UK Data Service Study Number 854293

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

Waves 1 to 3
List of measures

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Overview

This document can be used with UK Data Service Study Number 854293 PwD and Carer datasets to plan analyses and see which Waves contain desired measures. Table 1 can also be used with the T1to3 PwD List of variables and/or the T1to3 Carer List of variables to identify questions asked of both cohorts across multiple Waves. 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.

Carer CRFs were altered from Wave 2 so that CRF part 1 comprised questions only about the PwD, while CRF part 2 comprised questions only about the carer.

Table 1 in the Paid Carer column: S = self-rating; I = informant rating. There were two Paid Carers at Wave 2 and one at Wave 3, however to avoid potential re-identification of participants the Paid Carer datasets were not archived as part of SN 854293. The CRFs were archived for illustrative purposes only.

Table 1: List of measures in PwD and Carer CRFs at each Wave

Questionnaire Topic	Changes from baseline	PwD	Carer		Paid Carer (not at baseline)
			Informant rating	Self-rating	
Background information					
Demographics	Amended	1; 2; 3	1; 2; 3	1; 2; 3	S (Q1-13)
Education	PwD shortened, with screening question	1; 2; 3	Self-rating only	1; 2; 3	
Employment/job	Shortened	1; 2; 3	1; 2; 3	1; 2; 3	
Pets	Shortened	1; 2; 3	PwD only	PwD only	
Religious activity		1; 2; 3	Self-rating only	1; 2; 3	
Religious beliefs	PwD removed		Self-rating only	1; 2; 3	
Spirituality	Removed	1 only	1 only	1 only	
Health					
Subjective Health		1; 2; 3	Self-rating only	1; 2; 3	
Falls	Carer self-reporting removed	1; 2; 3	1; 2; 3	1 only	I (Q14)
Sensory Impairment		1; 2; 3	Self-rating only	1; 2; 3	
Neuropsychiatric Inventory Questionnaire (NPI-Q)		Carer only	1; 2; 3	Informant rating only	I (Q21-32)
Sleep	Shortened	1; 2; 3	1; 2; 3	Informant rating only	I (Q16-17)
General Practice Physical Activity Questionnaire (GPPAQ)		1; 2; 3	1; 2; 3	1; 2; 3	I (Q15)
Comorbidity/health conditions	Carer informant rating new from Wave 2; Carer responses only at Wave 2 and Wave 3 (unless no carer)	1; 2; 3	2; 3	1; 2; 3	I (Q18-20)
Health care services					
Client Service Receipt Inventory (CSRI)	Expanded; Carer responses only at Wave 2 and Wave 3 (unless no carer)	1; 2; 3	2; 3	Informant rating only	I (Q103-113)
Assistive technologies (CSRI)	Wave 3 only	3	3	Informant rating only	
Internet Use	Wave 3 only	3 only	Self-rating only	3 only	
Satisfaction with services	Carer new from Wave 2	1; 2; 3	Self-rating only	2; 3	
Named health professional	PwD removed; Carer expanded	1 only	1; 2; 3	Informant rating only	
Future care needs and planning	Wave 3 only	3 only	3 only	3 only	
Diet					
Taste/Smell		1; 2; 3	PwD only	PwD only	
Simplified Nutrition Appetite Questionnaire (SNAQ)	Shortened	1; 2; 3	1; 2; 3	Informant rating only	I (Q102)
Mini Nutritional Assessment		Carer only	1; 2; 3	Informant rating only	
Alcohol/smoking	Removed	1 only	Self-rating only	1 only	

Questionnaire Topic	Changes from baseline	PwD	Carer		Paid Carer (not at baseline)
			Informant rating	Self-rating	
Well-being					
Life Events Stress Test-Short		1; 2; 3	1; 2; 3	1; 2; 3	
Life Events open ended	New from Wave 2	2; 3	2; 3	2; 3	
Social comparison question	Removed	1 only	1 only	1 only	
Stigma		1; 2; 3	PwD only	PwD only	
Geriatric Depression Scale (GDS-10)		1; 2; 3	PwD only	PwD only	
Center for Epidemiologic Studies Depression Scale Revised (CESD-R)		Carer only	Self-rating only	1; 2; 3	
WHO-5 Well-Being Index		1; 2; 3	1; 2; 3	1; 2; 3	I (Q46-50)
Generalized Self-Efficacy Scale	Removed	1 only	Self-rating only	1 only	
Satisfaction with Life Scale		1; 2; 3	1; 2; 3	1; 2; 3	I (Q66-70)
Quality of life					
Quality of life in Alzheimer's Disease (QOL-AD)		1; 2; 3	1; 2; 3	Informant rating only	I (Q33-45)
Activity and Affect Indicators of QOL (AAIQOL) - Patient Activity Scale		1; 2; 3	1; 2; 3	Informant rating only	I (Q51-65)
Activity and Affect Indicators of QOL (AAIQOL) - Emotions scale		Carer only	1; 2; 3	Informant rating only	I (Q71-76)
EQ-5D-3L		1; 2; 3	1; 2; 3	1; 2; 3	
EQ-5D-3L -VAS	Removed	1 only	Self-rating only	1 only	
ONS Well-being questions	Wave 3 only	3 only	Self-rating only	3 only	
WHOQOL-BREF		Carer only	Self-rating only	1; 2; 3	
Social networks/relationships					
Lubben Social Network Scale-6		1; 2; 3	1; 2; 3	1; 2; 3	
Social satisfaction	Shortened	1; 2; 3	1; 2; 3	1; 2; 3	
Resource Generator-UK	Removed	1 only	Self-rating only	1 only	
Positive Affect Index – current		1; 2; 3	1; 2; 3	1; 2; 3	
Positive Affect Index – retrospective	Removed	1 only	Self-rating only	1 only	
Loneliness single item		1; 2; 3	Self-rating only	1; 2; 3	
Loneliness Scale	Not in Wave 2	1; 3	Self-rating only	1; 3	
Life space	New from Wave 2	2; 3	2; 3	Informant rating only	
Community					
Tenure/housing	Screening question added	1; 2; 3	1; 2; 3	1; 2; 3	
SES/Community ladders		1; 2; 3	Self-rating only	1; 2; 3	
Green or blue spaces		1; 2; 3	Self-rating only	1; 2; 3	
Dementia friendly community		Carer only	Self-rating only	1; 2; 3	
Social Capital	Shortened for Carers but PwD responses only at Wave 2 and Wave 3 (unless no PwD)	1; 2; 3	Self-rating only	1; 2; 3	

Questionnaire Topic	Changes from baseline	PwD	Carer		Paid Carer (not at baseline)
			Informant rating	Self-rating	
Resources & Activities					
CFAS-cognitive reserve	Shortened; Carer self-rating removed	1; 2; 3	1; 2; 3	1 only	
Cultural Capital (list of entertainments)	Carer removed	1; 2; 3	1 only	1 only	
Income	Expanded; Carer new from Wave 2 (carer only unless no carer)	1; 2; 3	2; 3	Informant rating only	
Sources of income	Carer new from Wave 2 (carer only unless no carer)	1; 2; 3	2; 3	Informant rating only	
Ageing					
Attitudes to ageing	Removed	1 only	PwD only	PwD only	
Subjective age		1; 2; 3	Self-rating only	1; 2; 3	
Functional ability					
Functional Activities Questionnaire		1; 2; 3	1; 2; 3	Informant rating only	I (Q77-87)
Select clothing appropriate for the weather	New from Wave 2	2; 3	2; 3	Informant rating only	I (Q88)
The Dependence Scale	Shortened for PwD	1; 2; 3	1; 2; 3	Informant rating only	I (Q89-101)
Awareness					
Representations and Adjustment to Dementia Index (RADIX)	Shortened for PwD; Removed Carer	1; 2; 3	1 only	Informant rating only	
Information/understanding of dementia	Removed	1 only	Self-rating only	1 only	
Open ended questions	Questions change for each Wave	1; 2; 3	Self-rating only	1; 2; 3	S (Q114-118)
Sense of self		1; 2; 3	PwD only	PwD only	
Subjective Memory	New from Wave 2	2; 3	PwD only	PwD only	
Dignity & respect	Shortened	1; 2; 3	1; 2; 3	Informant rating only	
Psychological					
Ryff Psychological Well-Being - Self-acceptance subscale		1; 2; 3	PwD only	PwD only	
Mini-IPIP	Removed	1 only	Self-rating only	1 only	
Self-esteem single item		1; 2; 3	Self-rating only	1; 2; 3	
Rosenberg Self-Esteem Scale	Removed	1 only	Self-rating only	1 only	
Decision-Making Involvement Scale		Carer only	1; 2; 3	Informant rating only	
Life Orientation Test	Shortened	1; 2; 3	Self-rating only	1; 2; 3	
Carer questions					
Caregiver coping - single item		Carer only	Self-rating only	1; 2; 3	
Carer stress - Role Captivity		Carer only	Self-rating only	1; 2; 3	
Left unsupervised	New from Wave 2	Carer only	Self-rating only	2; 3	
Modified Social Restriction Scale		Carer only	Self-rating only	1; 2; 3	
Caregiving Competence Scale		Carer only	Self-rating only	1; 2; 3	
Relative Stress Scale		Carer only	Self-rating only	1; 2; 3	

Questionnaire Topic	Changes from baseline	PwD	Carer		Paid Carer (not at baseline)
			Informant rating	Self-rating	
Carer questions continued					
Positive Aspects of Caregiving		Carer only	Self-rating only	1; 2; 3	
Caregiver coping - Management of Situation		Carer only	Self-rating only	1; 2; 3	
Caregiver coping - Management of Meaning		Carer only	Self-rating only	1; 2; 3	
Carer Medication Use	Removed	Carer only	Self-rating only	1 only	
Residential care questions					
Moving into residential care questions	Wave 3 only	Carer only	3 only	Informant rating only	
Study evaluation					
Feedback on the IDEAL study	Wave 3 only	3 only	Self-rating only	3 only	
Dementia staging					
Functional Assessment Staging	New variables from Wave 2 record justification for score and level of consciousness	1; 2; 3 Researcher ratings	PwD only	PwD only	
Global Deterioration Scale	New variables from Wave 2 record justification for score and level of consciousness	1; 2; 3 Researcher ratings	PwD only	PwD only	
Cognitive tests					
Mini-Mental State Examination	Slight change in data layout between Waves 1 and 2	1; 2; 3	PwD only	PwD only	
Addenbrooke's Cognitive Examination-III	Slight change in data layout between Waves 1 and 2	1; 2; 3	PwD only	PwD only	
Test for Severe Impairment	New from Wave 2	2; 3	PwD only	PwD only	

Appendix 1: Description of measures

Measures at Baseline

Background information

Demographics. Person with dementia - Relationship with carer, age, date of birth, gender, socio-economic status, marital status and if applicable length of marriage, country of birth, ethnic group, age started and left school, qualifications, main job, mobility, diagnosis, date of diagnosis, medication.

Demographics Carer - Relationship to the person with dementia, age, date of birth, gender, socio-economic status, marital status and if applicable length of marriage, country of birth, ethnic group, age started and left school, qualifications, main job, living arrangements and whether co-resident with person with dementia, hours/length of caring, other sources of help with providing care, support group involvement.

Pets. Person with dementia self-report
Connell, C.M., Janevic, M.R., Solway, E., & McLaughlin, S.J. (2007). Are pets a source of support or added burden for married couples facing dementia? *Journal of Applied Gerontology, 26*, 472-485. doi: 10.1177/0733464807305180
The pet questions in IDEAL were adapted from the Connell, Janevic, Solway and McLaughlin (2007) paper. We also included a question whether the person with dementia had no pets, one pet, or more than one pet and who mostly looks after the pet/pets.

Religiosity. Person with dementia self-report, carer self-report
Loewenthal, K.M., MacLeod, A.K., & Cinnirella, M. (2002). Are women more religious than men? Gender differences in religious activity among different religious groups in the UK. *Personality and Individual Differences, 32*, 133-139. doi: 10.1016/S0191-8869(01)00011-3
The religious questions comprises three items taken from Loewenthal, MacLeod and Cinnirella (2002): attendance, prayer and religious study. We ask a generic census question about which religion, if any, the participants associate themselves with. We also ask how important religion or being religious is to the person's life.

Spirituality. Person with dementia self-report, carer self-report
National Centre for Social Research. (2001). *Scottish Social Attitudes Survey, 2001*. Colchester, Essex: UK Data Archive. doi: 10.5255/UKDA-SN-4804-1
National Centre for Social Research. (2008). *British Social Attitudes Survey, 2008*. Colchester, Essex: UK Data Archive. doi: 10.5255/UKDA-SN-6390-1
King, M., Speck, P., & Thomas, A. (2001).The Royal Free Interview for Spiritual and Religious Beliefs: development and validation of a self-report version. *Psychological Medicine, 31*, 1015-1023. doi: 10.1017/S0033291701004160
The spirituality questions were taken from two UK surveys. The question "whether you attend religious services or not, would you say you are religious, spiritual, or, neither?" was taken from the Scottish Social Attitudes Survey, 2001. The question "Spiritually, what best describes you?" was taken from the British Social Attitudes Survey, 2008. The definition of spirituality was adapted from the definition used in the Royal Free Interview for Spiritual and Religious Beliefs (King, Speck & Thomas, 2001).

Health

Subjective health. Person with dementia self-report, carer self-report
Bowling, A. (2005). Just one question: if one question works, why ask several? *Journal of Epidemiology and Community Health, 59*, 342-345. doi: 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. Despite the subjective nature of this question, the answers received have been found to be a good predictor of people's future health care use. The question used in the IDEAL study is based on the current health item from the SF-36 questionnaire which 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.

Sensory impairment. Person with dementia self-report, carer self-report.
Two items were identified from the English Longitudinal Study of Ageing (ELSA), a single question about eyesight and a single question about hearing.

Falls. Person with dementia self-report, Informant rating by carer, carer self-report.
Two items were identified from the English Longitudinal Study of Ageing (ELSA); a question about how many falls over the last two years and a subsequent question about whether any of the falls, if applicable, required medical treatment.

Sleep. Person with dementia self-report, Informant rating by carer
Clare, L., Whitaker, C.J., Craik, F.I., Bialystok, E., Martyr, A., Martin-Forbes, P.A., Bastable, A.J., Pye, K.L., Quinn, C., Thomas, E.M., Gathercole, V.C., & Hindle, J.V. (2016). Bilingualism, executive control, and age at diagnosis among people with early-stage Alzheimer's disease in Wales. *Journal of Neuropsychology*, *10*, 163-185. doi: 10.1111/jnp.12061
These three questions were developed for the BANC study, a previous study conducted in the REACH team (Clare et al, 2016). The question "How well would you rate your sleep these days?" is loosely based on the final question in the Pittsburgh Sleep Quality Index: "During the past month, how would you rate your sleep quality overall?". Scores range from 1 = Very good to 5 = Very poor. Lower scores are therefore better.

Physical activity. Person with dementia self-report, Informant rating by carer, carer self-report
National Health Service. (2009). *The General Practice Physical Activity Questionnaire (GPPAQ): a screening tool to assess adult physical activity levels, within primary care*. London: Department of Health.
The General Practice Physical Activity Questionnaire (GPPAQ) is a seven item questionnaire that is used to assess current physical activity. It is widely used as a screening tool in GP surgeries to record the amount of physical activity people engage in.

Behaviour. Informant rating by carer and carer self-report
Kaufer, D.I., Cummings, J.L., Ketchel, P., Smith, V., MacMillan, A., Shelley, T., . . . DeKosky, S.T. (2000). Validation of the NPI-Q, a brief clinical form of the Neuropsychiatric Inventory. *The Journal of Neuropsychiatry and Clinical Neurosciences, 12*, 233-239. doi: 10.1176/appi.neuropsych.12.2.233
Morris, J.C., & National Alzheimer's Coordinating Center. (2008). NACC Uniform Data Set (UDS) Coding Guidebook for Initial Visit Packet. Seattle: National Institute on Aging, ADC Clinical Task Force, NACC, University of Washington.
The Neuropsychiatric Inventory Questionnaire addresses 12 neuropsychiatric domains: sleep, apathy, delusion, depression, anxiety, euphoria, agitation, eating/appetite, hallucination, disinhibition, irritability, and aberrant motor behaviour. There is a yes/no screening question for problems in each domain. Further questions rate the symptom severity of the person with dementia (the informant rating by carer component) and emotional distress to the carer (the carer self-report component). Higher scores indicate more symptoms/carer distress/severity of symptoms. The Neuropsychiatric Inventory Questionnaire provides a brief, reliable, informant-based assessment of neuropsychiatric symptoms and associated carer distress in dementia. This questionnaire is only completed by the carer. Wording of the items is taken from Morris & National Alzheimer's Coordinating Center (2008).

Co-morbidity. Person with dementia self-report, carer self-report
Charlson, M.E., Pompei, P., Ales, K.L., & MacKenzie, C.R. (1987). A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. *Journal of Chronic Diseases, 40*, 373-383. doi: 10.1016/0021-9681(87)90171-8
Charlson, M.E., Charlson, R.E., Peterson, J.C., Marinopoulos, S.S., Briggs, W.M., & Hollenberg, J.P. (2008). The Charlson comorbidity index is adapted to predict costs of chronic disease in primary care patients. *Journal of Clinical Epidemiology*, 61, 1234-1240. doi: 10.1016/j.jclinepi.2008.01.006
Nelis, S.M., Wu, Y.T., Matthews, F.E., Martyr, A., Quinn, C., Rippon, I., Rusted, J., Thom, J.M., Kopelman, M.D., Hindle, J.V., Jones, R.W., & Clare, L. (2019). The impact of comorbidity on the quality of life of people with dementia: findings from the IDEAL study. *Age and Aging*, *48*, 361-367. doi: 10.1093/ageing/afy155
The Charlson Co-morbidity Index (CCI) predicts the ten-year mortality for someone who may have a range of co-morbid conditions. The 2008 criteria includes more symptoms than were included in the original 1987 Index; all scores in IDEAL relate to the updated criteria, but if required a 1987 score can be computed as all symptoms included in the original 1987 Index are included in the 2008 revision. The CCI used in IDEAL will be administered to the person with dementia and carer together in a joint interview except where the person with dementia has no carer in which case it will be administered to the person with dementia only. The carer will also complete the questions about his/her own health. The IDEAL CCI also incorporates a yes/no question about whether s/he takes Warfarin, as presented in the updated Index (Charlson et al., 2008). There is also an opportunity to say whether the person has any other diagnosed health condition not listed in the Index. IDEAL has published data on the CCI, Nelis et al, (2019).

Health care services

Service utilisation. Person with dementia self-report, carer self-report
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). London: 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 has been created for the study. The IDEAL CSRI will be administered to the person with dementia and carer together in a joint interview except where the person with dementia has no carer in which case it will be administered to the person with dementia only.

Satisfaction with services. Person with dementia self-report, carer self-report
Morris, L.W., Morris, R.G., & Britton, P.G. (1989). Social support networks and formal support as factors influencing the psychological adjustment of spouse caregivers of dementia sufferers. *International Journal of Geriatric Psychiatry, 4*, 47-51. doi: 10.1002/gps.930040111
The satisfaction with services questionnaire contains two questions which were adapted from a single question in Morris, Morris and Britton (1989). The questions ask about satisfaction with formal support services, specifically health services and the amount of support the person with dementia receives. These two questions will be administered to the person with dementia and carer together at the end of CSRI in a joint interview except where the person with dementia has no carer in which case it will be administered to the person with dementia only.

Named health professional. Person with dementia self-report, Informant rating by carer
This question was designed for the study and asks whether there is a named health professional that the person with dementia or carer can contact at any time, such as a care coordinator, key worker or specialist nurse.

Diet

Taste/Smell. Person with dementia self-report
Heald, A.E., Pieper, C.F., & Schiffman, S.S. (1998). Taste and smell complaints in HIV-infected patients. *AIDS, 12*, 1667-1674. doi: 10.1097/00002030-199813000-00015
Two questions from the Taste and Smell Survey were adapted for use in IDEAL. The original questions were reworded so that they could be administered rather than self-completed as the original questionnaire was designed. "I have noticed a change in my sense of taste" was changed to "Over the past year have you noticed any changes in your sense of taste"; "I have noticed a change in my sense of smell" was changed to "Over the past year have you noticed any changes in your sense of smell".

Nutrition/diet. Person with dementia self-report
Wilson, M.M., Thomas, D.R., Rubenstein, L.Z., Chibnall, J.T., Anderson, S., Baxi, A., . . . Morley, J.E. (2005). Appetite assessment: simple appetite questionnaire predicts weight loss in community-dwelling adults and nursing home residents. *The American Journal of Clinical Nutrition*, *82*, 1074-1081. http://ajcn.nutrition.org/
The Simplified Nutritional Appetite Questionnaire (SNAQ) was developed for use in community-dwelling older people and residential care residents. It is a 4-item questionnaire asking about different aspects of appetite and eating such as how food tastes and how much does the participant normally eat. The carer will also be asked to provide a rating of the person with dementia for one item from SNAQ: "Would you say your relative's/friend's appetite is… 'very poor' to 'very good'".

Nutrition/diet. Informant rating by carer
Guigoz, Y., Vellas, B., & Garry, P.J. (1994). Mini Nutritional Assessment: a practical assessment tool for grading the nutritional state of elderly patients. *Facts and Research in Gerontology, 4*, 15-59.
Two items from the Mini Nutritional Assessment will be rated by the informant in the study. The first item will ask about food intake and the second will ask about weight loss.

Alcohol/smoking. Person with dementia self-report, Informant rating by carer
These questions were designed for the study. The alcohol questions are worded in such a way that an alcohol-unit-per-week calculation can be made.

Well-being

Stressful life events. Person with dementia self-report, Informant rating by carer, carer self-report
Holmes, T.H., & Rahe, R.H. (1967). The Social Readjustment Rating Scale. *Journal of Psychosomatic Research, 11*, 213-218. doi: 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 IDEAL we will be using an abbreviated version of the items containing 10 stressful life events 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.

Social comparison. Person with dementia self-report, Informant rating by carer, carer self-report
This question was designed for the study and asks "Do you think that compared to most other people your age, your overall situation is" with answers ranging from 'much worse' to 'much better'.

Stigma. Person with dementia self-report
Fife, B.L., & Wright, E.R. (2000). The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior, 41*, 50-67. doi: 10.2307/2676360
Burgener, S.C., & Berger, B. (2008). Measuring perceived stigma in persons with progressive neurological disease: Alzheimer's dementia and Parkinson's disease. *Dementia, 7*, 31-53. doi: 10.1177/1471301207085366
The Stigma Impact Scale is a 24-item questionnaire developed for people with HIV/AIDS. It contains four subscales and it has been adapted for use with people with dementia by Burgener and Berger (2008). In IDEAL we selected one item from each of the four subscales. The four stigma questions will only be administered if participants display some awareness of their dementia and they will be asked the questions following the Representations and Adjustment to Dementia Index (RADIX).

Mood. 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*, 858-865. doi: 10.1002/(SICI)1099-1166(199910)14:10<858::AID-GPS35>3.0.CO;2-8
Wu, Y.-T., Clare, L., Matthews, F.E., & on behalf of the Improving the experience of Dementia and Enhancing Active Life (IDEAL) study team. (2019). Relationship between depressive symptoms and capability to live well in people with dementia and their carers: results from the Improving the experience of Dementia and Enhancing Active Life (IDEAL) programme. *Aging & Mental Health*. doi: 10.1080/13607863.2019.1671316
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. It is easy to administer, needs no prior psychiatric knowledge and has been well validated in many environments. A score of 4 is used as a cutoff with scores of 0-3 indicates no depression, and a score of 4-10 indicates depression.

Mood. Carer self-report
Eaton, W. W., Smith, C., Ybarra, M., Muntaner, C., Tien, A. (2004). Center for Epidemiologic Studies Depression Scale: review and revision (CESD and CESD-R). In M.E. Maruish (Ed.). *The Use of Psychological Testing for Treatment Planning and Outcomes Assessment* (3rd Ed.), Volume 3: Instruments for Adults, pp. 363-377. Mahwah, NJ: Lawrence Erlbaum.
The Center for Epidemiologic Studies Depression Scale-Revised Short Form is a 20-item screening tool for depression. The scale is a widely-used tool to measure symptoms of depression in dementia caregiving research. Scores range from 0 to 60, with high scores indicating greater depressive symptoms.

Self-efficacy. Person with dementia self-report, carer self-report
Schwarzer, R., & Jerusalem, M. (1995). Generalized Self-Efficacy Scale. In J. Weinman, S. Wright & M. Johnston (Eds.), *Measures in health psychology: a user's portfolio. Causal and control beliefs* (pp. 35-37). Windsor, UK: NFER-NELSON.
Perceived self-efficacy can be regarded as a positive resistance resource factor. The 10-item Generalized Self-Efficacy Scale was created to assess a general sense of perceived self-efficacy with the aim of predicting coping with daily hassles as well as adaptation after experiencing all kinds of stressful life events. Responses are made on a 4-point scale. Responses to all 10 items are summed to yield the final composite score with a range from 10 to 40. Cronbach's alphas range from .76 to .90. Higher scores are better.

Well-being. Person with dementia self-report, Informant rating by carer, carer self-report
Bech, P. (2004). Measuring the dimensions of psychological general well-being by the WHO-5. *QoL 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). Each of the five items is rated on a 6-point Likert scale from 0 (at no time) to 5 (all the time). The raw score is calculated by totalling the five responses and scores can range from 0 to 25. A raw score below 13 indicates poor well-being. Raw scores can be transformed into a scale from 0 (worst possible well-being) to 100 (best possible well-being). The WHO-5 has good internal consistency and homogeneity and has been used with older populations.

Life satisfaction. Person with dementia self-report, Informant rating by carer, carer self-report
Diener, E., Emmons, R.A., Larsen, R.J., & Griffin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment, 49*, 71-75. doi: 10.1207/s15327752jpa4901_13
The Satisfaction with Life Scale is a 5-item instrument designed to measure global judgments of satisfaction with life. Respondents were asked to rate their agreement on a 7-point scale (strongly disagree - strongly agree) with statements on desire to change one's life and satisfaction with the past. Scores range from 5-35, with higher scores reflecting greater satisfaction with life. The measure has good internal consistency and high temporal reliability.

Quality of life

Quality of life. 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). Possible scores range from 13 to 52, with higher scores indicating greater QoL. Reliability for ratings by the person with dementia and Informant ratings by carers on the QOL-AD range from 0.83 to 0.90. The measure is suitable for people with Mini-Mental State Examination scores of 3 or above. It is recommended to use the 2000 reference when referring to the measure in publications, or to include both. The 2000 reference is identical to the 1999 reference but it is a chapter in an edited book, a scanned copy is included in the associated IDEAL description of measures EndNote library.

Health-related quality of life. Person with dementia self-report, Informant rating by carer, carer self-report
EuroQoL Group. EuroQoL: a new facility for the measurement of health-related quality of life. *Health Policy* 1990; 16: 199-208.
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. In the first section, 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. The second part of the measure is a visual analogue scale for self-rating of health-related quality of life ('your health state today'); the carer will not be asked to provide an informant rating of the visual analogue component of the EQ-5D.

Social participation. Person with dementia self-report, Informant rating by carer
Albert, S.M., Del Castillo-Castaneda, C., Sano, M., Jacobs, D.M., Marder, K., Bell, K., . . . Stern, Y. (1996). Quality of life in patients with Alzheimer's disease as reported by patient proxies. *Journal of the American Geriatrics Society, 44*, 1342-1347.
The Activity and Affect Indicators of QOL (AAIQOL) consists of two parts. The first part is the Patient Activity Scale which elicits the frequency of 15 activities judged to be within the capacity of individuals with dementia receiving supervision and aid in daily activities. The measure includes five activities conducted outside the home (going outside; going to movies or other forms of entertainment; going to church, or religious events; going shopping; going for a ride in a car) and 10 activities conducted mainly in the home (contact with a pet, getting together with family, talking to family or friends on the telephone, reading or being read to, listening to radio or watching television, exercising, playing games or puzzles, doing handicrafts, tending to plants or a garden, completing an additional unspecified task judged to be difficult). If the participant had the opportunity to do any of these 15 activities in the previous 2 weeks two sub-questions are asked concerning each activity; how frequently they performed it and also whether they enjoyed it. A summed activity score is calculated (number of activities performed that the person with dementia had the opportunity to perform). A higher score is better for all three scales. The standardised UK version is used in the study.

Positive emotions. Informant rating by carer
Albert, S.M., Del Castillo-Castaneda, C., Sano, M., Jacobs, D.M., Marder, K., Bell, K., . . . Stern, Y. (1996). Quality of life in patients with Alzheimer's disease as reported by patient proxies. *Journal of the American Geriatrics Society, 44*, 1342-1347.
The second part of the Activity and Affect Indicators of QOL (AAIQOL) the Emotions scale asks informants to report how often people with dementia express six affects over the previous 2 weeks. Each affect is specified by a clear set of facial and bodily indicators. The affects include both negative (anger, anxiety, depression) and positive (pleasure, interest, contentment) emotions. Informants specify whether each affect occurred "never/can't tell," "only once," "2 to 6 times per week," "1 or 2 times per day," or "several (3+) times per day." The standardised UK version will be used in the study.

Quality of life. Carer self-report
Skevington, S.M., Lotfy, M., & O'Connell, K.A. (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*, 299-310. doi: 10.1023/B:QURE.0000018486.91360.00
Clare, L., Wu, Y.-T., Quinn, C., Jones, I.R., Victor, C.R., Nelis, S.M., Martyr, A., Litherland, R., Pickett, J.A., Hindle, J.V., Jones, R.W., Knapp, M., Kopelman, M.D., Morris, R.G., Rusted, J.M., Thom, J.M., Lamont, R.A., Henderson, C., Rippon, I., Hillman, A., Matthews, F.E., & On behalf of the IDEAL study team. (2019). A comprehensive model of factors associated with capability to "live well" for family caregivers of people living with mild-to-moderate dementia: findings from the IDEAL study. *Alzheimer Disease and Associated Disorders*, *33*, 29-35. doi: 10.1097/WAD.0000000000000285
The WHOQOL-BREF instrument comprises 26 items, which measure the broad domains of: physical health, psychological health, social relationships, and environment. It also includes one facet on overall quality of life and general health. It provides a valid and reliable assessment of quality of life, for example, in large epidemiological studies and clinical trials where quality of life is of interest. This scale contains four subscales (Physical, Psychological, Social Relationship, Environment), there is no total score that combines all four subscales.

Social networks/relationships

Social networks. Person with dementia self-report, Informant rating by carer, carer self-report
Lubben, J., & Gironda, M. (Eds.). (2003). *Centrality of social ties to the health and well-being of older adults*. New York, NY: 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*, 503-513. doi: 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. The way the IDEAL Lubben was administered allows for researchers to calculate the total number of people that participants are in contact with as each question asks for the number of people participants see instead of using the original scoring system that groups the number of people together. The higher the score the more people participants are in contact with.

Social network satisfaction. Person with dementia self-report, Informant rating by carer, carer self-report
For the study we added four additional questions following the Lubben: how many different people have visited and telephoned over the last week, and how satisfied the person is with the support s/he receives from friends and family; these four questions are complementary to the Lubben questions and are not intended to be included into the score of Lubben.

Resource generator. Person with dementia self-report, carer self-report
Webber, M.P., & Huxley, P.J. (2007). Measuring access to social capital: the validity and reliability of the Resource Generator-UK and its association with common mental disorder. *Social Science & Medicine, 65*, 481-492. doi: 10.1016/j.socscimed.2007.03.030
The Resource Generator-UK was designed to measure an individual's access to social resources within his/her social network. It consists of three sections; the first section asks whether the participant knows anyone who possesses one or more 13 skills, the second section asks whether the participant knows anyone who s/he can ask for help and get help within one week in 14 different areas, and the third section asks whether the participant possesses each of the 13 skills themselves that were in the first section. There are four subscores for this measure; Expert Advice, Domestic Resources, Personal Skills, and Problem Solving Resources.

Relationship quality. Person with dementia self-report, carer self-report
Bengtson, V.L., & Schrader, S.S. (1982). Parent-child relationship. In D. J. Mangon & W. A. Peterson (Eds.), *Research Instruments in Social Gerontology* (pp. 115-185). Minneapolis: 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 and Associated Disorders*, *26*, 148-158. doi: 10.1097/WAD.0b013e318221ba23
Woods R.T. Relationship quality and quality of life in dementia. *19th International Congress of Gerontology*. Paris 2009.
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. The questions that we use in IDEAL were originally developed for use with parent child dyads; we have previously used these questions with PwD (Clare et al, 2012, Woods, 2009). The Positive Affect Index that we use in IDEAL are not strictly speaking part of the Positive Affect Index but five optional questions that can be used with the Positive Affect Index if required. We only use these optional questions in IDEAL and no questions from the main Positive Affect Index. Each of these optional questions contain responses rated on a 6-point scale; each question uses a different response key. Responses are summed for a total score. Possible scores range from 5-30, with higher scores indicating better relationship quality. Both current and retrospective versions will be used in the IDEAL study at T1, at subsequent time points only the current version is used.

Loneliness. Person with dementia self-report, carer self-report
De Jong Gierveld, J., & Tilburg, T.V. (2006). A 6-item scale for overall, emotional, and social loneliness confirmatory tests on survey data. *Research on Aging, 28*, 582-598. doi: 10.1177/0164027506289723
De Jong Gierveld, J., & Van Tilburg, T.G. (1999). Manual of the Loneliness Scale. Retrieved from Vrije Universiteit Amsterdam website: http://home.fsw.vu.nl/tg.van.tilburg/manual_loneliness_scale_1999.html
There are two components of loneliness commonly reported in the literature; emotional loneliness and social loneliness. The revised 6-item questionnaire covers both aspects of loneliness. The questionnaire has been used in a large sample of older people with acceptable reliability and validity coefficients. Higher scores indicate higher levels of loneliness. The authors recommend grouping the scores into not lonely (score of 0-1), moderately lonely (scores of 2-4) and severely lonely (scores of 5-6). This scale is included at T1 and T3 only.

Community

Tenure. Person with dementia self-report, Informant rating by carer, carer self-report
Office for National Statistics. (2011). *2011 Census*. Titchfield: Office for National Statistics.
Cardiff Research Centre. (2006). *Welsh Housing Quality Survey*. Cardiff: Cardiff Research Centre.
Welsh Government. (2013). *National Survey for Wales, 2012-2013*. Cardiff: Welsh Government. doi: 10.5255/UKDA-SN-7320-1
Centre for Longitudinal Studies. (2008). *Millennium Cohort Study: Fourth Survey*. London: University of London.
The tenure questions were adapted from five main sources; the CSRI (Q72-73), the National Survey for Wales (Q74), the Millennium Cohort Study (Q76), the 2011 UK Census (Q77) and the Welsh Housing Quality Survey (Q78). We have also included specific response keys that are likely to be more relevant for people with dementia, such as living in a care home etc.

SES ladders. Person with dementia self-report, carer self-report
Adler, N.E., Epel, E.S., Castellazzo, G., & Ickovics, J.R. (2000). Relationship of subjective and objective social status with psychological and physiological functioning: preliminary data in healthy white women. *Health Psychology, 19*, 586-592. doi: 10.1037/0278-6133.19.6.586
The MacArthur Scale of Subjective Socio-economic Status (SES) was developed to capture the common sense of social status across the SES indicators. In an easy pictorial format, it presents a "social ladder" and asks individuals to place an "X" on the rung on which they feel they stand. There are two versions of the ladder, one linked to traditional SES indicators (SES ladder) and the second linked to standing in one's community (community ladder). The difference between these two ladders may be of particular interest in poorer communities in which individuals may not be high on the SES ladder in terms of income, occupation, or education, but may have high standing within their social groups such as a religious or local community. Both SES and community ladder are included in IDEAL.

Green/blue spaces. Person with dementia self-report, carer self-report
Welsh Government. (2013). *National Survey for Wales, 2012-2013*. Cardiff: Welsh Government. doi: 10.5255/UKDA-SN-7320-1
This question, as used in IDEAL, was adapted from a simple 'yes' or 'no' question that was included in the National Survey for Wales. We have amended it so that each green or blue space has a tick box; this will provide the number and the quality of any green or blue spaces that participants live close to. At T2 and T3 this question was only asked if the participant had moved to a new home.

Dementia friendly community. Carer self-report
These two questions were designed for the study based on the new Alzheimer's Society initiative. Examples were taken from: http://www.alzheimers.org.uk/buildingdfcs.

Social capital including neighbourhood, civic engagement, local trust and reciprocity. Person with dementia self-report, carer self-report
Office for National Statistics. (2008). *Harmonised concepts and questions for social data sources, secondary standards. Social capital*. Titchfield, UK: Office for National Statistics.
Yu, G., Renton, A., Schmidt, E., Tobi, P., Bertotti, M., Watts, P., & Lais, S. (2011). A multilevel analysis of the association between social networks and support on leisure time physical activity: evidence from 40 disadvantaged areas in London. *Health & Place, 17*, 1023-1029. doi: 10.1016/j.healthplace.2011.07.002
The Office for National Statistics recommends a short list of core measures for each dimension of social capital. The measure collects data on issues relating to

- Problems in the neighbourhood (Views about the area) (7 items)
- Participation in local issues (Civic participation) (1 item)
- Unpaid help to groups (Social participation) (1 item)
- Reciprocity and trust (1 item)
- Contacts with friends, relatives and neighbours (Social networks and support) (5 items).

This allows comparisons to be made between different studies of social capital and corresponding national indicators. For IDEAL we will be using the CORE item set plus additional items from the recommended questions that concern social networks. We will also be using the scoring system employed by Yu et al., (2011) to score the social networks and social support sub-domain.

Resources & Activities

Cognitive reserve. Person with dementia self-report, Informant rating by carer, carer self-report
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*, 1004-1012. doi: 10.1093/aje/kwq476
The Cognitive Lifestyle Score consists of questions from the Cognitive Function and Ageing Study (CFAS) that were concerned with educational level, occupational complexity and social engagement. We have added additional questions from CFAS2 that focus on leisure activities which have a strong cognitive aspect such as doing puzzles, reading a newspaper etc. Some of the employment questions in the IDEAL background questions are those used in CFAS and these are necessary to calculate the Cognitive Lifestyle Score.

Cultural capital. Person with dementia self-report, Informant rating by carer, carer self-report
Thomson, K. (2004). *Cultural capital and social exclusion survey: technical report*. London: National Centre for Social Research.
These questions are interested in the engagement of social activities of people. There are 13 questions asking about how often people go to pubs, nightclubs, rock concerts, museums etc.

Income. Person with dementia self-report, carer self-report
Items will be taken from the Health Survey for England, 2012.
Bridges, S., Doyle, M., Fuller, E., Knott, C., Mindell, J., Moody, A., . . . Whalley, R. (2013). *Health Survey for England, 2012. Volume 2: Methods and Documentation*. London: Health and Social Care Information Centre.
The IDEAL income questions were adapted from the Health Survey for England and ask about current sources of income, including benefits, such as disability living allowance and pensions as well asking for a gross income figure. The IDEAL income questions will be administered to the person with dementia and carer together in a joint interview except where the person with dementia has no carer in which case it will be administered to the person with dementia only.

Ageing

Attitudes to ageing. Person with dementia self-report
Lawton, M.P. (1975). The Philadelphia Geriatric Center Morale Scale: a revision. *Journal of Gerontology, 30*, 85-89. doi: 10.1093/geronj/30.1.85
The Attitude Toward Own Aging questionnaire included in IDEAL is a subscale from the Philadelphia Geriatric Center Morale Scale (PGCMS). It contains five questions four of which are answered with either 'yes' or 'no' (the other question is answered with either 'better' or 'worse'). The items relate to the person's attitude toward the aging process and were designed to capture the individual's perception of the changes taking place in his or her life.

Subjective age. Person with dementia self-report, carer self-report
This single question "How old do you feel at the moment?" was developed for the BANC study and was designed to provide a rating of subjective ageing of older people.
Should be used to calculate the discrepancy between subjective age and chronological age as the (Age discrepancy = subjective age − chronological age). Anna Kleinspehn-Ammerlahn, Dana Kotter-Grühn, Jacqui Smith; Self-Perceptions of Aging: Do Subjective Age and Satisfaction With Aging Change During Old Age?, The Journals of Gerontology: Series B, Volume 63, Issue 6, 1 November 2008, Pages P377–P385, doi:10.1093/geronb/63.6.P377

Functional ability

Functioning. Person with dementia self-report, Informant rating by carer
Pfeffer, R.I. et al. (1982). Measurement of functional activities in older adults in the community. *Journal of Gerontology*, 37, 323-329. doi: 10.1093/geronj/37.3.323
Martyr, A., Clare, L., Nelis, S.M., Marková, I.S., Roth, I., Woods, R.T., . . . Morris, R.G. (2012). Verbal fluency and awareness of functional deficits in early-stage dementia. *The Clinical Neuropsychologist, 26*, 501-519. doi: 10.1080/13854046.2012.665482
Martyr, A., Nelis, S.M., Quinn, C., Rusted, J.M., Morris, R.G., Clare, L., & on behalf of the Ideal programme team. (2019). The relationship between perceived functional difficulties and the ability to live well with mild-to-moderate dementia: Findings from the IDEAL programme. *International Journal of Geriatric Psychiatry*, *34*, 1251-1261. doi: 10.1002/gps.5128
The 11-item amended version of the Functional Activities Questionnaire assesses the current functional ability of the person with dementia. The questionnaire covers instrumental activities of daily living such as shopping, keeping financial records and keeping track of current events. An additional question was added to address ability to use the telephone appropriately, see Martyr et al, (2012). Total scores range from 0-33 with higher scores reflecting poorer functional ability. The questionnaire has high reported correlations with other instruments assessing everyday functioning. The questionnaire has excellent inter-rater reliability 0.97 and has been widely-used in studies of people with dementia. IDEAL data for this measure has been published in Martyr et al, 2019.

Dependence. Person with dementia self-report, Informant rating by carer
Brickman, A.M., Riba, A., Bell, K., Marder, K., Albert, M., Brandt, J., & Stern, Y. (2002). Longitudinal assessment of patient dependence in Alzheimer disease. *Archives of Neurology, 59*, 1304. doi: 10.1001/archneur.59.8.1304
Stern, Y., Albert, S.M., Sano, M., Richards, M., Miller, L., Folstein, M., Albert, M., Bylsma, F.W., & Lafleche, G. (1994). Assessing patient dependence in Alzheimer's disease. *Journal of Gerontology*, *49*, M216-222. doi: 10.1093/geronj/49.5.m216
The Dependence Scale is a 13-item questionnaire completed by the primary caregiver and measures the amount of assistance needed by the person with dementia. Dependence Scale items require yes/no responses to questions such as: 'Does the person with dementia need reminders or advice to manage chores, shop, cook, play games, or handle money?' and 'Does the person with dementia need to be escorted when outside?' The scale ranges from zero, meaning not dependent at all, to 15, which would indicate full dependence. There is also a Dependence Level score (Stern et al, 1994). In the IDEAL study a slightly adapted version of the Dependence Scale will be self-completed by the person with dementia since a third of the sample are expected to have no available carer.

Awareness

Adjustment to Dementia. Person with dementia self-report, carer self-report
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*, 680-689. doi: 10.1016/j.jagp.2018.02.004
Quinn, C., Jones, I.R., Martyr, A., Nelis, S.M., Morris, R.G., Clare, L., & On behalf of the IDEAL study team. (2019). Caregivers' beliefs about dementia: findings from the IDEAL study. *Psychology and Health*, *34*, 1214-1230. doi: 10.1080/08870446.2019.1597098
Quinn, C., Jones, I.R., & Clare, L. (2017). Illness representations in caregivers of people with dementia. *Aging & Mental Health*, *21*, 553-561. doi: 10.1080/13607863.2015.1128882
The Representations and Adjustment to Dementia Index (RADIX) has been developed especially for the study (Quinn et al, 2018) and is based on earlier work around illness representations (Quinn et al., 2017). The RADIX questionnaire assess the way in which the condition is represented and, for people with dementia, the adjustment style adopted. The RADIX incorporates two elements, firstly an evaluation of dementia representations for use with people with dementia and secondly an evaluation of adjustment styles in people with dementia and carers. The RADIX was only administered if participants display some awareness of their dementia by answering yes to one or more of the RADIX screening questions which ask about recognising difficulties with memory, thinking, behaviour etc. A shorter, informant-rated version of the RADIX was included in the Carer CRF, it was described in Quinn et al., (2019). The published and validated version of the RADIX does not contain all the questions that appear in the datasets.

Information/understanding of dementia. Person with dementia self-report, carer self-report
These questions were designed for the study and for the person with dementia they will only be asked if s/he displays some awareness of his/her dementia during the initial RADIX questions.

Open-ended questions. Person with dementia self-report, Informant rating by carer
These questions were designed for the study. Some were added at the suggestion of the consultation with the ALWAYS group; an advisory group set-up for IDEAL by the Alzheimer's Society and Innovations in Dementia.

Sense of self. Person with dementia self-report
These three questions were designed for the study and ask whether the participant feels s/he is still the same person that s/he used to be.

Dignity and respect. Person with dementia self-report, Informant rating by carer
These four questions were designed for the study and ask about how the participant feels s/he has been treated by family, friends and care staff.

Psychological

Psychological traits. Person with dementia self-report
Ryff, C.D., & Keyes, C.L.M. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology, 69*, 719-727. doi: 10.1037/0022-3514.69.4.719
The Ryff Scales of Psychological Well-Being - self-acceptance subscale. The full Psychological Well-Being scale contains six subscales; Autonomy, Environmental Mastery, Personal Growth, Positive Relations with Others, Purpose in Life and Self-Acceptance. In IDEAL we are using the 7-item self-acceptance subscale that was part of the 43-item questionnaire used in the ELSA.

Personality. Person with dementia self-report, carer self-report
Donnellan, M.B., Oswald, F.L., Baird, B.M., & Lucas, R.E. (2006). The mini-IPIP scales: tiny-yet-effective measures of the Big Five factors of personality. *Psychological Assessment, 18*, 192-203.
The Mini-IPIP is a short 20-item measure of the Big Five personality traits (Extraversion, Agreeableness, Conscientiousness, Neuroticism, and Intellect/Imagination). The measure has consistent and acceptable internal consistencies and test-retest correlations. The Mini-IPIP scales showed a comparable pattern of convergent, discriminant, and criterion-related validity with other Big Five measures.

Self-esteem. Person with dementia self-report, carer self-report
Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.
The Rosenberg Self-Esteem Scale is a 10-item self-report measure of global self-esteem consisting of 10 statements related to overall feelings of self-worth or self-acceptance. The items are answered on a four-point scale ranging from 'strongly agree' to 'strongly disagree'. A higher score is associated with greater self-esteem. The scale has also been found to be reliable in assessing self-esteem in older populations.

Self-esteem. Person with dementia self-report, carer self-report
Robins, R.W., Hendin, H.M., & Trzesniewski, K.H. (2001). Measuring global self-esteem: construct validation of a single-item measure and the Rosenberg self-esteem scale. *Personality and Social Psychology Bulletin, 27*, 151-161. doi: 10.1177/0146167201272002
This single-item self-esteem question "I have high self-esteem" has been found to correlate highly with the Rosenberg Self-Esteem Scale. As dementia severity increases and people have difficulty with the longer version this single-item question will be used exclusively. The authors of this single-item self-esteem question have used various response keys, in IDEAL we used 'strongly agree' to 'strongly disagree' to be consistent with the Rosenberg Self-Esteem Scale.

Decision making. Informant rating by carer
Menne, H.L., Tucke, S.S., Whitlatch, C.J., & Feinberg, L.F. (2008). Decision-making involvement scale for individuals with dementia and family caregivers. *American Journal of Alzheimer's Disease and Other Dementias, 23*, 23-29. doi: 10.1177/1533317507308312
Most decision-making research focuses on medical treatment such as when to move into a care home. The Decision-Making Involvement Scale was designed to ask about more mundane everyday decision-making. The questionnaire contains 15 items and asks about things such as how involved the person with dementia is about where to spend his/her money, how involved the person with dementia is about having a pet etc.

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*, 1063-1078. doi: 10.1037/0022-3514.67.6.1063
The Life Orientation Test-Revised assesses individual differences in generalized optimism versus pessimism. Respondents rate each item on a 4-point scale: 0 to 4. The measure has demonstrated good internal consistency and stability over time. Higher levels of optimism have been related prospectively to better subjective well-being in times of adversity or difficulty. The original Life Orientation Test has examined pessimism and caring outcomes including those caring for people with dementia. The 10-item Life Orientation Test-Revised contains 4 filler questions; these filler questions have been removed from the version used in IDEAL.

Carer questions

Caregiver coping. Carer self-report
McKee, K.J., Philp, I., Lamura, G., Prouskas, C., Oberg, B., Krevers, B., . . . Partnership, C. (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*, 39-52. doi: 10.1080/1360786021000006956
This is a single item global carer coping question "Do you think you cope well as a carer?"

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 Gerontologis*t, 30, 583-594. doi: 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 total scores range from 0 to 15, with higher scores indicating more role captivity. The scale has a Cronbach alpha coefficient of .84.

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., Bien, B., & Oberg, B. (2008). Negative impact and positive value in caregiving: validation of the COPE index in a six-country sample of carers. *The Gerontologist*, 48, 276-286. doi: 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 s/he cares for if s/he was unwell, and if s/he needed a break from caring.

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*, 12-23. doi: 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 total scores range from 0 to 15, with higher scores indicating greater competence. The Caregiving Competence Scale has a Cronbach alpha coefficient of .81.

Carer stress. Carer self-report
Greene, J., Smith, R., Gardiner, M., & Timbury, G. (1982). Measuring behavioural disturbance of elderly demented patients in the community and its effects on relatives: a factor analytic study. *Age and Ageing, 11*, 121-126. doi: 10.1093/ageing/11.2.121
The Relative Stress Scale is a 15-item self-report measure designed to assess the degree of distress and social upset experienced by a relative as the result of caring for a person with physical and/or behavioural difficulties. Each item is assessed using a scale from 0 to 4 (never, rarely, sometimes, frequent, always), with higher scores indicating more severe stress. The measure contains three subscales; personal distress in relation to the elderly relative, life upset as a result of caregiving, and negative feelings toward the elderly relative.

Carer stress. Carer self-report
Tarlow, B.J., Wisniewski, S.R., Belle, S.H., Rubert, M., Ory, M.G., & Gallagher-Thompson, D. (2004). Positive Aspects of Caregiving contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging, 26*, 429-453. doi: 10.1177/0164027504264493
The Positive Aspects of Caregiving is a nine-item questionnaire that investigates positive aspects of being a carer such as whether proving help made the carer feel useful.

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 Gerontologis*t, 30, 583-594. doi: 10.1093/geront/30.5.583
Management of Situation is a 4-item measure designed to assess the extent carers of people with dementia feel that they have lost aspects of their personality because of caring. Each item is assessed using a scale from 0 to 3 (never, once in a while, fairly often, very often).

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 Gerontologis*t, 30, 583-594. doi: 10.1093/geront/30.5.583
Management of Meaning is a 9-item measure designed to assess the extent carers of people with dementia feel that they have lost aspects of their personality because of caring. Each item is assessed using a scale from 0 to 3 (never, once in a while, fairly often, very often).

Dementia staging

Dementia severity. Researcher judgement rating
Reisberg, B. (1988). Functional Assessment Staging (FAST). *Psychopharmacology Bulletin*, *24*, 653-659.
Sclan, S.G., & Reisberg, B. (1992). Functional assessment staging (FAST) in Alzheimer's disease: reliability, validity, and ordinality. *International Psychogeriatrics, 4 Suppl 1*, 55-69. doi: 10.1017/S1041610292001157
The Functional Assessment Staging (FAST) is a widely-used brief system for categorising severity of impairment in people with dementia. The FAST presents the progression of Alzheimer's disease in seven stages from normal (stage 1) to very severe dementia (stage 7). Functioning at each stage is broadly described, and some stages are subdivided, with sub-classifications reflecting progressive increases in severity within the broad classification. The FAST is mostly concerned with functional decline over time.

Dementia severity. Researcher judgement rating
Reisberg, B., Ferris, S. H., de Leon, M. J., Crook, T. (1982). The Global Deterioration Scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, *139*, 1136-1139.
The Global Deterioration Scale comprises of clinical descriptions of seven major clinically distinguishable stages of dementia, ranging from normal cognition to very severe dementia. The Global Deterioration Scale is related to the FAST staging system. The Global Deterioration Scale is mostly concerned with cognitive decline over time.

Cognitive tests

Cognition. Person with dementia test
Folstein, M.F., Folstein, S.E., & McHugh, P.R. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research, 12*, 189-198. doi: 10.1016/0022-3956(75)90026-6
The MMSE is a very widely-used screening test of cognition. A score of 15 or above will be used as the main inclusion criterion of the IDEAL study. We will be using a UK-standardised version of the MMSE in IDEAL.

Cognition. Person with dementia test
Hsieh, S., Schubert, S., Hoon, C., Mioshi, E., & Hodges, J.R. (2013). Validation of the Addenbrooke's Cognitive Examination III in frontotemporal dementia and Alzheimer's disease. *Dementia and Geriatric Cognitive Disorders*, *36*, 242-250. doi: 10.1159/000351671
The Addenbrooke's Cognitive Examination-III (ACE-III) is a brief cognitive test that assesses five cognitive domains: attention, memory, verbal fluency, language and visuospatial abilities. The total score is 100 with higher scores indicating better cognitive functioning. This test cannot meaningfully be completed by people with severe dementia, and in these cases the Test for Severe Impairment will be administered instead. Research staff will be trained in how to identify level of severity and apply the appropriate test.

Measures from Wave 2

Cognition. Person with dementia test
Albert, M., & Cohen, C. (1992). The Test for Severe Impairment: an instrument for the assessment of patients with severe cognitive dysfunction. *Journal of the American Geriatrics Society, 40*, 449-453. doi: 10.1111/j.1532-5415.1992.tb02009.x
The Test for Severe Impairment is a valid and reliable 24-item cognitive test, designed to be non-threatening, appealing, easily administered, and time efficient (it takes 10 minutes to administer), which uses small readily available objects. It tests a broad range of cognitive functions and was designed for use in people whose MMSE score is less than 10. The level of difficulty of the test is such that most people should be able to score on it unless they are in the end stages of dementia. This test will replace the ACE-III for people with severe dementia (MMSE 0-9) at time points 2 and 3 of IDEAL.

Subjective memory. Person with dementia self-report
This question was developed for a previous Masters study conducted in the REACH team. The question is: Compared to other people your age how would you describe your day-to-day memory? And the responses match the subjective health question which was itself adapted from the SF-36 scoring system which adds an additional response at the upper end of the scale; i.e. excellent, very good, good, average, poor, or very poor.

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*, 961–969. doi: 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.

Do you need help selecting clothing for yourself that is appropriate for the weather? Person with dementia self-report, Informant rating by carer
This question was added to the CRFs at the request of the researchers help researchers make a FAST judgement. It is not intended to be used in analyses.

Screening questions. Person with dementia self-report, Informant rating by carer, carer self-report
A number of screening questions have been added to help navigate the CRFs for researchers and carers. These screening questions have been added so that sections that are not applicable can be skipped more easily, i.e. where education, housing etc. has not changed between time points.

Open ended questions. Person with dementia self-report, Informant rating by carer, carer self-report
A few open-ended questions have been retained for T2 but most were new at T2. In addition a free text section was added to the life events question to capture additional stressful life events not covered in the main question. A free text option was added to the GDS and FAST so that researchers could give a brief justification for the score that they gave.

Named health professional. Informant rating by carer
An additional question was added to this section which asks about the number of times a named health professional has visited over the last 12 months.

PwD left unsupervised. Informant rating by carer
A new question was developed for the study asking the Carer whether the person with dementia they care for can be left unsupervised, and if so for how long in hours can the person be left supervised in one day.

CSRI. Person with dementia self-report, Informant rating by carer
Two questions concerning visits to the dentist and the optician were added to the "Community health and care" subsection of the CSRI. The major difference at T2 from T1 is at this time point the CSRI about the person with dementia is completed by the carer only, except where there is no carer in the study in which case it is administered to the PwD by the researcher.

Co-morbidity. Person with dementia self-report, Informant rating by carer, carer self-report
The Charlson Co-morbidity Index is administered differently at T2 compared to T1. The major difference is at this time point the Charlson Co-morbidity Index about the person with dementia is completed by the carer only, except where there is no carer in the study in which case it is administered to the PwD by the researcher.

Measures from Wave 3

Assistive technologies (CSRI). Person with dementia self-report, Informant rating by carer
Knapp, M., Barlow, J., Comas-Herrera, A., Damant, J., Freddolino, P.P., Hamblin, K., Hu, B., Lorenz, K., Perkins, M., & Rehill, A. (2015). The case for investment in technology to manage the global costs of dementia. London: Policy Innovation Research Unit, Personal Social Services Research Unit at the London School of Economics and Political Science.
The literature on assistive technologies in dementia as summarised in the PIRU report was considered in devising the assistive technologies questions. These questions are very loosely based on the technology functions listed on p. 33-34 of the PIRU report but are essentially created for the study. They are part of the CSRI so their primary aim is to gather costing information. They can also be used to investigate the number and variety of assistive technologies used by PwD.

Internet use. Informant rating by carer
Office for National Statistics, Social Survey Division. (2014). Opinions and Lifestyle Survey, Internet Access Module, January, February and March, 2014. [data collection]. UK Data Service. SN: 7572, 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 internet is used to assist caring for PwD.

Loneliness Scale. Person with dementia self-report, carer self-report
De Jong Gierveld, J., & Tilburg, T.V. (2006). A 6-item scale for overall, emotional, and social loneliness confirmatory tests on survey data. Research on Aging, 28, 582-598. doi: 10.1177/0164027506289723
This was included at T1 and reinserted into the T3 CRFs. See T1 Description of measures document for details of measure. There was no change to the wording of the questions between time points.

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]. Office for National Statistics, Social Survey Division, [original data producer(s)]. Office for National Statistics, Social Survey Division. SN: 7146, http://doi.org/10.5255/UKDA-SN-7146-1.
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These two 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 two questions that we included are usually presented with two additional questions that we decided not to include (Overall, how happy did you feel yesterday? Overall, how anxious did you feel yesterday?).
Note, there is an error in the Carer CRFs (Q186-187); the number 2 was inadvertently not included in the scale so adjustments may need to be used when looking at these questions for carers.

Future care needs and planning. Person with dementia self-report, Informant rating by carer
Fox, D., Holder, J., & Netten, A. Personal social services survey of adult carers in England –2009-10: Survey Development Project: Technical report. September, 2010. PSSRU Discussion Paper 2643. University of Kent. Available at: http://www.pssru.ac.uk/pdf/dp2643_2.pdf
The first question in the future care needs section was heavily adapted from Fox et al., 2010. However, it was reworded so much and did not used the same responses as in the original that it is essentially study specific. The other questions in this section are entirely study specific and investigate which, if any, advanced care planning services have been used.

Residential care questions

Moving into residential care questions. Informant rating by carer
The questions in this section are study specific are only completed by the carer if the PwD is living in residential care. They were designed to gain an understanding of the decision making process of moving the PwD into residential care.

Study evaluation

Taking part in IDEAL questions. Person with dementia self-report, carer self-report
The questions in this section are study specific. They were created for the study to gain an understanding of how PwD and carers felt about taking part in IDEAL as an evaluative exercise.

Derived variables

Location. Researcher rated
https://en.wikipedia.org/wiki/NUTS_statistical_regions_of_the_United_Kingdom
Nomenclature of Territorial Units for Statistics (NUTS) level 1 classification replaces the site name which has now been removed. 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.

Length of diagnosis. Researcher rated
Included in the PwD datasets is a variable that groups time since diagnosis into one of four groups: Less than one year, 1-2 years, 3-5 years, 6+ years.

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: Age group broken up into five epochs (1=<65, 2=65-69, 3=70-74, 4=75-79, 5=80+).

Education. Person with dementia self-report, carer self-report
Education has been grouped into four categories: No qualifications, GCSE/equivalent, A level/equivalent, College. To be understood internationally in publications these should be described as: 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*. Basingstoke: 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”.