

## Additional Files

### Additional file 1: Content of the IDEAL-2 study questionnaires administered to the cohort at T4

#### Protocol for the IDEAL-2 longitudinal study: following the experiences of people with dementia and their primary carers to understand what contributes to living well with dementia and enhances active life

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The IDEAL-2 study measures are provided in Table 1-2, indicating who will complete the measures and at what stage of the study they will be administered. New participants with dementia (and their carers where available) who did not take part in the IDEAL study will be required to complete further measurements in visit 1 (v1) at T4.

**Table 1.** Questions about the person with dementia

SOURCE OF INFORMATION	Person with dementia		Relative/friend		Member of care staff
TIME OF DATA COLLECTION	T4		T4		T4
MEASURES	v1	v2	v1	v2	v2
<b>PERSONAL CHARACTERISTICS</b>					
Location and living situation (1)		•		•	
Date of birth		•			
Gender		•			
Ethnicity	•				
Marital status		•			
Country of birth	•				
Main language	•				
Sexual orientation	•				
Ownership of pets (2)	•				
Number of children	•				
Religion	•				
Information on dementia diagnostic status		•			
<b>SOCIAL LOCATION</b>					
Occupation	•	•			
Social comparison	•				
The MacArthur Scale of Subjective Social Status - position on societal and community ladders (3)		•			
<b>CAPITALS, ASSETS AND RESOURCES</b>					
<i>Social capital - personal relations, social network support, civic engagement, trust and co-operative norms</i>					
Social networks and support - satisfaction (4, 5)		•		•	
Social networks and support – frequency of contact (4, 5)	•		•		
Social participation - civic engagement, volunteering (ONS) (6)		•			

SOURCE OF INFORMATION	Person with dementia		Relative/friend		Member of care staff
TIME OF DATA COLLECTION	T4		T4		T4
MEASURES	v1	v2	v1	v2	v2
Reciprocity and local trust in neighbourhood (Office for National Statistic) (6)		•			
<i>Cultural capital - institutionalised (education); incorporated (cultural participation)</i>					
Education	•				
<i>Economic capital</i>					
Income (7)		•			
<i>Other capital</i>					
Activity engagement (8-10)		•		•	
<b>ENVIRONMENT</b>					
Life space (11)		•			
Neighbourhood - green and blue spaces (12)		•		•	
<b>PSYCHOLOGICAL CHARACTERISTICS AND PSYCHOLOGICAL HEALTH</b>					
Personality - 5 dimensions (13)	•				
Religious practice (14)	•				
Spirituality (15-17)	•				
Optimism - Life Orientation Test (18)	•				
Optimism - Life Orientation Test - single item (18)		•			
Sense of self (continuity/discontinuity)		•			
Self-esteem - single item (19)		•			
Self-esteem - Rosenberg scale (20)	•				
General Self-Efficacy Scale (21)	•				
Loneliness - De Jong Gierveld Scale (22)		•			
Loneliness single item		•			
Stigma (23)	•				
Philadelphia Geriatric Center Morale Scale (24)	•				
the Yale Single question screen (25)		•			
Geriatric Depression Scale (26)		•			
<b>PHYSICAL FITNESS AND HEALTH</b>					
Falling in last year (27)		•		•	•
Sensory impairment – eyesight (27)		•			
Sensory impairment – hearing (27)		•			
Sleep quality (28, 29)	•		•		
Changes in sense of taste (30)		•			
The short nutritional assessment questionnaire - single item (31)				•	•
Mini-Nutritional Assessment (32)				•	•
Alcohol	•				

<b>SOURCE OF INFORMATION</b>	<b>Person with dementia</b>		<b>Relative/friend</b>		<b>Member of care staff</b>
<b>TIME OF DATA COLLECTION</b>	<b>T4</b>		<b>T4</b>		<b>T4</b>
<b>MEASURES</b>	<b>v1</b>	<b>v2</b>	<b>v1</b>	<b>v2</b>	<b>v2</b>
Smoking	•				
Subjective health rating (33-35)		•			
Subjective memory		•			
<b>RELATIONSHIP WITH CARER</b>					
Nature of relationship with carer		•			
Past relationship with carer (PAI) (36)	•				
Current relationship with carer (PAI) (36)		•			
<b>MANAGING EVERYDAY LIFE WITH DEMENTIA</b>					
Dependence Scale (37)				•	•
Mini-Mental State Examination (38)		•			
Test for Severe Impairment (39)		•			
Neuropsychiatric symptoms (NPI) (40)				•	•
The Global Deterioration Scale (41)		•			
Functional Assessment Staging (42, 43)		•			
<b>RESOURCE INPUTS</b>					
Health conditions completed with carer (where available) (44, 45)		•			•
CSRI completed with carer (where available): (46)					
CSRI hospital services		•			
CSRI GP services		•			
CSRI community healthcare services		•			
CSRI home care and support services		•			
CSRI community support services		•			
CSRI residential care services		•			
CSRI assistive technologies	•				
CSRI informal care and support from family and friends		•			
CSRI medication		•			•
Accommodation - satisfaction			•		
Accommodation (costs/type of residence) (46)		•		•	
<b>DESCRIPTIVE INFORMATION ABOUT INTERACTION WITH SERVICES</b>				•	
<b>FUTURE CARE NEEDS AND PLANNING</b>		•			
<b>DIGNITY AND RESPECT</b>					
Family treat with dignity and respect	•		•		
Other people treat with dignity and respect	•		•		
<b>ADJUSTMENT</b>					
Representations and Adjustment to Dementia Index (47)	•		•		
<b>MAIN LIVING WELL MEASURES</b>					

<b>SOURCE OF INFORMATION</b>	<b>Person with dementia</b>		<b>Relative/friend</b>		<b>Member of care staff</b>
<b>TIME OF DATA COLLECTION</b>	<b>T4</b>		<b>T4</b>		<b>T4</b>
<b>MEASURES</b>	<b>v1</b>	<b>v2</b>	<b>v1</b>	<b>v2</b>	<b>v2</b>
The Quality of Life-AD (48)		●		●	●
Satisfaction with Life Scale (49)		●		●	●
WHO5 well-being index (50)		●		●	●
<b>OTHER LIVING WELL MEASURES</b>					
Health state EQ5D (51)		●			
EQ5D visual analogue rating (51)		●			
The Activity and Affect Indicators of Quality of Life - AAIQOL frequency of activities informant rating (52)				●	●
AAIQOL expression of positive emotions - informant rating (52)				●	●
Life is meaningful to me (53)		●			
Open ended questions focusing on living well		●			
Open ended question: Is there anything else you'd like to tell us	●	●			

**Table 2.** Questions about carer

<b>SOURCE OF INFORMATION</b>	<b>Relative/friend</b>		<b>Member of care staff</b>
<b>TIME OF DATA COLLECTION</b>	<b>T4</b>		<b>T4</b>
<b>MEASURES</b>	<b>v1</b>	<b>v2</b>	<b>v2</b>
<b>PERSONAL CHARACTERISTICS</b>			
Date of birth		●	●
Country of birth (only asked if carer is new to the study)		●	
Location	●	●	
Main language (only asked if carer is new to the study)		●	●
Gender		●	●
Ethnicity (only asked if carer is new to the study)	●		●
Marital status		●	
Sexual orientation (only asked if carer is new to the study)	●		
Number of children	●		
Religion (only asked if carer is new to the study)	●		
Accommodation (only asked if carer is new to the study)		●	
Life events (54)		●	
<b>SOCIAL LOCATION</b>			
Occupational status		●	
Social comparison	●		
The MacArthur Scale of Subjective Social Status - position on societal ladder (3)		●	
The MacArthur Scale of Subjective Social Status - position on community ladder (3)		●	
<b>CAPITALS ASSETS AND RESOURCES</b>			
<i>Social capital - personal relations, social network support, civic engagement, trust and co-operative norms</i>			
Personal relations – Office for National Statistics (33)	●		
Social networks and support - Lubben scale (4, 5)		●	
Social networks and support - frequency of contact	●		
Social networks and support - satisfaction		●	
Willingness of people in neighbourhood to provide help (55)	●		
Social participation - civic engagement (Office for National Statistics) (6)	●		
Social participation - attendance at meetings of social and community groups (Office for National Statistics) (6)	●		
<i>Cultural capital - institutionalised (education); incorporated (cultural participation)</i>			
Education (only asked if carer is new to the study)	●		
Cultural capital - frequency and diversity of cultural activity (56)	●		

<b>SOURCE OF INFORMATION</b>	<b>Relative/friend</b>		<b>Member of care staff</b>
<b>TIME OF DATA COLLECTION</b>	<b>T4</b>		<b>T4</b>
<b>MEASURES</b>	<b>v1</b>	<b>v2</b>	<b>v2</b>
<i>Other</i>			
Activity engagement - social and cognitive activity (8-10)	•		
Whether live in dementia-friendly community (57)		•	
<b>ENVIRONMENT</b>			
Neighbourhood - satisfaction with neighbourhood		•	
<b>PSYCHOLOGICAL CHARACTERISTICS AND PSYCHOLOGICAL HEALTH</b>			
Personality - 5 dimensions (13)	•		
Spirituality (15-17)	•		
Optimism - Life Orientation Test – single item (18)		•	
Self-esteem - Rosenberg scale (20)	•		
Self-esteem - single item (19)		•	
Generalized Self-efficacy Scale (19)	•		
Loneliness - De Jong Gierveld Scale (22)		•	
The Center for Epidemiologic Studies Depression Scale-Revised Short Form (58)		•	
<b>PHYSICAL FITNESS AND HEALTH</b>			
Falling in last year (27)	•		
Medications	•		
Sensory impairment – eyesight (27)		•	
Sensory impairment – hearing (27)		•	
Alcohol	•		
Smoking	•		
Subjective health rating (33-35)		•	
Health conditions		•	
<b>RELATIONSHIP WITH CARE RECIPIENT</b>			
Relationship with care recipient		•	
Current relationship with participant (PAI) (36)		•	
Past relationship with participant (PAI) (36)	•		
<b>DESCRIPTIVE INFORMATION ABOUT CONTACT WITH SERVICES</b>			
Information or educational materials, participation in support groups	•		
<b>INTERNET USE</b>			
Access to the internet at home	•		
Use of the internet to assist or support relative/friend with dementia	•		
<b>EXPERIENCING CAREGIVING</b>			
Information on caregiving		•	
Positive aspects of caregiving (59)		•	
Caregiving Competence Scale (60)		•	
Coping single item - taken from COPE Index (61)		•	

<b>SOURCE OF INFORMATION</b>	<b>Relative/friend</b>		<b>Member of care staff</b>
<b>TIME OF DATA COLLECTION</b>	<b>T4</b>		<b>T4</b>
<b>MEASURES</b>	<b>v1</b>	<b>v2</b>	<b>v2</b>
Coping - management of meaning (the positive comparisons and reduction of expectations sub-scales) (62)		•	
Role Captivity (62)		•	
Relative/friend left unsupervised		•	
Relatives Stress Scale - total score (63)		•	
SIDECAR questionnaire		•	
<b>MAIN LIVING WELL MEASURES</b>			
The World Health Organization Quality of Life (WHOQOL)-BREF instrument (64)		•	
Satisfaction with Life (49)		•	
WHO5 well-being index (50)		•	
<b>OTHER LIVING WELL MEASURES</b>			
Health state EQ5D (51)		•	
EQ5D visual analogue rating (51)		•	
<b>RELATIVE/FRIEND IN A CARE HOME</b>		•	
Open ended questions for relatives/friends		•	
Open ended question: Is there anything else you'd like to tell us	•	•	•
<b>SPECIFIC QUESTIONS ABOUT PAID CARER'S BACKGROUND</b>			•

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