

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

Wave 2 Interview documents

12/03/2020

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

Investigators: L. Clare (CI), I.R. Jones, C. Victor, J.V. Hindle, R.W. Jones, M. Knapp, M. Kopelman, R. Litherland, A. Martyr, F.E. Matthews, R.G. Morris, S.M. Nelis, J. Pickett, C. Quinn, J. Rusted, J. Thom (2014-2019)

Funded jointly by the Economic and Social Research Council (UK) and the National Institute for Health Research (UK), ES/L001853/2

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P_ID

Participant ID

Researcher ID

Enhancing Active Life and Living Well: The IDEAL Study

Time 2

12 month follow-up

Participant

Part 1 of 2





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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, how you see yourself, how you feel about your memory and your activities and interests. We spoke with you about 12 months ago and asked you similar questions and we would like to see how things are for you at this time. 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.

New instructions for Time 2.

- We strongly encourage you to complete all individual items within each measure.
- We understand that a small percentage of people may find the assessment more difficult to complete at this time point. To allow for this we have identified core questions that should be completed for some of the measures. These are highlighted in boxes like this.
- Completion of the items highlighted in boxes is the minimum requirement for each measure and should only be used if the participant is finding the items in that questionnaire particularly challenging.

Instructions for the researcher: Most of the questions between 1-14 should be completed by the researcher. However, if the researcher is unsure please seek clarification from the participant.

P1_Todays_Date_t2

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

P_Sex_Prtcpnt_t2

2. Sex of the participant: ☐ Male ☐ Female

P1_Q3_t2

3. Date of birth of the participant (dd/mm/yyyy)

/ /

Diagnosis_change_t1_t2

4. Participant diagnostic status

☐ Diagnosis has not changed since Time 1 (skip to question 6)

☐ Diagnosis has changed since Time 1

Date_rediagnosis_t2

5. Date of rediagnosis (dd/mm/yyyy):

/ /

Diagnosis_t2

6. Current specific dementia diagnosis of the participant

☐ Alzheimer's disease

☐ Vascular dementia

☐ Mixed (Alzheimer's and vascular)

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

FTD_subtype_t2

☐ Behavioural variant frontotemporal dementia

☐ Progressive non-fluent aphasia

☐ Semantic dementia

HoehnYahr_t2

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

☐ Stage 0

☐ Stage 1

☐ Stage 1.5

☐ Stage 2

☐ Stage 2.5

☐ Stage 3

☐ Stage 4

☐ Stage 5

Date_HoehnYahr_t2

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

/ /

HoehnYahrNA_t2

☐ Hoehn and Yahr stage score Not Available

☐ Lewy body dementia

☐ Unspecified dementia

☐ Other; please specify: OtherDem_spec_t2

P1_Q7_t2

7. Record the postcode of the participant's home address:

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P1_Q8_t2

8. 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 involved in the study

P1_Q9_t2

9. 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_Q9_1_t2

P1_Q10_t2

10. Has the relative/friend changed since Time 1?

- ☐ No ☐ Yes

P1_Q11_t2

11. Will a paid carer be providing information about the participant for the study on this occasion?

- ☐ No ☐ Yes

P1_Q12_t2

12. Assessment took place:

- ☐ in own home ☐ general hospital ☐ mental health hospital/unit (including secure units)
- ☐ other hospital ☐ care home without nursing ☐ care home with nursing
- ☐ sheltered housing only ☐ other medical and care establishment
- ☐ other; please specify: P1_Q12_1_t2

P1_Q13_t2

13. Is this living situation specifically dedicated to providing dementia care?

- ☐ No ☐ Yes

P1_Q14_t2

14. 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_Q14_1_t2

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_Q15_t2

15. What is your current legal marital status?

- ☐ Single; that is, never married (skip to question 17)
- ☐ 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_Q15_1_t2

Instructions for the researcher: You must ask the participant this question unless s/he is single (never married) or if you noted an 'other' response above that would make it not applicable.

P1_Q16_t2

16. How many years have you been [married/widowed/separated/divorced, etc.]?

P1_Q16_1_t2

- ☐ Don't know

17. With whom do you live?

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

- P1_Q17_1_t2 P1_Q17_2_t2 P1_Q17_3_t2 P1_Q17_4_t2
- ☐ No-one ☐ Your spouse/partner ☐ Other family member(s) ☐ Other (non-family)

Education

P1_Q18_t2

18. Have you attended a full-time or part-time education course in the past year?

- ☐ No (skip to question 20) ☐ Yes

P1_Q19_t2

19. If yes, did this lead to a new qualification?

Instructions for the researcher: Please cross only one box

- ☐ No change in highest qualification achieved
- ☐ 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_Q19_1_t2

Employment

Now I'm going to ask you about your current employment status.

P1_Q20_t2

20. 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_Q20_3_t2

If s/he is in paid employment;

how many hours of work per week do you do in total across all your jobs? P1_Q20_1_t2

☐ Retired; if retired at what age did you retire? P1_Q20_2_t2

☐ 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_Q20_4_t2

Religious activity

(USE SHOWCARD 1B)

I'm now going to ask you some questions about religious activity. Please try to answer them even if you have little interest in religion. Select whichever is the closest to your usual practice.

Select whichever is the closest to your usual practice

P1_Q21_t2

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

Never	Occasionally	Monthly	Weekly	Daily
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P1_Q22_t2

22. How often do you pray?

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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P1_Q23_t2

23. How often do you study religious texts?

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

(USE SHOWCARD 1C)

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

P1_Q24_t2

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

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

P1_Q25_t2

25. Compared to other people your age how would you describe your day-to-day memory?

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

P1_Q26_t2

26. Have you fallen down in the last year for any reason?

☐ No (skip to question 27)

P1_Q26_1_t2

☐ Yes; if yes, how many times? ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Don't know

☐ Seven or more; please specify number:

P1_Q26_2_t2

P1_Q26_3_t2

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

☐ No ☐ Yes ☐ Don't know

(USE SHOWCARD 1D)

P1_Q27_t2

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

☐ Poor ☐ Fair ☐ Good ☐ Very good ☐ Excellent

P1_Q28_t2

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

☐ Poor ☐ Fair ☐ Good ☐ Very good ☐ Excellent

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

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

P1_Q34_t2

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

☐ No ☐ Yes

P1_Q35_t2

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

☐ No ☐ Yes

(USE SHOWCARD 1E)

P1_Q36_t2

36. Would you say your appetite is

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

Pets

Now I'm going to ask you about any pets that you may have.

P1_Q37_t2

37. Do you have any pets?

☐ No (skip to question 39) ☐ Yes, one ☐ Yes, more than one

P1_Q38_t2

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

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

Life events

(USE SHOWCARD 1F)

39. 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 apply to him/her.

Bereavement

P1_Q39_1_t2 ☐ Death of spouse or child

P1_Q39_2_t2 ☐ Death of a close family member (e.g. parent or sibling)

P1_Q39_3_t2 ☐ Death of a close friend

Marital difficulties

P1_Q39_4_t2 ☐ Divorce

P1_Q39_5_t2 ☐ Marital separation

Change in circumstances

P1_Q39_6_t2 ☐ Retirement

P1_Q39_7_t2 ☐ Moved home

P1_Q39_8_t2 ☐ Major change in financial state (e.g. a lot worse off or a lot better off)

P1_Q39_9_t2 ☐ Major change in health or behaviour of family member

P1_Q39_10_t2 ☐ Major personal injury or illness

None

P1_Q39_11_t2 ☐ None of the above

P1_Q40_1_t2

40. Have there been any other significant events that you have experienced in your life over the past 12 months?

☐ No ☐ Yes, if yes; please specify:

P1_Q40_2_t2

Mood

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

P1_Q41_t2

41. Are you basically satisfied with your life?

☐ No

☐ Yes

P1_Q42_t2

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

☐ No

☐ Yes

P1_Q43_t2

43. Do you often get bored?

☐ No

☐ Yes

P1_Q44_t2

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

☐ No

☐ Yes

P1_Q45_t2

45. Do you feel happy most of the time?

☐ No

☐ Yes

P1_Q46_t2

46. Do you often feel helpless?

☐ No

☐ Yes

P1_Q47_t2

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

☐ No

☐ Yes

P1_Q48_t2

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

☐ No

☐ Yes

P1_Q49_t2

49. Do you feel full of energy?

☐ No

☐ Yes

P1_Q50_t2

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

☐ No

☐ Yes

Please indicate for this statement the extent to which it applies to your situation or the way you feel now.

P1_Q51_t2

51. Do you feel lonely?

☐ No

☐ More or less

☐ Yes

(USE SHOWCARD 1G)

P1_Q52_t2

52. 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

Self-esteem

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

(USE SHOWCARD 1H)

P1_Q53_t2

53. I have high self-esteem

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

Optimism

P1_Q54_t2

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

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

Sense of self

P1_Q55_t2

55. I am still the same person as I have always been

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

P1_Q56_t2

56. I am satisfied with who I am

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

P1_Q57_t2

57. My life is meaningful to me

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

Sleep

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

(USE SHOWCARD 1I)

P1_Q58_t2

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

Very poor ☐ Poor ☐ Fair ☐ Good (skip to question 60) ☐ Very good (skip to question 60) ☐

(USE SHOWCARD 1J)

59. 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 apply to him/her.

P1_Q59_1_t2

☐ Not being able to get to sleep

P1_Q59_2_t2

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

P1_Q59_3_t2

☐ Waking up several times throughout the night

P1_Q59_4_t2

☐ Having bad dreams

P1_Q59_5_t2

☐ Being uncomfortable

P1_Q59_6_t2

☐ Other; please specify:

P1_Q59_7_t2

Quality of life

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)**.

(USE SHOWCARD 1K)

P1_Q60_t2

60. 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

P1_Q61_t2

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

☐ Poor ☐ Fair ☐ Good ☐ Excellent

P1_Q62_t2

62. 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

P1_Q63_t2

63. 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

P1_Q64_t2

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

☐ Poor ☐ Fair ☐ Good ☐ Excellent

P1_Q65_t2

65. 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

P1_Q66_t2

66. 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

P1_Q67_t2

67. 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)

P1_Q68_t2

68. 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 s/he has 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

P1_Q69_t2

69. 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

P1_Q70_t2

70. 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

P1_Q71_t2

71. 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

P1_Q72_t2

72. 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

P1_Q73_t2

73. 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

WHO-5 Well-Being Index

(USE SHOWCARD 1L)

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".

P1_Q74_t2

74. 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

☐

P1_Q75_t2

75. 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

☐

P1_Q76_t2

76. 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

☐

P1_Q77_t2

77. 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

☐

P1_Q78_t2

78. 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

☐

P1_Q79_t2 to P1_Q93_2_t2 are from 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

Social participation

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 also whether you enjoyed it.

P1_Q79_t2

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

☐ No (skip to question 80)

P1_Q79_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q80_t2

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

☐ No (skip to question 81)

P1_Q80_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q81_t2

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

☐ No (skip to question 82)

P1_Q81_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q82_t2

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

☐ No (skip to question 83)

P1_Q82_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q83_t2

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

☐ No (skip to question 84)

P1_Q83_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q79_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q80_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q81_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q82_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q83_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q84_t2

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

☐ No (skip to question 85)

P1_Q84_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q84_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q85_t2

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

☐ No (skip to question 86)

P1_Q85_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q85_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q86_t2

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

☐ No (skip to question 87)

P1_Q86_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q86_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q87_t2

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

☐ No (skip to question 88)

P1_Q87_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q87_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q88_t2

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

☐ No (skip to question 89)

P1_Q88_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q88_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q89_t2

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

☐ No (skip to question 90)

P1_Q89_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q89_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q90_t2

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

☐ No (skip to question 91)

P1_Q90_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q90_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q91_t2

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

☐ No (skip to question 92)

P1_Q91_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q91_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q92_t2

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

☐ No (skip to question 93)

P1_Q92_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q92_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

P1_Q93_t2

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

☐ No (skip to question 94)

P1_Q93_1_t2

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

☐ Never

☐ Up to three times a week

☐ More than three times a week

P1_Q93_2_t2

If yes, for all 3 "often" responses ask did s/he enjoy the activity

Did you enjoy [the activity]?

☐ No

☐ Yes

Satisfaction with Life

(USE SHOWCARD 1M)

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.

P1_Q94_t2

94. 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"/>

P1_Q95_t2

95. 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"/>

P1_Q96_t2

96. 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"/>

P1_Q97_t2

97. 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"/>

P1_Q98_t2

98. 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.:**

P1_Q99_t2

99. 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"/>

If more than ten please specify:

P1_Q100_t2

100. 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"/>

If more than ten please specify:

P1_Q101_t2

101. 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

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

If more than ten please specify: P1_Q101_1_t2

P1_Q102_t2 Considering all of your **friends** including those who live in your neighbourhood:

102. 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

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

If more than ten please specify: P1_Q102_1_t2

P1_Q103_t2

103. 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

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

If more than ten please specify: P1_Q103_1_t2

P1_Q104_t2

104. 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

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

If more than ten please specify: P1_Q104_1_t2

(USE SHOWCARD 1N)

P1_Q105_t2

105. 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

☐ ☐ ☐ ☐ ☐ ☐

P1_Q106_t2

106. 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

☐ ☐ ☐ ☐ ☐ ☐

Relationship Quality - current

P1_Q107_0_t2

☐ If no relative/friend taking part in the study at this time (skip to question 112)P1_Q107_t2 These questions are about the **current** relationship between you and [your relative/friend].

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

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

☐ ☐ ☐ ☐ ☐ ☐

P1_Q108_t2

108. 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	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"/>

P1_Q109_t2

109. In general, how similar are your views about life to those of [your relative/friend]?

Not similar at all	Not too similar	Quite similar	Similar	Very similar	Extremely similar
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P1_Q110_t2

110. How often do 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"/>

P1_Q111_t2

111. 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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Everyday activities

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

Instructions for the researcher: Please encourage the participants to provide one of the responses from showcard 10. In exceptional circumstances if the participant is unable to provide one of these responses then please use the No/Yes options. Only one of these sets of responses should be used for all questions, i.e. if the participant is able to provide a response from the showcard for the first question s/he **must** provide a response from the showcard for **all** remaining questions.

(USE SHOWCARD 10: provide either the standard response to these items OR use no/yes)

P1_Q112_t2

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

- ☐ Dependent on others
- ☐ Require assistance but can still do the task
- ☐ Have difficulty but do by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now
- ☐ No ☐ Yes

P1_Q113_t2

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

- ☐ Dependent on others
- ☐ Require assistance but can still do the task
- ☐ Have difficulty but do by self
- ☐ Never did, and would have difficulty now
- ☐ Normal (as you have always done)
- ☐ Never did, but could do now
- ☐ No ☐ Yes

P1_Q114_t2

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

- ☐ Dependent on others
 - ☐ Require assistance but can still do the task
 - ☐ Have difficulty but do by self
 - ☐ Never did, and would have difficulty now
 - ☐ Normal (as you have always done)
 - ☐ Never did, but could do now
- ☐ No ☐ Yes

P1_Q115_t2

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

- ☐ Dependent on others
 - ☐ Require assistance but can still do the task
 - ☐ Have difficulty but do by self
 - ☐ Never did, and would have difficulty now
 - ☐ Normal (as you have always done)
 - ☐ Never did, but could do now
- ☐ No ☐ Yes

P1_Q116_t2

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

- ☐ Dependent on others
 - ☐ Require assistance but can still do the task
 - ☐ Have difficulty but do by self
 - ☐ Never did, and would have difficulty now
 - ☐ Normal (as you have always done)
 - ☐ Never did, but could do now
- ☐ No ☐ Yes

P1_Q117_t2

117. Can you prepare a balanced meal?

- ☐ Dependent on others
 - ☐ Require assistance but can still do the task
 - ☐ Have difficulty but do by self
 - ☐ Never did, and would have difficulty now
 - ☐ Normal (as you have always done)
 - ☐ Never did, but could do now
- ☐ No ☐ Yes

P1_Q118_t2

118. Can you keep track of current events?

- ☐ Dependent on others
 - ☐ Require assistance but can still do the task
 - ☐ Have difficulty but do by self
 - ☐ Never did, and would have difficulty now
 - ☐ Normal (as you have always done)
 - ☐ Never did, but could do now
- ☐ No ☐ Yes

P1_Q119_t2

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

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

☐ No ☐ Yes

P1_Q120_t2

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

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

☐ No ☐ Yes

P1_Q121_t2

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

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

☐ No ☐ Yes

P1_Q122_t2

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

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

☐ No ☐ Yes

P1_Q123_t2

123. Do you need help selecting clothing for yourself that is appropriate for the weather?

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

P1_Q124_t2

124. 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)

P1_Q125_t2

125. 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)

P1_Q126_t2

126. 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

P1_Q127_t2

127. Do you need household chores done for you?

☐ No ☐ Yes

P1_Q128_t2

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

☐ No ☐ Yes

Difficulties that you may experience (RADIX)

Now I'm going to talk to you about any difficulties you may have experienced

P1_Q129_t2

129. 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?

(if so you can start by saying something like **Earlier on you mentioned you had problems with [your memory]**)

☐ No ☐ Yes

P1_Q130_t2

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

☐ No ☐ Yes

P1_Q131_t2

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

☐ No ☐ Yes

P1_Q132_t2

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

☐ No ☐ Yes

P1_Q133_t2

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

☐ No ☐ Yes

P1_Q134_t2

134. 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

P1_Q135_t2

135. 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

P1_Q136_t2

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

☐ No ☐ Yes

P1_Q137_t2

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

☐ No ☐ Yes

P1_Q138_t2

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

☐ No ☐ Yes

Instructions for the researcher: If all the answers to the questions in the box are 'no' skip to question 162 - the optional open ended questions.

P1_Q139_t2

139. 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?**

P1_Q140_t2

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

☐ No ☐ Yes, if yes please specify:

P1_Q140_1_t2

P1_Q141_t2

141. Instructions for the researcher: Please record the person's label for his/her condition here. How does s/he refer to his/her 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. If the [label] is the same as that in question 139, please still write the term here.

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

(USE SHOWCARD 1P)

P1_Q142_t2

142. I find myself worrying about my [label]

☐ Strongly disagree

☐ Disagree

☐ Agree

☐ Strongly agree

P1_Q143_t2

143. My [label] is/are not that bad; there are others worse off than me

☐ Strongly disagree

☐ Disagree

☐ Agree

☐ Strongly agree

P1_Q144_t2

144. Due to my [label] I have to accept the changes in my life

☐ Strongly disagree

☐ Disagree

☐ Agree

☐ Strongly agree

P1_Q145_t2

145. 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

P1_Q146_t2

146. I avoid thinking about my [label]

☐ Strongly disagree

☐ Disagree

☐ Agree

☐ Strongly agree

P1_Q147_t2

147. I take each day as it comes and do not think about the future

☐ Strongly disagree

☐ Disagree

☐ Agree

☐ Strongly agree

P1_Q148_t2

148. I rely on others for help

☐ Strongly disagree

☐ Disagree

☐ Agree

☐ Strongly agree

P1_Q149_t2

149. I find it helps to keep to a routine

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q150_t2

150. I try to hide the difficulties resulting from my [label]

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q151_t2

151. I am keen to learn more about my [label]

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q152_t2

152. I try to find practical ways of overcoming problems resulting from my [label]

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q153_t2

153. I try to avoid social contact because of my [label]

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q154_t2

154. I tell people that I have [label]

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q155_t2

155. I prefer not to talk about my [label]

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q156_t2

156. It helps to keep myself busy

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q157_t2

157. I give myself time and try and be patient with myself

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

Stigma

P1_Q158_t2

158. I feel I have been treated with less respect than usual by others

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q159_t2

159. I have experienced financial hardship that has affected how I feel about myself

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q160_t2

160. I feel others think I am to blame for my [label]

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

P1_Q161_t2

161. I feel set apart from others who are well

☐ Strongly disagree ☐ Disagree ☐ Agree ☐ Strongly agree

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

Instructions for the researcher: Please ask the participant the following questions. Participants may choose not to answer them, however all questions must be asked. Please transcribe his/her answers in the spaces below.

P1_Q162_t2

162. Do you feel things have changed for you over the last 12 months. If so, how?

P1_Q163_t2

163. What is the difference for you between a good and a bad day?

P1_Q164_t2

164. Is there something you used to do that you don't/can't do now, that if you could do it, would improve your life?

P1_Q165_t2

165. What does 'living well' mean for you?

P1_Q166_t2

166. Are there any things that you can think of that would make your life any easier at the moment?

P1_Q167_t2

167. Are there any additional kinds of support or services that you feel you need at the moment or that you may need in the future?

P1_Q168_t2

168. What do you think could be changed in the local community to enable people like yourself to 'live well'?

P1_Q169_t2

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

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

Researcher ratings: compulsory information

Functional Assessment Staging (FAST)

P1_Q170_t2

170. Information for this question should be collated from self-reports and information from the relative/friend or, if the person is living in a residential care setting, the care home staff. Please cross the box next to the stage that applies to the person with dementia. USE SHOWCARD 3A for descriptions of the different levels

- ☐ 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

P1_Q171_t2

171. Please provide justification for your score on the FAST here:

P1_Q172_t2

172. Please provide your rating of the level of consciousness of the participant during this assessment visit.

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

Instructions for researcher: Now complete the checklist on the next pages indicating where and why data may be missing from the CRF.

Instructions for researcher: Please ensure that you have checked the relative's/friend's CRF for any missing values and/or double entries and correct/seek clarification where

MMSE: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Information about you: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Education: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Employment: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Religious activity: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Health: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Health state: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Diet: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Pets: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Life events: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Mood: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Self-esteem: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Optimism: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Sense of self: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Sleep: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Quality of life: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

WHO-5 Well-Being Index:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Social participation: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Satisfaction with life: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Social Networks: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Relationship Quality - current:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Everyday activities: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Difficulties that you may experience (RADIX):

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Stigma: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Optional questions completed:

☐ Yes ☐ No ☐ Partial

Researcher ratings: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ 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.

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

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DO NOT PRINT/COPI

P_ID

Participant ID

Researcher ID

Enhancing Active Life and Living Well: The IDEAL Study

Time 2

12 month follow-up

Participant

Part 2 of 2

Instructions for the researcher: If the participant scored less than 10 on the MMSE as part of the Time 2 Part 1 assessment you should greet the participant by saying:

"Thank you for spending time with me" and extend your hand to shake hands.

You should note the participant's response in the Motor Performance Part 1 space on the next page.



P2_day_t2

Day of testing

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

P2_date_t2

Date of testing (dd/mm/yyyy)

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

Before continuing, the day and date of testing must be completed.

Instructions for the researcher: To be completed by the researcher

What score did the participant achieve on the MMSE during Part 1 of the Time 2 IDEAL assessment?

--	--

Instructions for the researcher: Please cross the appropriate box:

☐ If the MMSE score was less than ten: **Please administer the TSI only**

☐ If the MMSE score was ten or more: **Please administer the ACE-III only**

TSI (administer if MMSE is less than 10)

Items needed for specific parts are in *italics*: To administer the TSI you will need the testing pack provided, e.g. comb, pens, etc. You will also need a piece of paper.

Instructions for the researcher: If the participant does not hear a question or is distracted, you may repeat the question up to three times in order to engage his/her attention. Score 0 if the action is incorrect or not completed, score 1 if the action is completed correctly.

TSI_MP_P1_t2

Motor Performance Part 1

Score out of 1: ☐ 0 ☐ 1

TSI_1_t2

Thank you for spending time with me. Extend hand to shake hands. (You should score this from when you meet the participant at the start of the visit, as described on the front cover page).

0 ☐

Correctly shakes hand 1 ☐

TSI_MP_P2_t2

Motor Performance Part 2

Score out of 3: ☐ 0 ☐ 1 ☐ 2 ☐ 3

TSI_2_t2

Use: Comb

Hand the participant the comb. **Show me how you would use this comb.**

0 ☐

Correctly demonstrates combing 1 ☐

TSI_3_t2

Use: Pen and Top

Remove the top from the pen in full view of the participant. Hand the pen and top to the participant.

Can you put the top on the pen?

0 ☐

Correctly puts top on pen (not on bottom of pen) 1 ☐

TSI_4_t2

Use: Pen and Paper

Hand the participant the pen (without the top) and place a piece of paper on a table/clipboard in front of him/her. **Write your name.**

0 ☐

Writes name correctly (first or last name legible) 1 ☐

Instructions for the researcher: The separate sheet of paper in which the participant wrote his/her name **should not** be returned with this CRF since it contains personal information. The researcher should dispose of it securely, or leave it behind in the home of the participant.

Language-Comprehension

Score out of 4: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Point to your ear

0 ☐Correctly points to his/her ear 1 ☐

TSI_6_t2

Close your eyes

0 ☐Correctly closes his/her ear 1 ☐

TSI_7_t2

Use: Three pens: Red, Blue, Green

Place the three pens on the table spread out so that they have some space between them.

Show me the red pen.

0 ☐Correctly points to red pen 1 ☐

TSI_8_t2

Show me the green pen

0 ☐Correctly points to green pen 1 ☐

TSI_LangProd_t2

Language-Production

Score out of 4: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

TSI_9_t2

Point to your nose. What is this called?

0 ☐Correctly names nose 1 ☐

TSI_10_t2

Use: Two pens: Red, Green

Hold up a **red** pen in front of the participant. What colour is this pen?0 ☐Correctly names red 1 ☐

TSI_11_t2

Hold up a **green** pen in front of the participant. What colour is this pen?0 ☐Correctly names green 1 ☐

TSI_12_t2

Use: Key

Show the participant the key. What is this called?

0 ☐Correctly names key 1 ☐

TSI_MemImmed_t2

Memory-Immediate

Score out of 3: ☐ 0 ☐ 1 ☐ 2 ☐ 3

Use: One large paperclip

Watch carefully. Place paper clip in your hand so that the participant can see it. Hold both of your hands out to the participant.

With hands open. Which hand is the clip in?

0 ☐Correctly points to clip 1 ☐

TSI_14_t2

With hands closed. Which hand is the clip in?

0 ☐Correctly points to hand with clip 1 ☐

TSI_15_t2

Watch carefully. Move hands behind back. Which hand/side is the clip in/on?0 ☐Correctly points to hand with clip 1 ☐

General Knowledge

Score out of 4: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

TSI_16_t2

How many ears do I have?

0 ☐Correctly states two 1 ☐

TSI_17_t2

Place hands in front of the participant with fingers pointing up, palms toward the participant.

Count my fingers and thumbs. Give credit even if no one to one correspondence between fingers and numbers. If the participant only gives the final answer of ten, ask,
Can you count to 10 starting at 1?0 ☐Correctly counts to 10 1 ☐

TSI_18_t2

How many weeks are there in a year?

0 ☐Correctly states 52 1 ☐

TSI_19_t2

I'm going to sing a song. If you know the words, I want you to sing along with me.

Softly sing "Happy Birthday".

0 ☐Sings most of the words 1 ☐

TSI_Concept_t2

Conceptualization

Score out of 4: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

TSI_20_t2

*Use: Two large paperclips, one pen*Spread objects on the table. **Which one of these is different from the other two?**0 ☐Correctly points to pen or states pen 1 ☐

TSI_21_t2

Use: Two red pens, one green pen

Place 1 red and 1 green pen spread out on the table. Hand the participant the other red pen.

Put this next to the pen that is the same colour.0 ☐Correctly places the red pen next to the other red pen 1 ☐

TSI_22_t2

*Use: One large paperclip*Place hands out in front of the participant. **Watch me move the paperclip.** Alternate the paperclip between your open hands 4 times. **Which hand will I put the paperclip in next?**0 ☐Correctly points to correct hand 1 ☐

TSI_23_t2

After the participant responds, place clip in the correct hand. (If the participant is incorrect say **I'd put the clip in this hand**). Then say, **Which hand will I put the clip in next?**0 ☐Correctly points to correct hand 1 ☐

TSI_MemDelay_t2

Memory-Delayed

Score out of 1: ☐ 0 ☐ 1

TSI_24_t2

*Use: Thread, key, paperclip*Place objects spread out on the table. **Which one of these haven't we done something with while you were here with me?**0 ☐Correctly points to thread 1 ☐

TSI_TotalScore_t2

TSI Total Score =

(Total all item scores.) (24 points max.)

Att_O_D_S_t2

ACE-III (administer if MMSE is 10 or above)

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?". Please cross the don't know/no answer box and score 0 if the participant cannot respond.

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

Att_day_t2

What day of the week is it today?

Att_day_S_t2

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

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ 0

Don't know/no answer ☐ 1

☐

Att_date_t2

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

Att_date_S_t2

Score: ☐ 0

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ 11 ☐ 12 ☐ 13 ☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19 ☐ 20 ☐ 21 ☐ 22 ☐ 23 ☐ 24 ☐ 25 ☐ 26 ☐ 27 ☐ 28 ☐ 29 ☐ 30 ☐ 31 Don't know/no answer

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ 11 ☐ 12 ☐ 13 ☐ 14 ☐ 15 ☐ 16 ☐ 17 ☐ 18 ☐ 19 ☐ 20 ☐ 21 ☐ 22 ☐ 23 ☐ 24 ☐ 25 ☐ 26 ☐ 27 ☐ 28 ☐ 29 ☐ 30 ☐ 31 Don't know/no answer

Att_month_t2

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.)

Att_month_S_t2

Score: ☐ 0

☐ 1

☐ Jan ☐ Feb ☐ March ☐ April ☐ May ☐ June

☐ July ☐ Aug ☐ Sep ☐ Oct ☐ Nov ☐ Dec ☐ Don't know/no answer

Att_year_t2

What year are we in?

Att_year_S_t2

Score: ☐ 0

☐ 1

2010 2011 2012 2013 2014 2015 2016 2017 2018 2019

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

If another year is given please write response here: Att_year_t2

Don't know/no answer

☐

Att_season_t2

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

Att_season_S_t2

Score: ☐ 0

☐ 1

Spring Summer Autumn/Fall Winter

March, April, May June, July, August Sept, Oct, Nov Dec, Jan, Feb

☐ ☐ ☐ ☐

Don't know/no answer

☐

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.**Instructions for the researcher: Provide response for either Part A or Part B only.Part A: 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_t2 **Score:** ☐ 0 ☐ 1**What is the name of the street?**Att_street_S_t2 **Score:** ☐ 0 ☐ 1Part B: 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_t2

Att_orgname_S_t2

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_t2

Att_org_floor_S_t2

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

Att_town_t2

Att_town_S_t2

Part C: The next three questions are to be administered to everyone (*record responses*):**What town/city are we in?****Score:** ☐ 0 ☐ 1

Att_county_t2

Att_county_S_t2

What county are we in?**Score:** ☐ 0 ☐ 1

Att_country_t2

Att_country_S_t2

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_t2

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 (i.e. if the participant scored all 3 correct

Att_ItemTrials_t2

☐ 1 ☐ 2 ☐ 3during the first trial you would cross the 1 box here: **cross only 1 box**):

Att_S7_S_t2

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_t2 Att_S7_2_t2 Att_S7_3_t2 Att_S7_4_t2 Att_S7_5_t2

Mem_Item_rec_S_t2

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_lem_S_t2 [...] key_S_t2 [...] ball_S_t2 [...] none_t2

Cross the boxes for correctly recalled responses: ☐ lemon ☐ key ☐ ball ☐ no answer

VERBAL FLUENCY

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

P VF_P_015_t2	VF_P_1630_t2	VF_P_3145_t2	VF_P_4660_t2
VF_P_015_T_t2	VF_P_1630_T_t2	VF_P_3145_T_t2	VF_P_4660_T_t2

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. i.e. if a participant says 14 words you would write 14 in the "total responses" box, if only 10 were correct you would write 10 in the "correct responses" box. You would cross the 8-10 box in the first column and the "4" box in the second column.

<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_t2	VF_P_CR_list_t2
Total responses	Correct responses
VF_P_TotResp_t2	VF_P_CorrResp_t2

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_t2	VF_A_1630_t2	VF_A_3145_t2	VF_A_4660_t2
VF_A_015_T_t2	VF_A_1630_T_t2	VF_A_3145_T_t2	VF_A_4660_T_t2

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. i.e. if a participant says 14 words you would write 14 in the "total responses" box, if only 10 were correct you would write 10 in the "correct responses" box. You would cross the "9-10" box in the first column and the "3" box in the second column.

<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_t2 Total responses	VF_A_CR_list_t2 Correct responses
VF_A_TotResp_t2	VF_A_CorrResp_t2

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, but record responses for all three trials (ticks and crosses are enough, unless incorrect responses are names of actual places).

	1st Trial	2nd Trial	3rd Trial
Harry Barnes	Mem_AM_Trial1_t2	Mem_AM_Trial2_t2	Mem_AM_Trial3_t2
73 Orchard Close			
Kingsbridge			
Devon			

MEMORY-Retrograde Memory-Famous people

Score out of 4: ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4

Participant's response if not correct

What is the name of the current Prime Minister? Mem_PrimeM_t2 Score: ☐ 0 ☐ 1

What is the name of the woman who was Prime Minister?
(Margaret Thatcher) Mem_PrimeMF_t2 Score: ☐ 0 ☐ 1

What is the name of the US president? Mem_USA_t2 Score: ☐ 0 ☐ 1

What is the name of the US president who was assassinated in the
1960s? (John F. Kennedy) Mem_USA_JFK_t2 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, cross the "failed the practice trial" box 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.

Lan_Fail_t2 Failed the practice trial.

Place the paper on top of the pencil. (Reposition the pencil next to the paper in front of the participant.) Score: ☐ 0 ☐ 1

Pick up the pencil but not the paper. (Reposition the pencil next to the paper in front of the participant.) Score: ☐ 0 ☐ 1

Pass 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 RepetitionScore 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_t2

Caterpillar☐ ☐

Correct Incorrect

Lan_Eccentricity_t2

Eccentricity☐ ☐

Correct Incorrect

Lan_Unintelligible_t2

Unintelligible☐ ☐

Correct Incorrect

Lan_Statistician_t2

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_t2

LANGUAGE-Proverb RepetitionScore 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_t2 Lan_proverb1_S_t2 Score: ☐ 0 ☐ 1

A stitch in time saves nine Lan_proverb2_t2 Lan_proverb2_S_t2 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_t2

LANGUAGE-Object NamingScore 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_t2 Lan_ON_Spoon_S_t2 Score: ☐ 0 ☐ 1

2. Book Lan_ON_Book_R_t2 Lan_ON_Book_S_t2 Score: ☐ 0 ☐ 1

3. Kangaroo or Wallaby Lan_ON_Kanga_R_t2 Lan_ON_Kanga_S_t2 Score: ☐ 0 ☐ 1

4. Penguin Lan_ON_Peng_R_t2 Lan_ON_Peng_S_t2 Score: ☐ 0 ☐ 1

5. Anchor Lan_ON_Anchor_R_t2 Lan_ON_Anchor_S_t2 Score: ☐ 0 ☐ 1

6. Camel or Dromedary Lan_ON_Camel_R_t2 Lan_ON_Camel_S_t2 Score: ☐ 0 ☐ 1

7. Harp Lan_ON_Harp_R_t2 Lan_ON_Harp_S_t2 Score: ☐ 0 ☐ 1

8. Rhinoceros or Rhino Lan_ON_Rhino_R_t2 Lan_ON_Rhino_S_t2 Score: ☐ 0 ☐ 1

9. Barrel, Keg or Tub Lan_ON_Barrel_R_t2 Lan_ON_Barrel_S_t2 Score: ☐ 0 ☐ 1

10. Crown Lan_ON_Crown_R_t2 Lan_ON_Crown_S_t2 Score: ☐ 0 ☐ 1

11. Crocodile or Alligator Lan_ON_Croc_R_t2 Lan_ON_Croc_S_t2 Score: ☐ 0 ☐ 1

12. Piano accordion, Accordion or Squeeze box Lan_ON_Piano_R_t2 Lan_ON_Piano_S_t2 Score: ☐ 0 ☐ 1

Lan_Cmprhnsn_S_t2

LANGUAGE-ComprehensionScore 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_t2

Participant's response if not correct

Point to the one which is associated with the monarchy (Crown, 10) Score: ☐ 0 ☐ 1

Lan_marsupial_t2

Point to the one which is a marsupial (Kangaroo, 3) Score: ☐ 0 ☐ 1

Lan_Antarctic_t2

Point to the one which is found in the Antarctic (Penguin, 4) Score: ☐ 0 ☐ 1

Lan_nautical_t2

Point to the one which has a nautical connection (Anchor, 5) 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_IL_S_t2

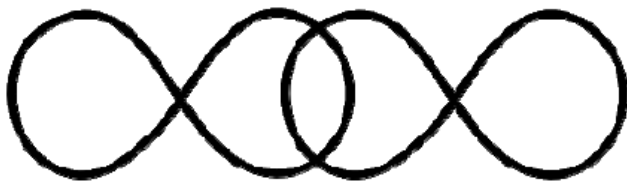
VISUOSPATIAL ABILITIES- Intersecting Infinity Loops

Score out of 1: ☐ 0 ☐ 1

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



Empty space for copying the shape.

VSA_3D_S_t2

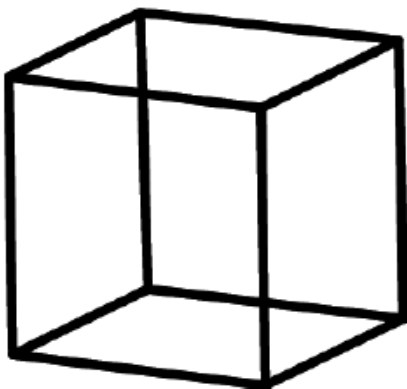
VISUOSPATIAL ABILITIES- 3D Wire Cube

Score out of 1: ☐ 0 ☐ 1 ☐ 2

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



Empty space for copying the shape.

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 them while drawing.
The following scoring criteria are used to give a total of 5 points (please choose the appropriate number for each of the three parts).

VSA_ClockCircle_t2 ☐ 1 point maximum if it is a reasonable circle

Circle

☐ 0

VSA_ClockNmbers_t2

Numbers

☐ 2 points if all numbers are included and well distributed within the circle

☐ 1 point if all numbers are included but poorly distributed or outside of the circle

☐ 0 points if not all numbers are included

VSA_ClockHands_t2

Hands

☐ 2 points if both hands are well drawn, different lengths and placed on correct numbers (you might ask which is the small and which is the big one)

☐ 1 point if both placed on the correct numbers but wrong lengths OR

☐ 1 point if one hand is placed on the correct number and drawn with correct length OR

☐ 1 point if only one hand is drawn and placed at the correct number i.e. 5 for 'ten past five'

☐ 0

VSA_Clock_TS_t2

PERCEPTUAL ABILITIES- Counting DotsScore 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_t2 PA_CD_Res10_S_t2
 PA_CD_Res8_t2 ☐ 8 ☐ 10 PA_CD_Res10_t2
 PA_CD_Res7_t2 ☐ 7 ☐ 9 PA_CD_Res9_t2
 PA_CD_Res7_S_t2 PA_CD_Res9_S_t2

PERCEPTUAL ABILITIES- Identifying LettersScore 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.

Score the correct answers: ☐ K ☐ M ☐ A ☐ T ☐ Don't know/no answer

PA_IL_K_t2 PA_IL_M_t2 PA_IL_A_t2 PA_IL_T_t2 PA_IL_Fail_t2

MEMORY- Recall of Name and AddressScore 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. Score 0 for incorrect or unrecalled items. For each element of the recall task either a 0 or 1 must be crossed, i.e. if the participant says s/he could not recall anything you should cross the 0 box for each item.

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

MEMORY- Recognition of Name and AddressScore 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_t2	MemR_Oakhamp_S_t2	Attention	<input type="checkbox"/>	<input type="checkbox"/>	(maximum possible score)
MemR_HarryB_S_t2	MemR_KingsB_S_t2				/ 18 ACE_Total_Atten_t2
MemR_HBrad_S_t2	MemR_Darting_S_t2	Memory	<input type="checkbox"/>	<input type="checkbox"/>	/ 26 ACE_Total_Mem_t2
MemR_HBRec_S_t2	MemR_KingsRec_S_t2				
MemR_37_S_t2	MemR_Devon_S_t2	Fluency	<input type="checkbox"/>	<input type="checkbox"/>	/ 14 ACE_Total_Flu_t2
MemR_73_S_t2	MemR_Dorset_S_t2				
MemR_76_S_t2	MemR_Somerset_S_t2	Language	<input type="checkbox"/>	<input type="checkbox"/>	/ 26 ACE_Total_Lang_t2
MemR_73Rec_S_t2	MemR_DevRec_S_t2				
MemR_OrcPlace_S_t2		Visuospatial/Perceptual	<input type="checkbox"/>	<input type="checkbox"/>	/ 16 ACE_Total_VisP_t2
MemR_OakClose_S_t2					
MemR_OrcClose_S_t2		TOTAL ACE-III SCORE:	<input type="checkbox"/>	<input type="checkbox"/>	/ 100 ACE_Total_Score_t2
MemR_OrchRec_S_t2					

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 health and well-being, your personality, your social activities, the kinds of things you do for fun and entertainment, and your local area. We spoke with you about 12 months ago and asked you similar questions and we would like to see how things are for you at this time. 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.

New instructions for Time 2.

- We strongly encourage you to complete all individual items within each measure.
- We understand that a small percentage of people may find the assessment more difficult to complete at this time point. To allow for this we have identified core questions that should be completed for some of the measures. These are highlighted in boxes like this.
- Completion of the items highlighted in boxes is the minimum requirement for each measure and should only be used if the participant is finding the items in that questionnaire particularly challenging.

Instructions for the researcher: To be completed by the researcher

P2_Q173_t2

173. 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 involved in the study

P2_Q174_t2

174. Assessment took place:

- ☐ in own home ☐ general hospital ☐ mental health hospital/unit (including secure units)
- ☐ other hospital ☐ care home without nursing ☐ care home with nursing
- ☐ sheltered housing only ☐ other medical and care establishment
- ☐ other; please specify: P2_Q174_1_t2

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 175, otherwise cross the "I am not in employment" box and skip to question 176

P2_Q175_t2

175. 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 2E)

P2_Q176_t2

176. 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

☐

P2_Q177_t2

177. 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

☐

P2_Q178_t2

178. 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

☐

P2_Q179_t2

179. 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

☐

P2_Q180_t2

180. 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

☐

P2_Q181_t2

181. 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 2F)

I am going to read you some statements about how you have been treated. Please choose the answer that best matches how you feel you have been treated.

P2_Q182_t2

182. Health professionals treat you with dignity and respect.

☐ Rarely or not at all

☐ Sometimes

☐ Mostly

☐ Always

☐ Not applicable

P2_Q183_t2

183. Care staff treat you with dignity and respect.

☐ Rarely or not at all

☐ Sometimes

☐ Mostly

☐ Always

☐ Not applicable

Psychological Well-Being

(USE SHOWCARD 2G)

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.

P2_Q184_t2

184. 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
☐

P2_Q185_t2

185. In general, I feel confident and positive about myself.

Strongly
disagree
☐

Moderately
disagree
☐

Slightly
disagree
☐

Slightly
agree
☐

Moderately
agree
☐

Strongly
agree
☐

P2_Q186_t2

186. 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
☐

P2_Q187_t2

187. I like most aspects of my personality.

Strongly
disagree
☐

Moderately
disagree
☐

Slightly
disagree
☐

Slightly
agree
☐

Moderately
agree
☐

Strongly
agree
☐

P2_Q188_t2

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

Strongly
disagree
☐

Moderately
disagree
☐

Slightly
disagree
☐

Slightly
agree
☐

Moderately
agree
☐

Strongly
agree
☐

P2_Q189_t2

189. 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
☐

P2_Q190_t2

190. 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
☐

Your accommodation

Now I'm going to ask you some questions about your home, including who lives with you.

P2_Q191_t2

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

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

If Other, please specify number: P2_Q191_1_t2

P2_Q192_t2

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

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

If Other, please specify number: P2_Q192_1_t2

P2_Q193_t2

193. Have you moved house in the last year?

☐ No (skip to question 199) ☐ Yes

(USE SHOWCARD 2H)

P2_Q194_t2

194. In which of these ways is your new 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:

P2_Q194_1_t2

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

(USE SHOWCARD 2I)

195. What were the main reasons you moved to this new address?

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

P2_Q195_1_t2

☐ Retirement

P2_Q195_2_t2

☐ Downsizing

P2_Q195_3_t2

☐ To be nearer relative(s)

P2_Q195_4_t2

☐ Needed more support

P2_Q195_5_t2

☐ Needed more care

P2_Q195_6_t2

☐ Needed to move into residential care

P2_Q195_7_t2

☐ Could no longer afford last home

P2_Q195_8_t2

☐ Relationship breakdown

P2_Q195_9_t2

☐ New relationship

P2_Q195_10_t2

☐ Wanted to move to better area

P2_Q195_11_t2

☐ For children's/grandchildren's education

P2_Q195_12_t2

☐ Just wanted a change

P2_Q195_13_t2

☐ Wanted a place of my own

P2_Q195_27_t2

☐ Other; please specify:

P2_Q195_27_oth_t2

P2_Q195_28_t2

☐ Don't know

P2_Q196_t2

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

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

197. What type of heating do you have?

P2_Q197_1_t2

☐ Gas central heating

P2_Q197_2_t2

☐ Electric storage heaters

P2_Q197_3_t2

☐ Gas fire only

P2_Q197_4_t2

☐ Other; please specify:

P2_Q197_5_t2

(USE SHOWCARD 2J)

198. 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 apply to him/her.

- P2_Q198_1_t2 ☐ Countryside
- P2_Q198_2_t2 ☐ Woodlands
- P2_Q198_3_t2 ☐ Parks and gardens
- P2_Q198_4_t2 ☐ Country parks
- P2_Q198_5_t2 ☐ Green corridors (e.g. river banks or roadside grass verges)
- P2_Q198_6_t2 ☐ Outdoor sports facilities
- P2_Q198_7_t2 ☐ Amenity green space (e.g. public playing fields or football pitches etc.)
- P2_Q198_8_t2 ☐ Play areas
- P2_Q198_9_t2 ☐ Allotments, community gardens and urban farms
- P2_Q198_10_t2 ☐ Cemeteries and churchyards
- P2_Q198_11_t2 ☐ River, lake or canal
- P2_Q198_12_t2 ☐ Sea
- P2_Q198_13_t2 ☐ None of the above
- P2_Q198_14_t2 ☐ Don't know (record if given as a spontaneous response)

Life Space

Now I'm going to ask you some questions about your movement inside and outside your home or place of residence during the past 3 days. The answers are either yes or no.

- P2_Q199_t2 **199. During the past 3 days, have you been to other rooms of your home or place of residence besides the room where you sleep?** ☐ No ☐ Yes
- P2_Q200_t2 **200. During the past 3 days, have you been to an area immediately outside your home or place of residence such as your porch, patio, hallway of an apartment building, or garage?** ☐ No ☐ Yes
- P2_Q201_t2 **201. During the past 3 days, have you been to an area outside your home or place of residence such as a yard, garden, driveway, or parking space?** ☐ No ☐ Yes
- P2_Q202_t2 **202. During the past 3 days, have you been to places in your immediate area, but beyond your own home or place of residence?** ☐ No ☐ Yes
- P2_Q203_t2 **203. During the past 3 days, have you been to places outside your immediate area, but within your town or community?** ☐ No ☐ Yes
- P2_Q204_t2 **204. During the past 3 days, have you been to places outside your immediate town or community?** ☐ No ☐ Yes

Society and Community

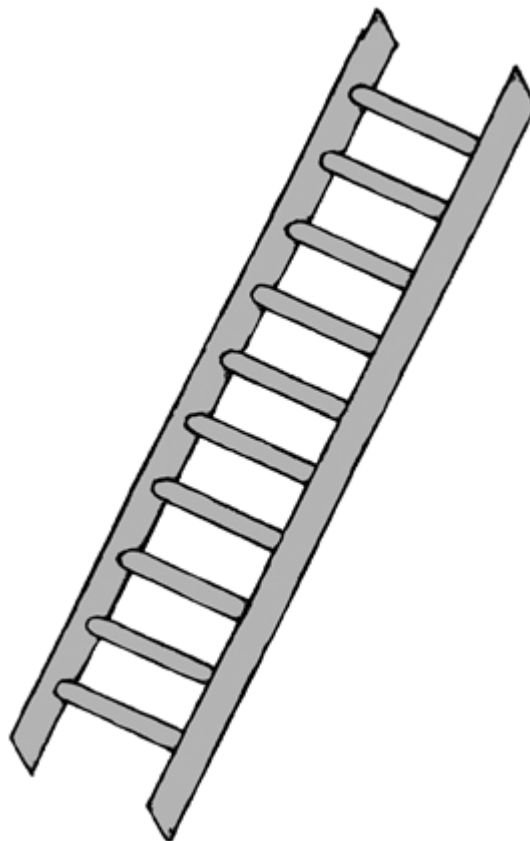
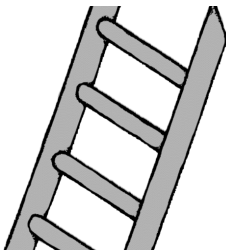
P2_Q205_t2

205. 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.

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). If the participant places his/her cross between two rungs, ask him/her to clarify which rung s/he intended to cross and record this in the appropriate box below and in the field notes.

Example



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

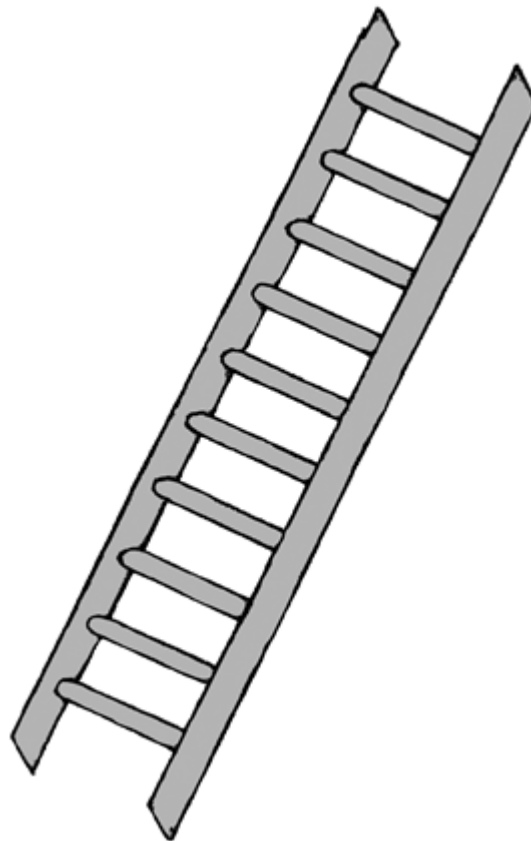
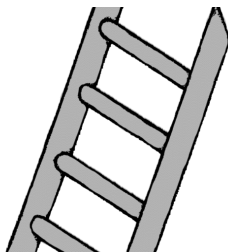
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
(bottom rung)									(top rung)

206. 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.

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). If the participant places his/her cross between two rungs, ask him/her to clarify which rung s/he intended to cross and record this in the appropriate box below and in the field notes.

Example



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)

Social Capital

(USE SHOWCARD 2K)

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

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

(record if given as a spontaneous response)

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"/>

Instructions for the researcher: For people who are more impaired you may need to rephrase the question to obtain the information. For example, if they do not answer the question: "How likely is it that it would be returned to you with nothing missing?" you may need to ask "Would your purse or wallet be returned to you?" etc. If they say 'no' rather than using one of the official response keys the "Not at all likely" box should be crossed.

(USE SHOWCARD 2L)

208. 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?

(record if given as a spontaneous response)

Very likely	Quite likely	Not very likely	Not at all likely	Don't know
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

(USE SHOWCARD 2M)

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.

Instructions for the researcher: For people who are more impaired you may need to rephrase the following questions to obtain the information. For example, if they do not answer the question: "How much of a problem are people being drunk or rowdy in public places in your neighbourhood?" you may need to ask "Are people being drunk or rowdy in public places a problem in your area?" etc. If they say 'no' rather than using one of the official response keys the "Not a problem at all" box should be crossed.

209. 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)

210. 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)

P2_Q211_t2

211. 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) |

P2_Q212_t2

212. 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) |

P2_Q213_t2

213. 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) |

P2_Q214_t2

214. 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) |

P2_Q215_t2

215. 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) |

(USE SHOWCARD 2N)

Instructions for the researcher: For people who are more impaired you may need to rephrase the question to obtain the information. For example, if they do not answer the question: "In your neighbourhood to what extent do you agree or disagree that people are willing to help their neighbours?" you may need to ask "Are people in your neighbourhood willing to help their neighbours?" If they say 'no' rather than using one of the official response keys the "strongly disagree" or "slightly disagree" box should be crossed depending on how they say "no".

P2_Q216_t2

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

- | |
|--------------------------------------------------------------------------------------------|
| <input type="checkbox"/> Strongly disagree |
| <input type="checkbox"/> Slightly disagree |
| <input type="checkbox"/> Neither agree nor disagree |
| <input type="checkbox"/> Slightly agree |
| <input type="checkbox"/> Strongly agree |
| <input type="checkbox"/> Don't know/No opinion (record if given as a spontaneous response) |
| <input type="checkbox"/> Refused (record if given as a spontaneous response) |

(USE SHOWCARD 2O)

217. 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 apply to him/her. For people who are more impaired you may need to rephrase the question to obtain the information. For example, if they do not answer the question: "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 need to ask "Have you taken any action in an attempt to solve a problem affecting people in your local area?" If they say 'no' rather than using one of the official response keys the "None of the above" box should be crossed.

P2_Q217_1 t2

☐ Contacted a local radio station, television station or newspaper

P2_Q217_2 t2

☐ Contacted the appropriate organisation to deal with the problem, such as the council

P2_Q217_3 t2

☐ Contacted a local councillor or member of parliament

P2_Q217_4 t2

☐ Attended a public meeting or neighbourhood forum to discuss local issues

P2_Q217_5 t2

☐ Attended a tenants' or local residents' group

P2_Q217_6 t2

☐ Attended a protest meeting or joined an action group

P2_Q217_7 t2

☐ Helped organise a petition on a local issue

P2_Q217_8 t2

☐ No local problems

P2_Q217_9 t2

☐ None of the above

P2_Q217_10 t2

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

Social activities

(USE SHOWCARD 2P)

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

P2_Q218 t2

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

☐ On most days

☐ Less often than once a month

☐ Once or twice a week

☐ Never

☐ Once or twice a month

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

P2_Q219 t2

219. How often do you write a letter or note to relatives?

☐ On most days

☐ Less often than once a month

☐ Once or twice a week

☐ Never

☐ Once or twice a month

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

P2_Q220 t2

220. How often do you text or email relatives, or use the internet to talk to relatives (e.g. FaceTime, Skype, chatrooms)?

☐ On most days

☐ Less often than once a month

☐ Once or twice a week

☐ Never

☐ Once or twice a month

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

P2_Q221_t2

221. 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) |

P2_Q222_t2

222. 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) |

P2_Q223_t2

223. 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) |

P2_Q224_t2

224. 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) |

P2_Q225_t2

225. 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) |

P2_Q226_t2

226. 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 2Q)

227. 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 apply to him/her. For people who are more impaired you may need to rephrase the question to obtain the information. For example, if they do not answer the question: "In the last 12 months have you given any unpaid help to any groups, clubs or organisations?" you may need to ask "In the last 12 months have you given any unpaid help to any groups, clubs or organisations?" If they say 'no' rather than using one of the official response keys the "None of the above" box should be crossed.

P2_Q227_1 t2

☐ Raising or handling money/taking part in sponsored events

P2_Q227_2 t2

☐ Leading the group/member of a committee

P2_Q227_3 t2

☐ Organising or helping to run an activity or event

P2_Q227_4 t2

☐ Visiting people

P2_Q227_5 t2

☐ Befriending or mentoring people

P2_Q227_6 t2

☐ Giving advice/information/counselling

P2_Q227_7 t2

☐ Secretarial, admin or clerical work

P2_Q227_8 t2

☐ Providing transport/driving

P2_Q227_9 t2

☐ Representing (e.g. addressing meetings, leading a delegation, talking to a council official)

P2_Q227_10 t2

☐ Campaigning

P2_Q227_11 t2

☐ Other practical help (e.g. helping out at school, religious group, shopping)

P2_Q227_12 t2

☐ Any other help

P2_Q227_13 t2

☐ None of the above

P2_Q227_14 t2

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

Cultural activities

Instructions for the researcher: For people who are more impaired you may need to rephrase the following questions to obtain the information. For example, if they do not answer the question: "How often do you go to the cinema?" you may need to ask "In the last 12 months have you been to the cinema?" etc. If they say 'no' rather than using one of the official response keys the "Never" box should be crossed

(USE SHOWCARD 2R)

I am going to read a list of places you might go. Please say how often you visit each place.

P2_Q228 t2

228. How often do you go to the cinema?

☐ 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

P2_Q229_t2

229. 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 | |

P2_Q230_t2

230. How often do you go to pubs?

- | | |
|-----------------------------------------------------------------------|----------------------------------------------|
| <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 | |

P2_Q231_t2

231. How often do you go to rock concerts?

- | | |
|-----------------------------------------------------------------------|----------------------------------------------|
| <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 | |

P2_Q232_t2

232. How often do you go to the opera?

- | | |
|-----------------------------------------------------------------------|----------------------------------------------|
| <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 | |

P2_Q233_t2

233. How often do you go to bingo?

- | | |
|-----------------------------------------------------------------------|----------------------------------------------|
| <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 | |

P2_Q234_t2

234. How often do you go to orchestral or choral concerts?

- | | |
|-----------------------------------------------------------------------|----------------------------------------------|
| <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 | |

P2_Q235_t2

235. How often do you go to stately homes or historic sites?

- | | |
|-----------------------------------------------------------------------|----------------------------------------------|
| <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 | |

P2_Q236_t2

236. How often do you go to musicals?

- | | |
|-----------------------------------------------------------------------|----------------------------------------------|
| <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 | |

P2_Q237_t2

237. How often do you go to the theatre?

- | | |
|-----------------------------------------------------------------------|----------------------------------------------|
| <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 | |

P2_Q238_t2

238. 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

P2_Q239_t2

239. 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

P2_Q240_t2

240. 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

Interests and Activities**(USE SHOWCARD 2S)**

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

Instructions for the researcher: For people who are more impaired you may need to rephrase the following questions to obtain the information. For example, if they do not answer the question: "How often do you listen to the radio?" you may need to ask "Do you listen to the radio?" If they say 'no' rather than using one of the official response keys the "once a year or less" box should be

P2_Q241_t2

241. 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_Q242_t2

242. 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_Q243_t2

243. 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_Q244_t2

244. 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_Q245_t2

245. 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

☐

P2_Q246_t2

246. 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

☐

P2_Q247_t2

247. 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

☐

P2_Q248_t2

248. 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

☐

P2_Q249_t2

249. 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

☐

P2_Q250_t2

250. 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

☐

P2_Q251_t2

251. 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

☐

P2_Q252_t2

252. How often do you play computer games?

Once a year or less
(includes never)

☐

Several
times a year

☐

Several times
a month

☐

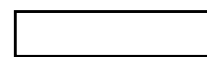
Several
times a week

☐

Every day or
almost every day

☐

Section B



If the study participant does have a relative/friend present, please ensure the following section is completed with both the study participant and his/her relative/friend as a joint interview.

OR

If the study participant does not have a relative/friend present, complete this section with just the study participant.

Section B

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 study participant does not have a relative/friend present, complete this section with just the study participant.

P2_Q253_t2

253. Section B completed by:

☐ the participant by himself/herself ☐ the participant and relative/friend together

Satisfaction with health services

(USE SHOWCARD 2T)

The next couple of questions are about how satisfied you are with the health services received by [you/the study participant].

P2_Q254_t2

254. How satisfied are [you/you both] with the formal support services that [you/the study participant] receive (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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

P2_Q255_t2

255. How satisfied are [you/you both] with the amount of formal support services that [you/the study participant] receive (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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Medication

The next few questions are about the medication taken by [you/the study participant].

Instructions for the researcher: If the participant does not know or is unsure of the number of prescribed medications but has a prescription handy, you can count the number of medications on the prescription and complete this yourself.

P2_Q256_t2

256. How many different prescribed medications [do you/does the study participant] take?

☐ None (skip to Section C)

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six ☐ Seven

☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve ☐ Thirteen ☐ Fourteen

☐ Fifteen or more; please specify number: P2_Q256_1_t2

P2_Q257_t2

257. [Have you/Has the study participant] taken any medications for [your/his/her] memory, thinking or behaviour difficulties in the last 3 months?

☐ No (skip to question 259) ☐ Yes

We would now like to record any medication that [you are/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 [you/the study participant] is/are currently taking?

Instructions for the researcher:

For each of the relevant medications (**USE SHOWCARD 3C**) please record the trade name, the date on which the medication was first taken, whether it is ongoing or the date on which the course of medication was completed, 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 _/_/_ ☒ 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 1/1/00.

P2_Q258[...]

258. DEMENTIA DRUGS

Trade name:	First day (dd/mm/yy)	Last day (if applies)	Ongoing (if applies)	Dose	Medication unit code	Frequency code
[...]_1_1_t2	<input type="text"/> <input type="text"/> / [...]_1_2_t2 / <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / [...]_1_3_t2 / <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> 8_t2	[...]_1_9_t2	[...]_1_10_t2	[...]_1_11_t2
[...]_2_1_t2	<input type="text"/> <input type="text"/> / [...]_2_2_t2 / <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / [...]_2_3_t2 / <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> 8_t2	[...]_2_9_t2	[...]_2_10_t2	[...]_2_11_t2
[...]_3_1_t2	<input type="text"/> <input type="text"/> / [...]_3_2_t2 / <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> / [...]_3_3_t2 / <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> 8_t2	[...]_3_9_t2	[...]_3_10_t2	[...]_3_11_t2

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	ML	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"

259. OTHER MENTAL HEALTH DRUGSOngoing
(if applies)

Dose

Medication
unit codeFrequency
code

Trade name: [...]_1_1_t2

First day (dd/mm/yy)

/

/

Last day (if applies)

/

/

/

/

/

/

Trade name: [...]_2_1_t2

First day (dd/mm/yy)

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Last day (if applies)

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Trade name: [...]_3_1_t2

First day (dd/mm/yy)

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Last day (if applies)

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Trade name: [...]_4_1_t2

First day (dd/mm/yy)

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Last day (if applies)

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Trade name: [...]_5_1_t2

First day (dd/mm/yy)

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Last day (if applies)

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Trade name: [...]_6_1_t2

First day (dd/mm/yy)

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Last day (if applies)

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Trade name: [...]_7_1_t2

First day (dd/mm/yy)

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Last day (if applies)

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Trade name: [...]_8_1_t2

First day (dd/mm/yy)

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Last day (if applies)

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Trade name: [...]_9_1_t2

First day (dd/mm/yy)

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Last day (if applies)

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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	ml	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"

Household income

260. Do you think about your household income in weekly, monthly or yearly terms?
(Instructions for the researcher: Give the appropriate SHOWCARD based on the 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.? Choose ONE option.

P2_Q260_1_t2

Weekly

(USE SHOWCARD 2U)

P2_Q260_2_t2

Monthly

(USE SHOWCARD 2V)

P2_Q260_3_t2

Annually

(USE SHOWCARD 2W)

<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

P2_Q260_4_t2

☐ Refused to answer

0748316593

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

261. 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. Choose ONE.

~~P2_Q261_1 t2~~
Weekly

~~P2_Q261_2 t2~~
Monthly

~~P2_Q261_3 t2~~
Annually

(USE SHOWCARD 2U)

(USE SHOWCARD 2V)

(USE SHOWCARD 2W)

- | | | |
|------------------------------------------------|--------------------------------------------------|----------------------------------------------------|
| <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 |

~~P2_Q261_4 t2~~
☐ Don't know ☐ Refused to answer

0891316592

Section C

This section of the questionnaire is to be completed only if the participant does not have a relative/friend taking part in the study.

P2_Q262_t2

262. Is there a relative/friend taking part in the study?

- ☐ No (complete all questions in Section C)
- ☐ Yes (skip to Section D researcher completed questions)

Section C

Instructions for the researcher: This section of the questionnaire is to be completed only if the participant does not have a relative/friend taking part in the study.

Health conditions

263. We are interested in whether you have any current health conditions or are taking any medication for any condition. Do you have any of these conditions listed on this card?

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

(USE SHOWCARD 2X)

- P2_Q263_1_t2 ☐ Myocardial infarction (history of heart attacks)
- P2_Q263_2_t2 ☐ Congestive heart failure
- P2_Q263_3_t2 ☐ Hypertension (high blood pressure)
- P2_Q263_4_t2 ☐ Diagnosed depression
- P2_Q263_5_t2 ☐ Peripheral vascular disease (includes ☐ aortic aneurysm, ☐ poor circulation)
- P2_Q263_6_t2 ☐ Cerebrovascular disease (☐ Stroke, ☐ CVA or ☐ TIA)
- P2_Q263_7_t2 ☐ Dementia
- P2_Q263_8_t2 ☐ Chronic bad chest (e.g. ☐ asthma, ☐ COPD; ☐ chronic bronchitis, ☐ emphysema)
- P2_Q263_9_t2 ☐ Inflammation affecting the joints (e.g. ☐ lupus, ☐ rheumatoid arthritis, ☐ connective tissue disease, ☐ vasculitis)
- P2_Q263_10_t2 ☐ Peptic/stomach ulcer disease
- P2_Q263_11_t2 ☐ Skin ulcer (☐ bedsores, ☐ repeated cellulitis)
- P2_Q263_12_t2 ☐ Diabetes controlled with insulin or equivalent
- P2_Q263_13_t2 ☐ Diabetes with end-organ damage (e.g. ☐ damage to the retina, ☐ nerve damage, ☐ kidney damage, ☐ brittle diabetes)
- P2_Q263_14_t2 ☐ Moderate or severe chronic kidney disease
- P2_Q263_15_t2 ☐ Hemiplegia
- P2_Q263_16_t2 ☐ 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
- P2_Q263_17_t2 ☐ Mild liver disease (includes hepatitis (☐ B or ☐ C), ☐ cirrhosis)
- P2_Q263_18_t2 ☐ Liver disease (moderate to severe: ☐ chronic jaundice, ☐ liver failure, ☐ liver transplant)
- P2_Q263_19_t2 ☐ AIDS or HIV
- P2_Q263_20_t2 ☐ None of the above or no health problems

P2_Q264_t2

264. Do you take warfarin? ☐ No ☐ Yes

P2_Q265_t2

265. Do you have any other major long term illnesses, health problems or disabilities?

☐ No ☐ Yes; please specify with diagnosis:

P2_Q265_1_t2

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 2Y)

266. Here are some various possible sources of income. Can you please tell me which kinds of income you [and your husband/wife/partner (if applicable)] receive?

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

P2_Q266_1_t2

☐ Earnings from employment or self-employment

P2_Q266_2_t2

☐ State retirement pension

P2_Q266_3_t2

☐ Pension from former employer

P2_Q266_4_t2

☐ Personal pension(s)

P2_Q266_5_t2

☐ Job-seekers' allowance

P2_Q266_6_t2

☐ Employment and support allowance

P2_Q266_7_t2

☐ Income support

P2_Q266_8_t2

☐ Attendance allowance (higher rate for attendance during day **AND** night)

P2_Q266_9_t2

☐ Attendance allowance (lower rate for day **OR** night)

P2_Q266_10_t2

☐ Pension credit

P2_Q266_11_t2

☐ Working tax credit

P2_Q266_12_t2

☐ Child tax credit

P2_Q266_13_t2

☐ Child benefit

P2_Q266_14_t2

☐ Housing benefit

P2_Q266_15_t2

☐ Council tax benefit

P2_Q266_16_t2

☐ Disability living allowance **OR** Personal Independence Payments – care component

P2_Q266_16a_t2

☐ Highest rate ☐ Middle rate ☐ Lowest rate

P2_Q266_17_t2

☐ Disability living allowance **OR** Personal Independence Payments – mobility component

P2_Q266_17a_t2

☐ Highest rate ☐ Lower rate

P2_Q266_18_t2

☐ Other state benefits

P2_Q266_19_t2

☐ Interest from savings and investments (e.g. stocks & shares)

P2_Q266_20_t2

☐ Other kinds of regular allowance from outside your household (e.g. maintenance, student grants, rent)

P2_Q266_21_t2

☐ No source of income

Now we would like to know about the health care and support services that you may have used recently.

P2_Q267_t2

267. In the last 3 months, have you been to hospital, for instance visited casualty/ accident and emergency/walk-in centre or attended a clinic appointment (such as a memory clinic) or stayed overnight?

☐ No (skip to question 285; primary care section)

☐ Yes

Accident and emergency

P2_Q268_t2

268. Thinking about the last 3 months, have you attended casualty/accident and emergency/walk-in centre as a patient?

☐ No (skip to question 271; in-patient section)

☐ Yes; approximately how many times did you attend?

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven or more; please specify number: P2_Q268_2_t2

P2_Q269_t2

269. What was the reason for using the service; why did you go?

(Please include the condition and the specialty of the hospital department)

P2_Q270_t2

270. If you attended casualty/accident and emergency/walk-in centre, did you attend by ambulance?

☐ No

☐ Yes; approximately how many times?

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven or more; please specify number: P2_Q270_2_t2

In-patient care

P2_Q271_t2

271. Thinking about the last 3 months, how many times have you been admitted to hospital as an in-patient overnight or longer?

☐ None (skip to question 280; out-patient section)

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven or more; please specify number: P2_Q271_1_t2

Instructions for the researcher: If more than four times please describe the four most recent occasions below.

P2_Q272_t2

272. What was the reason for using the service for the most recent occasion?

(Please include the condition and the specialty of the hospital department)

P2_Q273_t2

273. How many days did you spend in a hospital as an in-patient (most recent occasion)?

☐ One
☐ Two
☐ Three
☐ Four
☐ Five
☐ Six

☐ Seven or more; please specify number: P2_Q273_1_t2

P2_Q274_t2

274. What was the reason for using the service for the second most recent occasion?

(Please include the condition and the specialty of the hospital department)

P2_Q275_t2

275. How many days did you spend in a hospital as an in-patient (second most recent occasion)?

☐ One
☐ Two
☐ Three
☐ Four
☐ Five
☐ Six

☐ Seven or more; please specify number: P2_Q275_1_t2

P2_Q276_t2

276. What was the reason for using the service for the third most recent occasion?

(Please include the condition and the specialty of the hospital department)

P2_Q277_t2

277. How many days did you spend in a hospital as an in-patient (third most recent occasion)?

☐ One
☐ Two
☐ Three
☐ Four
☐ Five
☐ Six

☐ Seven or more; please specify number: P2_Q277_1_t2

P2_Q278_t2

278. What was the reason for using the service for the fourth most recent occasion?

(Please include the condition and the specialty of the hospital department)

P2_Q279_t2

279. How many days did you spend in a hospital as an in-patient (fourth most recent occasion)?

☐ One
☐ Two
☐ Three
☐ Four
☐ Five
☐ Six

☐ Seven or more; please specify number: P2_Q279_1_t2
Out-patient services

P2_Q280_t2

280. Thinking about the last 3 months, excluding visits to casualty/accident and emergency/walk-in centre, approximately how many times have you attended a hospital or clinic (such as a memory clinic) as an out-patient or day patient?
☐ None (skip to question 285; primary care section)

☐ One
☐ Two
☐ Three
☐ Four
☐ Five
☐ Six

☐ Seven or more; please specify number: P2_Q280_1_t2

Instructions for the researcher: If more than four times please describe the **four most recent** occasions below.

P2_Q281_t2

281. 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).

P2_Q282_t2

282. What was the reason for using the service for the **second most recent occasion**? Please describe the reason for the visit.

P2_Q283_t2

283. What was the reason for using the service for the **third most recent occasion**? Please describe the reason for the visit.

P2_Q284_t2

284. 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**, have you used any of these services from your local surgery or health centre?

P2_Q285_1_t2

285. Have you seen a GP at the surgery?

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P2_Q285_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q285_3_t2

P2_Q286_1_t2

286. Have you seen a GP at home?

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P2_Q286_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q286_3_t2

P2_Q287_1_t2

287. Have you spoken to a GP on the telephone?

Instructions for the researcher: Please also include the number of times that other people have done this on his/her behalf.

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P2_Q287_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q287_3_t2

P2_Q288_1_t2

288. Have you seen a nurse at the surgery?

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** P2_Q288_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q288_3_t2

Now we would like to know about some community health and care services that people can make use of.

Thinking about the last 3 months, have you seen any of the following in person?

P2_Q289_1_t2

289. In the last 3 months have you seen a community nurse or district nurse?

- ☐ No ☐ Not sure ☐ Yes, approximately how many times? P2_Q289_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q289_3_t2

P2_Q290_1_t2

290. In the last 3 months have you seen a community psychiatric nurse or community mental health nurse?

- ☐ No ☐ Not sure ☐ Yes, approximately how many times? P2_Q290_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q290_3_t2

P2_Q291_1_t2

291. In the last 3 months have you seen a psychiatrist?

- ☐ No ☐ Not sure ☐ Yes, approximately how many times? P2_Q291_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q291_3_t2

P2_Q292_1_t2

292. In the last 3 months have you seen a social worker or care manager?

- ☐ No ☐ Not sure ☐ Yes, approximately how many times? P2_Q292_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q292_3_t2

P2_Q293_1_t2

293. In the last 3 months have you seen a psychologist?

- ☐ No ☐ Not sure ☐ Yes, approximately how many times? P2_Q293_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q293_3_t2

P2_Q294_1_t2

294. In the last 3 months have you seen a physiotherapist or occupational therapist?

- ☐ No ☐ Not sure ☐ Yes, approximately how many times? P2_Q294_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q294_3_t2

P2_Q295_1_t2

295. In the last 3 months have you seen a dentist?

- ☐ No ☐ Not sure ☐ Yes, approximately how many times? P2_Q295_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: P2_Q295_3_t2

P2_Q296_1_t2

296. In the last 3 months have you seen an optician?☐ No ☐ Not sure ☐ Yes, approximately how many times? P2_Q296_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: P2_Q296_3_t2

P2_Q297_1_t2

297. In the last 3 months have you seen a specialist nurse (e.g. Admiral Nurse, Macmillan/palliative care nurse, respiratory nurse)?

(Please specify: P2_Q297_oth_t2)

☐ No ☐ Not sure ☐ Yes, approximately how many times? P2_Q297_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: P2_Q297_3_t2

Home help

*The next few questions are about help that you may have received in your home.*In the last 3 months, have you used any of these services?

P2_Q298_1_t2

298. In the last 3 months have you used home care/home help/a support worker?☐ No (skip to question 299) ☐ Not sure☐ Yes, approximately how many times in the last 3 months? P2_Q298_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Thirteen ☐ Twenty six ☐ Thirty nine ☐ Fifty two ☐ Sixty five ☐ Seventy eight
(once a week) (twice a week) (three times a week) (four times a week) (five times a week) (six times a week)☐ Ninety one (daily) ☐ If other; please specify number: P2_Q298_oth_t2

P2_Q298_4_t2

Did you or a family member pay all or part of the costs of this service?

☐ No ☐ Yes, all ☐ Yes, part

P2_Q299_1_t2

299. In the last 3 months have you had meals on wheels (including Wiltshire Farm Foods, etc.)?☐ No (skip to question 300) ☐ Not sure☐ Yes, approximately how many times in the last 3 months? P2_Q299_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Thirteen ☐ Twenty-six ☐ Thirty-nine ☐ Fifty-two ☐ Sixty-five ☐ Seventy-eight
(once a week) (twice a week) (three times a week) (four times a week) (five times a week) (six times a week)☐ Ninety-one (daily) ☐ If other; please specify number: P2_Q299_oth_t2

P2_Q299_4_t2

Did you or a family member pay all or part of the costs of this service?

☐ No ☐ Yes, all ☐ Yes, part

P2_Q300_1_t2

300. In the last 3 months have you used an incontinence laundry service?

☐ No (skip to question 301) ☐ Not sure

☐ Yes, approximately how many times in the last 3 months? P2_Q300_2_t2

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen (once a week) ☐ If other; please specify number: P2_Q300_oth_t2

P2_Q300_4_t2

Did you or a family member pay all or part of the costs of this service?

☐ No ☐ Yes, all ☐ Yes, part

P2_Q301_1_t2

301. In the last 3 months have you used a cleaner/cleaning service?

☐ No (skip to question 302) ☐ Not sure

☐ Yes, approximately how many times in the last 3 months? P2_Q301_2_t2

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen (once a week) ☐ If other; please specify number: P2_Q301_oth_t2

P2_Q301_4_t2

Did you or a family member pay all or part of the costs of this service?

☐ No ☐ Yes, all ☐ Yes, part

P2_Q302_1_t2

302. In the last 3 months have you used a sitting service for respite (e.g. Crossroads)?

☐ No (skip to question 303) ☐ Not sure

☐ Yes, approximately how many times in the last 3 months? P2_Q302_2_t2

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen (once a week) ☐ If other; please specify number: P2_Q302_oth_t2

P2_Q302_4_t2

Did you or a family member pay all or part of the costs of this service?

☐ No ☐ Yes, all ☐ Yes, part

P2_Q303_1_t2

303. In the last 3 months have you used a carer support worker service?

☐ No (skip to question 304) ☐ Not sure

☐ Yes, approximately how many times in the last 3 months? P2_Q303_2_t2

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen (once a week) ☐ If other; please specify number: P2_Q303_oth_t2

P2_Q303_4_t2

Did you or a family member pay all or part of the costs of this service?

☐ No ☐ Yes, all ☐ Yes, part

Now we would like to know about whether you have used various community services that may be available in some areas.

P2_Q304_1_t2

304. In the last 3 months have you attended a day centre?

☐ No (skip to question 305) ☐ Yes

P2_Q304_2_t2

If yes, **approximately how many times a week do you attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: P2_Q304_3_t2

P2_Q304_4_t2

If attending less often than once a week, **approximately how many times over the last 3 months did you attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen or more; please specify number: P2_Q304_5_t2

P2_Q305_1_t2

305. In the last 3 months have you attended a lunch club?

☐ No (skip to question 306) ☐ Yes

P2_Q305_2_t2

If yes, **approximately how many times a week do you attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: P2_Q305_3_t2

P2_Q305_4_t2

If attending less often than once a week, **approximately how many times over the last 3 months did you attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen or more; please specify number: P2_Q305_5_t2

Accommodation away from home

P2_Q306_1_t2

306. Have you lived in a residential care home during the last 3 months?☐ No (skip to question 307)☐ Yes; what was the reason for using the service?

P2_Q306_2_t2

How many days did you stay there? P2_Q306_3_t2

☐ One☐ Two☐ Three☐ Four☐ Five☐ Six☐ Seven☐ Fourteen☐ Twenty-one☐ Twenty-eight☐ If other; please specify number:

P2_Q306_3_oth_t2

P2_Q306_5_t2

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: P2_Q306_oth_t2

P2_Q306_6_t2

Did you or a family member pay all or part of the costs of this accommodation?

☐ No☐ Yes, all☐ Yes, part

P2_Q307_1_t2

307. Have you lived in a nursing home during the last 3 months?☐ No (skip to question 308)☐ Yes; what was the reason for using the service?

P2_Q307_2_t2

How many days did you stay there? P2_Q307_3_t2

☐ One☐ Two☐ Three☐ Four☐ Five☐ Six☐ Seven☐ Fourteen☐ Twenty-one☐ Twenty-eight☐ If other; please specify number:

P2_Q307_3_oth_t2

P2_Q307_5_t2

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: P2_Q307_oth_t2

P2_Q307_6_t2

Did you or a family member pay all or part of the costs of this accommodation?

☐ No☐ Yes, all☐ Yes, part

Equipment and adaptations

(USE SHOWCARD 2Z)

Now we're going to ask about whether you use 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 you 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
P2_Q308[...] 308. Electronic medication reminder dispenser (do not include blister packs)	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q309[...] 309. Calendar clock	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q310[...] 310. Falls detector or falls alarm	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q311[...] 311. Community or personal alarm (including pull-cord and pendant alarms)	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q312[...] 312. Outdoor railing	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q313[...] 313. Grab rail/Stair rail	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q314[...] 314. Walking stick	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q315[...] 315. Walking frame	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q316[...] 316. Walk-in shower/shower cubicle replacing bath	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q317[...] 317. Over-bath shower	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q318[...] 318. Bath seat/shower seat	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q319[...] 319. Kitchen/perching stool	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q320[...] 320. Bed lever/rail	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q321[...] 321. Toilet frame/raised toilet seat	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q322[...] 322. Commode	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q323[...] 323. Continence pads	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
P2_Q324 t2 324. 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 you.

P2_Q325_t2

325. In the last 3 months have relatives or friends regularly helped you with tasks which you had difficulty with, or could not do?

☐ No (skip to question 327) ☐ Yes;

P2_Q326_t2

326. In an average week, how much time do relatives or friends spend looking after you/ providing help for you with these 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 P2_Q326_oth_t2

Travel costs

P2_Q327_1_t2

327. In the last 3 months, have you attended any GP, clinic, hospital, or day services for your 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 Section D; researcher ratings) ☐ Yes

P2_Q327_2_t2

If yes, **over the last 3 months, how many times did you 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: P2_Q327_3_t2

P2_Q328_1_t2

328. How did you normally travel to get to the services you 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 P2_Q328_oth_t2

329. How long did it normally take to travel to the GP, clinic, hospital, or day service from home?

Hours : Minutes P2_Q329_1_t2 : P2_Q329_2_t2

Instructions for the researcher: If the study participant normally used public transport answer question 330, if the study participant normally went by taxi ask question 331, and if the study participant normally drove/went by car ask questions 332 and 333. Please remember to put a cross in the 'not applicable' box for those questions which are not applicable.

330. If you normally travelled by public transport, what was the cost of the fare in one direction (cost of a one-way ticket)?

£ ☐ Bus pass/travel for free ☐ Not applicable

331. If you normally travelled by taxi, what was the cost of the fare in one direction (cost of a one-way journey)?

£ ☐ Not applicable

332. If you normally travelled by car, how many miles/kilometres did you travel to get there (one-way journey)?

☐ Not applicable

Is this number in miles or kilometres?

☐ Miles ☐ Kilometres

333. 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

Instructions for the researcher: This is the end of the participant questions.

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

We will be contacting you again around 12 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. There is one £10 voucher to be given jointly to the relative/friend and participant, or to the participant only if there is no relative/friend taking part in the study.

Instructions for the researcher: The researcher must complete the ratings on the next page, the checklist in full, and the field notes (if appropriate) before returning the CRFs.

Researcher ratings: compulsory information**Global Deterioration Scale (GDS)**

P2_Q334_t2

334. 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 3B 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)

P2_Q335_t2

335. Please provide justification for your score on the GDS here:

P2_Q336_t2

336. Please provide your rating of the level of consciousness of the participant during this assessment visit.

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

Instructions for researcher: Now complete the checklist on the next pages indicating where and why data may be missing from the CRF.

Instructions for researcher: Please ensure that you have checked the relative's/friend's CRF for any missing values and/or double entries and correct/seek clarification where necessary before leaving their home.

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:

TSI: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

ACE-III: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Physical health: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Dignity and respect: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Psychological Well-Being: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Your accommodation: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Green/blue spaces : ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Life Space: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Society and Community: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Social Capital: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Social activities: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Cultural activities: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Interests and Activities: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Section B

Satisfaction with health services:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Medication: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Household income: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Section C

Health conditions: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Sources of income: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Service use: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Community health and care:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Home help: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Community services: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Accommodation away from home:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Equipment and adaptations: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Help and support: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Travel costs: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ 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.

I would like to add field notes or comments

☐ No ☐ Yes; please write your notes here:

DO NOT PRINT/CO

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Enhancing Active Life and Living Well: The IDEAL Study Time 2

12 month follow-up

Relative/Friend Part 1 of 2

Questions about your relative/friend

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?

In this part of the questionnaire we will be asking you for information **about the well-being of your relative/friend**. We asked you similar questions last year and we are interested in how things are at this time.

We will ask you to provide information **about your own experiences while supporting your relative/friend** in the next part.

The information you provide is extremely valuable to us. All the information that 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.

C1_Q1_t2

1. Today's date (dd/mm/yyyy) / / 2 0 1

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.

C1_Q2_t2

2. Has your relative's/friend's current legal marital status changed over the past 12 months?

- ☐ No (skip to question 5)
- ☐ Yes

C1_Q3_t2

3. If yes, 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:

C1_Q3_1_t2

C1_Q4_t2

4. If the status of your relative/friend has changed such that s/he is now married/widowed/separated/divorced how many months has s/he been married/widowed/separated/divorced?

1 2 3 4 5 6 7 8 9 10 11 12

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

Don't know

☐

Your relative's/friend's employment/job

The next questions are about your relative's/friend's current employment status.

C1_Q5_1_t2

5. 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)?

C1_Q5_2_t2

C1_Q5_3_t2

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 6)

☐ Retired; if retired **at what age did s/he retire?**

C1_Q5_4_t2

☐ 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_Q5_5_t2

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)**.

C1_Q6_t2

6. How is your relative's/friend's physical health right now? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C1_Q7_t2

7. How is your relative's/friend's energy level? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

C1_Q8_t2

8. 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

C1_Q9_t2

9. 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

C1_Q10_t2

10. How is your relative's/friend's memory? Is it...☐ Poor ☐ Fair ☐ Good ☐ Excellent

C1_Q11_t2

11. 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

C1_Q12_t2

12. 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

C1_Q13_t2

13. How is your relative's/friend's current relationship with his/her friends? *If your relative/friend has no other friends, does s/he have anyone s/he enjoys being with other than family? If so, how would you rate your relative's/friend's current relationship with this person? Is it...*☐ Poor ☐ Fair ☐ Good ☐ Excellent

C1_Q14_t2

14. 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

C1_Q15_t2

15. 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

C1_Q16_t2

16. How is your relative's/friend's ability to do things for fun, that s/he enjoys? Is it...☐ Poor ☐ Fair ☐ Good ☐ Excellent

C1_Q17_t2

17. How is your relative's/friend's current situation with money, i.e. his/her financial situation? Is it...☐ Poor ☐ Fair ☐ Good ☐ Excellent

C1_Q18_t2

18. 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

C1_Q19_t2

☐ 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

☐ 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

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

☐ ☐ ☐ ☐ ☐ ☐

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

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

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.

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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**. If yes, please say how often your relative/friend did each activity. We would also like to know how much s/he enjoys this activity, even if you answer "Never" to whether s/he has done this activity in the **last 2 weeks**.

C1_Q24_1_t2

24. Has your relative/friend had an opportunity to be outside, go for walks, enjoy nature?

☐ No (skip to question 25)

C1_Q24_2_t2

☐ Yes, if yes; **How often did s/he do the activity?** **Did s/he enjoy the activity?**

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q24_3_t2

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C1_Q25_1_t2

25. Has your relative/friend had an opportunity to be with pets or animals or to watch animals?

☐ No (skip to question 26)

C1_Q25_2_t2

☐ Yes, if yes; **How often did s/he do the activity?** **Did s/he enjoy the activity?**

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q25_3_t2

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C1_Q26_1_t2

26. Has your relative/friend had an opportunity to get together with family/friends?

☐ No (skip to question 27)

C1_Q26_2_t2

☐ Yes, if yes; **How often did s/he do the activity?** **Did s/he enjoy the activity?**

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q26_3_t2

☐ Never

☐ No

☐ Up to three times a week

☐ Yes

☐ More than three times a week

C1_Q27_1_t2

27. Has your relative/friend had an opportunity to talk to family/friends on the telephone?

☐ No (skip to question 28)

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q27_3_t2

C1_Q27_2_t2

☐ 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

C1_Q28_1_t2

28. Has your relative/friend had an opportunity to go to the cinema, museums or other entertainment events?

☐ No (skip to question 29)

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q28_3_t2

C1_Q28_2_t2

☐ 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

C1_Q29_1_t2

29. Has your relative/friend had an opportunity to go to church or other place of worship or religious events?

☐ No (skip to question 30)

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q29_3_t2

C1_Q29_2_t2

☐ 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

C1_Q30_1_t2

30. Has your relative/friend had an opportunity to go shopping for groceries, clothes, etc.?

☐ No (skip to question 31)

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q30_3_t2

C1_Q30_2_t2

☐ 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

C1_Q31_1_t2

31. Has your relative/friend had an opportunity to go for a ride in the car, train or bus?

☐ No (skip to question 32)

C1_Q31_2_t2

☐ Yes, if yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity **C1_Q31_3_t2**

Did s/he enjoy the activity?

☐ No

☐ Yes

C1_Q32_1_t2

32. Has your relative/friend had an opportunity to read or have stories read to him/her?

☐ No (skip to question 33)

C1_Q32_2_t2

☐ Yes, if yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity **C1_Q32_3_t2**

Did s/he enjoy the activity?

☐ No

☐ Yes

C1_Q33_1_t2

33. Has your relative/friend had an opportunity to listen to the radio, tapes or CDs, or watch TV?

☐ No (skip to question 34)

C1_Q33_2_t2

☐ Yes, if yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity **C1_Q33_3_t2**

Did s/he enjoy the activity?

☐ No

☐ Yes

C1_Q34_1_t2

34. Has your relative/friend had an opportunity to exercise, play or watch sports?

☐ No (skip to question 35)

C1_Q34_2_t2

☐ Yes, if yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity **C1_Q34_3_t2**

Did s/he enjoy the activity?

☐ No

☐ Yes

C1_Q35_1_t2

35. Has your relative/friend had an opportunity to play games or cards, do crosswords or puzzles?

☐ No (skip to question 36)

C1_Q35_2_t2

☐ Yes, if yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q35_3_t2

Did s/he enjoy the activity?

☐ No

☐ Yes

C1_Q36_1_t2

36. Has your relative/friend had an opportunity to do handiwork or crafts?

☐ No (skip to question 37)

C1_Q36_2_t2

☐ Yes, if yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q36_3_t2

Did s/he enjoy the activity?

☐ No

☐ Yes

C1_Q37_1_t2

37. Has your relative/friend had an opportunity to garden, plant care, indoors or outdoors?

☐ No (skip to question 38)

C1_Q37_2_t2

☐ Yes, if yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q37_3_t2

Did s/he enjoy the activity?

☐ No

☐ Yes

C1_Q38_1_t2

38. Has your relative/friend had an opportunity to complete a task that was difficult for him/her?

☐ No (skip to question 39)

C1_Q38_2_t2

☐ Yes, if yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity C1_Q38_3_t2

Did s/he enjoy the activity?

☐ No

☐ Yes

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.

C1_Q39_t2

39. 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"/>

C1_Q40_t2

40. 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"/>

C1_Q41_t2

41. 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"/>

C1_Q42_t2

42. 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"/>

C1_Q43_t2

43. 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"/>

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.

C1_Q44_t2

44. 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

C1_Q45_t2

45. 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

C1_Q46_t2

46. 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

C1_Q47_t2

47. 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

C1_Q48_t2

48. 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

C1_Q49_t2

49. 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

C1_Q50_t2

50. 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

C1_Q51_t2

51. 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

C1_Q52_t2

52. 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

C1_Q53_t2

53. 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

C1_Q54_t2

54. 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

C1_Q55_t2

55. Does your relative/friend need help selecting clothing for himself/herself that is appropriate for the weather?

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

C1_Q56_t2

56. 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)

C1_Q57_t2

57. 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)

C1_Q58_t2

58. 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

C1_Q59_t2

59. Does your relative/friend need household chores done for him/her?

☐ No ☐ Yes

C1_Q60_t2

60. Does your relative/friend need to be watched or kept company when awake?

☐ No ☐ Yes

C1_Q61_t2

61. Does your relative/friend need to be escorted when outside?

☐ No ☐ Yes

C1_Q62_t2

62. Does your relative/friend need to be accompanied when bathing or eating?

☐ No ☐ Yes

C1_Q63_t2

63. Does your relative/friend have to be dressed, washed, and groomed?

☐ No ☐ Yes

C1_Q64_t2

64. Does your relative/friend have to be taken to the toilet regularly to avoid incontinence?

☐ No ☐ Yes

C1_Q65_t2

65. Does your relative/friend have to be fed?

☐ No ☐ Yes

C1_Q66_t2

66. Does your relative/friend have to be turned, moved, or transferred?

☐ No ☐ Yes

C1_Q67_t2

67. Does your relative/friend wear an incontinence pad or a catheter?

☐ No ☐ Yes

C1_Q68_t2

68. Does your relative/friend need to be tube fed?

☐ No ☐ Yes

C1_Q69_t2

69. Would you say your relative's/friend's appetite is:

☐ Very poor ☐ Poor ☐ Fair ☐ Good ☐ Very good

C1_Q70_t2

70. 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

C1_Q71_t2

71. 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

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 or symptoms have 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.

C1_Q72_1_t2

72. 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 73)

☐ Yes

C1_Q72_2_t2

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)

C1_Q72_3_t2

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)

C1_Q73_1_t2

73. 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 74)

☐ Yes

C1_Q73_2_t2

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)

C1_Q73_3_t2

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)

C1_Q74_1_t2

74. Is your relative/friend stubborn and resistive to help from others?☐ No (skip to question 75)☐ Yes

C1_Q74_2_t2

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)

C1_Q74_3_t2

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)

C1_Q75_1_t2

75. Does your relative/friend act as if s/he is sad or in low spirits? Does s/he cry?☐ No (skip to question 76)☐ Yes

C1_Q75_2_t2

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)

C1_Q75_3_t2

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)

C1_Q76_1_t2

76. 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 77)

☐ Yes

C1_Q76_2_t2

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)

C1_Q76_3_t2

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)

C1_Q77_1_t2

77. Does your relative/friend appear to feel too good or act excessively happy?

☐ No (skip to question 78)

☐ Yes

C1_Q77_2_t2

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)

C1_Q77_3_t2

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)

78. Does your relative/friend seem less interested in his/her usual activities and in the activities and plans of others?

☐ No (skip to question 79)

☐ Yes

C1_Q78_2_t2

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)

C1_Q78_3_t2

☐ 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)

C1_Q79_1_t2

79. 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 80)

☐ Yes

C1_Q79_2_t2

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)

C1_Q79_3_t2

☐ 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)

C1_Q80_1_t2

80. Is your relative/friend impatient or cranky? Does s/he have difficulty coping with delays or waiting for planned activities?

☐ No (skip to question 81)

☐ Yes

C1_Q80_2_t2

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)

C1_Q80_3_t2

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)

C1_Q81_1_t2

81. 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 82)

☐ Yes

C1_Q81_2_t2

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)

C1_Q81_3_t2

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)

C1_Q82_1_t2

82. 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 83)

☐ Yes

C1_Q82_2_t2

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)

C1_Q82_3_t2

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)

C1_Q83_1_t2

83. Has your relative/friend lost or gained weight, or had a change in the food s/he likes?

☐ No (skip to question 84)

☐ Yes

C1_Q83_2_t2

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)

C1_Q83_3_t2

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)

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.

C1_Q84_t2

84. 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"/>

C1_Q85_t2

85. 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"/>

C1_Q86_t2

86. 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"/>

C1_Q87_t2

87. 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"/>

C1_Q88_t2

88. 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"/>

C1_Q89_t2

89. 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 health

C1_Q90_t2

90. 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.)

If employed select one of the four options below

- ☐ 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.)

C1_Q91_t2

91. 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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C1_Q92_t2

92. 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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C1_Q93_t2

93. 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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C1_Q94_t2

94. 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

☐☐☐☐

C1_Q95_t2

95. 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

☐☐☐☐

C1_Q96_t2

96. 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)

C1_Q97_1_t2

97. Has your relative/friend fallen down in the last year for any reason?

☐ No (skip to question 98)

☐ Yes; how many times: ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number:

☐ Don't know

C1_Q97_4_t2

If yes, did your relative/friend injure himself/herself seriously enough to need medical treatment?

☐ No ☐ Yes ☐ Don't know

C1_Q98_1_t2

98. 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 101)☐ Yes; please describe his/her role below

C1_Q98_2_t2

☐ Don't know

C1_Q99_t2

99. Is the health professional in place to help with your relative's/friend's memory, thinking or behaviour difficulties?

☐ No ☐ Yes ☐ Don't know

C1_Q100_1_t2

100. How many times over the last 12 months have you seen this health professional?

1 2 3 4 5 6 7 8 9 10 Don't know
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

☐ 11 or more; please specify number:

Your relative's/friend's health conditions

101. We are interested in whether your relative/friend has any current health conditions or is taking any medication for any condition. Does your relative/friend have any of these conditions listed below?

You may cross more than one box

- C1_Q101_1_t2 ☐ Myocardial infarction (history of heart attacks)
- C1_Q101_2_t2 ☐ Congestive heart failure
- C1_Q101_3_t2 ☐ Hypertension (high blood pressure)
- C1_Q101_4_t2 ☐ Diagnosed depression
- C1_Q101_5_t2 ☐ Peripheral vascular disease (includes C1_Q101_5a_t2 ☐ aortic aneurysm, C1_Q101_5b_t2 ☐ poor circulation)
- C1_Q101_6_t2 ☐ Cerebrovascular disease (C1_Q101_6a_t2 ☐ Stroke, C1_Q101_6b_t2 ☐ CVA or C1_Q101_6c_t2 ☐ TIA)
- C1_Q101_7_t2 ☐ Dementia
- C1_Q101_8_t2 ☐ Chronic bad chest (e.g. C1_Q101_8a_t2 ☐ asthma, C1_Q101_8b_t2 ☐ COPD; C1_Q101_8c_t2 ☐ chronic bronchitis, C1_Q101_8d_t2 ☐ emphysema)
- C1_Q101_9_t2 ☐ Inflammation affecting the joints (e.g. C1_Q101_9a_t2 ☐ lupus, C1_Q101_9b_t2 ☐ rheumatoid arthritis, C1_Q101_9c_t2 ☐ connective tissue disease, C1_Q101_9d_t2 ☐ vasculitis)
- C1_Q101_10_t2 ☐ Peptic/stomach ulcer disease
- C1_Q101_11_t2 ☐ Skin ulcer (C1_Q101_11a_t2 ☐ bedsores, C1_Q101_11b_t2 ☐ repeated cellulitis)
- C1_Q101_12_t2 ☐ Diabetes controlled with insulin or equivalent
- C1_Q101_13_t2 ☐ Diabetes with end-organ damage (e.g. C1_Q101_13a_t2 ☐ damage to the retina, C1_Q101_13b_t2 ☐ nerve damage, C1_Q101_13c_t2 ☐ kidney damage, C1_Q101_13d_t2 ☐ brittle diabetes)
- C1_Q101_14_t2 ☐ Moderate or severe chronic kidney disease
- C1_Q101_15_t2 ☐ Hemiplegia
- C1_Q101_16_t2 ☐ Cancer within the last five years (e.g. C1_Q101_16a_t2 ☐ breast, C1_Q101_16b_t2 ☐ colon, C1_Q101_16c_t2 ☐ prostate, C1_Q101_16d_t2 ☐ lung, C1_Q101_16e_t2 ☐ skin, C1_Q101_16f_t2 ☐ blood (lymphoma), C1_Q101_16g_t2 ☐ acute or chronic leukaemia)
- C1_Q101_16h_t2 **If your relative/friend has been diagnosed with cancer within the last five years, has it spread to other areas (metastasised)?** ☐ No ☐ Yes
- C1_Q101_17_t2 ☐ Mild liver disease (includes hepatitis (C1_Q101_17a_t2 ☐ B or C1_Q101_17b_t2 ☐ C), C1_Q101_17c_t2 ☐ cirrhosis)
- C1_Q101_18_t2 ☐ Liver disease (moderate to severe: C1_Q101_18a_t2 ☐ chronic jaundice, C1_Q101_18b_t2 ☐ liver failure, C1_Q101_18c_t2 ☐ liver transplant)
- C1_Q101_19_t2 ☐ AIDS or HIV
- C1_Q101_20_t2 ☐ None of the above or no health problems

C1_Q102_t2

102. Does your relative/friend take warfarin?

☐ No ☐ Yes

C1_Q103_1_t2

103. Does your relative/friend have any other major long term illnesses, health problems or disabilities?

☐ No ☐ Yes; please specify with diagnosis:

C1_Q103_2_t2

Your relative's/friend's sleep

C1_Q104_t2

104. How well would you rate your relative's/friend's sleep these days?

- ☐ Very poor
- ☐ Poor
- ☐ Fair
- ☐ Good (skip to question 106)
- ☐ Very good (skip to question 106)

105. 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

- C1_Q105_1_t2 ☐ Not being able to get to sleep
- C1_Q105_2_t2 ☐ Waking up too early and not being able to get back to sleep
- C1_Q105_3_t2 ☐ Waking up several times throughout the night
- C1_Q105_4_t2 ☐ Having bad dreams
- C1_Q105_5_t2 ☐ Being uncomfortable
- C1_Q105_6_t2 ☐ Other; please specify:

C1_Q105_oth_t2

Your relative's/friend's health state

We would like to know 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

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.:

C1_Q111_1_t2

111. 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
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C1_Q111_2_t2

If more than ten please specify:

Don't know
☐

C1_Q112_1_t2

112. 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
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C1_Q112_2_t2

If more than ten please specify:

Don't know
☐

C1_Q113_1_t2

113. 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

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C1_Q113_2_t2

If more than ten please specify:

Don't know
☐

Considering all of his/her friends including those who live in his/her neighbourhood:

C1_Q114_1_t2

114. 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

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C1_Q114_2_t2

If more than ten please specify:

Don't know
☐

C1_Q115_1_t2

115. 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

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C1_Q115_2_t2

If more than ten please specify:

Don't know
☐

C1_Q116_1_t2

116. 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

☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C1_Q116_2_t2

If more than ten please specify:

Don't know
☐

C1_Q117_t2

117. How satisfied is your relative/friend with the support s/he receives from family?

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

☐ ☐ ☐ ☐ ☐ ☐

C1_Q118_t2

118. How satisfied is your relative/friend with the support s/he receives from friends?

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

☐ ☐ ☐ ☐ ☐ ☐

Your relative's/friend's life space

*These questions are about your relative's/friend's movement inside and outside his/her home or place of residence during the **past 3 days**.*

C1_Q119_t2

119. During the past 3 days, has your relative/friend been to other rooms of his/her home or place of residence besides the room where s/he sleeps?

☐ No ☐ Yes

C1_Q120_t2

120. During the past 3 days, has your relative/friend been to an area immediately outside his/her home or place of residence such as a porch, patio, hallway of an apartment building, or garage?

☐ No ☐ Yes

C1_Q121_t2

121. During the past 3 days, has your relative/friend been to an area outside his/her home or place of residence such as a yard, garden, driveway, or parking space?

☐ No ☐ Yes

C1_Q122_t2

122. During the past 3 days, has your relative/friend been to places in his/her immediate area, but beyond his/her own home or place of residence?

☐ No ☐ Yes

C1_Q123_t2

123. During the past 3 days, has your relative/friend been to places outside his/her immediate area, but within his/her town/village or community?

☐ No ☐ Yes

C1_Q124_t2

124. During the past 3 days, has your relative/friend been to places outside his/her immediate town/village or community?

☐ No ☐ Yes

Your relative's/friend's accommodation

C1_Q125_t2

125. Has your relative/friend moved house in the last year?

☐ No (skip to question 129) ☐ Yes

C1_Q126_1_t2

126. What type of residence is this?

- ☐ own home ☐ general hospital ☐ mental health hospital/unit (including secure units)
☐ other hospital ☐ care home without nursing ☐ care home with nursing
☐ sheltered housing only ☐ other medical and care establishment
☐ other; please specify: C1_Q126_2_t2

C1_Q127_t2

127. Is this living situation specifically dedicated to providing dementia care?

☐ No ☐ Yes

128. What were the main reasons your relative/friend moved address?

You may cross more than one box

C1_Q128_1 t2

☐ Retirement

C1_Q128_2 t2

☐ Downsizing

C1_Q128_3 t2

☐ To be nearer relative(s)

C1_Q128_4 t2

☐ Needed more support

C1_Q128_5 t2

☐ Needed more care

C1_Q128_6 t2

☐ Needed to move into residential care

C1_Q128_7 t2

☐ Could no longer afford last home

C1_Q128_8 t2

☐ Relationship breakdown

C1_Q128_9 t2

☐ New relationship

C1_Q128_10 t2

☐ Wanted to move to better area

C1_Q128_11 t2

☐ For children's/grandchildren's education

C1_Q128_12 t2

☐ Just wanted a change

C1_Q128_13 t2

☐ Wanted a place of his/her own

C1_Q128_14 t2

☐ Problems with neighbours

C1_Q128_15 t2

☐ Moving away from crime

C1_Q128_16 t2

☐ Previous accommodation temporary

C1_Q128_17 t2

☐ Quality of previous accommodation

C1_Q128_18 t2

☐ Spouse or partner job change

C1_Q128_19 t2

☐ Job change/nearer work

C1_Q128_20 t2

☐ Overcrowding or no space

C1_Q128_21 t2

☐ Wanted to buy

C1_Q128_22 t2

☐ Wanted larger home

C1_Q128_23 t2

☐ Wanted better home

C1_Q128_24 t2

☐ Problems with landlord

C1_Q128_25 t2

☐ Evicted/repossessed from last home

C1_Q128_26 t2

☐ For financial reasons

C1_Q128_27 t2

☐ Other; please specify:

C1_Q128_oth t2

C1_Q128_29 t2

☐ 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.

C1_Q129_t2

129. 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

C1_Q130_t2

130. 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

C1_Q131_t2

131. 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

C1_Q132_t2

132. 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

C1_Q133_t2

133. 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

C1_Q134_t2

134. 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

C1_Q135_t2

135. 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

C1_Q136_t2

136. 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

C1_Q137_t2

137. 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

C1_Q138_t2

138. 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

C1_Q139_t2

139. 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

C1_Q140_t2

140. 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 involvement in decision-making

We would like to know how involved your relative/friend is in making decisions in each of the following areas

C1_Q141_t2

141. 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

C1_Q142_t2

142. How involved is your relative/friend in decisions about visiting with friends?

☐ Not at all involved ☐ A little involved ☐ Fairly involved ☐ Very involved

C1_Q143_t2

143. How involved is your relative/friend in decisions about what foods to buy?

☐ Not at all involved ☐ A little involved ☐ Fairly involved ☐ Very involved

C1_Q144_t2

144. 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

C1_Q145_t2

145. How involved is your relative/friend in decisions about when to get up?

☐ Not at all involved ☐ A little involved ☐ Fairly involved ☐ Very involved

C1_Q146_t2

146. 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

C1_Q147_t2

147. How involved is your relative/friend in decisions about being physically active?

☐ Not at all involved ☐ A little involved ☐ Fairly involved ☐ Very involved

C1_Q148_t2

148. 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

C1_Q149_t2

149. How involved is your relative/friend in decisions about expressing affection?

☐ Not at all involved ☐ A little involved ☐ Fairly involved ☐ Very involved

C1_Q150_t2

150. How involved is your relative/friend in decisions about having a pet?

- ☐ Not at all involved ☐ A little involved ☐ Fairly involved ☐ Very involved

C1_Q151_t2

151. 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

C1_Q152_t2

152. How involved is your relative/friend in decisions about choosing places to go?

- ☐ Not at all involved ☐ A little involved ☐ Fairly involved ☐ Very involved

C1_Q153_t2

153. How involved is your relative/friend in decisions about what clothes to wear?

- ☐ Not at all involved ☐ A little involved ☐ Fairly involved ☐ Very involved

C1_Q154_t2

154. How involved is your relative/friend in decisions about choosing where to live?

- ☐ Not at all involved ☐ A little involved ☐ Fairly involved ☐ Very involved

C1_Q155_t2

155. 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.

C1_Q156_t2

156. Health professionals treat your relative/friend with dignity and respect

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

C1_Q157_t2

157. Care staff 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

158. 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.

You may cross more than one box

Bereavement

C1_Q158_1_t2 ☐ Death of spouse or child

C1_Q158_2_t2 ☐ Death of a close family member (e.g. parent or sibling)

C1_Q158_3_t2 ☐ Death of a close friend

Marital difficulties

C1_Q158_4_t2 ☐ Divorce

C1_Q158_5_t2 ☐ Marital separation

Change in circumstances

C1_Q158_6_t2 ☐ Retirement

C1_Q158_7_t2 ☐ Moved home

C1_Q158_8_t2 ☐ Major change in financial state (e.g. a lot worse off or a lot better off)

C1_Q158_9_t2 ☐ Major change in health or behaviour of family member

C1_Q158_10_t2 ☐ Major personal injury or illness

None

C1_Q158_11_t2 ☐ None of the above

C1_Q159_1_t2

159. Have there been any other significant events that your relative/friend has experienced in his/her life over the past 12 months?

☐ No ☐ Yes, if yes; please specify:

C1_Q159_2_t2

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.

160. Here are some various possible sources of income. Please cross the boxes to indicate which kinds of income you and your relative/friend receive.

You may cross more than one box

- C1_Q160_1_t2 ☐ Earnings from employment or self-employment
- C1_Q160_2_t2 ☐ State retirement pension
- C1_Q160_3_t2 ☐ Pension from former employer
- C1_Q160_4_t2 ☐ Personal pension(s)
- C1_Q160_5_t2 ☐ Job-seekers' allowance
- C1_Q160_6_t2 ☐ Employment and support allowance
- C1_Q160_7_t2 ☐ Income support
- C1_Q160_8_t2 ☐ Attendance allowance (higher rate for attendance during day AND night)
- C1_Q160_9_t2 ☐ Attendance allowance (lower rate for day OR night)
- C1_Q160_10_t2 ☐ Pension credit
- C1_Q160_11_t2 ☐ Working tax credit
- C1_Q160_12_t2 ☐ Child tax credit
- C1_Q160_13_t2 ☐ Child benefit
- C1_Q160_14_t2 ☐ Housing benefit
- C1_Q160_15_t2 ☐ Council tax benefit
- C1_Q160_16_t2 ☐ Disability living allowance **OR** Personal Independence Payments – care component
- C1_Q160_16a_t2 ☐ Highest rate ☐ Middle rate ☐ Lowest rate
- C1_Q160_17_t2 ☐ Disability living allowance **OR** Personal Independence Payments – mobility component
- C1_Q160_17a_t2 ☐ Highest rate ☐ Lower rate
- C1_Q160_18_t2 ☐ Other state benefits
- C1_Q160_19_t2 ☐ Interest from savings and investments (e.g. stocks & shares)
- C1_Q160_20_t2 ☐ Other kinds of regular allowance from outside your household (e.g. maintenance, student grants, rent)
- C1_Q160_21_t2 ☐ No source of income

Your relative's/friend's service use

Now we would like to know about the health care and support services that your relative/friend may have used recently.

C1_Q161_t2

161. In the last 3 months, has your relative/friend been to hospital, for instance visited casualty/accident and emergency/walk-in centre or attended a clinic appointment (such as a memory clinic) or stayed overnight?

☐ No (skip to question 179; primary care section)

☐ Yes

Accident and emergency

C1_Q162_1_t2

162. Thinking about the last 3 months, has your relative/friend attended casualty/accident and emergency/walk-in centre as a patient?

☐ No (skip to question 165; in-patient section)

C1_Q162_2_t2

☐ Yes; **approximately how many times did your relative/friend attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: C1_Q162_3_t2

163. What was the reason for using the service; why did your relative/friend go? (Please include your relative's/friend's condition)

C1_Q163_t2

C1_Q164_1_t2

164. If your relative/friend attended casualty/accident and emergency/walk-in centre, did s/he attend by ambulance?

☐ No

C1_Q164_3_t2

☐ Yes; **approximately how many times?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: C1_Q164_3_t2

In-patient care

C1_Q165_1_t2

165. Thinking about the last 3 months, how many times has your relative/friend been admitted to hospital as an in-patient, overnight or longer?

☐ None (skip to question 174; out-patient section)

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: C1_Q165_2_t2

Please describe any hospital admissions occurring in the last 3 months, starting with the most recent occasion, below. In the space provided, please include your relative's/friend's condition and the specialty of the hospital department.

C1_Q166_t2

166. What was the reason for using the service for the most recent occasion?

C1_Q167_1_t2

167. How many days did your relative/friend spend in a hospital as an in-patient on the most recent occasion in the last 3 months?

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: C1_Q167_2_t2

C1_Q168_t2

168. What was the reason for using the service for the second most recent occasion?

C1_Q169_1_t2

169. How many days did your relative/friend spend in a hospital as an in-patient on the second most recent occasion in the last 3 months?

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: C1_Q169_2_t2

C1_Q170_t2

170. What was the reason for using the service for the third most recent occasion?

C1_Q171_1_t2

171. How many days did your relative/friend spend in a hospital as an in-patient on the third most recent occasion in the last 3 months?

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: C1_Q171_2_t2

C1_Q172_t2

172. What was the reason for using the service for the fourth most recent occasion?

C1_Q173_1_t2

173. How many days did your relative/friend spend in a hospital as an in-patient on the fourth most recent occasion in the last 3 months?

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: C1_Q173_2_t2

Out-patient services

C1_Q174_t2

174. Thinking about the last 3 months, excluding visits to casualty/accident and emergency/walk-in centre, approximately how many times has your relative/friend attended a hospital or clinic (such as a memory clinic) as an out-patient or day patient?

☐ None (skip to question 179; primary care section)

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven or more; please specify number:

C1	Q174	2	t2
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Please describe your relative's/friend's four most recent attendances in the last 3 months, starting with the most recent occasion, below. In the space provided, please include your relative's/friend's condition and the specialty of the hospital

C1_Q175_t2

175. What was the reason for using the service for the most recent occasion in the last 3 months?

C1_Q176_t2

176. What was the reason for using the service for the second most recent occasion in the last 3 months?

177. What was the reason for using the service for the third most recent occasion in the last 3 months?

C1_Q177_t2

C1_Q178_t2

178. What was the reason for using the service for the fourth most recent occasion in the last 3 months?

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Primary care

6621461028

Thinking about the last 3 months, has your relative/friend used any of these services from his/her local surgery or health centre?

C1_Q179_1_t2

179. Has your relative/friend seen a GP at the surgery?

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q179_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: C1_Q179_3_t2

C1_Q180_1_t2

180. Has your relative/friend seen a GP at home?

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q180_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: C1_Q180_3_t2

C1_Q181_1_t2

181. Has your relative/friend spoken to a GP on the telephone?

(Please also include the number of times that you have done this on his/her behalf.)

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q181_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: C1_Q181_3_t2

C1_Q182_1_t2

182. Has your relative/friend seen a nurse at the surgery?

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q182_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: C1_Q182_3_t2

Community health and care

Now we would like to know about some community health and care services that people can make use of.

Thinking about the last 3 months, has your relative/friend seen any of the following in person?

C1_Q183_1_t2

183. Community Nurse or District Nurse

- ☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q183_2_t2
- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
- ☐ Seven or more; please specify number: C1_Q183_3_t2

C1_Q184_1_t2

184. Community Psychiatric Nurse or Community Mental Health Nurse☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q184_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: C1_Q184_3_t2

C1_Q185_1_t2

185. Psychiatrist☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q185_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: C1_Q185_3_t2

C1_Q186_1_t2

186. Social worker or care manager☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q186_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: C1_Q186_3_t2

C1_Q187_1_t2

187. Psychologist☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q187_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: C1_Q187_3_t2

C1_Q188_1_t2

188. Physiotherapist or Occupational therapist☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q188_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: C1_Q188_3_t2

C1_Q189_1_t2

189. Dentist☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q189_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: C1_Q189_3_t2

C1_Q190_1_t2

190. Optician☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q190_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: C1_Q190_3_t2

C1_Q191_1_t2

191. Specialist nurse (e.g. Admiral Nurse, Macmillan/palliative care nurse, respiratory nurse)?

(Please specify: C1_Q191_4_t2)

☐ No ☐ Not sure ☐ Yes, **approximately how many times?** C1_Q191_2_t2☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six☐ Seven or more; please specify number: C1_Q191_3_t2

Home help

The next few questions are about help that your relative/friend may have received in his/her home.

In the last 3 months, (equivalent to 13 weeks) has your relative/friend used any of these services?

192. Home care/home help/support worker

☐ No (skip to question 193) ☐ Not sure

☐ Yes, **approximately how many times in the last 3 months?** C1_Q192_2_t2

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Thirteen (once a week)

☐ Twenty-six (twice a week)

☐ Thirty-nine (three times a week)

☐ Fifty-two (four times a week)

☐ Sixty-five (five times a week)

☐ Seventy-eight (six times a week)

☐ Ninety-one (daily)

☐ If other; please specify number: C1_Q192_3_t2

Did you or a family member pay all or part of the costs of this service?

☐ No ☐ Yes, all ☐ Yes, part

193. Meals on wheels (including Wiltshire Farm Foods, etc.)

☐ No (skip to question 194) ☐ Not sure

☐ Yes, **approximately how many times in the last 3 months?** C1_Q193_2_t2

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Thirteen (once a week)

☐ Twenty-six (twice a week)

☐ Thirty-nine (three times a week)

☐ Fifty-two (four times a week)

☐ Sixty-five (five times a week)

☐ Seventy-eight (six times a week)

☐ Ninety-one (daily)

☐ If other; please specify number: C1_Q193_3_t2

Did you or a family member pay all or part of the costs of this service?

☐ No ☐ Yes, all ☐ Yes, part

194. Incontinence laundry service☐ No (skip to question 195) ☐ Not sure☐ Yes, **approximately how many times in the last 3 months?** C1_Q194_2_t2

- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve
☐ Thirteen ☐ If other; please specify number: C1_Q194_3_t2

C1_Q194_4_t2

Did you or a family member pay all or part of the costs of this service?☐ No ☐ Yes, all ☐ Yes, part

C1_Q195_1_t2

195. Cleaner☐ No (skip to question 196) ☐ Not sure☐ Yes, **approximately how many times in the last 3 months?** C1_Q195_2_t2

- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve
☐ Thirteen ☐ If other; please specify number: C1_Q195_3_t2

C1_Q195_4_t2

Did you or a family member pay all or part of the costs of this service?☐ No ☐ Yes, all ☐ Yes, part

C1_Q196_1_t2

196. Sitting service (for respite, e.g. Crossroads)☐ No (skip to question 197) ☐ Not sure☐ Yes, **approximately how many times in the last 3 months?** C1_Q196_2_t2

- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve
☐ Thirteen ☐ If other; please specify number: C1_Q196_3_t2

C1_Q196_4_t2

Did you or a family member pay all or part of the costs of this service?☐ No ☐ Yes, all ☐ Yes, part

C1_Q197_1_t2

197. Carer support worker☐ No (skip to question 198) ☐ Not sure☐ Yes, **approximately how many times in the last 3 months?** C1_Q197_2_t2

- ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve
☐ Thirteen ☐ If other; please specify number: C1_Q197_3_t2

C1_Q197_4_t2

Did you or a family member pay all or part of the costs of this service?☐ No ☐ Yes, all ☐ Yes, part

Community services

Now we would like to know about whether your relative/friend has used various community services that may be available in some areas.

C1_Q198_1_t2

198. In the last 3 months has your relative/friend attended a day centre?

☐ No (skip to question 199) ☐ Yes

If yes, does your relative/friend attend weekly or less often than once a week?

C1_Q198_2_t2

If weekly, **approximately how many times a week does your relative/friend attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: C1_Q198_3_t2

C1_Q198_4_t2

If attending less often than once a week, **approximately how many times over the last 3 months did your relative/friend attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen or more; please specify number: C1_Q198_5_t2

C1_Q199_1_t2

199. In the last 3 months has your relative/friend attended a lunch club?

☐ No (skip to question 200) ☐ Yes

If yes, does your relative/friend attend weekly or less often than once a week?

C1_Q199_2_t2

If weekly, **approximately how many times a week does your relative/friend attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: C1_Q199_3_t2

C1_Q199_4_t2

If attending less often than once a week, **approximately how many times over the last 3 months did your relative/friend attend?**

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
☐ Seven ☐ Eight ☐ Nine ☐ Ten ☐ Eleven ☐ Twelve

☐ Thirteen or more; please specify number: C1_Q199_5_t2

Accommodation away from home

8931461024

C1_Q200_1_t2

200. Has your relative/friend lived in a residential care home during the last 3 months?

☐ No (skip to question 201)

☐ Yes; **what was the reason for using the service?**

C1_Q200_2_t2

C1_Q200_3_t2

How many days did your relative/friend stay there?

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven

☐ Fourteen

☐ Twenty-one

☐ Twenty-eight

☐ If other; please specify number: C1_Q200_3_oth_t2

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: C1_Q200_oth_t2

Did your relative/friend or a family member pay all or part of the costs for this accommodation?

☐ No ☐ Yes, all ☐ Yes, part

201. Has your relative/friend lived in a nursing home during the last 3 months?

☐ No (skip to question 202)

☐ Yes; **what was the reason for using the service?**

C1_Q201_2_t2

C1_Q201_3_t2

How many days did your relative/friend stay there?

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven

☐ Fourteen

☐ Twenty-one

☐ Twenty-eight

☐ If other; please specify number: C1_Q201_3_oth_t2

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: C1_Q201_oth_t2

Did your relative/friend or a family member pay all or part of the costs for this accommodation?

☐ No ☐ Yes, all ☐ Yes, part

Equipment and adaptations

Now we're interested in whether your relative/friend uses any of the following equipment or adaptations to the home.

For each item, cross the box for each type of equipment/adaptation your relative/friend has used. For example:

- if your relative/friend has **not used** a calendar clock, **leave the 'Uses' box blank**
- if your relative/friend uses a calendar clock, cross the 'Uses' box
- if the clock was provided in the last year, cross the 'Received in past year' box
- for each item used or received, indicate who or which organisation paid for each item. 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	Voluntary or charity	Self	Other
C1_Q202[...] 202. Electronic medication reminder dispenser (do not include blister packs)	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q203[...] 203. Calendar clock	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q204[...] 204. Falls detector or falls alarm	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q205[...] 205. Community or personal alarm (including pull-cord and pendant alarms)	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q206[...] 206. Outdoor railing	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q207[...] 207. Grab rail/Stair rail	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q208[...] 208. Walking stick	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q209[...] 209. Walking frame	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q210[...] 210. Walk-in shower/shower cubicle replacing bath	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q211[...] 211. Over-bath shower	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q212[...] 212. Bath seat/shower seat	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q213[...] 213. Kitchen/perching stool	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q214[...] 214. Bed lever/rail	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q215[...] 215. Toilet frame/raised toilet seat	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q216[...] 216. Commode	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q217[...] 217. Continence pads	[...] 1 t2 <input type="checkbox"/>	[...] 2 t2 <input type="checkbox"/>	[...] 3 t2 <input type="checkbox"/>	[...] 4 t2 <input type="checkbox"/>	[...] 5 t2 <input type="checkbox"/>	[...] 6 t2 <input type="checkbox"/>	[...] 7 t2 <input type="checkbox"/>
C1_Q218 t2 218. Your relative/friend does not use any of the above	<input type="checkbox"/>						

Help and support

The next few questions are about the help and support that people provide to your relative/friend.

219. Thinking about the last 3 months, in an average week, what tasks do you usually help your relative/friend with?

Please cross all that apply

C1_Q219_1_t2

☐ Personal care

C1_Q219_2_t2

☐ Helping with finances

C1_Q219_3_t2

☐ Practical help (housework, laundry)

C1_Q219_4_t2

☐ Taking relative/friend out to appointments (e.g. medical appointments)

C1_Q219_5_t2

☐ Medications

C1_Q219_6_t2

☐ Making sure your relative/friend is safe (supervision)

C1_Q219_7_t2

☐ Other: C1_Q219_oth_t2

C1_Q220_1_t2

220. In an average week, how much time do you spend providing help for your relative/friend with these kinds of tasks?

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 C1_Q220_oth_t2

C1_Q221_1_t2

221. In the last 3 months, have other friends or relatives regularly helped your relative/friend with tasks which s/he had difficulty with, or could not do?

☐ No ☐ Yes

C1_Q221_2_t2

Thinking about an average week, and about all such friends or relatives, for how many hours a week do they usually help your relative/friend?

C1_Q222_1_t2

222. Have any friends and relatives taken time off paid work over the last 3 months to help/provide care for your relative/friend?

☐ No ☐ Yes

C1_Q222_2_t2

Can you estimate the total number of days that friends or relatives have taken off work over the last 3 months to help/provide care for your relative/friend?

☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six

☐ Seven or more; please specify number: C1_Q222_3_t2

Travel costs

C1_Q223_1_t2

223. In the last 3 months, has your relative/friend attended any GP, clinic, hospital, or day services for his/her memory, thinking or behaviour difficulties?

For guidance, this does not include general health services such as travel to cardiac specialist, GP for blood pressure etc.

☐ No (skip to question 230) ☐ Yes

C1_Q223_2_t2

If yes, **over the last 3 months, how many times did your relative/friend 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: C1_Q223_3_t2

C1_Q223_4_t2

Did you both attend or did your relative/friend go by himself/herself?

☐ Both ☐ Study participant only

C1_Q224_1_t2

224. How did you both, or how did your relative/friend normally travel to get to the services your relative/friend 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: C1_Q224_oth_t2

225. How long did it normally take to travel to the GP, clinic, hospital, or day service from home?

For example, if the journey took ten minutes please write zeros in the first box and "10" in the second box, like this:

0 0 : 1 0

Hours : Minutes C1_Q225_1_t2 : C1_Q225_2_t2

If your relative/friend normally used public transport answer question 226, if your relative/friend normally went by taxi ask question 227, and if your relative/friend normally drove/went by car ask questions 228 and 229. Please remember to put a cross in the 'not applicable' box for those questions which are not applicable.

226. If you/your relative/friend normally travelled by public transport, what was the cost of the fare in one direction (cost of a one-way ticket)?

£

<small>C1_Q226_1_t2</small>	<small>C1_Q226_2_t2</small>
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C1_Q226_3_t2 ☐ Bus pass/travel for free ☐ Not applicable

227. If you/your relative/friend normally travelled by taxi, what was the cost of the fare in one direction (cost of a one-way journey)?

£

<small>C1_Q227_1_t2</small>	<small>C1_Q227_2_t2</small>
-----------------------------	-----------------------------

C1_Q227_3_t2 ☐ Not applicable

228. If you/your relative/friend normally travelled by car, how many miles/kilometres did you travel to get there (one-way journey)?

<small>C1_Q228_1_t2</small>	<small>C1_Q228_2_t2</small>
-----------------------------	-----------------------------

☐ Not applicable

C1_Q228_3_t2

Is this number in miles or kilometres?

☐ Miles ☐ Kilometres

229. If you normally travelled by car, if you had to pay for parking, how much did you pay?

£

<small>C1_Q229_1_t2</small>	<small>C1_Q229_2_t2</small>
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C1_Q229_3_t2 ☐ Blue badge/park for free ☐ Not applicable

Before you continue we would be grateful if you could please check that you have completed all the questions. Thank you.

Section B

This section of the questionnaire is to be completed only if your relative/friend is not taking part in the study at this time.

If your relative/friend is taking part in the study at this time please skip to question 238, Section C.

Section B

C1_Q230_t2

230. Please confirm that your relative/friend is not taking part in the study at this time by crossing this box:

☐ My relative/friend is not taking part in the study at this time

Satisfaction with health services

The next couple of questions are about how satisfied you are with the health services your relative/friend receives.

C1_Q231_t2

231. How satisfied are you with the formal support services that your relative/friend 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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C1_Q232_t2

232. How satisfied are you with the amount of formal support services that your relative/friend 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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Medication

The next few questions are about the medication that your relative/friend takes.

C1_Q233_1_t2

233. How many different prescribed medications does your relative/friend take?

☐ None (skip to Section C)

<input type="checkbox"/> One	<input type="checkbox"/> Two	<input type="checkbox"/> Three	<input type="checkbox"/> Four	<input type="checkbox"/> Five	<input type="checkbox"/> Six	<input type="checkbox"/> Seven
<input type="checkbox"/> Eight	<input type="checkbox"/> Nine	<input type="checkbox"/> Ten	<input type="checkbox"/> Eleven	<input type="checkbox"/> Twelve	<input type="checkbox"/> Thirteen	<input type="checkbox"/> Fourteen
<input type="checkbox"/> Fifteen or more; please specify number:				C1_Q233_2_t2		

C1_Q234_t2

234. Has your relative/friend taken any medications for his/her memory difficulties in the last 3 months (e.g. Aricept, Reminyl, etc.?)

☐ No ☐ Yes

C1_Q235_t2

235. Has your relative/friend taken any anti-depressant medication in the last 3 months (e.g. Citalopram, etc.?)

☐ No ☐ Yes

236. Do you think about your relative's/friend's household income in weekly, monthly or yearly terms? Here are incomes in weekly, monthly, annually amounts. Which of the figures represents your relative's/friend's combined income from all sources, before any deductions for income tax, National Insurance, etc.?

Please put a cross in only one box

<i>C1_Q236_1_t2</i> Weekly	<i>C1_Q236_2_t2</i> Monthly	<i>C1_Q236_3_t2</i> Annually
<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

C1_Q236_4_t2

☐ Don't know ☐ Prefer not to say

C1_Q237_0_t2

Are there are other adults in your relative's/friend's household?

☐ No☐ Yes (please complete the question on this page)

237. 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, please choose one column.

Please put a cross in only one box

C1_Q237_1_t2

Weekly

C1_Q237_2_t2

Monthly

C1_Q237_3_t2

Annually

<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

C1_Q237_4_t2

☐ Don't know ☐ Prefer not to say

5796461020

Section C

This section of the questionnaire contains open-ended questions.

These give you the opportunity to tell us more about your experiences in your own words.

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 how things are at this time and how things may have changed over the past year for your relative/friend.

These questions are optional

C1_Q238_t2

238. Do you feel things have changed for your relative/friend over the last 12 months? If so, how?

C1_Q239_t2

239. What is the difference between a good and a bad day for your relative/friend?

C1_Q240_t2

240. Is there something that your relative/friend used to do that s/he can't do now, that if s/he could do it, would improve his/her life?

C1_Q241_t2

241. How do you feel your relative/friend is getting on?

C1_Q242_t2

242. We are interested in hearing any other comments you may have. Is there anything else you would like to tell us about?

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

Before returning this questionnaire to the researcher we would be grateful if you could please check that you have completed all the questions. Thank you.

TO BE COMPLETED BY THE RESEARCHER**Your relative's/friend's background**

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's employment/job

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's quality of life

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's well-being

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

How your relative/friend spends his/her time

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's satisfaction with life

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's everyday activities

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's emotional well-being

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's emotions

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's health

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's health conditions

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's sleep

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's health state

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's support network

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's life space

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's accommodation

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your relative's/friend's interests and activities

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Your relative's/friend's involvement in decision-making

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Dignity and respect

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Your relative's/friend's life events

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Sources of income

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Your relative's/friend's service use

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Community health and care

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Home help

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Community services

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Accommodation away from home

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Equipment and adaptations

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Help and support

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Travel costs

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Section B**Satisfaction with health services**

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Medication

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Household income

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

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DO NOT PRINT/C

P ID

Participant ID

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Researcher ID

--	--	--

Enhancing Active Life and Living Well: The IDEAL Study Time 2

12 month follow-up

Relative/Friend Part 2 of 2

Questions about you



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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?

In this part of the questionnaire we will be asking you for information **about you and about your experiences supporting your relative/friend**. We asked you similar questions last year and we are interested in how things are at this time.

The information you provide is extremely valuable to us. All the information that 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 ☐

For example; what is your age?

- 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_t2

1. Did you take part in this study a year ago?

(If you are not sure please ask the researcher who gave you this questionnaire)

☐ No (please be sure to complete Section B of this questionnaire)

☐ Yes (you do not need to complete Section B of this questionnaire)

C2_Q2_t2

2. Today's date (dd/mm/yyyy) / / 2 0 1

Information about you

C2_Q3_t2

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

/ /

C2_Q4_t2

4. What is your sex?

☐ Male

☐ Female

C2_Q5_t2

5. What is your postcode?

C2_Q6_t2

6. What is your current legal marital status?

☐ Single; that is, never married (skip to question 8)

☐ 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:

C2_Q6_oth_t2

C2_Q7_t2

7. Please say for how many years you have been married/widowed/separated/divorced etc?

C2_Q8_t2

8. What is the relationship between you and your relative/friend?

- ☐ Spouse ☐ Partner ☐ Son/daughter ☐ Step-child ☐ Son/daughter-in-law
☐ Grandchild ☐ Brother/sister ☐ Nephew/niece ☐ Friend ☐ Neighbour
☐ Other; please specify: C2_Q8_oth_t2

C2_Q9_t2

9. Do you live with your relative/friend?

- ☐ No ☐ Yes

10. With whom do you live?*You may cross more than one box*

C2_Q10_1_t2

C2_Q10_2_t2

C2_Q10_3_t2

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

C2_Q10_4_t2

C2_Q11_t2

11. If you are not related to the person you are supporting, for how many years have you known him/her?

--	--

C2_Q12_t2

12. 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:

C2_Q12_oth_t2

C2_Q13_t2

13. Are you a registered carer?

- ☐ No ☐ Yes

C2_Q14_1_t2

14. Approximately how long have you been caring for your relative/friend with memory, thinking or behaviour difficulties?

--	--

C2_Q14_2_t2

Is this number in ☐ Months or ☐ years?

--

Religious activity

I'm now going to ask you some questions about religious activity. Please try to answer them even if you have little interest in religion. Select whichever is the closest to your usual practice.

C2_Q15_t2

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

(Select whichever is the closest to your usual practice)

☐ Never ☐ Occasionally ☐ Monthly ☐ Weekly ☐ Daily

C2_Q16_t2

16. How often do you pray?

(Select whichever is the closest to your usual practice)

☐ Never ☐ Occasionally ☐ Monthly ☐ Weekly ☐ Daily

C2_Q17_t2

17. How often do you study religious texts?

(Select whichever is the closest to your usual practice)

☐ Never ☐ Occasionally ☐ Monthly ☐ Weekly ☐ Daily

Education

If you did not take part in this study last year please skip to question 20

C2_Q18_t2

18. Have you attended a full-time or part-time education course in the past year?

☐ No (skip to question 20) ☐ Yes

C2_Q19_t2

19. If yes, did this lead to a new qualification?

Please cross only one box

- ☐ No change in highest qualification achieved
- ☐ 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:

C2_Q19_oth_t2

Employment

Now we would like to know about your current employment status.

C2_Q20_1_t2

20. 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?**

C2_Q20_2_t2

If you are in paid employment, **how many hours of work per week do you do in total across all your jobs?**

C2_Q20_3_t2

☐ Retired; if retired **at what age did you retire?**

C2_Q20_4_t2

☐ 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:

C2_Q20_5_t2

C2_Q21_t2

21. Are you unemployed, unable to work, 'at home' or retired?

☐ No (skip to question 24)

☐ Yes

22. When were you last employed?

m m y y y y
C2_Q22_1_t2 C2_Q22_2_t2

C2_Q23_t2

23. What was/were your most recent job(s)/occupation(s)?

C2_Q24_1_t2

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?

m m y y y y
C2_Q24_2a_t2 C2_Q24_2b_t2

☐ Yes, cut down

If so, by how many hours per week have you cut down on work each week?

C2_Q24_3_t2

Health

Now we would like to know about your health.

C2_Q25_t2

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

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

C2_Q26_t2

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

☐ Poor ☐ Fair ☐ Good ☐ Very good ☐ Excellent

C2_Q27_t2

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

☐ Poor ☐ Fair ☐ Good ☐ Very good ☐ Excellent

28. 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 (metastasised)?** ☐ 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

C2_Q29_t2

29. Do you take warfarin? ☐ No ☐ Yes

C2_Q30_1_t2

30. Do you have any other major long term illnesses, health problems or disabilities?

☐ No ☐ Yes; please specify with diagnosis:

C2_Q30_2_t2

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 state today.

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

Your physical health

C2_Q36_t2

36. 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.)

If employed select one of the four options below

☐ 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_Q37_t2

37. 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)

☐ None

☐ One hour but less than three hours

☐ Some but less than one hour

☐ Three hours or more

C2_Q38_t2

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

☐ None

☐ One hour but less than three hours

☐ Some but less than one hour

☐ Three hours or more

C2_Q39_t2

39. 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_Q40_t2

40. 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_Q41_t2

41. 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_Q42_t2

42. 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)

Life events

43. 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

- C2_Q43_1_t2 ☐ Death of spouse or child
 C2_Q43_2_t2 ☐ Death of a close family member (e.g. parent or sibling)
 C2_Q43_3_t2 ☐ Death of a close friend

Marital difficulties

- C2_Q43_4_t2 ☐ Divorce
 C2_Q43_5_t2 ☐ Marital separation

Change in circumstances

- C2_Q43_6_t2 ☐ Retirement
 C2_Q43_7_t2 ☐ Moved home
 C2_Q43_8_t2 ☐ Major change in financial state (e.g. a lot worse off or a lot better off)
 C2_Q43_9_t2 ☐ Major change in health or behaviour of family member
 C2_Q43_10_t2 ☐ Major personal injury or illness

None

- C2_Q43_11_t2 ☐ None of the above

C2_Q44_1_t2

44. Have there been any other significant events that you have experienced in your life over the past 12 months?

- ☐ No ☐ Yes, if yes; please specify:

C2_Q44_2_t2

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.

C2_Q45_1_t2

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

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

C2_Q45_2_t2

If other, please specify number:

C2_Q46_1_t2

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

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

C2_Q46_2_t2

If other, please specify number:

If you did not take part in this study last year please skip to question 53

C2_Q47_t2

47. Have you moved house in the last year?

☐ No (skip to question 54) ☐ Yes

C2_Q48_1_t2

48. 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:

C2_Q48_2_t2

☐ Don't know

49. What were the main reasons you moved to this new address?

You may cross more than one box

☐ 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

☐ Other; please specify:

☐ Don't know

☐ 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

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

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

51. What type of heating do you have?

☐ Gas central heating ☐ Electric storage heaters ☐ Gas fire only

☐ Other; please specify:

Your neighbourhood

These questions are about your immediate neighbourhood, by which I mean your street or surrounding area.

52. 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.

C2_Q52_1_t2

☐ Countryside

C2_Q52_2_t2

☐ Woodlands

C2_Q52_3_t2

☐ Parks and gardens

C2_Q52_4_t2

☐ Country parks

C2_Q52_5_t2

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

C2_Q52_6_t2

☐ Outdoor sports facilities

C2_Q52_7_t2

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

C2_Q52_8_t2

☐ Play areas

C2_Q52_9_t2

☐ Allotments, community gardens and urban farms

C2_Q52_10_t2

☐ Cemeteries and churchyards

C2_Q52_11_t2

☐ River, lake or canal

C2_Q52_12_t2

☐ Sea

C2_Q52_13_t2

☐ None of the above

C2_Q52_14_t2

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

C2_Q53_t2

53. 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

☐

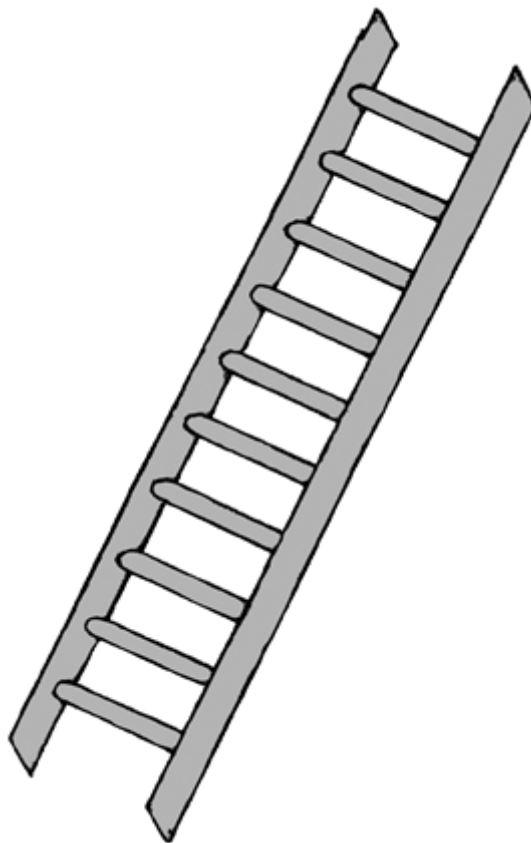
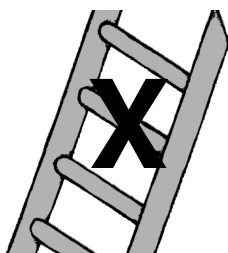
Society and Community

C2_Q54_t2

54. 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

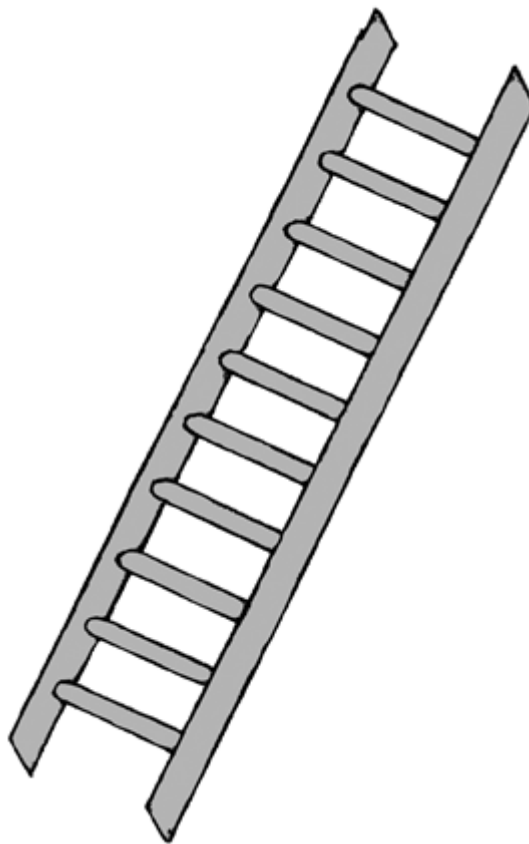
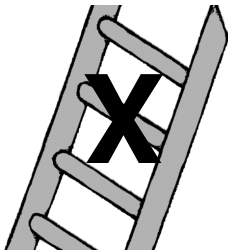
Instructions for the researcher: Please check the appropriate box:

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

55. 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

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_Q56_1_t2

56. 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_Q56_2_t2

If more than ten please specify:

C2_Q57_1_t2

57. 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_Q57_2_t2

If more than ten please specify:

C2_Q58_1_t2

58. 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_Q58_2_t2

If more than ten please specify:

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

C2_Q59_1_t2

59. 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_Q59_2_t2

If more than ten please specify:

C2_Q60_1_t2

60. 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
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C2_Q60_2_t2

If more than ten please specify:

C2_Q61_1_t2

61. 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
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐

C2_Q61_2_t2

If more than ten please specify:

C2_Q62_t2

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

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

C2_Q63_t2

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

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

Please indicate for each of these statements the extent to which they apply to your situation or the way you feel now.

C2_Q64_t2

64. Do you feel lonely?

Yes More or less No
☐ ☐ ☐

C2_Q65_t2

65. 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 current relationship with your relative/friend

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

C2_Q66_t2

66. Taking everything into consideration, how close do you feel in your relationship with your relative/friend?

Not close
at all

☐

Not too
close

☐

Quite
close

☐

Close

☐

Very
close

☐

Extremely
close

☐

C2_Q67_t2

67. 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

☐

Not too
well

☐

Quite
well

☐

Well

☐

Very
well

☐

Extremely
well

☐

C2_Q68_t2

68. In general, how similar are 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_Q69_t2

69. How often do you and your relative/friend do things together?

Never

☐

Very rarely

☐

Rarely

☐

Occasionally

☐

Frequently

☐

Very
frequently

☐

C2_Q70_t2

70. 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_Q71_t2

71. 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_Q72_t2

72. Has your relative/friend displayed any inappropriate sexual behaviour?

☐ No

☐ Yes

☐ Don't know

C2_Q73_t2

☐

□

5

☐☐☐

9

☐

□

☐☐☐☐☐

1

☐☐☐☐

5

□

☐☐☐☐

1

□

☐

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_Q78_t2

78. How would you rate your quality of life?

Very poor	Poor	Neither poor nor good	Good	Very good
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2_Q79_t2

79. How satisfied are you with your health?

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 questions ask about **how much** you have experienced certain things **in the last two weeks**.

C2_Q80_t2

80. 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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2_Q81_t2

81. 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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2_Q82_t2

82. How much do you enjoy life?

Not at all	A little	A moderate amount	Very much	An extreme amount
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2_Q83_t2

83. To what extent do you feel life to be meaningful?

Not at all	A little	A moderate amount	Very much	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2_Q84_t2

84. How well are you able to concentrate?

Not at all

☐

A little

☐A moderate
amount☐

Very much

☐

Extremely

☐

C2_Q85_t2

85. How safe do you feel in your daily life?

Not at all

☐

A little

☐A moderate
amount☐

Very much

☐

Extremely

☐

C2_Q86_t2

86. 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_Q87_t2

87. Do you have enough energy for everyday life?

Not at all

☐

A little

☐

Moderately

☐

Mostly

☐

Completely

☐

C2_Q88_t2

88. Are you able to accept your bodily appearance?

Not at all

☐

A little

☐

Moderately

☐

Mostly

☐

Completely

☐

C2_Q89_t2

89. To what extent do you have enough money to meet your needs?

Not at all

☐

A little

☐

Moderately

☐

Mostly

☐

Completely

☐

C2_Q90_t2

90. 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_Q91_t2

91. 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_Q92_t2

92. How well are you able to get around?

Very
poor

☐

Poor

☐

Neither poor
nor good

☐

Good

☐

Very
good

☐

C2_Q93_t2

93. How satisfied are you with your sleep?

Very
dissatisfied

☐

Dissatisfied

☐

Neither satisfied
nor dissatisfied

☐

Satisfied

☐

Very
satisfied

☐

C2_Q94_t2

94. How satisfied are you with your ability to perform your daily living activities?

Very
dissatisfied

☐

Dissatisfied

☐

Neither satisfied
nor dissatisfied

☐

Satisfied

☐

Very
satisfied

☐

C2_Q95_t2

95. How satisfied are you with your capacity for work?

Very
dissatisfied

☐

Dissatisfied

☐

Neither satisfied
nor dissatisfied

☐

Satisfied

☐

Very
satisfied

☐

C2_Q96_t2

96. How satisfied are you with yourself?

Very
dissatisfied

☐

Dissatisfied

☐

Neither satisfied
nor dissatisfied

☐

Satisfied

☐

Very
satisfied

☐

C2_Q97_t2

97. How satisfied are you with your personal relationships?

Very
dissatisfied

☐

Dissatisfied

☐

Neither satisfied
nor dissatisfied

☐

Satisfied

☐

Very
satisfied

☐

C2_Q98_t2

98. How satisfied are you with your sex life?

Very
dissatisfied

☐

Dissatisfied

☐

Neither satisfied
nor dissatisfied

☐

Satisfied

☐

Very
satisfied

☐

C2_Q99_t2

99. How satisfied are you with the support you get from your friends?

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_Q100_t2

100. 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_Q101_t2

101. 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_Q102_t2

102. 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_Q103_t2

103. 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"/>

Your 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.

C2_Q104_t2

104. 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"/>

C2_Q105_t2

105. 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"/>

106. 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_Q107_t2

107. 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_Q108_t2

108. 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"/>

Please indicate the extent to which you agree or disagree with the following statements.

C2_Q109_t2

109. I have high self-esteem

Strongly disagree	Disagree	Neutral	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2_Q110_t2

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

Strongly disagree	Disagree	Neutral	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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_Q111_t2

111. 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_Q112_t2

112. 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_Q113_t2

113. 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_Q114_t2

114. 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_Q115_t2

115. 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_Q116_t2

116. 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_Q117_t2

117. 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_Q118_t2

118. 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_Q119_t2

119. 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_Q120_t2

120. 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_Q121_t2

121. 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_Q122_t2

122. 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_Q123_t2

123. 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_Q124_t2

124. 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_Q125_t2

125. 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_Q126_t2

126. 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_Q127_t2

127. 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_Q128_t2

128. 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_Q129_t2

129. 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_Q130_t2

130. 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_Q131_t2

131. 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_Q132_t2

132. 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_Q133_t2

133. 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_Q134_t2

134. 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_Q135_t2

135. 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_Q136_t2

136. 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_Q137_t2

137. 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_Q138_t2

138. 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_Q139_t2

139. 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
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C2_Q140_t2

140. 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_Q141_t2

141. How much has your social life been affected?Never/
not at all☐Rarely/
a little☐Sometimes/
moderately☐Frequently/
quite a lot☐Always/
considerably☐

C2_Q142_t2

142. How much has the household routine been upset?Never/
not at all☐Rarely/
a little☐Sometimes/
moderately☐Frequently/
quite a lot☐Always/
considerably☐

C2_Q143_t2

143. Is your sleep interrupted by your relative/friend?Never/
not at all☐Rarely/
a little☐Sometimes/
moderately☐Frequently/
quite a lot☐Always/
considerably☐

C2_Q144_t2

144. Has your standard of living been reduced?Never/
not at all☐Rarely/
a little☐Sometimes/
moderately☐Frequently/
quite a lot☐Always/
considerably☐

C2_Q145_t2

145. 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_Q146_t2

146. Are you prevented from having visitors?Never/
not at all☐Rarely/
a little☐Sometimes/
moderately☐Frequently/
quite a lot☐Always/
considerably☐

C2_Q147_t2

147. 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☐

148. 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_Q149_t2

149. Providing help to my relative/friend has made me feel more usefulDisagree
a lot☐Disagree
a little☐Neither agree
nor disagree☐Agree
a little☐Agree
a lot☐

C2_Q150_t2

150. Providing help to my relative/friend has made me feel good about myselfDisagree
a lot☐Disagree
a little☐Neither agree
nor disagree☐Agree
a little☐Agree
a lot☐

C2_Q151_t2

151. Providing help to my relative/friend has made me feel neededDisagree
a lot☐Disagree
a little☐Neither agree
nor disagree☐Agree
a little☐Agree
a lot☐

C2_Q152_t2

152. Providing help to my relative/friend has made me feel appreciatedDisagree
a lot☐Disagree
a little☐Neither agree
nor disagree☐Agree
a little☐Agree
a lot☐

C2_Q153_t2

153. Providing help to my relative/friend has made me feel importantDisagree
a lot☐Disagree
a little☐Neither agree
nor disagree☐Agree
a little☐Agree
a lot☐

C2_Q154_t2

154. Providing help to my relative/friend has made me feel strong and confidentDisagree
a lot☐Disagree
a little☐Neither agree
nor disagree☐Agree
a little☐Agree
a lot☐

C2_Q155_t2

155. 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_Q156_t2

156. 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_Q157_t2

157. 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
☐

Your views

We would like to invite you to say how much each statement describes your thoughts about your role as a carer?

C2_Q158_t2

158. Do you feel you cope well as a carer?

☐ Never

☐ Sometimes

☐ Often

☐ Always

C2_Q159_t2

159. 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_Q160_t2

160. 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_Q161_t2

161. How much do you wish you could just run away?

☐ Not at all

☐ Just a little

☐ Somewhat

☐ Very much

C2_Q162_1_t2

162. Can your relative/friend be left unsupervised?

☐ No

☐ Yes, if yes; ^{C2_Q162_2_t2} how many hours in a day can s/he be left alone?

☐ None

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven or more; please specify number:

^{C2_Q162_3_t2}

C2_Q163_t2

163. 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_Q164_t2

164. 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

*Here are some things that people do to make caring easier for themselves.
How often do you behave in these ways?*

C2_Q165_t2

165. 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_Q166_t2

166. 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_Q167_t2

167. How often do you try to find ways to keep your relative/friend busy?

- ☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2_Q168_t2

168. 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_Q169_t2

169. 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_Q170_t2

170. How often do you try to think about the present rather than the future?

- ☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

171. How often do you try to keep your sense of humour?

- ☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2_Q172_t2

172. How often do you remind yourself that others are worse off?

- ☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2_Q173_t2

173. 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_Q174_t2

174. 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_Q175_t2

175. 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_Q176_t2

176. How often do you pray for strength to keep going?

- ☐ Never ☐ Once in a while ☐ Fairly often ☐ Very often

C2_Q177_t2

177. 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

These next two questions are about your local community.

C2_Q178_t2

178. 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 |

C2_Q179_t2

179. 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 |

Section B

Thank you for taking the time to answer these questions.

These next set of questions are only for people who did not take part in this study last year and who did not provide background information about themselves.

If you took part in this study last year please skip to question 205, Section C.

If you did not take part last year please complete the following questions about you, your life and your neighbourhood.

C2_Q180_t2

180. Please confirm that you did not take part in the study last time by crossing this box:

☐ I did not take part in the study last time

Information about you

C2_Q181_1_t2

181. In which country were you born?

☐ England ☐ Ireland ☐ Northern Ireland ☐ Scotland ☐ Wales

☐ Other; please specify: C2_Q181_2_t2

C2_Q182_1_t2

182. What is your main language?

☐ English (skip to question 184) ☐ Welsh ☐ Gaelic

☐ Other; please specify: C2_Q182_2_t2

C2_Q183_t2

183. How well can you speak English?

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

C2_Q184_1_t2

184. 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:

C2_Q184_2_t2

☐ Mixed White & Black: Caribbean

☐ Mixed White & Black: African

☐ Mixed White & Asian

☐ Any other Mixed/multiple ethnic background; please specify:

C2_Q184_3_t2

☐ Asian/Asian British: Indian

☐ Asian/Asian British: Pakistani

☐ Asian/Asian British: Bangladeshi

☐ Asian/Asian British: Chinese

☐ Any other Asian background; please specify:

C2_Q184_4_t2

☐ Black/Black British: African

☐ Black/Black British: Caribbean

☐ Any other Black/African/Caribbean background; please specify:

C2_Q184_5_t2

☐ Arab

☐ Any other ethnic group; please specify:

C2_Q184_6_t2

C2_Q185_1_t2

185. Which of these words best describes how you think of yourself?

☐ Heterosexual or straight

☐ Gay or lesbian

☐ Bisexual

☐ Other; please specify:

C2_Q185_2_t2

☐ Prefer not to say

☐ Don't know

C2_Q186_1_t2

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

☐ None

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Other

C2_Q186_2_t2

If other, please specify number:

Education

Now we're going to ask you some questions about your educational history and about your qualifications.

C2_Q187_t2

187. At what age did you start school?

C2_Q188_t2

188. 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 188)

C2_Q189_1_t2

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

☐ No

☐ Yes; if yes for how many years did you study?

C2_Q189_2_t2

(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 189)

C2_Q190_1_t2

190. 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:

C2_Q190_2_t2

Employment

Now we would like to know about your current employment status and the type of work you do/did.

C2_Q191_2_t2

191. 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 C2_Q191_1_t2

C2_Q192_2_t2

192. 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 C2_Q192_1_t2

C2_Q193_t2

193. Do/did you enjoy your job?

- ☐ No
- ☐ Yes
- ☐ Not applicable

C2_Q194_t2

194. Are/were you self-employed?

- ☐ No
- ☐ Yes

C2_Q195_t2

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

☐ No (skip to question 198) ☐ Foreman ☐ Supervisor ☐ Manager

C2_Q196_t2

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

C2_Q197_t2

197. 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.

C2_Q198_1_t2

198. 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:

C2_Q198_2_t2

☐ Prefer not to say

C2_Q199_1_t2

199. 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 |

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.

C2_Q200_1_t2

200. 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:

C2_Q200_2_t2

- ☐ Don't know

C2_Q201_t2

201. 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
- ☐ Don't know

C2_Q202_t2

202. How satisfied are you with your accommodation?

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

Your neighbourhood

This question is about your immediate neighbourhood, by which I mean your street or surrounding area.

203. 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.

- C2_Q203_1 ☐ Countryside
C2_Q203_2 ☐ Woodlands
C2_Q203_3 ☐ Parks and gardens
C2_Q203_4 ☐ Country parks
C2_Q203_5 ☐ Green corridors (e.g. river banks or roadside grass verges)
C2_Q203_6 ☐ Outdoor sports facilities
C2_Q203_7 ☐ Amenity green space (e.g. public playing fields or football pitches etc.)
C2_Q203_8 ☐ Play areas
C2_Q203_9 ☐ Allotments, community gardens and urban farms
C2_Q203_10 ☐ Cemeteries and churchyards
C2_Q203_11 ☐ River, lake or canal
C2_Q203_12 ☐ Sea
C2_Q203_13 ☐ None of the above

C2_Q204_t2

204. 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"/> |

Section C

This final section contains open-ended questions.

These give you the opportunity to tell us more about your experiences in your own words.

Section C

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.

205. What do you think makes it easy or difficult to live well with dementia?

206. How have you found the experience of supporting or caring for your relative/friend?

207. What is currently your greatest difficulty or concern in caring for your relative/friend?

208. What is your greatest satisfaction in caring for your relative/friend?

209. What do you think could be changed in the local community to enable people with dementia to 'live well' with dementia?

C2_Q210_t2

210. What do you think could be done by the government to help people live well with dementia?

C2_Q211_t2

211. We are interested in hearing any other comments you may have. Is there anything else you would like to tell us about?

Thank you for completing these additional questions.

Before returning this questionnaire to the researcher we would be grateful if you could please check that you have completed all the questions. Thank you.

The researcher may like to talk to both you and your relative/friend together with a few final questions for you both.

You may be asked questions about your relative's/friend's current prescribed medication, so if you could have a prescription to hand that would help. Thank you.

TO BE COMPLETED BY THE RESEARCHER

Information about you

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Religious activity

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Education

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Employment

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Health

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Health state

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your physical health

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Life events

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your accommodation

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your neighbourhood

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Society and Community

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Support from others

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your current relationship with your relative/friend

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your well-being

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your quality of life

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your satisfaction with life

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your mood

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your experiences of supporting your relative/friend

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

How you are managing

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your views

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Section B**Information about you**

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Education

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Employment

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Religious beliefs

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your accommodation

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Your neighbourhood

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

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Participant ID

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Researcher ID

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Enhancing Active Life and Living Well: The IDEAL Study Time 2 12 month follow-up

Paid Carer

Leading the fight
against dementia
**Alzheimer's
Society**



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?

We will ask you to provide some background information about yourself and for the majority of the questions we are interested in the **well-being of the study participant**.

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.

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.

6	5
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- For example; what is your age?

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.

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

To start we would like to know about you.

2. What is your age?

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

/ /

4. What is your sex? ☐ Male ☐ Female

5. What is your main language?

☐ English (skip to question 7) ☐ Welsh ☐ Gaelic

☐ Other; please specify: _____

6. How well can you speak English?

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

7. 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: _____

☐ Mixed White & Black: Caribbean

☐ Mixed White & Black: African

☐ Mixed White & Asian

☐ Any other Mixed/multiple ethnic background; please specify: _____

☐ Asian/Asian British: Indian

☐ Asian/Asian British: Pakistani

☐ Asian/Asian British: Bangladeshi

☐ Asian/Asian British: Chinese

☐ Any other Asian background; please specify: _____

☐ Black/Black British: African

☐ Black/Black British: Caribbean

☐ Any other Black/African/Caribbean background; please specify: _____

☐ Arab

☐ Any other ethnic group; please specify: _____

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8. What is your current job title?

- ☐ Manager
☐ Registered nurse
☐ Senior care assistant
☐ Care assistant/support worker
☐ Other; please specify:
-

9. In total, how long have you worked in the care industry?

- ☐ Less than 3 months
☐ Between 3 and 6 months
☐ Between 6 and 12 months
☐ Between 1 and 2 years
☐ Between 2 and 4 years
☐ 5 years or more, please specify how many years:

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10. How long have you worked at this specific/particular care home?

- ☐ Less than 3 months
☐ Between 3 and 6 months
☐ Between 6 and 12 months
☐ Between 1 and 2 years
☐ Between 2 and 4 years
☐ 5 years or more, please specify:

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11. How long have you known the participant?

- ☐ Less than 3 months
☐ Between 3 and 6 months
☐ Between 6 and 12 months
☐ Between 1 and 2 years
☐ Between 2 and 4 years
☐ 5 years or more, please specify:

--	--	--

12. How much contact do you have with the participant on a day you are working?

- ☐ Less than 15 minutes a day
☐ Between 15 and 30 minutes a day
☐ Between 30 and 60 minutes a day
☐ Between 1 and 1.5 hours a day
☐ Between 1.5 and 2 hours a day
☐ Between 2 and 3 hours a day
☐ Between 3 and 5 hours a day
☐ Between 5 and 10 hours a day
☐ 10 hours or more, please specify:

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13. What is the highest level of nursing training that you achieved?

- ☐ No nursing qualification
☐ National Vocational Qualification Level 1 or equivalent
☐ National Vocational Qualification Level 2 or equivalent
☐ National Vocational Qualification Level 3 or equivalent
☐ National Vocational Qualification Level 4 or equivalent
☐ Registered General Nurse
☐ State Enrolled Nurse
☐ Registered Mental Health Nurse
☐ Registered Mental Nurse
☐ Other; please specify: _____

Questions about the study participant

14. Has the study participant fallen down in the last year for any reason?

- ☐ No (skip to question 15)
☐ Yes; **how many times:** ☐ One ☐ Two ☐ Three ☐ Four ☐ Five ☐ Six
☐ Seven or more; please specify number:

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☐ Don't know

If yes, did the study participant injure himself/herself seriously enough to need medical treatment?

- ☐ No ☐ Yes ☐ Don't know

15. How would you describe the study participant's usual walking pace?

- ☐ Slow pace (i.e. less than 3 mph)
☐ Steady average pace
☐ Brisk pace
☐ Fast pace (i.e. over 4 mph)
☐ Not applicable

16. How well would you rate the study participant's sleep these days?

- ☐ Very poor ☐ Good (skip to question 18)
☐ Poor ☐ Very good (skip to question 18)
☐ Fair ☐ Don't know (skip to question 18)

17. Why do you think the quality of the study participant's sleep is not as good as it could be? Please choose from the following options:

You may cross more than one box

- ☐ Not being able to get to sleep
☐ Waking up too early and not being able to get back to sleep
☐ Waking up several times throughout the night
☐ Having bad dreams
☐ Being uncomfortable
☐ Other; please specify: _____

The study participant's health conditions

18. We are interested in whether the study participant has any current health conditions or is taking any medication for any condition. Does the study participant have any of these conditions? Please cross all that apply.

- ☐ 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 the study participant has been diagnosed with cancer within the last five years, has it spread to other areas (metastasised) ☐ 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

19. Does the study participant take warfarin? ☐ No ☐ Yes

20. Does the study participant have any other major long term illnesses, health problems or disabilities?

☐ No ☐ Yes; please specify with diagnosis:

The study participant's behaviour

Please answer the following questions based on the study participant's behaviour. Put a cross in the "yes" box only if the symptom or symptoms have 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.

21. Delusions: does the study participant have beliefs that you know are not true?

For example, does s/he say that others are stealing from him/her, or planning to harm him/her in some way?

☐ No (skip to question 22)

☐ Yes

Rate the severity of the symptom (how it affects the study participant):

☐ Mild (noticeable, but does not upset the resident that much)

☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)

☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

☐ Not at all

☐ Minimally (almost no change in work routine)

☐ Mildly (some change in work routine but little time reorganisation required)

☐ Moderately (disrupts work routine, requires time reorganisation)

☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

22. Hallucinations: does the study participant act as if s/he hears voices? For example, Does s/he talk to people who are not there?

☐ No (skip to question 23)

☐ Yes

Rate the severity of the symptom (how it affects the study participant):

☐ Mild (noticeable, but does not upset the resident that much)

☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)

☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

☐ Not at all

☐ Minimally (almost no change in work routine)

☐ Mildly (some change in work routine but little time reorganisation required)

☐ Moderately (disrupts work routine, requires time reorganisation)

☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

23. **Agitation/Agression:** does the study participant have periods when s/he refuses to let people help him/her? Is s/he hard to handle? Is s/he noisy or uncooperative? Does s/he attempt to hurt or hit others?

☐ No (skip to question 24)

☐ Yes

Rate the severity of the symptom (how it affects the study participant):

☐ Mild (noticeable, but does not upset the resident that much)

☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)

☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

☐ Not at all

☐ Minimally (almost no change in work routine)

☐ Mildly (some change in work routine but little time reorganisation required)

☐ Moderately (disrupts work routine, requires time reorganisation)

☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

24. **Depression:** does the study participant seem sad or in low spirits? Does s/he say that s/he is depressed? Does s/he cry?

☐ No (skip to question 25)

☐ Yes

Rate the severity of the symptom (how it affects the study participant):

☐ Mild (noticeable, but does not upset the resident that much)

☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)

☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

☐ Not at all

☐ Minimally (almost no change in work routine)

☐ Mildly (some change in work routine but little time reorganisation required)

☐ Moderately (disrupts work routine, requires time reorganisation)

☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

25. **Anxiety:** is the study participant nervous, worried, or frightened for no reason?
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 26)

☐ Yes

Rate the severity of the symptom (how it affects the study participant):

☐ Mild (noticeable, but does not upset the resident that much)

☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)

☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

☐ Not at all

☐ Minimally (almost no change in work routine)

☐ Mildly (some change in work routine but little time reorganisation required)

☐ Moderately (disrupts work routine, requires time reorganisation)

☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

26. **Elation:** does the study participant appear to feel too good or act excessively happy?
I don't mean normal happiness, but, for example, laughing at things that others do not find funny?

☐ No (skip to question 27)

☐ Yes

Rate the severity of the symptom (how it affects the study participant):

☐ Mild (noticeable, but does not upset the resident that much)

☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)

☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

☐ Not at all

☐ Minimally (almost no change in work routine)

☐ Mildly (some change in work routine but little time reorganisation required)

☐ Moderately (disrupts work routine, requires time reorganisation)

☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

27. **Apathy: Does the study participant sit quietly without paying attention to things going on around him/her? Has s/he lost interest in doing things or lack motivation for participating in activities?**

☐ No (skip to question 28)

☐ Yes

Rate the severity of the symptom (how it affects the study participant):

☐ Mild (noticeable, but does not upset the resident that much)

☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)

☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

☐ Not at all

☐ Minimally (almost no change in work routine)

☐ Mildly (some change in work routine but little time reorganisation required)

☐ Moderately (disrupts work routine, requires time reorganisation)

☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

28. **Disinhibition: Does the study participant do or say things that are not usually done or said in public? Does s/he seem to act impulsively without thinking? Does s/he say things that may hurt people's feelings?**

☐ No (skip to question 29)

☐ Yes

Rate the severity of the symptom (how it affects the study participant):

☐ Mild (noticeable, but does not upset the resident that much)

☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)

☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

☐ Not at all

☐ Minimally (almost no change in work routine)

☐ Mildly (some change in work routine but little time reorganisation required)

☐ Moderately (disrupts work routine, requires time reorganisation)

☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

[]

29. Irritability: does the study participant get easily irritated or disturbed? Are his/her moods very changeable? Is s/he extremely impatient?

- ☐ No (skip to question 30)
- ☐ Yes

Rate the severity of the symptom (how it affects the study participant):

- ☐ Mild (noticeable, but does not upset the resident that much)
- ☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)
- ☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

- ☐ Not at all
- ☐ Minimally (almost no change in work routine)
- ☐ Mildly (some change in work routine but little time reorganisation required)
- ☐ Moderately (disrupts work routine, requires time reorganisation)
- ☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

30. Motor behaviour: Does the study participant engage in repetitive activities, such as pacing around, wheeling back and forth, handling buttons, wrapping string, or doing other things repeatedly?

- ☐ No (skip to question 31)
- ☐ Yes

Rate the severity of the symptom (how it affects the study participant):

- ☐ Mild (noticeable, but does not upset the resident that much)
- ☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)
- ☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

- ☐ Not at all
- ☐ Minimally (almost no change in work routine)
- ☐ Mildly (some change in work routine but little time reorganisation required)
- ☐ Moderately (disrupts work routine, requires time reorganisation)
- ☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)
- ☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)
- []

31. Sleep behaviour: Does the study participant have difficulty sleeping?

Does s/he wake up during the night? Does s/he wander at night, get dressed, or go into others' rooms?

☐ No (skip to question 32)

☐ Yes

Rate the severity of the symptom (how it affects the study participant):

☐ Mild (noticeable, but does not upset the resident that much)

☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)

☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

☐ Not at all

☐ Minimally (almost no change in work routine)

☐ Mildly (some change in work routine but little time reorganisation required)

☐ Moderately (disrupts work routine, requires time reorganisation)

☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

32. Appetite: does the study participant have an extremely good or poor appetite, changes in weight, or unusual eating habits? Has there been any changes in type of food s/he prefers?

☐ No (skip to question 33)

☐ Yes

Rate the severity of the symptom (how it affects the study participant):

☐ Mild (noticeable, but does not upset the resident that much)

☐ Moderate (significant, stressful and upsetting to the resident and causes unusual or strange behaviour)

☐ Severe (very stressful and upsetting to the resident and causes a major amount of unusual or strange behaviour)

How much does this behaviour upset you and/or create more work for you?

☐ Not at all

☐ Minimally (almost no change in work routine)

☐ Mildly (some change in work routine but little time reorganisation required)

☐ Moderately (disrupts work routine, requires time reorganisation)

☐ Severely (disruptive, upsetting to staff and other residents, major time infringement)

☐ Very Severely or Extremely (very disruptive, major source of distress for staff and other residents, requires time usually devoted to other residents or activities)

The following questions are about the study participant's quality of life. When you think about the study participant's quality of life, there are different aspects, some of which are listed below. Please rate these aspects based on his/her life at the present time (e.g. **within the past few weeks**).

33. How is the study participant's physical health right now? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

34. How is the study participant's energy level? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

35. How is the study participant's mood lately? Have his/her spirits been good or has s/he been feeling down? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

36. How is the study participant's living situation? How would you rate the place s/he lives now? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

37. How is the study participant's memory? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

38. How is the study participant's relationship with his/her family (such as spouse, brothers, sisters, children etc.)? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

39. How is the study participant's marriage? How is his/her relationship with you or his/her spouse? If the study participant is single, widowed, divorced how would you rate his/her relationship with you? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

40. How is the study participant's current relationship with his/her friends?

If the study participant has no friends does s/he have anyone s/he enjoys being with other than family? If so, how would you rate the study participant's current relationship with this person? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

41. How does the study participant feel about himself/herself, his/her whole self, and all the different things about him/her? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

42. How is the study participant's ability to do things like chores or other things s/he needs to do? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

43. How is the study participant's ability to do things for fun, that s/he enjoys? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

44. How is the study participant's current situation with money, i.e. his/her financial situation? Is it...

☐ Poor ☐ Fair ☐ Good ☐ Excellent

45. How is the study participant'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

The study participant's well-being

Please indicate for each of these statements the one that is closest to how you think the study participant has been feeling. For example, if you think the study participant 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.

46. Over the past two weeks the study participant 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"/>

47. Over the past two weeks the study participant 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"/>

48. Over the past two weeks the study participant 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"/>

49. Over the past two weeks the study participant 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"/>

50. Over the past two weeks the study participant'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"/>

Q51 to Q65 are from the AAIQOL measure, provided as below:

Author and Owner: Steven Albert

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Reference publication: Albert SM, Castillo-Castaneda 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 the study participant spends his/her time

Please indicate whether the study participant 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.

If you answer "never" to whether the study participant did the activity, please also say whether s/he enjoys the activity.

51. Has the study participant had an opportunity to be outside, go for walks, enjoy nature?

☐ No (skip to question 52)

☐ Yes If yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity

Did s/he enjoy the activity?

☐ No

☐ Yes

52. Has the study participant had an opportunity to be with pets or animals or to watch animals?☐ No (skip to question 53)☐ Yes If yes; **How often did s/he do the activity?**☐ Never☐ Up to three times a week☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity

Did s/he enjoy the activity?☐ No☐ Yes**53. Has the study participant had an opportunity to get together with family/friends?**☐ No (skip to question 54)☐ Yes If yes; **How often did s/he do the activity?**☐ Never☐ Up to three times a week☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity

Did s/he enjoy the activity?☐ No☐ Yes**54. Has the study participant had an opportunity to talk to family/friends on the telephone?**☐ No (skip to question 55)☐ Yes If yes; **How often did s/he do the activity?**☐ Never☐ Up to three times a week☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity

Did s/he enjoy the activity?☐ No☐ Yes**55. Has the study participant had an opportunity to go to the cinema, museums or other entertainment events?**☐ No (skip to question 56)☐ Yes If yes; **How often did s/he do the activity?**☐ Never☐ Up to three times a week☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity

Did s/he enjoy the activity?☐ No☐ Yes**56. Has the study participant had an opportunity to go to church or other place of worship or religious events?**☐ No (skip to question 57)☐ Yes If yes; **How often did s/he do the activity?**☐ Never☐ Up to three times a week☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity

Did s/he enjoy the activity?☐ No☐ Yes

57. Has the study participant had an opportunity to go shopping for groceries, clothes, etc.?

☐ No (skip to question 58)

If yes, for all 3 "often" responses say whether s/he enjoys the activity

☐ 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

58. Has the study participant had an opportunity to go for a ride in the car, train or bus?

☐ No (skip to question 59)

If yes, for all 3 "often" responses say whether s/he enjoys the activity

☐ 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

59. Has the study participant had an opportunity to read or have stories read to him/her?

☐ No (skip to question 60)

If yes, for all 3 "often" responses say whether s/he enjoys the activity

☐ 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

60. Has the study participant had an opportunity to listen to the radio, tapes or CDs, or watch TV?

☐ No (skip to question 61)

If yes, for all 3 "often" responses say whether s/he enjoys the activity

☐ 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

61. Has the study participant had an opportunity to exercise, play or watch sports?

☐ No (skip to question 62)

If yes, for all 3 "often" responses say whether s/he enjoys the activity

☐ 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

62. Has the study participant had an opportunity to play games or cards, do crosswords or puzzles?

☐ No (skip to question 63)

☐ Yes If yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity

Did s/he enjoy the activity?

☐ No

☐ Yes

63. Has the study participant had an opportunity to do handiwork or crafts?

☐ No (skip to question 64)

☐ Yes If yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity

Did s/he enjoy the activity?

☐ No

☐ Yes

64. Has the study participant had an opportunity to garden, plant care, indoors or outdoors?

☐ No (skip to question 65)

☐ Yes If yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity

Did s/he enjoy the activity?

☐ No

☐ Yes

65. Has the study participant had an opportunity to complete a task that was difficult for him/her?

☐ No (skip to question 66)

☐ Yes If yes; **How often did s/he do the activity?**

☐ Never

☐ Up to three times a week

☐ More than three times a week

If yes, for all 3 "often" responses say whether s/he enjoys the activity

Did s/he enjoy the activity?

☐ No

☐ Yes

The study participant'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 the study participant.

66. In most ways the study participant's life is close to his/her ideal

Strongly disagree

☐

Disagree

☐

Slightly disagree

☐

Neither agree nor disagree

☐

Slightly agree

☐

Agree

☐

Strongly agree

☐

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The study participant's emotions

We would like to know how frequently the study participant 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.

71. 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

☐ ☐ ☐ ☐ ☐ ☐

72. 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

73. 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

☐ ☐ ☐ ☐ ☐ ☐

74. 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

75. 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"/>

76. 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"/>

The study participant's everyday activities

We would now like to ask about how well the study participant is able to carry out the following everyday activities. The participant may not have the opportunity to do these tasks but we are interested in how s/he manages these activities at the present time.

77. Can the study participant 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

78. Can the study participant 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

79. Can the study participant 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



80. Can the study participant 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

81. Can the study participant 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

82. Can the study participant 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

83. Can the study participant 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

84. Can the study participant 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

85. Can the study participant 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

86. Can the study participant 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

87. Is the study participant 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

88. Does the study participant need help selecting clothing for himself/herself that is appropriate for the weather?

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

89. Does the study participant 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)

90. Does the study participant 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)

91. Does the study participant need frequent (at least once a month) help finding misplaced objects, keeping appointments, or maintaining health or safety (locking doors, taking medication)?

☐ No ☐ Yes

92. Does the study participant need household chores done for him/her?

☐ No ☐ Yes

93. Does the study participant need to be watched or kept company when awake?

☐ No ☐ Yes

94. Does the study participant need to be escorted when outside?

☐ No ☐ Yes

95. Does the study participant need to be accompanied when bathing or eating?

☐ No ☐ Yes

96. Does the study participant have to be dressed, washed, and groomed?

☐ No ☐ Yes

97. Does the study participant have to be taken to the toilet regularly to avoid incontinence?

☐ No ☐ Yes

98. Does the study participant have to be fed?

☐ No ☐ Yes

99. Does the study participant have to be turned, moved, or transferred?

☐ No ☐ Yes

100. Does the study participant wear an incontinence pad or a catheter?

☐ No ☐ Yes

101. Does the study participant need to be tube fed?

☐ No ☐ Yes

102. Would you say the study participant's appetite is

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

The study participant's medication

The next few questions are about the medication that the study participant takes.

103. How many different prescribed medications does the study participant take?

☐ None

☐ One

☐ Two

☐ Three

☐ Four

☐ Five

☐ Six

☐ Seven

☐ Eight

☐ Nine

☐ Ten

☐ Eleven

☐ Twelve

☐ Thirteen

☐ Fourteen

☐ Fifteen or more; please specify number:

--	--

104. Has the study participant taken any medications for his/her dementia/memory difficulties in the last 3 months (e.g. Aricept, Reminyl, etc.)?

☐ No (skip to question 107)

☐ Yes, if yes; **what is the name of the memory medication or medications that the study participant takes:**

105. _____

106. _____

107. Has the study participant taken any other mental health medications in the last 3 months (antidepressants or antipsychotics, e.g. Citalopram, Risperidone, etc.)?

☐ No

☐ Yes, if yes; **what is the name(s) of the mental health medications that the study participant takes:**

108. _____

109. _____

110. _____

111. _____

112. _____

113. _____

--

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 how things are at this time.

These questions are optional

114. What is the difference between a good and a bad day for the study participant?

115. What do you think makes it easy or difficult to live well with dementia?

116. How do you find the experience of providing care for people with dementia?

117. What do you think could be changed in the local community to enable people with dementia to 'live well' with dementia?

118. What do you think could be done by the government to help people 'live well' with dementia?

Thank you for taking the time to answer these questions. The information and insights that you have provided are 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:

Information about you: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Your employment: ☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

Questions about the study participant:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

The study participant's health conditions:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

The study participant's behaviour:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

The study participant's quality of life:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

The study participant's well-being:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

- ☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood
☐ Other; please specify: _____

How the study participant spends his/her time:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

The study participant's satisfaction with life:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

The study participant's emotions:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

The study participant's everyday activities:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

The study participant's medication:

☐ Complete ☐ Partially complete ☐ None completed ☐ Not applicable

If 'Partial' or 'None completed', please give a reason:

☐ Refused ☐ Too impaired ☐ Too tired ☐ No time ☐ Questions not understood

☐ Other; please specify: _____

Optional questions completed:

☐ Yes ☐ No ☐ Partial

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Enhancing Active Life and Living Well: The IDEAL Study

Time 2

12 month follow-up

Showcard Booklet



Data linkage consent

Instructions for the researcher: Please read this statement to the participant when: THE PERSON WITH DEMENTIA **HAS** CAPACITY TO CONSENT

The information you provide will be even more valuable if we can link your answers to records that the NHS and other public organisations hold on your health circumstances. We included some information about linking your answers to these records in the letter that we sent you recently. I have another copy if you would like to look at this information and ask any questions.

If you are happy for us to do this, I would now to ask you to give your consent in writing.

Instructions for the researcher: Please read this statement to the **personal consultee** when: THE PERSON WITH DEMENTIA **DOES NOT** HAVE CAPACITY TO CONSENT

The information that your relative or friend provides will be even more valuable if we can link his/her answers to records that the NHS and other public organisations hold on his/her health circumstances. We included some information about linking your relative's or friend's answers to these records in the letter that we sent you recently. I have another copy if you would like to look at this information and ask any questions.

If you decide that your relative or friend would be happy for us to do this, I would now to ask you to give your consent in writing.

SHOWCARDS FOR CRF 1

All MMSE questions removed in line with user agreement

SHOWCARD 1B

Never

Occasionally

Monthly

Weekly

Daily

SHOWCARD 1C

Very poor

Poor

Fair

Good

Very good

Excellent

SHOWCARD 1D

Poor

Fair

Good

Very good

Excellent

SHOWCARD 1E

Very poor

Poor

Average

Good

Very good

SHOWCARD 1F

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

SHOWCARD 1G

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

SHOWCARD 1H

Strongly disagree

Disagree

Neutral

Agree

Strongly agree

SHOWCARD 1I

Very poor

Poor

Average

Good

Very good

Not being able to get to
sleep

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

Waking up several times
throughout the night

Having bad dreams

Being uncomfortable

Other; please specify

SHOWCARD 1K

Poor

Fair

Good

Excellent

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

Strongly disagree

Disagree

Slightly disagree

Neither agree nor disagree

Slightly agree

Agree

Strongly agree

SHOWCARD 1N

Very dissatisfied

Slightly dissatisfied

Neither satisfied nor dissatisfied

Slightly satisfied

Very satisfied

Dependent on others

Require assistance but can
still do the task

Have difficulty but do by self

Never did, and would have
difficulty now

Normal (as I have always
done)

Never did, but could do now

Strongly disagree

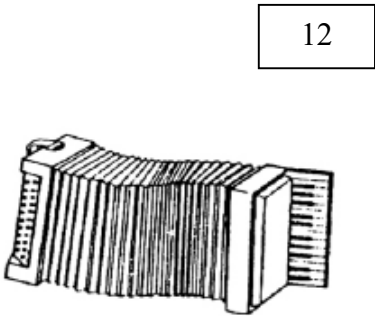
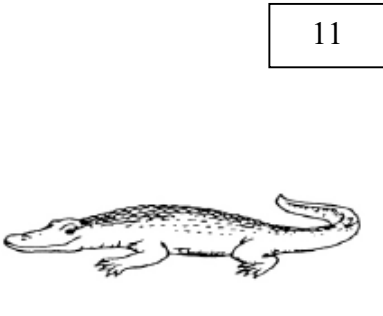
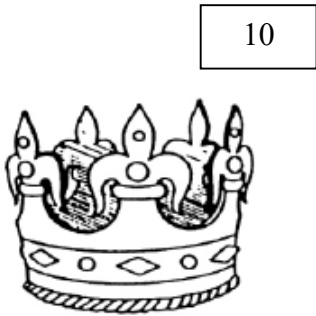
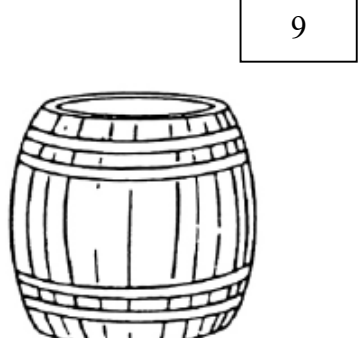
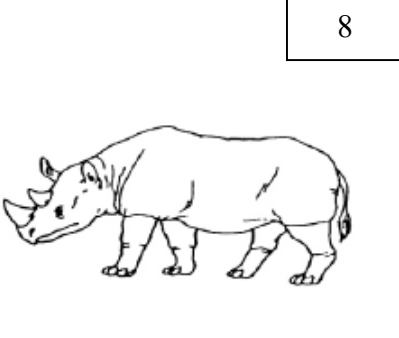
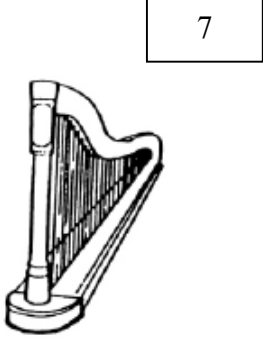
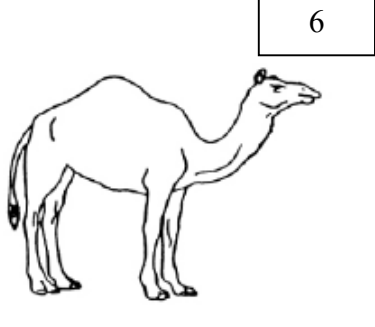
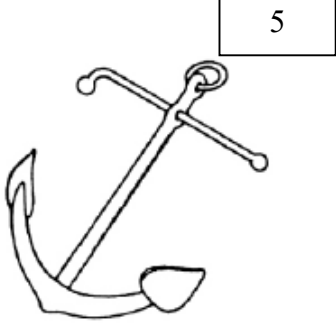
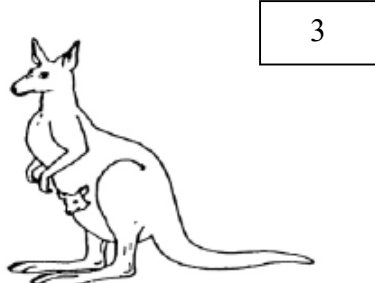
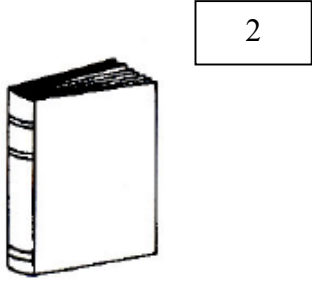
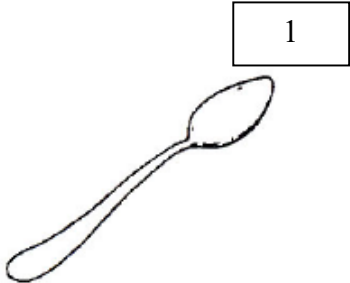
Disagree

Agree

Strongly agree

SHOWCARDS FOR CRF 2

SHOWCARD 2A

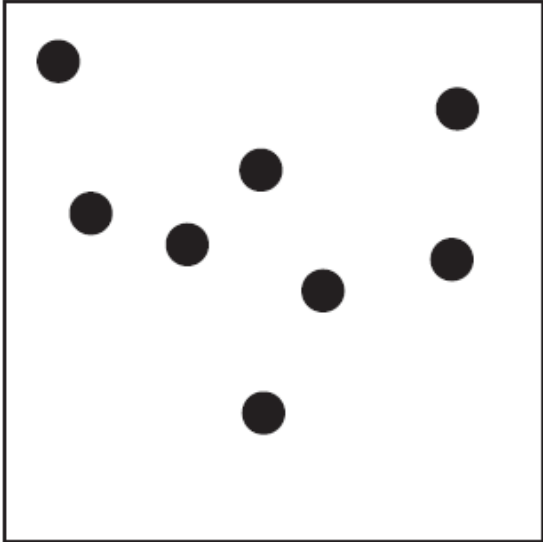


SHOWCARD 2B

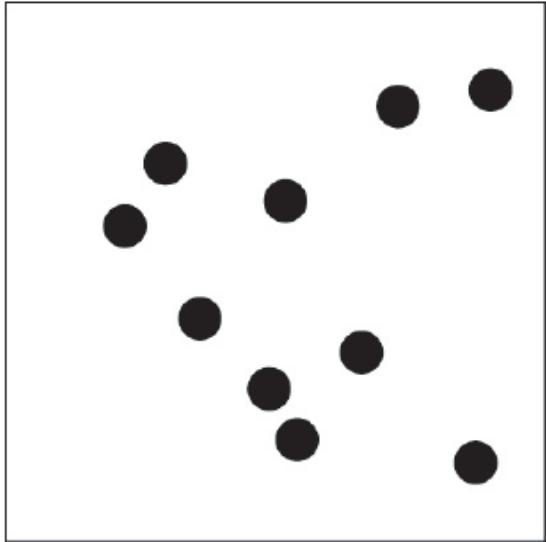
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SHOWCARD 2C

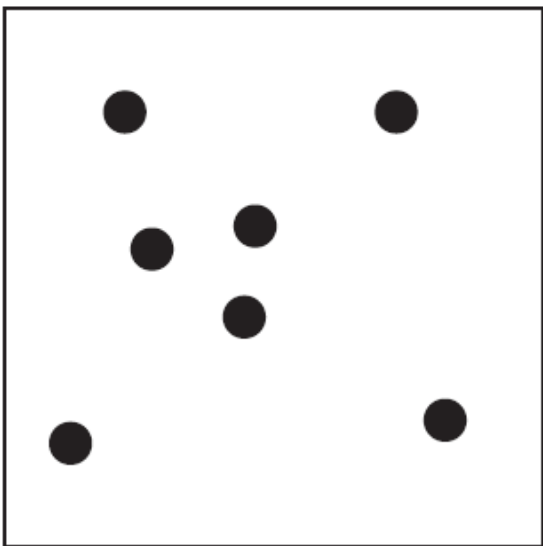
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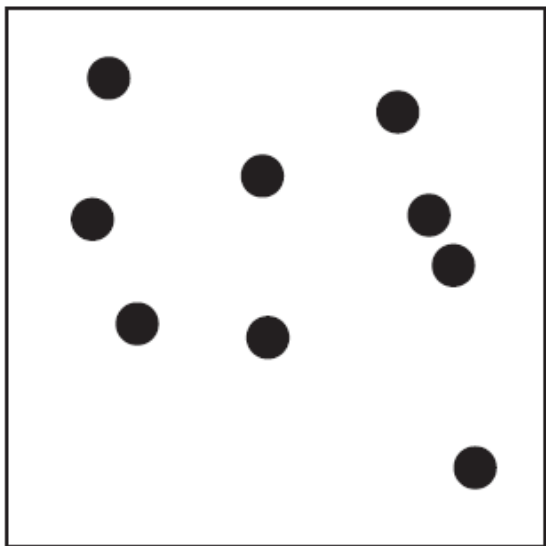
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3



4



SHOWCARD 2D

1



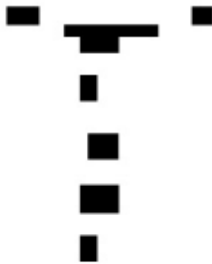
2



3



4



None

Some but less than one hour

One hour but less than three
hours

Three hours or more

Rarely or not at all

Sometimes

Mostly

Always

Strongly disagree

Moderately disagree

Slightly disagree

Slightly agree

Moderately agree

Strongly agree

SHOWCARD 2H

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 2I

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 2J

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

None of the above

Very dissatisfied

Fairly dissatisfied

Neither satisfied nor dissatisfied

Slightly satisfied

Very satisfied

Very likely

Quite likely

Not very likely

Not at all likely

Very big problem

Fairly big problem

Not a very big problem

Not a problem at all

It happens but it's not a
problem

Strongly disagree

Slightly disagree

Neither agree nor disagree

Slightly agree

Strongly agree

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

On most days

Once or twice a week

Once or twice a month

Less often than once a month

Never

SHOWCARD 2Q

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

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

Once a year or less/Never

Several times a year

Several times a month

Several times a week

Every day or almost every day

Extremely satisfied

Satisfied

Fairly satisfied

Neither satisfied nor dissatisfied

Slightly dissatisfied

Dissatisfied

Extremely dissatisfied

SHOWCARD 2U

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 2V

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 2W

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 2X

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 2Y

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 grants, rent)

SHOWCARD 2Z

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

Other equipment/adaptations

SHOWCARDS FOR RESEARCHER RATINGS

SHOWCARD 3A - 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 3B - 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 3C - CSRI medication

Dementia

acumor
aricept
donepezil
ebixa
exelon
galantamine
gatalin
memantine
nemdatine
reminyl
rivastigmine

Parkinsonism

adartrel
apo-go
apomorph
arpicolin
azilect
azzalure
biorphen
botox
broflex
cabaser
cabergoline
caramet
carbidopa
co-beneldopa
co-careldopa
comtess
disipal
duodopa
dysport
eldepryl
entacapone
half sinemet
kemadrin
madopar
mirapexin
neupro
neurobloc
nootropil
orphenadrine
pergolide
pramipexole
procyclidine
ralnea
requip
repinex
rilutek
riluzole
ropinirole
selegiline
sinemet
stalevo
symmetrel
tetrabenazine
trihexyphenidyl

Other Mental health

drugs

abilify
allegron
alventa
amisulpride
amitriptyline
anafranil
anquil
benperidol
bonilux
bromazepam
buspar
buspirone hcl
camcolit
chloral hydrate
chlordiazepox hcl
chlorpromazine
cipralext
cipramil
circadin
citalopram
clomethiazole
clomipramine
clopixol
cymbalta
depakote
depefex
depixol
diazepam
dolmatil
dosulepin
doxepin
dozic
edronax
efexor
faverin
fentazin
fluanaxol
fluoxetine
fluvoxamine
haldol
haloperidol
heminevrin
imipramine
invega
isocarboxazid
levinan
librium
li-liquid
liskonum
lithium carbonate
lithium citrate
lofepramine
lomont
loprazolam mesil
lorazepam
lormetazepam
lustral
manerix
melatonin
meprobamate
mianserin
mirtazapine
moclobemide
mogadon
molipaxin
nardil
nitrazepam
nortriptyline
nozinan
olanzapine
orap
oxactin
oxazepam
paroxetine
pericyazine
politid
priadel
promazine
prothiaden
prozac
prozep
psytixol
quetiapine
ranfaxine
risperidone
secobarbitol sodium
serenace

seroquel
seroxat
sertraline
sinepin
sodium-amytal
solian
somnite
sonata
soneryl
stelazine
stesolid
stilnoct
sulpiride
sulpor
surmontil
sycrest
temazepam
tifaxin
tranlycypromine
trazodone
triclofos sodium
trifluoperazine
trimipramine
triptafen
valclair
valdoxan
venaxx
venlafaxine
venlalic
viepax
welldorm
winfex
xanax
xyrem
zalasta
zaponex
zimovane
zispin
zolpidem tart
zopiclone
zyprexa

**ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY
CONSENT FORM FOR PARTICIPANT: 12 MONTH FOLLOW UP**

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 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 any changes to 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 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 understand that at some point during the next year I may be asked to meet with a researcher for an interview, which would be audio-recorded, and that I have the right to decline without affecting my participation in the study.	
9	I agree that my anonymised data from these 12-month follow up visits can be deposited in a data archive (UK Data Archive) which is available to researchers and the public for scholarly and educational purposes.	
10	I agree to take part in the study.	

Name of Participant

Date

Signature

Researcher taking consent

Date

Signature

[To be printed on study centre headed notepaper]

**ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY
CONSENT FORM FOR FAMILY MEMBER/FRIEND: 12 MONTH FOLLOW-UP**

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 any changes to 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 understand that at some point during the next year I may be asked to meet with a researcher for an interview, which would be audio-recorded, and that I have the right to decline without affecting my participation in the study.	
8	I agree that my anonymised data from these 12-month follow up 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 12 month follow-up

**ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY
CONSENT FORM FOR PAID CARER: 12 MONTH FOLLOW-UP**

Participant identification number: _____

**Initial here if
in agreement**

1	I have read and understand the information sheet dated 05/03/15 (version 1) 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.	
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 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.	
6	I agree that my anonymised data from these 12-month follow up visits can be deposited in a data archive (UK Data Archive) which is available to researchers and the public for scholarly and educational purposes.	
7	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

**ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY
CONSENT FORM FOR PERSONAL CONSULTEE: 12 MONTH FOLLOW-UP**

(Scotland – guardian, welfare attorney or nearest relative)

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 have been consulted regarding the participation of my relative/friend, as required by the Mental Capacity Act/ Adults with Incapacity (Scotland) Act 2000, and I believe s/he would wish to continue to take part in the study.	
3	I understand that my relative's/friend's participation is voluntary and that I am free to advise that s/he withdraw at any time, without giving any reason, without the care or legal rights of my relative/friend being affected.	
4	I understand that all information about my relative/friend given 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 that that the personal contact details of my relative/friend can be given to the research co-ordinating centre at the University of Exeter, to allow them to make contact about the research.	
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 that my relative's/friend's anonymised data from these 12-month follow up visits can be deposited in a data archive (UK Data Archive) which is available to researchers and the public for scholarly and educational purposes.	

Name of **Personal Consultee**

Date

Signature

Researcher taking consent

Date

Signature

One copy for participant; one copy for researcher; one copy for sponsor
IDEAL Consent form for personal consultee version 4 12 month follow-up 20/05/16

ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY

CONSENT FORM FOR PARTICIPANT: DATA LINKAGE

Participant identification number: _____

Initial here if
in agreement

1	I have read and understood the information provided in the data linkage information pamphlet dated 28/05/15 (version 3) and I have had the opportunity to ask questions about sharing my records held by other organisations with the research staff working in the IDEAL study.	
2	I agree that that my personal contact details can be given to the IDEAL research co-ordinating centre, to enable my records to be linked to the survey information that I provide within the IDEAL study.	
3	I give my permission to the research staff working on the above study to pass on my name, address, sex, date of birth and NHS/CHI number to the NHS, and other public organisations who hold information about me so that my data can be linked.	
4	I give my permission to the NHS and other public organisations to disclose a link to information they have routinely collected about me in the past, present and future that cover all of my health circumstances, diagnoses and treatment.	
5	I give my permission for this information to be linked to the information held about me in the IDEAL study for the purposes of their research studies into the frequency, causes, treatment or outcomes of diseases and health conditions only, even after any incapacity or my death.	
6	I understand that the details obtained through data linkage will be used for statistical and research purposes only.	
7	I understand that the link to this information can only be used by researchers who have gained ethical approval for analysing this data.	
8	This consent will remain valid unless withdrawn by me.	

Name of Participant

Date

Signature

Researcher taking consent

Date

Signature

One copy for participant; one copy for researcher; one copy for sponsor

ENHANCING ACTIVE LIFE AND LIVING WELL: THE IDEAL STUDY

CONSENT FORM FOR PERSONAL CONSULTEE: DATA LINKAGE

(Scotland – guardian, welfare attorney or nearest relative)

Participant identification number: _____

**Initial here if
in agreement**

1	I have read and understood the information provided in the data linkage information pamphlet for personal consultee dated 28/05/15 (version 2) and I have had the opportunity to ask questions about sharing my relative's/friend's records held by other organisations with the research staff working in the IDEAL study.	
2	I have been consulted regarding the participation of my relative/friend, as required by the Mental Capacity Act/ Adults with Incapacity (Scotland) Act 2000, and I believe s/he would wish his/her records to be linked to the survey information that he/she provides within the IDEAL study.	
3	I agree that that my relative's/friend's personal contact details can be given to the IDEAL research co-ordinating centre, to enable his/her records to be linked to the survey information that he/she provides within the IDEAL study.	
4	I agree that the research staff working on the above study can pass on my relative's/friend's name, address, sex, date of birth and NHS/CHI number to the NHS, and other public organisations who hold information about him/her so that his/her data can be linked.	
5	I agree that the NHS and other public organisations can disclose a link to information they have routinely collected about my relative/friend in the past, present and future that cover all of his/her health circumstances, diagnoses and treatment.	
6	I agree that this information can be linked to the information held about my relative/friend in the IDEAL study for the purposes of their research studies into the frequency, causes, treatment or outcomes of diseases and health conditions only, even after his/her death.	
7	I understand that the details obtained through data linkage will be used for statistical and research purposes only.	
8	I understand that the link to this information can only be used by researchers who have gained ethical approval for analysing this data.	
9	This declaration will remain valid unless withdrawn by me.	

Name of Personal Consultee

Date

Signature

Researcher taking consent

Date

Signature

One copy for personal consultee; one copy for researcher; one copy for sponsor

IDEAL Data Linkage Personal Consultee Consent Form v2 280515