

# Improving the experience of Dementia and Enhancing Active Life: The IDEAL Programme

## Wave 1 Interview documents

12/03/2020

University of Exeter, Centre for Research in Ageing and Cognitive Health (REACH)

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P\_ID

Participant ID

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Researcher ID

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# Enhancing Active Life and Living Well: The IDEAL Study

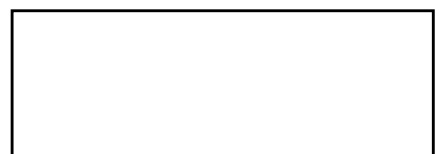
## Participant Part 1



[www.IDEALproject.org.uk](http://www.IDEALproject.org.uk)

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## What is the purpose of the study?

Instructions for the researcher: Please read this to the participant if s/he requires a reminder about the purpose of the study: This study aims to understand what 'living well' means to people who are experiencing difficulties in memory, thinking or behaviour, and/or have attended a Memory Clinic or similar service. The study will ask about your past experiences, your friends and family, your social life, the resources that you have, the support you get from members of your family, and the availability of social and health care provision. We will look at how all of these things relate to well-being, satisfaction with life and quality of life.

## What information are we going to ask for?

Instructions for the researcher: Please read this to the participant: *The questions today ask about your background, your health and well-being, and your home. Please be as honest and as accurate as you can throughout. There are no "right" or "wrong" answers. Answer according to your own feelings, rather than how you think "most people" would answer.*

*Your help is extremely valuable to us and of course any information you provide will be treated in strictest confidence.*

## This information will be scanned by a computer

Instructions for the researcher:

- Use black or blue ink to answer.
- For each question please cross ☒ clearly inside **one** box.
- For some questions you will be instructed that more than one box can be selected.
- If the participant changes his/her mind; simply fill in the box ☐ and put a cross ☒ in the correct box. You should draw a line through the incorrectly-selected box and then initial and date the box to make it clear that this response should be ignored.
- For some questions you will be asked to write information in boxes. When you see boxes like these, please write a single letter or number in each box provided.

For example; what is your age? 

6	5
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- There will be some instances where showcards are necessary and these are clearly marked in the questionnaire. Each showcard has a different identifying number; please show the corresponding showcard where indicated.
- All questions are written in bold text and they should be read out word for word.
- Where text is written in italics this represents information or instructions that you will give to the participant and this should be read out word for word.
- Where there are specific instructions for you these will be highlighted using this underlined phrase: "Instructions for the researcher" followed by the instruction or information.

P1\_Todays\_Date\_t1

$$\begin{array}{|c|c|} \hline & \\ \hline \end{array} / \begin{array}{|c|c|} \hline & \\ \hline \end{array} / \begin{array}{|c|c|c|c|} \hline 2 & 0 & 1 & \\ \hline \end{array}$$

Sex\_Prtcptnt\_t1

Diagnosis\_t1

☐ Alzheimer's disease

☐ Vascular dementia

☐ Mixed (Alzheimer's and vascular)

☐ Frontotemporal dementia (if known, select one of the three subtypes below)

FTD\_subtype\_t1

☐ Behavioural variant frontotemporal dementia

☐ Progressive non-fluent aphasia

☐ Semantic dementia

☐ Parkinson's disease dementia (if known, select one of the Hoehn and Yahr stages below)

HoehnYahr t1

☒ Stage 0    ☐ Stage 1    ☐ Stage 1.5    ☐ Stage 2

☐ Stage 2.5    ☐ Stage 3    ☒ Stage 4    ☐ Stage 5

Date HoehnYahr t1

Date of Hoehn and Yahr stage score (dd/mm/yyyy):

A diagram illustrating the decomposition of a 2x2 grid into four 1x1 grids. It consists of three 1x1 grids followed by a slash, then another 1x1 grid followed by a slash, and finally a 2x2 grid. The 2x2 grid is divided into four 1x1 quadrants, with the top-right quadrant shaded in light blue.

HoehnYahrNA t1

☐ Hoehn and Yahr stage score Not Available☐ Lewy body dementia☐ Unspecified dementia

☐ Other; please specify: OtherDem\_spec\_tl

Date diagnosis t1

**Date of diagnosis (dd/mm/yyyy):**

MMSE TimeDiag t1

**MMSE at time of diagnosis (if available)**

--	--

Diag Confirm YN t1

**Has the diagnosis been confirmed?**

☐ No    ☐ Yes

P1 Q3 t1

3. Record the county:

[illegible]

**4. Record the postcode of the participant's home address:**

P1_Q4_1_t1	P1_Q4_2_t1
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P1\_Q5\_1\_t1

**5. Assessment situation:**

- ☐ Participant and relative/friend were in the same room
- ☐ Participant and relative/friend were in different rooms
- ☐ Relative/friend will complete information separately and return by post
- ☐ Relative/friend available but s/he declined to take part
- ☐ Participant has no relative/friend

P1\_Q5\_2\_t1

**Assessment took place:**

- ☐ in own home      ☐ hospital
- ☐ other; please specify: P1\_Q5\_3\_t1

P1\_Q6\_1\_t1

**6. What is the relationship between the participant and the relative/friend (if involved in the study)?**

- ☐ Spouse      ☐ Partner      ☐ Son/daughter      ☐ Step-child      ☐ Son/daughter-in-law
- ☐ Grandchild      ☐ Brother/sister      ☐ Nephew/niece      ☐ Friend      ☐ Neighbour
- ☐ Other; please specify: P1\_Q6\_2\_t1

P1\_Q7\_1\_t1

**7. Has the participant taken part in a research project in the past year, or is s/he taking part in another project currently?**

- ☐ No      ☐ Yes      ☐ Unable to answer

If yes, please describe (what the study is about and who is organising it):

P1\_Q7\_2\_t1

Instructions for the researcher: The following questions should be answered by the participant

**Information about you**

*I'm going to start by asking you some questions about you, your life and your family.*

P1\_Q8\_1\_t1

**8. What is your age?**

P1\_Q8\_2\_t1

- ☐ Don't know/Not sure

Instructions for the researcher: Record what s/he says even if you know it is incorrect; '70s' etc. is acceptable

P1\_Q9\_t1

**9. What is your date of birth? (dd/mm/yyyy)**

 /  / 

P1\_Q10\_1\_t1

**10. In which country were you born?**

- ☐ England      ☐ Ireland      ☐ Northern Ireland      ☐ Scotland      ☐ Wales
- ☐ Other; please specify: P1\_Q10\_2\_t1

**11. What is your main language?**

- ☐ English (skip to question 13)    ☐ Welsh    ☐ Gaelic  
☐ Other; please specify: P1\_Q11\_2\_t1

P1\_Q12\_t1

**12. How well can you speak English?**

- ☐ Not at all    ☐ Not well    ☐ Well    ☐ Very well

P1\_Q13\_1\_t1

**13. What is your ethnic group?**

- ☐ White: English/Welsh/Scottish/Northern Irish/British  
☐ White: Irish  
☐ White: Gypsy or Irish Traveller  
☐ Any other White background; please specify:  
P1\_Q13\_2\_t1

- ☐ Mixed White & Black: Caribbean  
☐ Mixed White & Black: African  
☐ Mixed White & Asian  
☐ Any other Mixed/multiple ethnic background; please specify:  
P1\_Q13\_3\_t1

- ☐ Asian/Asian British: Indian  
☐ Asian/Asian British: Pakistani  
☐ Asian/Asian British: Bangladeshi  
☐ Asian/Asian British: Chinese  
☐ Any other Asian background; please specify:  
P1\_Q13\_4\_t1

- ☐ Black/Black British: African  
☐ Black/Black British: Caribbean  
☐ Any other Black/African/Caribbean background; please specify:  
P1\_Q13\_5\_t1

- ☐ Arab  
☐ Any other ethnic group; please specify:  
P1\_Q13\_6\_t1

P1\_Q14\_1\_t1

**14. What is your current legal marital status?**

- ☐ Single; that is, never married
- ☐ Married; first and only marriage
- ☐ Remarried; second or later marriage
- ☐ A civil partner in a legally-recognised civil partnership
- ☐ Legally separated
- ☐ Divorced
- ☐ Widowed
- ☐ Cohabiting
- ☐ Other; please specify:

P1\_Q14\_2\_t1

Instructions for the researcher: If the participant reports that s/he is married/widowed/separated/divorced ask:

P1\_Q15\_1\_t1

**15. How many years have you been [married/widowed/separated/divorced]?**

--	--

☐ Don't know P1\_Q15\_2\_t1

**(USE SHOWCARD 1B)**

P1\_Q16\_1\_t1

**16. Which of the options on this card best describes how you think of yourself?**

**Please just read out the letter next to the description.**

Instructions for the researcher: Ask the participant to choose a letter

- ☐ A Heterosexual or straight
- ☐ B Gay or lesbian
- ☐ C Bisexual
- ☐ D Other; please specify:

P1\_Q16\_2\_t1

☐ Refused to answer

☐ Don't know (record if given as a spontaneous response)

**17. With whom do you live?**

Instructions for the researcher: Please cross all that the participant says applies to him/her.

P1\_Q17\_1\_t1

P1\_Q17\_2\_t1

P1\_Q17\_3\_t1

P1\_Q17\_4\_t1

- ☐ No-one    ☐ Your spouse/partner    ☐ Other family member(s)    ☐ Other (non-family)

P1\_Q18\_1\_t1

18. How many living children do you have (including, if applicable, those you adopted)?

☐ None ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Other

P1\_Q18\_2\_t1

If Other, please specify number:

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## Education

Now I'm going to ask you some questions about your educational history and about your qualifications.

P1\_Q19\_t1

19. At what age did you start school?

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P1\_Q20\_t1

20. At what age did you leave *continuous* full-time education?

--	--

Instructions for the researcher: For guidance, if s/he left school at 18, but went back to education at 19 for two years, you would write '18' for question 20

P1\_Q21\_1\_t1

21. Did you go back to full-time or part-time education later on?

☐ No

☐ Yes; for how many years did you study?

P1_Q21_2_t1			
-------------	--	--	--

Instructions for the researcher: For guidance; 1 year of part-time education = half a year (0.5) of education

Instructions for the researcher: For guidance if s/he left school at 18, but went back to education at 19 for two years, you would write '2' for question 21

P1\_Q22\_1\_t1

22. What is the highest level of education that you achieved?

Instructions for the researcher: Please cross only one box

- ☐ No formal qualifications
- ☐ GCSEs or equivalent (O levels, CSEs, School Certificate, Standard Grades)
- ☐ Completed apprenticeship
- ☐ A levels or equivalent (Leaving Certificate, Higher Grades)
- ☐ National Vocational Qualification
- ☐ Higher National Diploma
- ☐ Undergraduate degree (BA, BSc)
- ☐ Master's degree (MA, MSc)
- ☐ PhD
- ☐ Other; please specify:

P1\_Q22\_2\_t1

## Employment

Now I'm going to ask you some questions about your current employment status and the type of work you do/did.

P1\_Q23\_1\_t1

**23. Which of the following best describes your current employment situation?**

☐ In paid employment (including self-employment/business owner)

If s/he is in paid employment; **what is/are your current jobs/occupations?**

P1\_Q23\_2\_t1

If s/he is in paid employment;

**how many hours of work per week do you do in total across all your jobs?** P1\_Q23\_3\_t1

☐ Retired; if retired **at what age did you retire?** P1\_Q23\_4\_t1

☐ Unable to work

☐ Unemployed and looking for work

☐ At home and not looking for work (e.g. housewife/househusband, full time carer)

☐ Doing voluntary (unpaid) work

☐ Student (full or part-time)

☐ Other; please describe:

P1\_Q23\_5\_t1

P1\_Q24\_2\_t1

**24. What is/has been your main occupation for most of your working life?**

Instructions for the researcher: This should be the occupation that was held for the longest period, **not** the most recent. Please include a full job title.

☐ Not applicable P1\_Q24\_1\_t1

P1\_Q25\_2\_t1

**25. What type of work is/was this?**

Instructions for the researcher: Please ask for a description of the work and a description of the employer including the name of the employer.

☐ Not applicable P1\_Q25\_1\_t1

P1\_Q26\_t1

**26. Do/did you enjoy your job?**

☐ No ☐ Yes ☐ Not applicable

P1\_Q27\_t1

**27. Are/were you self-employed?**

☐ No ☐ Yes

P1\_Q28\_t1

28. Are/were you a foreman, supervisor or manager?

☐ No (skip to question 31) ☐ Foreman ☐ Supervisor ☐ Manager

P1\_Q29\_t1

29. If you are/were a foreman/supervisor/manager; what do/did you do?

P1\_Q30\_t1

30. How many employees are/were you responsible for?

☐ Less than 25 ☐ 25 or more ☐ Don't know ☐ Not applicable

### Religious beliefs

*I'm now going to ask you some questions about religious beliefs. Please try to answer them even if you have little interest in religion. By religion we mean the actual practice of a faith, e.g. going to a church or synagogue, mosque or temple.*

P1\_Q31\_1\_t1

31. What is your religion? Please select one answer.

- ☐ No religion
- ☐ Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
- ☐ Buddhist
- ☐ Hindu
- ☐ Jewish
- ☐ Muslim
- ☐ Sikh
- ☐ Any other religion; please specify:

P1\_Q31\_2\_t1

☐ Prefer not to say

Select whichever is the closest to your usual practice

Never      Occasionally      Monthly      Weekly      Daily

P1\_Q32\_t1

32. How often do you attend a place of religious worship?

☐ ☐ ☐ ☐ ☐

P1\_Q33\_t1

33. How often do you pray?

☐ ☐ ☐ ☐ ☐

P1\_Q34\_t1

34. How often do you study religious texts?

☐ ☐ ☐ ☐ ☐

(USE SHOWCARD 1C)

P1\_Q35\_t1

35. How important is religion or being religious to your life?

- |  |   |  |
|--|---|--|
| <input type="checkbox"/> Not important | <input type="checkbox"/> Slightly important   | <input type="checkbox"/> Important           |
|  | <input type="checkbox"/> Somewhat important   | <input type="checkbox"/> Very important      |
|  | <input type="checkbox"/> Moderately important | <input type="checkbox"/> Extremely important |

## Spirituality

*I'm now going to ask you some questions about spirituality. Some people do not follow a specific religion but do have spiritual beliefs or experiences. For example, they may believe that there is some power or force other than themselves that might influence their life. Some people think of this as God or gods, others do not.*

P1\_Q36\_t1

**36. Whether you attend religious services or not, would you say you are religious, spiritual, or, neither?**

- ☐ Religious    ☐ Spiritual    ☐ Both religious and spiritual    ☐ Neither
- ☐ Can't choose (record if given as a spontaneous response)
- ☐ Don't know (record if given as a spontaneous response)

P1\_Q37\_t1

**37. Spiritually, what best describes you?**

- ☐ I follow a religion and am a spiritual person
- ☐ I follow a religion and am not a spiritual person
- ☐ I don't follow a religion, but am a spiritual person
- ☐ I don't follow a religion and am not a spiritual person
- ☐ Can't choose (record if given as a spontaneous response)
- ☐ Don't know (record if given as a spontaneous response)

**(USE SHOWCARD 1C)**

P1\_Q38\_t1

**38. How important is spirituality to your life?**

- |  |   |  |
|--|---|--|
| <input type="checkbox"/> Not important | <input type="checkbox"/> Slightly important   | <input type="checkbox"/> Important           |
|  | <input type="checkbox"/> Somewhat important   | <input type="checkbox"/> Very important      |
|  | <input type="checkbox"/> Moderately important | <input type="checkbox"/> Extremely important |

## Health

*Now I'm going to ask you some questions about your health.*

P1\_Q39\_t1

**39. Overall, how would you rate your health in the past four weeks?**

- ☐ Very poor    ☐ Poor    ☐ Fair    ☐ Good    ☐ Very good    ☐ Excellent

P1\_Q40\_1\_t1

**40. Have you fallen down in the last two years (for any reason)?**

- ☐ No (skip to question 41)    ☐ Yes    ☐ Don't know

P1\_Q40\_2\_t1

If yes, **how many times?**

P1\_Q40\_3\_t1

If yes, **did you injure yourself seriously enough to need medical treatment?**

- ☐ No    ☐ Yes    ☐ Don't know

41. Is your eyesight (using glasses or corrective lens if you use them)...

☐ Poor ☐ Fair ☐ Good ☐ Very good ☐ Excellent

P1\_Q42\_t1

42. Is your hearing (using a hearing aid if you use one)...

☐ Poor ☐ Fair ☐ Good ☐ Very good ☐ Excellent

P1\_Q43\_1\_t1

43. Is there a named health professional whom you can contact at any time, for example a care coordinator, key worker or specialist nurse?

☐ No (skip to question 44) ☐ Yes ☐ Don't know

If yes, what is this person's job title?

P1\_Q43\_2\_t1

---

P1\_Q43\_3\_t1

Instructions for the researcher: To be completed by the researcher

Is the health professional available because of the person's dementia diagnosis?

☐ No ☐ Yes

### Health state

*We would like to know about how you feel about your health in a number of areas. Please indicate which statements best describe your own health state today.*

**All EQ-5D questions removed in line with user agreement**



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## Life events

(USE SHOWCARD 1D)

50. From this list I'd like you to tell me which of the following events you have experienced in your life over the past 12 months. The aim is just to identify which of these events you have experienced lately.

Instructions for the researcher: Please cross all that the participant says applies to him/her.

### Bereavement

P1\_Q50\_1\_t1 ☐ Death of spouse or child

P1\_Q50\_2\_t1 ☐ Death of a close family member (e.g. parent or sibling)

P1\_Q50\_3\_t1 ☐ Death of a close friend

### Marital difficulties

P1\_Q50\_4\_t1 ☐ Divorce

P1\_Q50\_5\_t1 ☐ Marital separation

### Change in circumstances

P1\_Q50\_6\_t1 ☐ Retirement

P1\_Q50\_7\_t1 ☐ Moved home

P1\_Q50\_8\_t1 ☐ Major change in financial state (e.g. a lot worse off or a lot better off)

P1\_Q50\_9\_t1 ☐ Major change in health or behaviour of family member

P1\_Q50\_10\_t1 ☐ Major personal injury or illness

### None

P1\_Q50\_0\_t1 ☐ None of the above

P1\_Q51\_t1

51. Do you think that compared to most other people your age, your overall situation is:

☐ Much worse

☐ Somewhat worse

☐ About the same

☐ Somewhat better

☐ Much better

## Diet

Now I'm going to ask you some questions about your food preferences and how much you drink and smoke in a typical week.

P1\_Q52\_t1

52. Over the past year have you noticed any changes in your sense of taste?

☐ No ☐ Yes

P1\_Q53\_t1

53. Over the past year have you noticed any changes in your sense of smell?

☐ No ☐ Yes

P1\_Q54\_t1

54. Would you say your appetite is

☐ Very poor ☐ Poor ☐ Average ☐ Good ☐ Very good

(USE SHOWCARD 1E)

P1\_Q55\_t1

55. When you eat do you:

- ☐ feel full after eating only a few mouthfuls
- ☐ feel full after eating about a third of a meal
- ☐ feel full after eating over half a meal
- ☐ feel full after eating most of the meal
- ☐ hardly ever feel full

P1\_Q56\_t1

56. Would you say that food tastes

☐ Very bad ☐ Bad ☐ Average ☐ Good ☐ Very good

P1\_Q57\_t1

57. Would you say that normally you eat:

- ☐ less than one meal a day
- ☐ one meal a day
- ☐ two meals a day
- ☐ three meals a day
- ☐ more than three meals a day

## Alcohol

P1\_Q58\_t1

58. Do you drink alcohol?

☐ No (skip to question 66) ☐ Yes

P1\_Q59\_t1

59. How many pints of regular beer/lager/cider do you drink in a typical week?

--	--

P1\_Q60\_t1

60. How many alcopops or cans of beer/lager/cider do you drink in a typical week?

--	--

P1\_Q61\_t1

61. How many bottles of wine do you drink in a typical week?

--	--

P1\_Q62\_t1

62. How many small glasses of wine do you drink in a typical week?

--	--

P1\_Q63\_t1

63. How many large glasses of wine do you drink in a typical week?

--	--

P1\_Q64\_t1

64. How many single measures of spirits do you drink in a typical week?

--	--

P1\_Q65\_1\_t1

65. Do you drink any other alcoholic drinks? ☐ No ☐ Yes

Instructions for the researcher: Please specify what s/he drinks and how much in a typical week

P1\_Q65\_2\_t1

P1\_Q66\_1\_t1

## Smoking

66. Are you a current smoker?

☐ No ☐ Yes

If yes, how many cigarettes do you smoke a day?

P1\_Q66\_2\_t1

--	--	--

If yes, how many cigars do you smoke a day?

P1\_Q66\_3\_t1

--	--

P1\_Q67\_1\_t1

67. Are you a former smoker?

☐ No ☐ Yes

If yes, how many cigarettes did you smoke a day?

P1\_Q67\_2\_t1

--	--	--

If yes, how many cigars did you smoke a day?

P1\_Q67\_3\_t1

--	--

P1\_Q68\_t1

68. How old were you when you stopped smoking (if you have stopped smoking several times, how old were you at the most recent time)?

--	--	--

## Pets

*Now I'm going to ask you some questions about how many pets you have.*

P1\_Q69\_t1

69. Do you have any pets?

☐ No (skip to question 72) ☐ Yes, one ☐ Yes, more than one

70. Is your pet:

Instructions for the researcher: Please cross all that the participant says applies to him/her.

P1\_Q70\_1\_t1 P1\_Q70\_2\_t1 P1\_Q70\_3\_t1

☐ A cat ☐ A dog ☐ An/other animal(s);

Please specify what other animals you have

P1\_Q70\_oth\_t1

P1\_Q71\_t1

71. Who mostly looks after the pet(s)?

☐ You ☐ Your spouse/partner ☐ Both you and your spouse/partner ☐ Other

--

## Your accommodation

Now I'm going to ask you some questions about your home, including who lives with you, how long you have lived at this address and how satisfied you are with your accommodation.

P1\_Q72\_1\_t1

**72. How many adults (people aged 16 or over) are there in your household including you?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Other

P1\_Q72\_2\_t1

If Other, please specify number:

P1\_Q73\_1\_t1

**73. How many children under the age of 16 years are there in your household?**

☐ None ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Other

P1\_Q73\_2\_t1

If Other, please specify number:

**(USE SHOWCARD 1F)**

P1\_Q74\_1\_t1

**74. In which of these ways is your accommodation owned or paid for?**

- ☐ Own it outright
- ☐ Buying it with the help of a mortgage or loan
- ☐ Pay part rent and part mortgage (shared ownership)
- ☐ Housing association rented housing
- ☐ Council-rented housing
- ☐ Private rented housing
- ☐ Live here rent-free (including rent free in relative's/friend's property, excluding squatting)
- ☐ Squatting
- ☐ Care home
- ☐ Nursing home
- ☐ Sheltered accommodation (has a warden or scheme manager on site)
- ☐ Other; please specify:

P1\_Q74\_2\_t1

☐ Don't know (record if given as a spontaneous response)

P1\_Q75\_t1

**75. How long have you lived at this address?**

- ☐ Less than 12 months
- ☐ 12 months but less than 5 years
- ☐ 5 years but less than 10 years
- ☐ 10 years or more (skip to question 77)
- ☐ Don't know (record if given as a spontaneous response; skip to question 77)

**(USE SHOWCARD 1G)****76. What were the main reasons you moved to this address?**

Instructions for the researcher: Please cross all that the participant says applies to him/her.

- |              |   |              |   |
|--------------|---|--------------|---|
| P1_Q76_3_t1  | <input type="checkbox"/> Retirement                               | P1_Q76_16_t1 | <input type="checkbox"/> Problem with neighbours            |
| P1_Q76_4_t1  | <input type="checkbox"/> Downsizing                               | P1_Q76_17_t1 | <input type="checkbox"/> Moving away from crime             |
| P1_Q76_5_t1  | <input type="checkbox"/> To be nearer relative(s)                 | P1_Q76_18_t1 | <input type="checkbox"/> Previous accommodation temporary   |
| P1_Q76_6_t1  | <input type="checkbox"/> Needed more support                      | P1_Q76_19_t1 | <input type="checkbox"/> Quality of previous accommodation  |
| P1_Q76_7_t1  | <input type="checkbox"/> Needed more care                         | P1_Q76_20_t1 | <input type="checkbox"/> Spouse or partner job change       |
| P1_Q76_8_t1  | <input type="checkbox"/> Needed to move into residential care     | P1_Q76_21_t1 | <input type="checkbox"/> Job change/nearer work             |
| P1_Q76_9_t1  | <input type="checkbox"/> Could no longer afford last home         | P1_Q76_22_t1 | <input type="checkbox"/> Overcrowding or no space           |
| P1_Q76_10_t1 | <input type="checkbox"/> Relationship breakdown                   | P1_Q76_23_t1 | <input type="checkbox"/> Wanted to buy                      |
| P1_Q76_11_t1 | <input type="checkbox"/> New relationship                         | P1_Q76_24_t1 | <input type="checkbox"/> Wanted larger home                 |
| P1_Q76_12_t1 | <input type="checkbox"/> Wanted to move to better area            | P1_Q76_25_t1 | <input type="checkbox"/> Wanted better home                 |
| P1_Q76_13_t1 | <input type="checkbox"/> For children's/grandchildren's education | P1_Q76_26_t1 | <input type="checkbox"/> Problems with landlord             |
| P1_Q76_14_t1 | <input type="checkbox"/> Just wanted a change                     | P1_Q76_27_t1 | <input type="checkbox"/> Evicted/repossessed from last home |
| P1_Q76_15_t1 | <input type="checkbox"/> Wanted a place of my own                 | P1_Q76_28_t1 | <input type="checkbox"/> For financial reasons              |

- P1\_Q76\_29\_t1  
☐ Other; please specify:

P1\_Q76\_oth\_t1

- P1\_Q76\_1\_t1  
☐ Not applicable

- P1\_Q76\_2\_t1  
☐ Don't know (record if given as a spontaneous response)

P1\_Q77\_t1

**77. How many of the rooms in your household are bedrooms, including those not in use?**

- ☐ One   ☐ Two   ☐ Three   ☐ Four   ☐ Five   ☐ Six or more

**78. What type of heating do you have?**

- P1\_Q78\_1\_t1   P1\_Q78\_2\_t1   P1\_Q78\_3\_t1  
☐ Gas central heating   ☐ Electric storage heaters   ☐ Gas fire only

- P1\_Q78\_4\_t1  
☐ Other; please specify:

P1\_Q78\_Oth\_t1

**79. How satisfied are you with your accommodation?**

- ☐ Very dissatisfied
- ☐ Fairly dissatisfied
- ☐ Neither satisfied nor dissatisfied
- ☐ Slightly satisfied
- ☐ Very satisfied
- ☐ Don't know (record if given as a spontaneous response)

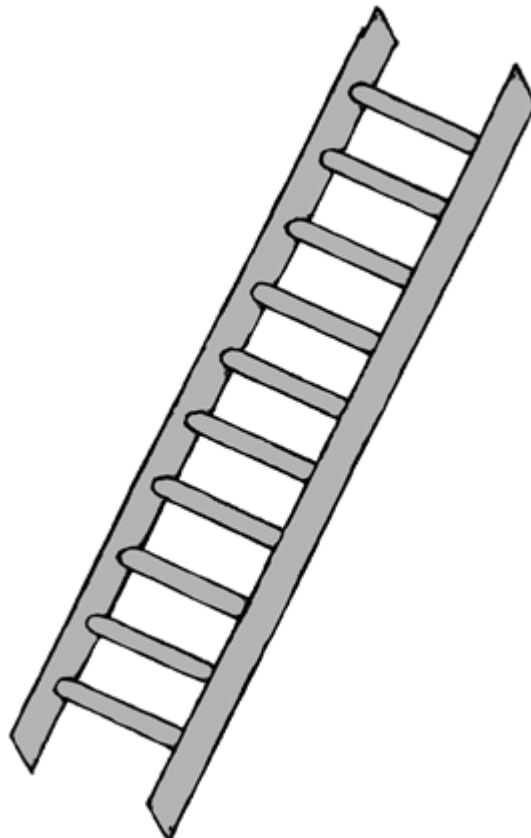
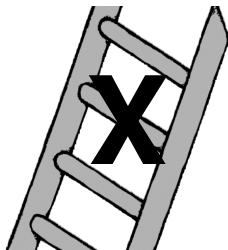
## Society and Community

P1\_Q80\_t1

80. Think of this ladder as representing where people stand in our society. At the top of the ladder are the people who are the best off - those who have the most money, most education, and best jobs. At the bottom are the people who are the worst off - who have the least money, least education, and the worst jobs or no jobs. The higher up you are on this ladder, the closer you are to the people at the very top and the lower you are, the closer you are to the people at the very bottom.

Please mark a cross on the rung on the ladder where you would place yourself, relative to other people in our society.

Example



Instructions for the researcher: If the participant is visually impaired, please ask him/her to give you a number between 1 and 10 (with 1 being the lowest rung).

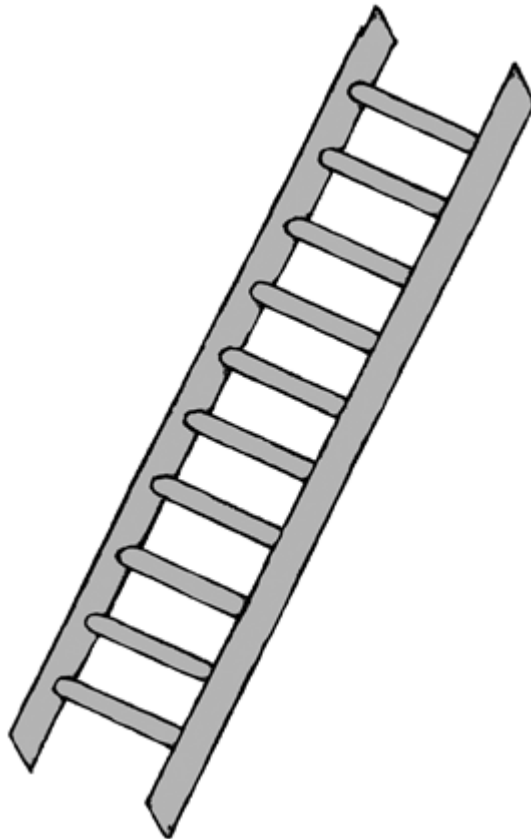
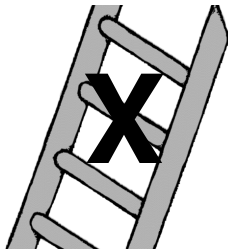
Instructions for the researcher: When the participant has indicated a position on the ladder or given a number, please check the appropriate box:

☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10  
(bottom rung) (top rung)

81. Think of this ladder as representing where people stand in their local communities. People define community in different ways; please define it in whatever way is most meaningful to you. At the top of the ladder are the people who have the highest standing in their local community. At the bottom are the people who have the lowest standing in their local community.

Please mark a cross on the rung on the ladder where you would place yourself, relative to other people in your local community.

Example



Instructions for the researcher: If the participant is visually impaired, please ask him/her to give you a number between 1 and 10 (with 1 being the lowest rung).

Instructions for the researcher: When the participant has indicated a position on the ladder or given a number, please check the appropriate box:

☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10  
 (bottom rung) (top rung)

Thank you for taking the time to answer these questions. The information and insight that you have provided is very valuable to us.



Instructions for the researcher: Checklist/Field notes

At the end of each part of the assessment please note reasons for any items which were not completed:

☐ All items have been completed (if so skip to field notes)

**Information about you**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Education**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Employment**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Religious beliefs**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Spirituality**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Health**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Health state**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

### Life events

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

### Diet

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

### Alcohol

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

### Smoking

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

### Pets

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

### Your accommodation

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

### Society and community

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:   ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Instructions for the researcher:** Please be aware that every month we will require information from this booklet to be uploaded to a Macro website. The information will be for all of the participants that you have assessed over the last month. The information to be uploaded will be the specific dementia diagnoses, the number of participants aged under and over 65, the number of participants that are male or female, the number of participants who live alone, the number of participants who do not live alone and the type of relationship between each dyad. Please make a note of this information in the Excel file that you will have been provided with to make this process as easy for you as possible.

**Participant ID**

--	--	--	--	--	--	--

Researcher ID

We would like you to record any additional information about the assessment which you may think is useful.

I would like to add field notes or comments

DO NOT PRINT/COPI

☐ Alert/Responsive      ☐ Drowsy

☐ Stuporous      ☐ Comatose/Unresponsive

P\_ID

Participant ID

--	--	--	--	--	--	--

Researcher ID

--	--	--

# Enhancing Active Life and Living Well: The IDEAL Study

## Participant Part 2



[www.IDEALproject.org.uk](http://www.IDEALproject.org.uk)

A3\_Day\_t1

Day of testing

--	--	--	--	--	--	--	--

A3\_Date\_t1

Date of testing (dd/mm/yyyy)

		/			/	2	0	1	
--	--	---	--	--	---	---	---	---	--

Before administering the test, make sure the day and date of testing has been completed.

Att\_O\_D\_S\_t1

**ATTENTION-** Orientation to date**Score out of 5:** ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

Instructions for the researcher: Ask the participant for the day, date, month, year and season. If the participant spontaneously answers multiple questions score the answers provided. You do not need to ask a question if an answer has already been provided, but prompt the participant for missing information by asking the relevant questions. For example, if you ask a participant "What day of the week is it today?" and the participant answers "It is Tuesday the 7th and we are in 2013", then you can score the day, date and year. You will then just need to ask: "What month are we in?" and "What is the season? What time of year is it?"

**First I'm going to ask you some questions about today.**

Att\_day\_t1

**What day of the week is it today?**

Sunday Monday Tuesday Wednesday Thursday Friday Saturday **Score:**

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

Att\_day\_S\_t1

☐ 0☐ 1

Att\_date\_t1

**What is today's date?** (Allow mistakes of plus or minus two days; if out by more than two days score as incorrect.)

<input type="checkbox"/> 1	<input type="checkbox"/> 6	<input type="checkbox"/> 11	<input type="checkbox"/> 16	<input type="checkbox"/> 21	<input type="checkbox"/> 26	<input type="checkbox"/> 31
<input type="checkbox"/> 2	<input type="checkbox"/> 7	<input type="checkbox"/> 12	<input type="checkbox"/> 17	<input type="checkbox"/> 22	<input type="checkbox"/> 27	
<input type="checkbox"/> 3	<input type="checkbox"/> 8	<input type="checkbox"/> 13	<input type="checkbox"/> 18	<input type="checkbox"/> 23	<input type="checkbox"/> 28	
<input type="checkbox"/> 4	<input type="checkbox"/> 9	<input type="checkbox"/> 14	<input type="checkbox"/> 19	<input type="checkbox"/> 24	<input type="checkbox"/> 29	
<input type="checkbox"/> 5	<input type="checkbox"/> 10	<input type="checkbox"/> 15	<input type="checkbox"/> 20	<input type="checkbox"/> 25	<input type="checkbox"/> 30	

Att\_date\_S\_t1

☐ 0**Score:**☐ 1

Att\_month\_t1

**What month are we in?** (If a number is given, such as the seventh month of the year, prompt the participant for the name of the month. Only score the name of the month as correct.)

<input type="checkbox"/> Jan	<input type="checkbox"/> Feb	<input type="checkbox"/> March	<input type="checkbox"/> April	<input type="checkbox"/> May	<input type="checkbox"/> June
<input type="checkbox"/> July	<input type="checkbox"/> Aug	<input type="checkbox"/> Sep	<input type="checkbox"/> Oct	<input type="checkbox"/> Nov	<input type="checkbox"/> Dec

Att\_month\_S\_t1

☐ 0**Score:**☐ 1

Att\_year\_t1

**What year are we in?**

2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Att\_year\_S\_t1

☐ 0**Score:**☐ 1

If another year is given please write response here: Att\_year\_oth\_t1

Att\_season\_t1

**What is the season? What time of year is it?**

Spring March, April, May	Summer June, July, August	Autumn/Fall Sept, Oct, Nov	Winter Dec, Jan, Feb
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Att\_season\_S\_t1

☐ 0**Score:**☐ 1

When the season is changing, i.e., end of August, and the participant says 'autumn', ask him/her 'could it be another season?' If the answer is 'summer', score as correct, as the two seasons are in transition. Do not score as correct if the answer is 'winter' or 'spring'.

**ATTENTION-** Orientation to place      **Score out of 5:** ☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5

Now I'm going to ask you some questions about where we are.

Ask the next two questions if in the home of the participant:

Instructions for the researcher: Do not record responses.

**What is the number/name of the house?**

Att\_house\_S\_tl      **Score:** ☐ 0   ☐ 1

**What is the name of the street?**

Att\_street\_S\_tl      **Score:** ☐ 0   ☐ 1

Ask the next two questions if somewhere other than the home of the participant, such as at a university or hospital (*record responses*):

Att\_org\_name\_tl

Att\_orgname\_S\_tl

**What is the name of the [university/hospital/etc] that we are in?** If the correct name of the specific building is given also score as correct.

**Score:** ☐ 0   ☐ 1

Att\_org\_floor\_tl

Att\_org\_floor\_S\_tl

**What floor are we on?** You may need to establish whether the participant refers to the ground floor as the first floor and score accordingly. If in a single floor building ask about a local landmark.

**Score:** ☐ 0   ☐ 1

The next three questions are to be administered to everyone (*record responses*):

Att\_town\_tl

Att\_town\_S\_tl

**What town/city are we in?**

**Score:** ☐ 0   ☐ 1

Att\_county\_tl

Att\_county\_S\_tl

**What county are we in?**

**Score:** ☐ 0   ☐ 1

Att\_country\_tl

Att\_county\_S\_tl

**What country are we in?** United Kingdom/Great Britain is scored as correct, as are the names of the individual countries within the UK, unless participant says England but is in Wales etc.

**Score:** ☐ 0   ☐ 1

Att\_Item\_reg\_S\_tl

**ATTENTION-** Registration of 3 Items

**Score out of 3:** ☐ 0   ☐ 1   ☐ 2   ☐ 3

**I'm going to give you three words and I'd like you to repeat them after me: lemon, key, ball.**

After the participant repeats, say: **Try to remember them because I'm going to ask you later.**

Score only the first trial (repeat 3 times if necessary). Record number of trials needed below:

Att\_S7\_S\_tl

Att\_ItemTrials\_tl   ☐ 1   ☐ 2   ☐ 3

**ATTENTION-** Serial 7 Subtraction

**Score out of 5:** ☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5

**Could you take 7 away from 100? I'd like you to keep taking 7 away from each new number until I tell you to stop.**

If the participant makes a mistake, do not stop him/her. Let him/her carry on and check subsequent answers (e.g. 92, **85**, 79, **72**, **65** would give a score of 3).

Stop after five subtractions (93, 86, 79, 72, 65)

Record responses: Att\_S7\_1\_tl   Att\_S7\_2\_tl   Att\_S7\_3\_tl   Att\_S7\_4\_tl   Att\_S7\_5\_tl

Mem\_Item\_rec\_S\_tl

**MEMORY-** Recall of 3 Items

**Score out of 3:** ☐ 0   ☐ 1   ☐ 2   ☐ 3

**Which 3 words did I ask you to repeat and remember?** Score 1 point for each correct item.

Instructions for the researcher: Do not prompt the participant for the items.

Mem\_Item\_lemon\_S\_tl   Mem\_Item\_key\_S\_tl   Mem\_Item\_ball\_S\_tl

Cross the boxes for correctly recalled responses:   ☐ lemon   ☐ key   ☐ ball

**Score out of 14:**

☐ 0   ☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7  
☐ 8   ☐ 9   ☐ 10   ☐ 11   ☐ 12   ☐ 13   ☐ 14

I'm going to give you a letter of the alphabet and I'd like you to generate as many words as you can beginning with that letter, but not names of people or places. For example, if I give you the letter "C", you could give me words like "cat, cry, clock" and so on. But, you can't give me words like Catherine or Canada. Do you understand? Are you ready? You have one minute. The letter I want you to use is the letter "P".

0-15 seconds

16-30 seconds

31-45 seconds

46-60 seconds

The diagram illustrates four parallel processing paths, each represented by a vertical rectangle divided into two main sections. The top section of each rectangle is labeled with a red text string: VF\_P\_015\_t1, VF\_P\_1630\_t1, VF\_P\_3145\_t1, and VF\_P\_4660\_t1. The bottom section of each rectangle is labeled with a red text string: VF\_P\_015\_T\_t1, VF\_P\_1630\_T\_t1, VF\_P\_3145\_T\_t1, and VF\_P\_4660\_T\_t1. Each bottom section is further divided into two sub-sections by a vertical line, with the left sub-section being slightly wider than the right one. The entire diagram is enclosed in a black border.

Count the total number of correct words, which do not include: (1) repetitions, (2) perseverations (e.g., pay, paid, pays, if all 3 are given, score 1), (3) intrusions (i.e., words beginning with other letters), (4) proper names (i.e., names of people or places. For guidance, words often have more than one meaning i.e. peter can be the name of a person or it could also mean to get smaller and smaller, to peter out. Only score proper names as incorrect if they are unambiguous, for example if a participant says Peter along with other proper names such as Peter, Paul, Brian, or if the participant says 'Peter, as in the boys' name') and (5) plurals (e.g., pot, pots, if both are given, score 1).

To help us, please circle all the words that the participant says which are incorrect.

Use the table to obtain the final score for this test. (Cross the appropriate box next to the score in the table.)


<input type="checkbox"/> >=18	<input type="checkbox"/> 7
<input type="checkbox"/> 14-17	<input type="checkbox"/> 6
<input type="checkbox"/> 11-13	<input type="checkbox"/> 5
<input type="checkbox"/> 8-10	<input type="checkbox"/> 4
<input type="checkbox"/> 6-7	<input type="checkbox"/> 3
<input type="checkbox"/> 4-5	<input type="checkbox"/> 2
<input type="checkbox"/> 2-3	<input type="checkbox"/> 1
<input type="checkbox"/> 0-1	<input type="checkbox"/> 0
VF_P_TR_list_t1	VF_P_CR_list_t1
Total responses	Correct responses
<input type="checkbox"/> VF_P_TotResp_t1	<input type="checkbox"/> VF_P_CorrResp_t1

Now can you name as many animals as possible? Words can begin with any letter.

0-15 seconds

16-30 seconds

31-45 seconds

46-60 seconds

VF_A_015_t1	VF_A_1630_t1	VF_A_3145_t1	VF_A_4660_t1
VF_A_015_T_t1	VF_A_1630_T_t1	VF_A_3145_T_t1	VF_A_4660_T_t1

Count the total number of correct words, which do not include higher order categories when specific exemplars are given (e.g., "fish" followed by "salmon" and "trout", score = 2). All types of animals are accepted, including insects, humans, prehistoric, extinct as well as mythical creatures (e.g., unicorn). If the participant misunderstands the instructions and perseverates by naming animals beginning with "p" (e.g., panda, possum, platypus etc), then reiterate to the participant that they should name animals beginning with any letter. Only use this prompt once and only if the first few animals start with the letter "p".

To help us, please circle all the words that the participant says which are incorrect.

Use the table to obtain the final score for this test. (Cross the appropriate box next to the score in the table.)

<input type="checkbox"/> >=22	<input type="checkbox"/> 7
<input type="checkbox"/> 17-21	<input type="checkbox"/> 6
<input type="checkbox"/> 14-16	<input type="checkbox"/> 5
<input type="checkbox"/> 11-13	<input type="checkbox"/> 4
<input type="checkbox"/> 9-10	<input type="checkbox"/> 3
<input type="checkbox"/> 7-8	<input type="checkbox"/> 2
<input type="checkbox"/> 5-6	<input type="checkbox"/> 1
<input type="checkbox"/> <5	<input type="checkbox"/> 0
VF_A_TR_list_t1 Total responses	VF_A_CR_list_t1 Correct responses
VF_A_TotResp_t1	VF_A_CorrResp_t1

**MEMORY**-Anterograde Memory-Name and Address

Score out of 7:

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

I'm going to give you a name and address and I'd like you to repeat the name and address after me. So you have a chance to learn, we'll be doing that 3 times. I'll ask you the name and address later. If the participant starts repeating along with you, ask him/her to wait until you give the name and address in full. Score only the third trial.

1st Trial

2nd Trial

3rd Trial

Harry Barnes 73 Orchard Close Kingsbridge Devon	MemA_1Harry_S_t1; MemA_1Harry_R_t1; MemA_1Barnes_S_t1; MemA_1Barnes_R_t1; MemA_173_S_t1; MemA_173_R_t1; MemA_1Orch_S_t1; MemA_1Orch_R_t1; MemA_1Close_S_t1; MemA_1Close_R_t1; MemA_1Kings_S_t1; MemA_1Kings_R_t1; MemA_1Devon_S_t1; MemA_1Devon_R_t1 [Repeat for MemA_2... and MemA_3...]
--	--



**MEMORY-Retrograde Memory-Famous people**Score out of 4: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4What is the name of the current Prime Minister? Mem\_PrimeM\_t1 Score: ☐ 0 ☐ 1What is the name of the woman who was Prime Minister?  
(Margaret Thatcher) Mem\_PrimeMF\_t1 Score: ☐ 0 ☐ 1What is the name of the US president? Mem\_USA\_t1 Score: ☐ 0 ☐ 1What is the name of the US president who was assassinated in the  
1960s? (John F. Kennedy) Mem\_USA\_JFK\_t1 Score: ☐ 0 ☐ 1

Allow surnames (e.g., "Obama") and ask for a surname if only the first name is given (e.g., "Maggie"). If the full name given is incorrect (e.g., "June Thatcher"), then the score would be 0. If there has been a recent change in leaders, probe for the name of the outgoing politician.

**LANGUAGE-Comprehension**Score out of 3: ☐ 0 ☐ 1 ☐ 2 ☐ 3

Place a pencil next to a piece of paper in front of the participant. As a practice trial, ask the participant to: **Pick up the pencil and then the paper.** If incorrect, score 0 and do not continue further. If the participant is correct on the practice trial, continue with the following three commands below. A score of 1 is given for each command performed correctly.

Place the paper on top of the pencil. (Reposition the pencil next to the  
paper in front of the participant.) Score: ☐ 0 ☐ 1Pick up the pencil but not the paper. (Reposition the pencil next to the  
paper in front of the participant.) Score: ☐ 0 ☐ 1Pass me the pencil after touching the paper. Score: ☐ 0 ☐ 1**LANGUAGE-Sentence Writing**Score out of 2: ☐ 0 ☐ 1 ☐ 2

Now I'm going to ask you to write two (or more) complete sentences about your last holiday (or weekend or Christmas if the time of year is applicable). Write in complete sentences and do not use abbreviations.

Give 1 point if there are two (or more) complete sentences about the one topic; and give 1 point if grammar and spelling are correct. If grammar and spelling are correct give this point even if the two sentences are on different topics.



**LANGUAGE-Single Word Repetition**Score out of 2: ☐ 0 ☐ 1 ☐ 2

I'm going to read out four words, and I'd like you to repeat each word after me. Say only one word at a time. Only the first attempt is scored.

Lan Caterpillar t1

**Caterpillar**☐ ☐

Correct Incorrect

Lan Eccentricity t1

**Eccentricity**☐ ☐

Correct Incorrect

Lan Unintelligible t1

**Unintelligible**☐ ☐

Correct Incorrect

Lan Statistician t1

**Statistician**☐ ☐

Correct Incorrect

Score 2 if all are correct; score 1 if 3 are correct; and score 0 if 2 or less are correct.

Lan PR S t1

**LANGUAGE-Proverb Repetition**Score out of 2: ☐ 0 ☐ 1 ☐ 2

I'm going to read out two proverbs, and I'd like you to repeat each proverb after me.

Proverb

Participant's response if not correct

**All that glitters is not gold**

Lan\_proverb1\_t1

Lan\_proverb1\_S\_t1

Score: ☐ 0 ☐ 1**A stitch in time saves nine**

Lan\_proverb2\_t1

Lan\_proverb2\_S\_t1

Score: ☐ 0 ☐ 1

Do not accept partially correct repetitions (e.g., "all that glistens is not gold"). Score 1 point for each proverb. Only the first attempt is scored.

Lan ON S t1

**LANGUAGE-Object Naming**Score out of 12: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6  
☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ 11 ☐ 12**(USE SHOWCARD 2A)**

Here are some pictures, could you tell me the name of each object in the picture.

Score 1 point for each item.

Acceptable answer(s)

Participant's response if not correct

1. Spoon

Lan\_ON\_Spoon\_R\_t1

Lan\_ON\_Spoon\_S\_t1

Score: ☐ 0 ☐ 1

2. Book

Lan\_ON\_Book\_R\_t1

Lan\_ON\_Book\_S\_t1

Score: ☐ 0 ☐ 1

3. Kangaroo or Wallaby

Lan\_ON\_Kanga\_R\_t1

Lan\_ON\_Kanga\_S\_t1

Score: ☐ 0 ☐ 1

4. Penguin

Lan\_ON\_Peng\_R\_t1

Lan\_ON\_Peng\_S\_t1

Score: ☐ 0 ☐ 1

5. Anchor

Lan\_ON\_Anchor\_R\_t1

Lan\_ON\_Anchor\_S\_t1

Score: ☐ 0 ☐ 1

6. Camel or Dromedary

Lan\_ON\_Camel\_R\_t1

Lan\_ON\_Camel\_S\_t1

Score: ☐ 0 ☐ 1

7. Harp

Lan\_ON\_Harp\_R\_t1

Lan\_ON\_Harp\_S\_t1

Score: ☐ 0 ☐ 1

8. Rhinoceros or Rhino

Lan\_ON\_Rhino\_R\_t1

Lan\_ON\_Rhino\_S\_t1

Score: ☐ 0 ☐ 1

9. Barrel, Keg or Tub

Lan\_ON\_Barrel\_R\_t1

Lan\_ON\_Barrel\_S\_t1

Score: ☐ 0 ☐ 1

10. Crown

Lan\_ON\_Crown\_R\_t1

Lan\_ON\_Crown\_S\_t1

Score: ☐ 0 ☐ 1

11. Crocodile or Alligator

Lan\_ON\_Croc\_R\_t1

Lan\_ON\_Croc\_S\_t1

Score: ☐ 0 ☐ 112. Piano accordion,  
Accordion or Squeeze box

Lan\_ON\_Piano\_R\_t1

Lan\_ON\_Piano\_S\_t1

Score: ☐ 0 ☐ 1

Lan Cmprhnsn S t1

**LANGUAGE-Comprehension**Score out of 4: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Ask the participant to point to the pictures according to the statement read. Do not provide any feedback regarding the word meaning. Score 1 point for each item. Self-corrections are allowed.

Lan\_monarchy\_R\_t1

**Point to the one which is associated with the monarchy (Crown, 10)**

Lan\_monarchy\_t1

Score: ☐ 0 ☐ 1

Lan\_marsupial\_R\_t1

**Point to the one which is a marsupial (Kangaroo, 3)**

Lan\_marsupial\_t1

Score: ☐ 0 ☐ 1

Lan\_Antarctic\_R\_t1

**Point to the one which is found in the Antarctic (Penguin, 4)**

Lan\_Antarctic\_t1

Score: ☐ 0 ☐ 1

Lan\_Nautical\_R\_t1

**Point to the one which has a nautical connection (Anchor, 5)**

Lan\_nautical\_t1

Score: ☐ 0 ☐ 1

(USE SHOWCARD 2B)

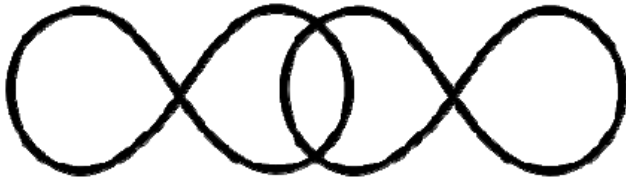
Could you read these words aloud for me please. Score 1 point only if all five words are read correctly.

VSA\_IIL\_S\_t1

Copy the shape in the space next to it.

A score of 1 is given if two infinity loops are drawn and overlap. Both infinity loops must come to a point/cross and must not look like circles.

Please copy this shape in the space provided



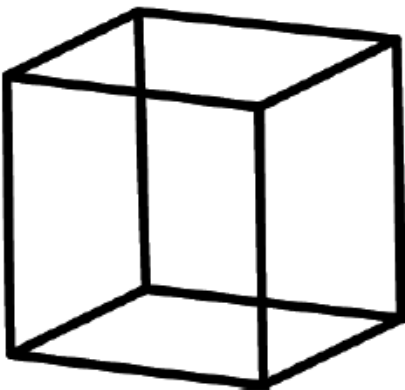
Blank space for copying the shape.

VSA\_3D\_S\_t1

Copy the shape in the space next to it.

The cube should have 12 lines to score 2 points, even if the proportions are not perfect. A score of 1 is given if the cube has fewer than 12 lines but a general cube shape is maintained.

Please copy this shape in the space provided



Blank space for copying the shape.

Blank space for scoring.

Please draw a clock face with numbers on it and then put the hands at "ten past five".

**Could you draw a clock face with numbers on it?** When the participant has finished, say:  
**Can you put the hands at ten past five?** If the participant does not like his/her first drawing and would like to draw it again, you can allow for that and score the second clock. Participants may correct their mistakes by erasing it while drawing.  
The following scoring criteria are used to give a total of 5 points (please choose the number for each of the three parts).

VSA_ClockCircle_tl	<input type="checkbox"/> 1	1 point maximum if it is a reasonable circle
<b>Circle</b>	<input type="checkbox"/> 0	
VSA_ClockNumbers_tl	<input type="checkbox"/> 2	2 points if all numbers are included and well distributed within the circle
<b>Numbers</b>	<input type="checkbox"/> 1	1 point if all numbers are included but poorly distributed or outside of the circle
	<input type="checkbox"/> 0	0 points if not all numbers are included
VSA_ClockHands_tl	<input type="checkbox"/> 2	2 points if both hands are well drawn, different lengths and placed on correct numbers (you might ask which one is the small and big one)
<b>Hands</b>	<input type="checkbox"/> 1	1 point if both placed on the correct numbers but wrong lengths OR
	<input type="checkbox"/> 1	1 point if one hand is placed on the correct number and drawn with correct length OR
	<input type="checkbox"/> 1	1 point if only one hand is drawn and placed at the correct number i.e. 5 for 'ten past five'
	<input type="checkbox"/> 0	
<b>Total:</b>	VSA_Clock_TS_tl	

PA\_CD\_S\_t1

**PERCEPTUAL ABILITIES- Counting Dots**Score out of 4: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

(USE SHOWCARD 2C)

Show the participant the showcard that contains the four dots. **Count the number of dots in each square without pointing to them.** Score 1 point for each correct answer.

Cross the boxes against the correct answers; record incorrect answer(s) in the space provided:

PA\_CD\_Res8\_S\_t1 PA\_CD\_Res10\_S\_t1  
 PA\_CD\_Res8\_t1 8 ☐ 10 ☐ PA\_CD\_Res10\_t1  
 PA\_CD\_Res7\_t1 7 ☐ 9 ☐ PA\_CD\_Res9\_t1  
 PA\_CD\_Res7\_S\_t1 PA\_CD\_Res9\_S\_t1

**PERCEPTUAL ABILITIES- Identifying Letters**Score out of 4: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

(USE SHOWCARD 2D)

Show the participant the showcard that contains the four letters.

**Could you identify the letter in each square?** The participant is allowed to point. Score 1 point for each correct answer.

Choose the correct answers: ☐ K ☐ M ☐ A ☐ T

PA\_IL\_K\_t1 PA\_IL\_M\_t1 PA\_IL\_A\_t1 PA\_IL\_T\_t1

Mem\_RNA\_S\_t1

**MEMORY- Recall of Name and Address**Score out of 7: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

**Now tell me what you remember of that name and address we were repeating at the beginning.** Score 1 point for each item recalled.

Harry Score: ☐ 0 ☐ 1 73 Score: ☐ 0 ☐ 1 Kingsbridge Score: ☐ 0 ☐ 1  
 Barnes Score: ☐ 0 ☐ 1 Orchard Score: ☐ 0 ☐ 1 Devon Score: ☐ 0 ☐ 1  
 Close Score: ☐ 0 ☐ 1

Mem\_RNA\_Har\_S\_t1

Mem\_RNA\_73\_S\_t1

Mem\_RNA\_King\_S\_t1

Mem\_RNA\_Bar\_S\_t1

Mem\_RNA\_Orch\_S\_t1

Mem\_RNA\_Dev\_S\_t1

Mem\_RNA\_Close\_S\_t1

Mem\_RecogNA\_S\_t1

**MEMORY- Recognition of Name and Address**Score out of 5: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5

This test should only be done if the participant failed to recall one or more items above. If all items were recalled, skip the test and score 5. If only part was recalled start by crossing off items recalled in the column on the right hand side, and then test non-recalled items by telling the participant:

[See below for value labels]

OK, I'll give you some hints:

Was it	Jerry Barnes	<input type="checkbox"/> 0	Harry Barnes	<input type="checkbox"/> 1	Harry Bradford	<input type="checkbox"/> 0	Recalled 1	<input type="checkbox"/>
Was it	37	<input type="checkbox"/> 0	73	<input type="checkbox"/> 1	76	<input type="checkbox"/> 0	Recalled 1	<input type="checkbox"/>
Was it	Orchard Place	<input type="checkbox"/> 0	Oak Close	<input type="checkbox"/> 0	Orchard Close	<input type="checkbox"/> 1	Recalled 1	<input type="checkbox"/>
Was it	Oakhampton	<input type="checkbox"/> 0	Kingsbridge	<input type="checkbox"/> 1	Dartington	<input type="checkbox"/> 0	Recalled 1	<input type="checkbox"/>
Was it	Devon	<input type="checkbox"/> 1	Dorset	<input type="checkbox"/> 0	Somerset	<input type="checkbox"/> 0	Recalled 1	<input type="checkbox"/>

Each recognised item scores one point, which is added to the point gained by recalling. Every item recognised correctly scores 1 point. Add the correctly recalled and recognised items to give a total of 5 points for this condition.

[Value labels for Memory - Recognition of Name and Address]

MemR\_JerryB\_S\_t1 MemR\_Oakhamp\_S\_t1  
 MemR\_HarryB\_S\_t1 MemR\_KingsB\_S\_t1  
 MemR\_HBrad\_S\_t1 MemR\_Darting\_S\_t1  
 MemR\_HBRec\_S\_t1 MemR\_KingsRec\_S\_t1

MemR\_37\_S\_t1 MemR\_Devon\_S\_t1  
 MemR\_73\_S\_t1 MemR\_Dorset\_S\_t1  
 MemR\_76\_S\_t1 MemR\_Somerset\_S\_t1  
 MemR\_73Rec\_S\_t1 MemR\_DevRec\_S\_t1

MemR\_OrcPlace\_S\_t1  
 MemR\_OakClose\_S\_t1  
 MemR\_OrcClose\_S\_t1  
 MemR\_OrchRec\_S\_t1

Attention ACE\_Total\_Atten\_t1  
 Memory ACE\_Total\_Mem\_t1  
 Fluency ACE\_Total\_Flu\_t1  
 Language ACE\_Total\_Lang\_t1  
 Visuospatial/Perceptual ACE\_Total\_VisP\_t1  
 TOTAL ACE-III SCORE: ACE\_Total\_Score\_t1

## What is the purpose of the study?

Instructions for the researcher: Please read this to the participant if s/he requires a reminder about the purpose of the study: This study aims to understand what 'living well' means to people who are experiencing difficulties in memory, thinking or behaviour, and/or have attended a Memory Clinic or similar service. The study will ask about your past experiences, your friends and family, your social life, the resources that you have, the support you get from members of your family, and the availability of social and health care provision. We will look at how all of these things relate to well-being, satisfaction with life and quality of life.

## What information are we going to ask for?

Instructions for the researcher: Please read this to the participant: *The questions today ask about your background, your health and well-being, and your home. Please be as honest and as accurate as you can throughout. There are no "right" or "wrong" answers. Answer according to your own feelings, rather than how you think "most people" would answer.*

*Your help is extremely valuable to us and of course any information you provide will be treated in strictest confidence.*

## This information will be scanned by a computer

Instructions for the researcher:

- Use black or blue ink to answer.
- For each question please cross ☒ clearly inside **one** box.
- For some questions you will be instructed that more than one box can be selected.
- If the participant changes his/her mind; simply fill in the box ☐ and put a cross ☒ in the correct box. You should draw a line through the incorrectly-selected box and then initial and date the box to make it clear that this response should be ignored.
- For some questions you will be asked to write information in boxes. When you see boxes like these, please write a single letter or number in each box provided.

For example; what is your age?

6	5
---	---

- There will be some instances where showcards are necessary and these are clearly marked in the questionnaire. Each showcard has a different identifying number; please show the corresponding showcard where indicated.
- All questions are written in bold text and they should be read out word for word.
- Where text is written in italics this represents information or instructions that you will give to the participant and this should be read out word for word.
- Where there are specific instructions for you these will be highlighted using this underlined phrase: "Instructions for the researcher" followed by the instruction or information.

Instructions for the researcher: To be completed by the researcher

P2\_Q82\_Date\_t1

**82. Today's date (dd/mm/yyyy)**

		/			/	2	0	1	
--	--	---	--	--	---	---	---	---	--

P2\_Q83\_1\_t1

**83. Assessment situation:**

- ☐ Participant and relative/friend were in the same room
- ☐ Participant and relative/friend were in different rooms
- ☐ Relative/friend will complete information separately and return by post
- ☐ Relative/friend available but s/he declined to take part
- ☐ Participant has no relative/friend

P2\_Q83\_2\_t1

**Assessment took place:**

- ☐ in own home    ☐ hospital    ☐ other; please specify:

P2\_Q83\_3\_t1

Instructions for the researcher: The following questions should be answered by the participant

### Interests and Activities

*To start with, I'm going to ask you some questions about social groups or organisations you may belong to.*

P2\_Q84\_t1

**84. Do you attend meetings or any community or social groups?**

- ☐ No (rate if less than yearly; skip to question 86)
- ☐ Yes, occasionally (rate if unpredictably, or regularly less than monthly)
- ☐ Yes, regularly (rate if daily, weekly, monthly or predictably)
- ☐ Don't know (skip to question 86)

**(USE SHOWCARD 2E)**

**85. If the participant answered yes please ask: Which of these activities do you attend?**

Instructions for the researcher: Please cross all that the participant says applies to him/her

P2\_Q85\_1\_t1 ☐ Political parties

P2\_Q85\_2\_t1 ☐ Trade unions (including student unions)

P2\_Q85\_3\_t1 ☐ Environmental groups

P2\_Q85\_4\_t1 ☐ Tenants, residents' groups or neighbourhood watch

P2\_Q85\_5\_t1 ☐ Evening classes

P2\_Q85\_6\_t1 ☐ U3A

P2\_Q85\_7\_t1 ☐ Other adult learning

P2\_Q85\_8\_t1 ☐ Arts, music or singing group

P2\_Q85\_9\_t1 ☐ Memory café or group

P2\_Q85\_10\_t1 ☐ Charity, voluntary or community group

P2\_Q85\_11\_t1 ☐ Group for older people (e.g. lunch club)

P2\_Q85\_12\_t1 ☐ Youth group (e.g. scouts/guides/youth club)

P2\_Q85\_13\_t1 ☐ Women's Institute, Townswomen's Guild

P2\_Q85\_14\_t1 ☐ Social club (Rotary, working men's club)

P2\_Q85\_15\_t1 ☐ Sports club, gym, exercise/dance group

P2\_Q85\_16\_t1 ☐ Other group or organisation; please specify:

P2\_Q85\_Oth\_t1



*I'm now going to ask you some questions about your interests and activities.*

**(USE SHOWCARD 2F)**

P2\_Q86\_t1

**86. How often do you listen to the radio?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q87\_t1

**87. How often do you read a newspaper?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q88\_t1

**88. How often do you read a magazine?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q89\_t1

**89. How often do you read a book?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q90\_t1

**90. How often do you play games such as cards or chess?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q91\_t1

**91. How often do you do crossword puzzles?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q92\_t1

**92. How often do you do Sudoku puzzles?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q93\_t1

**93. How often do you do other types of puzzles?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q94\_t1

**94. How often do you do jigsaws?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q95\_t1

**95. How often do you use the internet?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q96\_t1

**96. How often do you use social media (e.g. Twitter, Facebook)?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q97\_t1

**97. How often do you play computer games?**

Once a year or less (includes never)	Several times a year	Several times a month	Several times a week	Every day or almost every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



## Attitudes to ageing

*I'm now going to ask you some questions about how you feel as you get older. You can just answer yes or no to most of them.*

P2\_Q98\_t1

98. Do things keep getting worse as you get older?

☐ No

☐ Yes

P2\_Q99\_t1

99. Do you have as much energy/pep as you had last year?

☐ No

☐ Yes

P2\_Q100\_t1

100. Do you feel that as you get older you are less useful?

☐ No

☐ Yes

P2\_Q101\_t1

101. As you get older, are things better or worse than you thought they would be?

☐ Worse

☐ Better

P2\_Q102\_t1

102. Are you as happy now as you were when you were younger?

☐ No

☐ Yes

P2\_Q103\_t1

103. How old do you feel at the moment?

☐ A lot older than my age

☐ A little older

☐ Not much older

☐ About the same

☐ Not much younger

☐ A little younger

☐ A lot younger than my age

## Mood

*I'm now going to ask you some questions about your mood. The answers are either yes or no. Choose the best answer for how you have felt over the past week.*

P2\_Q104\_t1

104. Are you basically satisfied with your life?

☐ No

☐ Yes

P2\_Q105\_t1

105. Have you dropped many of your activities and interests?

☐ No

☐ Yes

P2\_Q106\_t1

106. Do you often get bored?

☐ No

☐ Yes

P2\_Q107\_t1

107. Are you in good spirits most of the time?

☐ No

☐ Yes

P2\_Q108\_t1

108. Do you feel happy most of the time?

☐ No

☐ Yes

P2\_Q109\_t1

109. Do you often feel helpless?

☐ No

☐ Yes

P2\_Q110\_t1

110. Do you prefer to stay at home, rather than going out and doing new things?

☐ No

☐ Yes

P2\_Q111\_t1

111. Do you feel pretty worthless the way you are now?

☐ No

☐ Yes

P2\_Q112\_t1

112. Do you feel full of energy?

☐ No

☐ Yes

P2\_Q113\_t1

113. Do you think that most people are better off than you are?

☐ No

☐ Yes

P2\_Q114\_t1

114. Do you feel lonely?

☐ No

☐ More or less

☐ Yes

## Quality of life

0680595564

*I'm now going to ask you some questions about your quality of life. When you think about your quality of life, there are different aspects, some of which are listed below. Please rate these items based on your life at the **present time** (e.g. **within the past few weeks**).*

P2\_Q115\_t1

**115. First of all, how do you feel about your physical health? Would you say it is poor, fair, good or excellent? Which word best describes your physical health right now?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q116\_t1

**116. How do you feel about your energy level? Do you think it is poor, fair, good or excellent?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q117\_t1

**117. How has your mood been lately? Have your spirits been good or have you been feeling down? Would you rate your mood as poor, fair, good or excellent?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q118\_t1

**118. How about your living situation? How do you feel about the place you live now? Would you say it is poor, fair, good or excellent?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q119\_t1

**119. How about your memory? Would you say it is poor, fair, good or excellent?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q120\_t1

**120. How about your relationship with your family and family members?**

*(For researcher guidance: If no family, ask about his/her relationship with his/her relative/friend. If no relative/friend, ask about brothers, sisters, children etc.)*

**Would you say it is poor, fair, good or excellent?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q121\_t1

**121. How do you feel about your marriage? How is your relationship with [your spouse/spouse's name]? *(For researcher guidance: If single, widowed, divorced ask about the closest relationship s/he has e.g. family member or friend.)* Would you say it is poor, fair, good or excellent?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q122\_t1

**122. How about your sex life? Would you say it is poor, fair, good or excellent?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

☐ Declined/refused to answer (record if given as a spontaneous response)

P2\_Q123\_t1

**123. How would you describe your current relationship with your friends?**

*(For researcher guidance: If s/he responds that s/he has no friends, ask if s/he has anyone s/he enjoys being with other than family? Would s/he call this person a friend? If s/he still says that they have no friends, ask **How do you feel about having no friends?**)*

**Would you say it is poor, fair, good or excellent?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q124\_t1

**124. How do you feel about yourself? What do you think of your whole self, and all the different things about you? Would you say it is poor, fair, good or excellent?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q125\_t1

**125. How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it is poor, fair, good or excellent?**

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q126\_t1

126. How about your ability to do things for fun, that you enjoy? Would you say it is poor, fair, good or excellent?

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q127\_t1

127. How do you feel about your current situation with money, your financial situation? Do you feel it is poor, fair, good or excellent?

☐ Poor

☐ Fair

☐ Good

☐ Excellent

P2\_Q128\_t1

128. How would you describe your life as a whole? When you think about your life as a whole, everything together, how do you feel about your life? Would you say it is poor, fair, good or excellent?

☐ Poor

☐ Fair

☐ Good

☐ Excellent

## Sleep

*Now I'm going to ask you some questions about how much sleep you get.*

P2\_Q129\_t1

129. How well would you rate your sleep these days?

Very poor

Poor

Fair

Good (skip to question 131)

Very good (skip to question 131)

☐

☐

☐

☐

☐

130. Why do you think the quality of your sleep is not as good as it could be? Please choose from the following options:

Instructions for the researcher: Please cross all that the participant says applies to him/her.

P2\_Q130\_1\_t1

☐ Not being able to get to sleep

P2\_Q130\_2\_t1

☐ Waking up too early and not being able to get back to sleep

P2\_Q130\_3\_t1

☐ Waking up several times throughout the night

P2\_Q130\_4\_t1

☐ Having bad dreams

P2\_Q130\_5\_t1

☐ Being uncomfortable

P2\_Q130\_6\_t1

☐ Other; please specify:

P2\_Q130\_oth\_t1

P2\_Q131\_1\_t1

131. Do you feel your sleep pattern has changed over the last twelve months?

☐ No

☐ Yes; if yes, please describe:

P2\_Q131\_2\_t1

## WHO-5 Well-Being Index

(USE SHOWCARD 2G)

Now I'm going to ask you to indicate for each of these statements which answer is closest to how you have been feeling over the **last two weeks**. For example: I will ask you if you have felt cheerful and in good spirits and you can choose the best answer from the list. If you have felt cheerful and in good spirits more than half of the time during the last two weeks, you would say "more than half of the time".

P2\_Q132\_t1

**132. I have felt cheerful and in good spirits**

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q133\_t1

**133. I have felt calm and relaxed**

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q134\_t1

**134. I have felt active and vigorous**

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q135\_t1

**135. I woke up feeling fresh and rested**

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q136\_t1

**136. My daily life has been filled with things that interest me**

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**P2\_Q137\_1\_t1 to P2\_Q151\_3\_t1 are from the AAIQOL measure, provided as below:**

Author and Owner: Steven Albert

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## Social participation

3761595567

Now I'm going to ask you to indicate whether you have **had an opportunity** to participate in the following activities in the **last 2 weeks**. If you have **had an opportunity** to do the activity, I'm going to ask you how often you did each activity and whether you enjoyed it.

P2\_Q137\_1\_t1

**137. Have you had an opportunity to be outside, go for walks, enjoy nature?**

☐ No (skip to question 138)

P2\_Q137\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q137\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q138\_1\_t1

**138. Have you had an opportunity to be with pets or animals or to watch animals?**

☐ No (skip to question 139)

P2\_Q138\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q138\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q139\_1\_t1

**139. Have you had an opportunity to get together with family/friends?**

☐ No (skip to question 140)

P2\_Q139\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q139\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q140\_1\_t1

**140. Have you had an opportunity to talk to family/friends on the telephone?**

☐ No (skip to question 141)

P2\_Q140\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q140\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q141\_1\_t1

**141. Have you had an opportunity to go to the cinema, museums or other entertainment events?**

☐ No (skip to question 142)

P2\_Q141\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q141\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q142\_1\_t1

**142. Have you had an opportunity to go to church or other place of worship or religious events?**

☐ No (skip to question 143)

P2\_Q142\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q142\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q143\_1\_t1

**143. Have you had an opportunity to go shopping for groceries, clothes, etc.?**

☐ No (skip to question 144)

P2\_Q143\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q143\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q144\_1\_t1

**144. Have you had an opportunity to go for a ride in the car, train or bus?**

☐ No (skip to question 145)

P2\_Q144\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q144\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q145\_1\_t1

**145. Have you had an opportunity to read or have stories read to you?**

☐ No (skip to question 146)

P2\_Q145\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q145\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q146\_1\_t1

**146. Have you had an opportunity to listen to the radio, tapes or CDs, or watch TV?**

☐ No (skip to question 147)

P2\_Q146\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q146\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q147\_1\_t1

**147. Have you had an opportunity to exercise, play or watch sports?**

☐ No (skip to question 148)

P2\_Q147\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q147\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q148\_1\_t1

**148. Have you had an opportunity to play games or cards, do crosswords or puzzles?**

☐ No (skip to question 149)

P2\_Q148\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q148\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q149\_1\_t1

**149. Have you had an opportunity to do handiwork or crafts?**

☐ No (skip to question 150)

P2\_Q149\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q149\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q150\_1\_t1

**150. Have you had an opportunity to garden, plant care, indoors or outdoors?**

☐ No (skip to question 151)

P2\_Q150\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q150\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

P2\_Q151\_1\_t1

**151. Have you had an opportunity to complete a task that was difficult for you?**

☐ No (skip to question 152)

P2\_Q151\_2\_t1

☐ Yes If yes; **How often did you do [the activity]?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

P2\_Q151\_3\_t1

**Did you enjoy [the activity]?**

☐ No

☐ Yes

## Self-efficacy

(USE SHOWCARD 2H)

*I'm going to read you some statements. On this card you can see some possible answers about how true each statement is of you. Please choose the answer that you think is closest to how true the statement is of you.*

P2\_Q152\_t1

**152. I can always manage to solve difficult problems if I try hard enough**

☐ Not at all true   ☐ Hardly true   ☐ Moderately true   ☐ Completely true

P2\_Q153\_t1

**153. If someone opposes me, I can find the means and ways to get what I want**

☐ Not at all true   ☐ Hardly true   ☐ Moderately true   ☐ Completely true

P2\_Q154\_t1

**154. It is easy for me to stick to my aims and accomplish my goals**

☐ Not at all true   ☐ Hardly true   ☐ Moderately true   ☐ Completely true

P2\_Q155\_t1

**155. I am confident that I could deal efficiently with unexpected events**

☐ Not at all true   ☐ Hardly true   ☐ Moderately true   ☐ Completely true

P2\_Q156\_t1

**156. Thanks to my resourcefulness, I know how to handle unforeseen situations**

☐ Not at all true   ☐ Hardly true   ☐ Moderately true   ☐ Completely true

P2\_Q157\_t1

**157. I can solve most problems if I invest the necessary effort**

☐ Not at all true   ☐ Hardly true   ☐ Moderately true   ☐ Completely true

P2\_Q158\_t1

**158. I can remain calm when facing difficulties because I can rely on my coping abilities**

☐ Not at all true   ☐ Hardly true   ☐ Moderately true   ☐ Completely true

P2\_Q159\_t1

**159. When I am confronted with a problem, I can usually find several solutions**

☐ Not at all true   ☐ Hardly true   ☐ Moderately true   ☐ Completely true

P2\_Q160\_t1

**160. If I am in trouble, I can usually think of a solution**

☐ Not at all true   ☐ Hardly true   ☐ Moderately true   ☐ Completely true

P2\_Q161\_t1

**161. I can usually handle whatever comes my way**

☐ Not at all true   ☐ Hardly true   ☐ Moderately true   ☐ Completely true



## Satisfaction with Life

*I'm now going to give you a list of statements dealing with your general feelings about yourself. Please indicate how much you agree or disagree with each statement.*

**(USE SHOWCARD 2I)**

P2\_Q162\_t1

**162. In most ways my life is close to my ideal**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q163\_t1

**163. The conditions of my life are excellent**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q164\_t1

**164. I am satisfied with my life**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q165\_t1

**165. So far I have got the important things I want in life**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q166\_t1

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

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Social Networks

*I'm now going to ask you some questions about the types of support from other people that you have in your life. Please answer the following questions by choosing an option that best describes your current situation.*

Instructions for the researcher: If the number of people is more than ten please write the exact number of people in the box provided.

*Considering the people to whom you are **related either by birth, marriage, adoption, etc.**:*

P2\_Q167\_1\_t1

**167. How many relatives do you see or hear from at least once a month?**

None	One	Two	Three	Four	Five	Six	Seven	Eight	Nine	Ten
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q167\_2\_t1

If more than ten please specify:

P2\_Q168\_1\_t1

**168. How many relatives do you feel at ease with that you can talk about private matters?**

None	One	Two	Three	Four	Five	Six	Seven	Eight	Nine	Ten
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2\_Q168\_2\_t1

If more than ten please specify:

P2\_Q169\_1\_t1

**169. How many relatives do you feel close to such that you could call on them for help?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

P2\_Q169\_2\_t1

If more than ten please specify:

*Considering all of your **friends** including those who live in your neighbourhood:*

P2\_Q170\_1\_t1

**170. How many of your friends do you see or hear from at least once a month?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

P2\_Q170\_2\_t1

If more than ten please specify:

P2\_Q171\_1\_t1

**171. How many friends do you feel at ease with that you can talk about private matters?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

P2\_Q171\_2\_t1

If more than ten please specify:

P2\_Q172\_1\_t1

**172. How many friends do you feel close to such that you could call on them for help?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

P2\_Q172\_2\_t1

If more than ten please specify:

*Now considering both family **and** friends:*

P2\_Q173\_1\_t1

**173. Over the last week how many different people have visited you each day?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

P2\_Q173\_2\_t1

If more than ten please specify:

P2\_Q174\_1\_t1

**174. Over the last week how many different people have telephoned you each day?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

P2\_Q174\_2\_t1

If more than ten please specify:

**(USE SHOWCARD 2J)**

P2\_Q175\_t1

**175. How satisfied are you with the support you receive from family?**

Very dissatisfied Slightly dissatisfied Neither satisfied nor dissatisfied Slightly satisfied Very satisfied Don't know  
☐ ☐ ☐ ☐ ☐ ☐

P2\_Q176\_t1

**176. How satisfied are you with the support you receive from friends?**

Very dissatisfied Slightly dissatisfied Neither satisfied nor dissatisfied Slightly satisfied Very satisfied Don't know  
☐ ☐ ☐ ☐ ☐ ☐

**6413595564**

*These questions are about the **current** relationship between you and [your relative/friend].*

Not close at all      Not too close      Quite close      Close      Very close      Extremely close

Not well at all      Not too well      Quite well      Well      Very well      Extremely well

Not similar at all      Not too similar      Quite similar      Similar      Very similar      Extremely similar

☐      ☐      ☐      ☐      ☐      ☐

Never      Very rarely      Rarely      Occasionally      Frequently      Very frequently

☐      ☐      ☐      ☐      ☐      ☐

Not well at all ☐ Not too well ☐ Quite well ☐ Well ☐ Very well ☐ Extremely well ☐

*These questions are about the **past** relationship between you and [your relative/friend]. By past we mean, let's say, **10 years ago**.*

182. Taking everything into consideration, how close did you feel in your relationship with [your relative/friend]?

Not close at all      Not too close      Quite close      Close      Very close      Extremely close

Not well at all      Not too well      Quite well      Well      Very well      Extremely well

Not similar at all      Not too similar      Quite similar      Similar      Very similar      Extremely similar

Never      Very rarely      Rarely      Occasionally      Frequently      Very frequently

Not well at all      Not too well      Quite well      Well      Very well      Extremely well

## Everyday activities

*I'm now going to ask you some questions about how well you are able to carry out various everyday activities.*

**(USE SHOWCARD 2K)**

**187. Can you write cheques, pay bills, and keep financial records?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

**188. Can you assemble tax records, make out business or insurance papers?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

**189. Can you shop alone for clothes, household necessities and groceries?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

**190. Can you play a game of skill (e.g. bridge, chess, cards, crosswords) or work on a hobby (e.g. gardening)?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

**191. Can you heat water for coffee or tea and turn off the stove?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

P2\_Q192\_t1

**192. Can you prepare a balanced meal?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

P2\_Q193\_t1

**193. Can you keep track of current events?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

P2\_Q194\_t1

**194. Can you pay attention to, understand and discuss a TV programme, book or magazine?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

P2\_Q195\_t1

**195. Can you remember appointments, family occasions and to take your medication?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

P2\_Q196\_t1

**196. Can you travel out of the immediate local area - driving, arranging to take buses etc.?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

P2\_Q197\_t1

**197. Are you able to use the telephone appropriately (e.g. finding and dialling correct numbers)?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Have difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now

P2\_Q198\_t1

**198. Do you need reminders or advice to manage chores, do shopping, cooking, play games, or handle money?**

- ☐ No
- ☐ Occasionally (i.e. at least once a month)
- ☐ Frequently (i.e. at least once a week)

P2\_Q199\_t1

**199. Do you need help to remember important things such as appointments, recent events, or names of family or friends?**

- ☐ No
- ☐ Occasionally (i.e. at least once a month)
- ☐ Frequently (i.e. at least once a week)

P2\_Q200\_t1

**200. Do you need frequent (at least once a month) help finding misplaced objects, keeping appointments, or maintaining health or safety (locking doors, taking medication)?**

☐ No ☐ Yes

P2\_Q201\_t1

**201. Do you need household chores done for you?**

☐ No ☐ Yes

*Please answer yes or no to the following questions. Some of the questions may not be relevant to you. If the question is not relevant, just say so.*

Instructions for the researcher: Some of the questions can be completed by the researcher. If the participant says that a question is not relevant put a cross in the 'no' box.

P2\_Q202\_t1

**202. Do you need to be watched or kept company when awake?**

☐ No ☐ Yes

P2\_Q203\_t1

**203. Do you need to be escorted when outside?**

☐ No ☐ Yes

P2\_Q204\_t1

**204. Do you need to be accompanied when bathing or eating?**

☐ No ☐ Yes

P2\_Q205\_t1

**205. Do you have to be dressed, washed, and groomed?**

☐ No ☐ Yes

P2\_Q206\_t1

**206. Do you have to be taken to the toilet regularly to avoid incontinence?**

☐ No ☐ Yes

P2\_Q207\_t1

**207. Do you have to be fed?**

☐ No ☐ Yes

P2\_Q208\_t1

**208. Do you need to be turned, moved, or transferred?**

☐ No ☐ Yes

P2\_Q209\_t1

**209. Do you wear an incontinence pad or a catheter?**

☐ No ☐ Yes

P2\_Q210\_t1

**210. Do you need to be tube fed?**

☐ No ☐ Yes

## Difficulties that you may experience (RADIX)

*Now I would like to talk to you about any difficulties you've been experiencing*

P2\_Q211\_t1

**211. To be completed by the researcher:** During your time with the participant has s/he acknowledged noticing or experiencing changes or difficulties in memory or other symptoms related to his/her dementia?

☐ No ☐ Yes (if so you can start by saying something like '**Earlier on you mentioned you had problems with [your memory]**')

P2\_Q212\_t1

**212. Have you, a family member or doctor noticed that you have been having difficulty with concentration?**

☐ No ☐ Yes

P2\_Q213\_t1

**213. Have you, a family member or doctor noticed that you have been having difficulty with being forgetful?**

☐ No ☐ Yes

P2\_Q214\_t1

**214. Have you, a family member or doctor noticed that you have been having difficulty with remembering (e.g. recent events)?**

☐ No ☐ Yes

P2\_Q215\_t1

**215. Have you, a family member or doctor noticed that you have been having difficulty with thinking?**

☐ No ☐ Yes

P2\_Q216\_t1

**216. Have you, a family member or doctor noticed that you have been having difficulty with your ability to say what you want to say?**

☐ No ☐ Yes

P2\_Q217\_t1

**217. Have you, a family member or doctor noticed that you have been having difficulty with your ability to manage your day-to-day activities?**

☐ No ☐ Yes

P2\_Q218\_t1

**218. Have you, a family member or doctor noticed that you have been having difficulty with planning ahead?**

☐ No ☐ Yes

P2\_Q219\_t1

**219. Have you, a family member or doctor noticed that you have been having difficulty with making decisions?**

☐ No ☐ Yes

P2\_Q220\_t1

**220. Are you different in some way to how you used to be?**

☐ No ☐ Yes

Instructions for the researcher: If **all** the answers to **questions 211-220** are 'no' skip to question 267

P2\_Q221\_t1

**221. Instructions for the researcher:** Acknowledge any difficulties that the person has discussed e.g. 'You said you were having difficulty with [your memory]' and then say; **What do you call [this difficulty/these difficulties/this condition] that you have?**

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P2\_Q222\_1\_t1

**222. Are you aware of a specific diagnosis? What does the doctor call it?**

☐ No ☐ Yes, if yes please specify:

P2\_Q222\_2\_t1

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Instructions for the researcher: Record the person's label for the condition. How does s/he refer to the condition; does s/he call it dementia or something else e.g. short-term memory problems, forgetfulness. Use this term, referred to as [label] in all subsequent questions. If the participant does not give a label, replace [label] with "your condition" or "your difficulties" instead.

P2\_Q222\_3\_t1; P2\_Q222\_3\_ext1\_t1; P2\_Q222\_3\_ext2\_t1

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P2\_Q223\_1\_t1

**223. What do you think caused or causes your [label]?**

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a) Instructions for the researcher: If no instant response then follow up with: **These are some of the things that other people say causes their problems; which one do you think applies to you?**

Instructions for the researcher: Please cross all that the participant says applies to him/her.

P2\_Q223a\_1\_t1 ☐ Ageing

P2\_Q223a\_2\_t1 ☐ Changes within the brain (e.g. something in your brain dies off)

P2\_Q223a\_3\_t1 ☐ Illness or disease (e.g. stroke)

P2\_Q223a\_4\_t1 ☐ Hereditary condition (e.g. genetics)

P2\_Q223a\_5\_t1 ☐ Lifestyle/life events (e.g. stress, bereavement)

P2\_Q223a\_6\_t1 ☐ Don't know (record if given as a spontaneous response)

P2\_Q223b\_t1

b) Instructions for the researcher: If more than one cause identified, ask him/her to nominate the most important one and cross the appropriate box below:

☐ Ageing

☐ Changes within the brain (e.g. something in your brain dies off)

☐ Illness or disease (e.g. stroke)

☐ Hereditary condition (e.g. genetics)

☐ Lifestyle/life events (e.g. stress, bereavement)



Please indicate how much you agree or disagree with the following statements:

(USE SHOWCARD 2L)

P2\_Q224\_t1

**224. My [label] will stay the same as it is now**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q225\_t1

**225. My [label] will get better**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q226\_t1

**226. My [label] will get worse**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q227\_t1

**227. There are medications that can help control my [label]**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q228\_t1

**228. Nothing I do will affect my [label]**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q229\_t1

**229. There is a lot which I can do to control the effects of my [label]**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q230\_t1

**230. As a result of my [label] I get annoyed or frustrated with myself**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q231\_t1

**231. As a result of my [label] I get very angry about what is happening to me**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q232\_t1

**232. I do not worry about my [label]**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q233\_t1

**233. As a result of my [label] I feel I have lost confidence in myself**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q234\_t1

**234. I feel low or upset when I think about my [label]**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q235\_t1

**235. As a result of my [label] people treat me differently**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q236\_t1

**236. My [label] does not cause any difficulties for my family/friends**

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q237\_t1

**237. As a result of my [label] I do not go out as much as I used to**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q238\_t1

**238. As a result of my [label] I cannot do some of the things that I used to do**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q239\_t1

**239. My [label] does not have much effect on my life**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q240\_t1

**240. As a result of my [label] I feel I have lost control over my life**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q241\_t1

**241. Despite my [label] I feel I am the same person as I used to be**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q242\_t1

**242. I find myself worrying about my [label]**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q243\_t1

**243. My [label] is/are not that bad; there are others worse off than me**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q244\_t1

**244. Due to my [label] I have to accept the changes in my life**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q245\_t1

**245. There's a lot I can do about my [label], I'm going to fight it as long as I can**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q246\_t1

**246. I avoid thinking about my [label]**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q247\_t1

**247. I take each day as it comes and do not think about the future**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q248\_t1

**248. I rely on others for help**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q249\_t1

**249. I find it helps to keep to a routine**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q250\_t1

**250. I try to hide the difficulties resulting from my [label]**☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P2\_Q251\_t1

**251. I am keen to learn more about my [label]**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

P2\_Q252\_t1

**252. I try to find practical ways of overcoming problems resulting from my [label]**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

P2\_Q253\_t1

**253. I try to avoid social contact because of my [label]**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

P2\_Q254\_t1

**254. I tell people that I have [label]**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

P2\_Q255\_t1

**255. I prefer not to talk about my [label]**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

P2\_Q256\_t1

**256. It helps to keep myself busy**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

P2\_Q257\_t1

**257. I give myself time and try and be patient with myself**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

### Stigma

P2\_Q258\_t1

**258. I feel I have been treated with less respect than usual by others**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

P2\_Q259\_t1

**259. I have experienced financial hardship that has affected how I feel about myself**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

P2\_Q260\_t1

**260. I feel others think I am to blame for my [label]**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

P2\_Q261\_t1

**261. I feel set apart from others who are well**☐ Strongly disagree☐ Disagree☐ Agree☐ Strongly agree

## Information about the condition

*I'm now going to ask you some questions about the kinds of information that you have found or been given in connection with your [label].*

P2\_Q262\_1\_t1

**262. Have you received any information or educational materials to help you with [label]?**

☐ No (skip to question 264) ☐ Yes, if yes please describe:

P2\_Q262\_2\_t1

P2\_Q263\_t1

**263. If you have received any information or educational materials, where did the information come from?**

P2\_Q264\_1\_t1

**264. Have you independently sought out information to help you with [label] e.g. have you contacted a national charity such as the Alzheimer's Society or Parkinson's UK, searched the internet for information, etc.?**

☐ No ☐ Yes, if yes please describe:

P2\_Q264\_2\_t1

P2\_Q265\_1\_t1

**265. Have you taken part in any intervention (e.g. a support group, sessions with a psychologist, etc.) to help you with [label]?**

☐ No (skip to question 267) ☐ Yes, if yes please describe:

P2\_Q265\_2\_t1

P2\_Q266\_t1

**266. If you have taken part in any intervention, who offered it to you?**

*I'm now going to ask you to indicate the extent to which you agree or disagree with the following statements.*

**(USE SHOWCARD 2M)**

P2\_Q267\_t1

**267. I have high self-esteem**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

### Optimism

P2\_Q268\_t1

**268. In uncertain times, I usually expect the best**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

P2\_Q269\_t1

**269. If something can go wrong for me, it will**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

P2\_Q270\_t1

**270. I'm always optimistic about the future**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

P2\_Q271\_t1

**271. I hardly ever expect things to go my way**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

P2\_Q272\_t1

**272. I rarely count on good things happening to me**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

P2\_Q273\_t1

**273. Overall, I expect more good things to happen to me than bad**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

### Sense of self

P2\_Q274\_t1

**274. I am still the same person as I have always been**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

P2\_Q275\_t1

**275. I am satisfied with who I am**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

P2\_Q276\_t1

**276. My life is meaningful to me**

☐ Strongly disagree ☐ Disagree ☐ Neutral ☐ Agree ☐ Strongly agree

### Loneliness scale

*I'm now going to ask you to indicate for each of these statements the extent to which they apply to your situation or the way you feel now.*

P2\_Q277\_t1

**277. I experience a general sense of emptiness**

☐ Yes ☐ More or less ☐ No

P2\_Q278\_t1

**278. There are plenty of people I can rely on when I have problems**

☐ Yes ☐ More or less ☐ No

P2\_Q279\_t1

**279. There are many people I can trust completely**

☐ Yes ☐ More or less ☐ No

P2\_Q280\_t1

**280. There are enough people I feel close to**

☐ Yes ☐ More or less ☐ No

P2\_Q281\_t1

**281. I miss having people around**

☐ Yes ☐ More or less ☐ No

P2\_Q282\_t1

**282. I often feel rejected**

☐ Yes ☐ More or less ☐ No

## Rosenberg Self-Esteem Scale

*I'm now going to read you a list of statements dealing with your general feelings about yourself. Please indicate how much you agree or disagree with each statement.*

**(USE SHOWCARD 2N)**

P2\_Q283\_t1

**283. On the whole, I am satisfied with myself**

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

P2\_Q284\_t1

**284. At times, I think I am no good at all**

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

P2\_Q285\_t1

**285. I feel that I have a number of good qualities**

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

P2\_Q286\_t1

**286. I am able to do things as well as most other people**

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

P2\_Q287\_t1

**287. I feel I do not have much to be proud of**

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

P2\_Q288\_t1

**288. I certainly feel useless at times**

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

P2\_Q289\_t1

**289. I feel that I'm a person of worth, at least on an equal plane with others**

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

P2\_Q290\_t1

**290. I wish I could have more respect for myself**

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

P2\_Q291\_t1

**291. All in all, I am inclined to feel that I am a failure**

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

P2\_Q292\_t1

**292. I take a positive attitude towards myself**

☐ Strongly agree ☐ Agree ☐ Disagree ☐ Strongly disagree

### Your comments

*This is the section where you can add comments about anything.*

Instructions for the researcher: This question is optional.

P2\_Q293\_1\_t1

**293. Is there anything else you would like to tell us about today?**

☐ No ☐ Yes, if yes please specify

P2\_Q293\_2\_t1; P2\_Q293\_2\_ext1\_t1; P2\_Q293\_2\_ext2\_t1

**Thank you for taking the time to answer these questions.  
The information and insight that you have provided is  
very valuable to us.**

Instructions for the researcher: To be completed by the researcher

### Functional Assessment Staging (FAST)

P2\_Q294\_t1

**294. Information for this questionnaire should be collated from self-reports and information from the relative/friend or, in the case of nursing home care, the nursing home staff. Please cross the box next to the stage that applies to the person with dementia.**

- ☐ Stage 1: No objective or subjective functional decrement
- ☐ Stage 2: Subjective deficit in recalling names or other word finding and/or subjective deficit in recalling location of objects and/or subjectively decreased ability to recall appointments
- ☐ Stage 3: Deficits noted in demanding occupational and social settings
- ☐ Stage 4: Deficits in performance of complex tasks of daily life
- ☐ Stage 5: Deficient performance in choosing proper attire, and assistance is required for independent community functioning
- ☐ Stage 6a: Requires actual physical assistance in putting on clothing properly
- ☐ Stage 6b: Requires assistance bathing properly
- ☐ Stage 6c: Requires assistance with mechanics of toileting
- ☐ Stage 6d: Urinary incontinence
- ☐ Stage 6e: Faecal incontinence
- ☐ Stage 7a: Speech limited to about 6 words in the course of an average day
- ☐ Stage 7b: Intelligible vocabulary limited to generally a single word in the course of an average day
- ☐ Stage 7c: Ambulatory ability lost
- ☐ Stage 7d: Ability to sit up lost
- ☐ Stage 7e: Ability to smile lost
- ☐ Stage 7f: Ability to hold head up lost

### Global Deterioration Scale

P2\_Q295\_t1

**295. Choose the most appropriate global stage based upon cognition and function. Please cross the box next to the level that applies to the person with dementia. USE SHOWCARD 4B for descriptions of the different levels**

- ☐ GDS Level 1: No cognitive decline
- ☐ GDS Level 2: Very mild cognitive decline (age associated memory impairment)
- ☐ GDS Level 3: Mild cognitive decline (mild cognitive impairment)
- ☐ GDS Level 4: Moderate cognitive decline (mild dementia)
- ☐ GDS Level 5: Moderately severe cognitive decline (moderate dementia)
- ☐ GDS Level 6: Severe cognitive decline (moderately severe dementia)
- ☐ GDS Level 7: Very severe cognitive decline (severe dementia)

**Instructions for the researcher:** Checklist/Field notes

At the end of each part of the assessment please note reasons for any items which were not completed:

☐ All items have been completed (if so skip to field notes)

**ACE-III**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                                       | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: <input type="checkbox"/> Too impaired | <input type="checkbox"/> Too tired | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____                   |                                    |   |

**Interests and Activities**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                                       | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: <input type="checkbox"/> Too impaired | <input type="checkbox"/> Too tired | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____                   |                                    |   |

**Attitudes to ageing**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                                       | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: <input type="checkbox"/> Too impaired | <input type="checkbox"/> Too tired | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____                   |                                    |   |

**Mood**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                                       | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: <input type="checkbox"/> Too impaired | <input type="checkbox"/> Too tired | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____                   |                                    |   |

**Quality of life**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                                       | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: <input type="checkbox"/> Too impaired | <input type="checkbox"/> Too tired | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____                   |                                    |   |

**Sleep**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                                       | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: <input type="checkbox"/> Too impaired | <input type="checkbox"/> Too tired | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____                   |                                    |   |

**WHO-5 Well-Being Index**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                                       | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: <input type="checkbox"/> Too impaired | <input type="checkbox"/> Too tired | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____                   |                                    |   |

**Social participation**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                                       | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: <input type="checkbox"/> Too impaired | <input type="checkbox"/> Too tired | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____                   |                                    |   |

**Self-efficacy**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                                       | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: <input type="checkbox"/> Too impaired | <input type="checkbox"/> Too tired | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____                   |                                    |   |

**Satisfaction with Life**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                                       | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: <input type="checkbox"/> Too impaired | <input type="checkbox"/> Too tired | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____                   |                                    |   |



## Social Networks

1133595568

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

## Relationship Quality- current

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

## Relationship Quality- retrospective

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

## Everyday activities

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

## Difficulties that you may experience (RADIX)

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

## Stigma

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

## Information about condition

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

## Optimism

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

## Sense of self

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

## Loneliness scale

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

## Rosenberg Self-Esteem Scale

- |                                   |   |   |
|-----------------------------------|---|---|
| <input type="checkbox"/> Complete | <input type="checkbox"/> Refused                      | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial: | <input type="checkbox"/> Too impaired                 | <input type="checkbox"/> Too tired                |
|                                   | <input type="checkbox"/> Too tired                    | <input type="checkbox"/> Questions not understood |
|                                   | <input type="checkbox"/> Other; please specify: _____ |   |

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We would like you to record any additional information about the assessment which you may think is useful.

Examples of comments could include any issues that affected or disrupted the course of the assessment today (e.g. visitors arriving during the ACE-III), details of specific items that were not completed, the demeanour of the participant, participant engagement and general reaction to the administration of the measures, any difficulties experienced by the researcher, details of why you decided on a particular score for the GDS and FAST, etc.

**I would like to add field notes or comments**

☐ No      ☐ Yes; please write your notes here:

DO NOT PRINT/CO

### Assessment of level of consciousness.

☐ Alert/Responsive☐ Drowsy☐ Stuporous☐ Comatose/Unresponsive

--

P\_ID

Participant ID

--	--	--	--	--	--	--

Researcher ID

--	--	--

# Enhancing Active Life and Living Well: The IDEAL Study

## Participant Part 3



[www.IDEALproject.org.uk](http://www.IDEALproject.org.uk)

# Enhancing Active Life and Living Well: The IDEAL Study

## What is the purpose of the study?

Instructions for the researcher: Please read this to the participant if s/he requires a reminder about the purpose of the study: This study aims to understand what 'living well' means to people who are experiencing difficulties in memory, thinking or behaviour, and/or have attended a Memory Clinic or similar service. The study will ask about your past experiences, your friends and family, your social life, the resources that you have, the support you get from members of your family, and the availability of social and health care provision. We will look at how all of these things relate to well-being, satisfaction with life and quality of life.

## What information are we going to ask for?

Instructions for the researcher: Please read this to the participant: *The questions today ask about your background, your health and well-being, and your home. Please be as honest and as accurate as you can throughout. There are no "right" or "wrong" answers. Answer according to your own feelings, rather than how you think "most people" would answer.*

*Your help is extremely valuable to us and of course any information you provide will be treated in strictest confidence.*

## This information will be scanned by a computer

Instructions for the researcher:

- Use black or blue ink to answer.
- For each question please cross ☒ clearly inside **one** box.
- For some questions you will be instructed that more than one box can be selected.
- If the participant changes his/her mind; simply fill in the box ☐ and put a cross ☒ in the correct box. You should draw a line through the incorrectly-selected box and then initial and date the box to make it clear that this response should be ignored.
- For some questions you will be asked to write information in boxes. When you see boxes like these, please write a single letter or number in each box provided.

For example; what is your age?

6	5
---	---

- There will be some instances where showcards are necessary and these are clearly marked in the questionnaire. Each showcard has a different identifying number; please show the corresponding showcard where indicated.
- All questions are written in bold text and they should be read out word for word.
- Where text is written in italics this represents information or instructions that you will give to the participant and this should be read out word for word.
- Where there are specific instructions for you these will be highlighted using this underlined phrase: "Instructions for the researcher" followed by the instruction or information.

## Section A

Instructions for the researcher: To be completed by the researcher

P3\_Q296\_Date\_t1

296. Today's date (dd/mm/yyyy)

		/			/	2	0	1	
--	--	---	--	--	---	---	---	---	--

P3\_Q297\_1\_t1

297. Assessment situation:

- ☐ Participant and relative/friend were in the same room
- ☐ Participant and relative/friend were in different rooms
- ☐ Relative/friend will complete information separately and return by post
- ☐ Relative/friend available but s/he declined to take part
- ☐ Participant has no relative/friend

Assessment took place:

- ☐ in own home
- ☐ hospital
- ☐ other; please specify:

P3\_Q297\_oth\_t1

Instructions for the researcher: The following questions should be answered by the participant

### Physical health

**To begin with, we would like to know whether you are currently employed.**

Instructions for the researcher: If the participant answers yes, ask question 298, otherwise cross the "I am not in employment" box and skip to question 299

298. Please tell us the type and amount of physical activity involved in your work.

- ☐ I am not in employment (e.g. retired, retired for health reasons, unemployed, full-time carer etc.)
- ☐ I spend most of my time at work sitting (such as in an office)
- ☐ I spend most of my time at work standing or walking. However, my work does not require much intense physical effort (e.g. shop assistant, hairdresser, security guard, childminder, etc.)
- ☐ My work involves definite physical effort including handling of heavy objects and use of tools (e.g. plumber, electrician, carpenter, cleaner, hospital nurse, gardener, postal delivery workers etc.)
- ☐ My work involves vigorous physical activity including handling of very heavy objects (e.g. scaffolder, construction worker, refuse collector, etc.)

(USE SHOWCARD 3A)

299. During the last week, how many hours did you spend doing physical exercise such as swimming, jogging, aerobics, football, tennis, gym workout etc.?

Instructions for the researcher: do not accept answers about walking for this question

None

Some but less  
than one hour

One hour but less  
than three hours

Three hours  
or more

☐☐☐☐

300. During the last week, how many hours did you spend cycling, including cycling to work and during leisure time?

None

Some but less  
than one hour

One hour but less  
than three hours

Three hours  
or more

☐☐☐☐

P3\_Q301\_t1

301. During the last week, how many hours did you spend walking, including walking to work, shopping, for pleasure etc?

None

☐

Some but less than one hour

☐

One hour but less than three hours

☐

Three hours or more

☐

P3\_Q302\_t1

302. During the last week, how many hours did you spend doing housework/childcare?

None

☐

Some but less than one hour

☐

One hour but less than three hours

☐

Three hours or more

☐

P3\_Q303\_t1

303. During the last week, how many hours did you spend gardening/doing DIY?

None

☐

Some but less than one hour

☐

One hour but less than three hours

☐

Three hours or more

☐

P3\_Q304\_t1

304. How would you describe your usual walking pace? Please mark one box only.

☐ Slow pace (i.e. less than 3 mph)

☐ Steady average pace

☐ Brisk pace

☐ Fast pace (i.e. over 4 mph)

### Dignity and respect

(USE SHOWCARD 3B)

*I'm going to ask you some questions about how you feel you have been treated.*

P3\_Q305\_t1

305. Health professionals treat you with dignity and respect.

☐ Rarely or not at all ☐ Sometimes ☐ Mostly ☐ Always ☐ Not applicable

P3\_Q306\_t1

306. Care staff treat you with dignity and respect.

☐ Rarely or not at all ☐ Sometimes ☐ Mostly ☐ Always ☐ Not applicable

P3\_Q307\_t1

307. Do you think in general your family treats you with dignity and respect?

☐ Rarely or not at all ☐ Sometimes ☐ Mostly ☐ Always ☐ Not applicable

P3\_Q308\_t1

308. Other people treat you with dignity and respect.

☐ Rarely or not at all ☐ Sometimes ☐ Mostly ☐ Always ☐ Not applicable

## Psychological Well-Being

(USE SHOWCARD 3C)

The following set of questions deals with how you feel about yourself and your life. Please remember that there are no right or wrong answers. Please give the answer that best describes your present agreement or disagreement with each statement.

P3\_Q309\_t1

**309. When I look at the story of my life, I am pleased with how things have turned out.**

Strongly  
disagree  
☐

Moderately  
disagree  
☐

Slightly  
disagree  
☐

Slightly  
agree  
☐

Moderately  
agree  
☐

Strongly  
agree  
☐

P3\_Q310\_t1

**310. In general, I feel confident and positive about myself.**

Strongly  
disagree  
☐

Moderately  
disagree  
☐

Slightly  
disagree  
☐

Slightly  
agree  
☐

Moderately  
agree  
☐

Strongly  
agree  
☐

P3\_Q311\_t1

**311. I feel like many of the people I know have got more out of life than I have.**

Strongly  
disagree  
☐

Moderately  
disagree  
☐

Slightly  
disagree  
☐

Slightly  
agree  
☐

Moderately  
agree  
☐

Strongly  
agree  
☐

P3\_Q312\_t1

**312. I like most aspects of my personality.**

Strongly  
disagree  
☐

Moderately  
disagree  
☐

Slightly  
disagree  
☐

Slightly  
agree  
☐

Moderately  
agree  
☐

Strongly  
agree  
☐

P3\_Q313\_t1

**313. In many ways, I feel disappointed about my achievements in life.**

Strongly  
disagree  
☐

Moderately  
disagree  
☐

Slightly  
disagree  
☐

Slightly  
agree  
☐

Moderately  
agree  
☐

Strongly  
agree  
☐

P3\_Q314\_t1

**314. My attitude about myself is probably not as positive as most people feel about themselves.**

Strongly  
disagree  
☐

Moderately  
disagree  
☐

Slightly  
disagree  
☐

Slightly  
agree  
☐

Moderately  
agree  
☐

Strongly  
agree  
☐

P3\_Q315\_t1

**315. When I compare myself to friends and acquaintances, it makes me feel good about who I am.**

Strongly  
disagree  
☐

Moderately  
disagree  
☐

Slightly  
disagree  
☐

Slightly  
agree  
☐

Moderately  
agree  
☐

Strongly  
agree  
☐

## Personality

### (USE SHOWCARD 3D)

On the following pages, there are phrases describing people's behaviours. Please indicate how accurately each statement describes you. Describe yourself as you generally are now, not as you wish to be in the future. Describe yourself as you honestly see yourself, in relation to other people you know of the same sex as you are, and roughly the same age as you.

P3\_Q316\_t1

**316. I am the life of the party.**

Very  
inaccurate

Moderately  
inaccurate

Neither  
inaccurate  
nor accurate

Moderately  
accurate

Very  
accurate

☐
☐
☐
☐
☐

P3\_Q317\_t1

**317. I sympathise with others' feelings.**

Very  
inaccurate

Moderately  
inaccurate

Neither  
inaccurate  
nor accurate

Moderately  
accurate

Very  
accurate

☐
☐
☐
☐
☐

P3\_Q318\_t1

**318. I get chores done right away.**

Very  
inaccurate

Moderately  
inaccurate

Neither  
inaccurate  
nor accurate

Moderately  
accurate

Very  
accurate

☐
☐
☐
☐
☐

P3\_Q319\_t1

**319. I have frequent mood swings.**

Very  
inaccurate

Moderately  
inaccurate

Neither  
inaccurate  
nor accurate

Moderately  
accurate

Very  
accurate

☐
☐
☐
☐
☐

P3\_Q320\_t1

**320. I have a vivid imagination.**

Very  
inaccurate

Moderately  
inaccurate

Neither  
inaccurate  
nor accurate

Moderately  
accurate

Very  
accurate

☐
☐
☐
☐
☐

P3\_Q321\_t1

**321. I don't talk a lot.**

Very  
inaccurate

Moderately  
inaccurate

Neither  
inaccurate  
nor accurate

Moderately  
accurate

Very  
accurate

☐
☐
☐
☐
☐

P3\_Q322\_t1

**322. I am not interested in other people's problems.**

Very  
inaccurate

Moderately  
inaccurate

Neither  
inaccurate  
nor accurate

Moderately  
accurate

Very  
accurate

☐
☐
☐
☐
☐

P3\_Q323\_t1

**323. I often forget to put things back in their proper place.**

Very  
inaccurate

Moderately  
inaccurate

Neither  
inaccurate  
nor accurate

Moderately  
accurate

Very  
accurate

☐
☐
☐
☐
☐



P3\_Q324\_t1

**324. I am relaxed most of the time.**Very  
inaccurate☐Moderately  
inaccurate☐Neither  
inaccurate  
nor accurate☐Moderately  
accurate☐Very  
accurate☐

Instructions for the researcher: If required, a definition of 'abstract ideas' would be an idea or concept that is theoretical and impossible to physically see or touch. An example of an abstract idea is 'time'.

P3\_Q325\_t1

**325. I am not interested in abstract ideas.**Very  
inaccurate☐Moderately  
inaccurate☐Neither  
inaccurate  
nor accurate☐Moderately  
accurate☐Very  
accurate☐

P3\_Q326\_t1

**326. I talk to a lot of different people at parties.**Very  
inaccurate☐Moderately  
inaccurate☐Neither  
inaccurate  
nor accurate☐Moderately  
accurate☐Very  
accurate☐

P3\_Q327\_t1

**327. I feel others' emotions.**Very  
inaccurate☐Moderately  
inaccurate☐Neither  
inaccurate  
nor accurate☐Moderately  
accurate☐Very  
accurate☐

P3\_Q328\_t1

**328. I like order.**Very  
inaccurate☐Moderately  
inaccurate☐Neither  
inaccurate  
nor accurate☐Moderately  
accurate☐Very  
accurate☐

P3\_Q329\_t1

**329. I get upset easily.**Very  
inaccurate☐Moderately  
inaccurate☐Neither  
inaccurate  
nor accurate☐Moderately  
accurate☐Very  
accurate☐

P3\_Q330\_t1

**330. I have difficulty understanding abstract ideas.**Very  
inaccurate☐Moderately  
inaccurate☐Neither  
inaccurate  
nor accurate☐Moderately  
accurate☐Very  
accurate☐

P3\_Q331\_t1

**331. I keep in the background.**Very  
inaccurate☐Moderately  
inaccurate☐Neither  
inaccurate  
nor accurate☐Moderately  
accurate☐Very  
accurate☐

P3\_Q332\_t1

**332. I am not really interested in others.**Very  
inaccurateModerately  
inaccurateNeither  
inaccurate  
nor accurateModerately  
accurateVery  
accurate☐☐☐☐☐

P3\_Q333\_t1

**333. I make a mess of things.**Very  
inaccurateModerately  
inaccurateNeither  
inaccurate  
nor accurateModerately  
accurateVery  
accurate☐☐☐☐☐

P3\_Q334\_t1

**334. I seldom feel blue.**Very  
inaccurateModerately  
inaccurateNeither  
inaccurate  
nor accurateModerately  
accurateVery  
accurate☐☐☐☐☐

P3\_Q335\_t1

**335. I do not have a good imagination.**Very  
inaccurateModerately  
inaccurateNeither  
inaccurate  
nor accurateModerately  
accurateVery  
accurate☐☐☐☐☐**Green/blue spaces**

*I'm going to ask you some questions about your immediate neighbourhood, by which I mean your street or surrounding area.*

**(USE SHOWCARD 3E)**

**336. Here is a list of natural green spaces (e.g. parks, woodlands) or blue spaces (e.g. lakes, rivers). We are interested in whether you live within a ten-minute walk of any green or blue spaces. Please tell me whether or not you live within a ten-minute walk of each of these places on this card.**

Instructions for the researcher: Please cross all that the participant says applies to him/her.

P3\_Q336\_1\_t1

☐ Countryside

P3\_Q336\_2\_t1

☐ Woodlands

P3\_Q336\_3\_t1

☐ Parks and gardens

P3\_Q336\_4\_t1

☐ Country parks

P3\_Q336\_5\_t1

☐ Green corridors (e.g. river banks or roadside grass verges)

P3\_Q336\_6\_t1

☐ Outdoor sports facilities

P3\_Q336\_7\_t1

☐ Amenity green space (e.g. public playing fields or football pitches etc.)

P3\_Q336\_8\_t1

☐ Play areas

P3\_Q336\_9\_t1

☐ Allotments, community gardens and urban farms

P3\_Q336\_10\_t1

☐ Cemeteries and churchyards

P3\_Q336\_11\_t1

☐ River, lake or canal

P3\_Q336\_12\_t1

☐ Sea

P3\_Q336\_13\_t1

☐ None of the above

P3\_Q336\_14\_t1

☐ Don't know (record if given as a spontaneous response)

**337. How satisfied are you with your neighbourhood as a place to live?**

- |                          |                          |  |                          |                          |   |
|--------------------------|--------------------------|--|--------------------------|--------------------------|---|
| Very<br>dissatisfied     | Fairly<br>dissatisfied   | Neither<br>satisfied nor<br>dissatisfied | Slightly<br>satisfied    | Very<br>satisfied        | (record if given as<br>a spontaneous<br>response)<br>Don't know |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>                 | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |

P3\_Q338\_t1

### Social Capital

**338. Suppose you lost your purse or wallet containing your address details, and it was found in the street by someone living in this neighbourhood. How likely is it that it would be returned to you with nothing missing?**

- |                          |                          |                          |                          |   |
|--------------------------|--------------------------|--------------------------|--------------------------|---|
| Very likely              | Quite likely             | Not very<br>likely       | Not at all<br>likely     | (record if given as<br>a spontaneous<br>response)<br>Don't know |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>  |

### (USE SHOWCARD 3F)

*I am going to read out a list of problems which some people face in their neighbourhood. For each one, please can you tell me how much of a problem it is for you.*

P3\_Q339\_t1

**339. How much of a problem are people being drunk or rowdy in public places in your neighbourhood?**

- |   |   |
|---|---|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all                                   |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem                      |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q340\_t1

**340. How much of a problem is rubbish or litter lying around in your neighbourhood?**

- |   |   |
|---|---|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all                                   |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem                      |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q341\_t1

**341. How much of a problem are vandalism, graffiti and other deliberate damage to property or vehicles in your neighbourhood?**

- |   |   |
|---|---|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all                                   |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem                      |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q342\_t1

**342. How much of a problem are people using or dealing drugs in your neighbourhood?**

- |   |   |
|---|---|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all                                   |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem                      |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q343\_t1

**343. How much of a problem is people being attacked or harassed because of their skin colour, ethnic origin or religion in your neighbourhood?**

- |   |   |
|---|---|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all                                   |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem                      |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q344\_t1

**344. How much of a problem are teenagers hanging around on the street in your neighbourhood?**

- |   |   |
|---|---|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all                                   |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem                      |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q345\_t1

**345. How much of a problem are troublesome neighbours in your neighbourhood?**

- |   |   |
|---|---|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all                                   |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem                      |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q346\_t1

**346. In your neighbourhood to what extent do you agree or disagree that people are willing to help their neighbours?**

- ☐ Strongly disagree
- ☐ Slightly disagree
- ☐ Neither agree nor disagree
- ☐ Slightly agree
- ☐ Strongly agree
- ☐ Don't know/No opinion (record if given as a spontaneous response)
- ☐ Refused (record if given as a spontaneous response)

**(USE SHOWCARD 3G)**

**347. In the last 12 months have you taken any of the following actions in an attempt to solve a problem affecting people in your local area?**

Instructions for the researcher: Please cross all that the participant says applies to him/her.

- ☐ Contacted a local radio station, television station or newspaper
- ☐ Contacted the appropriate organisation to deal with the problem, such as the council
- ☐ Contacted a local councillor or member of parliament
- ☐ Attended a public meeting or neighbourhood forum to discuss local issues
- ☐ Attended a tenants' or local residents' group
- ☐ Attended a protest meeting or joined an action group
- ☐ Helped organise a petition on a local issue
- ☐ No local problems
- ☐ None of the above
- ☐ Don't know (record if given as a spontaneous response)

## Social activities

(USE SHOWCARD 3H)

The next few questions are about how often you personally contact relatives, friends and neighbours.

P3\_Q348\_t1

**348. How often do you speak to relatives on the phone?**

- |  |   |
|--|---|
| <input type="checkbox"/> On most days          | <input type="checkbox"/> Less often than once a month                           |
| <input type="checkbox"/> Once or twice a week  | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once or twice a month | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q349\_t1

**349. How often do you write a letter or note to relatives?**

- |  |   |
|--|---|
| <input type="checkbox"/> On most days          | <input type="checkbox"/> Less often than once a month                           |
| <input type="checkbox"/> Once or twice a week  | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once or twice a month | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q350\_t1

**350. How often do you text or email relatives, or use the internet to talk to relatives (e.g. FaceTime, Skype, chatrooms)?**

- |  |   |
|--|---|
| <input type="checkbox"/> On most days          | <input type="checkbox"/> Less often than once a month                           |
| <input type="checkbox"/> Once or twice a week  | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once or twice a month | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q351\_t1

**351. How often do you speak to friends on the phone?**

- |  |   |
|--|---|
| <input type="checkbox"/> On most days          | <input type="checkbox"/> Less often than once a month                           |
| <input type="checkbox"/> Once or twice a week  | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once or twice a month | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q352\_t1

**352. How often do you write a letter or note to friends?**

- |  |   |
|--|---|
| <input type="checkbox"/> On most days          | <input type="checkbox"/> Less often than once a month                           |
| <input type="checkbox"/> Once or twice a week  | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once or twice a month | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q353\_t1

**353. How often do you text or email friends, or use the internet to talk to friends (e.g. FaceTime, Skype, chatrooms)?**

- |  |   |
|--|---|
| <input type="checkbox"/> On most days          | <input type="checkbox"/> Less often than once a month                           |
| <input type="checkbox"/> Once or twice a week  | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once or twice a month | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q354\_t1

**354. How often do you speak to neighbours?**

- |  |   |
|--|---|
| <input type="checkbox"/> On most days          | <input type="checkbox"/> Less often than once a month                           |
| <input type="checkbox"/> Once or twice a week  | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once or twice a month | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q355\_t1

**355. How often do you meet up with relatives who are not living with you?**

- |  |   |
|--|---|
| <input type="checkbox"/> On most days          | <input type="checkbox"/> Less often than once a month                           |
| <input type="checkbox"/> Once or twice a week  | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once or twice a month | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

P3\_Q356\_t1

**356. How often do you meet up with friends?**

- |  |   |
|--|---|
| <input type="checkbox"/> On most days          | <input type="checkbox"/> Less often than once a month                           |
| <input type="checkbox"/> Once or twice a week  | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once or twice a month | <input type="checkbox"/> Don't know (record if given as a spontaneous response) |

**(USE SHOWCARD 3I)**

**357. During the last 12 months have you given any unpaid help to any groups, clubs or organisations in any of the ways listed below?**

Instructions for the researcher: Please cross all that the participant says applies to him/her.

P3\_Q357\_1\_t1

- ☐ Raising or handling money/taking part in sponsored events

P3\_Q357\_2\_t1

- ☐ Leading the group/member of a committee

P3\_Q357\_3\_t1

- ☐ Organising or helping to run an activity or event

P3\_Q357\_4\_t1

- ☐ Visiting people

P3\_Q357\_5\_t1

- ☐ Befriending or mentoring people

P3\_Q357\_6\_t1

- ☐ Giving advice/information/counselling

P3\_Q357\_7\_t1

- ☐ Secretarial, admin or clerical work

P3\_Q357\_8\_t1

- ☐ Providing transport/driving

P3\_Q357\_9\_t1

- ☐ Representing (e.g. addressing meetings, leading a delegation, talking to a council official)

P3\_Q357\_10\_t1

- ☐ Campaigning

P3\_Q357\_11\_t1

- ☐ Other practical help (e.g. helping out at school, religious group, shopping)

P3\_Q357\_12\_t1

- ☐ Any other help

P3\_Q357\_13\_t1

- ☐ None of the above

P3\_Q357\_14\_t1

- ☐ Don't know (record if given as a spontaneous response)

**Cultural activities**

**(USE SHOWCARD 3J)**

*I am going to read a list of places you might go. Please say how often you visit each place.*

P3\_Q358\_t1

**358. How often do you go to the cinema?**

- |   |  |
|---|--|
| <input type="checkbox"/> At least once a week                         | <input type="checkbox"/> Once a year or less |
| <input type="checkbox"/> Less often but at least once a month         | <input type="checkbox"/> Never               |
| <input type="checkbox"/> Less often but at least several times a year |  |

P3\_Q359\_t1

**359. How often do you go to museums?**

- |   |  |
|---|--|
| <input type="checkbox"/> At least once a week                         | <input type="checkbox"/> Once a year or less |
| <input type="checkbox"/> Less often but at least once a month         | <input type="checkbox"/> Never               |
| <input type="checkbox"/> Less often but at least several times a year |  |

P3\_Q360\_t1

**360. How often do you go to pubs?**☐ At least once a week☐ Once a year or less☐ Less often but at least once a month☐ Never☐ Less often but at least several times a year

P3\_Q361\_t1

**361. How often do you go to rock concerts?**☐ At least once a week☐ Once a year or less☐ Less often but at least once a month☐ Never☐ Less often but at least several times a year

P3\_Q362\_t1

**362. How often do you go to the opera?**☐ At least once a week☐ Once a year or less☐ Less often but at least once a month☐ Never☐ Less often but at least several times a year

P3\_Q363\_t1

**363. How often do you go to bingo?**☐ At least once a week☐ Once a year or less☐ Less often but at least once a month☐ Never☐ Less often but at least several times a year

P3\_Q364\_t1

**364. How often do you go to orchestral or choral concerts?**☐ At least once a week☐ Once a year or less☐ Less often but at least once a month☐ Never☐ Less often but at least several times a year

P3\_Q365\_t1

**365. How often do you go to stately homes or historic sites?**☐ At least once a week☐ Once a year or less☐ Less often but at least once a month☐ Never☐ Less often but at least several times a year

P3\_Q366\_t1

**366. How often do you go to musicals?**☐ At least once a week☐ Once a year or less☐ Less often but at least once a month☐ Never☐ Less often but at least several times a year

P3\_Q367\_t1

**367. How often do you go to the theatre?**☐ At least once a week☐ Once a year or less☐ Less often but at least once a month☐ Never☐ Less often but at least several times a year

P3\_Q368\_t1

**368. How often do you go to art galleries?**☐ At least once a week☐ Once a year or less☐ Less often but at least once a month☐ Never☐ Less often but at least several times a year

P3\_Q369\_t1

**369. How often do you go to night clubs?**

- ☐ At least once a week ☐ Once a year or less
- ☐ Less often but at least once a month ☐ Never
- ☐ Less often but at least several times a year

P3\_Q370\_t1

**370. How often do you go somewhere to eat out?**

- ☐ At least once a week ☐ Once a year or less
- ☐ Less often but at least once a month ☐ Never
- ☐ Less often but at least several times a year

**Available resources (Resource Generator)****(USE SHOWCARD 3K)**

*These questions are about the size and quality of your social network.*

*The following questions are about the people you currently know. These might be family members, friends or acquaintances, but they do **not** include friends of friends or people that you are not personally in contact with. The questions will ask if you currently know someone with a particular skill or resource. If you know someone with more than one skill or resource you can refer to this person more than once.*

*Do you personally know anyone with the skill or resource listed below that you are able to gain access to **within one week** if you needed it? Please answer all these questions, even if you possess the skill or resource yourself or if you have never needed to ask for it before. You will be asked about your skills later on.*

Instructions for the researcher: If the answer is 'yes', please cross all that the participant says applies to him/her.

P3\_Q371\_1\_t1

**371. Do you currently have access to someone who can repair a broken-down car?**

- ☐ No
- ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague
- ☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

P3\_Q372\_1\_t1

**372. Do you currently have access to someone who is a reliable tradesperson (e.g. plumber, electrician)?**

- ☐ No
- ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague
- ☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

P3\_Q373\_1\_t1

**373. Do you currently have access to someone who can speak another language fluently?**

- ☐ No
- ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague
- ☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance



Instructions for the researcher: If the answer is 'yes', please cross all that the participant says applies to him/her.

P3\_Q374\_1\_t1

**374. Do you currently have access to someone who knows how to fix problems with computers?**

☐ No

P3\_Q374\_2\_t1

☐ Yes, immediate family

P3\_Q374\_3\_t1

☐ Yes, wider family

P3\_Q374\_4\_t1

☐ Yes, friend

P3\_Q374\_5\_t1

☐ Yes, neighbour

P3\_Q374\_6\_t1

☐ Yes, colleague

P3\_Q374\_7\_t1

☐ Yes, acquaintance

P3\_Q375\_1\_t1

**375. Do you currently have access to someone who is good at gardening?**

☐ No

P3\_Q375\_2\_t1

☐ Yes, immediate family

P3\_Q375\_3\_t1

☐ Yes, wider family

P3\_Q375\_4\_t1

☐ Yes, friend

P3\_Q375\_5\_t1

☐ Yes, neighbour

P3\_Q375\_6\_t1

☐ Yes, colleague

P3\_Q375\_7\_t1

☐ Yes, acquaintance

P3\_Q376\_1\_t1

**376. Do you currently have access to someone who has a professional occupation?**

☐ No

P3\_Q376\_2\_t1

☐ Yes, immediate family

P3\_Q376\_3\_t1

☐ Yes, wider family

P3\_Q376\_4\_t1

☐ Yes, friend

P3\_Q376\_5\_t1

☐ Yes, neighbour

P3\_Q376\_6\_t1

☐ Yes, colleague

P3\_Q376\_7\_t1

☐ Yes, acquaintance

P3\_Q377\_1\_t1

**377. Do you currently have access to someone who is a local councillor?**

☐ No

P3\_Q377\_2\_t1

☐ Yes, immediate family

P3\_Q377\_3\_t1

☐ Yes, wider family

P3\_Q377\_4\_t1

☐ Yes, friend

P3\_Q377\_5\_t1

☐ Yes, neighbour

P3\_Q377\_6\_t1

☐ Yes, colleague

P3\_Q377\_7\_t1

☐ Yes, acquaintance

P3\_Q378\_1\_t1

**378. Do you currently have access to someone who works for your local council?**

☐ No

P3\_Q378\_2\_t1

☐ Yes, immediate family

P3\_Q378\_3\_t1

☐ Yes, wider family

P3\_Q378\_4\_t1

☐ Yes, friend

P3\_Q378\_5\_t1

☐ Yes, neighbour

P3\_Q378\_6\_t1

☐ Yes, colleague

P3\_Q378\_7\_t1

☐ Yes, acquaintance

P3\_Q379\_1\_t1

**379. Do you currently have access to someone who can sometimes employ people?**

☐ No

P3\_Q379\_2\_t1

☐ Yes, immediate family

P3\_Q379\_3\_t1

☐ Yes, wider family

P3\_Q379\_4\_t1

☐ Yes, friend

P3\_Q379\_5\_t1

☐ Yes, neighbour

P3\_Q379\_6\_t1

☐ Yes, colleague

P3\_Q379\_7\_t1

☐ Yes, acquaintance

P3\_Q380\_1\_t1

**380. Do you currently have access to someone who knows a lot about government regulations?**

☐ No

P3\_Q380\_2\_t1

☐ Yes, immediate family

P3\_Q380\_3\_t1

☐ Yes, wider family

P3\_Q380\_4\_t1

☐ Yes, friend

P3\_Q380\_5\_t1

☐ Yes, neighbour

P3\_Q380\_6\_t1

☐ Yes, colleague

P3\_Q380\_7\_t1

☐ Yes, acquaintance

Instructions for the researcher: If the answer is 'yes', please cross all that the participant says applies to him/her.

P3\_Q381\_1\_t1

**381. Do you currently have access to someone who has good contacts with the local newspaper, radio or TV?**

☐ No

P3\_Q381\_2\_t1

☐ Yes, immediate family

P3\_Q381\_4\_t1

☐ Yes, friend

P3\_Q381\_6\_t1

☐ Yes, colleague

P3\_Q381\_3\_t1

☐ Yes, wider family

P3\_Q381\_5\_t1

☐ Yes, neighbour

P3\_Q381\_7\_t1

☐ Yes, acquaintance

P3\_Q382\_1\_t1

**382. Do you currently have access to someone who knows a lot about health and fitness?**

☐ No

P3\_Q382\_2\_t1

☐ Yes, immediate family

P3\_Q382\_4\_t1

☐ Yes, friend

P3\_Q382\_6\_t1

☐ Yes, colleague

P3\_Q382\_3\_t1

☐ Yes, wider family

P3\_Q382\_5\_t1

☐ Yes, neighbour

P3\_Q382\_7\_t1

☐ Yes, acquaintance

P3\_Q383\_1\_t1

**383. Do you currently have access to someone who knows a lot about DIY?**

☐ No

P3\_Q383\_2\_t1

☐ Yes, immediate family

P3\_Q383\_4\_t1

☐ Yes, friend

P3\_Q383\_6\_t1

☐ Yes, colleague

P3\_Q383\_3\_t1

☐ Yes, wider family

P3\_Q383\_5\_t1

☐ Yes, neighbour

P3\_Q383\_7\_t1

☐ Yes, acquaintance

*If you need someone to help you in the following areas, would you be able to obtain this help from anyone **within one week**? Please answer all these questions, even if you have never needed to ask for such help before.*

Instructions for the researcher: If the answer is 'yes', please cross all that the participant says applies to him/her.

P3\_Q384\_1\_t1

**384. Do you currently personally know anyone who would give you sound advice about money problems?**

☐ No

P3\_Q384\_2\_t1

☐ Yes, immediate family

P3\_Q384\_4\_t1

☐ Yes, friend

P3\_Q384\_6\_t1

☐ Yes, colleague

P3\_Q384\_3\_t1

☐ Yes, wider family

P3\_Q384\_5\_t1

☐ Yes, neighbour

P3\_Q384\_7\_t1

☐ Yes, acquaintance

P3\_Q385\_1\_t1

**385. Do you currently personally know anyone who would give you sound advice on problems at work?**

☐ No

P3\_Q385\_2\_t1

☐ Yes, immediate family

P3\_Q385\_4\_t1

☐ Yes, friend

P3\_Q385\_6\_t1

☐ Yes, colleague

P3\_Q385\_3\_t1

☐ Yes, wider family

P3\_Q385\_5\_t1

☐ Yes, neighbour

P3\_Q385\_7\_t1

☐ Yes, acquaintance

P3\_Q386\_1\_t1

**386. Do you currently personally know anyone who would help you to move or dispose of bulky items (e.g. lifting or use of a van)?**

☐ No

P3\_Q386\_2\_t1

☐ Yes, immediate family

P3\_Q386\_4\_t1

☐ Yes, friend

P3\_Q386\_6\_t1

☐ Yes, colleague

P3\_Q386\_3\_t1

☐ Yes, wider family

P3\_Q386\_5\_t1

☐ Yes, neighbour

P3\_Q386\_7\_t1

☐ Yes, acquaintance

Instructions for the researcher: If the answer is 'yes', please cross all that the participant says applies to him/her.

**387. Do you currently personally know anyone who would help you with small jobs around the house?**

☐ No

☐ Yes, immediate family

☐ Yes, wider family

☐ Yes, friend

☐ Yes, neighbour

☐ Yes, colleague

☐ Yes, acquaintance

**388. Do you currently personally know anyone who would do your shopping if you are ill?**

☐ No

☐ Yes, immediate family

☐ Yes, wider family

☐ Yes, friend

☐ Yes, neighbour

☐ Yes, colleague

☐ Yes, acquaintance

**389. Do you currently personally know anyone who would lend you a small amount of money (e.g. for a local taxi fare)?**

☐ No

☐ Yes, immediate family

☐ Yes, wider family

☐ Yes, friend

☐ Yes, neighbour

☐ Yes, colleague

☐ Yes, acquaintance

**390. Do you currently personally know anyone who would give you careers advice?**

☐ No

☐ Yes, immediate family

☐ Yes, wider family

☐ Yes, friend

☐ Yes, neighbour

☐ Yes, colleague

☐ Yes, acquaintance

**391. Do you currently personally know anyone who would discuss politics with you?**

☐ No

☐ Yes, immediate family

☐ Yes, wider family

☐ Yes, friend

☐ Yes, neighbour

☐ Yes, colleague

☐ Yes, acquaintance

**392. Do you currently personally know anyone who would give you sound legal advice?**

☐ No

☐ Yes, immediate family

☐ Yes, wider family

☐ Yes, friend

☐ Yes, neighbour

☐ Yes, colleague

☐ Yes, acquaintance

**393. Do you currently personally know anyone who would give you a good reference for a job?**

☐ No

☐ Yes, immediate family

☐ Yes, wider family

☐ Yes, friend

☐ Yes, neighbour

☐ Yes, colleague

☐ Yes, acquaintance

Instructions for the researcher: If the answer is 'yes', please cross all that the participant says applies to him/her.

P3\_Q394\_1\_t1

**394. Do you currently personally know anyone who would get you cheap goods or 'bargains'?**

☐ No

P3\_Q394\_2\_t1

☐ Yes, immediate family

P3\_Q394\_4\_t1

☐ Yes, friend

P3\_Q394\_6\_t1

☐ Yes, colleague

P3\_Q394\_3\_t1

☐ Yes, wider family

P3\_Q394\_5\_t1

☐ Yes, neighbour

P3\_Q394\_7\_t1

☐ Yes, acquaintance

P3\_Q395\_1\_t1

**395. Do you currently personally know anyone who would help you to find somewhere to live if you had to move home?**

☐ No

P3\_Q395\_2\_t1

☐ Yes, immediate family

P3\_Q395\_4\_t1

☐ Yes, friend

P3\_Q395\_6\_t1

☐ Yes, colleague

P3\_Q395\_3\_t1

☐ Yes, wider family

P3\_Q395\_5\_t1

☐ Yes, neighbour

P3\_Q395\_7\_t1

☐ Yes, acquaintance

P3\_Q396\_1\_t1

**396. Do you currently personally know anyone who would lend you a large amount of money (e.g. for a deposit on a flat or house)?**

☐ No

P3\_Q396\_2\_t1

☐ Yes, immediate family

P3\_Q396\_4\_t1

☐ Yes, friend

P3\_Q396\_6\_t1

☐ Yes, colleague

P3\_Q396\_3\_t1

☐ Yes, wider family

P3\_Q396\_5\_t1

☐ Yes, neighbour

P3\_Q396\_7\_t1

☐ Yes, acquaintance

P3\_Q397\_1\_t1

**397. Do you currently personally know anyone who would look after your home or pets if you go away?**

☐ No

P3\_Q397\_2\_t1

☐ Yes, immediate family

P3\_Q397\_4\_t1

☐ Yes, friend

P3\_Q397\_6\_t1

☐ Yes, colleague

P3\_Q397\_3\_t1

☐ Yes, wider family

P3\_Q397\_5\_t1

☐ Yes, neighbour

P3\_Q397\_7\_t1

☐ Yes, acquaintance

*About you: now we would like to know about your skills. The answers are either yes or no.*

P3\_Q398\_t1

**398. Are you able to repair a broken-down car?**

☐ No ☐ Yes

P3\_Q399\_t1

**399. Are you a tradesperson (e.g. plumber, electrician)?**

☐ No ☐ Yes

P3\_Q400\_t1

**400. Are you able to speak another language fluently?**

☐ No ☐ Yes

P3\_Q401\_t1

**401. Are you knowledgeable about fixing problems with computers?**

☐ No ☐ Yes

P3\_Q402\_t1

**402. Are you good at gardening?**

☐ No ☐ Yes

P3\_Q403\_t1

**403. Are you someone with a professional occupation?**

☐ No ☐ Yes

P3\_Q404\_t1

404. Are you a local councillor?

☐ No ☐ Yes

P3\_Q405\_t1

405. Are you working for your local council?

☐ No ☐ Yes

P3\_Q406\_t1

406. Are you able to sometimes employ people?

☐ No ☐ Yes

P3\_Q407\_t1

407. Are you knowledgeable about government regulations?

☐ No ☐ Yes

P3\_Q408\_t1

408. Are you someone with good contacts with a local newspaper, radio or TV?

☐ No ☐ Yes

P3\_Q409\_t1

409. Are you knowledgeable about health and fitness?

☐ No ☐ Yes

P3\_Q410\_t1

410. Are you knowledgeable about DIY?

☐ No ☐ Yes*This is the section where you can add comments about anything.*Instructions for the researcher: These questions are optional.

P3\_Q411\_t1

411. Is there anything else you would like to tell us about today?

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P3\_Q412\_t1

412. What does living well mean for you?

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P3\_Q413\_t1

**413. Are there any things that you can think of that would make your life any easier at the moment?**

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P3\_Q414\_t1

**414. Are there any additional support or services that you feel you need at the moment or that you may need in the future?**

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P3\_Q415\_t1

**415. What do you think could be changed in the local community to enable people like yourself to 'live well'?**

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Instructions for the researcher: If the participant does not have a relative/friend for the study skip to the next page (Section B), otherwise say this before moving to the next page:

**Thank you for taking the time to answer these questions. In the next section I am going to ask both you and [your relative/friend] to answer some questions together.**

## Section B

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Instructions for the researcher: This section of the questionnaire is to be completed with both the study participant and his/her relative/friend providing the information. If the participant does not have a relative/friend, complete the questionnaire with just the study participant.

### Health conditions

1. We are interested in whether [you/the study participant] has any current health conditions or is taking any medication for any condition. [Do you/does the study participant] have any of these conditions listed on this card.

Instructions for the researcher: Please cross all that the study participant, and his/her relative/friend if applicable, says that applies to the study participant.

#### (USE SHOWCARD 3L)

- P3\_Q1\_1\_t1 ☐ Myocardial infarction (history of heart attacks)
- P3\_Q1\_2\_t1 ☐ Congestive heart failure
- P3\_Q1\_3\_t1 ☐ Hypertension (high blood pressure)
- P3\_Q1\_4\_t1 ☐ Diagnosed depression
- P3\_Q1\_5\_t1 ☐ Peripheral vascular disease (includes ☐ aortic aneurysm, ☐ poor circulation)
- P3\_Q1\_6\_t1 ☐ Cerebrovascular disease ( ☐ Stroke, ☐ CVA or ☐ TIA)
- P3\_Q1\_7\_t1 ☐ Dementia
- P3\_Q1\_8\_t1 ☐ Chronic bad chest (e.g. ☐ asthma, ☐ COPD; ☐ chronic bronchitis, ☐ emphysema)
- P3\_Q1\_9\_t1 ☐ Inflammation affecting the joints (e.g. ☐ lupus, ☐ rheumatoid arthritis, ☐ connective tissue disease, ☐ vasculitis)
- P3\_Q1\_10\_t1 ☐ Peptic/stomach ulcer disease
- P3\_Q1\_11\_t1 ☐ Skin ulcer ( ☐ bedsores, ☐ repeated cellulitis)
- P3\_Q1\_12\_t1 ☐ Diabetes controlled with insulin or equivalent
- P3\_Q1\_13\_t1 ☐ Diabetes with end-organ damage (e.g. ☐ damage to the retina, ☐ nerve damage, ☐ kidney damage, ☐ brittle diabetes)
- P3\_Q1\_14\_t1 ☐ Moderate or severe chronic kidney disease
- P3\_Q1\_15\_t1 ☐ Hemiplegia
- P3\_Q1\_16\_t1 ☐ Cancer within the last five years (e.g. ☐ breast, ☐ colon, ☐ prostate, ☐ lung, ☐ skin, ☐ blood (lymphoma), ☐ acute or chronic leukaemia)

If [you/the study participant] has been diagnosed with cancer within the last five years, has it spread to other areas (metastasised) ☐ No ☐ Yes

- P3\_Q1\_17\_t1 ☐ Mild liver disease (includes hepatitis ( ☐ B or ☐ C), ☐ cirrhosis)
- P3\_Q1\_18\_t1 ☐ Liver disease (moderate to severe: ☐ chronic jaundice, ☐ liver failure, ☐ liver transplant)
- P3\_Q1\_19\_t1 ☐ AIDS or HIV
- P3\_Q1\_20\_t1 ☐ None of the above or no health problems

- P3\_Q2\_t1 2. [Do you/does the study participant] take warfarin?

☐ No ☐ Yes

P3\_Q3\_1\_t1

3. [Do you/does the study participant] have any other major long term illnesses, health problems or disabilities?

☐ No ☐ Yes; please specify with diagnosis:

P3\_Q3\_2\_t1

### Sources of income

*We are interested in the relationship between income, health and well-being. For us to be able to look at this we have to get some idea of your household's income. All information will be treated as strictly confidential and will only be used for the purposes of the research. We will not share this information with anybody else.*

(USE SHOWCARD 3M)

4. Here are some various possible sources of income. Can you please tell me which kinds of income you [and your husband/wife/partner] receive?

Instructions for the researcher: Please cross all that the participant says applies to him/her.

P3\_Q4\_1\_t1

☐ Earnings from employment or self-employment

P3\_Q4\_2\_t1

☐ State retirement pension

P3\_Q4\_3\_t1

☐ Pension from former employer

P3\_Q4\_4\_t1

☐ Personal pension(s)

P3\_Q4\_5\_t1

☐ Job-seekers' allowance

P3\_Q4\_6\_t1

☐ Employment and support allowance

P3\_Q4\_7\_t1

☐ Income support

P3\_Q4\_8\_t1

☐ Attendance allowance (higher rate for attendance during day **AND** night)

P3\_Q4\_9\_t1

☐ Attendance allowance (lower rate for day **OR** night)

P3\_Q4\_10\_t1

☐ Pension credit

P3\_Q4\_11\_t1

☐ Working tax credit

P3\_Q4\_12\_t1

☐ Child tax credit

P3\_Q4\_13\_t1

☐ Child benefit

P3\_Q4\_14\_t1

☐ Housing benefit

P3\_Q4\_15\_t1

☐ Council tax benefit

P3\_Q4\_16\_t1

☐ Disability living allowance **OR** Personal Independence Payments – care component

P3\_Q4\_16a\_t1

P3\_Q4\_16b\_t1

P3\_Q4\_16c\_t1

☐ Highest rate ☐ Middle rate ☐ Lowest rate

P3\_Q4\_17\_t1

☐ Disability living allowance **OR** Personal Independence Payments – mobility component

P3\_Q4\_17a\_t1

P3\_Q4\_17b\_t1

☐ Highest rate ☐ Lower rate

P3\_Q4\_18\_t1

☐ Other state benefits

P3\_Q4\_19\_t1

☐ Interest from savings and investments (e.g. stocks & shares)

P3\_Q4\_20\_t1

☐ Other kinds of regular allowance from outside your household (e.g. maintenance, student's grants, rent)

P3\_Q4\_21\_t1

☐ No source of income



## Household income

P3\_Q5\_t1

## 5. Do you think about your household income in weekly, monthly or yearly terms?

(Instructions for the researcher: Give the appropriate SHOWCARD based on his/her response.)

Here are incomes in [weekly/monthly/annually] amounts. Which of the figures represents your [and your husband's/wife's/partner's] combined income from all sources, before any deductions for income tax, National Insurance, etc.?

Weekly (USE SHOWCARD 3N)	Monthly (USE SHOWCARD 3O)	Annually (USE SHOWCARD 3P)
<input type="checkbox"/> Less than £10	<input type="checkbox"/> Less than £40	<input type="checkbox"/> Less than £520
<input type="checkbox"/> £10 less than £30	<input type="checkbox"/> £40 less than £130	<input type="checkbox"/> £520 less than £1600
<input type="checkbox"/> £30 less than £50	<input type="checkbox"/> £130 less than £220	<input type="checkbox"/> £1600 less than £2,600
<input type="checkbox"/> £50 less than £70	<input type="checkbox"/> £220 less than £300	<input type="checkbox"/> £2600 less than £3,600
<input type="checkbox"/> £70 less than £100	<input type="checkbox"/> £300 less than £430	<input type="checkbox"/> £3600 less than £5,200
<input type="checkbox"/> £100 less than £150	<input type="checkbox"/> £430 less than £650	<input type="checkbox"/> £5200 less than £7,800
<input type="checkbox"/> £150 less than £200	<input type="checkbox"/> £650 less than £870	<input type="checkbox"/> £7800 less than £10400
<input type="checkbox"/> £200 less than £250	<input type="checkbox"/> £870 less than £1100	<input type="checkbox"/> £10400 less than £13000
<input type="checkbox"/> £250 less than £300	<input type="checkbox"/> £1100 less than £1300	<input type="checkbox"/> £13000 less than £15600
<input type="checkbox"/> £300 less than £350	<input type="checkbox"/> £1300 less than £1500	<input type="checkbox"/> £15600 less than £18200
<input type="checkbox"/> £350 less than £400	<input type="checkbox"/> £1500 less than £1700	<input type="checkbox"/> £18200 less than £20800
<input type="checkbox"/> £400 less than £450	<input type="checkbox"/> £1700 less than £2000	<input type="checkbox"/> £20800 less than £23400
<input type="checkbox"/> £450 less than £500	<input type="checkbox"/> £2000 less than £2200	<input type="checkbox"/> £23400 less than £26000
<input type="checkbox"/> £500 less than £550	<input type="checkbox"/> £2200 less than £2400	<input type="checkbox"/> £26000 less than £28600
<input type="checkbox"/> £550 less than £600	<input type="checkbox"/> £2400 less than £2600	<input type="checkbox"/> £28600 less than £31200
<input type="checkbox"/> £600 less than £650	<input type="checkbox"/> £2600 less than £2800	<input type="checkbox"/> £31200 less than £33800
<input type="checkbox"/> £650 less than £700	<input type="checkbox"/> £2800 less than £3000	<input type="checkbox"/> £33800 less than £36400
<input type="checkbox"/> £700 less than £800	<input type="checkbox"/> £3000 less than £3500	<input type="checkbox"/> £36400 less than £41600
<input type="checkbox"/> £800 less than £900	<input type="checkbox"/> £3500 less than £3900	<input type="checkbox"/> £41600 less than £46800
<input type="checkbox"/> £900 less than £1000	<input type="checkbox"/> £3900 less than £4300	<input type="checkbox"/> £46800 less than £52000
<input type="checkbox"/> £1000 less than £1150	<input type="checkbox"/> £4300 less than £5000	<input type="checkbox"/> £52000 less than £60000
<input type="checkbox"/> £1150 less than £1350	<input type="checkbox"/> £5000 less than £5800	<input type="checkbox"/> £60000 less than £70000
<input type="checkbox"/> £1350 less than £1550	<input type="checkbox"/> £5800 less than £6700	<input type="checkbox"/> £70000 less than £80000
<input type="checkbox"/> £1550 less than £1750	<input type="checkbox"/> £6700 less than £7500	<input type="checkbox"/> £80000 less than £90000
<input type="checkbox"/> £1750 less than £1900	<input type="checkbox"/> £7500 less than £8300	<input type="checkbox"/> £90000 less than £100000
<input type="checkbox"/> £1900 less than £2100	<input type="checkbox"/> £8300 less than £9200	<input type="checkbox"/> £100000 less than £110000
<input type="checkbox"/> £2100 less than £2300	<input type="checkbox"/> £9200 less than £10000	<input type="checkbox"/> £110000 less than £120000
<input type="checkbox"/> £2300 less than £2500	<input type="checkbox"/> £10000 less than £10800	<input type="checkbox"/> £120000 less than £130000
<input type="checkbox"/> £2500 less than £2700	<input type="checkbox"/> £10800 less than £11700	<input type="checkbox"/> £130000 less than £140000
<input type="checkbox"/> £2700 less than £2900	<input type="checkbox"/> £11700 less than £12500	<input type="checkbox"/> £140000 less than £150000
<input type="checkbox"/> £2900 or more	<input type="checkbox"/> £12500 or more	<input type="checkbox"/> £150000 or more

P3\_Q5\_1\_t1

☐ Refused to answer

Instructions for the researcher: Ask if there are other adults in the household. If there are ask this question, otherwise cross 'not applicable':

☐ Not applicable

6. If anyone else in the household has an income from any source, which of these figures represents their total income before deductions for income tax, National Insurance, etc. Here are incomes in [weekly/monthly/annually] amounts.

Weekly (USE SHOWCARD 3N)	Monthly (USE SHOWCARD 3O)	Annually (USE SHOWCARD 3P)
<input type="checkbox"/> Less than £10	<input type="checkbox"/> Less than £40	<input type="checkbox"/> Less than £520
<input type="checkbox"/> £10 less than £30	<input type="checkbox"/> £40 less than £130	<input type="checkbox"/> £520 less than £1600
<input type="checkbox"/> £30 less than £50	<input type="checkbox"/> £130 less than £220	<input type="checkbox"/> £1600 less than £2,600
<input type="checkbox"/> £50 less than £70	<input type="checkbox"/> £220 less than £300	<input type="checkbox"/> £2600 less than £3,600
<input type="checkbox"/> £70 less than £100	<input type="checkbox"/> £300 less than £430	<input type="checkbox"/> £3600 less than £5,200
<input type="checkbox"/> £100 less than £150	<input type="checkbox"/> £430 less than £650	<input type="checkbox"/> £5200 less than £7,800
<input type="checkbox"/> £150 less than £200	<input type="checkbox"/> £650 less than £870	<input type="checkbox"/> £7800 less than £10400
<input type="checkbox"/> £200 less than £250	<input type="checkbox"/> £870 less than £1100	<input type="checkbox"/> £10400 less than £13000
<input type="checkbox"/> £250 less than £300	<input type="checkbox"/> £1100 less than £1300	<input type="checkbox"/> £13000 less than £15600
<input type="checkbox"/> £300 less than £350	<input type="checkbox"/> £1300 less than £1500	<input type="checkbox"/> £15600 less than £18200
<input type="checkbox"/> £350 less than £400	<input type="checkbox"/> £1500 less than £1700	<input type="checkbox"/> £18200 less than £20800
<input type="checkbox"/> £400 less than £450	<input type="checkbox"/> £1700 less than £2000	<input type="checkbox"/> £20800 less than £23400
<input type="checkbox"/> £450 less than £500	<input type="checkbox"/> £2000 less than £2200	<input type="checkbox"/> £23400 less than £26000
<input type="checkbox"/> £500 less than £550	<input type="checkbox"/> £2200 less than £2400	<input type="checkbox"/> £26000 less than £28600
<input type="checkbox"/> £550 less than £600	<input type="checkbox"/> £2400 less than £2600	<input type="checkbox"/> £28600 less than £31200
<input type="checkbox"/> £600 less than £650	<input type="checkbox"/> £2600 less than £2800	<input type="checkbox"/> £31200 less than £33800
<input type="checkbox"/> £650 less than £700	<input type="checkbox"/> £2800 less than £3000	<input type="checkbox"/> £33800 less than £36400
<input type="checkbox"/> £700 less than £800	<input type="checkbox"/> £3000 less than £3500	<input type="checkbox"/> £36400 less than £41600
<input type="checkbox"/> £800 less than £900	<input type="checkbox"/> £3500 less than £3900	<input type="checkbox"/> £41600 less than £46800
<input type="checkbox"/> £900 less than £1000	<input type="checkbox"/> £3900 less than £4300	<input type="checkbox"/> £46800 less than £52000
<input type="checkbox"/> £1000 less than £1150	<input type="checkbox"/> £4300 less than £5000	<input type="checkbox"/> £52000 less than £60000
<input type="checkbox"/> £1150 less than £1350	<input type="checkbox"/> £5000 less than £5800	<input type="checkbox"/> £60000 less than £70000
<input type="checkbox"/> £1350 less than £1550	<input type="checkbox"/> £5800 less than £6700	<input type="checkbox"/> £70000 less than £80000
<input type="checkbox"/> £1550 less than £1750	<input type="checkbox"/> £6700 less than £7500	<input type="checkbox"/> £80000 less than £90000
<input type="checkbox"/> £1750 less than £1900	<input type="checkbox"/> £7500 less than £8300	<input type="checkbox"/> £90000 less than £100000
<input type="checkbox"/> £1900 less than £2100	<input type="checkbox"/> £8300 less than £9200	<input type="checkbox"/> £100000 less than £110000
<input type="checkbox"/> £2100 less than £2300	<input type="checkbox"/> £9200 less than £10000	<input type="checkbox"/> £110000 less than £120000
<input type="checkbox"/> £2300 less than £2500	<input type="checkbox"/> £10000 less than £10800	<input type="checkbox"/> £120000 less than £130000
<input type="checkbox"/> £2500 less than £2700	<input type="checkbox"/> £10800 less than £11700	<input type="checkbox"/> £130000 less than £140000
<input type="checkbox"/> £2700 less than £2900	<input type="checkbox"/> £11700 less than £12500	<input type="checkbox"/> £140000 less than £150000
<input type="checkbox"/> £2900 or more	<input type="checkbox"/> £12500 or more	<input type="checkbox"/> £150000 or more

☐ Don't know ☐ Refused to answer

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## Service use

Now we would like to know about the health care and support services that [the study participant] may have utilised recently.

P3\_Q7\_t1

7. Screening question: In the **last 3 months**, has [the study participant] been to hospital, for instance visited casualty or attended a clinic appointment (such as a memory clinic) or stayed overnight?

☐ No (skip to question 25; Primary Care section)

☐ Yes

## A&E

P3\_Q8\_1\_t1

8. Thinking about the **last 3 months**, has [the study participant] attended casualty/A&E as a patient?

☐ No (skip to question 11; in-patient section)

P3\_Q8\_2\_t1

☐ Yes; **approximately how many times did [the study participant] attend?**

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven or more; please specify number:

P3\_Q8\_3\_t1

P3\_Q9\_t1

9. **What was the reason for using the service; why did [the study participant] go? (condition, specialty)**

P3\_Q10\_1\_t1

10. Did [the study participant] ever travel to casualty/A&E by ambulance?

☐ No

☐ Yes; **approximately how many times?**

P3\_Q10\_2\_t1

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven or more; please specify number:

P3\_Q10\_3\_t1

## In-patient care

P3\_Q11\_1\_t1

11. Thinking about the **last 3 months**, how many times has [the study participant] been admitted to hospital as an in-patient overnight or longer?

☐ None (skip to question 20; out-patient section)

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven or more; please specify number:

P3\_Q11\_2\_t1

Instructions for the researcher: If more than four times please describe the **four most recent** occasions below.

P3\_Q12\_t1

12. **What was the reason for using the service for the most recent occasion? (condition, specialty)**

P3\_Q13\_1\_t1

13. How many days did [the study participant] spend in a hospital as an in-patient?

☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six

☐ Seven or more; please specify number: P3\_Q13\_2\_t1

P3\_Q14\_t1

14. What was the reason for using the service for the second most recent occasion?  
(condition, specialty)

P3\_Q15\_1\_t1

15. How many days did [the study participant] spend in a hospital as an in-patient?

☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six

☐ Seven or more; please specify number: P3\_Q15\_2\_t1

P3\_Q16\_t1

16. What was the reason for using the service for the third most recent occasion?  
(condition, specialty)

P3\_Q17\_1\_t1

17. How many days did [the study participant] spend in a hospital as an in-patient?

☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six

☐ Seven or more; please specify number: P3\_Q17\_2\_t1

P3\_Q18\_t1

18. What was the reason for using the service for the fourth most recent occasion?  
(condition, specialty)

P3\_Q19\_1\_t1

19. How many days did [the study participant] spend in a hospital as an in-patient?

☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six

☐ Seven or more; please specify number: P3\_Q19\_2\_t1
**Out-patient services**

P3\_Q20\_1\_t1

20. Thinking about the last 3 months, excluding visits to accident and emergency, approximately how many times has [the study participant] attended a hospital or clinic (such as a memory clinic) as an out-patient or day patient?
☐ None (skip to question 25; primary care section)

☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six

☐ Seven or more; please specify number: P3\_Q20\_2\_t1

Instructions for the researcher: If more than four times please describe the **four most recent** occasions below.

P3\_Q21\_t1

21. What was the reason for using the service for the **most recent occasion**? Please describe the reason for the visit (e.g. cardiology, hydrotherapy, memory clinic, day case surgery).

P3\_Q22\_t1

22. What was the reason for using the service for the **second most recent occasion**? Please describe the reason for the visit.

P3\_Q23\_t1

23. What was the reason for using the service for the **third most recent occasion**? Please describe the reason for the visit.

P3\_Q24\_t1

24. What was the reason for using the service for the **fourth most recent occasion**? Please describe the reason for the visit.

### **Primary care**

Thinking about the **last 3 months**, has [the study participant] used any of these services from his/her local surgery or health centre?

P3\_Q25\_1\_t1

25. Has [the study participant] seen a GP at the surgery?

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q25\_2\_t1
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P3\_Q25\_3\_t1

P3\_Q26\_1\_t1

26. Has [the study participant] seen a GP at home?

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q26\_2\_t1
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P3\_Q26\_3\_t1

P3\_Q27\_1\_t1

27. Has [the study participant] spoken to a GP on the telephone?

Instructions for the researcher: Please also include the number of times that [the relative/friend] has done this on the study participant's behalf.

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q27\_2\_t1
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P3\_Q27\_3\_t1

P3\_Q28\_1\_t1

28. Has [the study participant] seen a nurse at the surgery?

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q28\_2\_t1
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P3\_Q28\_3\_t1

## Community health and care

Now we would like to know about some community health and care services that people can make use of.

(USE SHOWCARD 3Q)

Thinking about the last 3 months, has [the study participant] seen any of the following in person?

P3\_Q29\_1\_t1

### 29. Community Nurse or District Nurse

☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q29\_2\_t1

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: P3\_Q29\_3\_t1

P3\_Q30\_1\_t1

### 30. Community Psychiatric Nurse or Community Mental Health Nurse

☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q30\_2\_t1

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: P3\_Q30\_3\_t1

P3\_Q31\_1\_t1

### 31. Psychiatrist

☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q31\_2\_t1

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: P3\_Q31\_3\_t1

P3\_Q32\_1\_t1

### 32. Social worker or care manager

☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q32\_2\_t1

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: P3\_Q32\_3\_t1

P3\_Q33\_1\_t1

### 33. Psychologist

☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q33\_2\_t1

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: P3\_Q33\_3\_t1

P3\_Q34\_1\_t1

### 34. Physiotherapist or Occupational therapist

☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q34\_2\_t1

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: P3\_Q34\_3\_t1

P3\_Q35\_1\_t1

### 35. Specialist nurse (e.g. Admiral Nurse, palliative care nurse, respiratory nurse)?

(Please specify: P3\_Q35\_4\_t1)

☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P3\_Q35\_2\_t1

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: P3\_Q35\_3\_t1

## Home help

The next few questions are about help that [the study participant] may have received in his/her home.

(USE SHOWCARD 3R)

In the last 3 months, has [the study participant] used any of these services on this card?

### 36. Home care/home help/support worker

☐ No (skip to question 37) ☐ Not sure

☐ Yes, **approximately how many times in the \*last 3 months**? P3\_Q36\_2\_t1

- ☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six  
☐ Thirteen    ☐ Twenty six    ☐ Thirty nine    ☐ Fifty two    ☐ Sixty five    ☐ Seventy eight  
☐ Ninety one (daily)    ☐ If other; please specify number: P3\_Q36\_oth\_t1

**Did you or a family member pay all or part of the costs for this service?**

☐ No    ☐ Yes, all    ☐ Yes, part

### 37. Cleaner

☐ No (skip to question 38) ☐ Not sure

☐ Yes, **approximately how many times in the last 3 months**? P3\_Q37\_2\_t1

- ☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six  
☐ Seven    ☐ Eight    ☐ Nine    ☐ Ten    ☐ Eleven    ☐ Twelve  
☐ Thirteen    ☐ If other; please specify number: P3\_Q37\_oth\_t1

**Did you or a family member pay all or part of the costs for this service?**

☐ No    ☐ Yes, all    ☐ Yes, part

### 38. Laundry service

☐ No (skip to question 39) ☐ Not sure

☐ Yes, **approximately how many times in the last 3 months**? P3\_Q38\_2\_t1

- ☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six  
☐ Seven    ☐ Eight    ☐ Nine    ☐ Ten    ☐ Eleven    ☐ Twelve  
☐ Thirteen    ☐ If other; please specify number: P3\_Q38\_oth\_t1

**Did you or a family member pay all or part of the costs for this service?**

☐ No    ☐ Yes, all    ☐ Yes, part

### 39. Meals on wheels

☐ No (skip to question 40) ☐ Not sure

☐ Yes, **approximately how many times in the \*last 3 months**? P3\_Q39\_2\_t1

- ☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six  
☐ Thirteen    ☐ Twenty six    ☐ Thirty nine    ☐ Fifty two    ☐ Sixty five    ☐ Seventy eight  
☐ Ninety one (daily)    ☐ If other; please specify number: P3\_Q39\_oth\_t1

**Did you or a family member pay all or part of the costs for this service?**

☐ No    ☐ Yes, all    ☐ Yes, part

**\*Useful numbers when calculating frequency of visits:**

- 3 months is equivalent to 13 weeks, or 91 days (all figures rounded)
- 2 contacts a week over 3 months is equivalent to 26 contacts
- A weekly contact over 3 months is equivalent to 13 contacts
- 3 contacts a week over 3 months is equivalent to 39 contacts
- A daily contact over 3 months is equivalent to 91 contacts
- 4 contacts a week over 3 months is equivalent to 52 contacts



P3\_Q40\_1\_t1

**40. Sitting service (e.g. Crossroads)**☐ No (skip to question 41) ☐ Not sure☐ Yes, **approximately how many times in the last 3 months?** P3\_Q40\_2\_t1

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six  
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen ☐ If other; please specify number: P3\_Q40\_oth\_t1

P3\_Q40\_4\_t1

**Did you or a family member pay all or part of the costs for this service?**☐ No ☐ Yes, all ☐ Yes, part

P3\_Q41\_1\_t1

**41. Carer support worker**☐ No (skip to question 42) ☐ Not sure☐ Yes, **approximately how many times in the last 3 months?** P3\_Q41\_2\_t1

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six  
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen ☐ If other; please specify number: P3\_Q41\_oth\_t1

P3\_Q41\_4\_t1

**Did you or a family member pay all or part of the costs for this service?**☐ No ☐ Yes, all ☐ Yes, part**Community services**

*Now we would like to know about whether [the study participant] has used various community services that may be available in some areas.*

P3\_Q42\_1\_t1

**42. In the last 3 months has [the study participant] attended a day centre?**☐ No (skip to question 43) ☐ YesIf yes, **approximately how many times a week does [the study participant] attend?** P3\_Q42\_2\_t1☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: P3\_Q42\_3\_t1

P3\_Q42\_4\_t1

If attending less often than once a week, **approximately how many times over the last 3 months did [the study participant] attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six  
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen or more; please specify number: P3\_Q42\_5\_t1

P3\_Q43\_1\_t1

**43. In the last 3 months has [the study participant] attended a lunch club?**☐ No (skip to question 44) ☐ YesIf yes, **approximately how many times a week does [the study participant] attend?** P3\_Q43\_2\_t1☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: P3\_Q43\_3\_t1

P3\_Q43\_4\_t1

If attending less often than once a week, **approximately how many times over the last 3 months did [the study participant] attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six  
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen or more; please specify number: P3\_Q43\_5\_t1



## Accommodation away from home

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P3\_Q44\_1\_t1

44. Has [the study participant] lived in a residential care home during the last 3 months?

☐ No (skip to question 45)

☐ Yes; **what was the reason for using the service?**

P3\_Q44\_2\_t1

**How many days did [the study participant] stay there?** P3\_Q44\_3\_t1

- ☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six  
☐ Seven    ☐ Fourteen    ☐ Twenty one    ☐ Twenty eight

☐ If other; please specify number: P3\_Q44\_3\_oth\_t1

P3\_Q44\_5\_t1

**Thinking about the residential care home was this run by:**

☐ a local authority/Social Services/Council

☐ the NHS

☐ a voluntary/charitable organisation

☐ a private company/organisation

☐ Other: P3\_Q44\_oth\_t1

P3\_Q44\_6\_t1

**Did [the study participant] or a family member pay all or part of the costs for this accommodation?**

☐ No    ☐ Yes, all    ☐ Yes, part

P3\_Q45\_1\_t1

45. Has [the study participant] lived in a nursing home during the last 3 months?

☐ No (skip to question 46)

☐ Yes; **what was the reason for using the service?**

P3\_Q45\_2\_t1

**How many days did [the study participant] stay there?** P3\_Q45\_3\_t1

- ☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Six  
☐ Seven    ☐ Fourteen    ☐ Twenty one    ☐ Twenty eight

☐ If other; please specify number: P3\_Q45\_3\_oth\_t1

P3\_Q45\_5\_t1

**Thinking about the nursing home was this run by:**

☐ a local authority/Social Services/Council

☐ the NHS

☐ a voluntary/charitable organisation

☐ a private company/organisation

☐ Other: P3\_Q45\_oth\_t1

P3\_Q45\_6\_t1

**Did [the study participant] or a family member pay all or part of the costs for this accommodation?**

☐ No    ☐ Yes, all    ☐ Yes, part

## Equipment and adaptations

### (USE SHOWCARD 3S)

Now we're going to ask about whether [the study participant] uses any of the following equipment or adaptations to the home.

Instructions for the researcher: For each item, cross the box for each type of equipment/adaptation the participant has used and ask e.g. 'did [the study participant] get this [electronic medication reminder dispenser] in the past year?' and 'who or which organisation paid for these?'. Please cross as many organisations as apply.

Type of adaptation or equipment	Cross if uses	Cross if received in past year	Who/which organisation paid for this?				
			Council	NHS	Volunt./ charity	Self	Other
P3_Q46[...] 46. Electronic medication reminder dispenser (do not include blister packs)	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q47[...] 47. Calendar clock	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q48[...] 48. Falls detector or falls alarm	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q49[...] 49. Community or personal alarm (including pull-cord and pendant alarms)	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q50[...] 50. Outdoor railing	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q51[...] 51. Grab rail/Stair rail	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q52[...] 52. Walking stick	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q53[...] 53. Walking frame	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q54[...] 54. Walk-in shower/shower cubicle replacing bath	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q55[...] 55. Over-bath shower	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q56[...] 56. Bath seat/shower seat	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q57[...] 57. Kitchen/perching stool	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q58[...] 58. Bed lever/rail	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q59[...] 59. Toilet frame/raised toilet seat	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q60[...] 60. Commode	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q61[...] 61. Continence pads	[...] 1_t1 <input type="checkbox"/>	[...] 2_t1 <input type="checkbox"/>	[...] 3_t1 <input type="checkbox"/>	[...] 4_t1 <input type="checkbox"/>	[...] 5_t1 <input type="checkbox"/>	[...] 6_t1 <input type="checkbox"/>	[...] 7_t1 <input type="checkbox"/>
P3_Q62_t1 62. Participant does not use any of the above	<input type="checkbox"/>						

The next few questions are about the help and support that people provide to [the study participant]

**63. Thinking about the last 3 months, in an average week, what tasks [do you/does relative/friend] usually help [the study participant] with?**

Instructions for the researcher: Please cross all that apply to the study participant

P3\_Q63\_1\_t1

☐ Personal care

P3\_Q63\_2\_t1

☐ Helping with finances

P3\_Q63\_3\_t1

☐ Practical help (housework, laundry)

P3\_Q63\_4\_t1

☐ Taking [the study participant] out to appointments (e.g. medical appointments)

P3\_Q63\_5\_t1

☐ Medications

P3\_Q63\_6\_t1

☐ Making sure [the study participant] is safe (supervision)

P3\_Q63\_7\_t1

☐ Other: P3\_Q63\_oth\_t1

P3\_Q64\_1\_t1

**64. In an average week, how much time does [relative/friend] spend looking after/providing help for [the study participant] with these kinds of tasks?**

Instructions for the researcher: Please cross only one box

☐ No help in the last week

☐ 5-8 hours

☐ 23-30 hours

☐ 50-99 hours

☐ Less than one hour

☐ 9-14 hours

☐ 31-49 hours

☐ 100 hours or more

☐ 1-4 hours

☐ 15-22 hours

☐ Other, describe P3\_Q64\_oth\_t1

P3\_Q65\_1\_t1

**65. In the last 3 months, have other friends or relatives regularly helped [the study participant] with tasks which s/he had difficulty with, or could not do?**

☐ No

☐ Yes

Thinking about an average week, and about all such carers, for how many hours a week do they usually help [the study participant]?

P3\_Q65\_2\_t1

P3\_Q66\_1\_t1

**66. Have any friends and relatives taken time off paid work over the last 3 months to help/provide care for [the study participant]?**

☐ No

☐ Yes

P3\_Q66\_2\_t1

Can you estimate the total number of days that relatives/friends have taken off work over the last 3 months to help/provide care for [the study participant]?

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven or more; please specify number: P3\_Q66\_3\_t1

### Medication

The next few questions are about the medication that [study participant] takes.

**67. How many different prescribed medications does [the study participant] take?**

☐ None (skip to question 71)

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven

☐ Eight

☐ Nine

☐ Ten

☐ Eleven

☐ Twelve

☐ Thirteen

☐ Fourteen

☐ Fifteen or more; please specify number: P3\_Q67\_2\_t1

P3\_Q68\_t1

**68. Has [the study participant] taken any medications for his/her memory, thinking or behaviour difficulties in the last 3 months?**

☐ No (skip to question 70)

☐ Yes

We would now like to record any medication that [the study participant] is currently taking. Do you have a prescription to hand that I can look at or can you tell me about the medication that [the study participant] is currently taking?

#### Instructions for the researcher:

For each of the relevant medication (**USE SHOWCARD 4C**) please record the trade name, the first day of the medication, whether it is ongoing or the end date, if applicable. We also need to know the current dose. Please use the **medication unit codes** to indicate the dosage type (e.g. 1 = Mg) and the **medication frequency codes** (e.g. 2 = twice a day) provided below.

In the example below, Mrs Jones started taking Reminyl on the 31st of July 2012. She has been prescribed a daily dose of 16 Mg and she currently takes this in one 8 Mg tablet twice a day. This would be recorded as:

Trade name	First day	Last day (if applies)	Ongoing (if applies)	Dose	Medication unit code	Frequency code
DEMENTIA DRUGS	dd/mm/yy	dd/mm/yy				
Reminyl	31/07/2012	__/__/__	<input checked="" type="checkbox"/>	8	1	2

It is important to note that you should only record the medication that the study participant has been taking over the **last 3 months**. However, if s/he has taken the medication for longer than 3 months we still need the day that the medication was first taken.

Cross 'ongoing' if the study participant is currently taking the medication. If the respondent indicates that the study participant has taken the medication for longer than 3 months but cannot give the date first taken, write the 'first day' of taking the medication as 1/1/1900.

P3\_Q69[...]

#### 69. DEMENTIA DRUGS

Trade name: [...]_1_1_t1 [...]_1_10_oth_t1	Ongoing (if applies)	Dose	Medication unit code	Frequency code
First day (dd/mm/yy)      Last day (if applies) <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> _1_2_t1 / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> _1_3_t1 / <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Trade name: [...]_2_1_t1 [...]_2_10_oth_t1				
First day (dd/mm/yy)      Last day (if applies) <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> _2_2_t1 / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> _2_3_t1 / <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Trade name: [...]_3_1_t1 [...]_3_10_oth_t1				
First day (dd/mm/yy)      Last day (if applies) <input type="text"/> <input type="text"/> / <input type="text"/> <input type="text"/> _3_2_t1 / <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> _3_3_t1 / <input type="text"/> <input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

#### Medication unit codes

1	Mg	5	Tubs/tubes	9	Bottles
2	microgram	6	Puffs (inhalers)	10	Packs
3	Gram	7	Drops	11	IU (injections)
4	MI	8	Sprays (spray)	99	Other - give details

#### Medication frequency codes

1	Once daily	7	Once a week
2	Twice daily	8	Once every two weeks
3	Three times daily	9	Once every three weeks
4	Four times daily	10	Once every four weeks
5	Three times a week	11	Once every five weeks
6	Twice a week	88	As required/"PRN"

## 70. OTHER MENTAL HEALTH DRUGS

Ongoing  
(if applies)

Dose

Medication  
unit codeFrequency  
code

Trade name: [...] 1\_1\_t1 [...] 1\_10\_oth\_t1

First day (dd/mm/yy)

Last day (if applies)

Trade name: [...] 2\_1\_t1 [...] 2\_10\_oth\_t1

First day (dd/mm/yy)

Last day (if applies)

Trade name: [...] 3\_1\_t1 [...] 3\_10\_oth\_t1

First day (dd/mm/yy)

Last day (if applies)

Trade name: [...] 4\_1\_t1 [...] 4\_10\_oth\_t1

First day (dd/mm/yy)

Last day (if applies)

Trade name: [...] 5\_1\_t1 [...] 5\_10\_oth\_t1

First day (dd/mm/yy)

Last day (if applies)

Trade name: [...] 6\_1\_t1 [...] 6\_10\_oth\_t1

First day (dd/mm/yy)

Last day (if applies)

Trade name: [...] 7\_1\_t1 [...] 7\_10\_oth\_t1

First day (dd/mm/yy)

Last day (if applies)

Trade name: [...] 8\_1\_t1 [...] 8\_10\_oth\_t1

First day (dd/mm/yy)

Last day (if applies)

Trade name: [...] 9\_1\_t1 [...] 9\_10\_oth\_t1

First day (dd/mm/yy)

Last day (if applies)

## Medication unit codes

1	Mg	5	Tubs/tubes	9	Bottles
2	microgram	6	Puffs (inhalers)	10	Packs
3	Gram	7	Drops	11	IU (injections)
4	MI	8	Sprays (spray)	99	Other - give details

## Medication frequency codes

1	Once daily	7	Once a week
2	Twice daily	8	Once every two weeks
3	Three times daily	9	Once every three weeks
4	Four times daily	10	Once every four weeks
5	Three times a week	11	Once every five weeks
6	Twice a week	88	As required/"PRN"

## Travel costs

P3\_Q71\_1\_t1

71. In the **last 3 months**, has [the study participant] attended any GP, clinic, hospital, or day services **for his/her memory, thinking or behaviour difficulties**?

Instructions for the researcher: For guidance, this does not include general health services such as travel to cardiac specialist, GP for blood pressure etc.

☐ No (skip to question 78) ☐ Yes

P3\_Q71\_2\_t1

If yes, **over the last 3 months**, how many times did [the study participant] attend clinic, hospital, or day services?

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six ☐ Seven  
☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve ☐ Thirteen ☐ Fourteen  
☐ Fifteen or more; please specify number: P3\_Q71\_3\_t1

Instructions for the researcher: If the participant lives alone and has no relative/friend, put a cross in the 'study participant only' box and skip to question 72.

P3\_Q71\_4\_t1

Did you both attend or did [the study participant] go by himself/herself?

☐ Both ☐ Study participant only

P3\_Q72\_1\_t1

72. How did you normally travel to get to the services [the study participant] used (e.g. to go to any GP, clinic, hospital, or day services)? If you used more than one form of transport please say how you travelled for the main/longest part of your journey.

☐ Walked ☐ Cycled ☐ Took the bus  
☐ Took the train ☐ Took a taxi ☐ Drove the car  
☐ Took hospital transport ☐ Went by ambulance  
☐ Other; please specify P3\_Q72\_oth\_t1

73. How long did it normally take to travel to the GP, clinic, hospital, or day service from home?

Hours : Minutes P3\_Q73\_1\_t1 : P3\_Q73\_2\_t1

Instructions for the researcher: If the study participant normally used public transport answer question 74, if the study participant normally went by taxi ask question 75, and if the study participant normally drove/went by car ask questions 76 and 77. Please remember to put a cross in the 'not applicable' box for those questions which are not applicable.

74. If you normally travelled by public transport, what was the cost of the fare in one direction (cost of a one-way ticket)?

£ P3\_Q74\_1\_t1 P3\_Q74\_2\_t1 P3\_Q74\_3\_t1 P3\_Q74\_4\_t1  
☐ Bus pass/travel for free ☐ Not applicable

75. If you normally travelled by taxi, what was the cost of the fare in one direction (cost of a one-way journey)?

£ P3\_Q75\_1\_t1 P3\_Q75\_2\_t1 P3\_Q75\_3\_t1  
☐ Not applicable

76. If you normally travelled by car, how many miles/kilometres did you travel to get there (one-way journey)?

P3\_Q76\_1\_t1 P3\_Q76\_3\_t1  
☐ Not applicable

P3\_Q76\_2\_t1

Is this number in miles or kilometres?

☐ Miles ☐ Kilometres

**77. If you normally travelled by car, if you had to pay for parking, how much did you pay?**

£    Blue badge/park for free  Not applicable

## Satisfaction with health services

*The next couple of questions are about how satisfied you are with the health services [you/the study participant] receives.*

**(USE SHOWCARD 3T)**

78. How satisfied are [you/you both] with the formal support services that [the study participant] receives (e.g. visits by his/her GP, community nurse, social worker, care worker or any other professional person)?

Extremely satisfied      Satisfied      Fairly satisfied      Neither satisfied nor dissatisfied      Slightly dissatisfied      Dissatisfied      Extremely dissatisfied

79. How satisfied are [you/you both] with the amount of formal support services that [the study participant] receives (is enough support being received or do you feel more should be offered)?

Extremely satisfied      Satisfied      Fairly satisfied      Neither satisfied nor dissatisfied      Slightly dissatisfied      Dissatisfied      Extremely dissatisfied

**Thank you for taking the time to answer these questions. The information and insight that you have provided is very valuable to us.**

Instructions for the researcher: This final question can be asked individually or as a couple. Please record who said what if asked as a couple.

80. That concludes your contribution to our research project for the moment. What did you think about the experience of being interviewed and what are your impressions of the research project?

*Participant's response:*

P3 Q80 1 t1

*Relative's/friend's response:*

P3 Q80 2 t1

**We will be contacting you again in twelve months from now. We will keep you updated with newsletters on the progress of the study.**

Instructions for the researcher: Please now give the £10 gift token to the participant.

Instructions for the researcher: Checklist/Field notes

At the end of each part of the assessment please note reasons for any items which were not completed:

☐ All items have been completed (if so skip to field notes)

**Physical health**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Dignity and respect**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Psychological Well-Being**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Personality**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Green/blue spaces**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Social Capital**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Social activities**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Cultural activities**

☐ Complete    ☐ Refused    ☐ No time to complete

☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_



**Available resources (Resource Generator)**☐ Complete ☐ Refused ☐ No time to complete☐ Partial: ☐ Too impaired ☐ Too tired ☐ Questions not understood☐ Other; please specify: \_\_\_\_\_**Optional questions completed**☐ Yes ☐ No ☐ Partial**Health conditions**☐ Complete ☐ Refused ☐ No time to complete☐ Partial: ☐ Too impaired ☐ Too tired ☐ Questions not understood☐ Other; please specify: \_\_\_\_\_**Sources of income**☐ Complete ☐ Refused ☐ No time to complete☐ Partial: ☐ Too impaired ☐ Too tired ☐ Questions not understood☐ Other; please specify: \_\_\_\_\_**Household income**☐ Complete ☐ Refused ☐ No time to complete☐ Partial: ☐ Too impaired ☐ Too tired ☐ Questions not understood☐ Other; please specify: \_\_\_\_\_**Service use**☐ Complete ☐ Refused ☐ No time to complete☐ Partial: ☐ Too impaired ☐ Too tired ☐ Questions not understood☐ Other; please specify: \_\_\_\_\_**Community health and care**☐ Complete ☐ Refused ☐ No time to complete☐ Partial: ☐ Too impaired ☐ Too tired ☐ Questions not understood☐ Other; please specify: \_\_\_\_\_**Home help**☐ Complete ☐ Refused ☐ No time to complete☐ Partial: ☐ Too impaired ☐ Too tired ☐ Questions not understood☐ Other; please specify: \_\_\_\_\_**Community services**☐ Complete ☐ Refused ☐ No time to complete☐ Partial: ☐ Too impaired ☐ Too tired ☐ Questions not understood☐ Other; please specify: \_\_\_\_\_**Accommodation away from home**☐ Complete ☐ Refused ☐ No time to complete☐ Partial: ☐ Too impaired ☐ Too tired ☐ Questions not understood☐ Other; please specify: \_\_\_\_\_

**Participant ID**

--	--	--	--	--	--	--

**Researcher ID**

--	--	--

**Equipment and adaptations**

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

**Help and support**

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

**Medication**

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

**Travel costs**

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

**Satisfaction with health services**

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:    ☐ Too impaired    ☐ Too tired    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

Field notes or comments.

We would like you to record any additional information about the assessment which you may think is useful.

Examples of comments could include any issues that affected or disrupted the course of the assessment today (e.g. visitors arriving), details of specific items that were not completed, the demeanour of the participant, participant engagement and general reaction to the administration of the measures, any difficulties experienced by the researcher, etc.

I would like to add field notes or comments: ☐ No ☐ Yes; please write your notes here:


**Assessment of level of consciousness.**

- ☐ Alert/Responsive    ☐ Drowsy    ☐ Stuporous    ☐ Comatose/Unresponsive

**5051275544**

P\_ID

Participant ID

--	--	--	--	--	--	--

Researcher ID

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# Enhancing Active Life and Living Well: The IDEAL Study

## Relative/Friend Part 1



[www.IDEALproject.org.uk](http://www.IDEALproject.org.uk)

## What is the purpose of the study?

This study aims to understand what 'living well' means to people who have difficulties with memory, thinking or behaviour, that may have been described as dementia or an associated condition, both from their own perspective and from the perspective of those who are close to them. You have been asked to take part as you provide help and assistance to someone with a condition of this kind.

## What information are we going to ask for?

The information we will be asking you to provide in the study will consist of two parts:

- We will ask you to provide information **about the person with memory, thinking or behaviour difficulties.**
- We will ask you to provide information **about you and your experiences.**

The information you provide is extremely valuable to us. All information you provide will be treated in strictest confidence.

The questions in this part are all about you; there are questions about your background, your health and well-being, and your home. Please try to be as honest and as accurate as you can throughout. There are no "right" or "wrong" answers; we are interested in how you see things.

## This information will be scanned by a computer.

- Use black or blue ink to answer.
- For each question please cross ☒ clearly inside **one** box.
- For some questions you will be instructed that you may cross more than one box.
- Don't worry if you make a mistake; simply fill in the box ☐ and put a cross ☒ in the correct box.
- For some questions you will be asked to write information in boxes. When you see boxes like these, please write a single letter or number in each box provided.

For example; what is your age? 

6	5
---	---

- For some questions you will be asked to write your answers in the space provided; please write only in the space provided. If you make a mistake or change your mind, just cross out the word and continue writing, but please make sure you write only in the space provided.

## What to do if you have any questions or need help.

If you have any queries about how to complete the following questions please ask the researcher.

C1\_Q1\_date\_t1

1. Today's date is (dd/mm/yyyy)

		/			/	2	0	1	
--	--	---	--	--	---	---	---	---	--

## Information about you

To start we would like to know about you, your life and your family.

C1\_Q2\_t1

2. What is your age? 

--	--	--

C1\_Q3\_t1

3. What is your date of birth? (dd/mm/yyyy)

		/			/				
--	--	---	--	--	---	--	--	--	--

C1\_Q4\_t1

4. What is your sex?

☐ Male

☐ Female

C1\_Q5\_t1

5. In which county, city or London borough do you live?


6. What is your postcode?

C1_Q6_1_t1	C1_Q6_2_t1																					
------------	------------	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

C1\_Q7\_1\_t1

7. In which country were you born?

☐ England ☐ Ireland ☐ Northern Ireland ☐ Scotland ☐ Wales

☐ Other; please specify: C1\_Q7\_2\_t1

C1\_Q8\_1\_t1

8. What is your main language?

☐ English (skip to question 10) ☐ Welsh ☐ Gaelic

☐ Other; please specify: C1\_Q8\_2\_t1

C1\_Q9\_t1

9. How well can you speak English?

☐ Not at all ☐ Not well ☐ Well ☐ Very well

C1\_Q10\_1\_t1

## 10. What is your ethnic group?

- ☐ White: English/Welsh/Scottish/Northern Irish/British
- ☐ White: Irish
- ☐ White: Gypsy or Irish Traveller
- ☐ Any other White background; please specify:

C1\_Q10\_2\_t1

- ☐ Mixed White & Black: Caribbean
- ☐ Mixed White & Black: African
- ☐ Mixed White & Asian
- ☐ Any other Mixed/multiple ethnic background; please specify:

C1\_Q10\_3\_t1

- ☐ Asian/Asian British: Indian
- ☐ Asian/Asian British: Pakistani
- ☐ Asian/Asian British: Bangladeshi
- ☐ Asian/Asian British: Chinese
- ☐ Any other Asian background; please specify:

C1\_Q10\_4\_t1

- ☐ Black/Black British: African
- ☐ Black/Black British: Caribbean
- ☐ Any other Black/African/Caribbean background; please specify:

C1\_Q10\_5\_t1

- ☐ Arab
- ☐ Any other ethnic group; please specify:

C1\_Q10\_6\_t1

C1\_Q11\_1\_t1

**11. What is your current legal marital status?**

- ☐ Single; that is, never married
- ☐ Married; first and only marriage
- ☐ Remarried; second or later marriage
- ☐ A civil partner in a legally-recognised civil partnership
- ☐ Legally separated
- ☐ Divorced
- ☐ Widowed
- ☐ Cohabiting
- ☐ Other; please specify:

C1\_Q11\_2\_t1

C1\_Q12\_t1

**12. If you are married/widowed/separated/divorced, please say for how many years you have been married/widowed/separated/divorced?**

--	--

C1\_Q13\_1\_t1

**13. Which of these words best describes how you think of yourself?**

- ☐ Heterosexual or straight      ☐ Gay or lesbian      ☐ Bisexual
- ☐ Other; please specify:

C1\_Q13\_2\_t1

- ☐ Prefer not to say
- ☐ Don't know

**14. With whom do you live?***You may cross more than one box*

C1\_Q14\_1\_t1

☐ No-one

C1\_Q14\_2\_t1

☐ Your spouse/partner

C1\_Q14\_3\_t1

☐ Other family member(s)

C1\_Q14\_4\_t1

☐ Other (non-family)

C1\_Q15\_t1

**15. If you are not related to the study participant, for how many years have you known him/her?**

--	--

C1\_Q16\_1\_t1

**16. How many living children do you have (including, if applicable, those you adopted)?**

- ☐ None    ☐ One    ☐ Two    ☐ Three    ☐ Four    ☐ Five    ☐ Other

If other, please specify number:

C1\_Q16\_2\_t1

--

C1\_Q17\_1\_t1

**17. On a typical day, how much time do you spend looking after/providing help for your relative/friend with memory, thinking or behaviour difficulties?**

- ☐ Provide no help in a typical day
 ☐ More than 3 hours and up to 5 hours  
☐ Less than 1 hour
 ☐ More than 5 hours and up to 10 hours  
☐ More than 1 hour and up to 2 hours
 ☐ More than 10 hours, but not overnight  
☐ More than 2 hours and up to 3 hours
 ☐ More than 10 hours and/including overnight  
☐ Other; please describe:

C1\_Q17\_2\_t1

## Education

*Now we're going to ask you some questions about your educational history and about your qualifications.*

C1\_Q18\_t1

**18. At what age did you start school?**

C1\_Q19\_t1

**19. At what age did you leave continuous full-time education?**

*(For example, if you left school at 18, but went back to education at 19 for two years, you would write '18' for question 19)*

C1\_Q20\_1\_t1

**20. Did you go back to full-time or part-time education later on?**

☐ No

☐ Yes; if yes for how many years did you study?

*(1 year of part-time education = half a year (0.5) of education)*

*(For example, if you left school at 18, but went back to education at 19 for two years, you would write '2' for question 20)*

C1\_Q21\_1\_t1

**21. What is the highest level of education that you achieved?**

*(Please cross only one box)*

- ☐ No formal qualifications  
☐ GCSEs or equivalent (O levels, CSEs, School Certificate, Standard Grades)  
☐ Completed apprenticeship  
☐ A levels or equivalent (Leaving Certificate, Higher Grades)  
☐ National Vocational Qualification  
☐ Higher National Diploma  
☐ Undergraduate degree (BA, BSc)  
☐ Master's degree (MA, MSc)  
☐ PhD  
☐ Other; please specify:

C1\_Q21\_2\_t1



## Employment

Now we would like to know about your current employment status and the type of work you do/did.

C1\_Q22\_1\_t1

**22. Which of the following best describes your current employment situation?**

☐ In paid employment (including self-employment/business owner)

If you are in paid employment, **what is/are your current jobs/occupations?**

C1\_Q22\_2\_t1

C1\_Q22\_3\_t1

If you are in paid employment, **how many hours of work per week do you do in total across all your jobs?**   (skip to question 24)

☐ Retired; if retired **at what age did you retire?**

☐ Unable to work

☐ Unemployed and looking for work

☐ At home and not looking for work (e.g. housewife/househusband, full time carer)

☐ Doing voluntary (unpaid) work

☐ Student (full or part-time)

☐ Other; please describe:

C1\_Q22\_5\_t1

C1\_Q23\_1\_t1

**23. If you are unemployed, unable to work, 'at home' or retired:**

When were you last employed?

**What was/were your most recent job(s)/occupation(s)?**

C1\_Q23\_2\_t1

C1\_Q24\_1\_t1

**24. Have you given up or cut down on work in order to provide care for your relative/friend with memory, thinking or behaviour difficulties?**

☐ No (skip to question 25)

☐ Yes, given up work

**If so, when did this happen?**

☐ Yes, cut down

**If so, by how many hours per week have you cut down on work each week?**

C1\_Q25\_2\_t1

**25. What is/has been your main occupation for most of your working life?**

(This should be the occupation that was held for the longest period, not the most recent. Please include a full job title.)

☐ Not applicable C1\_Q25\_1\_t1

C1\_Q26\_2\_t1

**26. What type of work is/was this?**

(Please include a description of the work and a description of the employer including the name of the employer.)

☐ Not applicable C1\_Q26\_1\_t1

C1\_Q27\_t1

**27. Do/did you enjoy your job?**

☐ No ☐ Yes ☐ Not applicable

C1\_Q28\_t1

**28. Are/were you self-employed?**

☐ No ☐ Yes

C1\_Q29\_t1

**29. Are/were you a foreman, supervisor or manager?**

☐ No (skip to question 32) ☐ Foreman ☐ Supervisor ☐ Manager

C1\_Q30\_t1

**30. If you are/were a foreman/supervisor/manager; what do/did you do?**

C1\_Q31\_t1

**31. How many employees are/were you responsible for?**

☐ Less than 25 ☐ 25 or more ☐ Don't know ☐ Not applicable

### Religious beliefs

*Now we would like to know about your religious beliefs. Please try to answer them even if you have little interest in religion. By religion we mean the actual practice of a faith, e.g. going to a church or synagogue, mosque or temple.*

C1\_Q32\_1\_t1

**32. What is your religion? (Please cross only one box)**

☐ No religion

☐ Christian (including Church of England, Catholic, Protestant and all other Christian denominations)

☐ Buddhist

☐ Hindu

☐ Jewish

☐ Muslim

☐ Sikh

☐ Any other religion; please specify:

C1\_Q32\_2\_t1

☐ Prefer not to say

C1\_Q33\_t1

**33. How often do you attend a place of religious worship?**

(Select whichever is the closest to your usual practice.)

- ☐ Never   ☐ Occasionally   ☐ Monthly   ☐ Weekly   ☐ Daily

C1\_Q34\_t1

**34. How often do you pray?**

(Select whichever is the closest to your usual practice.)

- ☐ Never   ☐ Occasionally   ☐ Monthly   ☐ Weekly   ☐ Daily

C1\_Q35\_t1

**35. How often do you study religious texts?**

(Select whichever is the closest to your usual practice.)

- ☐ Never   ☐ Occasionally   ☐ Monthly   ☐ Weekly   ☐ Daily

C1\_Q36\_t1

**36. How important is religion or being religious to your life?**

- |  |   |  |
|--|---|--|
| <input type="checkbox"/> Not important | <input type="checkbox"/> Slightly important   | <input type="checkbox"/> Important           |
|  | <input type="checkbox"/> Somewhat important   | <input type="checkbox"/> Very important      |
|  | <input type="checkbox"/> Moderately important | <input type="checkbox"/> Extremely important |

**Spirituality**

*Now we would like to know about spirituality. Some people do not follow a specific religion but do have spiritual beliefs or experiences. For example, they may believe that there is some power or force other than themselves that might influence their life. Some people think of this as God or gods, others do not.*

C1\_Q37\_t1

**37. Whether you attend religious services or not, would you say you are religious, spiritual, or, neither?**

- ☐ Religious   ☐ Spiritual   ☐ Both religious and spiritual   ☐ Neither
- ☐ Can't choose   ☐ Don't know

C1\_Q38\_t1

**38. Spiritually, what best describes you?**

- ☐ I follow a religion and am a spiritual person
- ☐ I follow a religion and am not a spiritual person
- ☐ I don't follow a religion, but am a spiritual person
- ☐ I don't follow a religion and am not a spiritual person
- ☐ Can't choose
- ☐ Don't know

C1\_Q39\_t1

**39. How important is spirituality to your life?**

- |  |   |  |
|--|---|--|
| <input type="checkbox"/> Not important | <input type="checkbox"/> Slightly important   | <input type="checkbox"/> Important           |
|  | <input type="checkbox"/> Somewhat important   | <input type="checkbox"/> Very important      |
|  | <input type="checkbox"/> Moderately important | <input type="checkbox"/> Extremely important |

## Health

*Now we would like to know about your health.*

C1\_Q40\_t1

**40. Overall, how would you rate your health in the past four weeks?**

☐ Very poor   ☐ Poor   ☐ Fair   ☐ Good   ☐ Very good   ☐ Excellent

C1\_Q41\_1\_t1

**41. Have you fallen down in the last two years (for any reason)?**

☐ No (skip to question 42)   ☐ Yes   ☐ Don't know

C1\_Q41\_2\_t1

If yes, **how many times?**

C1\_Q41\_3\_t1

If yes, **did you injure yourself seriously enough to need medical treatment?**

☐ No   ☐ Yes   ☐ Don't know

C1\_Q42\_t1

**42. Is your eyesight (using glasses or corrective lens if you use them)...**

☐ Poor   ☐ Fair   ☐ Good   ☐ Very good   ☐ Excellent

C1\_Q43\_t1

**43. Is your hearing (using a hearing aid if you use one)...**

☐ Poor   ☐ Fair   ☐ Good   ☐ Very good   ☐ Excellent

C1\_Q44\_t1

**44. How many different prescribed medications do you take?**

## Health state

*Now we would like to know about how you feel about your health in a number of areas. Please indicate which statements best describe your own health*

**All EQ-5D questions removed in line with user agreement**

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## Life events

**51. Read each of the events listed below, and check the box next to any event which you have experienced in your life over the past 12 months. The aim is just to identify how many of these events you have experienced lately.**

*You may cross more than one box*

### Bereavement

C1\_Q51\_1\_t1 ☐ Death of spouse or child

C1\_Q51\_2\_t1 ☐ Death of a close family member (e.g. parent or sibling)

C1\_Q51\_3\_t1 ☐ Death of a close friend

### Marital difficulties

C1\_Q51\_4\_t1 ☐ Divorce

C1\_Q51\_5\_t1 ☐ Marital separation

### Change in circumstances

C1\_Q51\_6\_t1 ☐ Retirement

C1\_Q51\_7\_t1 ☐ Moved home

C1\_Q51\_8\_t1 ☐ Major change in financial state (e.g. a lot worse off or a lot better off)

C1\_Q51\_9\_t1 ☐ Major change in health or behaviour of family member

C1\_Q51\_10\_t1 ☐ Major personal injury or illness

### None

C1\_Q51\_0\_t1 ☐ None of the above

C1\_Q52\_t1

**52. Do you think that compared to most other people your age, your overall situation is:**

☐ Much worse

☐ About the same

☐ Somewhat better

☐ Somewhat worse

☐ Much better

## Alcohol

*Now we would like to know how much you drink and smoke during a typical week.*

C1\_Q53\_t1 **53. Do you drink alcohol?**

☐ No (skip to question 61) ☐ Yes

C1\_Q54\_t1 **54. How many pints of regular beer/lager/cider do you drink in a typical week?**

--	--

C1\_Q55\_t1

55. How many alcopops or cans of beer/lager/cider do you drink in a typical week?

--	--

C1\_Q56\_t1

56. How many bottles of wine do you drink in a typical week?

--	--

C1\_Q57\_t1

57. How many small glasses of wine do you drink in a typical week?

--	--

C1\_Q58\_t1

58. How many large glasses of wine do you drink in a typical week?

--	--

C1\_Q59\_t1

59. How many single measures of spirits do you drink in a typical week?

--	--

C1\_Q60\_1\_t1

60. Do you drink any other alcoholic drinks?

☐ No ☐ Yes

If yes; please specify what else you drink and how much in a typical week

C1\_Q60\_2\_t1

## Smoking

C1\_Q61\_1\_t1

61. Are you a current smoker?

☐ No ☐ Yes

If yes, how many cigarettes do you smoke a day? C1\_Q61\_2\_t1

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If yes, how many cigars do you smoke a day? C1\_Q61\_3\_t1

--	--

C1\_Q62\_1\_t1

62. Are you a former smoker?

☐ No ☐ Yes

If yes, how many cigarettes did you smoke a day? C1\_Q62\_2\_t1

--	--	--

If yes, how many cigars did you smoke a day? C1\_Q62\_3\_t1

--	--

C1\_Q63\_t1

63. How old were you when you stopped smoking (if you have stopped smoking several times, how old were you at the most recent time)?

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## Information about memory problems

*Now we would like to know whether you have received or actively looked for information about memory, thinking or behaviour difficulties, which may have been described as dementia or an associated condition.*

C1\_Q64\_1\_t1

**64. Have you or your relative/friend with memory, thinking or behaviour difficulties received any information or educational materials to help support him/her with his/her memory, thinking or behaviour difficulties?**

☐ No (skip to question 66)    ☐ Yes; please specify:

C1\_Q64\_2\_t1

C1\_Q65\_t1

**65. If you or your relative/friend with memory, thinking or behaviour difficulties have received any information or educational materials, where did the information come from?**

C1\_Q66\_1\_t1

**66. Have you independently sought out information to help you support your relative/friend with memory, thinking or behaviour difficulties e.g. have you contacted a national charity such as the Alzheimer's Society or Parkinson's UK, or carers support groups, or searched the internet for information, etc.?**

☐ No    ☐ Yes; please specify:

C1\_Q66\_2\_t1

C1\_Q67\_1\_t1

**67. Have you taken part in any intervention (such as an educational group for carers) to help you support your relative/friend with memory, thinking or behaviour difficulties?**

☐ No (skip to question 69)    ☐ Yes; please specify:

C1\_Q67\_2\_t1



C1\_Q68\_t1

**68. If you have taken part in any intervention, which organisation/who offered the intervention?**

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C1\_Q69\_1\_t1

**69. Has your relative/friend with memory, thinking or behaviour difficulties taken part in any intervention (such as a coping with memory difficulties group) to help with his/her memory, thinking or behaviour difficulties?**

☐ No (skip to question 71)    ☐ Yes; please specify:

C1\_Q69\_2\_t1

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C1\_Q70\_t1

**70. If your relative/friend with memory, thinking or behaviour difficulties has taken part in any intervention for his/her memory, thinking or behaviour difficulties, which organisation/who offered the intervention?**

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C1\_Q71\_1\_t1

**71. Have you taken part in research in the past year, or are you taking part in another project currently?**

☐ No    ☐ Yes; please specify:

C1\_Q71\_2\_t1

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## Your accommodation

Now we would like to know about your home, including who lives with you, how long you have lived at this address and how satisfied you are with your accommodation.

C1\_Q72\_1\_t1

**72. How many adults (people aged 16 or over) are there in your household including you?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Other

C1\_Q72\_2\_t1

If other, please specify number:

C1\_Q73\_1\_t1

**73. How many children under the age of 16 years are there in your household?**

☐ None ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Other

C1\_Q73\_2\_t1

If other, please specify number:

C1\_Q74\_1\_t1

**74. In which of these ways is your accommodation owned or paid for?**

- ☐ Own it outright
- ☐ Buying it with the help of a mortgage or loan
- ☐ Pay part rent and part mortgage (shared ownership)
- ☐ Housing association rented housing
- ☐ Council-rented housing
- ☐ Private rented housing
- ☐ Live here rent-free (including rent free in relative's/friend's property, but excluding squatting)
- ☐ Squatting
- ☐ Care home
- ☐ Nursing home
- ☐ Sheltered accommodation (has a warden or scheme manager on site)
- ☐ Other; please specify:

C1\_Q74\_2\_t1

☐ Don't know

C1\_Q75\_t1

**75. How long have you lived at this address?**

- ☐ Less than 12 months
- ☐ 10 years or more (skip to question 77)
- ☐ 12 months but less than 5 years
- ☐ Don't know (skip to question 77)
- ☐ 5 years but less than 10 years

## 76. What were the main reasons you moved to this address?

You may cross more than one box

C1\_Q76\_3\_t1

☐ Retirement

C1\_Q76\_4\_t1

☐ Downsizing

C1\_Q76\_5\_t1

☐ To be nearer relative(s)

C1\_Q76\_6\_t1

☐ Needed more support

C1\_Q76\_7\_t1

☐ Needed more care

C1\_Q76\_8\_t1

☐ Needed to move into residential care

C1\_Q76\_9\_t1

☐ Could no longer afford last home

C1\_Q76\_10\_t1

☐ Relationship breakdown

C1\_Q76\_11\_t1

☐ New relationship

C1\_Q76\_12\_t1

☐ Wanted to move to better area

C1\_Q76\_13\_t1

☐ For children's/grandchildren's education

C1\_Q76\_14\_t1

☐ Just wanted a change

C1\_Q76\_15\_t1

☐ Wanted a place of my own

C1\_Q76\_16\_t1

☐ Problem with neighbours

C1\_Q76\_17\_t1

☐ Moving away from crime

C1\_Q76\_18\_t1

☐ Previous accommodation temporary

C1\_Q76\_19\_t1

☐ Quality of previous accommodation

C1\_Q76\_20\_t1

☐ Spouse or partner job change

C1\_Q76\_21\_t1

☐ Job change/nearer work

C1\_Q76\_22\_t1

☐ Overcrowding or no space

C1\_Q76\_23\_t1

☐ Wanted to buy

C1\_Q76\_24\_t1

☐ Wanted larger home

C1\_Q76\_25\_t1

☐ Wanted better home

C1\_Q76\_26\_t1

☐ Problems with landlord

C1\_Q76\_27\_t1

☐ Evicted/repossessed from last home

C1\_Q76\_28\_t1

☐ For financial reasons

C1\_Q76\_29\_t1

☐ Other; please specify:

C1\_Q76\_oth\_t1

C1\_Q77\_t1

## 77. How many of the rooms in your household are bedrooms, including those not in use?

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six or more

## 78. What type of heating do you have?

C1\_Q78\_1\_t1

☐ Gas central heating

C1\_Q78\_2\_t1

☐ Electric storage heaters

C1\_Q78\_3\_t1

☐ Gas fire only

C1\_Q78\_4\_t1

☐ Other; please specify:

C1\_Q78\_Oth\_t1

C1\_Q79\_t1

## 79. How satisfied are you with your accommodation?

☐ Very dissatisfied

☐ Fairly dissatisfied

☐ Neither satisfied nor dissatisfied

☐ Slightly satisfied

☐ Very satisfied

☐ Don't know

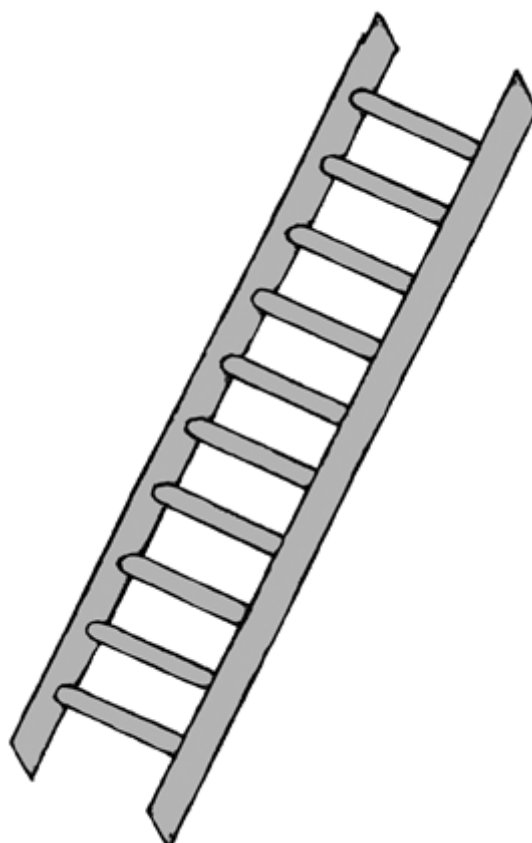
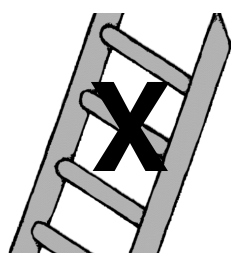
## Society and Community

C1\_Q80\_t1

80. Think of this ladder as representing where people stand in our society. At the top of the ladder are the people who are the best off - those who have the most money, most education, and best jobs. At the bottom are the people who are the worst off - who have the least money, least education, and the worst jobs or no jobs. The higher up you are on this ladder, the closer you are to the people at the very top and the lower you are, the closer you are to the people at the very bottom.

Please mark a cross on the rung on the ladder where you would place yourself, relative to other people in our society.

Example



TO BE COMPLETED BY THE RESEARCHER

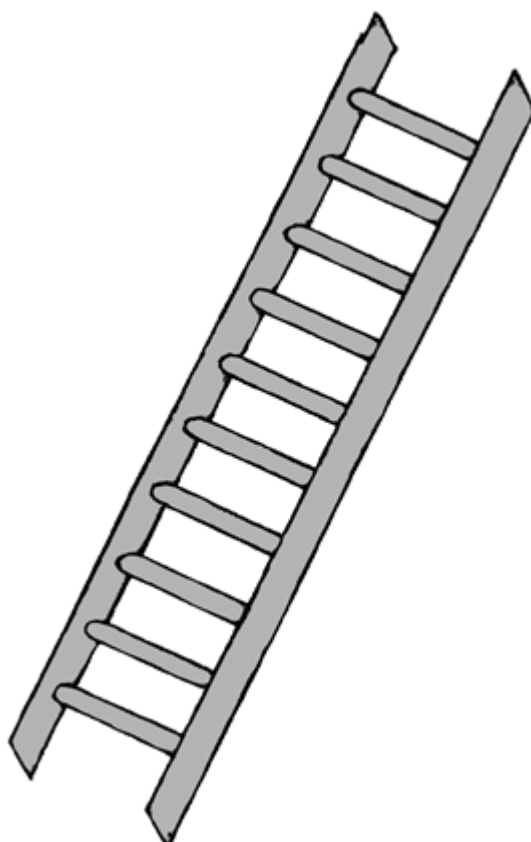
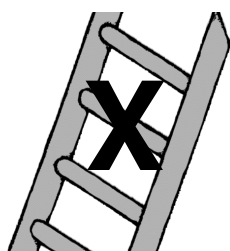
Instructions for the researcher: Please check the appropriate box:

☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10

81. Think of this ladder as representing where people stand in their local communities. People define community in different ways; please define it in whatever way is most meaningful to you. At the top of the ladder are the people who have the highest standing in their local community. At the bottom are the people who have the lowest standing in their local community.

Please mark a cross on the rung on the ladder where you would place yourself, relative to other people in your local community.

### Example



TO BE COMPLETED BY THE RESEARCHER

Instructions for the researcher: Please check the appropriate box:

☐ 1   ☐ 2   ☐ 3   ☐ 4   ☐ 5   ☐ 6   ☐ 7   ☐ 8   ☐ 9   ☐ 10

Thank you for taking the time to answer these questions. The information and insight that you have provided is very valuable to us.

## TO BE COMPLETED BY THE RESEARCHER

Instructions for the researcher: Checklist/Field notes

At the end of each part of the assessment please note reasons for any items which were not completed:

- ☐ Please check that all questions have been completed and cross the appropriate boxes below  
☐ All items have been completed (if so skip to field notes)

### Information about you

- ☐ Complete    ☐ Refused    ☐ No time to complete  
☐ Partial:   ☐ Tiredness    ☐ Questions not understood  
☐ Other; please specify: \_\_\_\_\_

### Education

- ☐ Complete    ☐ Refused    ☐ No time to complete  
☐ Partial:   ☐ Tiredness    ☐ Questions not understood  
☐ Other; please specify: \_\_\_\_\_

### Employment

- ☐ Complete    ☐ Refused    ☐ No time to complete  
☐ Partial:   ☐ Tiredness    ☐ Questions not understood  
☐ Other; please specify: \_\_\_\_\_

### Religious beliefs

- ☐ Complete    ☐ Refused    ☐ No time to complete  
☐ Partial:   ☐ Tiredness    ☐ Questions not understood  
☐ Other; please specify: \_\_\_\_\_

### Spirituality

- ☐ Complete    ☐ Refused    ☐ No time to complete  
☐ Partial:   ☐ Tiredness    ☐ Questions not understood  
☐ Other; please specify: \_\_\_\_\_

### Health

- ☐ Complete    ☐ Refused    ☐ No time to complete  
☐ Partial:   ☐ Tiredness    ☐ Questions not understood  
☐ Other; please specify: \_\_\_\_\_

### Health state

- ☐ Complete    ☐ Refused    ☐ No time to complete  
☐ Partial:   ☐ Tiredness    ☐ Questions not understood  
☐ Other; please specify: \_\_\_\_\_

### Life events

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:   ☐ Tiredness    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

### Alcohol

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:   ☐ Tiredness    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

### Smoking

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:   ☐ Tiredness    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

### Information about memory problems

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:   ☐ Tiredness    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

### Your accommodation

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:   ☐ Tiredness    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

### Society and community

- ☐ Complete    ☐ Refused    ☐ No time to complete
- ☐ Partial:   ☐ Tiredness    ☐ Questions not understood
- ☐ Other; please specify: \_\_\_\_\_

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We would like you to record any additional information about the assessment which you may think is useful.

☐ No      ☐ Yes, please write your notes here

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P\_ID

Participant ID

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Researcher ID

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# Enhancing Active Life and Living Well: The IDEAL Study

## Relative/Friend Part 2



[www.IDEALproject.org.uk](http://www.IDEALproject.org.uk)

## Enhancing Active Life and Living Well: The IDEAL Study

### What is the purpose of the study?

This study aims to understand what 'living well' means to people who have difficulties with memory, thinking or behaviour, that may have been described as dementia or an associated condition, both from their own perspective and the perspective of those who are close to them. You have been asked to take part as you provide help and assistance to someone with a condition of this kind.

### What information are we going to ask for?

The information we will be asking you in this part will consist of two sections:

- Firstly, we will ask you to provide information **about the well-being of your relative/friend**.
- Secondly, we will ask you to provide information **about your experiences supporting your relative/friend**.

The information you provide is extremely valuable to us. All information you provide will be treated in strictest confidence.

Please be as honest and as accurate as you can throughout. There are no "right" or "wrong" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

### This information will be scanned by a computer.

- Use black or blue ink to answer.
- For each question please cross ☐ clearly inside **one** box.
- For some questions you will be instructed that you may cross more than one box.
- Don't worry if you make a mistake; simply fill in the box ☐ and put a cross ☐ in the correct box.
- For some questions you will be asked to write information in boxes. When you see boxes like these, please write a single letter or number in each box provided.

For example; what is your age? 

6	5
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- For some questions you will be asked to write your answers in the space provided; please write only in the space provided. If you make a mistake or change your mind, just cross out the word and continue writing, but please make sure you write only in the space provided.

### What to do if you have any questions or need help.

If you have any queries about how to complete the following questions please ask the researcher.

C2\_Q1\_Date\_t1

1. Today's date (dd/mm/yyyy)   /   / 2 0 1

## Your relative's/friend's quality of life

*The following questions are about your relative's/friend's quality of life. When you think about your relative's/friend's quality of life, there are different aspects, some of which are listed below. Please rate these aspects based on your relative's/friend's life at the **present time (e.g. within the past few weeks)**.*

C2\_Q2\_t1

2. How is your relative's/friend's physical health right now? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q3\_t1

3. How is your relative's/friend's energy level? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q4\_t1

4. How is your relative's/friend's mood lately? Have his/her spirits been good or has s/he been feeling down? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q5\_t1

5. How is your relative's/friend's living situation? How would you rate the place s/he lives now? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q6\_t1

6. How is your relative's/friend's memory? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q7\_t1

7. How is your relative's/friend's relationship with his/her family (such as spouse, brothers, sisters, children etc.)? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q8\_t1

**8. How is your relative's/friend's marriage? How is his/her relationship with you or his/her spouse?** *If your relative/friend is single, widowed, divorced how would you rate his/her relationship with you? Is it...*

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q9\_t1

**9. How is your relative's/friend's current relationship with his/her friends?** *If your relative/friend has no friends does s/he have anyone s/he enjoys being with other than family? Would s/he call this person a friend? If so, how would you rate your relative's/friend's current relationship with this person? Is it...*

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q10\_t1

**10. How does your relative/friend feel about himself/herself, his/her whole self, and all the different things about him/her? Is it...**

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q11\_t1

**11. How is your relative's/friend's ability to do things like chores around the house or other things s/he needs to do? Is it...**

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q12\_t1

**12. How is your relative's/friend's ability to do things for fun, that s/he enjoys? Is it...**

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q13\_t1

**13. How is your relative's/friend's current situation with money, i.e. his/her financial situation? Is it...**

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C2\_Q14\_t1

**14. How is your relative's/friend's life as a whole? When you think about his/her life as a whole, everything together, how do you feel about his/her life? Is it...**

☐ Poor ☐ Fair ☐ Good ☐ Excellent

## Your relative's/friend's well-being

Please indicate for each of these statements the one that is closest to how you think your relative/friend has been feeling. For example, if you think your relative/friend has felt cheerful and in good spirits more than half of the time during the last two weeks, put a cross in the "more than half of the time" box.

C2\_Q15\_t1

**15. Over the past two weeks your relative/friend has felt cheerful and in good spirits.**

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q16\_t1

**16. Over the past two weeks your relative/friend has felt calm and relaxed.**

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q17\_t1

**17. Over the past two weeks your relative/friend has felt active and vigorous.**

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q18\_t1

**18. Over the past two weeks your relative/friend has woken up feeling fresh and rested.**

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q19\_t1

**19. Over the past two weeks your relative's/friend's daily life has been filled with things that interest him/her.**

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**C2\_Q20\_1\_t1 to C2\_Q34\_3\_t1 are based on the AAIQOL measure, provided as below:**

Author and Owner: Steven Albert

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Reference publication: Albert SM, Castillo-Castenada C, Sano M, Jacobs DM, Marder K, Bell K, Lafleche G, Brandt J, Albert M, Stern Y. "Quality of life in patients with Alzheimer's disease as reported by patient proxies." J Amer Geriatrics Soc, 44:1342-1347, 1996.

Contact information and permission to use: Mapi Research Trust, Lyon, France.

E-mail: PROinformation@mapi-trust.org – Internet: www.proqolid.org

## How your relative/friend spends his/her time

*Please indicate whether your relative/friend has **had an opportunity** to participate in the following activities in the **last 2 weeks**. Also, please indicate how often s/he did each activity and whether s/he enjoyed it.*

C2\_Q20\_1\_t1

**20. Has your relative/friend had an opportunity to be outside, go for walks, enjoy nature?**

☐ No (skip to question 21)

C2\_Q20\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?** **Did s/he enjoy the activity?**

C2\_Q20\_3\_t1

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q21\_1\_t1

**21. Has your relative/friend had an opportunity to be with pets or animals or to watch animals?**

☐ No (skip to question 22)

C2\_Q21\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?** **Did s/he enjoy the activity?**

C2\_Q21\_3\_t1

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q22\_1\_t1

**22. Has your relative/friend had an opportunity to get together with family/friends?**

☐ No (skip to question 23)

C2\_Q22\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?** **Did s/he enjoy the activity?**

C2\_Q22\_3\_t1

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q23\_1\_t1

**23. Has your relative/friend had an opportunity to talk to family/friends on the telephone?**

☐ No (skip to question 24)

C2\_Q23\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?** **Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q24\_1\_t1

**24. Has your relative/friend had an opportunity to go to the cinema, museums or other entertainment events?**

☐ No (skip to question 25)

C2\_Q24\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?** **Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q25\_1\_t1

**25. Has your relative/friend had an opportunity to go to church or other place of worship or religious events?**

☐ No (skip to question 26)

C2\_Q25\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?** **Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q26\_1\_t1

**26. Has your relative/friend had an opportunity to go shopping for groceries, clothes, etc.?**

☐ No (skip to question 27)

C2\_Q26\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?** **Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q27\_1\_t1

**27. Has your relative/friend had an opportunity to go for a ride in the car, train or bus?**

☐ No (skip to question 28)

C2\_Q27\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?**

C2\_Q27\_3\_t1

**Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q28\_1\_t1

**28. Has your relative/friend had an opportunity to read or have stories read to him/her?**

☐ No (skip to question 29)

C2\_Q28\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?**

C2\_Q28\_3\_t1

**Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q29\_1\_t1

**29. Has your relative/friend had an opportunity to listen to the radio, tapes or CDs, or watch TV?**

☐ No (skip to question 30)

C2\_Q29\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?**

C2\_Q29\_3\_t1

**Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q30\_1\_t1

**30. Has your relative/friend had an opportunity to exercise, play or watch sports?**

☐ No (skip to question 31)

C2\_Q30\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?**

C2\_Q30\_3\_t1

**Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week



C2\_Q31\_1\_t1

**31. Has your relative/friend had an opportunity to play games or cards, do crosswords or puzzles?**

☐ No (skip to question 32)

C2\_Q31\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?**

C2\_Q31\_3\_t1

**Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q32\_1\_t1

**32. Has your relative/friend had an opportunity to do handiwork or crafts?**

☐ No (skip to question 33)

C2\_Q32\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?**

C2\_Q32\_3\_t1

**Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q33\_1\_t1

**33. Has your relative/friend had an opportunity to garden, plant care, indoors or outdoors?**

☐ No (skip to question 34)

C2\_Q33\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?**

C2\_Q33\_3\_t1

**Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C2\_Q34\_1\_t1

**34. Has your relative/friend had an opportunity to complete a task that was difficult for him/her?**

☐ No (skip to question 35)

C2\_Q34\_2\_t1

☐ Yes, if yes; **How often did s/he do the activity?**

C2\_Q34\_3\_t1

**Did s/he enjoy the activity?**

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

## Your relative's/friend's satisfaction with life

*Below are five statements with which you may agree or disagree. Please indicate how much you agree or disagree with each statement in relation to your relative/friend.*

C2\_Q35\_t1

**35. In most ways my relative's/friend's life is close to his/her ideal**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q36\_t1

**36. The conditions of my relative's/friend's life are excellent**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q37\_t1

**37. My relative/friend is satisfied with his/her life**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q38\_t1

**38. So far my relative/friend has got the important things s/he wants in life**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q39\_t1

**39. If my relative/friend could live his/her life over, s/he would change almost nothing**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Difficulties that your relative/friend may experience

*Your relative/friend is taking part in this study because s/he has been to the doctor, or attended a clinic, due to difficulties with memory, thinking or behaviour. We are interested in how you understand the changes and difficulties with memory, thinking or behaviour, or the condition, that your relative/friend experiences and what you think causes them.*

**40. Have you or a family member/doctor noticed that your relative/friend has been having difficulty with:**

- |             |   |                             |                              |
|-------------|---|-----------------------------|------------------------------|
| C2_Q40_1_t1 | <b>a. Concentration</b>                                   | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| C2_Q40_2_t1 | <b>b. Being forgetful</b>                                 | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| C2_Q40_3_t1 | <b>c. Remembering (e.g. recent events)</b>                | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| C2_Q40_4_t1 | <b>d. Thinking</b>  | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| C2_Q40_5_t1 | <b>e. Ability to say what s/he wants to say</b>           | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| C2_Q40_6_t1 | <b>f. Ability to manage his/her day-to-day activities</b> | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| C2_Q40_7_t1 | <b>g. Planning ahead</b>                                  | <input type="checkbox"/> No | <input type="checkbox"/> Yes |
| C2_Q40_8_t1 | <b>h. Making decisions</b>                                | <input type="checkbox"/> No | <input type="checkbox"/> Yes |

C2\_Q41\_t1  
**41. Is your relative/friend different in some way to how s/he used to be?**

☐ No    ☐ Yes

C2\_Q42\_t1  
**42. What do you call this difficulty/these difficulties, or condition, that your relative/friend has?**

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C2\_Q43\_1\_t1  
**43. Are you aware of a specific diagnosis? What does the doctor call it?**

☐ No    ☐ Yes

If yes, please specify:

C2\_Q43\_2\_t1

---

44. These are some of the things that other people say causes the kind of difficulties your relative/friend may experience; which do you think apply to your relative/friend?

*You may cross more than one box*

C2\_Q44\_1 ☐ Ageing

C2\_Q44\_2 ☐ Changes within the brain (e.g. something in your brain dies off)

C2\_Q44\_3 ☐ Illness or disease (e.g. stroke)

C2\_Q44\_4 ☐ Hereditary condition (e.g. genetics)

C2\_Q44\_5 ☐ Lifestyle/life events (e.g. stress, bereavement)

C2\_Q44\_6 ☐ Other; please specify:

C2\_Q44\_6\_oth\_t1

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---

C2\_Q44\_7 ☐ Don't know

C2\_Q44\_8\_t1

*If you have selected more than one option, which do you think is the most important cause?*

☐ Ageing

☐ Changes within the brain (e.g. something in your brain dies off)

☐ Illness or disease (e.g. stroke)

☐ Hereditary condition (e.g. genetics)

☐ Lifestyle/life events (e.g. stress, bereavement)

☐ Other; please specify:

C2\_Q44\_8\_oth\_t1

---

---

*We would now like you to indicate how much you agree or disagree with the following statements:*

C2\_Q45\_t1

**45. My relative's/friend's condition will stay the same as it is now**

☐ Strongly disagree   ☐ Disagree   ☐ Agree   ☐ Strongly agree

C2\_Q46\_t1

**46. My relative's/friend's condition will get better**

☐ Strongly disagree   ☐ Disagree   ☐ Agree   ☐ Strongly agree

C2\_Q47\_t1

**47. My relative's/friend's condition will get worse**

☐ Strongly disagree   ☐ Disagree   ☐ Agree   ☐ Strongly agree

C2\_Q48\_t1

**48. There are medications that can help control my relative's/friend's condition**

☐ Strongly disagree   ☐ Disagree   ☐ Agree   ☐ Strongly agree

C2\_Q49\_t1

**49. Nothing my relative/friend does will affect his/her condition**

☐ Strongly disagree   ☐ Disagree   ☐ Agree   ☐ Strongly agree

C2\_Q50\_t1

**50. There is a lot which my relative/friend can do to control the effects of the condition**

☐ Strongly disagree   ☐ Disagree   ☐ Agree   ☐ Strongly agree

## **Your relative's/friend's everyday activities**

*We would now like to ask about how well your relative/friend is able to carry out the following everyday activities.*

C2\_Q51\_t1

### **51. Can your relative/friend write cheques, pay bills, and keep financial records?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

C2\_Q52\_t1

### **52. Can your relative/friend assemble tax records, make out business or insurance papers?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

C2\_Q53\_t1

### **53. Can your relative/friend shop alone for clothes, household necessities and groceries?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

C2\_Q54\_t1

**54. Can your relative/friend play a game of skill (e.g. bridge, chess, cards, crosswords) or work on a hobby (e.g. gardening)?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

C2\_Q55\_t1

**55. Can your relative/friend heat water for coffee or tea and turn off the stove?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

C2\_Q56\_t1

**56. Can your relative/friend prepare a balanced meal?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

C2\_Q57\_t1

**57. Can your relative/friend keep track of current events?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

C2\_Q58\_t1

**58. Can your relative/friend pay attention to, understand and discuss a TV programme, book or magazine?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

C2\_Q59\_t1

**59. Can your relative/friend remember appointments, family occasions and to take his/her medication?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

C2\_Q60\_t1

**60. Can your relative/friend travel out of the immediate local area - driving, arranging to take buses etc.?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now

C2\_Q61\_t1

**61. Is your relative/friend able to use the telephone appropriately (e.g. finding and dialling correct numbers)?**

- ☐ Dependent on others
- ☐ Requires assistance but can still do the task
- ☐ Has difficulty but does by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as s/he has always done)
- ☐ Never did, but could do now





C2\_Q62\_t1

**62. Does your relative/friend need reminders or advice to manage chores, do shopping, cooking, play games, or handle money?**

- ☐ No
- ☐ Occasionally (i.e. at least once a month)
- ☐ Frequently (i.e. at least once a week)

C2\_Q63\_t1

**63. Does your relative/friend need help to remember important things such as appointments, recent events, or names of family or friends?**

- ☐ No
- ☐ Occasionally (i.e. at least once a month)
- ☐ Frequently (i.e. at least once a week)

C2\_Q64\_t1

**64. Does your relative/friend need frequent (at least once a month) help finding misplaced objects, keeping appointments, or maintaining health or safety (locking doors, taking medication)?**

- ☐ No ☐ Yes

C2\_Q65\_t1

**65. Does your relative/friend need household chores done for him/her?**

- ☐ No ☐ Yes

C2\_Q66\_t1

**66. Does your relative/friend need to be watched or kept company when awake?**

- ☐ No ☐ Yes

C2\_Q67\_t1

**67. Does your relative/friend need to be escorted when outside?**

- ☐ No ☐ Yes

C2\_Q68\_t1

**68. Does your relative/friend need to be accompanied when bathing or eating?**

- ☐ No ☐ Yes

C2\_Q69\_t1

**69. Does your relative/friend have to be dressed, washed, and groomed?**

- ☐ No ☐ Yes

C2\_Q70\_t1

**70. Does your relative/friend have to be taken to the toilet regularly to avoid incontinence?**

- ☐ No ☐ Yes

C2\_Q71\_t1

**71. Does your relative/friend have to be fed?**

☐ No ☐ Yes

C2\_Q72\_t1

**72. Does your relative/friend have to be turned, moved, or transferred?**

☐ No ☐ Yes

C2\_Q73\_t1

**73. Does your relative/friend wear an incontinence pad or a catheter?**

☐ No ☐ Yes

C2\_Q74\_t1

**74. Does your relative/friend need to be tube fed?**

☐ No ☐ Yes

C2\_Q75\_t1

**75. Has the food intake of your relative/friend declined over the past 3 months due to loss of appetite, digestive problems, chewing or swallowing difficulties?**

- ☐ Severe decrease in food intake
- ☐ Moderate decrease in food intake
- ☐ No decrease in food intake
- ☐ Don't know

C2\_Q76\_t1

**76. Has your relative/friend had any weight loss during the last 3 months?**

- ☐ Weight loss greater than 3 kg (6.6 lbs)
- ☐ Weight loss between 1 and 3 kg (2.2 and 6.6 lbs)
- ☐ No weight loss
- ☐ Don't know

## Your relative's/friend's emotional well-being

9069242035

Please answer the following questions based on changes that have occurred since your relative/friend first began to experience problems with memory, thinking or behaviour. Put a cross in the "yes" box only if the symptom(s) has been present in the **past month**, and then answer the follow up questions.

Otherwise, put a cross in the "no" box and go to the next question.

C2\_Q77\_1\_t1

**77. Does your relative/friend believe that others are stealing from him/her, or planning to harm him/her in some way?**

☐ No (skip to question 78)

☐ Yes

C2\_Q77\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

C2\_Q77\_3\_t1

☐ Severe (very marked or prominent; a dramatic change)

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

C2\_Q78\_1\_t1

**78. Does your relative/friend act as if s/he hears voices? Does s/he talk to people who are not there?**

☐ No (skip to question 79)

☐ Yes

C2\_Q78\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

C2\_Q78\_3\_t1

☐ Severe (very marked or prominent; a dramatic change)

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

C2\_Q79\_1\_t1

**79. Is your relative/friend stubborn and resistive to help from others?**

☐ No (skip to question 80)

☐ Yes

C2\_Q79\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

☐ Severe (very marked or prominent; a dramatic change)

C2\_Q79\_3\_t1

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

C2\_Q80\_1\_t1

**80. Does your relative/friend act as if s/he is sad or in low spirits? Does s/he cry?**

☐ No (skip to question 81)

☐ Yes

C2\_Q80\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

☐ Severe (very marked or prominent; a dramatic change)

C2\_Q80\_3\_t1

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

C2\_Q81\_1\_t1

**81. Does your relative/friend become upset when separated from you? Does s/he have any other signs of nervousness, such as shortness of breath, sighing, being unable to relax, or feeling excessively tense?**

☐ No (skip to question 82)

☐ Yes C2\_Q81\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

☐ Severe (very marked or prominent; a dramatic change)

C2\_Q81\_3\_t1

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

C2\_Q82\_1\_t1

**82. Does your relative/friend appear to feel too good or act excessively happy?**

☐ No (skip to question 83)

☐ Yes C2\_Q82\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

☐ Severe (very marked or prominent; a dramatic change)

C2\_Q82\_3\_t1

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

C2\_Q83\_1\_t1

**83. Does your relative/friend seem less interested in his/her usual activities and in the activities and plans of others?**

☐ No (skip to question 84)

☐ Yes

C2\_Q83\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

☐ Severe (very marked or prominent; a dramatic change)

C2\_Q83\_3\_t1

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

C2\_Q84\_1\_t1

**84. Does your relative/friend seem to act impulsively? For example, does s/he talk to strangers as if s/he knows them, or does s/he say things that may hurt people's feelings?**

☐ No (skip to question 85)

☐ Yes

C2\_Q84\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

☐ Severe (very marked or prominent; a dramatic change)

C2\_Q84\_3\_t1

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

C2\_Q85\_1\_t1

**85. Is your relative/friend impatient or cranky? Does s/he have difficulty coping with delays or waiting for planned activities?**

☐ No (skip to question 86)

☐ Yes

C2\_Q85\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

☐ Severe (very marked or prominent; a dramatic change)

C2\_Q85\_3\_t1

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

C2\_Q86\_1\_t1

**86. Does your relative/friend engage in repetitive activities, such as pacing around the house, handling buttons, wrapping string, or doing other things repeatedly?**

☐ No (skip to question 87)

☐ Yes

C2\_Q86\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

☐ Severe (very marked or prominent; a dramatic change)

C2\_Q86\_3\_t1

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)



C2\_Q87\_1\_t1

**87. Does your relative/friend wake you during the night, rise too early in the morning, or take excessive naps during the day?**

☐ No (skip to question 88)

☐ Yes

C2\_Q87\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

☐ Severe (very marked or prominent; a dramatic change)

C2\_Q87\_3\_t1

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

C2\_Q88\_1\_t1

**88. Has your relative/friend lost or gained weight, or had a change in the food s/he likes?**

☐ No (skip to question 89)

☐ Yes

C2\_Q88\_2\_t1

Rate the severity of the symptom (how it affects your relative/friend):

☐ Mild (noticeable, but not a significant change)

☐ Moderate (significant, but not a dramatic change)

☐ Severe (very marked or prominent; a dramatic change)

C2\_Q88\_3\_t1

Rate the distress you experience because of that symptom (how it affects you):

☐ Not distressing at all

☐ Minimal (slightly distressing, not a problem to cope with)

☐ Mild (not very distressing, generally easy to cope with)

☐ Moderate (fairly distressing, not always easy to cope with)

☐ Severe (very distressing, difficult to cope with)

☐ Extreme or very severe (extremely distressing, unable to cope with)

**Thank you for providing this information about your relative/friend**



## Now we would like to know more about you and your experiences

### Support from others

*These questions are about the types of support from others that you have in your life. Please answer the following questions by choosing an option that best describes your current situation.*

*Please add the exact number of people in the box provided if the number of people is more than ten.*

***Considering the people to whom you are related either by birth, marriage, adoption, etc.:***

C2\_Q89\_1\_t1

**89. How many relatives do you see or hear from at least once a month?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C2\_Q89\_2\_t1

If more than ten please specify:

C2\_Q90\_1\_t1

**90. How many relatives do you feel at ease with that you can talk about private matters?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C2\_Q90\_2\_t1

If more than ten please specify:

C2\_Q91\_1\_t1

**91. How many relatives do you feel close to such that you could call on them for help?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C2\_Q91\_2\_t1

If more than ten please specify:

***Considering all of your friends including those who live in your neighbourhood:***

C2\_Q92\_1\_t1

**92. How many of your friends do you see or hear from at least once a month?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C2\_Q92\_2\_t1

If more than ten please specify:

C2\_Q93\_1\_t1

**93. How many friends do you feel at ease with that you can talk about private matters?**

None	One	Two	Three	Four	Five	Six	Seven	Eight	Nine	Ten
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q93\_2\_t1

If more than ten please specify:

C2\_Q94\_1\_t1

**94. How many friends do you feel close to such that you could call on them for help?**

None	One	Two	Three	Four	Five	Six	Seven	Eight	Nine	Ten
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q94\_2\_t1

If more than ten please specify:

***Now considering both family and friends:***

C2\_Q95\_1\_t1

**95. Over the last week how many different people have visited you each day?**

None	One	Two	Three	Four	Five	Six	Seven	Eight	Nine	Ten
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q95\_2\_t1

If more than ten please specify:

C2\_Q96\_1\_t1

**96. Over the last week how many different people have telephoned you each day?**

None	One	Two	Three	Four	Five	Six	Seven	Eight	Nine	Ten
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q96\_2\_t1

If more than ten please specify:

C2\_Q97\_t1

**97. How satisfied are you with the support you receive from family?**

Very dissatisfied	Slightly dissatisfied	Neither satisfied nor dissatisfied	Slightly satisfied	Very satisfied	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q98\_t1

**98. How satisfied are you with the support you receive from friends?**

Very dissatisfied	Slightly dissatisfied	Neither satisfied nor dissatisfied	Slightly satisfied	Very satisfied	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please indicate for each of these statements the extent to which they apply to your situation or the way you feel now.

	Yes	More or less	No
C2_Q99_t1 99. I experience a general sense of emptiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C2_Q100_t1 100. There are plenty of people I can rely on when I have problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C2_Q101_t1 101. There are many people I can trust completely	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C2_Q102_t1 102. There are enough people I feel close to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C2_Q103_t1 103. I miss having people around	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C2_Q104_t1 104. I often feel rejected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C2_Q105_t1 105. Do you feel lonely?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### Your current relationship with your relative/friend

These questions are about the current relationship between you and your relative/friend.

C2_Q106_t1 106. Taking everything into consideration, how close do you feel in your relationship with your relative/friend?	Not close at all <input type="checkbox"/>	Not too close <input type="checkbox"/>	Quite close <input type="checkbox"/>	Close <input type="checkbox"/>	Very close <input type="checkbox"/>	Extremely close <input type="checkbox"/>
C2_Q107_t1 107. How is communication between yourself and your relative/friend? How well can you exchange ideas or talk about things that really concern you?	Not well at all <input type="checkbox"/>	Not too well <input type="checkbox"/>	Quite well <input type="checkbox"/>	Well <input type="checkbox"/>	Very well <input type="checkbox"/>	Extremely well <input type="checkbox"/>
C2_Q108_t1 108. In general, how similar are your views about life to those of your relative/friend?	Not similar at all <input type="checkbox"/>	Not too similar <input type="checkbox"/>	Quite similar <input type="checkbox"/>	Similar <input type="checkbox"/>	Very similar <input type="checkbox"/>	Extremely similar <input type="checkbox"/>

C2\_Q109\_t1

**109. How often do you and your relative/friend do things together?**

Never      Very rarely      Rarely      Occasionally      Frequently      Very frequently

☐      ☐      ☐      ☐      ☐      ☐

C2\_Q110\_t1

**110. Generally, how well do you and your relative/friend get along together?**

Not well at all      Not too well      Quite well      Well      Very well      Extremely well

☐      ☐      ☐      ☐      ☐      ☐

C2\_Q111\_t1

**111. Has there been a change in the nature or frequency (increase or decrease) of the sexual activities of your relative/friend?**

☐ No      ☐ Yes      ☐ Don't know

C2\_Q112\_t1

**112. Has your relative/friend displayed any inappropriate sexual behaviour?**

☐ No      ☐ Yes      ☐ Don't know

### **Your past relationship with your relative/friend**

*These questions are about the past relationship between you and your relative/friend. By the past we mean, let's say, **10 years ago**. If you have known your relative/friend for less than ten years skip to question 118.*

C2\_Q113\_0\_t1

**Have you known your relative/friend for 10 years or more?**

☐ No (skip to question 118)      ☐ Yes

C2\_Q113\_1\_t1

**113. Taking everything into consideration, how close did you feel in your relationship with your relative/friend?**

Not close at all      Not too close      Quite close      Close      Very close      Extremely close

☐      ☐      ☐      ☐      ☐      ☐

C2\_Q114\_t1

**114. How was communication between yourself and your relative/friend? How well could you exchange ideas or talk about things that really concerned you?**

Not well at all      Not too well      Quite well      Well      Very well      Extremely well

☐      ☐      ☐      ☐      ☐      ☐

C2\_Q115\_t1

**115. In general, how similar were your views about life to those of your relative/friend?**

Not similar at all      Not too similar      Quite similar      Similar      Very similar      Extremely similar

☐      ☐      ☐      ☐      ☐      ☐

C2\_Q116\_t1

**116. How often did you and your relative/friend do things together?**

- |                          |                          |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Never                    | Very rarely              | Rarely                   | Occasionally             | Frequently               | Very frequently          |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

C2\_Q117\_t1

**117. Generally, how well did you and your relative/friend get along together?**

- |                          |                          |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Not well at all          | Not too well             | Quite well               | Well                     | Very well                | Extremely well           |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

### Your physical health

C2\_Q118\_t1

**118. Please tell us the type and amount of physical activity involved in your work**

- ☐ I am not in employment  
(e.g. retired, retired for health reasons, unemployed, full-time carer etc.)
- ☐ I spend most of my time at work sitting (such as in an office)
- ☐ I spend most of my time at work standing or walking. However, my work does not require much intense physical effort (e.g. shop assistant, hairdresser, security guard, childminder etc.)
- ☐ My work involves definite physical effort including handling of heavy objects and use of tools (e.g. plumber, electrician, carpenter, cleaner, hospital nurse, gardener, postal delivery workers etc.)
- ☐ My work involves vigorous physical activity including handling of very heavy objects (e.g. scaffolder, construction worker, refuse collector etc.)

C2\_Q119\_t1

**119. During the last week, how many hours did you spend doing physical exercise such as swimming, jogging, aerobics, football, tennis, gym workout etc.? (This does not include walking)**

- |  |   |
|--|---|
| <input type="checkbox"/> None                        | <input type="checkbox"/> One hour but less than three hours |
| <input type="checkbox"/> Some but less than one hour | <input type="checkbox"/> Three hours or more                |

C2\_Q120\_t1

**120. During the last week, how many hours did you spend cycling, including cycling to work and during leisure time?**

- |  |   |
|--|---|
| <input type="checkbox"/> None                        | <input type="checkbox"/> One hour but less than three hours |
| <input type="checkbox"/> Some but less than one hour | <input type="checkbox"/> Three hours or more                |

C2\_Q121\_t1

**121. During the last week, how many hours did you spend walking, including walking to work, shopping, for pleasure etc.?**

- ☐ None ☐ One hour but less than three hours  
☐ Some but less than one hour ☐ Three hours or more

C2\_Q122\_t1

**122. During the last week, how many hours did you spend doing housework/childcare?**

- ☐ None ☐ One hour but less than three hours  
☐ Some but less than one hour ☐ Three hours or more

C2\_Q123\_t1

**123. During the last week, how many hours did you spend gardening/doing DIY?**

- ☐ None ☐ One hour but less than three hours  
☐ Some but less than one hour ☐ Three hours or more

C2\_Q124\_t1

**124. How would you describe your usual walking pace?**

- ☐ Slow pace (i.e. less than 3 mph)  
☐ Steady average pace  
☐ Brisk pace  
☐ Fast pace (i.e. over 4 mph)

C2\_Q125\_t1

**125. How old do you feel at the moment?**

- ☐ A lot older than my age  
☐ A little older  
☐ Not much older  
☐ About the same  
☐ Not much younger  
☐ A little younger  
☐ A lot younger than my age

## Your well-being

Please indicate for each of these statements how you have been feeling in the last fortnight. For example; if you have felt cheerful and in good spirits more than half of the time during the **last two weeks**, put a cross in the "more than half of the time" box.

C2\_Q126\_t1

### 126. I have felt cheerful and in good spirits

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q127\_t1

### 127. I have felt calm and relaxed

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q128\_t1

### 128. I have felt active and vigorous

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q129\_t1

### 129. I woke up feeling fresh and rested

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q130\_t1

### 130. My daily life has been filled with things that interest me

All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your quality of life

The following questions ask how you feel about your quality of life, both generally and in relation to particular aspects of life. If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks**.

Please read each question, assess your feelings, and put a cross in the box next to the word on the scale for each question that gives the best answer for you.

C2\_Q131\_t1

**131. How would you rate your quality of life?**

Very  
poor

☐

Poor

☐

Neither poor  
nor good

☐

Good

☐

Very  
good

☐

C2\_Q132\_t1

**132. How satisfied are you with your health?**

Very  
dissatisfied

☐

Dissatisfied

☐

Neither satisfied  
nor dissatisfied

☐

Satisfied

☐

Very  
satisfied

☐

The following questions ask about **how much** you have experienced certain things **in the last two weeks**.

C2\_Q133\_t1

**133. How much do you feel that pain prevents you from doing what you need to do?**

Not at all

☐

A little

☐

A moderate  
amount

☐

Very much

☐

An extreme  
amount

☐

C2\_Q134\_t1

**134. How much do you need medical treatment to function in your daily life?**

Not at all

☐

A little

☐

A moderate  
amount

☐

Very much

☐

An extreme  
amount

☐

C2\_Q135\_t1

**135. How much do you enjoy life?**

Not at all

☐

A little

☐

A moderate  
amount

☐

Very much

☐

An extreme  
amount

☐

C2\_Q136\_t1

**136. To what extent do you feel life to be meaningful?**

Not at all

☐

A little

☐

A moderate  
amount

☐

Very much

☐

Extremely

☐



C2\_Q137\_t1

**137. How well are you able to concentrate?**

Not at all

A little

A moderate  
amount

Very much

Extremely

☐☐☐☐☐

C2\_Q138\_t1

**138. How safe do you feel in your daily life?**

Not at all

A little

A moderate  
amount

Very much

Extremely

☐☐☐☐☐

C2\_Q139\_t1

**139. How healthy is your physical environment?**

Not at all

A little

A moderate  
amount

Very much

Extremely

☐☐☐☐☐

*The following questions ask about **how completely** you experience or were able to do certain things **in the last two weeks**.*

C2\_Q140\_t1

**140. Do you have enough energy for everyday life?**

Not at all

A little

Moderately

Mostly

Completely

☐☐☐☐☐

C2\_Q141\_t1

**141. Are you able to accept your bodily appearance?**

Not at all

A little

Moderately

Mostly

Completely

☐☐☐☐☐

C2\_Q142\_t1

**142. To what extent do you have enough money to meet your needs?**

Not at all

A little

Moderately

Mostly

Completely

☐☐☐☐☐

C2\_Q143\_t1

**143. How available to you is the information that you need in your day-to-day life?**

Not at all

A little

Moderately

Mostly

Completely

☐☐☐☐☐

C2\_Q144\_t1

**144. To what extent do you have the opportunity for leisure activities?**

Not at all

A little

Moderately

Mostly

Completely

☐☐☐☐☐

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the last two weeks**.

C2\_Q145\_t1

**145. How well are you able to get around?**

Very  
poor

☐

Poor

☐

Neither poor  
nor good

☐

Good

☐

Very  
good

☐

C2\_Q146\_t1

**146. How satisfied are you with your sleep?**

Very  
dissatisfied

☐

Dissatisfied

☐

Neither satisfied  
nor dissatisfied

☐

Satisfied

☐

Very  
satisfied

☐

C2\_Q147\_t1

**147. How satisfied are you with your ability to perform your daily living activities?**

Very  
dissatisfied

☐

Dissatisfied

☐

Neither satisfied  
nor dissatisfied

☐

Satisfied

☐

Very  
satisfied

☐

C2\_Q148\_t1

**148. How satisfied are you with your capacity for work?**

Very  
dissatisfied

☐

Dissatisfied

☐

Neither satisfied  
nor dissatisfied

☐

Satisfied

☐

Very  
satisfied

☐

C2\_Q149\_t1

**149. How satisfied are you with yourself?**

Very  
dissatisfied

☐

Dissatisfied

☐

Neither satisfied  
nor dissatisfied

☐

Satisfied

☐

Very  
satisfied

☐

C2\_Q150\_t1

**150. How satisfied are you with your personal relationships?**

Very  
dissatisfied

☐

Dissatisfied

☐

Neither satisfied  
nor dissatisfied

☐

Satisfied

☐

Very  
satisfied

☐

C2\_Q151\_t1

**151. How satisfied are you with your sex life?**

Very  
dissatisfied

☐

Dissatisfied

☐

Neither satisfied  
nor dissatisfied

☐

Satisfied

☐

Very  
satisfied

☐

C2\_Q152\_t1

**152. How satisfied are you with the support you get from your friends?**

Very  
dissatisfied

☐

Dissatisfied

☐

Neither satisfied  
nor dissatisfied

☐

Satisfied

☐

Very  
satisfied

☐

C2\_Q153\_t1

**153. How satisfied are you with the conditions of your living place?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q154\_t1

**154. How satisfied are you with your access to health services?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q155\_t1

**155. How satisfied are you with your transport?**

Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*The following question refers to **how often** you have felt or experienced certain things **in the last two weeks**.*

C2\_Q156\_t1

**156. How often do you have negative feelings, such as blue mood, despair, anxiety, depression?**

Never	Seldom	Quite often	Very often	Always
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

### **How you feel about yourself**

*Here is list of statements dealing with your general feelings about yourself.  
Please indicate how much you agree or disagree with each statement.*

C2\_Q157\_t1

**157. On the whole, I am satisfied with myself**

<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly disagree
---	--------------------------------	-----------------------------------	--

C2\_Q158\_t1

**158. At times, I think I am no good at all**

<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly disagree
---	--------------------------------	-----------------------------------	--

C2\_Q159\_t1

**159. I feel that I have a number of good qualities**

<input type="checkbox"/> Strongly agree	<input type="checkbox"/> Agree	<input type="checkbox"/> Disagree	<input type="checkbox"/> Strongly disagree
---	--------------------------------	-----------------------------------	--

☐ Strongly agree      ☐ Agree      ☐ Disagree      ☐ Strongly disagree

C2\_Q161\_t1

☐ Strongly agree      ☐ Agree      ☐ Disagree      ☐ Strongly disagree

C2\_Q162\_t1

☐ Strongly agree      ☐ Agree      ☐ Disagree      ☐ Strongly disagree

C2 Q163 t1

☐ Strongly agree      ☐ Agree      ☐ Disagree      ☒ Strongly disagree

C2 Q164 t1

☐ Strongly agree      ☐ Agree      ☐ Disagree      ☐ Strongly disagree

C2 Q165 t1

☐ Strongly agree      ☐ Agree      ☐ Disagree      ☐ Strongly disagree

C2\_Q166\_t1

☐ Strongly agree    ☒ Agree    ☐ Disagree    ☐ Strongly disagree

*Below are five statements with which you may agree or disagree. Please indicate how much you agree or disagree with each statement.*

C2\_Q167\_t1

Strongly disagree   Disagree   Slightly disagree   Neither agree nor disagree   Slightly agree   Agree   Strongly agree

C2 Q168 t1

Strongly disagree    Disagree    Slightly disagree    Neither agree nor disagree    Slightly agree    Agree    Strongly agree

C2\_Q169\_t1

**169. I am satisfied with my life**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q170\_t1

**170. So far I have got the important things I want in life**

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q171\_t1

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

Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**How you see yourself**

*For each of the following statements, please indicate which is closest to how true you think it is for you.*

C2\_Q172\_t1

**172. I can always manage to solve difficult problems if I try hard enough**

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Completely true

C2\_Q173\_t1

**173. If someone opposes me, I can find the means and ways to get what I want**

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Completely true

C2\_Q174\_t1

**174. It is easy for me to stick to my aims and accomplish my goals**

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Completely true

C2\_Q175\_t1

**175. I am confident that I could deal efficiently with unexpected events**

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Completely true

C2\_Q176\_t1

**176. Thanks to my resourcefulness, I know how to handle unforeseen situations**

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Completely true

C2\_Q177\_t1

**177. I can solve most problems if I invest the necessary effort**

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Completely true

C2\_Q178\_t1

**178. I can remain calm when facing difficulties because I can rely on my coping abilities**

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Completely true

C2\_Q179\_t1

**179. When I am confronted with a problem, I can usually find several solutions**

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Completely true

C2\_Q180\_t1

**180. If I am in trouble, I can usually think of a solution**

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Completely true

C2\_Q181\_t1

**181. I can usually handle whatever comes my way**

☐ Not at all true    ☐ Hardly true    ☐ Moderately true    ☐ Completely true

Please indicate the extent to which you agree or disagree with the following statements.

C2\_Q182\_t1

**182. I have high self-esteem**

Strongly  
disagree

☐

Disagree

☐

Neutral

☐

Agree

☐

Strongly  
agree

☐

C2\_Q183\_t1

**183. In uncertain times, I usually expect the best**

Strongly  
disagree

☐

Disagree

☐

Neutral

☐

Agree

☐

Strongly  
agree

☐

C2\_Q184\_t1

**184. If something can go wrong for me, it will**

Strongly  
disagree

☐

Disagree

☐

Neutral

☐

Agree

☐

Strongly  
agree

☐

C2\_Q185\_t1

**185. I'm always optimistic about the future**

Strongly  
disagree

☐

Disagree

☐

Neutral

☐

Agree

☐

Strongly  
agree

☐

C2\_Q186\_t1

**186. I hardly ever expect things to go my way**

Strongly  
disagree

☐

Disagree

☐

Neutral

☐

Agree

☐

Strongly  
agree

☐

C2\_Q187\_t1

**187. I rarely count on good things happening to me**

Strongly  
disagree

☐

Disagree

☐

Neutral

☐

Agree

☐

Strongly  
agree

☐

C2\_Q188\_t1

**188. Overall, I expect more good things to happen to me than bad**

Strongly  
disagree

☐

Disagree

☐

Neutral

☐

Agree

☐

Strongly  
agree

☐

On the following pages, there are phrases describing people's behaviours. Please indicate how accurately each statement describes you. Describe yourself as you generally are now, not as you wish to be in the future. Describe yourself as you honestly see yourself, in relation to other people you know of the same sex as you are, and roughly the same age as you.

C2\_Q189\_t1

**189. I am the life of the party**

Very inaccurate	Moderately inaccurate	Neither inaccurate nor accurate	Moderately accurate	Very accurate
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q190\_t1

**190. I sympathise with others' feelings**

Very inaccurate	Moderately inaccurate	Neither inaccurate nor accurate	Moderately accurate	Very accurate
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q191\_t1

**191. I get chores done right away**

Very inaccurate	Moderately inaccurate	Neither inaccurate nor accurate	Moderately accurate	Very accurate
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q192\_t1

**192. I have frequent mood swings**

Very inaccurate	Moderately inaccurate	Neither inaccurate nor accurate	Moderately accurate	Very accurate
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q193\_t1

**193. I have a vivid imagination**

Very inaccurate	Moderately inaccurate	Neither inaccurate nor accurate	Moderately accurate	Very accurate
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q194\_t1

**194. I don't talk a lot**

Very inaccurate	Moderately inaccurate	Neither inaccurate nor accurate	Moderately accurate	Very accurate
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



C2\_Q195\_t1

**195. I am not interested in other people's problems**Very  
inaccurate  
☐Moderately  
inaccurate  
☐Neither inaccurate  
nor accurate  
☐Moderately  
accurate  
☐Very  
accurate  
☐

C2\_Q196\_t1

**196. I often forget to put things back in their proper place**Very  
inaccurate  
☐Moderately  
inaccurate  
☐Neither inaccurate  
nor accurate  
☐Moderately  
accurate  
☐Very  
accurate  
☐

C2\_Q197\_t1

**197. I am relaxed most of the time**Very  
inaccurate  
☐Moderately  
inaccurate  
☐Neither inaccurate  
nor accurate  
☐Moderately  
accurate  
☐Very  
accurate  
☐

C2\_Q198\_t1

**198. I am not interested in abstract ideas**Very  
inaccurate  
☐Moderately  
inaccurate  
☐Neither inaccurate  
nor accurate  
☐Moderately  
accurate  
☐Very  
accurate  
☐

C2\_Q199\_t1

**199. I talk to a lot of different people at parties**Very  
inaccurate  
☐Moderately  
inaccurate  
☐Neither inaccurate  
nor accurate  
☐Moderately  
accurate  
☐Very  
accurate  
☐

C2\_Q200\_t1

**200. I feel others' emotions**Very  
inaccurate  
☐Moderately  
inaccurate  
☐Neither inaccurate  
nor accurate  
☐Moderately  
accurate  
☐Very  
accurate  
☐

C2\_Q201\_t1

**201. I like order**Very  
inaccurate  
☐Moderately  
inaccurate  
☐Neither inaccurate  
nor accurate  
☐Moderately  
accurate  
☐Very  
accurate  
☐

**202. I get upset easily**

Very  
inaccurate  
☐

Moderately  
inaccurate  
☐

Neither inaccurate  
nor accurate  
☐

Moderately  
accurate  
☐

Very  
accurate  
☐

C2\_Q203\_t1

**203. I have difficulty understanding abstract ideas**

Very  
inaccurate  
☐

Moderately  
inaccurate  
☐

Neither inaccurate  
nor accurate  
☐

Moderately  
accurate  
☐

Very  
accurate  
☐

C2\_Q204\_t1

**204. I keep in the background**

Very  
inaccurate  
☐

Moderately  
inaccurate  
☐

Neither inaccurate  
nor accurate  
☐

Moderately  
accurate  
☐

Very  
accurate  
☐

C2\_Q205\_t1

**205. I am not really interested in others**

Very  
inaccurate  
☐

Moderately  
inaccurate  
☐

Neither inaccurate  
nor accurate  
☐

Moderately  
accurate  
☐

Very  
accurate  
☐

C2\_Q206\_t1

**206. I make a mess of things**

Very  
inaccurate  
☐

Moderately  
inaccurate  
☐

Neither inaccurate  
nor accurate  
☐

Moderately  
accurate  
☐

Very  
accurate  
☐

C2\_Q207\_t1

**207. I seldom feel blue**

Very  
inaccurate  
☐

Moderately  
inaccurate  
☐

Neither inaccurate  
nor accurate  
☐

Moderately  
accurate  
☐

Very  
accurate  
☐

C2\_Q208\_t1

**208. I do not have a good imagination**

Very  
inaccurate  
☐

Moderately  
inaccurate  
☐

Neither inaccurate  
nor accurate  
☐

Moderately  
accurate  
☐

Very  
accurate  
☐

## Your mood

*Below is a list of the ways you might have felt or behaved recently. Please mark the boxes to say how often you have felt this way in the **past week or so**.*

C2\_Q209\_t1

**209. My appetite was poor**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q210\_t1

**210. I could not shake off the blues**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q211\_t1

**211. I had trouble keeping my mind on what I was doing**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q212\_t1

**212. I felt depressed**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q213\_t1

**213. My sleep was restless**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q214\_t1

**214. I felt sad**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q215\_t1

**215. I could not get going**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q216\_t1

**216. Nothing made me happy**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q217\_t1

**217. I felt like a bad person**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q218\_t1

**218. I lost interest in my usual activities**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q219\_t1

**219. I slept much more than usual**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q220\_t1

**220. I felt like I was moving too slowly**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q221\_t1

**221. I felt fidgety**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q222\_t1

**222. I wished I were dead**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

--

C2\_Q223\_t1

**223. I wanted to hurt myself**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q224\_t1

**224. I was tired all the time**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q225\_t1

**225. I did not like myself**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q226\_t1

**226. I lost a lot of weight  
without trying to**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q227\_t1

**227. I had a lot of trouble  
getting to sleep**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

C2\_Q228\_t1

**228. I could not focus on the  
important things**

- ☐ Not at all *or* Less than 1 day last week
- ☐ 1 - 2 days last week
- ☐ 3 - 4 days last week
- ☐ 5 - 7 days last week
- ☐ Nearly every day for 2 weeks

## Your experiences of supporting your relative/friend

*Here are some thoughts and feelings that people sometimes have about themselves as carers. You may not see yourself as a carer, but this is a term that is often used, and we have used it here for convenience. Please answer the questions in relation to your relationship with your relative/friend who is participating in the study. How much does each statement describe your thoughts about your role as a carer?*

C2\_Q229\_t1

**229. Do you feel you cope well as a carer?**

- ☐ Never ☐ Sometimes ☐ Often ☐ Always

C2\_Q230\_t1

**230. How much do you wish you were free to lead a life of your own?**

- ☐ Not at all ☐ Just a little ☐ Somewhat ☐ Very much

C2\_Q231\_t1

**231. How much do you feel trapped by your relative's/friend's memory, thinking or behaviour difficulties?**

- ☐ Not at all ☐ Just a little ☐ Somewhat ☐ Very much

C2\_Q232\_t1

**232. How much do you wish you could just run away?**

- ☐ Not at all ☐ Just a little ☐ Somewhat ☐ Very much

C2\_Q233\_t1

**233. If you were ill, is there anybody who would step in to help your relative/friend?**

- ☐ Yes, I could find someone quite easily  
☐ Yes, I could find someone but with some difficulty  
☐ No, there is no one

C2\_Q234\_t1

**234. If you needed a break from your caring role, is there someone who would look after your relative/friend for you?**

- ☐ Yes, I could find someone quite easily  
☐ Yes, I could find someone but with some difficulty  
☐ No, there is no one
-

C2\_Q235\_t1

**235. How often do you feel confident that you are meeting the needs of your relative/friend?**

☐ Never   ☐ Some of the time   ☐ Most of the time   ☐ All of the time

C2\_Q236\_t1

**236. How often do you feel that you are doing a good job as a carer?**

☐ Never   ☐ Some of the time   ☐ Most of the time   ☐ All of the time

C2\_Q237\_t1

**237. How often do you feel competent in your ability to care for your relative/friend?**

☐ Never   ☐ Some of the time   ☐ Most of the time   ☐ All of the time

### How you are managing

*Please think about how often/how much each of the statements below applies to you during the **past two weeks**.*

C2\_Q238\_t1

**238. Do you ever feel that you can no longer cope with the situation?**

Never/ not at all	Rarely/ a little	Sometimes/ moderately	Frequently/ quite a lot	Always/ considerably
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q239\_t1

**239. Do you ever feel that you need a holiday?**

Never/ not at all	Rarely/ a little	Sometimes/ moderately	Frequently/ quite a lot	Always/ considerably
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q240\_t1

**240. Do you ever get depressed by the situation?**

Never/ not at all	Rarely/ a little	Sometimes/ moderately	Frequently/ quite a lot	Always/ considerably
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q241\_t1

**241. Has your own health suffered at all?**

Never/ not at all	Rarely/ a little	Sometimes/ moderately	Frequently/ quite a lot	Always/ considerably
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2\_Q242\_t1

**242. Do you worry about accidents happening to your relative/friend?**

Never/ not at all	Rarely/ a little	Sometimes/ moderately	Frequently/ quite a lot	Always/ considerably
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



C2\_Q243\_t1

**243. Do you ever feel there will be no end to the problem?**Never/  
not at all☐Rarely/  
a little☐Sometimes/  
moderately☐Frequently/  
quite a lot☐Always/  
considerably☐

C2\_Q244\_t1

**244. Do you find it difficult to get away on holiday?**Never/  
not at all☐Rarely/  
a little☐Sometimes/  
moderately☐Frequently/  
quite a lot☐Always/  
considerably☐

C2\_Q245\_t1

**245. How much has your social life been affected?**Never/  
not at all☐Rarely/  
a little☐Sometimes/  
moderately☐Frequently/  
quite a lot☐Always/  
considerably☐

C2\_Q246\_t1

**246. How much has the household routine been upset?**Never/  
not at all☐Rarely/  
a little☐Sometimes/  
moderately☐Frequently/  
quite a lot☐Always/  
considerably☐

C2\_Q247\_t1

**247. Is your sleep interrupted by your relative/friend?**Never/  
not at all☐Rarely/  
a little☐Sometimes/  
moderately☐Frequently/  
quite a lot☐Always/  
considerably☐

C2\_Q248\_t1

**248. Has your standard of living been reduced?**Never/  
not at all☐Rarely/  
a little☐Sometimes/  
moderately☐Frequently/  
quite a lot☐Always/  
considerably☐

C2\_Q249\_t1

**249. Do you ever feel embarrassed by your relative/friend?**Never/  
not at all☐Rarely/  
a little☐Sometimes/  
moderately☐Frequently/  
quite a lot☐Always/  
considerably☐

C2\_Q250\_t1

**250. Are you prevented from having visitors?**Never/  
not at all☐Rarely/  
a little☐Sometimes/  
moderately☐Frequently/  
quite a lot☐Always/  
considerably☐

C2\_Q251\_t1

**251. Do you ever get cross or angry with your relative/friend?**Never/  
not at all☐Rarely/  
a little☐Sometimes/  
moderately☐Frequently/  
quite a lot☐Always/  
considerably☐

C2\_Q252\_t1

**252. Do you ever feel frustrated with your relative/friend?**Never/  
not at all☐Rarely/  
a little☐Sometimes/  
moderately☐Frequently/  
quite a lot☐Always/  
considerably☐

*Some people say that, despite all the difficulties involved in giving care to a family member or friend with problems in memory, thinking or behaviour, or other health problems, good things have come out of their experience too. Listed below are a few of the good things some people report. Please say how much you agree or disagree with these statements.*

C2\_Q253\_t1

**253. Providing help to my relative/friend has made me feel more useful**Disagree  
a lot☐Disagree  
a little☐Neither agree  
nor disagree☐Agree  
a little☐Agree  
a lot☐

C2\_Q254\_t1

**254. Providing help to my relative/friend has made me feel good about myself**Disagree  
a lot☐Disagree  
a little☐Neither agree  
nor disagree☐Agree  
a little☐Agree  
a lot☐

C2\_Q255\_t1

**255. Providing help to my relative/friend has made me feel needed**Disagree  
a lot☐Disagree  
a little☐Neither agree  
nor disagree☐Agree  
a little☐Agree  
a lot☐

C2\_Q256\_t1

**256. Providing help to my relative/friend has made me feel appreciated**Disagree  
a lot☐Disagree  
a little☐Neither agree  
nor disagree☐Agree  
a little☐Agree  
a lot☐

C2\_Q257\_t1

**257. Providing help to my relative/friend has made me feel important**

Disagree  
a lot  
☐

Disagree  
a little  
☐

Neither agree  
nor disagree  
☐

Agree  
a little  
☐

Agree  
a lot  
☐

C2\_Q258\_t1

**258. Providing help to my relative/friend has made me feel strong and confident**

Disagree  
a lot  
☐

Disagree  
a little  
☐

Neither agree  
nor disagree  
☐

Agree  
a little  
☐

Agree  
a lot  
☐

C2\_Q259\_t1

**259. Providing help to my relative/friend has enabled me to appreciate life more**

Disagree  
a lot  
☐

Disagree  
a little  
☐

Neither agree  
nor disagree  
☐

Agree  
a little  
☐

Agree  
a lot  
☐

C2\_Q260\_t1

**260. Providing help to my relative/friend has enabled me to develop a more positive attitude towards life**

Disagree  
a lot  
☐

Disagree  
a little  
☐

Neither agree  
nor disagree  
☐

Agree  
a little  
☐

Agree  
a lot  
☐

C2\_Q261\_t1

**261. Providing help to my relative/friend has strengthened my relationships with others**

Disagree  
a lot  
☐

Disagree  
a little  
☐

Neither agree  
nor disagree  
☐

Agree  
a little  
☐

Agree  
a lot  
☐

*Here are some things that people do to make caring easier for themselves.  
How often do you behave in these ways?*

C2\_Q262\_t1

**262. How often do you try to be firm in directing your relative's/friend's behaviour?**

☐ Never

☐ Once in a while

☐ Fairly often

☐ Very often

C2\_Q263\_t1

**263. How often do you do things you really have to do and let the other things slide?**

☐ Never

☐ Once in a while

☐ Fairly often

☐ Very often

C2\_Q264\_t1

**264. How often do you try to find ways to keep your relative/friend busy?**☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2\_Q265\_t1

**265. How often do you try to learn as much as you can about memory, thinking or behaviour difficulties (e.g. read books, talk to doctors, go to lectures)?**☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

*Here are ways that some people think about caring, and about the relative/friend they support. How often do you think in these ways?*

C2\_Q266\_t1

**266. How often do you try to accept your relative/friend as s/he is, not as you wish s/he could be?**☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2\_Q267\_t1

**267. How often do you try to think about the present rather than the future?**☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2\_Q268\_t1

**268. How often do you try to keep your sense of humour?**☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2\_Q269\_t1

**269. How often do you remind yourself that others are worse off?**☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2\_Q270\_t1

**270. How often do you try to think about the good times you had in the past?**☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2\_Q271\_t1

**271. How often do you look for the things that you always liked and admired in your relative/friend?**☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2\_Q272\_t1

**272. How often do you try to make sense of your relative's/friend's memory, thinking or behaviour difficulties?**

☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2\_Q273\_t1

**273. How often do you pray for strength to keep going?**

☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2\_Q274\_t1

**274. How often do you remind yourself that this is something to expect as people get older?**

☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

**Thank you for taking the time to answer these questions. The information and insight that you have provided is very valuable to us.**

*Now we would like to offer you the opportunity to give us your views by responding to some more general questions where you can tell us more about your experiences. We are interested in what is helpful for people who have difficulties with memory, thinking or behaviour, that may have been described as dementia or an associated condition (we will call this 'dementia' from here on, for convenience) and for those who support and care for them.*

These questions are optional.

C2\_Q275\_t1

**275. How do you feel your relative/friend is doing?**

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C2\_Q276\_t1

**276. What does living well with dementia mean for you?**

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C2\_Q277\_t1

277. What do you think makes it easier to live well with dementia?

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C2\_Q278\_t1

278. What do you think makes it more difficult to live well with dementia?

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C2\_Q279\_t1

279. How have you found the experience of supporting or caring for your relative/friend?

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C2\_Q280\_t1

280. What is currently your greatest difficulty or concern in caring for your relative/friend?

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C2\_Q281\_t1

281. What is your greatest satisfaction in caring for your relative/friend?

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Thank you for completing these additional questions. Please return this questionnaire to the researcher.

## TO BE COMPLETED BY THE RESEARCHER

Instructions for the researcher: Checklist/Field notes  
At the end of each part of the assessment please note reasons for any items which were not completed:

- ☐ Please check that all questions have been completed and cross the appropriate boxes below
- ☐ All items have been completed (if so skip to field notes)

**Your relative's/friend's quality of life**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your relative's/friend's well-being**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**How your relative/friend spends his/her time**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your relative's/friend's satisfaction with life**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Difficulties that your relative/friend may experience**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your relative's/friend's everyday activities**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your relative's/friend's emotional well-being**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Support from others**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your current relationship with your relative/friend**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your past relationship with your relative/friend**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your physical health**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your well-being**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your quality of life**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**How you feel about yourself**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your satisfaction with life**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**How you see yourself**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your mood**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your experiences of supporting your relative/friend**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |



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☐ Complete
 ☐ Refused
 ☐ No time to complete  
☐ Partial (give reason)
 ☐ Tiredness
 ☐ Questions not understood  
☐ Other; please specify: \_\_\_\_\_

☐ Yes    ☐ No    ☐ Partial

We would like you to record any additional information about the assessment which you may think is useful.

☐ No    ☐ Yes, please write your notes here:

DO NOT PRINT/CO



P ID

Participant ID

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Researcher ID

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# Enhancing Active Life and Living Well: The IDEAL Study

## Relative/Friend Part 3



[www.IDEALproject.org.uk](http://www.IDEALproject.org.uk)

## Enhancing Active Life and Living Well: The IDEAL Study

### What is the purpose of the study?

This study aims to understand what 'living well' means to people who have difficulties with memory, thinking or behaviour, that may have been described as dementia or an associated condition, both from their own perspective and the perspective of those who are close to them. You have been asked to take part as you provide help and assistance to someone with a condition of this kind.

### What information are we going to ask for?

The information we will be asking you in this part will consist of two sections:

- Firstly, we will ask you to provide **some background information and information about the well-being of your relative/friend.**
- Secondly, we will ask you to provide information **about your experiences of supporting your relative/friend.**

The information you provide is extremely valuable to us. All information you provide will be treated in strictest confidence.

Please be as honest and as accurate as you can throughout. There are no "right" or "wrong" answers. Answer according to your own feelings, rather than how you think "most people" would answer.

### This information will be scanned by a computer.

- Use black or blue ink to answer.
- For each question please cross ☐ clearly inside **one** box.
- For some questions you will be instructed that you may cross more than one box.
- Don't worry if you make a mistake; simply fill in the box ☐ and put a cross ☐ in the correct box.
- For some questions you will be asked to write information in boxes. When you see boxes like these, please write a single letter or number in each box provided.

For example; what is your age? 

6	5
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- For some questions you will be asked to write your answers in the space provided; please write only in the space provided. If you make a mistake or change your mind, just cross out the word and continue writing, but please make sure you write only in the space provided.

### What to do if you have any questions or need help.

If you have any queries about how to complete the following questions please ask the researcher.

**0570486381**

## Your relative's/friend's background

*The following questions are about your relative's/friend's background. These questions ask about his/her marital status, current and past employment history and health.*

**2. What is your relative's/friend's current legal marital status?**

- ☐ Single; that is, never married
- ☐ Married; first and only marriage
- ☐ Remarried; second or later marriage
- ☐ A civil partner in a legally-recognised civil partnership
- ☐ Legally separated
- ☐ Divorced
- ☐ Widowed
- ☐ Cohabiting
- ☐ Other; please specify:

C3 Q2 oth t1

C3 Q3 1 t1

**3. If your relative/friend is married/widowed/separated/divorced how many years has s/he been married/widowed/separated/divorced?** (If your relative/friend has been married before, please only write for how many years s/he has been married to his/her current spouse.)

C3 Q3 2 t1

☐ Don't know

## Your relative's/friend's employment/job

*Now I'm going to ask you some questions about your relative's/friend's current employment status and the type of work s/he does/did.*

C3 Q4 1 t1

4. Which of the following best describes your relative's/friend's current employment situation?

- ☐
- In paid employment (including self-employment/business owner)

*If s/he is in paid employment; what is/are his/her current job(s)/occupation(s)?*

C3 O4 2 t1

If s/he is in paid employment; how many hours of work per week does s/he do in total across all of his/her jobs?   (skip to question 5)

C3	Q4	(sk
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(skip to question 5)

- ☐ Retired; if retired **at what age did s/he retire?** C3\_Q4\_t1
- ☐ Unable to work
- ☐ Unemployed and looking for work
- ☐ At home and not looking for work (e.g. housewife/househusband, full time carer)
- ☐ Doing voluntary (unpaid) work
- ☐ Student (full or part-time)
- ☐ Other: please describe: C3\_Q4\_oth\_t1

C3 Q4 oth tl

**5. What is/has been your relative's/friend's main occupation for most of his/her working life?** *(This should be the occupation that was held for the longest period, not the most recent. Please include a full job title.)*

C3\_Q5\_t1

**6. What type of work is/was this?** *(Please include a description of the work and a description of the employer including the name of the employer.)*

C3\_Q6\_t1

C3\_Q7\_t1

**7. Is/was your relative/friend self-employed/a business owner?**

☐ No ☐ Yes ☐ Don't know

C3\_Q8\_t1

**8. Is/was your relative/friend a foreman, supervisor or manager?**

☐ No (skip to question 11)

☐ Foreman ☐ Supervisor ☐ Manager ☐ Don't know

C3\_Q9\_t1

**9. If your relative/friend is/was a foreman/supervisor/manager: What did/does your relative/friend do?**

C3\_Q10\_t1

**10. How many employees is/was your relative/friend responsible for?**

☐ Less than 25 ☐ 25 or more ☐ Don't know

### **Your relative's/friend's health**

C3\_Q11\_t1

**11. Please tell us the type and amount of physical activity involved in your relative's/friend's work.**

☐ S/he is not in employment (e.g. retired, retired for health reasons, unemployed, full-time carer etc.)

☐ S/he spends most of his/her time at work sitting (such as in an office)

☐ S/he spends most of his/her time at work standing or walking. However, his/her work does not require much intense physical effort (e.g. shop assistant, hairdresser, security guard, childminder, etc.)

☐ His/her work involves definite physical effort including handling of heavy objects and use of tools (e.g. plumber, electrician, carpenter, cleaner, hospital nurse, gardener, postal delivery workers etc.)

☐ His/her work involves vigorous physical activity including handling of very heavy objects (e.g. scaffolder, construction worker, refuse collector, etc.)

C3\_Q12\_t1

12. During the last week, how many hours did your relative/friend spend doing physical exercise such as swimming, jogging, aerobics, football, tennis, gym workout etc.? (This does not include walking)

None

☐

Some but less than one hour

☐

One hour but less than three hours

☐

Three hours or more

☐

C3\_Q13\_t1

13. During the last week, how many hours did your relative/friend spend cycling, including cycling to work and during leisure time?

None

☐

Some but less than one hour

☐

One hour but less than three hours

☐

Three hours or more

☐

C3\_Q14\_t1

14. During the last week, how many hours did your relative/friend spend walking, including walking to work, shopping, for pleasure etc.?

None

☐

Some but less than one hour

☐

One hour but less than three hours

☐

Three hours or more

☐

C3\_Q15\_t1

15. During the last week, how many hours did your relative/friend spend doing housework/childcare?

None

☐

Some but less than one hour

☐

One hour but less than three hours

☐

Three hours or more

☐

C3\_Q16\_t1

16. During the last week, how many hours did your relative/friend spend gardening/doing DIY?

None

☐

Some but less than one hour

☐

One hour but less than three hours

☐

Three hours or more

☐

C3\_Q17\_t1

17. How would you describe your relative's/friend's usual walking pace?

☐ Slow pace (i.e. less than 3 mph)

☐ Steady average pace

☐ Brisk pace

☐ Fast pace (i.e. over 4 mph)

C3\_Q18\_1\_t1

18. Has your relative/friend fallen down in the last two years (for any reason)?

☐ No (skip to question 19)

☐ Yes; how many times: ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number:

☐ Don't know

C3\_Q18\_4\_t1

If yes, did your relative/friend injure himself/herself seriously enough to need medical treatment?

☐ No ☐ Yes ☐ Don't know

C3\_Q19\_1\_t1

**19. Is there a named health professional whom you or your relative/friend can contact at any time, for example a care coordinator, key worker or specialist nurse?**

- ☐ No (skip to question 21)  
☐ Yes; please describe his/her role below

C3\_Q19\_2\_t1

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- ☐ Don't know

C3\_Q20\_t1

**20. Is the health professional in place to help with your relative's/friend's memory, thinking or behaviour difficulties?**

- ☐ No   ☐ Yes   ☐ Don't know

C3\_Q21\_t1

**21. How well would you rate your relative's/friend's sleep these days?**

- ☐ Very poor  
☐ Poor  
☐ Fair  
☐ Good (skip to question 23)  
☐ Very good (skip to question 23)

**22. Why do you think the quality of your relative's/friend's sleep is not as good as it could be? Please choose from the following options:**

You may cross more than one box

C3\_Q22\_1\_t1

- ☐ Not being able to get to sleep

C3\_Q22\_2\_t1

- ☐ Waking up too early and not being able to get back to sleep

C3\_Q22\_3\_t1

- ☐ Waking up several times throughout the night

C3\_Q22\_4\_t1

- ☐ Having bad dreams

C3\_Q22\_5\_t1

- ☐ Being uncomfortable

C3\_Q22\_6\_t1

- ☐ Other; please specify:

C3\_Q22\_oth\_t1

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C3\_Q23\_1\_t1

**23. Do you feel your relative's/friend's sleep pattern has changed over the last 12 months?**

- ☐ No   ☐ Yes; if yes, please describe:

C3\_Q23\_2\_t1

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C3\_Q23\_3\_t1

- ☐ Don't know

C3\_Q24\_t1

**24. Would you say your relative's/friend's appetite is:**

- ☐ Very poor   ☐ Poor   ☐ Fair   ☐ Good   ☐ Very good

## Your relative's/friend's health state

*We would like to know about how you feel about your relative's/friend's health in a number of areas. Please indicate which statements best describe your relative's/friend's health state today.*

**All EQ-5D questions removed in line with user agreement**

**C3\_Q30\_t1 to C3\_Q35\_t1 are from the AAIQOL measure, provided as below:**

Author and Owner: Steven Albert

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Contact information and permission to use: Mapi Research Trust, Lyon, France.

E-mail: PROinformation@mapi-trust.org – Internet: www.proqolid.org

## Your relative's/friend's emotions

*We would like to know how frequently your relative/friend has exhibited signs of various types of emotion over the past **2 weeks**. We have listed some possible signs of such emotions. If you see **no sign** of a particular feeling, cross "Never". Use "Can't tell" only when you are really uncertain.*

**C3\_Q30\_t1**

**30. Have you seen any signs of pleasure e.g. smiling; laughing; stroking; touching with affection; nodding; singing; arm or hand outreach; open-arm gesture?**

Never	Only once	Two to six times per week	One or two times per day	Several (3+) times per day	Can't tell
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



C3\_Q31\_t1

**31. Have you seen any signs of anger e.g. clenching teeth; grimacing; shouting; cursing; berating; pushing; physical aggression?**

Never	Only once	Two to six times per week	One or two times per day	Several (3+) times per day	Can't tell
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q32\_t1

**32. Have you seen any signs of anxiety e.g. furrowed brow; physical restlessness; repeated or agitated motions; facial expression of fear or worry; sighing; withdrawing from others; tremor; tight facial muscles; calling repetitively?**

Never	Only once	Two to six times per week	One or two times per day	Several (3+) times per day	Can't tell
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q33\_t1

**33. Have you seen any signs of depression e.g. crying; tears; moaning; gloomy expression (mouth turned down at corners)?**

Never	Only once	Two to six times per week	One or two times per day	Several (3+) times per day	Can't tell
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q34\_t1

**34. Have you seen any signs of interest e.g. eyes follow object; fixing attention on object or person; examining things or people around; feedback to others by an expression of the face, a movement or a word; eye contact maintained; body or vocal response to music; looking around; turning body or moving towards person or object?**

Never	Only once	Two to six times per week	One or two times per day	Several (3+) times per day	Can't tell
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q35\_t1

**35. Have you seen any signs of contentment e.g. comfortable posture (sitting or lying down); smooth facial muscles; lack of tension in limbs or neck; slow movements; relaxed body stance; relaxing of frown or worry line?**

Never	Only once	Two to six times per week	One or two times per day	Several (3+) times per day	Can't tell
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

## Your relative's/friend's support network

These questions are about the types of support from other people that your relative/friend has in his/her life. Please answer the following questions by choosing an option that best describes his/her current situation. Please add the exact number of people in the box provided if the number of people is more than ten.

**Considering the people to whom your relative/friend is related either by birth, marriage, adoption, etc.:**

C3\_Q36\_1\_t1

**36. How many relatives does s/he see or hear from at least once a month?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C3\_Q36\_2\_t1

If more than ten please specify:

Don't know  
☐

C3\_Q37\_1\_t1

**37. How many relatives does s/he feel at ease with that s/he can talk about private matters?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C3\_Q37\_2\_t1

If more than ten please specify:

Don't know  
☐

C3\_Q38\_1\_t1

**38. How many relatives does s/he feel close to such that s/he could call on them for help?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C3\_Q38\_2\_t1

If more than ten please specify:

Don't know  
☐

**Considering all of his/her friends including those who live in his/her neighbourhood:**

C3\_Q39\_1\_t1

**39. How many of his/her friends does s/he see or hear from at least once a month?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C3\_Q39\_2\_t1

If more than ten please specify:

Don't know  
☐

C3\_Q40\_1\_t1

**40. How many friends does s/he feel at ease with that s/he can talk about private matters?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C3\_Q40\_2\_t1

If more than ten please specify:

Don't know  
☐

C3\_Q40\_1\_t1

**41. How many friends does s/he feel close to such that s/he could call on them for help?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C3\_Q40\_2\_t1

If more than ten please specify:

Don't know  
☐

**Now considering both family and friends:**

C3\_Q42\_1\_t1

**42. Over the last week how many different people have visited him/her each day?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C3\_Q42\_2\_t1

If more than ten please specify:

Don't know  
☐

C3\_Q43\_1\_t1

**43. Over the last week how many different people have telephoned him/her each day?**

None One Two Three Four Five Six Seven Eight Nine Ten  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C3\_Q43\_2\_t1

If more than ten please specify:

Don't know  
☐

C3\_Q44\_t1

**44. How satisfied is your relative/friend with the support s/he receives from family?**

Very dissatisfied Slightly dissatisfied Neither satisfied Slightly satisfied Very satisfied Don't know  
☐ ☐ ☐ ☐ ☐ ☐

C3\_Q45\_t1

**45. How satisfied is your relative/friend with the support s/he receives from friends?**

Very dissatisfied Slightly dissatisfied Neither satisfied Slightly satisfied Very satisfied Don't know  
☐ ☐ ☐ ☐ ☐ ☐

## Your relative's/friend's accommodation

**46. If your relative/friend has lived at his/her current address for less than ten years what were the main reasons s/he moved to this address?**

*You may cross more than one box*

- C3\_Q46\_1\_t1 ☐ Retirement
- C3\_Q46\_2\_t1 ☐ Downsizing
- C3\_Q46\_3\_t1 ☐ To be nearer relative(s)
- C3\_Q46\_4\_t1 ☐ Needed more support
- C3\_Q46\_5\_t1 ☐ Needed more care
- C3\_Q46\_6\_t1 ☐ Needed to move into residential care
- C3\_Q46\_7\_t1 ☐ Could no longer afford last home
- C3\_Q46\_8\_t1 ☐ Relationship breakdown
- C3\_Q46\_9\_t1 ☐ New relationship
- C3\_Q46\_10\_t1 ☐ Wanted to move to better area
- C3\_Q46\_11\_t1 ☐ For children's/grandchildren's education
- C3\_Q46\_12\_t1 ☐ Just wanted a change
- C3\_Q46\_13\_t1 ☐ Wanted a place of his/her own
- C3\_Q46\_14\_t1 ☐ Problems with neighbours
- C3\_Q46\_15\_t1 ☐ Moving away from crime
- C3\_Q46\_16\_t1 ☐ Previous accommodation temporary
- C3\_Q46\_17\_t1 ☐ Quality of previous accommodation
- C3\_Q46\_18\_t1 ☐ Spouse or partner job change
- C3\_Q46\_19\_t1 ☐ Job change/nearer work
- C3\_Q46\_20\_t1 ☐ Overcrowding or no space
- C3\_Q46\_21\_t1 ☐ Wanted to buy
- C3\_Q46\_22\_t1 ☐ Wanted larger home
- C3\_Q46\_23\_t1 ☐ Wanted better home
- C3\_Q46\_24\_t1 ☐ Problems with landlord
- C3\_Q46\_25\_t1 ☐ Evicted/repossessed from last home
- C3\_Q46\_26\_t1 ☐ For financial reasons
- C3\_Q46\_27\_t1 ☐ Other; please specify:
- C3\_Q46\_28\_t1 C3\_Q46\_oth\_t1
- C3\_Q46\_29\_t1 ☐ Not applicable (your relative/friend has lived at his/her current address for more than ten years)
- C3\_Q46\_29\_t1 ☐ Don't know

## Your relative's/friend's interests and activities

*This next set of questions are about your relative's/friend's interests and activities e.g. crosswords, reading, etc. Please say how often your relative/friend does each of these activities.*

C3\_Q47\_t1

**47. How often does your relative/friend listen to the radio?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q48\_t1

**48. How often does your relative/friend read a newspaper?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q49\_t1

**49. How often does your relative/friend read a magazine?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q50\_t1

**50. How often does your relative/friend read a book?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q51\_t1

**51. How often does your relative/friend play games such as cards or chess?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q52\_t1

**52. How often does your relative/friend do crossword puzzles?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day



C3\_Q53\_t1

**53. How often does your relative/friend do Sudoku puzzles?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q54\_t1

**54. How often does your relative/friend do other types of puzzles?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q55\_t1

**55. How often does your relative/friend do jigsaws?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q56\_t1

**56. How often does your relative/friend use the internet?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q57\_t1

**57. How often does your relative/friend use social media (e.g. Twitter, Facebook)?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q58\_t1

**58. How often does your relative/friend play computer games?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

## Your relative's/friend's entertainment activities

*Here is a list of places your relative/friend might go. Please say how often your relative/friend visits each place.*

C3\_Q59\_t1

**59. How often does your relative/friend go to the cinema?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q60\_t1

**60. How often does your relative/friend go to museums?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q61\_t1

**61. How often does your relative/friend go to pubs?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q62\_t1

**62. How often does your relative/friend go to rock concerts?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q63\_t1

**63. How often does your relative/friend go to the opera?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q64\_t1

**64. How often does your relative/friend go to bingo?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q65\_t1

**65. How often does your relative/friend go to orchestral or choral concerts?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q66\_t1

**66. How often does your relative/friend go to stately homes or historic sites?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q67\_t1

**67. How often does your relative/friend go to musicals?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q68\_t1

**68. How often does your relative/friend go to the theatre?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q69\_t1

**69. How often does your relative/friend go to art galleries?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

--



C3\_Q70\_t1

**70. How often does your relative/friend go to night clubs?**

- ☐ At least once a week  
☐ Less often but at least once a month  
☐ Less often but at least several times a year  
☐ Once a year or less  
☐ Never

C3\_Q71\_t1

**71. How often does your relative/friend go somewhere to eat out?**

- ☐ At least once a week  
☐ Less often but at least once a month  
☐ Less often but at least several times a year  
☐ Once a year or less  
☐ Never

### **Your relative's/friend's involvement in decision-making**

*We would like to know how involved your relative/friend is in making decisions in each of the following areas*

C3\_Q72\_t1

**72. How involved is your relative/friend in decisions about what to spend his/her money on?**

- ☐ Not at all involved    ☐ A little involved    ☐ Fairly involved    ☐ Very involved

C3\_Q73\_t1

**73. How involved is your relative/friend in decisions about visiting with friends?**

- ☐ Not at all involved    ☐ A little involved    ☐ Fairly involved    ☐ Very involved

C3\_Q74\_t1

**74. How involved is your relative/friend in decisions about what foods to buy?**

- ☐ Not at all involved    ☐ A little involved    ☐ Fairly involved    ☐ Very involved

C3\_Q75\_t1

**75. How involved is your relative/friend in decisions about when to go to bed?**

- ☐ Not at all involved    ☐ A little involved    ☐ Fairly involved    ☐ Very involved

C3\_Q76\_t1

**76. How involved is your relative/friend in decisions about when to get up?**

- ☐ Not at all involved    ☐ A little involved    ☐ Fairly involved    ☐ Very involved

C3\_Q77\_t1

**77. How involved is your relative/friend in decisions about what to do in his/her spare time?**

- ☐ Not at all involved    ☐ A little involved    ☐ Fairly involved    ☐ Very involved

C3\_Q78\_t1

**78. How involved is your relative/friend in decisions about being physically active?**

- ☐ Not at all involved    ☐ A little involved    ☐ Fairly involved    ☐ Very involved

C3\_Q79\_t1

**79. How involved is your relative/friend in decisions about participating in religious/spiritual activities?**

☐ Not at all involved   ☐ A little involved   ☐ Fairly involved   ☐ Very involved

C3\_Q80\_t1

**80. How involved is your relative/friend in decisions about expressing affection?**

☐ Not at all involved   ☐ A little involved   ☐ Fairly involved   ☐ Very involved

C3\_Q81\_t1

**81. How involved is your relative/friend in decisions about having a pet?**

☐ Not at all involved   ☐ A little involved   ☐ Fairly involved   ☐ Very involved

C3\_Q82\_t1

**82. How involved is your relative/friend in decisions about what to eat at meals?**

☐ Not at all involved   ☐ A little involved   ☐ Fairly involved   ☐ Very involved

C3\_Q83\_t1

**83. How involved is your relative/friend in decisions about choosing places to go?**

☐ Not at all involved   ☐ A little involved   ☐ Fairly involved   ☐ Very involved

C3\_Q84\_t1

**84. How involved is your relative/friend in decisions about what clothes to wear?**

☐ Not at all involved   ☐ A little involved   ☐ Fairly involved   ☐ Very involved

C3\_Q85\_t1

**85. How involved is your relative/friend in decisions about choosing where to live?**

☐ Not at all involved   ☐ A little involved   ☐ Fairly involved   ☐ Very involved

C3\_Q86\_t1

**86. How involved is your relative/friend in decisions about getting medical care?**

☐ Not at all involved   ☐ A little involved   ☐ Fairly involved   ☐ Very involved

## **Dignity and respect**

*We would like to know how you feel your relative/friend has been treated.*

C3\_Q87\_t1

**87. Health professionals treat your relative/friend with dignity and respect**

☐ Rarely or not at all   ☐ Sometimes   ☐ Mostly   ☐ Always   ☐ Not applicable

C3\_Q88\_t1

**88. Care staff treat your relative/friend with dignity and respect**

☐ Rarely or not at all   ☐ Sometimes   ☐ Mostly   ☐ Always   ☐ Not applicable

C3\_Q89\_t1

**89. Do you think in general your relative's/friend's family treats him/her with dignity and respect?**

- ☐ Rarely or not at all    ☐ Sometimes    ☐ Mostly    ☐ Always    ☐ Not applicable

C3\_Q90\_t1

**90. Other people treat your relative/friend with dignity and respect**

- ☐ Rarely or not at all    ☐ Sometimes    ☐ Mostly    ☐ Always    ☐ Not applicable

### **Your relative's/friend's life events**

**91. From this list I'd like you to tell me which of the following events your relative/friend has experienced in his/her life over the past 12 months. The aim is just to identify which of these events your relative/friend has experienced lately.**

#### **Bereavement**

C3\_Q91\_1\_t1 ☐ Death of spouse or child

C3\_Q91\_2\_t1 ☐ Death of a close family member (e.g. parent or sibling)

C3\_Q91\_3\_t1 ☐ Death of a close friend

#### **Marital difficulties**

C3\_Q91\_4\_t1 ☐ Divorce

C3\_Q91\_5\_t1 ☐ Marital separation

#### **Change in circumstances**

C3\_Q91\_6\_t1 ☐ Retirement

C3\_Q91\_7\_t1 ☐ Moved home

C3\_Q91\_8\_t1 ☐ Major change in financial state (e.g. a lot worse off or a lot better off)

C3\_Q91\_9\_t1 ☐ Major change in health or behaviour of family member

C3\_Q91\_10\_t1 ☐ Major personal injury or illness

#### **None**

C3\_Q91\_YN\_t1 ☐ None of the above

C3\_Q92\_t1

**92. Do you think that compared to most other people of equivalent age your relative's/friend's situation is:**

- ☐ Much worse                      ☐ About the same                      ☐ Somewhat better  
☐ Somewhat worse                      ☐ Much better

**Thank you for providing this information about your relative/friend.**

Now we would like to know more about you and your experiences.

## Your health conditions

**93. We are interested in whether you have any health conditions. Do you have any of the conditions listed below?**

- ☐ Myocardial infarction (history of heart attacks)
- ☐ Congestive heart failure
- ☐ Hypertension (high blood pressure)
- ☐ Diagnosed depression
- ☐ Peripheral vascular disease (includes ☐ aortic aneurysm, ☐ poor circulation)
- ☐ Cerebrovascular disease (☐ Stroke, ☐ CVA or ☐ TIA)
- ☐ Dementia
- ☐ Chronic bad chest (e.g. ☐ asthma, ☐ COPD; ☐ chronic bronchitis, ☐ emphysema)
- ☐ Inflammation affecting the joints (e.g. ☐ lupus, ☐ rheumatoid arthritis, ☐ connective tissue disease, ☐ vasculitis)
- ☐ Peptic/stomach ulcer disease
- ☐ Skin ulcer (☐ bedsores, ☐ repeated cellulitis)
- ☐ Diabetes controlled with insulin or equivalent
- ☐ Diabetes with end-organ damage (e.g. ☐ damage to the retina, ☐ nerve damage, ☐ kidney damage, ☐ brittle diabetes)
- ☐ Moderate or severe chronic kidney disease
- ☐ Hemiplegia
- ☐ Cancer within the last five years (e.g. ☐ breast, ☐ colon, ☐ prostate, ☐ lung, ☐ skin, ☐ blood (lymphoma), ☐ acute or chronic leukaemia)
- If you have been diagnosed with cancer within the last five years, has it spread to other areas (metastatised)?** ☐ No ☐ Yes
- ☐ Mild liver disease (includes hepatitis (☐ B or ☐ C), ☐ cirrhosis)
- ☐ Liver disease (moderate to severe: ☐ chronic jaundice, ☐ liver failure, ☐ liver transplant)
- ☐ AIDS or HIV
- ☐ None of the above or no health problems

**94. Do you take warfarin?** ☐ No ☐ Yes

C3\_Q95\_1\_t1

**95. Do you have any other major long term illnesses, health problems or disabilities?**

☐ No ☐ Yes; please specify with diagnosis:

C3\_Q95\_2\_t1

## Your neighbourhood

*These questions are about your immediate neighbourhood, by which I mean your street or surrounding area.*

**96. Below is a list of natural green spaces (e.g. parks, woodlands) or blue spaces (e.g. lakes, rivers). We are interested in whether you live within a ten-minute walk of any of the green or blue spaces listed below. Please cross all that apply.**

C3\_Q96\_1\_t1

☐ Countryside

C3\_Q96\_2\_t1

☐ Woodlands

C3\_Q96\_3\_t1

☐ Parks and gardens

C3\_Q96\_4\_t1

☐ Country parks

C3\_Q96\_5\_t1

☐ Green corridors (e.g. river banks or roadside grass verges)

C3\_Q96\_6\_t1

☐ Outdoor sports facilities

C3\_Q96\_7\_t1

☐ Amenity green space (e.g. public playing fields or football pitches etc.)

C3\_Q96\_8\_t1

☐ Play areas

C3\_Q96\_9\_t1

☐ Allotments, community gardens and urban farms

C3\_Q96\_10\_t1

☐ Cemeteries and churchyards

C3\_Q96\_11\_t1

☐ River, lake or canal

C3\_Q96\_12\_t1

☐ Sea

C3\_Q96\_13\_t1

☐ None of the above

C3\_Q97\_t1

**97. How satisfied are you with your neighbourhood as a place to live?**

Very dissatisfied	Fairly dissatisfied	Neither satisfied nor dissatisfied	Slightly satisfied	Very satisfied	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q98\_t1

**98. To what extent do you think your local community is dementia friendly? By 'dementia friendly' we mean a community which includes people with dementia and shows a good level of awareness and understanding of dementia.**

<input type="checkbox"/> Not at all	<input type="checkbox"/> To a moderate extent
<input type="checkbox"/> To an extremely limited extent	<input type="checkbox"/> To a large extent
<input type="checkbox"/> To a very limited extent	<input type="checkbox"/> To a very large extent
<input type="checkbox"/> To a limited extent	<input type="checkbox"/> To an extremely large extent

C3\_Q99\_t1

**99. To what extent do you think your village/town/city is dementia friendly?  
By 'dementia friendly' we mean does your village/town/city offer  
practical support to enable engagement of people with dementia in  
community life (e.g. transport, easy to navigate environments, etc.).**

- |   |   |
|---|---|
| <input type="checkbox"/> Not at all                     | <input type="checkbox"/> To a moderate extent         |
| <input type="checkbox"/> To an extremely limited extent | <input type="checkbox"/> To a large extent            |
| <input type="checkbox"/> To a very limited extent       | <input type="checkbox"/> To a very large extent       |
| <input type="checkbox"/> To a limited extent            | <input type="checkbox"/> To an extremely large extent |

C3\_Q100\_t1

**100. Suppose you lost your purse or wallet containing your address details,  
and it was found in the street by someone living in this neighbourhood.  
How likely is it that it would be returned to you with nothing missing?**

- |                          |                          |                          |                          |                          |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Very<br>likely           | Quite<br>likely          | Not very<br>likely       | Not at all<br>likely     | Don't<br>know            |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

*Here is a list of problems which some people face in their neighbourhood. For each  
one, please can you tell me how much of a problem it is for you.*

C3\_Q101\_t1

**101. How much of a problem are people being drunk or rowdy in public places  
in your neighbourhood?**

- |   |  |
|---|--|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all              |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know                        |

C3\_Q102\_t1

**102. How much of a problem is rubbish or litter lying around in your  
neighbourhood?**

- |   |  |
|---|--|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all              |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know                        |

C3\_Q103\_t1

**103. How much of a problem are vandalism, graffiti and other deliberate  
damage to property or vehicles in your neighbourhood?**

- |   |  |
|---|--|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all              |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know                        |

C3\_Q104\_t1

**104. How much of a problem are people using or dealing drugs in your  
neighbourhood?**

- |   |  |
|---|--|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all              |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know                        |

C3\_Q105\_t1

**105. How much of a problem is people being attacked or harassed because of their skin colour, ethnic origin or religion in your neighbourhood?**

- |   |  |
|---|--|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all              |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know                        |

C3\_Q106\_t1

**106. How much of a problem are teenagers hanging around on the street in your neighbourhood?**

- |   |  |
|---|--|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all              |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know                        |

C3\_Q107\_t1

**107. How much of a problem are troublesome neighbours in your neighbourhood?**

- |   |  |
|---|--|
| <input type="checkbox"/> Very big problem       | <input type="checkbox"/> Not a problem at all              |
| <input type="checkbox"/> Fairly big problem     | <input type="checkbox"/> It happens but it's not a problem |
| <input type="checkbox"/> Not a very big problem | <input type="checkbox"/> Don't know                        |

C3\_Q108\_t1

**108. In your neighbourhood to what extent do you agree or disagree that people are willing to help their neighbours?**

- |                          |                          |                            |                          |                          |                          |
|--------------------------|--------------------------|----------------------------|--------------------------|--------------------------|--------------------------|
| Strongly disagree        | Slightly disagree        | Neither agree nor disagree | Slightly agree           | Strongly agree           | Don't know/ No opinion   |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/>   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

**109. In the last 12 months have you taken any of the following actions in an attempt to solve a problem affecting people in your local area?**

*You may cross more than one box*

C3\_Q109\_1\_t1

☐ Contacted a local radio station, television station or newspaper

C3\_Q109\_2\_t1

☐ Contacted the appropriate organisation to deal with the problem, such as the council

C3\_Q109\_3\_t1

☐ Contacted a local councillor or member of parliament

C3\_Q109\_4\_t1

☐ Attended a public meeting or neighbourhood forum to discuss local issues

C3\_Q109\_5\_t1

☐ Attended a tenants' or local residents' group

C3\_Q109\_6\_t1

☐ Attended a protest meeting or joined an action group

C3\_Q109\_7\_t1

☐ Helped organise a petition on a local issue

C3\_Q109\_8\_t1

☐ No local problems

C3\_Q109\_9\_t1

☐ None of the above

C3\_Q109\_10\_t1

☐ Don't know



## Your social activities

*The next few questions are about how often you personally contact relatives, friends and neighbours.*

C3\_Q110\_t1

**110. How often do you speak to relatives on the phone?**

On most days	Once or twice a week	Once or twice a month	Less often than once a month	Never	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q111\_t1

**111. How often do you write a letter or note to relatives?**

On most days	Once or twice a week	Once or twice a month	Less often than once a month	Never	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q112\_t1

**112. How often do you text or email relatives, or use the internet to talk to relatives (e.g. FaceTime, Skype, chatrooms)?**

On most days	Once or twice a week	Once or twice a month	Less often than once a month	Never	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q113\_t1

**113. How often do you speak to friends on the phone?**

On most days	Once or twice a week	Once or twice a month	Less often than once a month	Never	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q114\_t1

**114. How often do you write a letter or note to friends?**

On most days	Once or twice a week	Once or twice a month	Less often than once a month	Never	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q115\_t1

**115. How often do you text or email friends, or use the internet to talk to friends (e.g. FaceTime, Skype, chatrooms)?**

On most days	Once or twice a week	Once or twice a month	Less often than once a month	Never	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



C3\_Q116\_t1

**116. How often do you speak to neighbours?**

On most days	Once or twice a week	Once or twice a month	Less often than once a month	Never	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q117\_t1

**117. How often do you meet up with relatives who are not living with you?**

On most days	Once or twice a week	Once or twice a month	Less often than once a month	Never	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C3\_Q118\_t1

**118. How often do you meet up with friends?**

On most days	Once or twice a week	Once or twice a month	Less often than once a month	Never	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**119. During the last 12 months have you given any unpaid help to any groups, clubs or organisations in any of the ways listed below?***You may cross more than one box*
☐ Raising or handling money/taking part in sponsored events

☐ Leading the group/member of a committee

☐ Organising or helping to run an activity or event

☐ Visiting people

☐ Befriending or mentoring people

☐ Giving advice/information/counselling

☐ Secretarial, admin or clerical work

☐ Providing transport/driving

☐ Representing (e.g. addressing meetings, leading a delegation, talking to a council official)

☐ Campaigning

☐ Other practical help (e.g. helping out at school, religious group, shopping)

☐ Any other help

☐ None of the above

The next few questions are about social groups or organisations you may belong to.

C3\_Q120\_t1

**120. Do you attend meetings or any community or social groups?**

- ☐ No (if less than yearly; skip to question 122)
- ☐ Yes, occasionally (if unpredictably, or regularly less than monthly)
- ☐ Yes, regularly (if daily, weekly, monthly or predictably)
- ☐ Don't know

**121. If you answered yes please indicate which activity/activities you attend.**

You may cross more than one box

C3\_Q121\_1\_t1

☐ Political parties

C3\_Q121\_2\_t1

☐ Trade unions (including student unions)

C3\_Q121\_3\_t1

☐ Environmental groups

C3\_Q121\_4\_t1

☐ Tenants, residents' groups or neighbourhood watch

C3\_Q121\_5\_t1

☐ Evening classes

C3\_Q121\_6\_t1

☐ U3A

C3\_Q121\_7\_t1

☐ Other adult learning

C3\_Q121\_8\_t1

☐ Arts, music or singing group

C3\_Q121\_9\_t1

☐ Memory café or group

C3\_Q121\_10\_t1

☐ Charity, voluntary or community group

C3\_Q121\_11\_t1

☐ Group for older people (e.g. lunch club)

C3\_Q121\_12\_t1

☐ Youth group (e.g. scouts/guides/youth club)

C3\_Q121\_13\_t1

☐ Women's Institute, Townswomen's Guild

C3\_Q121\_14\_t1

☐ Social club (Rotary, working men's club)

C3\_Q121\_15\_t1

☐ Sports club, gym, exercise/dance group

C3\_Q121\_16\_t1

☐ Other group or organisation; please specify:

C3\_Q121\_oth\_t1

The next few questions are about your interests and activities.

C3\_Q122\_t1

**122. How often do you listen to the radio?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q123\_t1

**123. How often do you read a newspaper?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q124\_t1

**124. How often do you read a magazine?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q125\_t1

**125. How often do you read a book?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q126\_t1

**126. How often do you play games such as cards or chess?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q127\_t1

**127. How often do you do crossword puzzles?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q128\_t1

**128. How often do you do Sudoku puzzles?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q129\_t1

**129. How often do you do other types of puzzles?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q130\_t1

**130. How often do you do jigsaws?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q131\_t1

**131. How often do you use the internet?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q132\_t1

**132. How often do you use social media (e.g. Twitter, Facebook)?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

C3\_Q133\_t1

**133. How often do you play computer games?**

- ☐ Once a year or less/Never
- ☐ Several times a year
- ☐ Several times a month
- ☐ Several times a week
- ☐ Every day or almost every day

## Your entertainment activities

0436486382

*Here is a list of places you might go. Please say how often you visit each place:*

C3\_Q134\_t1

### 134. How often do you go to the cinema?

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q135\_t1

### 135. How often do you go to museums?

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q136\_t1

### 136. How often do you go to pubs?

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q137\_t1

### 137. How often do you go to rock concerts?

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q138\_t1

### 138. How often do you go to the opera?

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q139\_t1

### 139. How often do you go to bingo?

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

--

C3\_Q140\_t1

**140. How often do you go to orchestral or choral concerts?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q141\_t1

**141. How often do you go to stately homes or historic sites?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q142\_t1

**142. How often do you go to musicals?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q143\_t1

**143. How often do you go to the theatre?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q144\_t1

**144. How often do you go to art galleries?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

C3\_Q145\_t1

**145. How often do you go to night clubs?**

- ☐ At least once a week
- ☐ Less often but at least once a month
- ☐ Less often but at least several times a year
- ☐ Once a year or less
- ☐ Never

--

## 146. How often do you go somewhere to eat out?

- ☐ At least once a week  
☐ Less often but at least once a month  
☐ Less often but at least several times a year  
☐ Once a year or less  
☐ Never

## Resources available to you from others

*These questions are about the size and quality of your social network.*

*The following questions are about the people you currently know. These might be family members, friends or acquaintances, but they do **not** include friends of friends or people that you are not personally in contact with. The questions will ask if you currently know someone with a particular skill or resource. If you know someone with more than one skill or resource you can refer to this person more than once.*

*Do you personally know anyone with the skill or resource listed below that you are able to gain access to **within one week** if you needed it? Please answer all these questions, even if you possess the skill or resource yourself or if you have never needed to ask for it before. You will be asked about your skills later on.*

*If the answer is 'yes', you can put a cross in more than one box.*

C3\_Q147\_1\_t1

## 147. Do you currently have access to someone who can repair a broken-down car?

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q148\_1\_t1

## 148. Do you currently have access to someone who is a reliable tradesperson (e.g. plumber, electrician)?

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q149\_1\_t1

## 149. Do you currently have access to someone who can speak another language fluently?

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q150\_1\_t1

## 150. Do you currently have access to someone who knows how to fix problems with computers?

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q151\_1\_t1

## 151. Do you currently have access to someone who is good at gardening?

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

If the answer is 'yes', you can put a cross in more than one box.

C3\_Q152\_1\_tl

**152. Do you currently have access to someone who has a professional occupation?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q153\_1\_tl

**153. Do you currently have access to someone who is a local councillor?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q154\_1\_tl

**154. Do you currently have access to someone who works for your local council?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q155\_1\_tl

**155. Do you currently have access to someone who can sometimes employ people?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q156\_1\_tl

**156. Do you currently have access to someone who knows a lot about government regulations?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q157\_1\_tl

**157. Do you currently have access to someone who has good contacts with the local newspaper, radio or TV?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q158\_1\_tl

**158. Do you currently have access to someone who knows a lot about health and fitness?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q159\_1\_tl

**159. Do you currently have access to someone who knows a lot about DIY?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance



If you need someone to help you in the following areas, would you be able to obtain this help from anyone **within one week**? Please answer all these questions, even if you have never needed to ask for such help before.

If the answer is 'yes', you can put a cross in more than one box.

C3\_Q160\_1\_tl

**160. Do you currently personally know anyone who would give you sound advice about money problems?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q161\_1\_tl

**161. Do you currently personally know anyone who would give you sound advice on problems at work?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q162\_1\_tl

**162. Do you currently personally know anyone who would help you to move or dispose of bulky items (e.g. lifting or use of a van)?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q163\_1\_tl

**163. Do you currently personally know anyone who would help you with small jobs around the house?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q164\_1\_tl

**164. Do you currently personally know anyone who would do your shopping if you are ill?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q165\_1\_tl

**165. Do you currently personally know anyone who would lend you a small amount of money (e.g. for a local taxi fare)?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q166\_1\_tl

**166. Do you currently personally know anyone who would give you careers advice?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

C3\_Q167\_1\_tl

**167. Do you currently personally know anyone who would discuss politics with you?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

**168. Do you currently personally know anyone who would give you sound legal advice?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

**169. Do you currently personally know anyone who would give you a good reference for a job?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

**170. Do you currently personally know anyone who would get you cheap goods or 'bargains'?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

**171. Do you currently personally know anyone who would help you to find somewhere to live if you had to move home?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

**172. Do you currently personally know anyone who would lend you a large amount of money (e.g. for a deposit on a flat or house)?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

**173. Do you currently personally know anyone who would look after your home or pets if you go away?**

- ☐ No ☐ Yes, immediate family ☐ Yes, friend ☐ Yes, colleague  
☐ Yes, wider family ☐ Yes, neighbour ☐ Yes, acquaintance

About you: now we would like to know about your skills. The answers are either yes or no.

**174. Are you able to repair a broken-down car?**

- ☐ No ☐ Yes

**175. Are you a tradesperson (e.g. plumber, electrician)?**

- ☐ No ☐ Yes

**176. Are you able to speak another language fluently?**

- ☐ No ☐ Yes

**177. Are you knowledgeable about fixing problems with computers?**

- ☐ No ☐ Yes

**178. Are you good at gardening?**

- ☐ No ☐ Yes

C3\_Q179\_t1

0952486385

**179. Are you someone with a professional occupation?**

☐ No ☐ Yes

C3\_Q180\_t1

**180. Are you a local councillor?**

☐ No ☐ Yes

C3\_Q181\_t1

**181. Are you working for your local council?**

☐ No ☐ Yes

C3\_Q182\_t1

**182. Are you able to sometimes employ people?**

☐ No ☐ Yes

C3\_Q183\_t1

**183. Are you knowledgeable about government regulations?**

☐ No ☐ Yes

C3\_Q184\_t1

**184. Are you someone with good contacts with a local newspaper, radio or TV?**

☐ No ☐ Yes

C3\_Q185\_t1

**185. Are you knowledgeable about health and fitness?**

☐ No ☐ Yes

C3\_Q186\_t1

**186. Are you knowledgeable about DIY?**

☐ No ☐ Yes

### **Your views**

*We would like to invite you to add your comments in response to the following questions. These questions are optional.*

*We are interested in your views on what can be done to help people live well with difficulties with memory, thinking or behaviour, that may have been described as dementia or an associated condition (we will use the term 'dementia' from here on for convenience). We would be grateful if you can take the time to give us your views in response to the questions below.*

C3\_Q187\_t1

**187. What does 'living well' with dementia mean for you?**

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C3\_Q188\_t1

**188. What do you think makes it easy or difficult to live well with dementia?**

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C3\_Q189\_t1

**189. What do you think could be done by the government to help people live well with dementia?**

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C3\_Q190\_t1

**190. What do you think could be changed in the local community to enable people with dementia to live well with dementia?**

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C3\_Q191\_t1

**191. We are interested in hearing any other comments you may have. Is there anything else you would like to tell us about?**

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**Thank you for taking the time to answer these questions. The information and insight that you have provided is very valuable to us.**

**Please return the questionnaire to the researcher as the researcher would like to talk to both you and your relative/friend together and has a few final questions for both of you.**

Instructions for the researcher: Checklist/Field notes

At the end of each part of the assessment please note reasons for any items which were not completed:

☐ Please check that all questions have been completed and cross the appropriate boxes below

☐ All items have been completed (if so skip to field notes)

**Your relative's/friend's background**

☐ Complete

☐ Refused

☐ No time to complete

☐ Partial (give reason)

☐ Tiredness

☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Your relative's/friend's employment/job**

☐ Complete

☐ Refused

☐ No time to complete

☐ Partial (give reason)

☐ Tiredness

☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Your relative's/friend's health**

☐ Complete

☐ Refused

☐ No time to complete

☐ Partial (give reason)

☐ Tiredness

☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Your relative's/friend's health state**

☐ Complete

☐ Refused

☐ No time to complete

☐ Partial (give reason)

☐ Tiredness

☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Your relative's/friend's emotions**

☐ Complete

☐ Refused

☐ No time to complete

☐ Partial (give reason)

☐ Tiredness

☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Your relative's/friend's support network**

☐ Complete

☐ Refused

☐ No time to complete

☐ Partial (give reason)

☐ Tiredness

☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Your relative's/friend's accommodation**

☐ Complete

☐ Refused

☐ No time to complete

☐ Partial (give reason)

☐ Tiredness

☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Your relative's/friend's interests and activities**

☐ Complete

☐ Refused

☐ No time to complete

☐ Partial (give reason)

☐ Tiredness

☐ Questions not understood

☐ Other; please specify: \_\_\_\_\_

**Your relative's/friend's entertainment activities**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your relative's/friend's involvement in decision making**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Dignity and respect**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your relative's/friend's life events**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your health conditions**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your neighbourhood**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your social activities**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Your entertainment activities**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Resources available to you from others**

- |   |                                    |   |
|---|------------------------------------|---|
| <input type="checkbox"/> Complete                     | <input type="checkbox"/> Refused   | <input type="checkbox"/> No time to complete      |
| <input type="checkbox"/> Partial (give reason)        | <input type="checkbox"/> Tiredness | <input type="checkbox"/> Questions not understood |
| <input type="checkbox"/> Other; please specify: _____ |                                    |   |

**Optional questions completed**

- ☐ Yes   ☐ No   ☐ Partial

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We would like you to record any additional information about the assessment which you may think is useful.

☐ No      ☐ Yes, please write your notes here:

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# Enhancing Active Life and Living Well: The IDEAL Study

## Showcard Booklet



Funded by the ESRC: ES/L001853/1

[www.IDEALproject.org.uk](http://www.IDEALproject.org.uk)







**All MMSE questions removed in line with user agreement**

**SHOWCARD 1B**

A Heterosexual or straight

B Gay or lesbian

C Bisexual

D Other; please specify

**SHOWCARD 1C**

Not important

Slightly important

Somewhat important

Moderately important

Important

Very important

Extremely important

## **SHOWCARD 1D**

### **Bereavement**

Death of spouse or child

Death of a close family member (e.g. parent or sibling)

Death of a close friend

### **Marital difficulties**

Divorce

Marital separation

### **Change in circumstances**

Retirement

Moved home

Major change in financial state (e.g. a lot worse off or a lot better off)

Major change in health or behaviour of family member

Major personal injury or illness

### **None**

None of the above

## **When you eat do you:**

feel full after eating only a few mouthfuls

feel full after eating about a third of a meal

feel full after eating over half a meal

feel full after eating most of the meal

hardly ever feel full

## SHOWCARD 1F

Own it outright

Buying it with the help of a mortgage or loan

Pay part rent and part mortgage (shared ownership)

Housing association rented housing

Council-rented housing

Private rented housing

Live here rent-free (including rent free in relative's/friend's property, excluding squatting)

Squatting

Care home

Nursing home

Sheltered accommodation (has a warden or scheme manager on site)

Other; please specify:

## **SHOWCARD 1G**

Retirement

Downsizing

To be nearer relative(s)

Needed more support

Needed more care

Needed to move into residential care

Could no longer afford last home

Relationship breakdown

New relationship

Wanted to move to better area

For children's/grandchildren's education

Just wanted a change

Wanted a place of my own

Problem with neighbours

Moving away from crime

Previous accommodation temporary

Quality of previous accommodation

Spouse or partner job change

Job change/nearer work

Overcrowding or no space

Wanted to buy

Wanted larger home

Wanted better home

Problems with landlord

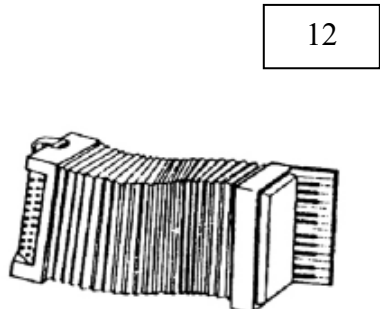
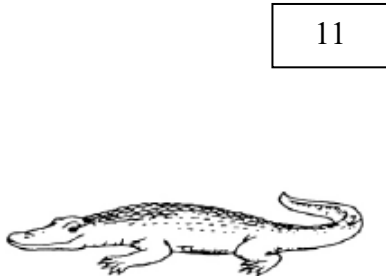
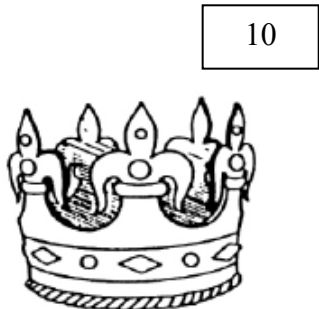
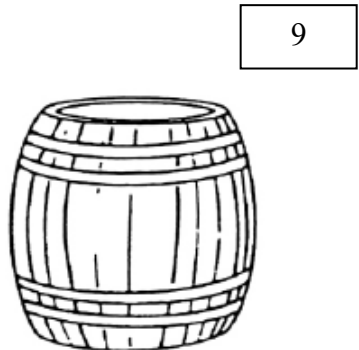
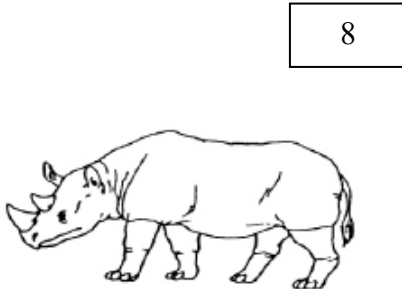
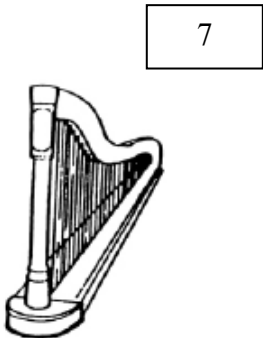
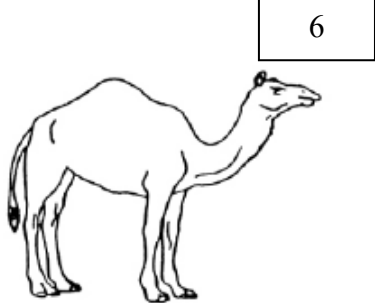
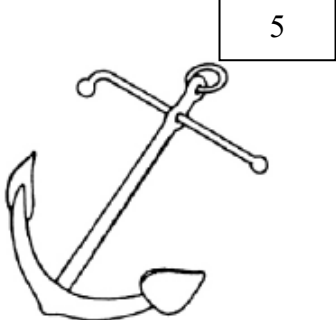
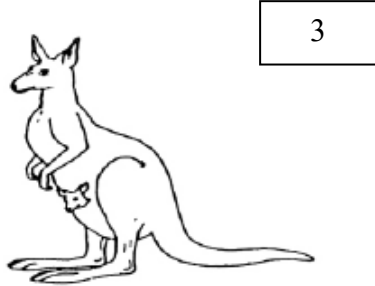
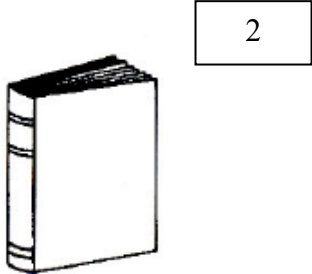
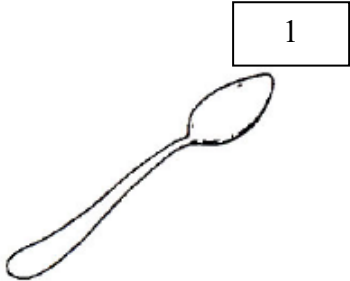
Evicted/repossessed from last home

For financial reasons

Other; please specify:



SHOWCARD 2A

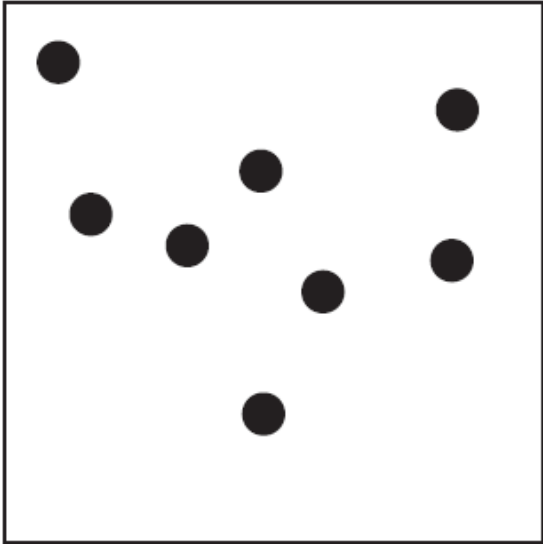


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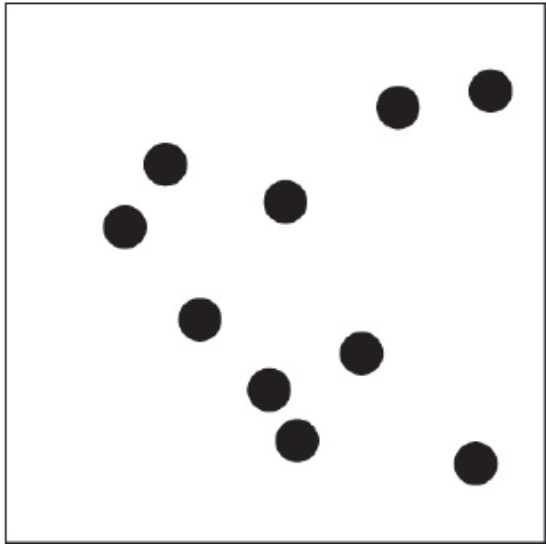
sew  
pint  
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SHOWCARD 2C

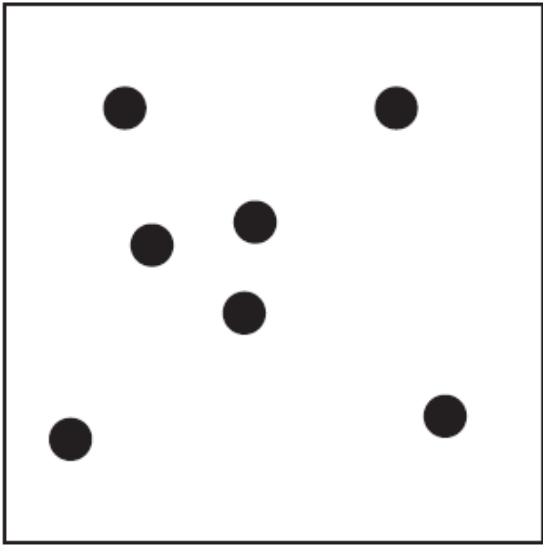
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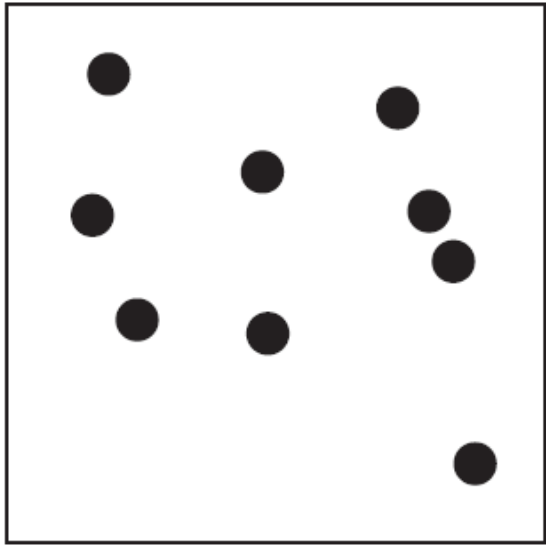
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4



SHOWCARD 2D

1



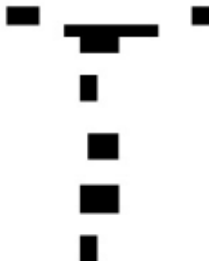
2



3



4



## **SHOWCARD 2E**

Political parties

Trade unions (including student unions)

Environmental groups

Tenants, residents' groups or neighbourhood watch

Evening classes

U3A

Other adult learning

Arts, music or singing group

Memory café or group

Charity, voluntary or community group

Group for older people (e.g. lunch club)

Youth group (e.g. scouts/guides/youth club)

Women's Institute, Townswomen's Guild

Social club (Rotary, working men's club)

Sports club, gym, exercise/dance group

Other group or organisation

Once a year or less/Never

Several times a year

Several times a month

Several times a week

Every day or almost every day

All of the time

Most of the time

More than half of the time

Less than half of the time

Some of the time

At no time

Not at all true

Hardly true

Moderately true

Completely true



Strongly disagree

Disagree

Slightly disagree

Neither agree nor disagree

Slightly agree

Agree

Strongly agree

Very dissatisfied

Slightly dissatisfied

Neither satisfied nor dissatisfied

Slightly satisfied

Very satisfied

Dependent on others

Requires assistance but can  
still do the task

Have difficulty but does by self

Never did, and would have  
difficulty now

Normal (as you have always  
done)

Never did, but could do now

Strongly disagree

Disagree

Agree

Strongly agree

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

Strongly agree

Agree

Disagree

Strongly disagree

**SHOWCARD 3A**

None

Some but less than one hour

One hour but less than three hours

Three hours or more

**SHOWCARD 3B**

Rarely or not at all

Sometimes

Mostly

Always

Not applicable



**SHOWCARD 3C**

Strongly disagree

Moderately disagree

Slightly disagree

Slightly agree

Moderately agree

Strongly agree

## SHOWCARD 3D

Very inaccurate

Moderately inaccurate

Neither inaccurate nor accurate

Moderately accurate

Very accurate

## SHOWCARD 3E

Countryside

Woodlands

Parks and gardens

Country parks

Green corridors (e.g. river banks or  
roadside grass verges)

Outdoor sports facilities

Amenity green space (e.g. public playing  
fields or football pitches etc.)

Play areas

Allotments, community gardens and urban  
farms

Cemeteries and churchyards

River, lake or canal

Sea

SHOWCARD 3F

Very big problem

Fairly big problem

Not a very big problem

Not a problem at all

It happens but it's not a problem

SHOWCARD 3G

**In the last 12 months have you taken any of the following actions in an attempt to solve a problem affecting people in your local area?**

*Please say as many as apply.*

Contacted a local radio station, television station or newspaper

Contacted the appropriate organisation to deal with the problem, such as the council

Contacted a local councillor or member of parliament

Attended a public meeting or neighbourhood forum to discuss local issues

Attended a tenants' or local residents' group

Attended a protest meeting or joined an action group

Helped organise a petition on a local issue

No local problems

None of the above

SHOWCARD 3H

On most days

Once or twice a week

Once or twice a month

Less often than once a month

Never

SHOWCARD 3I

**During the last 12 months have you given any unpaid help to any groups, clubs or organisations in any of the ways listed below?**

*Please say as many as apply.*

Raising or handling money/taking part in  
sponsored events

Leading the group/member of a committee

Organising or helping to run an activity or event

Visiting people

Befriending or mentoring people

Giving advice/information/counselling

Secretarial, admin or clerical work

Providing transport/driving

Representing (e.g. addressing meetings, leading  
a delegation, talking to a council official)

Campaigning

Other practical help (e.g. helping out at school,  
religious group, shopping)

Any other help

None of the above

SHOWCARD 3J

At least once a week

Less often but at least once a  
month

Less often but at least several times  
a year

Once a year or less

Never



## SHOWCARD 3K

No

Yes, immediate family

Yes, wider family

Yes, friend

Yes, neighbour

Yes, colleague

Yes, acquaintance

### **SHOWCARD 3L**

Myocardial infarction (history of heart attacks)

Congestive heart failure

High blood pressure

Diagnosed depression

Peripheral vascular disease (e.g. aortic aneurysm, poor circulation)

Cerebrovascular disease (Stroke or TIAs)

Dementia

Chronic bad chest (e.g. asthma, COPD; chronic bronchitis, emphysema)

Inflammation affecting the joints (e.g. lupus, rheumatoid arthritis, connective tissue disease, vasculitis)

Peptic/stomach ulcer disease

Skin ulcer (bedsores, repeated cellulitis)

Diabetes controlled with insulin or equivalent

Diabetes with end-organ damage ( e.g. damage to the retina, nerve damage, kidney damage, brittle diabetes)

Moderate or severe chronic kidney disease

Hemiplegia

Cancer within the last five years (breast, colon, prostate, lung, skin, blood cancer (lymphoma), acute or chronic leukaemia)

Mild liver disease (e.g. hepatitis (B or C), cirrhosis)

Liver disease (moderate to severe: chronic jaundice, liver failure, liver transplant)

AIDS or HIV

### SHOWCARD 3M

Earnings from employment or self-employment

State retirement pension

Pension from former employer

Personal pension(s)

Job-seekers' allowance

Employment and support allowance

Income support

Attendance allowance (higher rate for attendance during day  
**AND** night) or (lower rate for day **OR** night)

Pension credit

Working tax credit

Child tax credit

Child benefit

Housing benefit

Council tax benefit

Disability living allowance or Personal Independence Payments—  
care component

Highest rate

Middle rate

Lowest rate

Disability living allowance or Personal Independence Payments –  
mobility component

Highest rate

Lower rate

Other state benefits

Interest from savings and investments (e.g. stocks & shares)

Other kinds of regular allowance from outside your household (e.g.  
maintenance, student's grants, rent)

## SHOWCARD 3N

### Weekly

Less than £10  
£10 less than £30  
£30 less than £50  
£50 less than £70  
£70 less than £100  
£100 less than £150  
£150 less than £200  
£200 less than £250  
£250 less than £300  
£300 less than £350  
£350 less than £400  
£400 less than £450  
£450 less than £500  
£500 less than £550  
£550 less than £600  
£600 less than £650  
£650 less than £700  
£700 less than £800  
£800 less than £900  
£900 less than £1000  
£1000 less than £1150  
£1150 less than £1350  
£1350 less than £1550  
£1550 less than £1750  
£1750 less than £1900  
£1900 less than £2100  
£2100 less than £2300  
£2300 less than £2500  
£2500 less than £2700  
£2700 less than £2900  
£2900 or more

## SHOWCARD 30

### Monthly

Less than £40

£40 less than £130

£130 less than £220

£220 less than £300

£300 less than £430

£430 less than £650

£650 less than £870

£870 less than £1100

£1100 less than £1300

£1300 less than £1500

£1500 less than £1700

£1700 less than £2000

£2000 less than £2200

£2200 less than £2400

£2400 less than £2600

£2600 less than £2800

£2800 less than £3000

£3000 less than £3500

£3500 less than £3900

£3900 less than £4300

£4300 less than £5000

£5000 less than £5800

£5800 less than £6700

£6700 less than £7500

£7500 less than £8300

£8300 less than £9200

£9200 less than £10000

£10000 less than £10800

£10800 less than £11700

£11700 less than £12500

£12500 or more

## SHOWCARD 3P

### Annually

Less than £520

£520 less than £1600

£1600 less than £2,600

£2600 less than £3,600

£3600 less than £5,200

£5200 less than £7,800

£7800 less than £10400

£10400 less than £13000

£13000 less than £15600

£15600 less than £18200

£18200 less than £20800

£20800 less than £23400

£23400 less than £26000

£26000 less than £28600

£28600 less than £31200

£31200 less than £33800

£33800 less than £36400

£36400 less than £41600

£41600 less than £46800

£46800 less than £52000

£52000 less than £60000

£60000 less than £70000

£70000 less than £80000

£80000 less than £90000

£90000 less than £100000

£100000 less than £110000

£110000 less than £120000

£120000 less than £130000

£130000 less than £140000

£140000 less than £150000

£150000 or more

**SHOWCARD 3Q**

Community Nurse or District Nurse

Community Psychiatric Nurse or Community  
Mental Health Nurse

Psychiatrist

Social worker or care manager

Psychologist

Physiotherapist or Occupational therapist

Specialist nurse (e.g. Admiral Nurse, palliative  
care nurse, respiratory nurse)

SHOWCARD 3R

Home care/home help/support worker

Cleaner

Laundry service

Meals on wheels

Sitting service (e.g. Crossroads)

Carer support worker



### **SHOWCARD 3S**

Electronic medication reminder dispenser

Calendar clock

Falls detector or falls alarm

Community or personal alarm (including pull-cord  
and pendant alarms)

Outdoor railing

Grab rail/Stair rail

Walking stick

Walking frame

Walk-in shower/shower cubicle replacing bath

Over-bath shower

Bath seat/shower seat

Kitchen/perching stool

Bed lever/rail

Toilet frame/raised toilet seat

Commode

Continence pads

SHOWCARD 3T

Extremely satisfied

Satisfied

Fairly satisfied

Neither satisfied nor dissatisfied

Slightly dissatisfied

Dissatisfied

Extremely dissatisfied

## SHOWCARD 4A - FAST

Stage 1: *No objective or subjective functional decrement.*

Stage 2: *Subjective deficit in recalling names or other word finding and/or subjective deficit in recalling location of objects and/or subjectively decreased ability to recall appointments.* No objectively manifest functional deficits.

Stage 3: *Deficits noted in demanding occupational and social settings* (e.g., the individual may begin to forget important appointments for the first time; work productivity may decline); problems may be noted in travelling to unfamiliar locations (e.g., may get lost travelling by car and/or public transportation to a “new” location or place).

Stage 4: *Deficits in performance of complex tasks of daily life* (e.g., paying bills and/or balancing chequebook; decreased capacity in planning and/or preparing an elaborate meal; decreased capacity in shopping, such as in the correct purchase of grocery items).

Stage 5: *Deficient performance in choosing proper attire, and assistance is required for independent community functioning* - the spouse or other carer frequently must help the individual choose the appropriate clothing for the occasion and/or season (e.g., the individual will wear incongruous clothing); over the course of this stage some individuals may also begin to forget to bathe regularly (unless reminded) and car driving capability becomes compromised (e.g., carelessness in driving a car and violations of driving rules).

Stage 6a: *Requires actual physical assistance in putting on clothing properly* - the carer must provide increasing assistance with the actual mechanics of helping the individual clothe himself/herself properly (e.g., putting on clothing in the proper sequence, tying shoelaces, putting shoes on proper feet, buttoning and/or zipping clothing, putting on blouse, shirt, trousers, skirt, etc., correctly).

Stage 6b: *Requires assistance bathing properly* - the individual's ability to adjust bathwater temperature diminishes; the individual may have difficulty entering and leaving the bath; there may be problems with washing properly and completely drying oneself.

Stage 6c: *Requires assistance with mechanics of toileting* - individuals at this stage may forget to flush the toilet and may begin to wipe themselves improperly or less fastidiously when toileting.

Stage 6d: *Urinary incontinence* - this occurs in the absence of infection or other genitourinary tract pathology; the individual has episodes of urinary incontinence. Frequency of toileting may mitigate the occurrence of incontinence somewhat.

Stage 6e: *Faecal incontinence* - in the absence of gastrointestinal pathology, the individual has episodes of faecal incontinence. Frequency of toileting may mitigate the occurrence of incontinence somewhat.

Stage 7a: *Speech limited to about 6 words in the course of an average day* - during the course of an average day the individual's speech is restricted to single words (e.g., "Yes," "No," "Please") or short phrases (e.g., "please don't hurt me"; "get away"; "get out of here"; "I like you").

Stage 7b: *Intelligible vocabulary limited to generally a single word in the course of an average day* - as the illness progresses the ability to utter even short phrases on a regular basis is lost so that the spoken vocabulary becomes limited to generally 1 or 2 single words as an indicator for all things and needs (e.g., "Yes," "No," "O.K." for all verbalisation-provoking phenomena).

Stage 7c: *Ambulatory ability lost* - individuals gradually lose the ability to ambulate independently; in the early part of this sub-stage they may require actual support (e.g., being physically supported by a carer) and physical assistance to walk, but as the sub-stage progresses, the ability to ambulate even with assistance is lost; the onset is somewhat varied with some individuals simply taking progressively smaller and slower steps-other individuals begin to tilt forwards, backwards or laterally when ambulating; twisted gaits have also been noted as antecedents of ambulatory loss.

Stage 7d: *Ability to sit up lost* - individuals lose the ability to sit up without assistance (e.g., they need some form of physical brace-an arm rest, a belt, or other brace or other special devices to keep them from sliding down in the chair).

Stage 7e: *Ability to smile lost* - individuals are no longer observed to smile, although they do manifest other facial movements and sometimes grimace.

Stage 7f: *Ability to hold head up lost* - individuals can no longer hold up their head unless the head is supported.

## SHOWCARD 4B - GDS

### Stage 1: *No cognitive impairment*

Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

### Stage 2: *Very mild cognitive decline*

Individuals at this stage feel as if they have memory lapses, especially in forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.

### Stage 3: *Mild cognitive decline*

Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview. Common difficulties include:

- Word- or name-finding problems noticeable to family or close associates
- Decreased ability to remember names when introduced to new people
- Performance issues in social or work settings noticeable to family, friends or co-workers
- Reading a passage and retaining little material
- Losing or misplacing a valuable object
- Decline in ability to plan or organise.

### Stage 4: *Moderate cognitive decline*

At this stage, a careful medical interview detects clear-cut deficiencies in the following areas:

- Decreased knowledge of recent occasions or current events
- Impaired ability to perform challenging mental arithmetic-for example, to count backward from 100 by 7s
- Decreased capacity to perform complex tasks, such as shopping, planning dinner for guests or paying bills and managing finances
- Reduced memory of personal history
- The affected individual may seem subdued and withdrawn, especially in socially or mentally challenging situations.

### Stage 5: *Moderately severe cognitive decline*

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential. At this stage, individuals may:

- Be unable during a medical interview to recall such important details as their current address, their telephone number or the name of the college or high school from which they graduated
- Become confused about where they are or about the date, day of the week, or season
- Have trouble with less challenging mental arithmetic; for example, counting backward from 40 by 4s or from 20 by 2s
- Need help choosing proper clothing for the season or the occasion
- Usually retain substantial knowledge about themselves and know their own name and the names of their spouse or children
- Usually require no assistance with eating or using the toilet.

#### Stage 6: *Severe cognitive decline*

Memory difficulties continue to worsen, significant personality changes may emerge and affected individuals need extensive help with customary daily activities. At this stage, individuals may:

- Lose most awareness of recent experiences and events as well as of their surroundings
- Recollect their personal history imperfectly, although they generally recall their own name
- Occasionally forget the name of their spouse or primary carer but generally can distinguish familiar from unfamiliar faces
- Need help getting dressed properly; without supervision, may make such errors as putting pyjamas over daytime clothes or shoes on wrong feet
- Experience disruption of their normal sleep/waking cycle
- Need help with handling details of toileting (flushing toilet, wiping and disposing of tissue properly)
- Have increasing episodes of urinary or faecal incontinence
- Experience significant personality changes and behavioural symptoms, including suspiciousness and delusions (for example, believing that their carer is an impostor); hallucinations (seeing or hearing things that are not really there); or compulsive, repetitive behaviours such as hand-wringing or tissue shredding
- Tend to wander and become lost.

#### Stage 7: *Very severe cognitive decline*

This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak and, ultimately, the ability to control movement.

- Frequently individuals lose their capacity for recognisable speech, although words or phrases may occasionally be uttered
- Individuals need help with eating and toileting and there is general incontinence of urine
- Individuals lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. Reflexes become abnormal and muscles grow rigid. Swallowing is impaired.

## SHOWCARD 4C - CSRI medication

### *Dementia*

Donepezil/Aricept  
Ebixa/Memantine  
Exelon/Rivastigmine  
Reminyl/Galantamine

### *Parkinsonism*

Azilect  
Broflex  
Caramet  
Co-beneldopa  
Co-careldopa  
Comtess  
Half sinemet  
Madopar  
Orphenadrine  
Pramipexole  
Procyclidine  
Requip  
Ropinirole  
Selegiline  
Sinemet  
Stalevo  
Symmetrel  
Tetrabenazine  
Trihexyphenidyl

### *Other mental health drugs*

#### *Antidepressants*

Amitriptyline  
Cipralex  
Citalopram  
Clomipramine  
Cymbalta  
Dosulepin  
Edronax  
Fluanxol  
Fluoxetine  
Imipramine  
Lofepramine  
Mirtazapine  
Nardil  
Nortriptyline  
Oxactin  
Paroxetine  
Sorexat  
Sertraline  
Trazodone  
Trimipramine  
Venlafaxine  
Venlalic  
Viepax

### *Antipsychotics*

Abilify  
Amisulride  
Camcolit  
Chlorpromazine  
Clopixol  
Depakote  
Depixol  
Dozic  
Haloperidol  
Li-liquid  
Nozinan  
Olanzapine  
Pericyazine  
Priadel  
Promazine  
Quetiapine  
Risperidone  
Serenace  
Seroquel  
Stelazine  
Sulpiride  
Trifluoperazine  
Zyprexa

### *Hypnotics and Anxiolytics*

Bio-melatonin  
Buspirone hcl  
Chloral hydrate  
Choriadiazepox hcl  
Circadin  
Clomethi  
Diazepam  
Loprazolam mesil  
Lorazepam  
Lormetazepam  
Melatonin  
Nitrazepam  
Oxazepam  
Somnite  
Temazepam  
Welldorm  
Zimovane  
Zolpidem tart  
Zopiclone

**ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY  
CONSENT FORM FOR PARTICIPANT**

Participant identification number:

**Initial here if  
in agreement**

1	I have read and understand the information sheet dated 05/03/15 (version 3) for this study and I have had the opportunity to ask questions about the study.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect my health care or my legal rights in any way.	
3	I understand that if I withdraw from the study the researchers will use the information I have provided up to that point, unless I indicate that I do not want them to.	
4	I understand that the information I give to the researchers will only be used for the purposes of research, and that personal details will be treated in the strictest confidence.	
5	I agree to my GP and (if relevant) my Hospital Consultant being informed that I am taking part in this study.	
6	I understand that if the researchers hear or observe anything that causes serious concern about my health, safety or well-being, they have a duty to inform my GP or another appropriate professional.	
7	I understand that if I lose the ability to decide whether or not I want to continue to take part during the period of the research, the researchers will seek advice regarding continued participation from the personal consultee I have nominated. I understand that if my personal consultee is in favour of me continuing in the study, I will continue in the study as long as I do not object.	
8	I agree that that my personal contact details can be given to the research co-ordinating centre at the University of Exeter, to allow them to contact me about the research.	
9	I agree to the researchers retaining my personal contact details after the end of the study so that they can contact me again in the future should resources become available to find out how well I am doing after a longer period.	
10	I agree that my anonymised data collected during these initial visits can be deposited in a data archive (UK Data Archive) which is available to researchers and the public for scholarly and educational purposes.	
11	I agree to take part in the study.	

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature



**ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY  
CONSENT FORM FOR FAMILY MEMBER/FRIEND**

Participant identification number:

**Initial here if  
in agreement**

1	I have read and understand the information sheet dated 05/03/15 (version 2) for this study and I have had the opportunity to ask questions about the study.	
2	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that if I withdraw this will not affect my health care or my legal rights in any way.	
3	I understand that if I withdraw from the study the researchers will use the information I have provided up to that point, unless I indicate that I do not want them to.	
4	I understand that the information I give to the researchers will only be used for the purposes of research, and that personal details will be treated in the strictest confidence.	
5	I understand that if the researchers hear or observe anything that causes serious concern about my health, safety or well-being, they have a duty to inform my GP or another appropriate professional.	
6	I agree that that my personal contact details can be given to the research co-ordinating centre at the University of Exeter, to allow them to contact me about the research.	
7	I agree to the researchers retaining my personal contact details after the end of the study so that they can contact me again in the future should resources become available to find out how well I am doing after a longer period.	
8	I agree that my anonymised data from these initial visits can be deposited in a data archive (UK Data Archive) which is available to researchers and the public for scholarly and educational purposes.	
9	I agree to take part in the study.	

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

One copy for participant; one copy for researcher; one copy for sponsor

*Consent form for family member/friend – version 2 – 050315 - Initial*