

**Identifying and mitigating the individual and dyadic impact of COVID-19
and life under physical distancing on people with dementia and carers
(INCLUDE)**

An additional COVID-19-specific module for the IDEAL-2 study

List of measures

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Overview

This document can be used with UK Data Service Study Number 855800 PwD and Carer datasets to plan analyses. Table 1 can also be used with the people with dementia list of variables and/or the carer list of variables to identify questions asked of both cohorts. All list documents were formatted to match the ordering in Table 1.

Appendix 1 describes the measures in Table 1 and provides citations for the standardised measures used in the CRFs.

Table 1

Questionnaire topic	People with dementia	Carer	
		Self-rating	Informant rating
Background			
Demographics	X	X	
Education	X	X	
Quality of life			
ONS well-being questions	X	X	
Quality of life- AD	X		X
Quality of life	X	X	X
Satisfaction with life	X		
Health-related quality of life	X		X
Community			
Social capital	X	X	
Satisfaction with neighbourhood	X	X	
Reciprocity and trust in neighbourhood	X		
Health			
Subjective health	X	X	X
Health during the pandemic	X	X	X
Medication	X		X
Healthcare services			
Service utilisation	X		X
Healthcare during COVID-19	X	X	
Support services		X	
Internet use	X	X	X
Smartphone use	X		
Managing everyday life during the pandemic			
Managing everyday life	X	X	X
Adjustment to dementia	X		X
Subjective cognition	X		
Social networks/relationships			
Close relationships	X	X	
Social networks	X	X	X
Social network satisfaction	X	X	
Life space	X		X
Additional life space questions	X		X
Resources and activities			
Activity engagement	X		X
Well-being			
Stressful life events			X
Well-being	X	X	X
Psychological well-being	X	X	
The Yale Single Question Screen	X		

Optimism	X	X	
Experience of self	X		
Carer questions			
Caregiving competence		X	
Caregiving coping		X	
Restriction in caregiver's life		X	
Carer stress		X	
Feedback			
Further information	X	X	
Cognitive tests			
Cognition	X		
Derived variables	X	X	

Appendix 1

Background

Demographics. Person with dementia- Returning or enrichment participant, whether they were part of a dyad, sex*, age groups*, diagnosis*, marital status*, COVID restrictions at the time of assessment, ethnicity groups*, assessment method, housing situation, and whether a carer is taking part.

Demographics. Carer- Returning or enrichment participant, whether they were part of a dyad, sex*, age groups*, marital status*, relationship to the person with dementia*, whether the carer is different from previous IDEAL timepoint, carer status*, ethnicity groups*, living situation, whether they have had a carer assessment and are a registered carer, hours of care provided per day, person with dementia age group*, person with dementia sex*, and person with dementia diagnosis*.

*** Data collected from IDEAL/IDEAL-2**

Note: below, the wording of the questions has been included. The wording that was read to people with dementia has been included only, where the carer was asked to provide an informant rating, the wording is generally identical other than the addition of the words “relative/friend” instead of “you” or “your” etc.

Quality of life

Office for National Statistics well-being questions. Person with dementia self-report, carer self-report

University of Manchester, Cathie Marsh Centre for Census and Survey Research, ESDS Government. (2012). *ONS Opinions Survey, Well-Being Module, April 2011: Unrestricted Access Teaching Dataset*. [data collection]. <https://doi.org/http://doi.org/10.5255/UKDA-SN-7146-1>. Contains public sector information licensed under the Open Government Licence v2.0

These four questions are taken from the ONS Opinions Survey 2011. They are used to investigate general well-being and are widely used by the ONS in many of their surveys. The scale is from 0-10 and the higher the rating the higher the subjective well-being of the respondent. The four questions are:

- On a scale of zero to 10, where zero is “not at all” and 10 is “very”, to what extent do you feel the things you do in your life are worthwhile?
- On a scale of zero to 10, where zero is “not at all” and 10 is “very”, how satisfied are you with your life nowadays?
- On a scale of zero to 10, where zero is “not at all” and 10 is “very”, how happy overall did you feel yesterday?
- On a scale of zero to 10, where zero is “not at all” and 10 is “very”, how anxious overall did you feel yesterday?

Quality of life-AD. Person with dementia self-report, Informant rating by carer
Logsdon, R.G., Gibbons, L.E., McCurry, S.M., & Teri, L. (1999). Quality of Life in Alzheimer's Disease: patient and caregiver reports. *Journal of Mental Health and Aging*, 5, 21-32.

Logsdon, R.G., Gibbons, L.E., McCurry, S.M., & Teri, L. (2000). Quality of life in Alzheimer's disease: patient and caregiver reports. In S. M. Albert & R. G. Logsdon (Eds.), *Assessing quality of life in dementia* (pp. 17-30). New York: Springer.

The Quality of Life-AD (QoL-AD) asks participants to rate aspects of their current situation such as physical health, mood, memory, functional abilities, interpersonal relationships, and financial situation, and making global assessments of satisfaction with self and QoL.

Responses are assessed using a scale from 1 to 4 (poor, fair, good, excellent). Only one question from the QoL-AD was included: 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?

Quality of life. Person with dementia self-report, Carer self-report, Informant rating by carer Skevington, S. M., Lotfy, M., O'Connell, K. A., & Group, W. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: psychometric properties and results of the international field trial. A report from the WHOQOL group. *Quality of Life Research*, 13(2), 299-310. <https://doi.org/10.1023/B:QURE.0000018486.91360.00>

One question was adapted from this measure, and it asks the participant to rate his/her quality of life in the last two weeks, with options ranging from 1 (very poor) to 5 (very good). The wording is: How would you rate your quality of life in the last two weeks?

Satisfaction with life. Person with dementia self-report

Almeida, O. P., & Almeida, S. A. (1999). Short versions of the Geriatric Depression Scale: a study of their validity for the diagnosis of a major depressive episode according to ICD-10 and DSM-IV. *International Journal of Geriatric Psychiatry*, 14(10), 858-865.

[https://doi.org/10.1002/\(SICI\)1099-1166\(199910\)14:10<858::AID-GPS35>3.0.CO;2-8](https://doi.org/10.1002/(SICI)1099-1166(199910)14:10<858::AID-GPS35>3.0.CO;2-8)

The Geriatric Depression Scale short form is a 10-item yes/no screening test for depressive symptoms in older people with a high sensitivity and specificity. In INCLUDE, one question was included which asks the participant if they are satisfied with their life. The wording is: Are you basically satisfied with your life?

Health-related quality of life. Person with dementia self-report, Informant rating by carer The EuroQol Group. (1990). EuroQol - a new facility for the measurement of health-related quality of life. *Health Policy*, 16(3), 199-208. [https://doi.org/10.1016/0168-8510\(90\)90421-9](https://doi.org/10.1016/0168-8510(90)90421-9)

The EQ-5D-3L (www.euroqol.org/eq-5d) is a standardised measure of health status and health outcome, applicable to a wide range of health conditions. The respondent is asked to select one of three options for each of five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. For each dimension, the three response options are coded on a 3-point scale from 1 (no problems) to 3 (unable to perform/extreme problem). This yields a descriptive profile (e.g., 11232) across the five dimensions. All five questions from the EQ-5D-3L were included, wording of questions not included due to EQ-5D user agreement.

Community

Social capital. Person with dementia self-report, Carer self-report

Steptoe, A., Addario, G., Banks, J., Batty, G. David, Coughlin, K., Crawford, R., Dangerfield, P., Marmot, M., Nazroo, J., Oldfield, Z., Pacchiotti, B., Steel, N., Wood, M.,

Zaninotto, P. (2021). *English Longitudinal Study of Ageing COVID-19 Study, Waves 1-2, 2020*. [data collection]. 2nd Edition. UK Data Service. SN: 8688, DOI: 10.5255/UKDA-SN-8688-3

Questions about the participant's financial situation and having enough food during the coronavirus outbreak were adapted from the English Longitudinal Study of Ageing (ELSA) COVID-19 Study. The financial situation question response options were between 1 (Much worse off) to 5 (Much better off). The question about the worry of having enough food was rated from 1 (not at all worried) to 5 (extremely worried). The wording of the questions is:

- How do you feel your financial situation now compares to before the coronavirus outbreak?
- How worried, if at all, have you been about having enough food during the coronavirus outbreak?

Satisfaction with neighbourhood. Person with dementia self-report, Carer self-report

Questions about satisfaction with the neighbourhood and willingness to help are taken from the IDEAL survey and were adapted in IDEAL from widely used UK government surveys.

Satisfaction with the neighbourhood responses options are as follows: 1 (very satisfied), 2 (slightly satisfied), 3 (neither satisfied nor dissatisfied), 4 (slightly dissatisfied), 5 (very dissatisfied), 6 (don't know). Willingness to help responses range from 1 (strongly disagree) to 5 (strongly agree), and also includes the following options: 6 (don't know/no opinion) and 7 (refused); this question was not included in the carer interview. The wording of the questions is:

- How satisfied are you with your neighbourhood as a place to live?
- In your neighbourhood to what extent do you agree or disagree that people are willing to help their neighbours?

Reciprocity and trust in neighbourhood. Person with dementia self-report

Office for National Statistics. (2008). *Harmonised concepts and questions for social data sources, secondary standards. Social capital*. Office for National Statistics.

One question was used which asks about the likelihood of someone returning a purse/wallet if it was lost, with the responses as follows: 1 (don't know), 2 (not at all likely), 3 (not very likely), 4 (quite likely), 5 (very likely). The wording is: 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?

Living situation. Person with dementia self-report

We asked whether the person with dementia had moved since the last IDEAL assessment. If the participant responded that they had moved they were asked some follow-up questions, namely whether they were living in a care home, where they were living at the time of the assessment, and whether anyone else lives there with them. The wording is:

- Can I check - have you moved home since the time of the last IDEAL visit which was about a year ago?
- Are you living in a care home or nursing home?
- Can you tell me where you are living at the moment?
- Does anyone else live there with you? Who else lives there with you? Is there anyone else living there?

Health

Subjective health. Person with dementia self-report, Carer self-report, Informant rating by carer

Bowling, A. (2005). Just one question: if one question works, why ask several? *Journal of Epidemiology and Community Health*, 59(5), 342-345.

<https://doi.org/10.1136/jech.2004.021204>

A single question asking respondents to rate their general health is increasingly being used in population studies as an indication of overall health status. The commonly asked question, "How is your health?" is one way of collecting data on self-perceived health status and has been used in surveys worldwide, including the 2011 UK Census. The question used in the INCLUDE study adds an additional response at the upper end of the scale, i.e., excellent, very good, good, average, poor, or very poor. Scores range from 1-6 with higher scores indicating higher subjective health. The wording is: Overall, how would you rate your health in the past 4 weeks?

Health during the pandemic. Person with dementia self-report, Carer self-report, Informant rating by carer

Participants were asked questions about whether they had previously had coronavirus, had been tested and treated in hospital, if they had been in close contact with someone who had coronavirus, and if they had developed any new health problems since the outbreak. These questions were devised for the study. The wording is:

- Have you had the coronavirus?
- Were you tested for coronavirus?
- Were you treated in hospital for coronavirus?
- Has anyone close to you had the virus?

This additional question was included in the carer survey: Overall, how do you feel the coronavirus outbreak has affected your relative/friend?

Medication. Person with dementia self-report, Informant rating by carer

Person with dementia's number of prescribed medication including names, dosage and frequency have been recorded. This was completed by either the person with dementia or the carer, and only the person with dementia if there was no carer taking part. Where the person with dementia was living in care, carers often did not know what the medication the person with dementia was taking and could not go into the care home due to the pandemic, so where this applies the code "In care home so unaware of medications" was added into the datasets.

The wording is:

- How many different prescribed medications do you take?
- Please write the names of these medications (i.e., Donepezil), dosage (i.e., 10mg) and frequency in the specific boxes below (choose from the drop-down menu i.e., once daily). If the frequency
- doesn't fit these options please write this information in the dosage section, i.e., "10mg
- four times a week". If they take the same medication but in different dosages or frequencies,
- i.e., Donepezil 10mg once a day and Donepezil 5mg twice a week, please add these as
- separate entries.

Healthcare services

Service utilisation. Person with dementia self-report, Informant rating by carer

Beecham, J., & Knapp, M. (2001). Costing psychiatric interventions. In G. Thornicroft, C. Brewin, & J. Wing (Eds.), *Measuring mental health needs* (2 ed., pp. 203-227). Gaskell.

The Client Service Receipt Inventory (CSRI) is a questionnaire for collecting retrospective information about study participants' use of health and social care services, accommodation and living situation, income, employment and benefits. A shortened version of the CSRI was used for the study. The wording of the questions is:

- In the last 3 months have relatives or friends regularly helped you with tasks you had difficulty with or could not do?
- Thinking about an average week, and about all such friends or relatives, for how many hours do they usually help you with these tasks?
- In the last 3 months, have you used any of these services?
- Home care/home help/a support worker
- Meals on wheels (including Wiltshire Farm Foods etc.)
- An incontinence laundry service
- A cleaner/cleaning service
- Has there been someone to stay with you so [carer] can have a break/respite?
- Has there been someone to support [carer]?
- Have there been any other services (please specify)?
- In the last 3 months have you been in contact with your GP?
- In the last 3 months how many times have you seen a GP at the surgery? What was the reason(s) you saw the GP at the surgery?
- Have you seen a GP at the surgery?
- Have you seen a GP at home?
- Have you spoken to a GP on the telephone (including where someone else spoke to the GP on your behalf)?
- Have you seen a nurse at the surgery?
- In the last 3 months how many times have you spoken to a GP on the telephone? This can include any instances where someone else spoke to the GP on your behalf. What was the reason(s) you or someone else spoke to the GP on the telephone?
- In the last 3 months how many times have you seen a nurse at the surgery? What was the reason(s) you saw a nurse at the surgery?
- Now we would like to know about some community health and care services that people can make use of.
- In the last 3 months have you seen a:
 - o Community Nurse or District Nurse?
 - o Community Psychiatric Nurse or Community Mental Health Nurse?
 - o Psychiatrist
 - o Social worker or care manager
 - o Psychologist
 - o Physiotherapist or Occupational therapist
 - o Dentist
 - o Optician
 - o Specialist nurse (e.g., Admiral Nurse, palliative care nurse, respiratory nurse)?
- In the last 3 months how many times have you seen a GP at home?
- What was the reason(s) you were seen by a GP at home?

- Why did you see a Community Psychiatric Nurse or Community Mental Health Nurse? How many times?
- Why did you see a psychiatrist? How many times?
- Why did you see a social worker or care manager? How many times?
- Why did you see a psychologist? How many times?
- Why did you see a Community Nurse or District Nurse? How many times?
- Why did you see a Dentist? (Prompt for dental work done, check-up, fillings etc.). How many times?
- Why did you see an Optician? (Prompt whether regular check-up or emergency work etc.). How many times?
- Why did you see "specialist nurse"? How many times?
- Why did you see a Physiotherapist or Occupational therapist? How many times?
- In the last 3 months have you been to hospital as an outpatient or day patient to see a specialist, attend a clinic or go to A&E?
- What was the reason for using the service? How many times did you attend the service? How long was the stay?
- In the last 3 months have you had to stay in hospital as an in-patient overnight or longer?
- What was the reason for going to the hospital? How many times have you attended the hospital?
- In the last 3 months have you had to stay in a nursing home or care home?
- What was the reason for staying in a nursing home or care home? How many days do you stay at the nursing home or care home?
- Before the coronavirus outbreak, did you normally go to a day centre?
- When this closed due to coronavirus, did anyone keep in touch with you?

Questions that were included in the carer survey only.

- Thinking about the last 3 months, in an average week, what tasks do you usually help your relative/friend with?
 - o Personal care
 - o Helping with finances
 - o Practical help (housework, laundry)
 - o Taking your relative/friend out to appointments (e.g., medical appointments)
 - o Medications
 - o Making sure your relative/friend is safe (e.g., supervision)
 - o Other
 - o None
- In an average week how many hours do you spend helping your relative/friend with these kinds of tasks?
- On a typical day, how many hours do you spend looking after or providing help for your relative/friend?
- In the last 3 months have relatives or friends, apart from you, regularly helped your relative/friend with tasks that s/he had difficulty with or could not do?
- Thinking about an average week, and about all such friends or relatives, for how many hours do they usually help your relative/friend with these tasks? This doesn't include any help that you give him/her.

Healthcare during COVID-19. Person with dementia self-report, Carer self-report

Participants were asked questions about whether their healthcare needs had been affected due to the coronavirus outbreak, whether any services had stopped, and the impact this had on

them. They were also asked about whether they avoided seeking help and why. The wording of the questions is:

- Did you get any extra help at home during the coronavirus outbreak that you were not having before?
- Ask for details about extra help at home during the coronavirus outbreak that they were not having before.
- Has this extra help at home continued?
- Which extra help has continued?
- Did any of these kinds of help you were receiving stop due to coronavirus? Which ones stopped due to coronavirus?
- Have any started again now? Which ones have started again now?
- Have your healthcare needs been affected by the coronavirus outbreak – for example, appointments postponed, or planned operations delayed?
- Have you avoided seeking help for any health issues because of the coronavirus?
- Why did you avoid seeking help for any health issues because of the coronavirus?
- What healthcare services stopped due to coronavirus?
- Did any healthcare services you were already receiving stop due to coronavirus?
- What impact did these healthcare services stopping have on you?
- (Ask for details, like what services stopped when they stopped, etc? Were they replaced by phone services? prompt: Are there any others?)
- In what ways have your healthcare needs been affected by the coronavirus outbreak?

Support services. Carer self- report

Carers were asked about the support they received such as support groups and respite services, whether the person with dementia had a named healthcare professional and what would help them feel more supported. The wording of the questions is:

- What support do you receive as a carer? Do you attend a support group, do you get respite services, etc.? If yes please say which groups, though please do not include people's names or names of towns instead write "local group" etc.
- Is there a named health professional whom you or your relative/friend can contact at any time, for example a care coordinator, key worker, specialist nurse, dementia navigator, GP, Admiral nurse etc.?
- Please describe his/her job and professional role in relation to you
- (e.g., dementia navigator, GP, Admiral nurse etc.; please do not record names of Drs or names of hospitals.
- If there is more than one, please say, if applicable, which is/are in place to help with your relative/friend's dementia.
- Is the health professional in place to help with your relative/friend's dementia?
- What, if anything, would help you feel more supported?

Internet use. Person with dementia self-report, Carer self-report, Informant rating by carer Office for National Statistics, S. S. D. (2014). *Opinions and lifestyle survey, internet access module, January, February and March, 2014. [data collection]* UK Data Service. SN: 7572. <https://doi.org/http://doi.org/10.5255/UKDA-SN-7572-1>

The internet use questions are heavily adapted from the ONS Opinions and Lifestyles survey module on internet use. Some options were omitted from those questions and other alternatives were added. The questions were devised to investigate how participants uses the internet and whether this had changed since the coronavirus outbreak. The wording of the questions is:

- Do you have access to the internet at home?
- Do you use the internet?
- In what way do you use the internet?
- Has your internet use changed since the coronavirus outbreak started?
 - o Sending and/or receiving emails
 - o Telephoning over the internet (e.g., Skype, Facetime, Whatsapp)
 - o Social networking (e.g., using Facebook, Twitter, Instagram)
 - o Reading online news
 - o Playing or downloading entertainment (e.g., games, films, music, TV)
 - o Buying groceries
 - o Buying household or electronic items (e.g., books, toys, games, tablets, mobile phones, cameras)
 - o Organising home repair and maintenance services (e.g., plumbers, electricians, gardeners)
 - o Booking and organising travel services (e.g., holidays and flights)
 - o Making an appointment with a doctor or other health practitioners
 - o Selling goods or services (e.g., via websites such as eBay)
 - o Internet banking
 - o Visiting websites or online forums that offer peer support
 - o Visiting websites or online forums that offer practical advice for people with memory problems or similar difficulties
 - o Visiting non-profit organisations' websites (e.g., Alzheimer's Society, Age UK)
 - o Visiting health-related websites (e.g., NHS Choices, local NHS services)
 - o Other (please specify)
- How has your use of the internet changed since the coronavirus outbreak? (Prompt: more or less now? different sites? etc.)

This question was only answered by the carer:

- Do you help your relative/friend to use the internet, or does s/he use the internet independently?

Smartphone use. Person with dementia self-report.

Participants were asked whether they used a smartphone and if the usage had changes since the coronavirus outbreak. The wording of the questions is:

- Do you use a smartphone?
- In what ways do you use your smartphone?
- Has this changed since the coronavirus outbreak started?

Managing everyday life during the pandemic

Managing everyday life. Person with dementia self-report, Carer self-report, Informant rating by carer

Participants were asked about how the pandemic has affected them including positive and negative aspects, how they have coped and whether anything could have helped them better cope with the situation. The wording of the questions is:

- What have been the most difficult aspects of the coronavirus outbreak for you?
- Have there been any positive aspects or benefits of the coronavirus outbreak?
- What were/have been the positive aspects or benefits of the coronavirus outbreak?

- Overall, how do you feel the coronavirus outbreak has affected you? Have you received the coronavirus vaccine? (Note, the sub-question about the vaccine was added into the survey once the vaccine was available)
- Overall, how well do you feel you have coped since the coronavirus outbreak?
- How easy or difficult was it to keep yourself occupied at home during the coronavirus lockdown?
- Can you think of anything that would have made the situation more manageable and/or help you cope better?

Adjustment to dementia. Person with dementia self-report, Informant rating by carer Quinn, C., Morris, R. G., & Clare, L. (2018). Beliefs about dementia: development and validation of the representations and adjustment to dementia index (RADIX). *The American Journal of Geriatric Psychiatry*, 26(6), 680-689. <https://doi.org/10.1016/j.jagp.2018.02.004> These questions are based on the Representations and Adjustment to Dementia Index (RADIX). The questions focus on changes in ability to remember everyday things, remember recent events, concentrate, say what you want to say, plan ahead and make decisions. For each of those abilities, participants are asked whether this is better or worse than before the coronavirus outbreak. The wording of the questions is:

- Since the coronavirus outbreak, have you noticed any changes in your ability to remember everyday things?
- Is this better or worse than before the coronavirus outbreak?
- Since the coronavirus outbreak, have you noticed any changes in your ability to remember recent events?
- Is this better or worse than before the coronavirus outbreak?
- Since the coronavirus outbreak, have you noticed any changes in your ability to concentrate?
- Is this better or worse than before the coronavirus outbreak?
- Since the coronavirus outbreak, have you noticed any changes in your ability to say what you want to say?
- Is this better or worse than before the coronavirus outbreak?
- Since the coronavirus outbreak, have you noticed any changes in your ability to plan ahead?
- Is this better or worse than before the coronavirus outbreak?
- Since the coronavirus outbreak, have you noticed any changes in your ability to make decisions?
- Is this better or worse than before the coronavirus outbreak?
- This question is not part of the RADIX and was provided by members of the ALWAYS group:
- Since the coronavirus outbreak, do you feel you get confused more often?

Subjective cognition. Person with dementia self-report Opdebeeck, C., Yates, J. A., Kudlicka, A., & Martyr, A. (2019). What are subjective cognitive difficulties and do they matter? *Age and Ageing*, 48(1), 122-127. <https://doi.org/10.1093/ageing/afy148> This question was developed for a previous study conducted in the Research in Ageing and Cognitive Health team at the University of Exeter. The question is: Compared to other people your age, how would you describe your day-to-day memory?

Social networks/ relationships

Close relationships. Person with dementia self-report, Carer self-report

Bengtson, V. L., & Schrader, S. S. (1982). Parent-child relations. In D. J. Mangon & W. A. Peterson (Eds.), *Research instruments in social gerontology: Social roles and social participation* (Vol. 2, pp. 115-185). University of Minnesota Press.

Clare, L., Nelis, S. M., Whitaker, C. J., Martyr, A., Marková, I. S., Roth, I., Woods, R. T., & Morris, R. G. (2012). Marital relationship quality in early-stage dementia: perspectives from people with dementia and their spouses. *Alzheimer Disease & Associated Disorders*, 26(2), 148-158. <https://doi.org/10.1097/WAD.0b013e318221ba23>

Woods, R. T. (2009). Relationship quality and quality of life in dementia. 19th International Congress of Gerontology, Paris.

The Positive Affect Index assesses the extent of positive affect that the respondent has for another person, with five questions addressing communication quality, closeness, similarity of views on life, engagement in joint activities and overall relationship quality. The Positive Affect Index can be used to rate current relationship quality and rephrased to rate pre-illness relationship quality (Clare et al, 2012, Woods, 2009). The wording of the question is: Generally, how well do you and [Carer] get along together?

Where there was no carer taking part, the question was adapted. This was question was only included in the people with dementia survey and was instead worded to:

Thinking of the person closest to you, currently how well do you get along together? (If they have difficulty thinking of someone, they consider they are close to, you may need to ask things like "What about a neighbour that visits you? etc.)

Social networks. Person with dementia self-report, Carer self-report, Informant rating by carer

Lubben, J., & Gironde, M. (Eds.). (2003). *Centrality of social ties to the health and well-being of older adults*. Springer.

Lubben, J., Blozik, E., Gillmann, G., Iliffe, S., von Renteln Kruse, W., Beck, J. C., & Stuck, A. E. (2006). Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations. *The Gerontologist*, 46(4), 503-513. <https://doi.org/10.1093/geront/46.4.503>

The 6-item Lubben Social Network Scale is designed to gauge social isolation in older adults by measuring perceived social support received by family and friends. In INCLUDE, only two of these questions were asked: number of relatives and number of friends the participant sees/hears from. Both questions were followed up with whether the number of people had changed since the coronavirus outbreak, and what is different about it now. The wording of the questions is:

- Considering the people to whom you are related either by birth, marriage or adoption, how many relatives do you see or hear from at least once a month?
- Has this changed since the coronavirus outbreak began?
- What is different about it now?
- Considering all of your friends including those who live in your neighbourhood, how many friends do you see or hear from at least once a month?
- Has this changed since the coronavirus outbreak?
- What is different about it now?

Social network satisfaction. Person with dementia self-report, Carer self-report

Participants were asked about their satisfactions with the support they receive from family and friends. These questions were asked after the corresponding Lubben question. The wording of the questions is:

- How satisfied are you with the support you receive from family?
- How satisfied are you with the support you receive from friends?

Life space. Person with dementia self-report, Informant rating by carer

James, B. D., Boyle, P. A., Buchman, A. S., Barnes, L. L., & Bennett, D. A. (2011). Life space and risk of Alzheimer disease, mild cognitive impairment, and cognitive decline in old age. *The American Journal of Geriatric Psychiatry*, 19(11), 961-969.

<https://doi.org/10.1097/JGP.0b013e318211c219>

These questions were adapted from James et al and are designed to measure how mobile people with dementia are in their homes and local communities. The yes/no questions start by asking whether the participant has left his/her bedroom and gradually ask about places around the home, local area and beyond. The wording of the question is:

- During the past 3 days have you been to places outside your immediate town or community?
- During the past 3 days have you been to places outside your immediate area, but within your town or community?
- During the past 3 days have you been to places in your immediate area, beyond your own home or place of residence?
- During the past 3 days have you been to an area outside your home or place of residence, such as a garden, yard, driveway or parking space?
- 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?
- During the past 3 days have you been to other rooms of your home or place of residence besides the room where you sleep?

Additional life space questions. Person with dementia self-report, Informant rating by carer

Participants were asked if they have access to a garden/outside area, and about their use of public transport in general and since the coronavirus outbreak. These questions were only asked if the participant responded positively to having used public transport and/or whether they went into their garden. Carers were asked additional questions about whether the person with dementia feels safe using public transport, and what, if any, are the reasons for not using public transport. The wording of the questions is:

- Do you have a garden or outside area that you can spend time in?
- Do you use public transport, such as buses, trams or trains?
- Has your use of public transport changed since the coronavirus outbreak?

These questions were only answered by the carer:

- Why doesn't your relative/friend use public transport? (Only asked if response to earlier question was "no")
- How safe does s/he feel using public transport?

Resources and activities

Activity engagement. Person with dementia self-report, Informant rating by carer Valenzuela, M., Brayne, C., Sachdev, P., Wilcock, G., Matthews, F., & Medical Research Council Cognitive Function and Ageing Study. (2011). Cognitive lifestyle and long-term risk of dementia and survival after diagnosis in a multicenter population-based cohort. *American Journal of Epidemiology*, 173(9), 1004-1012. <https://doi.org/10.1093/aje/kwq476>
This question was adapted from the Cognitive Function and Ageing Study (CFAS), and asked about participation in different activities, groups and clubs. This was followed by asking if there was any contact when these activities stopped due to the coronavirus outbreak and whether any of them had started up again. Religious group was included as an option due to how often it was given as a response to “other group or organisation” response during IDEAL. The wording of the questions is:

- Which of these activities do you attend? Do you attend...
 - Political parties
 - Trade unions (including student unions)
 - Environmental groups
 - Tenants, residents' groups or neighbourhood watch
 - Evening classes
 - University of the Third Age (U3A)
 - Other adult learning
 - Arts, music or singing group
 - Memory cafe or group
 - Charity, voluntary or community group
 - Group for older people (e.g., lunch club)
 - Youth group (e.g., scouts/guides/youth club)
 - Women's Institute, Townswomen's Guild
 - Social club (Rotary, working men's club)
 - Sports club, gym, exercise/dance group
 - Religious group
 - Another group or organisation; please specify:
 - None
- When these stopped due to coronavirus, did anyone from these groups keep in contact with you during that time?
- How did they keep in contact with you? How frequently did they contact you? Did they keep you updated with changes?
- Have any of these started up again now? Which activities have started up again?

Well-being

Stressful life events. Informant rating by carer Holmes, T. H., & Rahe, R. H. (1967). The Social Readjustment Rating Scale. *Journal of Psychosomatic Research*, 11(2), 213-218. [https://doi.org/10.1016/0022-3999\(67\)90010-4](https://doi.org/10.1016/0022-3999(67)90010-4)
The Social Readjustment Rating Scale, known more commonly as the Holmes and Rahe Stress Scale, is a list of 49 stressful life events that have been linked to increased chances of becoming ill. In INCLUDE, an abbreviated version of the items containing 10 stressful life events was used. These are items that are most likely to be relevant to older people falling in

three general subheadings: bereavement, marital difficulties, and change in circumstances such as retirement and moving home. The wording of the question is:

- From this list we'd like you to indicate which of the following events your relative/friend has experienced in his/her life in the last 12 months?
 - Death of spouse or child
 - Death of a close family member (e.g., parent or sibling)
 - Death of a close friend
 - Divorce
 - Marital separation
 - 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
 - Other
 - None of the above

Well-being. Person with dementia self-report, Carer self-report, Informant rating by carer Bech, P. (2004). Measuring the dimension of psychological general well-being by the WHO-5. *Quality of Life Newsletter*, 32, 15-16.

The WHO-5 Well-Being Index covers positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interests (being interested in things). One question from the WHO-5 Well-Being Index was asked. The wording is: In the last two weeks, how much of the time have you felt cheerful and in good spirits?

Psychological well-being. Person with dementia self-report, Carer self-report <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/datasets/coronavirusandthesocialimpactsongreatbritaindata>

Participants were asked about whether they feel lonely, and the response scale was changed from the scaling used in IDEAL to fit with a similar question from the Office of National Statistics (ONS). : often, some of the time, occasionally, hardly ever, never. People with dementia were asked an additional question about whether they felt sad or depressed. The wording is: Do you feel lonely?

The Yale Single Question screen. Person with dementia self-report Mahoney, J., Drinka, T. J., Abler, R., Gunter-Hunt, G., Matthews, C., Gravenstein, S., & Carnes, M. (1994). Screening for depression: single question versus GDS. *Journal of the American Geriatrics Society*, 42(9), 1006-1008. <https://doi.org/10.1111/j.1532-5415.1994.tb06597.x>

The question is as follows: "Do you feel sad or depressed?" with the response in a yes/no format.

Optimism. Person with dementia self-report, Carer self-report Scheier, M. F., Carver, C. S., & Bridges, M. W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a reevaluation of the Life Orientation Test. *Journal of Personality and Social Psychology*, 67(6), 1063-1078. <https://doi.org/10.1037/0022-3514.67.6.1063>

The Life Orientation Test-Revised assesses individual differences in generalized optimism versus pessimism. One of the questions was included which asked about the participant's expectations of more good things happening to them than bad. The wording is: Overall, I expect more good things to happen to me than bad?

Experience of self. Person with dementia self-report

Clare, L., Martyr, A., Morris, R. G., & Tippet, L. J. (2020). Discontinuity in the subjective experience of self among people with mild-to-moderate dementia is associated with poorer psychological health: findings from the IDEAL cohort. *Journal of Alzheimer's Disease*, 77(1), 127-138. <https://doi.org/10.3233/JAD-200407>

Participants were asked about whether they feel that they are still the person they used to be. The wording is: I am still the same person as I have always been?

Carer questions

Caregiving competence. Carer self-report

Carer competence. Carer self-report

Robertson, S. M., Zarit, S. H., Duncan, L. G., Rovine, M. J., & Femia, E. E. (2007). Family caregivers' patterns of positive and negative affect. *Family Relations*, 56(1), 12-23.

<https://doi.org/10.1111/j.1741-3729.2007.00436.x>

The Caregiving Competence Scale is a 3-item measure designed to assess the extent to which carers of people with dementia feel that they are doing an adequate job as a carer. The Caregiving Competence Scale has a Cronbach alpha coefficient of .81. The wording of the questions is:

- How often do you feel confident that you are meeting the needs of your relative/friend?
- How often do you feel that you are doing a good job as a carer?
- How often do you feel competent in your ability to care for your relative/friend?

Caregiver coping. Carer self-report

McKee, K. J., Philp, I., Lamura, G., Prouskas, C., Oberg, B., Krevers, B., Spazzafumo, L., Bien, B., Parker, C., Nolan, M. R., Szczerbinska, K., & Cope Partnership. (2003). The COPE index--a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. *Aging & Mental Health*, 7(1), 39-52.

<https://doi.org/10.1080/1360786021000006956>

This is a single item global carer coping question "Do you feel you cope well as a carer?"

Restriction in caregiver's life. Carer self-report

Restriction in caregiver's life. Carer self-report

Balducci, C., Mnich, E., McKee, K. J., Lamura, G., Beckmann, A., Krevers, B., Wojszel, Z. B., Nolan, M., Prouskas, C., Bień, B., & Öberg, B. (2008). Negative impact and positive value in caregiving: validation of the COPE index in a six-country sample of carers. *The Gerontologist*, 48(3), 276-286. <https://doi.org/10.1093/geront/48.3.276>

The Modified Social Restriction Scale is a two-item questionnaire that asks how easy it is for the carer to find someone to look after the person with dementia they care for if they were unwell, and if they needed a break from caring. The wording of the questions is:

- If you were ill, is there anybody who would step in to help your relative/friend?
- If you needed a break from your caring role, is there someone who would look after your relative/friend for you?

Carer stress. Carer self-report

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, 30(5), 583-594.

<https://doi.org/10.1093/geront/30.5.583>

Role Captivity is a 3-item measure designed to assess the extent carers of people with dementia feel trapped in their role. The scale has a Cronbach alpha coefficient of .84. The wording of the questions is:

- How much do you wish you were free to lead a life of your own?
- How much do you feel trapped by your relative/friend's dementia?
- How much do you wish you could just run away?

Carers' assessment/registered carer. Carer self-report

These questions were asked to find out the carer had had a carers' assessment and when that occurred. We also asked if the carer was a registered carer. The wording of the questions is:

- Have you had a carer's assessment?
- When did your carer's assessment take place?
- Are you a registered carer?

Feedback

Furter information. Person with dementia self-report, Carer self-report

Participants were asked to provide any information that they think is relevant that had not been covered by the other questions. The wording is: Is there anything else you'd like to tell me about, that we haven't covered?

Cognitive tests

Cognition. Person with dementia test

Wong, A., Xiong, Y. Y., Kwan, P. W., Chan, A. Y., Lam, W. W., Wang, K., Chu, W. C., Nyenhuis, D. L., Nasreddine, Z., Wong, L. K., & Mok, V. C. (2009). The validity, reliability and clinical utility of the Hong Kong Montreal Cognitive Assessment (HK-MoCA) in patients with cerebral small vessel disease. *Dementia and Geriatric Cognitive Disorders*, 28(1), 81-87. <https://doi.org/10.1159/000232589>

Wong, A., Black, S. E., Yiu, S. Y. P., Au, L. W. C., Lau, A. Y. L., Soo, Y. O. Y., Chan, A. Y. Y., Leung, T. W. H., Wong, L. K. S., Kwok, T. C. Y., Cheung, T. C. K., Leung, K. T., Lam, B. Y. K., Kwan, J. S. K., & Mok, V. C. T. (2018). Converting MMSE to MoCA and MoCA 5-minute protocol in an educationally heterogeneous sample with stroke or transient ischemic attack. *International Journal of Geriatric Psychiatry*, 33(5), 729-734.

<https://doi.org/10.1002/gps.4846>

The Montreal Cognitive Assessment (MoCA) is a cognitive screening tool. For INCLUDE, a five-minute version was used as this could be administered remotely. We used a Chinese/Hong Kong variant of the 5-Minute MoCA as this had available data that permitted conversion to an estimated MMSE score (Wong, 2018). The main difference between the Chinese/Hong Kong version and the original 5-Minute MoCA is the scoring system, and that letter fluency was replaced by animal fluency as the Chinese language is character based so words do not start with letters. The 5-minute version of the MoCA comprises 4 subtests

examining 5 cognitive domains: attention, verbal learning and memory, executive functions/language, and orientation. Animal fluency was scored after the survey had been completed, this is why the question number for this variable is out of order from its position in the survey. The MoCA total has a maximum score of 30, where lower scores indicate higher cognitive impairment. The score range is 0-30.

- The attention domain comprises immediate recall of 5 words, where there is 1 point for each word correctly recalled in the first trial. (Maximum score: 5)
- Executive functions/language comprises a 1-minute verbal fluency task (animal fluency) where there is half a point for each correct output. (Maximum score: 9)
- Orientation is a 6-item date and geographic orientation task, where there is 1 point for each correct response. (Maximum score: 6)
- Memory relates to delayed recall and/or recognition of 5 words recited in the immediate recall subtest. There are 2 points for each of the words spontaneously recalled, and 1 point for each word recognised by cued recall or recognition but not spontaneously recalled. (Maximum score: 10)

Derived variables

Age. Person with dementia self-report, Carer self-report

The age group of each participant is included; this was calculated by subtracting the date of birth of the participant from the date of assessment and rounding the number down: Age group is broken up into five epochs: (1=<65, 2=65-69, 3=70-74, 4=75-79, 5=80+).

Location. Research rated.

<https://www.ons.gov.uk/methodology/geography/ukgeographies/eurostat>

Nomenclature of Territorial Units for Statistics (NUTS) level 1 classification have been used to describe the participant's location. This variable uses standardised wording for different regions of Great Britain; this includes Scotland and Wales as categories and breaks England into 9 statistical regions: East Midlands, East of England, London, North East, North West, South East, South West, West Midlands, Yorkshire and The Humber.

Education. Person with dementia self-report, carer self- report

Education has been grouped into four categories: No qualifications, School leaving certificate at age 16, School leaving certificate at age 18, University.

Social class

Office for National Statistics. (2010). *Standard occupational classification 2010. Volume 3. The national statistics socioeconomic classification: (Rebased on the SOC2010) User Manual*. Palgrave Macmillan.

The standard UK classification groups participants into: I (Professional), II (Managerial and technical), III-NM (Skilled non-manual), III-M (Skilled manual), IV (Partly skilled), V (Unskilled); also included in this variable are "Not applicable", "Missing" and "Armed forces".