_0_4 = 2, then ask PC_26_4

IWER: Record here if individual and/or proxy needed to check the actual PCP for

this information.

1. Yes, **Go to PC_27_4**
5. No **Go to PC_27_4**
98. Don't Know **Go to PC_27_4**

PC_27_4:

IWER: Ask All Participants

Think about [your/his/her] plan last year, did [you/he/she] achieve the goals included

in [your/his/her] plan?

    1. Yes, all **Go to PC_5_4**
    2. Yes, most **Go to PC_28_4**
    3. Yes, some **Go to PC_28_4**
    4. No none of the goals **Go to PC_28_4**

    97. Unclear response **Go to PC_5_4**
    98. Don't know **Go to PC_5_4**
    99. Refused to answer **Go to PC_5_4**

PC_28_4:

What were the reasons [you/he/she] didn't achieve [your/his/her] goals last year?

PC_5_4:

IWER: [Do/Does] [you/he/she] have a key worker?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

    1. Yes, **Go to PC_9_4**
    5. No **Go to PC_9_4**

    97. Unclear response **Go to PC_9_4**
    98. Don't know **Go to PC_9_4**
    99. Refused to answer **Go to PC_9_4**

(IDS-TILDA/HIQA National Quality Standard)

PC_9_4:

IWER: [Do/Does] [you/he/she] have an independent advocate? An independent advocate

is a person who assists and enables more effective communication and who is

a person outside the normal services [you/he/she] [receive/receives] and can include

family and friends

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

      1. Yes, **Go to PC_9_4**
      5. No **Go to PC_9_4**

      97. Unclear response **Go to PC_9_4**
      98. Don't know **Go to PC_9_4**
      99. Refused to answer **Go to PC_9_4**

(IDS-TILDA/HIQA National Quality Standard)

PC_10_4:

IWER: [Do/Does] [you/he/she] have access to a professional advocacy service, if [you/Rname]

so, wished? This can be provided within the service provider organisation or external to it.

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

      1. Yes, **Go to PC_10A_4**
      5. No **Go to PC_11_4**

      97. Unclear response **Go to PC_11_4**
      98. Don't know **Go to PC_11_4**
      99. Refused to answer **Go to PC_11_4**

(IDS-TILDA/National Quality Standards)

PC_10a_4:

IWER: Is this an internal or external advocate?

                1. Internal
                2. External

                97. Unclear response
                98. Don't know
                99. Refused to answer

(IDS-TILDA)

PC_11_4:

Any Other Information (Personal Choices)

5.1   Quality of Life

PC_46_4:

INTRO: Now I would like to ask you about [your/Rname's] quality of life.

Would you say [your/Rname's] quality of life is...?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

PC_29_4:

IWER: SELF-REPORT ONLY

IF PC_0_4 = 1 or if PC_0_4 = 2, then ask PC_29_4

IWER: Now we are going to ask you some questions about how you feel about your life

and what things make you happy.

IWER: How happy do you feel about your life as a whole?

	Sad (0)	Neither happy or sad (1)	Happy (2)	**SR not present Proxy -NOT to answer question (-0)**
How happy do you feel about your life as a whole?				

Personal wellbeing Index – Intellectual Disability Robert a Cummins

PC_30_4:

IWER: SELF-REPORT ONLY

If PC_0_3 = 1 or if PC_0_3 = 2, then ask **PC_30_4**

How happy do you feel about……?

	Sad (0)	Neither happy or sad (1)	Happy (2)	SR not present - Proxy NOT to answer question (-0)
The things you have? Like the money you have and the things you have and the things you own?				
How healthy you are?				
The things you make or the things you learn?				
Getting on with the people you know?				
How safe you feel?				
Doing things outside your home?				
How things will be later on in your life?				

Personal wellbeing Index – Intellectual Disability Robert A Cummin

5.2 Satisfaction with life scale (SWLS)

PC_SWLS_4:

IWER: SELF-REPORT ONLY

IWER: Below are five statements that you may agree or disagree with.

Using the 1-7 scale below, indicate your agreement with each item by placing the appropriate Number on the line preceding that item.

IWER: Please be open and honest in your responding.

Reference: Diener, E., Emmons, R.A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction with

Life Scale. Journal of Personality Assessment, 49, 71-75.

PC_33_4:

IWER: SELF-REPORT ONLY

In most ways my life is close to my ideal

Strongly agree		7
Agree		5.5
Neither agree nor disagree		4
Disagree		2.5
Strongly disagree		1

PC_34_4:

IWER: SELF-REPORT ONLY

The conditions of my life are excellent

Strongly agree		7
Agree		5.5
Neither agree nor disagree		4
Disagree		2.5
Strongly disagree		1

PC_35__4:

The conditions of my life are excellent

Strongly agree		7
Agree		5.5
Neither agree nor disagree		4
Disagree		2.5
Strongly disagree		1

PC_36_4:

I am satisfied with my life

Strongly agree		7
Agree		5.5
Neither agree nor disagree		4
Disagree		2.5
Strongly disagree		1

PC_37_4:

So far, I have gotten the important things I want in life

Strongly agree		7
Agree		5.5
Neither agree nor disagree		4
Disagree		2.5
Strongly disagree		1

PC_38_4:

If I could live my life over, I would change almost nothing. 85

Strongly agree		7
Agree		5.5
Neither agree nor disagree		4
Disagree		2.5
Strongly disagree		1

6   Section 6: Ageing Perceptions (AP)

AP_0_4:

 IWER: TO BE COMPLETED THE BY INTERVIEWER

 IWER: Who is completing this section

1. Self-report only **Go to AP_1_4**
2. SR and Proxy **Go to AP_1_4**
3. Proxy only **Go to next section**

AP_1_4:

IWER: SELF-REPORT ONLY

IWER: TO BE COMPLETED BY THE INTERVIEWER

NOTE: This is a SELF-REPORT SECTION. Only the SR can answer the questions in this section. It cannot be answered by a proxy.

IWER: Please indicate the status of completion.

IWER: CODE THE ONE THAT APPLIES

SR is present and will be invited to complete (Coded 1)

SR is present but proxy has answered all the questions for SR (link to cautionary note) (Coded 0)

SR is not present - unable to complete (Coded 0)

NOTE: Select this option with caution. Although the proxy has answered all the questions for SR, the SR may be able to complete some of the tasks in this section.

INTRO: We are interested in your own personal views and experience about getting older.

NOTE: Use the following questions as your topic guide.

IWER: When you hear someone described as 'old' what do you think that it means?

IWER: Record the SR's response below.

```



```

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to answer question

(IDS-TILDA)

AP_2_4:

IWER: SELF-REPORT ONLY

IWER: How would you describe yourself, would you say you are a young adult, middle aged, or old?

IWER: CODE THE ONE THAT APPLIES

1. Young adult
2. Middle aged
3. Old
95. Other

Other (please specify)

```



```

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to answer question

(IDS-TILDA)

AP_3_4:

IWER: SELF-REPORT ONLY

IWER: Would you say as you get older, things are…

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. better
2. worse
3. the same

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to answer question

(IDS-TILDA)

AP_4_4:

IWER: SELF-REPORT ONLY

IWER: Are there any good things about getting older?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to AP_5_4**
5. No Go **to AP_6_4**

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to answer question

(IDS-TILDA)

AP_5_4:

IWER: SELF-REPORT ONLY

IWER: What would you say are the good things about getting older?

IWER: Record the SR's response below.

```
┌─────────────────────────────────────────────────────────────────────┐
│                                                                     │
│                                                                     │
│                                                                     │
│                                                                     │
│                                                                     │
└─────────────────────────────────────────────────────────────────────┘
```

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to answer question

(IDS-TILDA)

AP_6_4:

IWER: SELF-REPORT ONLY

IWER: Do you have any concerns or worries about getting older?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

    1. Yes, **Go to AP_7_4**
    5. No **Go to AP_8_4**

    93. Unable to understand **Go to AP_8_4**
    97. Unclear response **Go to AP_8_4**
    98. Don't know **Go to AP_8_4**
    99. Refused to answer **Go to AP_8_4**
    0. SR not present - Proxy NOT to answer question **Go to AP_8_4**

(IDS-TILDA)

AP_7_4:

IWER: SELF-REPORT ONLY

IWER: What might these concerns be?

IWER: Record the SR's response below.

    93. Unable to understand
    97. Unclear response
    98. Don't know
    99. Refused to answer
    0. SR not present - Proxy NOT to answer question

(IDS-TILDA)

AP_8_4:

IWER: Do you think older people can do most things like work, go out, play sport, use the computer etc?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to answer question

(IDS-TILDA)

AP_9_4:

IWER: What activities do you think older people like to do?

IWER: Record the SR's response below.

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to answer question

(IDS-TILDA)

AP_10_4:

IWER: SELF-REPORT ONLY

IWER: Do you think that people who are older can support you?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

<div style="margin-left: 40%;">

1. Yes
5. No

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present - Proxy NOT to answer question

</div>

(IDS-TILDA)

AP_11_4:

Any Other Information (Ageing Perceptions):

7   Section 7: Occupation (OC)

OC_0_4:

IWER: TO BE COMPLETED THE BY INTERVIEWER

IWER: How will this section completed?

1. Self- report only
2. SR and Proxy
3. Proxy only

(TILDA)

OC_2A_4:

INTRO: Now I would like to ask you questions about work and retirement.

Which one of these would you say best describes [your/Rname's] current situation?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Paid Employment (in a shop, restaurant etc
2. Unemployed
3. Retired

95. Other
97. Unclear response **Go to OC_2B_4**
98. Don't know **Go to OC_2B_4**
99. Refused to answer **Go to OC_2B_4**

(IDS-TILDA)

OC_4_4:

IWER: How many hours [do/does] [you/Rname] spend in paid work per week?

Hours: _____

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

OC_7_4:

IWER: In what kind of business, industry or service [do/does] [you/Rname] work in (that is, what did they make or do at the place where [you/Rname] [work/works])?

<div style="text-align: center;">

97. Unclear response
98. Don't know
99. Refused to answer

</div>

(IDS-TILDA)

OC_2A3_4:

What is [your/Rnames] typical wage per week?

<div style="text-align: center;">

97. Unclear response
98. Don't know
99. Refused to answer

</div>

(IDS-TILDA)

OC_2B_4:

[Do/Does] [you/he/she] attend/do any of the following?

				If yes, for how long per week (in hours)	
				Hours	
OC_2B_1_4	In education or training	1		OC_2B_1hrs_4	
OC_2B_2_4	Attend day service/activation in the community	1		OC_2B_2hrs_4	
OC_2B_3_4	Attend day service / activation in a service provider setting	1		OC_2B_3hrs_4	
OC_2B_4_4	Receive day activation at home	1		OC_2B_4hrs_4	
OC_2B_5_4	Attend active age facility	1		OC_2B_5hrs_4	
OC_2B_95_4	Other	95		OC_2B_95hrs_4	
OC_2B_oth_4	(Please specify)	oth			

93. [I/He/She] [don't/doesn't] do anything specific during the day
97. Unclear response
98. Don't know
99. Refused to answer

OC_63_4:

How many days in the last week (including the weekend) did [you/he/she] stay at home all day?

_____ number of days (from 0 to 7)

(If OC_63_3 = 0 Go to OC_65_3, OTHERS GO TO OC_64_3)

> 97. Unclear response **Go to next section**
> 98. Don't know **Go to next section**
> 99. Refused to answer **Go to next section**

OC_64_4:

What were the reasons [you/he/she] did not leave the house?

IWER: Select one only

> 1. Staff / resource issues
> 2. Ill Health
> 3. Bad Weather
> 4. Challenging behaviour
> 5. Mood / didn't feel like it
> 6. Personal choice / didn't want to
> 95. Other (Please specify): _____
>
> 97. Unclear response **Go to next section**
> 98. Don't know **Go to next section**
> 99. Refused to answer

OC_65_4:

Any Other Information (Occupation)

8   Section 8: Learning and Technology (LE)

LE_9_4:

IWER: Ask All Participants

IWER: Now we would like to ask you some questions about reading, writing and numbers

Do you have any difficulty with reading?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

Adapted from Adult Literacy and Life Skills Survey 2003 & International Adult Literacy Survey

LE_11_4:

IWER: Do you have any difficulty with writing?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

Adapted from Adult Literacy and Life Skills Survey 2003 & International Adult Literacy Survey

LE_13_4:

IWER: Do you have any difficulty with numbers e.g. knowing the numbers on a phone or doing some simple sums?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

Adapted from Adult Literacy and Life Skills Survey 2003 & International Adult Literacy Survey

8.1 Technology

LE_17_4: [Do/Does] [you/Rname] own a mobile phone?

      1.   Yes
      5.   No

      97. Unclear response
      98. Don't know
      99. Refused to answer

(IDS-TILDA & Wehmeyer et al 2006)

LE_25_4: [Do/Does] [you/he/she] use [your/his/her] mobile phone?

      1.   Yes
      5.   No
      2.   [I/He/She] [do/does] not know how to use a mobile phone

      97. Unclear response
      98. Don't know
      99. Refused to answer

(IDS-TILDA)

LE_27_4: [Do/Does] [you/he/she] or anyone in your household have access to the internet at home?

      1.   Yes
      5.   No

      97. Unclear response
      98. Don't know
      99. Refused to answer

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LE_28_4: [Do/Does] [you/he/she] use the internet at home?

      1.   Yes
      5.   No

      97. Unclear response
      98. Don't know
      99. Refused to answer

(TILDA)

LE_19_4: [Do/Does] [you/he/she] have access to a computer, laptop, tablet or smartphone on a regular basis?

IWER prompt: For example [do/does] [you/he/she] attend computer classes?

      1. Yes, **Go to LE_26_4**
      5. No **Go to LE_22_4**

      97. Unclear response **Go to LE_22_4**
      98. Don't know **Go to LE_22_4**
      99. Refused to answer **Go to LE_22_4**

(IDS-TILDA)

LE_26_4: How often [do/does] [you/he/she] use a computer, laptop, tablet or smartphone

      1. Most of the time/often
      2. Sometimes
      3. Rarely
      4. Never

      97. Unclear response
      98. Don't know
      99. Refused to answer

(IDS-TILDA)

LE_22_4:

Please answer yes or no to the following statements

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?

LE_22_i_4 for i = 1 to 6

LE_22_1_4: [I/He/She] can type [my/his/her] name on a keyboard

      1. Yes, with assistance
      2. Yes, without assistance
      5. No

(IDS-TILDA)

LE_22_2_4: [I/He/She] can type a letter

      1. Yes, with assistance
      2. Yes, without assistance
      5. No

(IDS-TILDA)

LE_22_3_4: [I/He/She] can turn on a computer

1. Yes, with assistance
2. Yes, without assistance
5. No

(IDS-TILDA)

LE_22_4_4: [I/He/She] can send an email

1. Yes, with assistance
2. Yes, without assistance
5. No

(IDS-TILDA)

LE_22_5_4: [I/He/She] can look up topics of interests on Google

1. Yes, with assistance
2. Yes, without assistance
5. No

(IDS-TILDA)

LE_22_6_4: [I/He/She] can use social media sites such as Facebook, Twitter

1. Yes, with assistance
2. Yes, without assistance
5. No

(IDS-TILDA)

LE_23_4:

Any Other Information (Technology):

9   Section 9: Physical Health (PH)

9.1   Overall Health

PH_0_4:

IWER: Ask All Participants

How will this section be completed?

> 1. Self-Report Only
> 2. Self-Report and Proxy
> 3. Proxy Only

PH_1_4:

INTRO: Now I would like to ask you some questions about [your/Rname's] health.

Would you say [your/Rname's] health is...?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

> 1. Excellent
> 2. Very good
> 3. Good
> 4. Fair
> 5. Poor
>
> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

(ELSA/HRS/SHARE)

PH_2_4: Now thinking about [your/his/her] physical health, which includes physical illness and injury, how many days during the past 30 days was [your/Rname's] physical health not good?

_____ Day(s)   (Constrain to 30 days: 0……….30)

> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

(Health Related Quality of Life)

PH_12_4:
If PH_0_4 = 1 or PH_0_4 = 2 then ask PH_12_4, others go to PH_13_4

IWER: SELF REPORT ONLY

In general, compared to other people [your/his/her] age, would you say [your/Rname's] health is…?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

      1.   Excellent
      2.   Very good
      3.   Good
      4.   Fair
      5.   Poor

      93. Unable to understand
      97. Unclear response
      98. Don't know
      99. Refused to answer
      0.   SR not present - Proxy NOT to complete

(VES)(TILDA)

PH_13_4:

Any Other Information (Overall Health and Functional Limitations):

9.2 Eyesight

PH_14_3:

Is your eyesight (using glasses or contact lenses if you use them)?

1. Excellent **Go to PH_15_4**
2. Very good **Go to PH_15_4**
3. Good **Go to PH_15_4**
4. Fair **Go to PH_15_4**
5. Poor **Go to PH_15_4**
6. Registered or legally blind Go **to PH_17_4**

97. Unclear Response **Go to PH_15_4**
98. Don't Know **Go to PH_15_4**
99. Refused to Answer **Go to PH_15_4**

(ELSA/HRS/SHARE/TILDA)

PH_15_3:

How good is [your/his/her] eyesight for seeing things at a distance, like recognizing a friend across the street (using glasses or corrective lens if [you/he/she] [use/uses] them)?

Would you say it is...?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

97. Unclear Response
98. Don't Know
99. Refused to Answer

(ELSA/ HRS/ SHARE)

PH_16_3:

How good is [your/his/her] eyesight for seeing things up close, for example like reading ordinary newspaper print or looking at photographs (using glasses or corrective lens if [you/he/she] [use/uses] them)? Would you say it is…?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

        1. Excellent
        2. Very good
        3. Good
        4. Fair
        5. Poor

        97. Unclear Response
        98. Don't Know
        99. Refused to Answer

(ELSA/ HRS/ SHARE)

PH_17_4:

[Have/Has] [you/he/she] been prescribed glasses or contact lenses?

        1. Yes, **Go to PH_18_4**
        5. No **Go to PH_20_4**

        97. Unclear Response **Go to PH_20_4**
        98. Don't Know **Go to PH_20_4**
        99. Refused to Answer **Go to PH_20_4**

(Adapted form CHAP)

PH_18_4:

[Do/Does] [you/he/she] usually wear ordinary glasses, bifocals or contact lenses?

IWER: CODE THE ONE THAT APPLIES

        1. Ordinary glasses
        2. Bifocals
        3. Contact Lenses

        97. Unclear Response
        98. Don't Know
        99. Refused to Answer

(TILDA)

PH_20_4:

When was [your/Rname's] last eye exam?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Less than one year **Go to PH_300a_4**
2. One-three years ago **Go to PH_300a_4**
3. More than three years ago **Go to PH_21_4**
4. Never **Go to PH_21_4**

97. Unclear Response **Go to PH_300a_4**
98. Don't Know **Go to PH_300a_4**
99. Refused to Answer **Go to PH_300a_4**

(Adapted from Special Olympics – H.A.S. Opening Eyes Screening Form)

PH_21_4:

Can you tell me the reasons why [you/he/she] [haven't/hasn't] had an eye exam recently?

IWER: READ OUT AND CODE ALL THAT APPLY

PH_21_i_4 for i = 1 to7, 95, oth, 97, 98,99

1. The environment is not accessible e.g. the chair is too high, no wheelchair access
1. No need
1. [I/He/She] [don't/doesn't] get enough time at [my/his/her] appointment
1. [I/He/She] [have/has] to wait too long in the waiting room
1. Fear
1. Transport
1. Cost
95. Other (Please tell us)

Please tell us

| |
| |

97. Unclear Response
98. Don't Know
99. Refused to Answer

(IDS-TILDA)

9.3 Eye Disease

The logic for creating the above variable is as follows:

FOR i = 01 TO 03

IF (intstatusW4 = 1 & PH_300_iFF (Fed forward from wave 3) = 1) THEN PH_300_iFF_4 = 1; Otherwise PH_300_iFF_4 =0

IF (INTSTATUSW4 = 1 & PH_300_iFF_4_01-03=1), ASK PH_300a_4

ALL OTHERS GO TO PH_300_4

PH_300a_4:

Last time you were interviewed, you told us that you [had] (insert conditions from PH_300FFW3_i). PAUSE

> 1. Continue GO TO PH_300Y_i_4
> 2. Respondent disputes having one/all of these conditions

CONDITION DISPUTED

PH_300X0_4:

IWER: Which of the conditions is being disputed

> 1. Cataracts (display if PH_300_01FF_4 =1)
>   [PH_300X0_01_4]
> 2. Glaucoma (display PH_300_02FF_4 =1)
>   [PH_300X0_02_4]
> 3. Age related macular degeneration (display if
> 4. PH_300_03FF_4=1)
>   [PH_300X0_03_4]

IF (PH_300X0_01_4=1) THEN ASK

PH_300X_01_4:

It may be that we have a recording error about you having Cataracts.

IWER: Can you confirm, that… READ OUT.

> 1. You never had Cataracts (error from previous wave)
> 2. Cataracts were misdiagnosed

IF (PH_300X0_02_4=1) THEN ASK

PH_300X_02_4:

IWER: It may be that we have a recording error about you having Glaucoma. Can you confirm, that ...READ OUT.

          1. You never had Glaucoma (error from previous wave)
          2. Glaucoma was misdiagnosed

IF (PH_300X0_3_4=1) THEN ASK

PH_300X_03_4:

IWER: It may be that we have a recording error about you having Age related macular degeneration. Can you confirm, that ...READ OUT.

          1. You never had Age related macular degeneration (error from previous wave)
          2.   Age related macular degeneration was misdiagnosed

IF (PH_300_01FF_4 = 1 & PH_300a_4 = 1,2 & PH_300X0_01_4≠ 1), ASK PH_300Y_01_4. OTHERS GO TO PH_300Y_02_4

PH_300Y_01_4: Do you still have Cataracts?

          1. Yes
          5. No

IF (PH_300_02FF_4= 1 & PH_300a_4= 1,2 & PH_300X0_02_4≠ 1), ASK PH_300Y_02_4. OTHERS GO TO PH_300Y_03_4

PH_300Y_02_4: Do you still have Glaucoma?

          1. Yes
          5. No

PH_300Y_03_4: Do you still have Age related macular degeneration?

          1. Yes
          5. No

PH_300_4:

IF (intstatusW4 = 2), USE WORDING 'B', OTHERWISE USE WORDING 'A'

A. Has a doctor ever told [you/Rname] that [you/he/she] [have/has] any of the following [other] eye diseases?
B. Has a doctor ever told [you/Rname] that [you/he/she] [have/has] any of the following eye diseases? [DISPLAY ALL CONDITIONS]

IWER: READ OUT. CODE ALL THAT APPLY.

1. Cataracts **Go To PH_300_01_4**
2. Glaucoma **Go to PH_300_02_4**
3. Age related macular degeneration **Go to PH_300_03_4**
4. Keratoconus **Go to PH_300_04_4**
95. Other (please specify) **Go to PH_300_95_4] [PH_300_oth_4]**

96. None **Go to PH_300_96_4**
97. Unclear response **Go to PH_300_97_4**
98. DK **Go to PH_300_98_4**
99. RF **Go to PH_300_99_4**

(ELSA)

IF (PH_300_01_4=1), ASK PH_300Yb_01_4. OTHERS GO TO PH_300Yb_02_4

PH_300Yb_01_4: Do you still have Cataracts?

1. Yes
5. No

IF (PH_300_02_4=1), ASK PH_300Yb_02_4. OTHERS GO TO PH_300Yb_03_4

PH_300Yb_02_4: Do you still have Glaucoma?

1. Yes
5. No

IF (PH_300_03_4=1), ASK PH_300Yb_03_4. OTHERS GO TO PH_300Yb_04_4

PH_300Yb_03_4: Do you still have Age related macular degeneration?

      1. Yes
      5. No

IF (PH_300_04_4=1), ASK PH_300Yb_04_4. OTHERS GO TO PH_301_4

PH_300Yb_04_4: Do you still have keratoconus?

      1. Yes
      5. No

IF ((PH_300 _01_4= 1) OR (PH_300_01FF_4= 1 & PH_300a_4= 1, 2 & PH_300X0_01_4≠ 1)) THEN ASK PH_301_4.

OTHERS GO TO PH_22_4

PH_301_4: [Have/Has] [you/he/she] had cataract surgery?

      1. Yes, one eye
      2. Yes both eyes
      3. No

      97. UR
      98. DK
      99. RF

(ELSA/ HRS)

PH_22_3:

Any other information (Eyesight):

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9.4 Hearing

PH_24a_4: [Do/Does] [you/he/she] use any of the following aids or appliances to help [you/him/her] with [your/his/her] hearing?

1. Hearing aid (all the time) **Go to PH_24a_01_4**
4. Hearing aid (most of the time) **Go to PH_24a_02_4**
2. Hearing aid (some of the time) **Go to PH_24a_03_4**
95. Other hearing support (please specify) **Go to PH_24a_95_4** [**PH_24aOTH_4**]

96. None of the above **Go to PH_24a_96_4**
97. UR **Go to PH_24a_97_4**
98. DK **Go to PH_24a_98_4**
99. RF **Go to PH_24a_99_4**

PH_25a_4: Is [your/his/her] hearing (without a hearing aid) …?

 IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Excellent **Go to PH_25b_4**
2. Very good **Go to PH_25b_4**
3. Good **Go to PH_25b_4**
4. Fair **Go to PH_25b_4**
5. Poor **Go to PH_25b_4**
94. Not applicable – deaf **Go to PH_25b_4**

97. Unclear response **Go to PH_25b_4**
98. Don't know **Go to PH_25b_4**
99. Refused to answer **Go to PH_25b_4**

(ELSA/ HRS/ SHARE/IDS-TILDA)

PH_25b_4:

IF (PH_24a__96_4 = 1 OR   IF PH_24a__97_4 = 1 OR IF PH_24a__98_4 = 1 OR IF PH_24a__99_4 = 1)
skip PH_25b_4 and go to PH_26_4

1. Excellent **Go to PH_26_4**
2. Very good **Go to PH_26_4**
3. Good **Go to PH_26_4**
4. Fair **Go to PH_26_4**
5. Poor **Go to PH_26_4**
95. Not applicable – deaf **Go to PH_28_4**

97. Unclear response **Go to PH_26_4**
98. Don't know **Go to PH_26_4**
99. Refused to answer **Go to PH_26_4**

(ELSA/ HRS/ SHARE/IDS-TILDA)

PH_26_4: Can [you/he/she] follow a conversation with one person (with or without a hearing aid)?

NOTE: If SR asks, the environment to think of should be non-noisy, i.e. their home.

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. No difficulty **Go to PH_27_4**
2. Some difficulty **Go to PH_27_4**
3. Much difficulty **Go to PH_27_4**
4. Cannot do at all **Go to PH_28_4**

97. Unclear response **Go to PH_27_4**
98. Don't know **Go to PH_27_4**
99. Refused to answer **Go to PH_27_4**

(TILDA)

PH_27_4: Can [you/he/she] follow a conversation with four people (with or without a hearing aid)?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. No difficulty
2. Some difficulty
3. Much difficulty
4. Cannot do at all

97. Unclear response
98. Don't know
99. Refused to answer

(TILDA)

PH_28_4: When was [your/Rname's] last hearing test?

1. Less than one year **Go to PH_140_4**
2. One-three years ago **Go to PH_140_4**
3. More than three years ago **Go to PH_29_4**
4. Never **Go to PH_29_4**

97. Unclear response **Go to PH_140_4**
98. Don't know **Go to PH_140_4**
99. Refused to answer **Go to PH_140_4**

(IDS-TILDA/Adapted from Special Olympics)

PH_29_4: Can you tell me why [you/he/she] [haven't/hasn't] had [your/his/her] hearing tested recently?

IWER: READ OUT AND CODE ALL THAT APPLY

PH_29_i_4 for i = 1 to 7, 95, oth, 97, 98, 99

1. The environment is not accessible e.g. the chair is too high, no wheelchair access
1. No need
1. [I/He/She] [don't/doesn't] get enough time at [my/his/her] appointment
1. [I/He/She] [have/has] to wait too long in the waiting room
1. Fear
1. Transport
1. Cost
95. Other (Please tell us)

Please tell us

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

PH_140_4:

If PH_25b_4=94 skip PH_140_4 and go to PH_30_4

Do you feel [you/he/she] [have/has] a hearing loss?

IWER: READ OUT

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

(TILDA)

PH_30_4:

Any Other Information (Hearing)

9.5 General Communication

INTROD: Now I would like to ask you a couple of questions about the day-to-day communication [you/Rname] [use/uses].

[Do/Does] [you/Rname] have any difficulty speaking or making [yourself/himself/herself] understood when speaking?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. No difficulty **Go to PH_32_4**
2. Some difficulty **Go to PH_32_4**
3. Much difficulty **Go to PH_32_4**
4. Cannot do at all **Go to PH_32_4**

97. Unclear response **Go to PH_33_4**
98. Don't know **Go to PH_33_4**
99. Refused to answer **Go to PH_33_4**

(NDS)

PH_32_4: How well [are/is] [you/he/she] able to make [yourself/himself/herself] understood when speaking with ……….?

IWER: READ OUT AND CODE ONE BOX ON EACH LINE

PH_32_i_4 for i = 1 to 4

	Completely		Partially		Not at all		Unclear Response		Don't know		Refused to answer		Not Applicable	
Members of [your/his/her] own family	1		2		3		97		98		99		94	
[Your/His/Her] friends	1		2		3		97		98		99		94	
Professionals and service providers such as doctors and home help workers	1		2		3		97		98		99		94	
Other people	1		2		3		97		98		99		94	

(NDS)

PH_33_3:

Any other information (General communication):

9.6   Oral Health

PH_0B4:

IWER: How will this section be completed?

1. Self-Report Only
2. Self-Report and Proxy
3. Proxy Only

PH_34_4:

INTRO: I would now like to ask you some questions about [your/Rname's] oral health.

Which best describes the teeth [you/he/she] [have/has]?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. [I/He/She] [have/has] all [my/his/her] own natural teeth – none missing **Go to PH_124_4**
2. [I/He/She] [have/has] [my/his/her] own teeth, no dentures / but some missing **Go to PH_124_4**
3. [I/He/She] [have/has] dentures as well as some of [my/his/her] own teeth **Go to PH_124_4**
4. [I/He/She] [have/has] full dentures **Go to PH_124_4**
5. [I/He/She] [have/has] no teeth or dentures **Go to PH_124_4**

97. Unclear response **Go to PH_124_4**
98. Don't know **Go to PH_124_4**
99. Refused to answer **Go to PH_124_4**

(Adapted from SLAN) (comparable to wave 1)

PH_124_4: Would you say [your/Rname's] dental health (mouth, teeth and or dentures) is

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Excellent **Go to PH_38_4**
2. Very good **Go to PH_38_4**
3. Good **Go to PH_38_4**
4. Fair **Go to PH_38_4**
5. Poor **Go to PH_38_4**

97. Unclear response **Go to PH_38_4**
98. Don't know **Go to PH_38_4**
99. Refused to answer **Go to PH_38_4**

(TILDA)

PH_38_4: How often [do/does] [you/he/she] brush [your/his/her] teeth or dentures/have them brushed OR how often [do/does] [you/he/she] clean [your/his/her] mouth/have it cleaned for [you/him/her]?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Once or more a day **Go to PH_118_4**
2. Two to six times per week **Go to PH_118_4**
3. Once per week **Go to PH_118_4**
4. Less than once per week **Go to PH_118_4**
5. Never **Go to PH_118_4**

97. Unclear response **Go to PH_118_4**
98. Don't know **Go to PH_118_4**
99. Refused to answer **Go to PH_118_4**

(Adapted from SLAN)

PH_118_4: What best describes the physical help [you/he/she] [get/gets] from someone else to clean [your/his/her] teeth?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. [I/He/She] [clean/cleans] [my/his/her] teeth [myself/himself/herself] without help **Go to PH_117_4**
2. [I/He/She] [clean/cleans] [my/his/her] teeth with a little help **Go to PH_117_4**
3. [I/He/She] [clean/cleans] [my/his/her] teeth with a lot of help **Go to PH_117_4**
4. [I/He/She] [do/does] not clean [my/his/her] teeth **Go to PH_117_4**
5. [I/He/She] [don't/doesn't] have any teeth to clean **Go to PH_117_4**

97. Unclear response **Go to PH_117_4**
98. Don't know **Go to PH_117_4**
99. Refused to answer **Go to PH_117_4**

(IDS_TILDA) (reworked)

PH_117_4: Which of these best describes the toothbrush you use?

IWER: Read out and code all that apply

PH_117_i_4 for i = 1 to 3, 95, oth, 96

2. [I/He/She] use a standard toothbrush **Go to PH_117A_4**
3. [I/He/She] use a modified toothbrush (like a Superbrush or a brush with a special handle) **Go to PH_117A_4**
4. [I/He/She] use an electric tooth-brush **Go to PH_117A_4**
95. Other (Please specify) **Go to PH_117A_4**
96. [I/He/She] [don't/doesn't] use any **Go to PH_117A_3**
97. Unclear response **Go to PH_117A_4**
98. Don't know **Go to PH_117A_4**
99. Refused to answer **Go to PH_117A_4**

(IDS-TILDA)

PH_117A_4: Do you use floss or interdental cleaners regularly (At least once a week)?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

PH_117B_4: Do you have a current Oral Healthcare Plan in place?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

PH_119_4:

If PH_118_4 = 2 or PH_118_4 = 3 ask PH_119_4 others go to PH_39_4

Which of these best describes how [you/he/she] [clean/cleans] [your/his/her] teeth?

IWER: READ OUT AND CODE ALL THAT APPLY

PH_119_i_4 for i = 1 to 5, 95, oth, 97, 98, oth, 99

1. Some degree of holding still is used when cleaning [my/his/her] teeth **Go to PH_39_4**
2. A second toothbrush is used to bite on during tooth cleaning **Go to PH_39_4**
3.   Another person places their hand over [my/his/her] hand to improve [my/his/her] tooth cleaning **Go to PH_39_4**
4. Another person cleans [my/his/her] teeth after [I/he/she] [clean/cleans] them **Go to PH_39_4**
5. [I/He/She] [am/is] supervised/reminded/encouraged while [I/he/she] [clean/cleans] [my/his/her] teeth **Go to PH_39_4**
95. Other (Please Specify) **Go to PH_39_4**

97. Unclear response **Go to PH_39_4**
98. Don't know **Go to PH_39_4**
99. Refused to answer **Go to PH_39_4**

(IDS-TILDA)

PH_39_4: When was the last time [you/he/she] visited a dentist or dental hygienist?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Less than a year ago **Go to PH_120_4**
2. One to two years ago **Go to PH_120_4**
3. More than two years **Go to PH_120_4**
4. Never **Go to PH_123_4**

97. Unclear response **Go to PH_123_4**
98. Don't know **Go to PH_123_4**
99. Refused to answer **Go to PH_123_4**

(Adapted from SLAN)

PH_120_4: What treatment did [you/he/she] get when you last visited with the dentist or dental hygienist?

IWER: READ OUT AND CODE ALL THAT APPLY

PH_120_i_4 for i = 1 to 6, 94,95, oth, 97,98, 99

    1. Check-up **Go to PH_123_4**
    1. Gum/tooth cleaning (scale / polish) **Go to PH_123_4**
    1. Extraction **Go to PH_123_4**
    1. Filling **Go to PH_123_4**
    1. Preventive treatment like Fissure sealants or fluoride varnish **Go to PH_123_4**
    1. Advice on how to brush your teeth **Go to PH_123_4**
    94. None **Go to PH_123_4**
    95. Other (Please tell us) **Go to PH_123_4**

    97. Unclear response **Go to PH_123_4**
    98. Don't know **Go to PH_123_4**
    99. Refused to answer **Go to PH_123_4**

(IDS-TILDA)

PH_123_4: If [you/he/she] needed a routine dental visit who would [you/he/she] visit?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

    1. A HSE dentist or hygienist
    2. A general dentist or hygienist, on the medical card
    8. A general dentist or hygienist, privately
    95. Other (Please Specify)

    97. Unclear response
    98. Don't know
    99. Refused to answer

(modified from TILDA)

PH_123A_4: If [you/he/she] needed a routine dental visit, where does would this visit take place?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

    1. At the dentists'
    2. At my home / workplace or day service
    95. Other (Please Specify)

    97. Unclear response
    98. Don't know
    99. Refused to answer

PH_124_4: Do you have any recommendations that would improve your dental visits?

PH_43_4:

Any Other Information (Oral Health):

9.7 Heart Conditions

INTRO: Read out: We are interested in finding out more information about heart problems people may suffer from.

PH_0B2_4: How will this section be completed?

1. Self-Report Only
2. Self-Report and Proxy
3. Proxy Only

INTRO: READ OUT We are interested in finding out more information about heart problems people may suffer from.

IF (INTSTATUSW4 = 1 & PH_310_01-12FF_4=1), GO TO PH_310a_4. ALL OTHERS GO TO PH_310_4.

PH_310a_4:

Last time you were interviewed, you told us that you had (insert conditions from PH_310_iFF_4).

1. Continue (go to PH_310Y_i_4)
2. Respondent disputes having one/all of these conditions

CONDITION DISPUTED

PH_310X0:

IWER: Which of the conditions is being disputed

1. High blood pressure or hypertension   (display if PH_310_01FF_4= 1)

2. Angina   (display if PH_310_02FF_4 = 1)

3. A heart attack (inc. myocardial infarction or coronary thrombosis) (display if PH_310_03FF_4 = 1)

4. Congestive heart failure   (display if PH_310_04FF_4 = 1)

5. Diabetes or high blood sugar   (display if PH_310_05FF_4 = 1)

6. A stroke (cerebral vascular disease)   (display if PH_310_06FF_4 = 1)

7. Ministroke or TIA   (display if PH_310_07FF_4 = 1)

8. High cholesterol   (display if PH_310_08FF_4 = 1)

9. A heart murmur   (display if PH_310_09FF_4 = 1)

10. Abnormal heart rhythm   (display if PH_310_10FF_4 = 1)

11. Atrial fibrillation   (display if PH_310_11FF_4 = 1)

12. An abnormal heart rhythm (not atrial fibrillation)   (display if PH_310_12FF_4 = 1

IWER: ASK FOR EACH SELECTION AT PH_310X0

PH_310X_01-PH_310X_12 It may be that we have a recording error about you having [condition selected at PH_310X0]. Can you confirm that …READ OUT.

1. You never had [condition selected at PH_310X0] (error from previous wave)
2. [condition selected at PH_310X0] was misdiagnosed

IF (PH_310_01FF_4 = 1 & PH_310a_4= 1,2 & PH_310X0_01 ≠ 1), ASK PH_310Y_01_4. OTHERS GO TO PH_310Y_02_4

PH_310Y_01_4: Do you still have High blood pressure or hypertension?

1. Yes
5. No

IF (PH_310_02FF_4 = 1 & PH_310a_4= 1,2 & PH_310X0_02 ≠ 1), ASK PH_310Y_02_4. OTHERS GO TO PH_310Y_03_4

PH_310Y_02_4: Do you still have Angina?

1. Yes
5. No

IF (PH_310_04FF_4 = 1 & PH_310a_4= 1,2 & PH_310X0_04 ≠ 1), ASK PH_310Y_04_4. OTHERS GO TO PH_310Y_/05_4

PH_310Y_04_4: Do you still have Congestive heart failure?

1. Yes
5. No

IF (PH_310_05FF_4 = 1 & PH_310a_4= 1,2 & PH_310X0_05 ≠ 1), ASK PH_310Y_05_4. OTHERS GO TO PH_310Y_08_4

PH_310Y_05_4: Do you still have Diabetes or high blood sugar?

1. Yes
5. No

IF (PH_310_08FF_4 = 1 & PH_310a_4= 1,2 & PH_310X0_08 ≠ 1), ASK PH_310Y_08_4. OTHERS GO TO PH_310Y_09_4

PH_310Y_08_4: Do you still have High cholesterol?

    1. Yes
    5. No

IF (PH_310_09FF_4 = 1 & PH_310a_4= 1,2 & PH_310X0_09 ≠ 1), ASK PH_310Y_09_4. OTHERS GO TO

PH_310Y_09_4: Do you still have a heart murmur?

    1. Yes
    5. No

If (PH_310_10FF_4 = 1), ASK PH_311_4. Others go to PH_310Y_11_4

PH_311_4: With regards to your abnormal heart rhythm, can you tell me if that was "Atrial Fibrillation" or not?

IWER: CODE ONE ONLY

    1. Atrial Fibrillation
    2. An abnormal heart rhythm (not Atrial Fibrillation)

    97. Unclear response
    98. Don't know
    99. Refused to answer

IF (PH_311_4= 1) OR (PH_310_11FF_4 = 1 & PH_310X0_11 ≠ 1) ASK PH_310Y_11_4, OTHERS GO TO PH_310Y_12_4

PH_310Y_11_4: Do you still have Atrial Fibrillation

    1. Yes, **Go To PH_310_4**
    5. No **Go To PH_310_4**

IF (PH_311_4= 2) OR (PH_310_12FF_4= 1 & PH_310A_4 = 1,2 & PH_310X0_12 ≠ 1), ASK PH_410Y_12_4, OTHERS GO TO PH_310_4

PH_310Y_12_4: Do you still have an abnormal heart rhythm (not Atrial Fibrillation)?

    1. Yes **Go To PH_310_4**
    5. No **Go To PH_310_4**

IF (INTSTATUSW4 = 2), USE WORDING 'B'. ALL OTHERS, USE WORDING 'A'.

PH_310_4:

A. Since [your/his/her/the] last interview, has a doctor ever told [you/Rname] that [you/he/she] [have/has] any of the [other] conditions on this card?
B. Has a doctor ever told [you/Rname] that [you/he/she] [have/has] any of the conditions on this card?

IWER: PROBE - 'WHAT OTHERS?' CODE ALL THAT APPLY.

1. High blood pressure or hypertension **[Go To PH_310_01_4]**
2. Angina **[Go To PH_310_02_4**]
3. A heart attack (including myocardial infarction or coronary thrombosis) **[Go To PH_310_03_4]**
4. Congestive heart failure [**Go To PH_310_04_4]**
5. Diabetes or high blood sugar **[Go To PH_310_05_4]**
6. A stroke (cerebral vascular disease) [**Go To PH_310_06_4**]
7. Ministroke or TIA **[Go To PH_310_07_4]**
8. High cholesterol **[Go To PH_310_08_4]**
9. A heart murmur **[Go To PH_310_09_4]**
11. Atrial Fibrillation **[Go To PH_310_11_4]**
12. An abnormal heart rhythm (not atrial fibrillation) **[Go To PH_310_12_4]**
95. Any other heart trouble (please specify) **[Go To PH_310_95_4] [PH_310oth_4]**
96. None of these **[Go To PH_310_96_4]**

97. Unclear response **[Go to PH_310_97_4]**
98. Don't know **[Go to PH_310_98_4]**
99. Refused to answer **[Go to PH_310_99_4]**

(ELSA/ similar questions in HRS/ SHARE)

IF (PH_310_01_4 =1), ASK PH_310Yb_01_4. OTHERS GO TO PH_310Yb_02_4

PH_310Yb_01_4: Do you still have High blood pressure or hypertension?

1. Yes
5. No

PH_310Y_02_4: Do you still have Angina?

1. Yes
5. No

IF (PH_310_04FF_4 = 1 & PH_310a_4= 1,2 & PH_310X0_04 ≠ 1), ASK PH_310Y_04_4. OTHERS GO TO PH_310Y_/05_4

PH_310Y_04_4: Do you still have Congestive heart failure?

1. Yes
5. No

IF (PH_310_05FF_4 = 1 & PH_310a_4= 1,2 & PH_310X0_05 ≠ 1), ASK PH_310Y_05_4. OTHERS GO TO PH_310Y_08_4

PH_310Y_05_4: Do you still have Diabetes or high blood sugar?

1. Yes
5. No

IF (PH_310_08FF_4 = 1 & PH_310a_4= 1,2 & PH_310X0_08 ≠ 1), ASK PH_310Y_08_4. OTHERS GO TO PH_310Y_09_4

PH_310Y_08_4: Do you still have High cholesterol?

1. Yes
5. No

IF (PH_310_11_4=1) ASK PH_310Yb_11_4, OTHERS GO TO PH_310Yb_12_4

PH_310Yb_11_4: Do you still have Atrial Fibrillation?

1. Yes, **Go To PH_310b_4**
5. No **Go To PH_310b_4**

IF (PH_310_12_4=1), ASK PH_410Y_12_4, OTHERS GO TO PH_312_4

PH_310Yb_12_4: Do you still have an abnormal heart rhythm (not Atrial Fibrillation)?

1. Yes, **Go To PH_312_4**
2. No **Go To PH_312_2**

IF (PH_310_01_4= 1), ASK PH_312_4

PH_312_4: When [were/was] [you/Rname] first told by a doctor that [you/he/she] had high blood pressure?

(MM/YYYY)

_____/_____   [**PH_312m_4**][**PH_312y_4**]

_____ UR DK RF MONTH

_____UR DK RF YEAR

(ELSA/HRS)

IF (PH_310_01_4= 1) OR (PH_310_01FF1_4 = 1 & PH_310a_4= 1,2 & PH_310X0_01 ≠ 1), ASK PH_312a_4.

PH_312a_4: [Is/Are] [you/he/she] currently doing any of the following to manage [your/his/her] blood pressure? (Select all that apply)

  1. Taking medications [**Go To PH_312a_01_4**]
  2. Lifestyle changes (e.g. diet, exercise, etc.) **[Go To PH_312a_02_4]**
  95. Other **[Go To PH_312a _95_4]**
  96. None of the above **[Go To PH_312a _96_4]**
  97. UR **[Go To PH_312a _97_4]**
  98. DK **[Go To PH_312a _98_4]**
  99. RF **[Go To PH_312a _99_4]**

IF (PH_310_02_4= 1), ASK PH_313_4.

PH_313_4: When [were/was] [you/he/she] first told by a doctor that [you/he/she] had angina? (MM/YYYY)

_____/_____   [PH_313m_4] [PH_313y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

(ELSA/HRS)

IF (PH_310_02_4 = 1 OR PH_310Y_02_4=1), ASK PH_314_4. OTHERS GO TO PH_315_4.

PH_314_4: [Are/Is] [you/he/she] limiting [your/his/her] usual activities because of [your/his/her] angina?

  1. Yes
  5. No
  97. UR
  98. DK
  99. RF

(HRS)

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IF (PH_310_03_4 = 1), GO TO PH_315_4. OTHERS GO TO PH_318_4.

PH_315_4: When [were/was] [you/Rname] first told by a doctor that [you/he/she] had a heart attack (including myocardial infarction or coronary thrombosis)?

(MM/YYYY)

_____/_____   [PH_315m_4] [PH_315y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

IF (PH_310_03_4= 1), GO TO PH_316_4. OTHERS GO TO PH_318_4

PH_316_4: According to the doctor how many heart attacks [have/has] [you/he/she] had?

_____ Number

     97. UR
     98. DK
     99. RF

(ELSA)

IF (PH_316_4 > 1), ASK PH_317_4. OTHERS GO TO PH_318_4

PH_317_4: In what year/month was [your/his/her] (most recent) heart attack?

(MM/YYYY)

_____/_____   [PH_317m_4] [PH_317y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

(HRS)

PH_318_4:

    1. Yes, **Go To PH_319_4**
    5. No **Go To PH_321b_4**

    97. UR   **Go To PH_321b_4**
    98. DK **Go To PH_321b_4**
    99. RF **Go To PH_321b_4**

PH_319_4:

In what year/month was your] (most recent) heart attack?

(MM/YYYY)

_____/_____   [PH_319m_4] [PH_319y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

(HRS)

PH_320_4:

According to your doctor, how many heart attacks have] you had since your] last interview?

_____ Number

     97. UR
     98. DK
     99. RF

(ELSA)

IF (INTSTATUSW4=1) & ((PH_310_02FF_4 = 1 & PH_310X0_02 ≠ 1) OR (PH_310_03FF_4 = 1 & PH_310X0_03 ≠ 1)), GO TO PH_321b_4. OTHERS GO TO PH_321_4

PH_321_4: [Have/Has] [you/he/she] ever had an angioplasty or Stent?

    1. Yes,   **Go to PH_322_4**
    5. No   **Go to PH_323_4**
    97. UR   **Go to PH_323_4**
    98. DK   **Go to PH_323_4**
    99. RF   **Go to PH_323_4**

PH_322_04:

In what year/month was [your/his/her] last angioplasty or Stent?

(MM/YYYY)

_____/_____   **[Go To PH_322m_4] [PH_322y_4]**

_____ UR DK RF MONTH

_____ UR DK RF YEAR

PH_323_4: [Have/Has] [you/he/she] ever had open heart surgery?

1. Yes, **Go To PH_324_4**
5. No **Go To PH_325_4**
97. UR **Go To PH_325_4**
98. DK **Go To PH_325_4**
99. RF **Go To PH_325_4**

PH_324_4: In what year/month was [your/his/her] last heart surgery?

(MM/YYYY)

_____/_____   Go To PH_325_4   [**Go To PH_324_4m] [PH_324_4y]**

_____ UR DK RF MONTH   Go To PH_325_4

_____ UR DK RF YEAR   Go To PH_325_4

IF (INTSTATUSW3=1) & ((PH_310_02FF_4 = 1 & PH_310X0_02 ≠ 1) OR (PH_310_03FF_4 = 1 & PH_310X0_03 ≠ 1)), GO TO PH_321b. OTHERS GO TO PH_325_4.

PH_321b_4: Since your last interview, have you had an angioplasty or Stent?

1. Yes, **Go to PH_322b_4**
5. No **Go to PH_323b_4**
97. UR **Go to PH_323b_4**
98. DK **Go to PH_323b_4**
99. RF **Go to PH_323b_4**

PH_322b_4:

In what year/month was your last angioplasty or Stent?

(MM/YYYY)   [PH_322bm_4] [PH_322by_4]

_____/_____

_____ UR DK RF MONTH

_____ UR DK RF YEAR

PH_323b_4: Since your last interview, have you had open heart surgery?

1. Yes, **Go To PH_324b_4**
5. No **Go To PH_325_4**
97. UR **Go To PH_325_4**
98. DK **Go To PH_325_4**
99. RF Go **To PH_325_4**

PH_324b_4: In what year/month was your last heart surgery?

(MM/YYYY)

_____/_____   [PH_324bm_4] [PH_324by_4]

_____UR DK RF MONTH

_____UR DK RF YEAR

IF (PH_310_04_4= 1), ASK PH_325_4, OTHERS GO TO PH_326_4 PH_325_4

PH_325_4: When [were/was] [you/he/she] first told by a doctor that [you/he/she] had congestive heart failure?

(MM/YYYY)

_____/_____   [PH_325m_4] [PH_325y_4]

_____ UR DK RF MONTH

_____UR DK RF YEAR

IF (PH_310_05_4= 1), ASK PH_326_4. OTHERS GO TO PH_327_4

PH_326_4: When [were/was] [you/he/she] first told by a doctor that [you/he/she] had diabetes or high blood sugar?

(MM/YYYY)

_____/_____   [PH_326m_4][PH_326y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

(ELSA)

IF PH_310_05_4 = 1, ASK PH_327_4, OTHERS GO TO PH_328_4.

PH_327_4: What type of diabetes [do/does] [you/Rname] have?

    1. Type I
    2. Type II
    95. Other

    97. UR
    98. DK
    99. RF

IF (PH_310_05_4= 1 OR PH_310_05FF1_4 = 1 & PH_310X0_05 ≠ 1), ASK PH_328_4. OTHERS GO TO PH_329_4.

PH_328_4: [Are/Is] [you/Rname] currently doing any of the following:

IWER: Select all that apply

1. Taking medication, other than insulin, for diabetes	**[PH_328_01_4]**
2. Taking insulin injections	**[PH_328_02_4]**
3. Taking other injections for diabetes	**[PH_328_03_4]**
4. Lifestyle changes (e.g. diet, exercise, etc.) to manage diabetes	**[PH_328_04_4]**
95. Other	**[PH_328_95_4]**
96. None of these	**[PH_328_96_4]**
97. UR	**[PH_328_97_4]**
98. DK	**[PH_328_98_4]**
99. RF	**[PH_328_99_4]**

IF (PH_310_05= 1) OR (PH_310_05FF_4 = 1 & PH_310X0_05 ≠ 1), ASK PH_329_4. OTHERS GO TO PH_330_4

PH_329_4:

1. Leg ulcers	**[PH_329_01_4]**
2. Protein in [your/his/her] urine	**[PH_329_02_4]**
3. Lack of feeling and tingling pain in [your/his/her] legs and feet due to nerve damage (diabetic neuropathy)	**[PH_329_03_4]**
4. Damage to the back of [your/his/her] eye (diabetic retinopathy)	**[PH_329_04_4]**
5. Damage to [your/his/her] kidneys (diabetic nephropathy)	**[PH_329_05_4]**
96. No, none of these	**[PH_329_96_4]**
97. UR	**[PH_329_97_4]**
98. DK	**[PH_329_98_4]**
99. RF	**[PH_329_99_4]**

IF (PH_310_05= 1) OR (PH_310_05FF_4 = 1 & PH_310X0_05 ≠ 1), ASK PH_329a_4. OTHERS GO TO PH_330_4

PH_329a_4: How often do you have your blood glucose levels checked?

    1. Before meals
    2. Daily
    3. Weekly
    4. Monthly
    5. Never
    95. Other (please specify)   [PH_329a_95_4][PH_329aoth_4]

    97. UR
    98. DK
    99. RF

PH_329E_4: How do you usually check your blood glucose levels?

    1. Independently
    2. With some assistance
    3. Full assistance

    97. Unclear response
    98. Don't know
    99. Refused to answer

(TILDA)

IF (PH_310_05= 1) OR (PH_310_05FF_4 = 1 & PH_310X0_05 ≠ 1), ASK PH_329b_4. OTHERS GO TO PH_330_4

PH_329b_4:

    1. Yes
    2. No

    97. Unclear response
    98. Don't know
    99. Refused to answer

IF (PH_310_05= 1) OR (PH_310_05FF_4 = 1 & PH_310X0_05 ≠ 1), ASK PH_329C_4. OTHERS GO TO PH_330_4

PH_329C_4: [Have/Has] [you/Rname] been invited for an eye exam by the national retinal screening programme (Diabetic Retina Screen) in the last 24 months?

> 1. Yes,   **Go To PH_329D_4**
> 5. No   **Go To PH_330_4**
>
> 97. Unclear response **Go To PH_330_4**
> 98. Don't know **Go To PH_330_4**
> 99. Refused to answer **Go To PH_330_4**

PH_329D_4: Did you attend this service?

> 1. Yes
> 5. No
>
> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

IF (PH_310_06_4 = 1) GO TO PH_330_4. OTHERS GO TO PH_333_4.

PH_330_4: When [were/was] [you/he/she] first told by a doctor that [you/he/she] had a stroke?

(MM/YYYY)

_____/_____   [PH_330m_4][PH_330y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

(ELSA similar question HRS/QVSFS)

IF (PH_310_06_4= 1), ASK PH_331_4. OTHERS GO TO PH_333_4

PH_331_4: How many strokes [have/has] [you/he/she] had?

_____Number

> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

(ELSA)

IF (PH_331_4 > 1), ASK PH_332_4. OTHERS GO TO PH_333_4

PH_332_4: In what year/month was [your/his/her] most recent stroke?

(MM/YYYY)

_____/_____   [PH_332m_4][PH_332y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

(HRS)

IF (PH_310_06FF_4 = 1 & PH_310X0_06 ≠ 1), ASK PH_333_4. OTHERS GO TO PH_334_4

PH_333_4: Since your last interview, have you had any further strokes?

> 1. Yes, **Go To PH_334_4**
> 5. No **Go To PH_336_4**
>
> 97. Unclear response **Go To PH_336_4**
> 98. Don't know **Go To PH_336_4**
> 99. Refused to answer **Go To PH_336_4**

(ELSA)

IF (PH_333_4= 1), GO TO PH_334_4. OTHERS GO TO PH_336_4

PH_334_4: Since your last interview, how many strokes have you had?

_____ Number

> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

(ELSA)

PH_335_4: **When was your most recent stroke?**

(MM/YYYY)

_____/_____   [PH_335m_4][PH_335y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

(HRS)

IF (PH_310_07_4= 1), ASK PH_336_4. OTHERS GO TO PH_339_4

PH_336_4: When [were/was] [you/Rname] first told by a doctor that [you/he/she] had a TIA, ministroke, or transient ischaemic attack?

(MM/YYYY)

_____/_____   [PH_336m_4][PH_336y_4]

_____UR DK RF MONTH

_____ UR DK RF YEAR

(TILDA/QVSFS)

PH_337_4: How many TIA's or ministrokes [have/has] [you/he/she] had?

_____ Number

     97. Unclear response
     98. Don't know
     99. Refused to answer

(TILDA)

IF (PH_337_4 > 1), GO TO PH_338_4. OTHERWISE GO TO PH_339_4

PH_338_4: In what month/year was [your/his/her] most recent TIA or ministrokes?

(MM/YYYY)

_____/_____   [PH_338m_4][PH_338y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

(TILDA)

IF (PH_310_07FF_4 = 1 & PH_310X0_07 ≠ 1), ASK PH_339_4. OTHERS GO TO PH_342_4

PH_339_4: Since your last interview, have you had any further TIA's or ministrokes?

1. Yes, **Go To PH_340_4**
5. No **Go To PH_342_4**
97. Unclear response **Go To PH_342_4**
98. Don't know **Go To PH_342_4**
99. Refused to answer **Go To PH_342_4**

(TILDA)

IF PH_339_4=1, GO TO PH_340_4. OTHERS GO TO PH_342_4

PH_340_4: Since your last interview, how many TIA's or ministrokes have/you had?

_____ Number

97. Unclear response
98. Don't know
99. Refused to answer

(ELSA)

PH_341_4: When was your most recent TIA or ministroke?

When was your most recent TIA or ministroke?

(MM/YYYY)

_____/_____   [PH_341m_4][PH_341y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

(TILDA)

IF (PH_310_08_4= 1) OR (PH_310_08FF1_4 = 1 & PH_310X0_08 ≠ 1), ASK PH_342_4. OTHERS GO TO PH_343_4

PH_342_4: [Is/Are] [you/he/she] currently doing any of the following to manage [your/his/her] cholesterol?

IWER: Select all that apply

1. Taking medications	[PH_342_01_4]
2. Lifestyle changes (e.g. diet, exercise, etc.)	[PH_342_02_4]
95. Other	[PH_342_95_4]
96. None of the above	[PH_342_96_4]
97. UR	[PH_342_97_4]
98. DK	[PH_342_98_4]
99. RF	[PH_342_99_4]

IF (PH_310_95_4= 1), ASK PH_343_4. OTHERS GO TO PH_344_4

PH_343_4: When [were/was] [you/Rname] first told by a doctor that [you/he/she] had other heart trouble?

(MM/YYYY)

_____/_____   [PH_343m_4][PH_343y_4]

_____UR DK RF MONTH

_____ UR DK RF YEAR

(IDS-TILDA)

PH_344_4: [Are/Is] [you/Rname] taking blood thinning medications e.g. warfarin for [your/his/her] irregular heart rhythm?

IWER: Ask All Participants

1. Yes, **Go To PH_345_4**
5. No **Go To PH_346_4**

97. Unclear response **Go To PH_346_4**
98. Don't know **Go To PH_346_4**
99. Refused to answer **Go To PH_346_4**

PH_345_4: In the last 2 months, has [your/Rname's] warfarin or blood thinning medication dose been changed more than 3 times by [your/his/her] doctor?

1. Yes, **Go To PH_346_4**
5. No **Go To PH_346_4**

97. Unclear response **Go To PH_346_4**
98. Don't know **Go To PH_346_4**
99. Refused to answer **Go To PH_346_4**

PH_346_4: Have [you/Rname] ever had any of the following?

IWER: TICK ALL THAT APPLY

    1. Blood Clot   **[PH_346_01_4]**
    2. DVT   **[PH_346_02_4]**
    3. Pulmonary embolism   **[PH_346_03_4]**
    96. None of these   **[PH_346_96_4]**
    97. Unclear response   **[PH_367_97_4]**
    98. Don't know   **[PH_367_98_4]**
    99. Refused to answer   **[PH_367_99_4]**

IWER: All participants go to GO TO PH_0C_4

9.8   Other Health Conditions

PH_0C4: How will this section be completed?

1. Self-Report Only
2. Self-Report and Proxy
3. Proxy Only

This can be updated for subsequent waves. The logic for creating the above variable is as follows:

Other chronic conditions

FOR i = 01 TO 04, 06, 08 TO 21, 24 TO 26... IF (intstatusW4 = 1 & PH_350_iFF (wave 3) = 1), THEN PH_350_iFF_4 = 1;

IF (INTSTSTUSW4 = 1 & PH_350_1FF_4 - PH_350_26FF_4, GO TO PH_350a_4

ALL OTHERS GO TO PH_350_4.

PH_350a_4: Last time you were interviewed, you told us that you had (insert conditions from PH_350_iFF_4).

1. Continue (go to PH_350Y_i_4)
2. Respondent disputes having one/all of these conditions

CONDITION DISPUTED

PH_350X0:

IWER: Which of the conditions is being disputed?

1. Asthma   (display if PH_350_01FF_4 = 1)
2. Stomach ulcers   (display if PH_350_02FF_4 = 1)
3. Varicose ulcers   (display if PH_350_03FF_4 = 1)
4. Cirrhosis, or serious liver damage   (display if PH_350_04FF_4 = 1)
6. Coeliac disease   (display if PH_350_06FF_4 = 1)
7. Phenlketonuria   (display if PH_350_07FF_4 = 1)
8. Thyroid disease   (display if PH_350_08FF_4 = 1)
9. Gastroesophageal reflux disease   (display if PH_350_09FF_4 = 1)
10. Osteoporosis   (display if PH_350_10FF_4 = 1)
11. Multiple sclerosis   (display if PH_350_11FF_4 = 1)
12. Cerebral palsy   (display if PH_350_12FF_4 = 1)
13. Scoliosis   (display if PH_350_13FF_4 = 1)
14. Muscular dystrophy   (display if PH_350_14FF_4 = 1)
15. Spina bifida   (display if PH_350_15FF_4 = 1)
16. Chronic lung disease such as chronic bronchitis or emphysema (display if PH_350_16FF_4 = 1)
17. Parkinsons   (display if PH_350_17FF_4 = 1)
18. Arthritis   (display if PH_350_18FF_4 = 1)
19. Cancer   (display if PH_350_19FF_4 = 1)
20. Epilepsy   (display if PH_350_20FF_4 = 1)
21. Emotional, nervous or psychiatric problems   (display if PH_350_21FF_4 = 1)

23. a. Dementia (including Alzheimers Disease)   (display if PH_350_23aFF_4 = 1)
24. Chronic Kidney disease   (display if PH_350_24FF_4 = 1)
25. Severe anaemia   (display if PH_350_25FF_4 = 1)
26. Irritable bowel syndrome   (display if PH_350_26FF_4 = 1)

IWER: ASK FOR EACH SELECTION AT PH_350X0

PH_350X_01-26 It may be that we have a recording error about you having [condition selected at PH_350X0].

IWER: Can you confirm, that …READ OUT.

1. You never had [condition selected at PH_350X0] (error from previous wave)
2. [condition selected at PH_350X0] was misdiagnosed

IF (PH_350_01FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _01 ≠ 1) ASK PH_350Y_01_4, OTHERS GO TO PH_350Y_01_4

PH_350Y_01_4: Do you still have asthma?

1. Yes
5. No

IF (PH_350_02FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _02 ≠ 1) ASK PH_350Y_02_4, OTHERS GO TO PH_350Y_03_4

PH_350Y_02_4: Do you still have stomach ulcers?

1. Yes
5. No

IF (PH_350_03FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _03 ≠ 1) ASK PH_350Y_03_4, OTHERS GO TO PH_350Y_04_4

PH_350Y_03_4: Do you still have Varicose ulcers?

1. Yes
5. No

IF (PH_350_04FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _04 ≠ 1) ASK PH_350Y_04_4, OTHERS GO TO PH_350Y_06_4

PH_350Y_04_4: Do you still have Cirrhosis, or serious liver damage?

1. Yes
5. No

IF (PH_350_06FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _06 ≠ 1) ASK PH_350Y_06_4, OTHERS GO TO PH_350Y_08_4

PH_350Y_06_4: Do you still have Coeliac disease ?

1. Yes
5. No

IF (PH_350_08FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _08 ≠ 1) ASK PH_350Y_08_4, OTHERS GO TO PH_350Y_09_4

PH_350Y_08_4: Do you still have Thyroid disease?

1. Yes
5. No

IF (PH_350_09FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _09 ≠ 1) ASK PH_350Y_09_4, OTHERS GO TO PH_350Y_10_4

PH_350Y_09_4: Do you still have Gastroesophageal reflux disease?

1. Yes
5. No

IF (PH_350_10FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_10 ≠ 1) ASK PH_350Y_10_4, OTHERS GO TO PH_350Y_16_4

PH_350Y_10_4: Do you still have Osteoporosis?

1. Yes
5. No

IF (PH_350_16FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_16 ≠ 1) ASK PH_350Y_16_4, OTHERS GO TO PH_350Y_13_4

PH_350Y_16_4: Do you still have Chronic lung disease?

1. Yes
5. No

IF (PH_350_19FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_19 ≠ 1) ASK PH_350Y_19_4, OTHERS GO TO PH_350Y_21_4

PH_350Y_19_4: Do you still have Cancer?

1. Yes
5. No

IF (PH_350_25FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_25 ≠ 1) ASK PH_350Y_25_4, OTHERS GO TO PH_350_4

PH_350Y_25_4:

PH301Y_19: Do you still have severe anaemia?

1. Yes
5. No

IF (PH_350_26FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_26 ≠ 1) ASK PH_350Y_26_4, OTHERS GO TO PH_350_4

PH_350Y_26_4: Do you still have Irritable Bowel Syndrome ?

1. Yes
5. No

IF (intstatusW4 = 2), USE WORDING 'B', OTHERWISE USE WORDING 'A'

PH_350_4:

A. Since your last interview, has a doctor ever told you/ that you have any of the [other] conditions on this card?
B. Has a doctor ever told [you/Rname] that [you/he/she] [have/has] any of the conditions on this card?

IWER: PROBE - 'WHAT OTHERS?' CODE ALL THAT APPLY.

1. Asthma   **[PH_350_01_4]**
2. Stomach ulcers   **[PH_350_02_4]**
3. Varicose ulcers (an ulcer due to varicose veins)   **[PH_350_03_4]**
4. Cirrhosis, or serious liver damage   **[PH_350_04_4]**
6. Coeliac disease   **[PH_350_06_4]**
7. Phenlketonuria   [**PH_350_07_4**]
8. Thyroid disease   **[Go to PH_351_4]   [PH_350_08_4]**
9. Gastroesophageal reflux disease   [**PH_350_09_4**]
10. Osteoporosis   **[PH_350_10_4]**
11. Multiple sclerosis   **[PH_350_11_4]**
12. Cerebral palsy   **[PH_350_12_4]**
13. Scoliosis   **[PH_350_13_4]**
14. Muscular dystrophy   **[PH_350_14_4]**
15. Spina bifida   **[PH_350_15_4]**
16. Chronic lung disease   **[Go to PH_352_4]   [PH_350_16_4]**
17. Parkinsons   **[Go to PH_354_4] [PH_350_17_4]**
18. Arthritis   **[Go to PH_356_4]   [PH_350_18_4]**
19. Cancer or a malignant tumor (including leukaemia or lymphoma) **[Go to PH_361_4]**
    [PH_350_19_4]
20. Epilepsy   **[Go to PH_366_4]   [PH_350_20_4]**
23. a. Dementia including Alzheimers **Disease**   **[Go to PH_384_4] [PH_350_23a_4]**
24. Chronic kidney disease   **[Go to PH_385_4]   [PH_350_24_4]**
25. Severe Anaemia   **[PH_350_25_4]**
26. Irritable Bowel Syndrome   **[PH_350_26_4]**
27. Chest infection   **[PH_350_27_4]**
95. Other (please specify**)**   **[PH_350_95_4][PH_350_oth_4]**
96. None of these   **[Go to   PH_386_4] [PH_350_96_4]**
97. Unclear Response   **[Go to   PH_386_4] [PH_350_97_4]**
98. Don't know   **[Go to   PH_386_4] [PH_350_98_4]**
99. Refused to answer   **[Go to   PH_386_4] [PH_350_99_4]**

IF (PH_350_01FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _01 ≠ 1) ASK PH_350Y_01_4, OTHERS GO TO PH_350Y_01_4

PH_350Y_01_4: Do you still have asthma?

> 1. Yes
> 5. No

IF (PH_350_02FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _02 ≠ 1) ASK PH_350Y_02_4, OTHERS GO TO PH_350Y_03_4

PH_350Y_02_4: Do you still have stomach ulcers?

> 1. Yes
> 5. No

IF (PH_350_03FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _03 ≠ 1) ASK PH_350Y_03_4, OTHERS GO TO PH_350Y_04_4

PH_350Y_03_4: Do you still have Varicose ulcers?

> 1. Yes
> 5. No

IF (PH_350_04FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _04 ≠ 1) ASK PH_350Y_04_4, OTHERS GO TO PH_350Y_06_4

PH_350Y_04_4: Do you still have Cirrhosis, or serious liver damage?

> 1. Yes
> 5. No

IF (PH_350_06FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _06 ≠ 1) ASK PH_350Y_06_4, OTHERS GO TO PH_350Y_08_4

PH_350Y_06_4: Do you still have Coeliac disease ?

> 1. Yes
> 5. No

IF (PH_350_08FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _08 ≠ 1) ASK PH_350Y_08_4, OTHERS GO TO PH_350Y_09_4

PH_350Y_08_4: Do you still have Thyroid disease?

1. Yes
5. No

IF (PH_350_09FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _09 ≠ 1) ASK PH_350Y_09_4, OTHERS GO TO PH_350Y_10_4

PH_350Y_09_4: Do you still have Gastroesophageal reflux disease?

1. Yes
5. No

IF (PH_350_10FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_10 ≠ 1) ASK PH_350Y_10_4, OTHERS GO TO PH_350Y_16_4

PH_350Y_10_4: Do you still have Osteoporosis?

1. Yes
5. No

IF (PH_350_16FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_16 ≠ 1) ASK PH_350Y_16_4, OTHERS GO TO PH_350Y_13_4

PH_350Y_16_4: Do you still have Chronic lung disease?

1. Yes
5. No

IF (PH_350_19FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_19 ≠ 1) ASK PH_350Y_19_4, OTHERS GO TO PH_350Y_21_4

PH_350Y_19_4: Do you still have Cancer?

1. Yes
5. No

IF (PH_350_25FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_25 ≠ 1) ASK PH_350Y_25_4, OTHERS GO TO PH_350_4

PH_350Y_25_4:

PH301Y_19: Do you still have severe anaemia?

> 1. Yes
> 5. No

IF (PH_350_26FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_26 ≠ 1) ASK PH_350Y_26_4, OTHERS GO TO PH_350_4

PH_350Y_26_4: Do you still have Irritable Bowel Syndrome ?

> 1. Yes
> 5. No

IF (PH_350_08_4= 1 OR PH_350Y_08_4= 1), ASK PH_351_4. OTHERS GO TO PH_352_4

PH_351_4: [Do/Does] [you/Rname] have an overactive (hyperactive) thyroid or an underactive (hypoactive) thyroid?

> 1. Overactive (Hyperactive) thyroid
> 2. Underactive (Hypoactive) thyroid
> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

IF (PH_350_16_4 = 1 OR PH_350Y_16_4=1) ASK PH_352_4. OTHERS GO TO PH_354_4

PH_352_4: [Are/Is] [you/Rname] receiving oxygen for [your/his/her] lung condition?

> 1. Yes
> 5. No
> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

PH_353_4: Does [your/his/her] lung condition limit [your/his/her] usual activities, such as household chores or work?

    1. Yes
    5. No
    97. Unclear response
    98. Don't know
    99. Refused to answer

IF (PH_350_17_4= 1) ASK PH_354. OTHERS GO TO PH_355_4

PH_354_4: When [were/was] [you/Rname] first told by a doctor that [you/he/she] had Parkinson's disease?

(MM/YYYY)

_____/_____   [PH_354m_4][PH_354y_4]

_____ UR DK RF MONTH

_____UR DK RF YEAR

IF (PH_350_18_4 = 1 OR PH_350_18FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_18 ≠ 1) ASK PH_355_4. OTHERS GO TO PH_361_4

IWER: CODE ALL THAT APPLY

PH_355_4: Which type or types of arthritis [do/does/did] [you/Rname] have?

IWER: READ OUT

    1. Osteoarthritis   **[PH_355_01_4]**
    2. Rheumatoid arthritis   **[PH_355_02_4]**
    95. Some other kind of arthritis   **[PH_355_95_4]**
    97. Unclear response   **[PH_355_97_4]**
    98. Don't know   **[PH_355_98_4]**
    99. Refused to answer   **[PH_355_99_4]**

IF (PH_355_4=2) ASK PH_355a_4. OTHERS GO TO PH_356_4

PH_355a_4: How was your rheumatoid arthritis diagnosed?

IWER: Tick all that apply

    1. Rheumatoid Factor anti-CCP antibodies ESR   **[PH_355a_01_4]**
    2. Scans/Xrays   **[PH_355a_02_4]**
    3. Clinical history   **[PH_355a_03_4]**
    95. Other   **[PH_355a_95_4] [PH_355aoth_4]**
    97. Unclear response   **[PH_355a_97_4]**
    98. Don't know   **[PH_355a_98_4]**
    99. Refused to answer   **[PH_355a_99_4]**

(IDS-TILDA)

IF (PH_350_18_4= 1) ASK PH_356_4. IF PH_350_18FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0_18 ≠ 1 GO TO PH_357_4

PH_356_4: When [were/was] [you/Rname] first told that [you/he/she] had arthritis?

(MM/YYYY)

_____/_____   [PH_356m_4][PH_356y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

IF (PH_350_18_4= 1 OR PH_350Y_18_4 = 1)   ASK PH_357_4

PH_357_4: Does [your/his/her] arthritis make it difficult for [you/him/her] to do [your/his/her] usual activities such as household chores or work?

    1. Yes, all the time
    3. Yes, sometimes
    5. No
    97. Unclear response
    98. Don't know
    99. Refused to answer

PH_358_4: Does the arthritis limit [your/his/her] social and leisure activities?

1. Yes, all the time
3. Yes, sometimes
5. No
97. Unclear response
98. Don't know
99. Refused to answer

PH_359_4: Does [your/his/her] arthritis make it difficult for [you/him/her] to sleep at night?

1. Yes, all the time
3. Yes, sometimes
5. No
97. Unclear response
98. Don't know
99. Refused to answer

IF (PH_350_19_4= 1) ASK PH_361_4. OTHERS GO TO PH_362a_4

PH_361_4: When [were/was] [you/Rname] first told by a doctor that [you/he/she] had cancer or a malignant tumour?

(MM/YYYY)

_____/_____   [PH_361m_4][PH_361y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

This can be updated for subsequent waves. The logic for creating the above variable is as follows:

FOR i = 01 TO 23

IF (intstatusW4 = 1 & PH_362_iFF (Wave 3) = 1) THEN PH_362_iFF_4 = 1; OTHERWISE PH_362_iFF_4 = 0

IF (PH_350_19FF_4 =1 & PH_350a_4 = 1,2 & PH_350X0_19 ≠ 1) OR (PH_350_19FF_4 = 0 & PH_362_iFF_4 = 1)),   ASK PH_362a_4. OTHERS GO TO PH_362_4

PH_362a_4: In your last interview, you reported having (type of cancer from PH_362_iFF_4 if cancer not disputed at PH_362X0_19) cancer

1. Continue (go to PH_362Y_01_4)
2. Respondent disputes having this type of cancer

CONDITION DISPUTED

PH_362X0:

IWER: Which type of cancer is being disputed.

1. Lung   (display if PH_362_01FF_4 = 1)
2. Breast   (display if PH_362_02FF_4 = 1)
3. Colon or rectum   (display if PH_362_03FF_4 = 1)
4. Stomach   (display if PH_362_04FF_4 = 1)
5. Oesophagus   (display if PH_362_05FF_4 = 1)
6. Prostate   [males only]   (display if PH_362_06FF_4 = 1)
7. Bladder   (display if PH_362_07FF_4 = 1)
8. Liver   (display if PH_362_08FF_4 = 1)
9. Brain   (display if PH_362_09FF_4 = 1)
10. Ovary   [females only]   (display if PH_362_10FF_4 = 1)
11. Cervix   [females only]   (display if PH_362_11FF_4 = 1)
12. Endometrium   [females only]   (display if PH_362_12FF_4 = 1)
13. Thyroid   (display if PH_362_13FF_4 = 1)
14. Kidney   (display if PH_362_14FF_4 = 1)
15. Testicle   [males only]   (display if PH_362_15FF_4 = 1)
16. Pancreas   (display if PH_362_16FF_4 = 1)
17. Malignant melanoma (skin)   (display if PH_362_17FF_4 = 1)
18. Oral cavity   (display if PH_362_18FF_4 = 1)
19. Larynx   (display if PH_362_19FF_4 = 1)
20. Other pharynx (including nasopharynx, oropharynx, laryngopharynx or hypopharynx)
                                                           (display if PH_362_20FF_4 = 1)
21. Non-Hodgkin Lymphoma   (display if PH_362_21FF_4 = 1)
22. Leukaemia   (display if PH_362_22FF_4 = 1)
95. Other   (display if PH_362_95FF_4 = 1)

ASK FOR EACH SELECTION AT PH_362X0

PH_362X0_01-22,95 It may be that we have a recording error about you having [type of cancer listed at PH_362X0]. Can you confirm, that …READ OUT.

    1. You never had [cancer listed in PH_362X0] (error from previous wave)
    2. [type of cancer selected at PH_362X0] was misdiagnosed

IF (PH_362_01FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _01 ≠ 1) ASK PH_362Y_01_4. OTHERS GO TO PH_362Y_02_4

PH_362Y_01_4: Do you still have lung cancer?

    1. Yes
    5. No

IF (PH_362_02 FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _02 ≠ 1) ASK PH_362Y_02_4. OTHERS GO TO PH_362Y_03_4

PH_362Y_02_4: Do you still have breast cancer?

    1. Yes
    5. No

IF (PH_362_03 FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _03 ≠ 1) ASK PH_362Y_03_4. OTHERS GO TO PH_362Y_04_4

PH_362Y_03_4: Do you still have colon or rectum cancer?

    1. Yes
    5. No

IF (PH_362_04 FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _04 ≠ 1) ASK PH_362Y_04_4. OTHERS GO TO PH_362Y_05_4

PH_362Y_04_4: Do you still have stomach cancer?

    1. Yes
    5. No

IF (PH_362_05 FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _05 ≠ 1) ASK PH_362Y_05_4. OTHERS GO TO PH_362Y_06_4

PH_362Y_05_4: Do you still have cancer of the oesophagus?

1. Yes
5. No

IF (PH_362_06FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _06 ≠ 1) ASK PH_362Y_06_4. OTHERS GO TO PH_362Y_07_4

PH_362Y_06_4: Do you still have prostate cancer?

1. Yes
5. No

IF (PH_362_07FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _07 ≠ 1) ASK PH_362Y_07_4. OTHERS GO TO PH_362Y_08_4

PH_362Y_07_4: Do you still have cancer of the bladder?

1. Yes
5. No

IF (PH_362_08FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _08 ≠ 1) ASK PH_362Y_08_4. OTHERS GO TO PH_362Y_09_4

PH_362Y_08_4: Do you still have liver cancer?

1. Yes
5. No

IF (PH_362_09FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _09 ≠ 1) ASK PH_362Y_09_4. OTHERS GO TO PH_362Y_10_4

PH_362Y_09_4: Do you still have brain cancer?

1. Yes
5. No

IF (PH_362_10FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _10 ≠ 1) ASK PH_362Y_10_4. OTHERS GO TO PH_362Y_11_4

PH_362Y_10_4: Do you still have cancer of the ovary?

>   1. Yes
>   5. No

IF (PH_362_11FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _11 ≠ 1) ASK PH_362Y_11_4. OTHERS GO TO PH_362Y_12_4

PH_362Y_11_4: Do you still have cancer of the cervix?

>   1. Yes
>   5. No

IF (PH_362_12FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _12 ≠ 1) ASK PH_362Y_12_4. OTHERS GO TO PH_362Y_13_4

PH_362Y_12_4: Do you still have cancer of the endometrium?

>   1. Yes
>   5. No

IF (PH_362_13FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _13 ≠ 1) ASK PH_362Y_13_4. OTHERS GO TO PH_362Y_14_4

PH_362Y_13_4: Do you still have cancer of the thyroid?

>   1. Yes
>   5. No

IF (PH_362_14FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _14 ≠ 1) ASK PH_362Y_14_4. OTHERS GO TO PH_362Y_15_4

PH_362Y_14_4: Do you still have cancer of the kidney?

>   1. Yes
>   5. No

IF (PH_362_15FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _15 ≠ 1) ASK PH_362Y_15_4. OTHERS GO TO PH_362Y_16_4

PH_362Y_15_4: Do you still have testicular cancer?

> 1. Yes
> 5. No

IF (PH_362_16FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _16 ≠ 1) ASK PH_362Y_16_4. OTHERS GO TO PH_362Y_17_4

PH_362Y_16_4: Do you still have cancer of the pancreas?

> 1. Yes
> 5. No

IF (PH_362_17FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _17 ≠ 1) ASK PH_362Y_17_4. OTHERS GO TO PH_362Y_18_4

PH_362Y_17_4: Do you still have malignant melanoma (skin)?

> 1. Yes
> 5. No

IF (PH_362_18FF_4= 1 & PH_362a_4 = 1,2 & PH_362X0 _18 ≠ 1) ASK PH_362Y_18_4. OTHERS GO TO PH_362Y_19_4

PH_362Y_18_4: Do you still have cancer of the oral cavity?

> 1. Yes
> 5. No

IF (PH_362_19FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _19≠ 1) ASK PH_362Y_19_4. OTHERS GO TO PH_362Y_20_4

PH_362Y_19_4: Do you still have cancer of the larynx?

> 1. Yes
> 5. No

IF (PH_362_20FF_4= 1 & PH_362a_4 = 1,2 & PH_362X0 _20≠ 1) ASK PH_362Y_20_4. OTHERS GO TO PH_362Y_21_4

PH_362Y_20_4: Do you still have cancer of the other pharynx?

1. Yes
5. No

IF (PH_362_21FF_4= 1 & PH_362a_4 = 1,2 & PH_362X0 _21≠ 1) ASK PH_362Y_21_4. OTHERS GO TO PH_362Y_22_4

PH_362Y_21_4: Do you still have Non-Hodgkin Lymphoma cancer?

1. Yes
5. No

IF (PH_362_22FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _22≠ 1) ASK PH_362Y_22_4. OTHERS GO TO PH_362Y_23_4

PH_362Y_22_4: Do you still have Leukaemia?

1. Yes
5. No

IF (PH_362_95FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _95≠ 1) ASK PH_362Y_95_4. OTHERS GO TO PH_362_4

PH_362Y_95_4: Do you still have another type of cancer?

1. Yes
5. No

If (PH_362_95FF_4 = 1 & & PH_362a_4 = 1,2 & PH_362X0 _95≠ 1) then ask PH_36XX_4. OTHERS GO TO PH_362_4

PH_362Y_OTH_4: What type of cancer is it?

[Text response]

97. Unclear response
98. Don't know
99. Refused to answer

IF (PH_350_19_4= 1), USE WORDING 'B'. OTHERWISE USE WORDING 'A' OTHERS GO TO PH_366_4

PH_362_4:

A. Since our last interview, has a doctor ever told you that you have any of these [other] types of cancer? IF SO ASK, Which one?
B. What type of cancer [have/has] [you/he/she] had?

IWER: CODE ALL THAT APPLY

1. Lung   [PH_362_01_4]
2. Breast   [females only]   [PH_362_02_4]
3. Colon or rectum   [PH_362_03_4]
4. Stomach   [PH_362_04_4]
5. Oesophagus   [PH_362_05_4]
6. Prostate   [males only]   [PH_362_06_4]
7. Bladder   [PH_362_07_4]
8. Liver   [PH_362_08_4]
9. Brain   [PH_362_09_4]
10. Ovary   [females only]   [PH_362_10_4]
11. Cervix   [females only]   [PH_362_11_4]
12. Endometrium [females only]   [PH_362_12_4]
13. Thyroid   [PH_362_13_4]
14. Kidney   [PH_362_14_4]
15. Testicle   [males only]   [PH_362_15_4]
16. Pancreas   [PH_362_16_4]
17. Malignant melanoma (skin)   [PH_362_17_4]
18. Oral cavity   [PH_362_18_4]
19. Larynx   [PH_362_19_4]
20. Other pharynx (including nasopharynx, oropharynx,laryngopharynx or hypopharynx)
    [PH_362_20_4]
21. Non-Hodgkin Lymphoma   [PH_362_21_4]
22. Leukaemia   [PH_362_22_4]
95. Other organ   (please specify)   [PH_362_95_4] [PH_362oth_4]

96. None of these   [PH_362_96_4]
97. Unclear Response   [PH_362_97_4]
98. Don't Know   [PH_362_98_4]
99. Refused to Answer   [PH_362_99_4]

(SHARE/ similar question in ELSA)

IF PH_350Yb_19_4 = 5 SKIP PH_362Y_01_4 TO PH_362Yb_22_4 AND GO TO PH_362_95_4

IE THOSE WHO PREVIOUSLY CONFIRMED THEY DO NOT STILL HAVE CANCER

IF (PH_362_01FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _01 ≠ 1) ASK PH_362Y_01_4. OTHERS GO
TO PH_362Y_02_4

PH_362Y_01_4: Do you still have lung cancer?

   1. Yes
   5. No

IF (PH_362_02 FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _02 ≠ 1) ASK PH_362Y_02_4. OTHERS GO
TO PH_362Y_03_4

PH_362Y_02_4: Do you still have breast cancer?

   1. Yes
   5. No

IF (PH_362_03 FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _03 ≠ 1) ASK PH_362Y_03_4. OTHERS GO
TO PH_362Y_04_4

PH_362Y_03_4: Do you still have colon or rectum cancer?

   1. Yes
   5. No

IF (PH_362_04 FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _04 ≠ 1) ASK PH_362Y_04_4. OTHERS GO
TO PH_362Y_05_4

PH_362Y_04_4: Do you still have stomach cancer?

   1. Yes
   5. No

IF (PH_362_05 FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _05 ≠ 1) ASK PH_362Y_05_4. OTHERS GO TO PH_362Y_06_4

PH_362Y_05_4: Do you still have cancer of the oesophagus?

    1. Yes
    5. No

IF (PH_362_06FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _06 ≠ 1) ASK PH_362Y_06_4. OTHERS GO TO PH_362Y_07_4

PH_362Y_06_4: Do you still have prostate cancer?

    1. Yes
    5. No

IF (PH_362_07FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _07 ≠ 1) ASK PH_362Y_07_4. OTHERS GO TO PH_362Y_08_4

PH_362Y_07_4: Do you still have cancer of the bladder?

    1. Yes
    5. No

IF (PH_362_08FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _08 ≠ 1) ASK PH_362Y_08_4. OTHERS GO TO PH_362Y_09_4

PH_362Y_08_4: Do you still have liver cancer?

    1. Yes
    5. No

IF (PH_362_09FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _09 ≠ 1) ASK PH_362Y_09_4. OTHERS GO TO PH_362Y_10_4

PH_362Y_09_4: Do you still have brain cancer?

    1. Yes
    5. No

IF (PH_362_10FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _10 ≠ 1) ASK PH_362Y_10_4. OTHERS GO TO PH_362Y_11_4

PH_362Y_10_4: Do you still have cancer of the ovary?

- 1. Yes
- 5. No

IF (PH_362_11FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _11 ≠ 1) ASK PH_362Y_11_4. OTHERS GO TO PH_362Y_12_4

PH_362Y_11_4: Do you still have cancer of the cervix?

- 1. Yes
- 5. No

IF (PH_362_12FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _12 ≠ 1) ASK PH_362Y_12_4. OTHERS GO TO PH_362Y_13_4

PH_362Y_12_4: Do you still have cancer of the endometrium?

- 1. Yes
- 5. No

IF (PH_362_13FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _13 ≠ 1) ASK PH_362Y_13_4. OTHERS GO TO PH_362Y_14_4

PH_362Y_13_4: Do you still have cancer of the thyroid?

- 1. Yes
- 5. No

IF (PH_362_14FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _14 ≠ 1) ASK PH_362Y_14_4. OTHERS GO TO PH_362Y_15_4

PH_362Y_14_4: Do you still have cancer of the kidney?

- 1. Yes
- 5. No

IF (PH_362_15FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _15 ≠ 1) ASK PH_362Y_15_4. OTHERS GO TO PH_362Y_16_4

PH_362Y_15_4: Do you still have testicular cancer?

1. Yes
5. No

IF (PH_362_16FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _16 ≠ 1) ASK PH_362Y_16_4. OTHERS GO TO PH_362Y_17_4

PH_362Y_16_4: Do you still have cancer of the pancreas?

1. Yes
5. No

IF (PH_362_17FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _17 ≠ 1) ASK PH_362Y_17_4. OTHERS GO TO PH_362Y_18_4

PH_362Y_17_4: Do you still have malignant melanoma (skin)?

1. Yes
5. No

IF (PH_362_18FF_4= 1 & PH_362a_4 = 1,2 & PH_362X0 _18 ≠ 1) ASK PH_362Y_18_4. OTHERS GO TO PH_362Y_19_4

PH_362Y_18_4: Do you still have cancer of the oral cavity?

1. Yes
5. No

IF (PH_362_19FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _19≠ 1) ASK PH_362Y_19_4. OTHERS GO TO PH_362Y_20_4

PH_362Y_19_4: Do you still have cancer of the larynx?

1. Yes
5. No

IF (PH_362_20FF_4= 1 & PH_362a_4 = 1,2 & PH_362X0 _20≠ 1) ASK PH_362Y_20_4. OTHERS GO TO PH_362Y_21_4

PH_362Y_20_4: Do you still have cancer of the other pharynx?

1. Yes
5. No

IF (PH_362_21FF_4= 1 & PH_362a_4 = 1,2 & PH_362X0 _21≠ 1) ASK PH_362Y_21_4. OTHERS GO TO PH_362Y_22_4

PH_362Y_21_4: Do you still have Non-Hodgkin Lymphoma cancer?

1. Yes
5. No

IF (PH_362_22FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _22≠ 1) ASK PH_362Y_22_4. OTHERS GO TO PH_362Y_23_4

PH_362Y_22_4: Do you still have Leukaemia?

1. Yes
5. No

IF (PH_362_95FF_4 = 1 & PH_362a_4 = 1,2 & PH_362X0 _95≠ 1) ASK PH_362Y_95_4. OTHERS GO TO PH_362_4

PH_362Y_95_4: Do you still have an other type of cancer?

1. Yes
5. No

IF (PH_362_01_4- PH_362_95_4=1), ASK PH_363_4 TO PH_365_4 FOR EACH TYPE OF CANCER (e.g. if PH_362_01_4 = 1, variables used are PH_363_01_4, PH_364_01_x_4, PH_365_01_4 etc). IF PH_362_95_4, ASK PH_363_4 TO PH_365_4 FOR CANCER LISTED IN PH_362oth_4 textbox.

97. Unclear response
98. Don't know
99. Refused to answer

IF (PH_362_01FF_4 - PH_362_95FF_4 =1 & PH_362X0_01-95 ⬚ 1), ASK PH_363a_4 TO PH_365a_4 FOR EACH TYPE OF CANCER (e.g. variables used are PH_363a_01_4, PH_364a_01_x_4, PH_365a_01_4, etc.)

PH_363_4:[Have/Has] [you/he/she] received any treatment for [your/his/her] [cancer type listed at PH_362_i_4]?   [PH_363_01_4 to PH_363_95_4]

- 1. Yes,   **Go To PH_364_4**
- 5. No   **SKIP PH_364_4 & PH_365_4**
- 97. UR   **SKIP PH_364_4 & PH_365_4**
- 98. DK   **SKIP PH_364_4 & PH_365_4**
- 99. RF   **SKIP PH_364_4 & PH_365_4**

(ELSE/HRS)

PH_364_4: What sort of treatments [have/has] [you/he/she] received for [cancer type listed at PH_362_i_4]? [PH_364_01_4 to PH_364_95_99_4]

IWER: CODE ALL THAT APPLY

- 1.   Chemotherapy   **[PH_364_i_01_4]**
- 2.   Medication   **[PH_364_i_02_4]**
- 3.   Surgery   **[PH_364_i_03_4]**
- 4.   Biopsy   **[PH_364_i_04_4]**
- 5.   Radiation/X-Ray   **[PH_364_i_05_4]**
- 6.   Treatment for symptoms (pain, nausea, rashes)   **[PH_364_i_06_4]**
- 95. Other (specify)   **[PH_364_i_95_4] [PH_364oth_i]**
- 96. None   **[PH_364_i_96_4]**
- 97. Unclear Response   **[PH_364_i_97_4**]
- 98. DK   **[PH_364_i_98_4]**
- 99. RF   **[PH_364_i_99_4]**

(HRS)

PH_365_4: Since [you/he/she] received this treatment has the [cancer type listed at PH_362_i_4] got worse, better or stayed about the same?   [PH_365_01_4 to PH_365_95_4]

- 1. Better
- 2. About the same
- 3. Worse
- 97. UR
- 98. DK
- 99. RF

(HRS)

IF(PH_363_4=5 OR PH_364_4 = 96), Ask PH_365b_4, OTHERS go to PH_363a_4 Ask PH_365b_4 Why have you not received treatment? [text box]

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IF (PH_362_01FF_4 - PH_362_22FF_4 =1 & PH_362X0_01-22 ꙅ 1), ASK PH_363a_4 TO PH_365a_4 FOR EACH TYPE OF CANCER (e.g. variables used are PH_363a_01_4, PH_364a_01_x_4, PH_365a_01_4, etc.)

OTHERS GO TO PH_366_4

PH_363a_4: Since our last interview, have you received any treatment for your [cancer type listed at PH_362FF_i_4 and not disputed at PH_362X0_i]?   [PH_363a_01_4 to PH_363a_22_4]

1. Yes,   GO TO PH_364a_4
5. No   SKIP PH_364a_4 & PH_365a_4
97. UR   SKIP PH_364a_4 & PH_365a_4
98. DK   SKIP PH_364a_4 & PH_365a_4
99. RF   SKIP PH_364a_4 & PH_365a_4

(ELSA/HRS)

PH_364a_4:   Since our last interview, what sort of treatments have you received for [cancer type listed at PH_362_iFF_4 and not disputed at PH_362X0_i]? [PH_364a_01_01_4 to PH_364a_22_99_4]

IWER: CODE ALL THAT APPLY

1. Chemotherapy   **[PH_364a_i_01_4]**
2. Medication   **[PH_364a_i_02_4]**
3. Surgery   **[PH_364a_i_03_4]**
4. Biopsy   **[PH_364a_i_04_4]**
5. Radiation/X-Ray   **[PH_364a_i_05_4]**
6. Treatment for symptoms (pain, nausea, rashes)   **[PH_364a_i_06_4]**
95. Other (specify)   **[PH_364a_i_95_4] [PH_364aoth_i]**
96. None   **[PH_364a_i_96_4]**
97. UR   **[PH_364a_i_97_4]**
98. DK   [**PH_364a_i_98_4]**
99. RF   **[PH_364a_i_99_4]**

(HRS)

PH_365a_4: Since you received treatment since the last interview has the [cancer type listed at PH_362_iFF_4 and not disputed at PH_362X0_i] got worse, better or stayed about the same? **[PH_365a_01 to PH_365a_22]**

1. Better
2. About the same
3. Worse
97. UR
98. DK
99. RF

(HRS)

IF (PH_363a_4= 5 OR PH_364a_4 = 96), Ask PH_365c_4, OTHERS go to PH_366_4

Ask PH_365c_4: Why have you not received treatment? [text box]

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IF (PH_350_20_4= 1) ASK PH_366_4. OTHERS GO TO PH_367_4

PH_366_4: When [were/was] [you/Rname] first told by a doctor that [you/he/she] had epilepsy?

(MM/YYYY)

_____/_____   **[PH_366m_4][PH_366y_4]**

_____ UR DK RF MONTH

_____ UR DK RF YEAR

IF (PH_350_20_4= 1 OR PH_350_20FF_4 = 1 & PH_350a_4= 1,2 & PH_350X0_20 ≠ 1), ASK PH_367_4. OTHERS GO TO PH_377_4

PH_367_4: What type of epilepsy [you/he/she] have?

IWER: TICK ALL THAT APPLY

1.	Tonic-clonic seizures	**[PH_367_01_4]**
2.	Tonic seizures	**[PH_367_02_4]**
3.	Atonic seizures	**[PH_367_03_4]**
4.	Clonic seizures	**[PH_367_04_4]**
5.	Myoclonic seizures	**[PH_367_05_4]**
6.	Absence seizures	**[PH_367_06_4]**
7.	Simple partial seizures	**[PH_367_07_4]**
8.	Complex partial seizures	**[PH_367_08_4]**
95.	Other	**[PH_367_95_4] [PH_367_oth_4]**
97.	UR	**[PH_367_97_4]**
98.	DK	**[PH_367_98_4]**
99.	RF	**[PH_367_99_4]**

PH_368_4: [Do/ Did] [you/Rname] attend an Epilepsy clinic or see a specialist?

1. Yes
5. No
97. UR
98. DK
99. RF

PH_369_4: When did [your/his/her] last have your epilepsy reviewed (e.g. medication or seizure

activity)?

(MM/YYYY)

_____/_____   **[PH_366m_4][PH_366y_4]**

_____ UR DK RF MONTH

_____ UR DK RF YEAR

If PH_369_4 ≠ Never, OTHERS go to PH_371_4

PH_370_4: Who reviewed [your/his/her] epilepsy?

IWER: PLEASE TICK ALL THAT APPLY

1. General Practitioner **[PH_198_01_4]**
2. Psychiatrist **[PH_198_02_4]**
3. Neurologist **[PH_198_03_4]**
4. CNS **[PH_198_04_4]**
95. Other **[PH_198_95_4] [PH_198_oth_4]**
97. UR **[PH_198_97_4]**
98. DK **[PH_198_98_4]**
99. RF **[PH_198_99_4]**

IF (PH_350_20_4= 1 OR PH_350_20FF_4 = 1 & PH_350a_4= 1,2 & PH_350X0_20 ≠ 1), ASK PH_367_4.
OTHERS GO TO PH_377_4

PH_371_4: Does epilepsy limit [your/Rname] doing the following?

1. Household chores **[PH_371_01_4]**
2. Work **[PH_371_02_4]**
3. Social activities **[PH_371_03_4]**
4. Sports activities **[PH_371_04_4]**
5. Driving **[PH_371_05_4]**
6. Going out alone **[PH_371_06_4]**
7. None of the above **[PH_371_07_4]**
95. Other **[PH_371_95_4] [PH_371_oth_4]**
97. UR **[PH_371_97_4]**
98. DK **[PH_371_98_4]**

PH_372_4: Are any of the following medication prescribed for [you/he/she] to use in an emergency (rescue medication)

1. Epistatus (Buccal Midazolam) **[PH_372_01_4]**
2. Frisium (Clobazam) **[PH_372_02_4]**
3. Stesolid (Rectal Diazepam) **[PH_372_03_4]**
4. Clonazapam (Rivotril) **[PH_372_04_4]**
5. Lorazepam (Ativan) **[PH_372_05_4]**
6. None of the above **[PH_372_07_4]**
95. Other **[PH_372_95_4] [PH_372_oth_4]**
97. UR **[PH_372_97_4]**
98. DK **[PH_372_98_4]**

PH_373_4: [Have\Has] [you/Rname} used any of the emergency medications (rescue medication) in the last 12 months, If so please tell us?)

IWER: Tick all that apply

1. Epistatus (Buccal Midazolam)   **[PH_201_01_4]**
2. Frisium (Clobazam)   **[PH_201_02_4]**
3. Stesolid (Rectal Diazepam**)**   **[PH_201_03_4]**
4. Clonazapam (Rivotril)   **[PH_201_04_4]**
5. Lorazepam (Ativan)   **[PH_201_05_4]**
6. None of the above   **[PH_201_07_4]**
95. Other   **[PH_201_95_4] [PH_201_oth_4]**
97. UR   **[PH_201_97_4]**
98. DK   **[PH_201_98_4]**

PH_374_4: [Do\Does] [you/Rname] or[your/his/her] carer keep a record of [your/his/her] seizures?

1. Yes
5. No
97. UR
98. DK

PH_375_4: How often [have\has] [you/he/she] had a seizure in the past two years?

1. Have not had a seizure in 2 years
2. Daily
3. Weekly (but not daily)
4. More than once a month (but not weekly)
5. Less than once a month
97. UR
98. DK

PH_376_4: [Have\Has] [you/Rname] ever had education on how best to take care of/manage your epilepsy?

1. Yes
5. No
97. UR
98. DK

IF (PH_350_23a_4=1) ASK PH_384a_4. OTHERS GO TO PH_384b_4

PH_384_4: When [were/was] [you/Rname] first told by a doctor that [you/he/she] had dementia (including Alzheimers disease)?

(MM/YYYY)

_____/_____   [PH_384m_4][PH_384y_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

PH_384b_4:

IF (PH_350_23a_4=1 OR PH_350_23aFF_4 = 1 & PH_350a_4= 1,2 & PH_350X0_23a ≠ 1) ask PH_384b_4. OTHERS GO TO PH_385_4

What type of dementia were you diagnosed with?

1. Alzheimers Dementia
2. Lewy Body Dementia
3. Fronto Temporal
4. Vascular Dementia
95. Other (please specify)

97. Unclear Response
98. Don't Know
99. Refused to answer

(IDS-TILDA)

IF (PH_350_24_4= 1 OR PH_350_24FF_4 = 1 & & PH_350a_4= 1,2 & PH_350X0_24 ≠ 1), ASK PH_385_4. OTHERS GO TO PH_386_4

PH_385_4: Have you ever had dialysis or a kidney transplant?

1. Yes
5. No
97. UR
98. DK
99. RF

(TILDA)

Severe Anaemia

Irritable Bowel Syndrome

IWER: ALL RESPONDENTS ARE ASKED PH_386_4

PH_386_4: [Have/Has] [you/Rname] ever had a major bleed which required hospitalisation or a blood transfusion?

1. Yes
5. No
97. UR
98. DK
99. RF

(TILDA)

IF (PH_350_26_4= 1), ASK PH_398a_4. OTHERS GO TO Next Section PH_0C2_4

PH_398f_4: In the last three years have you had recurrent chest infections (where recurrent is defined as 3 in 6 months or 4 in 12 months)

1. Yes
5. No
97. UR
98. DK
99. RF

PH_398a_4: In the last 3 years, how many times [have/has] [you/Rname] gone to [your/his/her] GP because of a chest infection?

_____Number

97. UR
98. DK
99. RF

PH_398b_4: On how many occasions in the last 3 years, [were/was] [you/Rname] prescribed antibiotics for a chest infection?

_____Number

97. UR
98. DK
99. RF

PH_398c_4: On how many occasions in the last 3 years, [were/was] [you/Rname] hospitalised as a result of a chest infection?

_____Number

97. UR
98. DK
99. RF

PH_399a_4: On any of these occasions did [your/his/her] GP or a doctor in the hospital ever tell [you/him/her] that [you/he/she] had pneumonia?

1. Never
2. Once
3. Twice
4. Three or more times

97. UR
98. DK
99. RF

IF (PH_399a = 2 | 3 | 4), ASK PH_399b_4. OTHERS GO TO PH_0C2_4

PH399b_4: [Were/was] [you/Rname] admitted to hospital due to pneumonia?

1. Never
2. Once
3. Twice
4. Three or more times

97. UR
98. DK
99. RF

IF PH_399b_4 =2 | 3 | 4 ASK PH_399c_4 – PH_399e_4 OTHERS GO TO PH_0C2_4

PH_399c_4: [Were/was] [you/Rname] admitted to the intensive care department due to pneumonia?

1. Never
2. Once
3. Twice
4. Three or more times

97. UR
98. DK
99. RF

9.9   Eating and Drinking

PH_0C2_4: How will this section be completed?

1. Self-Report Only
2. Self-Report and Proxy
3. Proxy Only

INTRO: Now I would like to ask you about [your/Rname's] nutritional health

Tick which applies to [you/him/her]

1. Tube Dependent – **skip to tube dependent subsection PH_125b_4**
2. Total oral intake – **skip to PH_44_4**
3. Both oral intake and tube dependent – **Go to PH_125b_4**

PH_125b_4:

If PH_125a = 1 or 3 then ask PH_125b_4 i.e. indicated tube dependency

What type of feeding tube do you have in place?

1. PEG tube (Percutaneous Endoscopic Gastrostomy)
2. PEG-J tube (Percutaneous Endoscopic Gastro-Jejunostomy)
3. RIG (Radiologically Inserted Gastrostomy)
4. NG tube (Nasogastric)
95. Other (Please specify)

97. Unclear response
98. Don't know
99. Refused to answer

PH_125_4: Please tick which applies to [you/Rname]

If (PH_125a_4 = 1 OR PH_125a_4 =3) then ask PH_125_4

1. No oral intake
2. Tube dependent with minimal/inconsistent oral intake
3. Tube supplements with consistent oral intake

Functional Oral Intake Scale – Crary et al 2005

PH_44_4: In general, how healthy is [your/Rname's] overall diet? Would you say…?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Excellent
2. Very Good
3. Good
4. Fair
5. Poor

97. Unclear response
98. Don't know
99. Refused to answer

(NHANES)

PH_45_4: [Do/Does]   [you/he/she] add salt to food while at the table?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Always
2. Usually
3. Sometimes
4. Rarely
5. Never

97. Unclear response
98. Don't know
99. Refused to answer

(Slan 2007)

PH_46_4: In general, would you consider [yourself/him/her to be …?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Overweight
2. Underweight
3. About the right weight

97. Unclear response
98. Don't know
99. Refused to answer

(Adapted from NHANES 2005-2006)

PH_47_4: [Are/Is] [you/he/she] on any special diet?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

    1. Yes, **Go to PH_48_4**
    5. No **Go to PH_50_4**

    97. Unclear response **Go to PH_50_4**
    98. Don't know **Go to PH_50_4**
    99. Refused to answer **Go to PH_50_4**

(Adapted from Nutritional Risk Index/IDS-TILDA)

PH_48_4: Who advised [you/him/her] to follow this diet?

IWER: CODE ALL THAT APPLY

PH_48_i_4 for i = 1 to 7,95, 97, 98, 99

     1. A dietician
     2. A nurse
     3. A doctor
     4. A family member
     5. A key worker/support worker
     6. [Yourself/Himself/Herself]
     7. Speach and Language Therapist
    95. Other (Please specify)

    97. Unclear response
    98. Don't know
    99. Refused to answer

(IDS-TILDA)

PH_49_4: What type of diet [are/is] [you/he/she] following?

IWER: CODE ALL THAT APPLY

PH_49_i_4 for i = 1 to 9, 95,oth, 97, 98, 99

1. Low fat / cholesterol
1. Low sodium
1. High calorie
1. Gluten free
1. Weight reducing
1. Diabetic diet
1. PKU
1. Lactose intolerant
1. Low potassium

97. Unclear response
98. Don't know
99. Refused to answer

(Adapted from Nutritional Risk Index/IDS-TILDA)

PH_49a_4: Do you use thickeners for your fluids?

IWER: ASK ALL PARTICIPANTS

1. Yes- Slightly thick (i.e. thicker than water, but easily flows through a straw)
2. Yes - Mildly thick (i.e. sippable, pours quickly from a spoon, but slower than water)
3. Yes - Moderately thick (i.e. fruit syrup: can be eaten with a spoon, drips slowly through the slot of a fork)
4. Yes - Extremely thick (i.e. cannot be sucked from a straw or drunk from a cup, when the spoon is tilted, falls but holds the shape of the spoon
5. No, I do not use any thickeners for fluids

97. Unclear response
98. Don't know
99. Refused to answer

PH_49b_4: Do you modify the consistency of your food like being liquidised, pureed, minced and moist, etc.?]

IWER: ASK ALL PARTICIPANTS

1. Yes liquidised (i.e. fruit syrup: can only be eaten with a spoon, drips slowly through   the slot of a fork)
2. Yes Pureed (i.e. pureed meat, thick cereal)
3. Yes, Minced and Moist (i.e. finely minced and chopped meat/fish/vegetables; mashed fruit)
4. Yes Soft/ Bite-sized (i.e. cooked, tender meat, steamed or boiled vegetables, banana)
5. No, I eat every type of food (e.g. meat consistency)

97. Unclear response
98. Don't know
99. Refused to answer

PH_50_4: Within the last year, [have/has] [you/Rname] lost or gained ten pounds (4.5kg) or more in weight when [you/he/she] [weren't/wasn't] trying to?

[NOTE: By losing or gaining weight when [you/he/she] [weren't/wasn't] trying to, for example, because of illness. Also, if the person answers 'Yes', probe for whether they gained, lost or both gained and lost ten or more pounds]

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Yes, gained weight
2. Yes, lost weight
3. Yes, gained and lost weight
5. No, weight has remained the same

97. Unclear response
98. Don't know
99. Refused to answer

(HRS/ELSA/TILDA)

PH_127a_4: Do you have any chewing difficulty?

1. Yes, with any type of food
2. Yes, with some type of food (please specify)
5. No
95. Other (please specify)

97. Unclear response
98. Don't know
99. Refused to answer

PH_127oth_4: If PH_127a_4 = 2 or 95 then please specify here [Text box]

PH_127b_4: [Do/Does] [you/he/she] receive any type of assistance during mealtime? Tick ALL that apply:

PH_127b_01_4: Prompting, pacing and/or encouraging (e.g. Encouraging to slow down/finish one mouthful of food before the next, prompting to open mouth, chew or swallow...)

PH_127b_02_4: Provision of adapted equipment (e.g. special cutlery, modified cups, plastic spoons.)

PH_127b_03_4: Assistance in getting food to the mouth (e.g. hand-over-hand support, fed by the caregiver)

PH_127b_04_4: Modification of mealtime environment or routine (e.g. removing distractions, adjusting mealtime length according to proneness to get tired.)

> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

PH_127c_4: [Do/Does] [you/he/she] experience any of the following feeding behaviors? Tick all that apply:

PH_127c_01_4: Food refusal

PH_127c_02_4: Rigid food preferences

PH_127c_03_4: Overfilling the mouth

PH_127c_04_4: Fast rate of eating and/or drinking

PH_127c_05_4: Pocketing food in the mouth

PH_127c_06_4: Voluntary spitting up of food after eating (Rumination)

PH_127c_07_4: Ingestion of items with no nutritional value- e.g. hair, butts. (Pica)

> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

PH_127_4: [Do/Does] [you/he/she] have a history of choking episodes?

> 1. Yes, **Go to PH_128_4**
> 5. No **Go to PH_51_4**
>
> 97. Unclear response **Go to PH_51_4**
> 98. Don't know **Go to PH_51_4**
> 99. Refused to answer **Go to PH_51_4**

PH_128_4: If yes, please indicate the number of choking episodes [you/he/she] [have/has] experienced.

PH_128_1_4: In the last week _____ (insert number here)

PH_128_2_4: In the last month _____ (insert number here)

PH_128_3_4: In the last year _____(insert number here)

PH_129_4: In the last year did [you/he/she] require an intervention as a result of a choking episode?

IWER: For example, Heimlich, hospitalization, attention of nurse / doctor on call

IWER: Code ONE that applies

1. Yes, for each of the episodes
2. Yes, for some of the episodes
3. No, never

PH_130_4: Please indicate the food item or items (food or other) and/or specific behaviours (e.g. eating too quickly) that resulted in the choking episode

Please specify

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PH_51_4: Any other Information (Nutritional Health)

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9.10 Foot Health

PH_0C_4: How will this section be completed?

1. Self-Report Only
2. Self-Report and Proxy
3. Proxy Only

PH_52_4:

INTRO: I would now like to ask you some questions about [you/Rname's] foot health.

In general, what condition would you say [your/his/her] feet are in?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

97. Unclear response
98. Don't know
99. Refused to answer

(Adapted from FHSQ)

PH_53_4: [Do/Does] [you/he/she] have any pain in [your/his/her] feet?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to PH_54_4**
5. No **Go to PH_56_4**

97. Unclear response **Go to PH_56_4**
98. Don't know **Go to PH_56_4**
99. Refused to answer **Go to PH_56_4**

(Adapted from OK Health Check)

PH_54_4: What is the cause of this pain?

IWER: Record the response below.

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97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

PH_55_4: How much does [your/his/her] foot health limit [you/him/her] walking (e.g. because of foot pain)?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Not at all
2. Slightly
3. Moderately
4. Quite a bit
5. Extremely

97. Unclear response
98. Don't know
99. Refused to answer

(Adapted from FHSQ)

PH_56_4: Any Other Information (Foot Health):

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Falls/Fracture section

NOTE: A fall is defined as an unexpected event in which the participant comes to rest on the ground, floor or lower level (Lamb et al 2005).

PH_57a_4:

If (intstatusW4 = 1), use wording 'B'

B. Have you fallen since your last interview?

    1.   Yes,   IF intstatusW4= 1, **Go To PH_57B_3. OTHERWISE Go ToPH_57_4**
    5.   No   **Go To PH_70_4**
    98. DK   **Go To PH_70_4**
    99. RF   **Go To PH_70_4**

(ELSA/HRS)

PH_57B_3: How many times have you fallen since your last interview?

_____Number

    97. Unclear response
    98. Don't know
    99. Refused to answer

(ELSA/HRS)

PH_57_4:

IWER: ASK ALL PARTICIPANTS

NOTE: A fall is defined as an unexpected event in which the participant comes to rest on the ground, floor or lower level (Lamb et al 2005).

In the past month [have/has] [you/he/she] had any fall including a slip or trip in which [you/he/she] lost [your/his/her] balance and landed on the floor or ground or lower level?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

    1.   Yes, **Go to PH_58_4**
    5.   No **Go to PH_61_4**

    97. Unclear response **Go to PH_61_4**
    98. Don't know **Go to PH_61_4**
    99. Refused to answer **Go to PH_61_4**

(ELSA/HRS/Lamb et al 2005)

PH_58_4: How often [have/has] [you/he/she] fallen down in the past month?

Insert number here: _____

     95. Other (please specify)

     97. Unclear response
     98. Don't know
     99. Refused to answer

(ELSA/HRS/IDS-TILDA)

PH_59_4: In general, were most of these falls…?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

     1.   Accidental (e.g. slipping or tripping over something) **Go to PH_61_4**
     2.   Non-accidental **Go to PH_60_4**

     97. Unclear response **Go to PH_61_4**
     98. Don't know **Go to PH_61_4**
     99. Refused to answer **Go to PH_61_4**

(TILDA/IDS-TILDA)

PH_60_4: Were these non-accidental falls because of…?

IWER: READ OUT AND CODE ONE THAT APPLY

     1.   No apparent or obvious reason
     2.   Due to a pre-existing physical or mental health condition (e.g. epilepsy, parkinson's disease, diabetes)
     3.   As a result of being pushed
     95. Other (please specify)

     97. Unclear response
     98. Don't know
     99. Refused to answer

(TILDA/IDS-TILDA)

PH_61_4: In the past year [have/has] [you/he/she] had any fall including a slip or trip in which [you/he/she] lost [your/his/her] balance and landed on the floor or ground or lower level?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

    1. Yes, **Go to PH_62_4**
    5. No **Go to PH_67_4**

    97. Unclear response **Go to PH_67_4**
    98. Don't know **Go to PH_67_4**
    99. Refused to answer **Go to PH_67_4**

(ELSA/HRS/Lamb et al 2005)

PH_62_4: How often [have/has] [you/he/she] fallen down in the past year?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

Insert number here: _____

    95. Other (please specify)

    97. Unclear response
    98. Don't know
    99. Refused to answer

(ELSA/HRS/IDS-TILDA)

PH_63_4: In general, were most of these falls…?

IWER: READ OUT AND CODE THE ONE THAT APPLIEs

    1. Accidental (e.g. slipping or tripping over something) **Go to PH_133_4**
    2. Non-accidental **Go to PH_64_4**

    97. Unclear response **Go to PH_133_4**
    98. Don't know **Go to PH_133_4**
    99. Refused to answer **Go to PH_133_4**

(TILDA/IDS-TILDA)

PH_64_4: Were these non-accidental falls because of…?

IWER: READ OUT AND CODE ONE THAT APPLY

    1. No apparent or obvious reason
    2. Due to pre-existing physical or mental health condition (e.g. epilepsy, diabetes, Parkinson's)
    3. As a result of being pushes
    95. Other (Please specify)

    97. Unclear response
    98. Don't know
    99. Refused to answer

(TILDA/IDS-TILDA)

PH_133_4:

IWER: Most of the time in the last year where [were/was] [you/he/she] most likely to fall?

IWER: TICK ONE THAT APPLIES

    1. Bathroom
    2. Kitchen
    3. Living Room
    4. Bedroom
    5. Outside in garden/driveway
    95. Other (Please specify)

    97. Unclear response
    98. Don't know
    99. Refused to answer

PH_134_4:

IWER: In the last year what time of the day [were/was] [you/he/she] most likely to fall?

IWER: TICK ONE THAT APPLIES

1. 6am – 10 am (early morning)
2. 10am – 2pm (midday)
3. 2pm – 6pm (afternoon)
4. 6pm – 10pm (early evening)
5. 10pm – 6am (during the night)

97. Unclear response
98. Don't know
99. Refused to answer

PH_65_4: Because of a fall, did [you/he/she] ever injure [yourself/himself/herself] seriously enough to need medical treatment? (i.e. at an A&E Department or visit to or by a General Practitioner or Resident Physician)

IWER: IF YES, PROBE: DID YOU GET MEDICAL TREATMENT?

1. Yes and [I/he/she] got treatment **Go to PH_66_4**
2. Yes and [I/he/she] did not get treatment **Go to PH_66_4**
3. No **Go to PH_67_4**

97. Unclear response **Go to PH_67_4**
98. Don't know **Go to PH_67_4**
99. Refused to answer **Go to PH_67_4**

(ELSA/HRS)

PH_66_4: What type of injury did [you/he/she] sustain/receive?

IWER: READ OUT AND CODE ALL THAT APPLY

PH_66_i_4 for i = 1 to 5, 95, oth, 97, 98, 99

1. Bruise
1. Scratch or small cut
1. Cut that required stitches
1. Fracture / broken bone
1. Head injury
95. Other

97. Unclear response
98. Don't know
99. Refused to answer

PH_67_4: IF (intstatusW4 = 2), USE WORDING 'A'. IF (intstatusW4 = 1), USE WORDING 'B'.

    A. [Have/Has] [you/Rname] ever had a blackout or fainted?

    B. Since your/the last interview, have you had a blackout or fainted?

    1. Yes, IF intstatusW4=1 Go To PH_68a_4; OTHERWISE, Go To PH_68_4
    5. No G0 T0 PH_69_4
    97. Unclear response Go to PH_69_4
    98. Don't know Go to PH_69_4
    99. Refused to answer Go to PH_69_4

(TILDA)

PH_68a_4: Approximately, how many times [have/has] [you/he/she] had a blackout or fainted since your last interview?

_____ time(s) in the last year

    97. Unclear response
    98. Don't know
    99. Refused to answer

(TILDA)

PH_68_4: IF PH_67_4 = 1 then ask PH_68_4. OTHERS GO TO PH_69_4

Approximately, how many times [have/has] [you/he/she] had a blackout or fainted in the last year?

_____: time(s) in the last year

    97. Unclear response
    98. Don't know
    99. Refused to answer

(TILDA)

PH_69_4: IF (intstatusW4 = 2), use wording 'A' If (intstatusW4 = 1), use wording 'B'

A. [Have/Has] [you/Rname] ever attended a falls clinic?

B. Have [you/Rname] attended a falls clinic since your last interview?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

    1. Yes
    5. No
    2. SR / Proxy not aware of falls clinic
    97. Unclear response
    98. Don't know
    99. Refused to answer

(IDS-TILDA)

PH_70_4: Any Other Information (Falls):

PH_71_4: [Are/Is] [you/he/she] afraid of falling?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

    1.   Yes, **Go to PH_72_4**
    5.   No Go to PH_74_4
    97. Unclear response **Go to PH_72_4**
    98. Don't know **Go to PH_72_4**
    99. Refused to answer **Go to PH_72_4**

(TILDA)

PH_72_4: [Do/Does] [you/he/she] feel somewhat afraid or very much afraid of falling?

IWER: CODE THE ONE THAT APPLIES

    1.   Somewhat afraid of falling
    2.   Very much afraid of falling
    97. Unclear response
    98. Don't know
    99. Refused to answer

(TILDA)

PH_73_4: [Do/Does] [you/he/she] ever limit [your/his/her] activities, for example, what [you/he/she] [do/does] or where do [you/he/she] [go/goes], because [you/he/she] [are/is] afraid of falling?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

    1.   Yes
    5.   No
    97. Unclear response
    98. Don't know
    99. Refused to answer

(TILDA)

9.13 Falls Efficacy

PH_82_4:

IWER: Now we would like to ask some questions about how concerned [you/Rname] [are/is] about the possibility of falling. Please reply thinking about how [you/he/she] usually [do/does] the activity. If [you/he/she] currently [don't/doesn't] do the activity, please answer to show whether you think [you/he/she] would be concerned about falling IF [you/he/she] did the activity.

IWER: PLEASE TICK THE BOX WHICH

IS CLOSEST TO YOUR OWN OPINION TO SHOW HOW CONCERNED [YOU/Rname] [ARE/IS] THAT [YOU/HE/SHE] MIGHT FALL IF [YOU/HE/SHE] DID THIS ACTIVITY

PH_82_i_4 for I = 1 to 7

	Not at all concerned		Somewhat concerned		Fairly concerned		Very concerned
Getting dressed or undressed		1		2		3	4
Taking a bath or a shower		1		2		3	4
Getting in or out of a chair		1		2		3	4
Going up or down stairs		1		2		3	4
Reaching for something over [your/his/her] head or on the ground		1		2		3	4
Walking up or down a slope		1		2		3	4
Going out to a social event		1		2		3	4

(SHORT FES-1)

PH_74_4: Any Other Information (Fear of Falling):

9.14 Steadiness and Fractures

We are interested in [your/Rname's] steadiness when walking, standing or getting up from a chair. How steady [do/does] [you/he/she] feel…?

IWER: READ OUT AND CODE ONE BOX ON EACH LINE

PH_75_i_4 for I = 1 to 3

	Very Steady	Slightly Steady	Slightly unsteady	Very unsteady	Not applicable	Unclear response	Don't know	Refused to answer
Walking	1	2	3	4	94	97	98	99
Standing	1	2	3	4	94	97	98	99
Getting up from a chair	1	2	3	4	94	97	98	99

(TILDA)

PH_300a_4: Last time you were interviewed, you told us that you had fractured your (insert fracture locations from PH_400_iFF_4).

1. Continue (go to PH_400_03)
2. Respondent disputes having one/all of these conditions

CONDITION DISPUTED

PH_400X0_4:

IWER: Which fracture is being disputed

1. Hip (display if (PH_400_01FF_4= 1)   **[PH_400X0_01_4]**
2. Wrist (display if (PH_400_02FF_4 = 1)   **[PH_400X0_02_4]**
3. Back/spine (vertebral) (display if PH_400_03FF_4 = 1) **[PH_400X0_03_4]**

IF (PH_400X0_01_4 = 1) THEN ASK

PH_400X_01_03: It may be that we have a recording error about you fracturing your hip. Can you confirm, that ...READ OUT.

1. You never fractured your hip (error from previous wave)
2. The hip fracture was misdiagnosed

IF (PH_400X0_02_4 = 1) THEN ASK

PH_400X_02_4: It may be that we have a recording error about you fracturing your wrist. Can you confirm, that ...READ OUT.

1. You never fractured your wrist (error from previous wave)
2. The wrist fracture was misdiagnosed

IF (PH_400X0_03_4 = 1) THEN ASK

PH_400X_03_4: It may be that we have a recording error about you fracturing bones in your back/spine. Can you confirm, that ...READ OUT.

1. You never fractured bones in your back/spine (error from previous wave)
2. The back/spine fracture was misdiagnosed

PH_400_4: IF (intstatusW4= 2), USE WORDING 'A'. OTHERS, USE WORDING 'B'

A. [Have/Has] [you/Rname] ever fractured any of the following?
B. Since [your/his/her/the] last interview, [have/has] [you/Rname] fractured any of the following?

IWER: CODE ALL THAT APPLY

1. Hip **[PH_400_01_4]**
2. Wrist **[PH_400_02_4]**
3. Bones in [your/his/her] back/spine (Vertebral) **[PH_400_03_4]**
95. Other (please specify) [PH_400_95_4] **[PH_400_oth_4]**
96. None of the above **[PH_400_96_4]**
97. Unclear response **[PH_400_97_4]**
98. DK **[PH_400_98_4]**
99. RF **[PH_400_99_4]**

(ELSA/HRS/WHO FRAX)

IF (PH_400_01FF_4= 1 & PH_400x0_01_4≠1) OR (PH_400_01_4=1), GO TO PH_401a_4

IF (PH_400_02FF_4 = 1 & PH_400x0_02_4≠1) OR (PH_400_02_4=1), GO TO PH_401b_4

IF (PH_400_03FF_4 =1 & PH_400x0_03_4≠1) OR (PH_400_02_4=1), GO TO PH_401b_4

If no fractures, go to PH_141_4

If R indicates that they have a history of hip, wrist or vertebral fracture.... Repeat the following loop for each fracture (i.e. PH_401a_4 to PH_404a_4 for hip; PH_401b_4 to PH_404b_4 for wrist; PH_401c_4 to PH_404c_4 for vertebral)

PH_401a_4: [Were/Was] [you/Rname] aged 40 or over when [you/he/she] fractured [your/his/her] hip?

1. Yes, **Go To PH_402a_4**
5. No **Go To PH_401b_4**
97. Unclear response **Go To PH_401b_4**
98. Don't know **Go To PH_401b_4**
99. Refused to answer **Go To PH_401b_4**

PH_402a_4: In what month/year did this fracture occur?

(MM/YYYY)

_____/_____ [PH_402am_4][PH_402ay_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

PH_403a_4: Was this fracture the result of a fall, a car accident or another event?

1. Fall **Go To PH_404a_4**
2. Car accident **Go To PH_401b_4**
95. Other event **Go To PH_401b_4**
97. UR **Go To PH_401b_4**
98. DK **Go To PH_401b_4**
99. RF Go To PH_401b_4

PH_404a_4: Which of the following best describes the circumstances of this fall?

1. Fell while sitting, standing still or walking slowly
2. Fell while walking quickly, jogging or running
3. Fell when turning
4. Fell when getting out of bed
5. Fell when sitting down, standing up or using the toilet
6. Fell from a height e.g. off a chair, when using stairs, steps, ladders, etc.
95. Other (please specify in text box) **[PH_404aoth_4]**
97. UR
98. DK
99. RF

IF (PH_400_02FF_4 = 1= 1 & PH_400x0_02_4≠1) OR (PH_400_02_4=1) ASK PH_401b_4, OTHERS GO TO PH_401c_4.

PH_401b_4: [Were/Was] [you/Rname] aged 40 or over when [you/he/she] fractured [your/his/her] wrist?

1. Yes, **Go To PH_402b_4**
5. No **Go To PH_401c_4**
97. UR **Go To PH_401c_4**
98. DK **Go To PH_401c_4**
99. RF **Go To PH_401c_4**

PH_402b_4: In what month/year did this fracture occur?

(MM/YYYY)

_____/_____ [PH_402bm_4][PH_402by_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

PH_403b_4: Was this fracture the result of a fall, a car accident or another event?

1. Fall **Go To PH_404b_4**
2. Car accident **Go To PH_401c_4**
95. Other event **Go To PH_401c_4**
97. UR Go To PH_401c_4
98. DK **Go To PH_401c_4**
99. RF **Go To PH_401c_4**

PH_404b_4: Which of the following best describes the circumstances of this fall?

1. Fell while sitting, standing still or walking slowly
2. Fell while walking quickly, jogging or running
3. Fell when turning
4. Fell when getting out of bed
5. Fell when sitting down, standing up or using the toilet
6. Fell from a height e.g. off a chair, when using stairs, steps, ladders, etc.
95. Other (please insert in text box) [PH_404both_4]
97. UR
98. DK
99. R

IF (PH_400_03FF_4 = 1 & PH_400x0_03_4≠1) OR (PH_400_03_4=1) ASK P PH_401c_4, OTHERS GO TO PH_405_4.

PH_401c_4: [Were/Was] [you/Rname] aged 40 or over when [you/he/she] fractured [your/his/her] back/spine (vertebrae)?

1. Yes, **Go To PH_402c_4**
5. No **Go To PH_405_4**
97. UR **Go To PH_405_4**
98. DK **Go To PH_405_4**
99. RF **Go To PH_405_4**

PH_402c_4: In what month/year did this fracture occur?

(MM/YYYY)

_____/_____ [ph_439cm_4][ph_439cy_4]

_____ UR DK RF MONTH

_____ UR DK RF YEAR

PH_403c_4: Was this fracture the result of a fall, a car accident or another event?

1. Fall **Go To PH_404c_4**
2. Car accident **Go To PH_405_4**
95. Other event **Go To PH_405_4**
97. UR **Go To PH_405_4**
98. DK **Go To PH_405_4**
99. RF **Go To PH_405_4**

PH_404c_4: Which of the following best describes the circumstances of this fall?

1. Fall   **Go To PH_404c_4**
2. Car accident   **Go To PH_405_4**
95. Other event   **Go To PH_405_4**
97. UR   **Go To PH_405_4**
98. DK   **Go To PH_405_4**
99. RF   **Go To PH_405_4**

PH_404c_4: Which of the following best describes the circumstances of this fall?

1. Fell while sitting, standing still or walking slowly
2. Fell while walking quickly, jogging or running
3. Fell when turning
4. Fell when getting out of bed
5. Fell when sitting down, standing up or using the toilet
6. Fell from a height e.g. off a chair, when using stairs, steps, ladders, etc.
95. Other (please insert in text box)   [PH_404coth_4]
97. UR
98. DK
99. RF

PH_405_4: Did either of [your/his/her] parents ever have a hip or wrist fracture?

1. Yes,   **Go to PH_406_4**
5. No   **Go to PH_407_4**
97. UR   **Go to PH_407_4**
98. DK   **Go to PH_407_4**
99. RF   **Go to PH_407_4**

PH_406_4: Which of [your/his/her] parents had a previous hip or wrist fracture?

1. Mother
2. Father
3. Both
97. UR
98. DK
99. RF

PH_78_4: [Have/Has] [you/Rname] had any joint replacements?

1. Yes,   **Go To PH_79_4**
5. No   **Go To PH_81_4**
97. UR   **Go To PH_81_4**
98. DK   **Go To PH_81_4**
99. RF   **Go To PH_81_4**

(ELSA)

PH_79_4: Which joints did [you/he/she] have replaced?

1.	Hip	[PH_79_01_4]
2.	Both hips	[PH_79_02_4]
3.	Knee	[PH_79_03_4]
4.	Both knees	[PH_79_04_4]
95.	Other joint	[PH_79_95_4]
97.	UR	[PH_79_97_4]
98.	DK	[PH_79_98_4]
99.	RF	[PH_79_99_4]

(ELSA/HRS)

PH_80_4: Was the joint replacement(s) because of arthritis, a fracture or for some other reason?

1. Arthritis
2. Fracture
3. Both arthritis and a fracture
95. Other reason
97. UR
98. DK
99. RF

(ELSA)

PH_81_4:

IWER: ASK ALL PARTICIPANTS

Any Other Information (Steadiness & Fractures):

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PH_141_4:

IWER: ASK ALL PARTICIPANTS

Have you been on a sun holiday in the past six months?

1. Yes, **Go to PH_142_4**
5. No **Go to PH_81_4**

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

PH_142_4: Where was this holiday?

(please specify here)

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      97. Unclear response
      98. Don't know
      99. Refused to answer

(IDS-TILDA)

PH_143_4: Do you enjoy staying in the Sunshine?

      1. Enjoy
      2. Sometimes
      3. Avoid the sunshine

      97. Unclear response
      98. Don't know
      99. Refused to answer

(IDS-TILDA)

PH_144_4: Do you use sun protection

      1. Always
      2. Usually
      3. Sometimes
      4. Rarely
      5. Never

      97. Unclear response
      98. Don't know
      99. Refused to answer

(IDS-TILDA)

PH_83_4:

NOTE: I would now like to ask you some questions about pain.

[Are/Is] [you/Rname] often troubled with pain?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

> 1. Yes, **Go to PH_126_4**
> 5. No **Go to PH_89_4**
>
> 97. Unclear response **Go to PH_89_4**
> 98. Don't know **Go to PH_89_4**
> 99. Refused to answer **Go to PH_89_4**

(ELSA/HRS)(TILDA)

PH_126_4: Has this pain lasted more than 3 months?

> 1. Yes
> 5. No
>
> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

(TILDA)

PH_84_4: How bad is the pain most of the time? Is it...?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

> 1. Mild
> 2. Moderate
> 3. Severe
>
> 97. Unclear response
> 98. Don't know
> 99. Refused to answer

(ELSA/HRS)(TILDA)

PH_85_4:

IWER: ASK ALL PARTICIPANTS

IWER: Now thinking about this pain, in which part of [your/his/her] body is the pain most?

IWER: CODE ALL THAT APPLY

PH_85_i_4for i = 1 to 7, 95, oth, 93,97,98, 99, 0

1. Back
1. Hips
1. Knees
1. Feet
1. Abdomen / Stomach
1. Mouth / Teeth
1. Head
1. Chest
1. All over
95. Other (please specify): _____

97. Unclear response
98. Don't know
99. Refused to answer

(TILDA/IDS-TILDA)

PH_86_4: Does the pain make it difficult for [you/him/her] to do [your/his/her] usual activities such as household chores, work, social or leisure activities?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

(ELSA)(TILDA)

PH_87_4: [Are/Is] [you/he/she] taking any medication to control the pain?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

(ELSA)(TILDA)

PH_89_4: Any Other Information (Pain):

9.16 Constipation

PH_0D_4: How will this section be completed?

    1. Self-Report Only
    2. Self-Report and Proxy
    3. Proxy Only

IF (intstatusW4= 1 & PH_350_05FF_4 = 1), ASK PH_390a_4

ALL OTHERS GO TO PH_350_05_4

PH_390a_4: Last time you were interviewed, you told us that you [had] constipation. (insert conditions from PH_350_05FF_4).   PAUSE

    1. Continue (go to PH_390Y_5_4)
    2. Respondent disputes having one/all of these conditions

CONDITION DISPUTED

PH_390X0_4:

IWER: Which of the conditions is being disputed

    5. Constipation (display if PH_350_05FF_4 =1)   **[PH_390X0_05_4]**

IF (PH_390X0_05_4=1) THEN ASK

PH_390X_05_4: It may be that we have a recording error about you having Constipation. Can you confirm, that …READ OUT.

    1. You never had Constipation (error from previous wave)
    2. Constipation was misdiagnosed

IF (PH_350_05FF_4 = 1 & PH_350a_4 = 1,2 & PH_350X0 _05 ≠ 1) ASK PH_390Y_05_4, OTHERS GO TO PH_350_05_4

PH_390Y_05_4: Do you still have Constipation?

    1. Yes
    5. No

PH_350_05_4

IF (intstatusW4 = 2), USE WORDING 'B', OTHERWISE USE WORDING 'A'

> A. Since [your/his/her/the] last interview, has a doctor ever told [you/Rname] that [you/he/she] [have/has] constipation?
> B. Has a doctor ever told [you/Rname] that [you/he/she] [have/has] constipation?

1. Yes
5. No

97. Unclear response
98. DK
99. RF

IF (PH_350_05_4 = 1) ASK PH_390Yb_05_4, OTHERS GO TO PH_391_4

PH_390Yb_05_4: Do you still have Constipation?

1. Yes
5. No

IF (PH_350_05_4 = 1) OR (PH_350_05FF_4 = 1 & PH_350X0 _05 ≠ 1), ASK PH_391_4. OTHERS GO TO PH_392_4

PH_391_4: [Is/Are] [you/he/she] currently doing any of the following to manage [your/his/her] constipation?

IWER: Select all that apply

1. Taking medications	**[PH_391_01_4]**
2. Lifestyle changes (e.g. diet, exercise, etc.)	**[PH_391_02_4]**
95. Other	**[PH_391 _95_4]**
96. None of the above	**[PH_391 _96_4]**
97. UR	**[PH_391 _97_4]**
98. DK	**[PH_391 _98_4]**
99. RF	**[PH_391 _99_4]**

IF (PH_350_05_4 = 1) OR (PH_390Y_05_4), ASK PH_392_4. OTHERS GO TO PH_393_4

PH_392_4: Have you ever mentioned this problem to a doctor or nurse?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

IF (PH_350_05_4 = 1) OR (PH_390Y_05_4), ASK PH_392_4. OTHERS GO TO NEXT SECTION

PH_393_4: Do you ever limit your activities, for example, what you do or where you go because of this problem?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

PH_394_4: Over the past 6 months [have/has] [you/he/she] experienced any of the following for at least 25% of defecations and have they been active for 3 months?

IWER: PLEASE TICK ALL THAT APPLY

1. Straining
1. Lumpy or hard stool
1. Sensation of incomplete evacuation
1. Sensation of anorectal obstruction/blockage
1. Manual maneuvers (e.g. digital evacuation, support to the pelvic floor)
1. Fewer than three defecations per week
1. Pain during defecation
95. None of the above

(Rome III Criteria)

PH_395_4: [Do/Does] [you/he/she] ever have normal or loose stool without the use of laxatives?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

PH_367_4: [Have/Has] [you/he/she] ever experienced encopresis? By this we mean a small leakage of bowel movements which result in stained under wear?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

9.17 Bowel Incontinence

PH_95_4: During the last 12 months, [have/has] [you/Rname] lost any amount of faeces beyond [your/his/her] control?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes **Go to PH_96_4**
5. No **Go to PH_99_4**
3. Not relevant, never continent **Go to PH_99_4**

97. Unclear response **Go to PH_99_4**
98. Don't know **Go to PH_99_4**
99. Refused to answer **Go to PH_99_4**

PH_96_4: Did this happen more than once during a 1-month period?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

(Adapted from ELSA)

PH_97_4: [Have/Has] [you/he/she] ever mentioned this problem to a doctor, nurse or other health professional?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

(Adapted from ELSA)

PH_98_4: [Do/Does] [you/he/she] ever limit [your/his/her] activities, for example, what [you/he/she] [do/does] or where [you/he/she] [go/goes] because of this problem?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

PH_99_4: Any Other Information (Bowel Incontinence):

9.18 Bladder Incontinence

PH_90_4:

INTRO: We are interested in finding out more about problems that affect people's quality of life.　I would therefore like to ask you some questions about going to the toilet/urinary incontinence.

IWER: During the last 12 months, have [you/Rname] lost any amount of urine beyond [your/his/her] control?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

    1. Yes, **Go to PH_91_4**
    5. No **Go to PH_94_4**
    3. Not relevant, never continent **Go to PH_94_4**

    97. Unclear response **Go to PH_94_4**
    98. Don't know **Go to PH_94_4**
    99. Refused to answer **Go to PH_94_4**

(ELSA/HRS/IDS-TILDA)

PH_91_4:

IWER: Did this happen more than once during a 1-month period?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

    1. Yes
    5. No

    97. Unclear response
    98. Don't know
    99. Refused to answer

(ELSA)(TILDA)

PH_92_4:

IWER: [Have/Has] [you/he/she] ever mentioned this problem to a doctor, nurse or other health professional?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

(ELSA)(TILDA)

PH_93_4:

IWER: [Do/Does] [you/he/she] ever limit [your/his/her] activities, for example, what [you/he/she] [do/does] or where [you/he/she] [go/goes] because of this problem?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

(TILDA)

PH_94_4: Any Other Information (Bladder Incontinence):

PH_104_4:

IWER: ASK ALL PARTICIPANTS

IWER: In the pre-interview questionnaire, we asked you to record all medications that [you/Rname] [take/takes] on a regular basis, like every day or every week. This included prescription and non-prescription medications, over-the-counter medicines, vitamins, and herbal and alternative medicines (see examples on PIQ)

IWER: Do I have all of [your/Rname's] medications here and the correct medical card number (see pre-interview questionnaire)?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to PH_105_4**
5. No **Refer to Operational protocol and Go to PH_105_4**
3. Not relevant, don't take any medication **Go to PH_115_4**
95. Other (please specify) **Go to PH_105_4**

97. Unclear response **Go to PH_105_4**
98. Don't know **Go to PH_105_4**
99. Refused to answer **Go to PH_105_4**

(TILDA/IDS-TILDA)

PH_105_4:

IWER: (SELF-REPORT ONLY)

IF PH_0D_4 = 1 or IF PH_0D_4 =2 ASK PH_105_4. OTHERS GO TO PH_110_4.

Do you know what medication you take and how often you take them?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – PROXY NOT to complete

(IDS-TILDA)

PH_106_4:

IWER: SELF-REPORT ONLY

Do you administer/take your own medication/tablets?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes independently
2. Yes, with support
5. No

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – PROXY NOT to complete

(IDS-TILDA)

PH_107_4:

IWER: SELF-REPORT ONLY

Have you ever received training/instructions about taking medications?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

If yes, please tell us (PH_107yes_4)

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – PROXY NOT to complete

(IDS-TILDA)

PH_108_4:

IWER: SELF-REPORT ONLY

Do you know what your medications are for?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – PROXY NOT to complete

(IDS-TILDA)

PH_109_4:

IWER: SELF-REPORT ONLY

Do you experience any side effects from taking any of your medications?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – PROXY NOT to complete

If yes, please tell us which tablet and what side effect.

(IDS-TILDA)

PH_145_4:

Do you ever miss taking your medications?

1. Yes
5. No

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – PROXY NOT to complete

If yes, please tell us why you miss taking your medications

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(IDS-TILDA)

If PH_0D_4=1 or PH_0D_4 = 2, GO TO FL_61_4

NOTE if proxy present at interview go to PH_110_4 otherwise go to FL_61_4

PH_110_4:

Do you know how often [Rname] has to take medication?

1. Yes
5. No

(IDS-TILDA)

PH_112_4:

Have you ever received training/instructions about administering medications?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

If yes, please tell us

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

PH_113_4:

Do you know what [Rnames] medications are for?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

PH_114_4:

Do you understand the side effects of the medications?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

PH_146_4:

Does [Rname] ever miss taking his/her medications

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

If yes, please tell us why [Rname] misses taking his/her medications

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(IDS-TILDA)

FL_61_4: [Please indicate the level of difficulty, if any,] [you/he/she] [have/has] with taking medication

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. No difficulty **Go to FL_64_4**
2. Some difficulty **Go to FL_62_4**
3. A lot of difficulty **Go to FL_62_4**
4. Cannot do at all **Go to FL_62_4**
5. Not applicable do not take medication **Go to FL_64_4**

97. Unclear response **Go to FL_64_4**
98. Don't know **Go to FL_64_4**
99. Refused to answer **Go to FL_64_4**

(HRS/SHARE/ELSA/NDS)

FL_62_4: Does anyone help [you/Rname] to take [your/his/her] medication(s)?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to FL_64_4**
5. No **Go to FL_64_4**

97. Unclear response **Go to FL_64_4**
98. Don't know **Go to FL_64_4**
99. Refused to answer **Go to FL_64_4**

(HRS/SHARE/ELSA)

PH_115_4:

Any Other Information (Medication):

10 Section 10: Mental Health (MH)

MH_0_4: Who will be completing this section

1. Self-report only
2. Self-report and proxy
3. Proxy only

PH_3_4:

IWER: Ask ALL Participants

Would you say [your/his/her] emotional or mental health is...?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor

97. Unclear response
98. Don't know
99. Refused to answer

(ELSA/HRS/SHARE/TILDA)

PH_4_4: Now thinking about [your/Rname's] mental health, which includes stress, depression, and problems with emotions, how many days during the past 30 days was [your/his/her] mental health not good

_____ Day(s) (Constrain to 30 days: 0………..30)

97. Unclear response
98. Don't know
99. Refused to answer

(Health Related Quality of Life)

IF (intstatusW4 = 1, & MH_350_21FF_4 = 1), GO TO MH_350a_4.

ALL OTHERS GO TO MH_350_4.

MH_350a_4: Last time you were interviewed, you told us that you had (insert condition MH_350_21FF_4).

1. Continue (go to MH_350Y_21_4)
2. Respondent disputes having one/all of these conditions

CONDITION DISPUTED

MH_350X0:

IWER: Which of the conditions is being disputed?

    21. Emotional, nervous or psychiatric problems   (display if MH_350_21FF_4 = 1)

IWER: ASK FOR EACH SELECTION AT MH_350X0

MH_350X_21: It may be that we have a recording error about you having [condition selected at MH_350X0].

IWER: Can you confirm, that …READ OUT.

1. You never had [condition selected at MH_350X0] (error from previous wave)
2. [condition selected at MH_350X0] was misdiagnosed

IF (MH_350_21FF_4 = 1 & MH_350a_4 = 1,2 & MH_350X0_21 ≠ 1) ASK MH_350Y_21_4, OTHERS GO TO MH_350_4

MH_350Y_21_4: Do you still have Emotional, nervous or psychiatric problems   ?

1. Yes
5. No

IF (intstatusW4 = 2), USE WORDING 'B', OTHERWISE USE WORDING 'A'

MH_350_4:

A. Since your last interview, has a doctor ever told you/ that you have any of the [other] conditions on this card?
B. Has a doctor ever told [you/Rname] that [you/he/she] [have/has] any of the conditions on this card?

    21. Emotional, nervous or psychiatric problems [Go to MH_350Yb_21_4] [MH_350_21_4]

IF (MH_350_21_4 = 1) ASK MH_350Yb_21_4, OTHERS GO TO MH_350_4

MH_350Yb_21_4: Do you still have Emotional, nervous or psychiatric problems?

1. Yes
5. No

PH_377_4:

IF (MH_350_21_4=1) ASK PH_377_4 OTHERS GO TO PH_378_4

When [were/was] [you/Rname] first told by a doctor that [you/he/she] had emotional, nervous or psychiatric problems?

Month [MM] _____ Year [YYYY] _____   [PH_377m_4] [PH_377y_4]

  97. Unclear response
  98. Don't know
  99. Refused to answer

IF MH_350Yb_21_4 OR PH_350Y_21_4) ASK PH_378_4. OTHERS GO TO MH_11_4

PH_378_4: What type of emotional, nervous or psychiatric problems [do/does] [you/he/she] have?

IWER: CODE ALL THAT APPLY

1.	Hallucinations	**[PH_378_01_4]**
2.	Anxiety	**[PH_378_02_4]**
3.	Depression	**[PH_378_03_4]**
4.	Emotional problems	**[PH_378_04_4]**
5.	Schizophrenia	**[PH_378_05_4]**
6.	Psychosis	**[PH_378_06_4]**
7.	Mood swings	**[PH_378_07_4]**
8.	Manic depression	**[PH_378_08_4]**
9.	Post-traumatic stress disorder	**[PH_378_09_4]**
95.	Something else	**[PH_378_95_4][PH_378oth_4]**
97.	Unclear Response	**[PH_378_97_4]**
98.	DK	**[PH_378_98_4]**
99.	RF	**[PH_378_99_4]**

(ELSA)

IF MH_350Yb_21_4=1) ASK PH_379_4. OTHERS GO TO PH_379a_4

PH_379_4: [Do/Does] [you/he/she] get psychiatric treatment for [your/his/her] problems, such as attending a psychiatrist?

  1. Yes
  5. No

  97. Unclear response
  98. Don't know
  99. Refused to answer

IF (PH_379_4= 1) ASK PH_380_4.   OTHERS GO TO PH_381_4

PH_380_4: Who gives [you/he/she] get psychiatric treatment for [your/his/her]conditions?

IWER: PLEASE TICK ALL THAT APPLY

1.	Psychiatrist	**[PH_380_01_4]**
2.	General Practitioner	**[PH_380_02_4]**
95.	Other	**[PH_380_95_4] [PH_380_oth_4]**
97.	UR	**[PH_380_97_4]**
98.	DK	**[PH_380_98_4]**
99.	RF	**[PH_380_99_4]**

IF MH_350Yb_21_4=1) ASK PH_381_4. OTHERS GO TO PH_379a_4

PH_381_4: [Do/Does] [you/he/she] get psychological treatment for [your/his/her] problems, such as counselling or behaviour support?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

IF (PH_381_4= 1) ASK PH_382_4. OTHERS GO TO PH_379a_4:

PH_382_4: Who gives [you/he/she] get psychological treatment for [your/his/her]conditions?

IWER: PLEASE TICK ALL THAT APPLY

1.	Psychologist	**[PH_382_01_4]**
2.	Counsellor	**[PH_382_02_4]**
3.	Clinical Nurse Specialist (CNS)	**[PH_382_03_4]**
4.	Psychotherapist	**[PH_382_04_4]**
95.	Other	**[PH_382_98_4] [PH_382_oth_4]**
97.	UR	**[PH_382_97_4]**
98.	DK	**[PH_382_98_4]**
99.	RF	**[PH_382_99_4]**

IF (PH_350_21FF_4 = 1 & PH_350X0_21 ≠ 1) ASK PH_379a_4. OTHERS GO TO PH_383_4

PH_379a_4: Since [your/Rname's] last interview, did [you/he/she] get psychiatric treatment for [your/his/her] problems, such as attending a psychiatrist?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

IF (PH_379a_4= 1) ASK PH_380a_4. OTHERS GO TO PH_381a_4

PH_380a_4: Who gives [you/he/she] get psychiatric treatment for [your/his/her]conditions?

IWER: PLEASE TICK ALL THAT APPLY

1. Psychiatrist   **[PH_380a_01_4]**
2. General Practitioner   **[PH_380a_02_4]**
95. Other   **[PH_380a_98_4] [PH_380a_oth_4]**
97. UR   **[PH_380a_97_4]**
98. DK   **[PH_380a_98_4]**
99. RF   **[PH_380a_99_4]**

IF (PH_350_21FF_4 = 1 & PH_350X0_21 ≠ 1) ASK PH_381a_4. OTHERS GO TO PH_383_4

PH_381a_4: Since [your/his/her] last interview, did [you/he/she] get psychological treatment for [your/his/her] problems, such as counselling?

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

IF (PH_381a_4= 1) ASK PH_382a_4. OTHERS GO TO PH_383_4

PH_382a_4: Who gives [you/he/she] get psychological treatment for [your/his/her]conditions?

IWER: PLEASE TICK ALL THAT APPLY

1. Psychologist   **[PH_382a_01_4]**
2. Counsellor   **[PH_382a_02_4]**
3. Clinical Nurse Specialist (CNS)   **[PH_382a_03_4]**
4. Psychotherapist   **[PH_382a_04_4]**
95. Other   **[PH_382a_98_4] [PH_382a_oth_4]**
97. UR   **[PH_382a_97_4]**
98. DK   **[PH_382a_98_4]**
99. RF   **[PH_382a_99_4]**

10.1 Glasgow Depression Scale

MH_Intro_4:

INTRO: The next section of the interview is about people's mood, feelings and wellbeing. I am going to read a list of statements that describe some of the ways [you/Rname} may have felt or behaved in the last week. Please tell me how often [you/Rname] have felt this way during the past week.

MH_11_4:

IWER: SELF-REPORT ONLY

If MH_0_4 = 1 or MH_0_4 = 2 then ask MH_11_4

IWER: PLEASE COMPLETE THE GLASGOW ANXIETY AND DEPRESSION SCALE WITH ALL PARTICIPANTS OR THEIR PROXY

Glasgow Depression Scale (score of 13 or over indicates depression) .

MH_11_i_4 for i =1-20

In the last week….		Prompts	No	Sometimes	A Lot
1.	Have you felt sad?	Have you felt upset, depressed, miserable, fed up, low?	0	1	2
2.	Have you been in a bad mood?	Have you felt bad tempered, wanted to shout at people?	0	1	2
3.	Have you enjoyed doing things?	Have you had fun?	2	1	0

In the last week….		Prompts	No	Sometimes	A Lot
4.	Have you enjoyed talking and being with people?	Have you liked having people around?	2	1	0
5.	Have you had a bath/shower and changed your clothes?	Have you taken care of the way you look / appearance?	2	1	0
6.	Have you felt tired during the day?	Have you gone to sleep during the day, found it hard to stay awake?	0	1	2
7.	Have you cried?	What made you cry?	0	1	2

	In the last week….	Prompts	No	Sometimes	A Lot
8.	Have you felt people don't like you?	Have you felt you are a horrible person?	0	1	2
9.	Have you been able to concentrate, such as watch TV?	What is your favourite TV programme? Are you able to watch it all?	2	1	0
10.	Have you found it hard to choose things?	Have you found it hard to decide what to wear, eat or do?	0	1	2
11.	Have you found it hard to sit still?	Have you fidgeted moved around a lot more?	0	1	2

	In the last week….	Prompts	No	Sometimes	A Lot
12.	Have you eaten less? Have you eaten more?	Have people said you should eat more or less?	0	1	2
13.	Have you found it hard to get a good night's sleep?	Have you found it hard to fall asleep, woken up a lot	0	1	2
14.	Have you wished you were dead?	Have you wanted to stop living?	0	1	2
15.	Have you felt everything is your fault?	Have you felt people blame you for things?	0	1	2

	In the last week….	Prompts	No	Sometimes	A Lot
16.	Have you felt people are looking at you, talking about you?	Have you worried about what other people think of you?	0	1	2
17.	Have you been upset if people say you have done something wrong?	Do you feel sad, or feel like crying if someone tells you off?	0	1	2
18.	Have you felt worried?	Have you felt nervous, tense, wound up or on edge	0	1	2
19.	Have you thought that bad things will happen to you?	Have you felt nothing nice happens to you?	0	1	2

	In the last week….	Prompts	No	Sometimes	A Lot
20.	Have you felt happy when something good happens?	What makes you feel happy?	2	1	0
		TOTAL SCORE:			

MH_11A_4:

IWER: PROXY ONLY

If MH_0_4 = 3 then ask MH_11A_4

Carer Supplement to the Glasgow Depression Scale for people with a Learning Disability.

MH_11A_i_4 for i =1-12, 12a, 12b, 12c, 13, 14, 15, 16, 16info

		Never / No	Sometimes / a little	Always / A lot
1	Has [Rname] appeared depressed?	0	1	2
2	Has [he/she] been more physically or verbally aggressive than usual?	0	1	2
3	Has [he/she] avoided company or social contact?	0	1	2
4	Has [he/she] looked after [his/her] appearance?	2	1	0
5	Has [he/she] spoken or communicated as much as [he/she] used to?	2	1	0
6	Has [he/she] cried?	0	1	2
7	Has [he/she] complained of headaches or other aches and pains?	0	1	2
8	Has [he/she] still taken part in activities which used to interest [him/her]?	2	1	0
9	Has [he/she] appeared restless or fidgety?	0	1	2
10	Has [he/she] appeared lethargic or sluggish?	0	1	2
11	Has [he/she] eaten too little / too much?	0	1	2
12	If no problem, score 0. (A positive answer to either question means it should be scored. Has [he/she] found it hard to get a good night's sleep?	0	1	2

12a	**IWER**: Please also tick which one of the following options is relevant if MH_11A_12_4 = 1 or MH_11A_12_4 = 2 Code one that applies Has [he/she] had difficulty falling asleep when going to bed at night? [Yes (1)] Has [he/she] been waking in the middle of the night and finding it hard to get back to sleep again? [Yes (2)] Has [he/she] been waking very early in the morning and finding it hard to get back to sleep? [Yes (3)]			
13	Has [he/she] been sleeping during the day?	0	1	2
14	Has [he/she] said that [he/she] does not want to go on living?	0	1	2
15	Has [he/she] asked you for reassurance?	0	1	2
16	Have you noticed any change in [he/she] recently?	0	1	2
16info	Please explain what changes you have noticed, in either mood or behaviour			

IWER: SELF-REPORT ONLY

MH_12_4: If MH_0_4 = 1 or if MH_0_4 = 2 then ask MH_12_4

Glasgow Anxiety Scale (score of 15 or over indicates depression) .

MH_12_i_4 for i

		Prompts	No	Sometimes	A Lot
1.	Do you worry a lot?	Feel wound up, get worked up	0	1	2
2.	Do you have lots of thoughts in your head?	Can't stop thinking, can't keep thoughts away	0	1	2
3.	Do you worry about your family or friends?	Think something bad will happen?	0	1	2
4.	Do you worry about the future?	Link prompt to individual	0	1	2
5.	Do you worry that something bad will happen?		0	1	2
6.	Do you worry about being ill?	If you feel poorly	0	1	2
7.	Do you worry about doing something new?	Afraid to try new things	0	1	2
8.	Do you worry about what you are doing tomorrow?		0	1	2

MH_12_4: If MH_0_4 = 1 or if MH_0_4 = 2 then ask MH_12_4

		Prompts	No	Sometimes	A Lot
9.	Can you stop yourself worrying?	Make yourself think about something else	2	1	0
10.	Do you worry about dying?		0	1	2
11.	Are you scared of the dark?	Do you turn the lights off at night?	0	1	2
12.	Do you feel scared when you are high up?	Do you like multi storey car parks	0	1	2
13.	Do you feel scared in lifts?	Would you get in one?	0	1	2
14.	Are you scared of dogs?	Would you stroke one?	0	1	2

		Prompts	No	Sometimes	A Lot
15.	Are you scared of spiders?	Would you touch one?	0	1	2
16.	Are you scared of going to the doctor or dentist?	Would you go if you needed to ?	0	1	2
17.	Are you scared of meeting new people?	Are you shy?	0	1	2
18.	Are you scared in busy places or crowds?	Such as supermarkets?	0	1	2

		Prompts	No	Sometimes	A Lot
19.	Are you scared of open spaces?	Where there is nothing around you?	0	1	2
20.	Do you get hot and sweaty?	All hot and bothered	0	1	2
21.	Does your heart beat fast?	Feel your heart is thumping?	0	1	2
22.	Do your hands and legs shake?		0	1	2
23.	Do you get butterflies in your stomach?	Knots in your stomach, fluttering.	0	1	2

		Prompts	No	Sometimes	A Lot
24.	Do you find it hard to breath?	Are you out of breath a lot?	0	1	2
25.	Do you have to wee more often?		0	1	2
26.	Is it difficult to sit still?		0	1	2
27.	Do you panic?	Get in a panic or a state?	0	1	2
		TOTAL SCORE:			

10.3 Vitality Scale

MH_3_4:

INTRO: The following questions are about how [you/Rname] [feel/feels] and how things have been with [you/him/her] during the past 4 weeks

How much of the time during the past 4 weeks

Did [you/he/she] feel full of pep? (By pep I mean lively, full of spirit or vigour)

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

97. Unclear response
98. Don't know
99. Refused to answer

(Vitality Scale: RAND Health Survey Tool CEV4 Slan 2007)

MH_4_4: How much of the time during the past 4 weeks

Did [you/he/she] have a lot of energy?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

97. Unclear response
98. Don't know
99. Refused to answer

Vitality Scale: RAND Health Survey Tool CEV4 Slan 2007

MH_5_4: How much of the time during the past 4 weeks

Did [you/he/she] feel worn out?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

97. Unclear response
98. Don't know
99. Refused to answer

Vitality Scale: RAND Health Survey Tool CEV4 Slan 2007

MH_6_4: How much of the time during the past 4 weeks

Did [you/he/she] feel tired?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. All of the time
2. Most of the time
3. A good bit of the time
4. Some of the time
5. A little of the time
6. None of the time

97. Unclear response
98. Don't know
99. Refused to answer

Vitality Scale: RAND Health Survey Tool

MH_7_4:

TO BE COMPLETED BY THE INTERVIEWER

IWER: PLEASE INDICATE HOW THE VITALITY QUESTIONS (PREVIOUS FOUR QUESTIONS) WERE COMPLETED

1. Self-Report Only
2. SR & Proxy
3. Proxy only

MH_8_4:

INTRO: The following are a list of Life Events [you/Rname] may have experienced in the last 12 months. By a life event I mean something that would have caused significant distress in [your/his/her] life. Please indicate if [you/Rname] [have/has] gone through any of the following in the last 12 months.

IWER: READ OUT AND CODE ALL THAT APPLY

MH_8 _i_4 for i = 1 to 18, 94, 95

Level of stress variable names: MH_8A_i_4 for i = 1 to 31

[Have/Has] [you/he/she] experienced in the last 12 months	YES			Level of Stress					
				A lot		A little		None	
Change of staff in [my/his/her] home where [I/he/she] [live/lives] or day service [I/he/she] [attend/attends]		1			1		2		3
Holiday	1				1		2		3
New resident moved into [my/his/her] home	1				1		2		3
Minor illness or injury	1				1		2		3
Change of [my/his/her] key worker	1				1		2		3
Problems with fellow resident	1				1		2		3
Change at or from work or day service	1				1		2		3
Death of a parent	1				1		2		3
Death of a sibling	1				1		2		3
Death of other relative	1				1		2		3
Death of a friend	1				1		2		3
Death of a pet	1				1		2		3
Decline or loss of mobility	1				1		2		3
Major illness of a relative, caregiver or friend	1				1		2		3

Death of a significant other (other than a relative, or friend)	1			1		2	3
Moving within service organisation	1			1		2	3
Moving from [my/his/her] family home to a service supported home (community group home/residential setting)	1			1		2	3
Change in frequency of visits from or to family / friend	1			1		2	3
Major illness or injury	1			1		2	3
Loss of leisure-time activities	1			1		2	3
Rapid loss of vision or hearing	1			1		2	3
Problems with relative, friend or staff	1			1		2	3
Menopause (Ask only if gender = female)							
Loss of something valuable							
Sexual problem							
Break up of a steady relationship / Divorce	1			1		2	3
Alcohol or drug related problems							
Experience of crime (mugged or burgled)	1			1		2	3
Financial problems							
Fired from work/unemployment							
Problems with justice and or authorities	1			1		2	3
No significant life event	94						
Any other event or change of routine which may have caused distress, please tell us							
(Adapted from the Life events scale Hermans et al 2012 & IDS-TILDA Study)							

10.4 The Schedule for Meaning in Life Evaluation (SMiLE)

MH_26_4:

IWER: SELF REPORT ONLY

MH_26_i_4 for i = 1 to 7

Name 3 to 7 areas that give meaning to your life; things that you really look forward to and enjoy doing.

Area 1: _____

Area 2: _____

Area 3: _____

Area 4: _____

Area 5: _____

Area 6: _____

Area 7: _____

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present – PROXY NOT to complete

MH_27_4:

IWER: SELF REPORT ONLY

Please rate how **happy or sad** you are with each of the areas you named. That is how much the area affects your life in a good or not so good way.

MH_27_i_4 for i = 1 to 7

How happy are you with …	Very sad (-2)	Sad (-1)	Neither Sad nor Happy (0)	Happy (+1)	Very Happy (+2)
Area 1					
Area 2					
Area 3					
Area 4					
Area 5					
Area 6					
Area 7					

- 93. Unable to understand
- 97. Unclear response
- 98. Don't know
- 99. Refused to answer
- 0. SR not present – PROXY NOT to complete

MH_29_4:

IWER: Ask ALL Participants

How many hours do you sleep? (Please specify)

Hours: _____

(IDS-TILDA)

MH_9_4:

Any other information (Mental Health)

11 Section 11: Behavioural Health (BH)

11.1 Physical Activity

BH_0_4:

IWER: How will this be section completed?

1. Self-Report Only
2. SR and Proxy
3. Proxy only

(TILDA)

BH_Intro_4:

INTRO: We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. The next set of questions will ask you about the time [you/Rname] spent being physically active in the last 7 days. Please answer each question even if you do not consider [yourself/him/her] to be an active person. Please think about the activities [you/he/she] [do/does] at work, as part of [your/his/her] house and garden work, to get from place to place and in [your/his/her] spare time for recreation, exercise or sport.

Vigorous physical activities can be considered anything that lasts at least 10 to 20 minutes, which causes heavy sweating and makes [you/him/her] breathe harder than normal.

For example: running or jogging, exercise bike, vigorous swimming, cycling, aerobics or gym workout, tennis, heavy housework or gardening like digging with a spade or shovel.

BH_15_4: During the last 7 days on how many days did [you/he/she] do vigorous physical exercise.

IWER: READ OUT

1. Vigorous physical activities: Day/Days (1 – 7) **Go to BH_16_4**
5. No, [I/he/she] [have/has] not done any vigorous physical exercise **Go to BH_17_4**

97. Unclear response **Go to BH_17_4**
98. Don't know **Go to BH_17_4**
99. Refused to answer **Go to BH_17_4**

(ELSA/SHARE/TILDA/IDS-TILDA)

BH_16_4: How much time did [you/he/she] usually spend doing vigorous physical activities on one of those days?

Minutes per day: _____

  97. Unclear response
  98. Don't know
  99. Refused to answer

(ELSA/SHARE/TILDA/IDS-TILDA)

BH_17_4:

Moderately energetic physical activities can be considered anything that lasts at least 10 to 20 minutes that causes only light sweating or a moderate increase in breathing or heart rate.

For example: gardening, cleaning the car, dancing, floor or stretching exercises, swimming or cycling. Do NOT include walking.

During the last 7 days on how many days did [you/he/she] do moderate physical exercise.

IWER: READ OUT AND CODE ONE BOX ON EACH LINE

  1. Moderate physical activities: Day/Days (0 – 7) **Go to BH_18_4**
  5. No, [I/he/she] [have/has] not done any moderate physical exercise **Go to BH_19_4**
  97. Unclear response **Go to BH_19_4**
  98. Don't know **Go to BH_19_4**
  99. Refused to answer **Go to BH_19_4**

BH_18_4: How much time did [you/he/she] usually spend doing moderate physical activities on one of those days?

Minutes per day: _____

  97. Unclear response
  98. Don't know
  99. Refused to answer

(ELSA/SHARE/TILDA/IDS-TILDA)

BH_19_4: Now think about the time [you/he/she] spent walking in the last 7 days. This includes at work and at home, walking to travel from place to place, and any other walking that [you/he/she] might do solely for recreation, sport, exercise, or leisure.

IWER: During the last 7 days on how many days did [you/he/she] walk for at least 10 minutes at at time?

IWER: READ OUT AND CODE ONE BOX ON EACH LINE

1. Walking: _____   Day/Days (0 – 7) **Go to BH_20_4**
5. No, [I/he/she] [have/has] not done any walking **Go to BH_21_4**

97. Unclear response **Go to BH_21_4**
98. Don't know **Go to BH_21_4**
99. Refused to answer **Go to BH_21_4**

(ELSA/SHARE/TILDA/IDS-TILDA)

BH_20_4: How much time did [you/he/she] usually spend walking on one of those days?

Minutes per day: _____

97. Unclear response
98. Don't know
99. Refused to answer

(ELSA/SHARE/TILDA/IDS-TILDA)

BH_21_4: What type of physical activity [do/does] [you/he/she] regularly take part in?

IWER: READ OUT AND CODE THE ALL THAT APPLIES

BH_21_i_4for i = 1 to 18,95,oth,94,97,98,99

1. Bowling
1. Swimming
1. Walking
1. Gym/treadmill / cycling bike
1. Cycling
1. Running/jogging
1. Aerobics
1. Golf
1. Basketball
1. Badminton
1. Horseback riding
1. Soccer/football
1. Dancing
1. Yoga
1. Bocce
1. Tai Chi
1. Athletics
1. Table tennis
95. Other (please specify)

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94. Not applicable – [I/he/she] [don't/doesn't] take part in regular physical activity
97. Unclear response
98. Don't know
99. Refused to answer

(NHANES)

BH_22_4:

What difficulties might stop [you/him/her] doing physical activity?

IWER: CODE ALL THAT APPLY

BH_22_i_4 for i = 1 to 18, 95, oth,94,97,98,99

1. Health considerations or physically unable
1. Wheelchair user
1. Motor impairment
1. Don't have enough money
1. Can't get a lift
1. Transport services are inadequate or not accessible
1. Have no one to go with for company
1. Not allowed to go
1. Need someone's assistance but there is no one to help [you/him/her]
1. Get too tired
1. Don't have enough time
1. There is nothing you can do at the leisure centre
1. Don't like exercise
1. Service facilities are not accessible
1. [You/He/She] [are/is] self-conscious
1. Unfriendly or negative attitudes towards [you/him/her]
1. No available exercise facilities
1. Getting too old
95. Other (please specify)

94. Not applicable – [I/he/she] [don't/doesn't] take part in regular physical activity
97. Unclear response
98. Don't know
99. Refused to answer

(Adapted from POMONA/Special Olympics)

BH_23_4: Would [you/he/she] like to do more (or some, where applicable) physical activities?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to BH_24_4**
5. No **Go to BH_35_4**

97. Unclear response **Go to BH_35_4**
98. Don't know **Go to BH_35_4**
99. Refused to answer **Go to BH_35_4**

(IDS-TILDA)

BH_24_4: Which physical activities would [you/he/she] like to do more of?

IWER: Record the response below.

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

11.2 Perception of Physical Activity and Sport

BH_35_4:

Please answer the following questions in your opinion. Mark one answer.

	Yes (1)	Do not (0)
Does physical activity help you maintain and/or improve your health?	○	○
Does physical activity help you lose/control weight?	○	○
Does physical activity help you look better?	○	○
If you practice physical activity, do you feel stronger and more agile for activities of daily living or work?	○	○
Does physical activity or playing sports make you feel happier?	○	○
Do you have fun playing sports?	○	○
Does physical activity help you be more relaxed?	○	○
Overall, do you have time to do any physical activity or playing sports?	○	○
Do you practice physical activity because you have decided yourself?	○	○

BH_25_4:

Any Other Information (Physical Activity):

11.3 Smoking

BH_1_4:

INTRO: Now I would like to ask you some questions about your lifestyle.

IWER: Have you ever smoked cigarettes, cigars, cigarillos or a pipe daily for a period of at least one year?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to BH_2_4**
5. No **Go to BH_5_4**

97. Unclear response **Go to BH_5_4**
98. Don't know **Go to BH_5_4**
99. Refused to answer **Go to BH_5_4**

(SHARE/Similar question ELSA/HRS)

BH_2_4:

IWER: Do you smoke at the present time?

NOTE: Respond 'yes' if the SR has smoked anytime in the past 3 months.

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Yes, **Go to BH_4_4**
5. No **Go to BH_5_4**

97. Unclear response **Go to BH_5_4**
98. Don't know **Go to BH_5_4**
99. Refused to answer **Go to BH_5_4**

(SHARE/ Similar question ELSA/HRS)

BH_3_4:

IWER: How old were you when you stopped smoking?

_____years old

97. Unclear response
98. Don't know
99. Refused to answer

(SHARE/Similar question HRS)

BH_4_4:

IWER: For how many years have you smoked altogether?

_____years old

    97. Unclear response
    98. Don't know
    99. Refused to answer

(SHARE/Similar question HRS)

BH_5_4:

Any other Information (Smoking):

11.4 Alcohol

BH_6_4:

IWER: Do you drink alcohol?

NOTE: Respond 'yes' if the SR has drank alcohol anytime in the last 6 months.

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to BH _7_4**
5. No **Go to BH _10_4**

97. Unclear response **Go to BH _10_4**
98. Don't know **Go to BH _10_4**
99. Refused to answer **Go to BH _10_4**

BH_7_4:

IWER: During the last 12 months, how often have you drunk any alcoholic beverages, like beer, cider, wine, spirits or cocktails?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Almost every day
2. Five or six days a week
3. Three or four days a week
4. Once or twice a week
5. Once or twice a month
6. Less than once a month
7. Not at all in the last 12 months

97. Unclear response
98. Don't know
99. Refused to answer

(SHARE/Similar question HRS)

BH_8_4:

IWER: During the last 12 months, how often have you had more than two drinks in a single day?

NOTE: A drink is a half pint of beer or a glass of wine.

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Almost every day
2. Five or six days a week
3. Three or four days a week
4. Once or twice a week
5. Once or twice a month
6. Less than once a month
7. Not at all in the last 12 months

97. Unclear response
98. Don't know
99. Refused to answer

(SHARE)

BH_9_4:

IWER: During the last12 months, on the days you drank alcohol, about how many drinks did you have?

_____drinks

97. Unclear response
98. Don't know
99. Refused to answer

(HRS)

BH_10_4: Any Other Information (Alcohol):

BH_33_4: Any Other Information (Behavioural Health)

12 Section 12: Evaluation Questions (EQ)

EQ_0_4: TO BE COMPLETED BY THE INTERVIEWER

IWER: HOW WILL THIS SECTION BE COMPLETED?

1. Self-report only
2. SR & Proxy
3. Proxy only

EQ_1_4:

IWER: Self-Report ONLY

IF EQ_0_4 = 1 or EQ_0_4 = 2, then ask EQ_1_4

INTRO: Now I just have a few final questions before we reach the end of my visit.

In general, did you find the questions in the interview easy to understand?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to EQ_7_4**
5. No **Go to EQ_2_4**

93. Unable to understand **Go to EQ_7_4**
97. Unclear response **Go to EQ_7_4**
98. Don't know **Go to EQ_7_4**
99. Refused to answer **Go to EQ_7_4**
0. SR not present **Go to EQ_7_4**

(IDS-TILDA)

EQ_2_4:

IF EQ_0_4 = 1 or EQ_0_4 = 2, then ask EQ_2_4

Which questions did you find most difficult to understand?

IWER: Record the response below

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┌─────────────────────────────────────────────────────────────┐
│                                                             │
│                                                             │
│                                                             │
│                                                             │
└─────────────────────────────────────────────────────────────┘
```

93. Unable to understand
97. Unclear response
98. Don't know
99. Refused to answer
0. SR not present

(IDS-TILDA)

EQ_7_4:

Once we have spoken to everyone taking part in this study and reviewed the findings, we will be writing about parts of it. Are there any particular topics that [you/ you OR Rname] would like to see written about and published?

[Probe: Are there parts you think are important?]

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to EQ_8**
5. No **Go to EQ_9**

97. Unclear response **Go to EQ_9_4**
98. Don't know **Go to EQ_9_4**
99. Refused to answer **Go to EQ_9_4**

(IDS-TILDA)

EQ_8_4:

Which topics or areas would [you/you OR Rname] like to know more about or read more about?

IWER: Record the response below.

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```

    97. Unclear response
    98. Don't know
    99. Refused to answer

(IDS-TILDA)

EQ_9_4: How would [you/he/she] like us to present the findings from this study? Please tell us [your/his/her] first preference.

IWER: Would you say...?

IWER: READ OUT AND CODE THE ONE THAT APPLIES

1. Full written report
2. Short written report (summary of main findings only)
3. Host information evenings
4. Audio recording of key findings
5. DVD of key findings
6. Video of key findings
95. Other (please specify):_____

    97. Unclear response
    98. Don't know
    99. Refused to answer

(IDS-TILDA)

EQ_12_4: Did [you /he/she] enjoy taking part in the study?

1. Yes
5. No

    97. Unclear response
    98. Don't know
    99. Refused to answer

EQ_10_4: Any other information (Evaluation):

13 Section 13: Final Checks (FC)

FC_0_4:

IWER: TO BE COMPLETED THE BY INTERVIEWER

IWER: How will this section be completed?

1. Self-report only
2. SR & Proxy
3. Proxy only

(IDS-TILDA)

FC_1_4: We are coming to the end of the interview, before we move to the final questions is there anything else you would like to tell us about [yourself/Rname]? Or the people who support [you/him/her], where applicable?

IWER: Record the response below

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

FC_2_4: Would [you/Rname] agree to us contacting [you/him/her] again, if needed, so we can talk about certain areas of your life in more depth, such as where [you/he/she] [live/lives] and what [you/he/she] [like/likes] to do during the day, how [you/he/she] feel about getting older?

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes
5. No

97. Unclear response
98. Don't know
99. Refused to answer

FC_2A_4: And, where applicable talk to …(name of your informal carer) about their own health?

1. Yes
5. No
94. Not applicable

97. Unclear response
98. Don't know
99. Refused to answer

(IDS-TILDA)

FC_3_4: As I explained earlier this is a longitudinal study which means that people who take part will be visited once every three years. [Are/Is] [you/he/she] willing to be re-contacted to participate in a similar interview in the next 3 years? Again [your/his/her] participation will be voluntary.

IWER: PROBE IF NECESSARY - 'WOULD YOU SAY YES OR NO?'

1. Yes, **Go to FC_5_4**
5. No **Go to FC_4_4**

97. Unclear response **Go to FC_4_4**
98. Don't know **Go to FC_4_4**
99. Refused to answer **Go to FC_4_4**

FC_4_4:

IWER: Interviewers should make every effort to outline to the respondent of the importance of the study and the benefits to people with intellectual disability living in Ireland. Also attempt to understand reasons for not wanting to be re-contacted (where applicable) and address these i.e. give assurances on confidentiality and anonymity.

IWER: Please record response below.

(TILDA)

FC_5_4:

Any other information (Final check)

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│                                                                │
│                                                                │
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IWER: That is the end of the interview. Thank you very much for taking part.

14 Section 14: Final Status (FS)

FS_0_4:

IWER: TO BE COMPLETED BY THE INTERVIEWER

IWER: Please record any other relevant information below:

FS_info_4	Any other information	

FS_3_4:

IWER: TO BE COMPLETED BY THE INTERVIEWER

IWER: What was the SR's general communication style?

IWER: CODE THE ONE THAT APPLIES

1. Verbal communication **Go to FS_4_4**
2. Non-verbal communication mostly **Go to FS_4_4**
95. Other (Please Specify) **Go to FS_4_4**
94. Not applicable SR not present **Go to FS_4_4**

FS_4_4:

IWER: TO BE COMPLETED BY THE INTERVIEWER

IWER: What methods did the SR use to communicate during the interview?

IWER: CODE ALL THAT APPLY

Fs_4_i_4 for I = 1-7, 95, oth

1. Words
1. Signs
1. Vocalisations
1. Eye expressions
1. Facial expressions
1. Bodily movements
1. Gestures
95. Other (please Specify): _____

FS_7_4:

IWER: TO BE COMPLETED BY THE INTERVIEWER

How many visits were required to complete the interview?

Number [Insert number from 1 to 10]: _____

FS_7a_4:

Approximately how long was each visit?

FS_7Ai_hours_4:

Hours: _____

FS_7Ai_mins_4

Mins: _____

(Record for each visit given in FS_7_4)

FS_7b_4:

If FS_7_4 is greater than one then ask

What were the reasons for multiple visits.

1. CAPI too long
2. Proxy rearranged interview
3. Challenging behaviour
4. SR not present
5. Collect Piq
95. Other (please specify)

FS_7Both_4:

FS_6_4:

IWER: TO BE COMPLETED BY THE INTERVIEWER

IWER: Please complete the final checklist.

IWER: CODE ONE BOX ON EACH LINE

FS_6_PIQ_4: Pre-Interview Questionnaire collected

1. Yes
5. No

FS_6_PI_4: Participant information sheet updated

1. Yes
5. No

FS_6_CF_4: Consent form

1. Yes
5. No