

Supplementary Material

Impact of COVID-19 on ‘Living Well’ with Mild-to-Moderate Dementia in the Community: Findings from the IDEAL Cohort

Supplementary Table 1. Characteristics of people with dementia (PwD) and carers participating in the IDEAL cohort at Time-point 3 (IDEAL T3).

Variable	Category	IDEAL PwD; N (%)	IDEAL Carers; N (%)
Sex	Male	476 (55.9)	238 (31.4)
	Female	375 (44.1)	521 (68.6)
Age	<65	67 (7.9)	177 (23.3)
	65-69	71 (8.3)	123 (16.2)
	70-74	160 (18.8)	169 (22.3)
	75-79	171 (20.1)	134 (17.7)
	80+	382 (44.9)	156 (20.6)
	Mean (SD); range	77.52 (8.4); 48-97	70.69 (10.6); 28-94
Ethnicity	White British	795 (93.4)	711 (93.7)
	White Other	25 (2.9)	18 (1.9)
	Other	9 (0.9)	5 (0.6)
	Missing	22 (2.6)	25 (3.3)
Education	No qualifications	225 (26.4)	146 (19.2)
	school leaving certificate at age 16	136 (16.0)	161 (21.2)
	school leaving certificate at age 18	292 (34.3)	213 (28.1)
	University	178 (20.9)	201 (26.5)
	Missing	20 (2.4)	38 (5.0)
Socioeconomic Status [1] ^	I Professionals	66 (7.8)	49 (6.5)
	II Managerial and technical	311 (36.5)	293 (38.6)
	III-NM Skilled occupations - non-manual	151 (17.7)	196 (25.8)
	III-M Skilled occupations - manual	166 (19.5)	90 (11.9)
	IV Partly skilled	79 (9.3)	40 (5.3)
	V Unskilled	15 (1.8)	6 (0.8)
	Armed forces	12 (1.4)	4 (0.5)
	N/A	34 (4.0)	24 (3.2)
	Missing	17 (2.0)	40 (5.3)
Current marital status	Single	14 (1.6)	18 (2.4)
	Married; first	477 (56.1)	534 (70.4)
	Remarried	144 (16.9)	133 (17.5)
	A civil partnership	6 (0.7)	9 (1.2)
	Legally separated	2 (0.2)	2 (0.3)
	Divorced	55 (6.5)	19 (2.5)
	Widowed	133 (15.6)	5 (0.7)
	Cohabiting	12 (1.4)	19 (2.5)
	Missing	8 (0.9)	20 (2.6)
Carer status	Spouse/partner		627 (82.6)
	Other family/friend		132 (17.4)

Living situation [2]	Living alone	134 (15.7)	
	Live with spouse/partner	642 (75.4)	
	Other living arrangement	73 (8.7)	
	Unclassifiable	1 (0.1)	
Diagnosis	Alzheimer's disease (AD)	488 (57.3)	
	Vascular dementia (VaD)	82 (9.6)	
	Mixed AD and VaD	185 (21.7)	
	Frontotemporal dementia (FTD)	32 (3.8)	
	Parkinson's disease dementia (PDD)	17 (2.0)	
	Dementia with Lewy bodies (DLB)	27 (3.2)	
	Unspecified/Other	20 (2.4)	
MMSE score [3]	Mean (SD); range	20.54 (6.21)	

IDEAL, Improving the experience of Dementia and Enhancing Active Life; MMSE, Mini-Mental State Examination. ^Socioeconomic status is based on self-reported information on main occupation and categorised based on the standard occupational classification for the UK.

Supplementary Table 2. Characteristics of the core members taking part in the ELSA COVID-19 Sub-Study Wave 2

Variable	Categories	ELSA core members	
		N	Weighted % or mean
Sex	Male	2,399	47.4%
	Female	3,159	52.6%
Age	<65	1,371	46.9%
	65-69	1,153	14.4%
	70-74	1,287	14.3%
	75-79	822	10.0%
	80+	925	14.6%
	Mean (SD); range		66.88 (10.44), 38-52
Ethnicity	White (any)	5,331	92.0%
	Black, Asian and minority ethnic	227	8.0%
Education	No qualifications	836	17.0%
	school leaving certificate at age 16	1,332	23.4%
	school leaving certificate at age 18	1,399	23.5%
	University	1,242	19.4%
	Other/foreign	473	9.7%
	Missing	276	7.0%
Current marital status	Single	293	6.6%
	Married	3,556	62.6%
	In registered civil partnership	22	0.5%
	Living with partner	289	5.9%
	With partner but don't live together	100	2.1%
	Separated	71	1.9%
	Divorced	472	9.0%
	Widowed	751	11.4%
Missing	2	0.0%	
Living situation	Living alone	1,459	24.6%
	Lives with others	4,078	75.0%
	Missing	21	0.4%
Dementia	Diagnosed	62	1.2%
	Not known to have a diagnosis	5,496	98.8%

ELSA, English Longitudinal Study of Ageing.

Supplementary Table 3. Health of people with dementia (PwD) and receipt of services during the pandemic, and comparison with benchmark where applicable

A) Healthcare needs and receipt of services

Item	Response key	All		Dyads only		Benchmark (where applicable)	Benchmarking data [†] (where applicable)	Statistical comparison (INCLUDE all carers versus benchmark)
		PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)	PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)			
Have you had COVID-19?	Yes No Missing	6 (3.5) 167 (96.5) -	6 (2.5) 235 (97.1) 1 (0.4)	4 (3.2) 122 (96.8) -	3 (2.4) 123 (97.6) -	Population data for 50+ in England as of 8/5/2021*	1284225 (6.1) 19759438 (93.9) -	
If yes, were you treated in hospital? [4]	Yes No/No prev Q Missing	1 (0.6) 172 (99.4) -	2 (0.8) 239 (98.8) 1 (0.4)	- 126 (100.0) -	- 126 (100.0) -	ELSA	22 (0.5) 5534 (99.4) 2 (0.0)	$\chi^2(1) = 0.00$, p = 1.00
Did anyone close to you have COVID-19? [4]	Yes No Don't know	29 (16.8) 144 (16.8) -		18 (14.3) 108 (85.7) -		ELSA	1133 (22.8) 4417 (77.1) 8 (0.2)	$\chi^2(1) = 3.15$, p = 0.076
Since the coronavirus outbreak, have you developed any new health problems?	Yes No Missing	38 (22.0) 129 (74.6) 6 (3.5)		22 (17.5) 99 (78.6) 5 (4.0)				
Have you avoided seeking help for health issues because of the coronavirus?	Yes No Missing	34 (19.7) 133 (76.9) 6 (3.5)	18 (7.4) 221 (91.3) 3 (1.2)	19 (15.1) 102 (81.0) 5 (4.0)	13 (10.3) 112 (88.9) 1 (0.8)			
Have your healthcare needs been affected by the coronavirus outbreak – for example, appointments postponed or planned operations delayed?	Yes No Missing	83 (48.0) 84 (48.6) 6 (3.5)	91 (37.6) 148 (61.2) 3 (1.2)	58 (46.0) 63 (50.0) 5 (4.0)	55 (43.7) 70 (55.6) 1 (0.8)			
Did any healthcare services you were already receiving stop due to the coronavirus?	Yes No Missing/ Unsure	24 (13.9) 143 (82.7) 6 (3.5)	37 (15.3) 201 (83.1) 4 (1.7)	13 (10.3) 108 (85.7) 5 (4.0)	19 (15.1) 106 (84.1) 1 (0.8)			
In the last 3 months have you seen your GP at the surgery? [5]	Yes No Missing/ Unsure	41 (23.7) 126 (72.8) 6 (3.5)	46 (19.0) 193 (79.8) -	31 (24.6) 90 (71.4) 5 (4.0)	29 (23.0) 96 (76.2) 1 (0.8)	IDEAL T3 Carer Q179	444 (58.5) 275 (36.2) 40 (5.3)	$\chi^2(1) =$, 128.01, p < 0.001
In the last 3 months have you spoken to a GP on the telephone? [5]	Yes No Missing	65 (37.6) 102 (59.0) 6 (3.5)	121 (50.0) 118 (48.8) 3 (1.2)	43 (34.1) 78 (61.9) 5 (4.0)	63 (50.0) 62 (49.2) 1 (0.8)	IDEAL T3 Carer Q181	122 (16.1) 616 (81.2) 21 (2.7)	$\chi^2(1) =$ 110.50, p < 0.001

Is there a named health professional whom you can contact at any time? [#]	Yes No Missing/DK		150 (62.0) 91 (37.6) 1 (0.4)		81 (64.3) 45 (35.7) -	IDEAL T3 Carer Q98	267 (35.2) 461 (60.7) 31 (4.1)	$\chi^2(1) = 47.23,$ $p < 0.001$
Is this named health professional in place to help specifically with the dementia? [#]	Yes No No previous Q Missing/DK		123 (50.8) 27 (11.2) 91 (37.6) 1 (0.4)		67 (53.2) 14 (11.1) 45 (35.7) -	IDEAL T3 Carer Q99	174 (22.9) 70 (9.2) 461 (64.8) 54 (3.0)	$\chi^2(1) = 56.71,$ $p < 0.001$
Before the coronavirus outbreak did you normally go to a day center? [5]	Yes No Missing	21 (12.1) 147 (85.0) 5 (2.9)	38 (15.7) 202 (83.5) 2 (0.8)	14 (11.1) 108 (85.7) 4 (3.2)	11 (8.7) 115 (91.3) -	IDEAL T3 Carer Q198	146 (19.2) 605 (79.7) 8 (1.1)	$\chi^2(1) =$ 1.34, $p =$ 0.248
If yes, has this restarted?	Yes No Missing NA	7 (4.0) 14 (8.1) - 152 (87.9)	9 (3.7) 28 (11.1) 2 (0.07) 243 (84.4)	6 (4.8) 8 (6.3) - 112 (88.9)	4 (3.2) 7 (5.6) - 115 (91.3)			

ELSA, English Longitudinal Study of Ageing; IDEAL, Improving the experience of Dementia and Enhancing Active Life. *Population estimate for people aged 50+ in England as of 8 May 2021; source: <https://coronavirus.data.gov.uk/details/download>. † For ELSA COVID wave 2, percentages displayed are for weighted data. # Question taken from IDEAL
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B) Physical health

Item	Response key	Whole sample		Dyads only		Benchmark (where applicable)	Benchmarking data		Statistical comparison (where applicable)	
		PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)	PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)		PwD	Carers (informants)	PwD all INCLUDE versus benchmark	Carers all INCLUDE versus benchmark
Overall, how would you rate your health in the past 4 weeks? [6]	Very poor	2 (1.2)	6 (2.5)	1 (0.8)	-	IDEAL T3 PwD Q24	24 (2.8)		χ^2 (5) = 7.80, p = 0.168	
	Poor	17 (9.8)	23 (9.5)	12 (9.5)	10 (7.9)		79 (9.3)			
	Fair	42 (24.3)	60 (24.8)	28 (22.2)	31 (24.6)		183 (21.5)			
	Good	55 (31.8)	91 (37.6)	44 (34.9)	46 (36.5)		314 (36.9)			
	Very good	33 (19.1)	51 (21.1)	22 (17.5)	33 (26.2)		184 (21.6)			
	Excellent	18 (10.4)	9 (3.7)	14 (11.1)	6 (4.8)		51 (6.0)			
	Missing	6 (3.5)	2 (0.8)	5 (4.0)	-		16 (1.9)			
Which of these options best describes your level of pain or discomfort today? [7]	1 no pain	90 (52.0)	125 (51.7)	64 (50.8)	63 (50.0)	IDEAL T3	511 (60.0)	325 (42.8)	χ^2 (2) = 3.53, p = 0.171	χ^2 (2) = 12.24, p = 0.002
	2 moderate pain	67 (38.7)	109 (45.0)	51 (40.5)	61 (48.4)	PwD Q32	287 (33.7)	369 (48.6)		
	3 extreme pain	10 (5.8)	4 (1.7)	6 (4.8)	1 (0.8)	IDEAL T3	35 (4.1)	51 (6.7)		
	Missing	6 (3.5)	4 (1.7)	5 (4.0)	1 (0.8)	Carer Q109	18 (2.1)	14 (1.8)		
Which of these options best describes your mobility today? [7]	1 no problems	90 (52.0)	93 (38.4)	67 (53.2)	60 (47.6)	IDEAL T3	479 (56.3)	309 (40.7)	χ^2 (2) = 1.04, p = 0.595	χ^2 (2) = 1.13, p = 0.568
	2 some problems	76 (43.9)	141 (58.3)	53 (42.1)	66 (52.4)	PwD Q29	350 (41.1)	431 (56.8)		
	3 confined to bed	1 (0.6)	6 (2.5)	1 (0.8)	-	IDEAL T3	9 (1.1)	12 (1.6)		
	Missing	6 (3.5)	2 (0.8)	5 (4.0)	-	Carer Q106	13 (1.5)	7 (0.9)		

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Supplementary Table 4. Managing everyday life with dementia during the pandemic, and comparison with benchmark where applicable

Item	Response key	Whole sample		Dyads only		Benchmark (where applicable)	Benchmarking data		Statistical comparison (where applicable)	
		PwD n (%) or mean (n, SD, range)	Carer (informants) n (%) or mean (n, SD, range)	PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)		PwD	Carers	PwD all INCLUDE versus benchmark	Carers all INCLUDE versus benchmark
Compared to other people of your age, how would you describe your day-to-day memory? [8]	Very poor	15 (8.7)		10 (7.9)		IDEAL T3 PwD Q25	43 (5.1)		$\chi^2 (5) =$ 11.99, p = 0.035	
	Poor	38 (22.0)		29 (23.0)			156 (18.3)			
	Fair	56 (32.4)		40 (31.7)			319 (37.5)			
	Good	35 (20.2)		26 (20.6)			219 (25.7)			
	Very good	18 (10.4)		14 (11.1)			64 (7.5)			
	Excellent	5 (2.9)		2 (1.6)			9 (1.1)			
	Missing	6 (3.5)		5 (4.0)			41 (4.8)			
Since the coronavirus outbreak have you noticed any changes in your ability to remember everyday things? ^o	Better	3 (1.7)	2 (0.8)	2 (1.6)	1 (0.8)					
	No change	86 (49.7)	50 (20.7)	67 (53.2)	28 (22.2)					
	Worse	76 (43.9)	188 (77.7)	51 (40.5)	97 (77.0)					
	Missing	8 (4.6)	2 (0.8)	6 (4.8)	-					
Since the coronavirus outbreak have you noticed any changes in your ability to remember recent events? ^o	Better	1 (0.6)	4 (1.7)	1 (0.8)	2 (1.6)					
	No change	85 (49.1)	59 (24.4)	67 (53.2)	32 (25.4)					
	Worse	78 (45.1)	177 (73.1)	51 (40.5)	92 (73.0)					
	Missing	9 (5.2)	2 (0.8)	7 (5.6)	-					
Since the coronavirus outbreak have you noticed any changes in your ability to concentrate? ^o	Better	3 (1.7)	1 (0.4)	3 (2.4)	-					
	No change	76 (43.9)	68 (28.1)	56 (44.4)	36 (28.6)					
	Worse	85 (49.1)	170 (70.2)	61 (48.4)	89 (70.6)					
	Missing	9 (5.2)	3 (1.2)	6 (4.8)	1 (0.8)					
Since the coronavirus outbreak have you noticed any changes in your ability to say what you want to say? ^o	Better	1 (0.6)	-	1 (0.8)	-					
	No change	90 (52.0)	87 (36.0)	68 (54.0)	53 (42.1)					
	Worse	74 (42.8)	153 (63.2)	51 (40.5)	73 (57.9)					
	Missing	8 (4.6)	2 (0.8)	6 (4.8)	-					
Since the coronavirus outbreak have you noticed any changes in your ability to plan ahead? ^o	Better	2 (1.2)	1 (0.4)	2 (1.6)	1 (0.8)					
	No change	106 (61.3)	120 (49.6)	75 (59.5)	69 (54.8)					
	Worse	55 (31.8)	119 (49.2)	41 (32.5)	56 (44.4)					
	Missing	10 (5.8)	2 (0.8)	8 (6.3)	-					
Since the coronavirus outbreak have you noticed any changes in your ability to make decisions? ^o	Better	2 (1.2)	-	2 (1.6)	-					
	No change	110 (63.6)	107 (44.2)	81 (64.3)	62 (49.2)					
	Worse	53 (30.6)	133 (55.0)	37 (29.4)	64 (50.8)					
	Missing	8 (4.6)	2 (0.8)	6 (4.8)	-					

Since the coronavirus outbreak do you find yourself feeling confused more often or about the same as before?	Yes No Missing	82 (47.4) 84 (48.6) 7 (4.0)	187 (77.3) 52 (21.5) 3 (1.2)	58 (46.0) 62 (49.2) 6 (4.8)	95 (75.4) 30 (23.8) 1 (0.8)					
Which of these options best describes your ability for self-care? [7]	1 no problems 2 some problems 3 unable to wash or dress Missing	120 (69.4) 42 (24.3) 7 (4.0) 4 (2.3)	108 (44.6) 88 (36.4) 44 (18.2) 2 (0.8)	82 (65.1) 33 (26.2) 7 (5.6) 4 (3.2)	76 (60.3) 38 (30.2) 12 (9.5) -	IDEAL T3 PwD Q30 IDEAL T3 Carer Q109	654 (76.9) 139 (16.3) 40 (4.7) 18 (2.1)	370 (48.7) 288 (37.9) 91 (12.0) 10 (1.3)	$\chi^2 (2) = 6.34, p = 0.042$	$\chi^2 (2) = 5.97, p = 0.050$
Which of these options best describes your ability to do your usual activities? [7]	1 no problems 2 some problems 3 unable to perform usual activities Missing	101 (58.4) 62 (35.8) 6 (3.5) 4 (2.3)	73 (30.2) 110 (45.5) 57 (23.6) 2 (0.8)	74 (58.7) 43 (34.1) 5 (4.0) 2 (3.2)	56 (44.4) 54 (42.9) 16 (12.7) -	IDEAL T3 PwD Q31 IDEAL T3 Carer Q108	522 (61.3) 252 (29.6) 58 (6.8) 19 (2.2)	166 (21.9) 379 (49.9) 203 (26.7) 11 (1.4)	$\chi^2 (2) = 4.60, p = 0.100$	$\chi^2 (2) = 6.73, p = 0.035$
Do you use the Internet? [9]	Yes No Missing	119 (68.8) 50 (28.9) 4 (2.3)	92 (38.0) 148 (61.2) 2 (0.8)	85 (67.5) 37 (29.4) 4 (3.2)	67 (53.2) 59 (46.8) .	IDEAL T3 PwD Q250 IDEAL T3 Carer Q138	245 (28.8) 526 (61.8) 80 (9.4)	185 (24.3) 566 (74.6) 8 (1.1)	$\chi^2 (1) = 85.59, p < 0.001$	$\chi^2 (1) = 16.28, p < 0.001$
How easy was it to keep yourself occupied during the coronavirus outbreak?	Not very Fairly easy Very easy Missing	30 (17.3) 72 (41.6) 69 (39.9) 2 (1.2)	82 (33.9) 95 (39.3) 63 (26.0) 2 (0.8)	20 (15.9) 52 (41.3) 52 (41.3) 2 (1.6)	32 (25.4) 57 (45.2) 36 (28.6) 1 (0.8)					
Overall how well do you feel you have coped since the coronavirus outbreak?	Not very Fairly well Very well Missing	12 (6.9) 74 (42.8) 84 (48.6) 3 (1.7)	36 (14.9) 110 (45.5) 94 (38.8) 2 (0.8)	9 (7.1) 48 (38.1) 66 (52.4) 3 (2.4)	13 (10.3) 57 (45.2) 56 (44.4) -					
Have there been any positive aspects or benefits of the coronavirus outbreak?	Yes No Missing	78 (45.1) 87 (50.3) 8 (4.6)	54 (22.3) 186 (76.9) 2 (0.8)	54 (42.9) 65 (51.6) 7 (5.6)	31 (24.6) 95 (75.4) -					

IDEAL, Improving the experience of Dementia and Enhancing Active Life[®] Questions based on the Representations and Adjustment to Dementia Index (RADIX) [10]

Supplementary Table 5. Social capitals, assets and resources during the pandemic, and comparison with benchmark where applicable

Item	Response key	Whole sample		Dyads only		Benchmark (where applicable)	Benchmarking		Statistical comparison (where applicable)	
		PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)	PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)		PwD †	Carers	PwD all INCLUDE versus benchmark	Carers All INCLUDE versus benchmark
Considering the people to whom you are related by birth, marriage or adoption, how many relatives do you see or hear from at least once a month? [11]	None	2 (1.2)	7 (2.9)	1 (0.8)	2 (1.6)	IDEAL T3	45 (5.3)	22 (2.9)	U = 76867, z = -2.66, p = 0.008	U = 93958, z = -1.07, p = 0.286
	One	15 (8.7)	16 (6.6)	5 (4.0)	8 (6.3)	PwD Q99	71 (8.3)	49 (6.5)		
	Two	19 (11.0)	32 (13.2)	15 (11.9)	13 (10.3)	IDEAL T3	131 (15.4)	112 (14.8)		
	Three	27 (15.6)	35 (14.5)	24 (19.0)	21 (16.7)	Carer Q111	137 (16.1)	124 (16.3)		
	Four	19 (11.0)	36 (14.9)	14 (11.1)	22 (17.5)		98 (11.5)	121 (15.9)		
	Five	22 (12.7)	31 (12.8)	14 (11.1)	15 (11.9)		73 (8.6)	88 (11.6)		
	Six	16 (9.2)	23 (9.5)	13 (10.3)	9 (7.1)		76 (8.9)	71 (9.4)		
	Seven	9 (5.2)	12 (5.0)	7 (5.6)	7 (5.6)		31 (3.6)	30 (4.0)		
	Eight	6 (3.5)	14 (5.8)	3 (2.4)	8 (6.3)		34 (4.0)	44 (5.8)		
	Nine	5 (2.9)	10 (4.1)	4 (3.2)	5 (4.0)		30 (3.5)	10 (1.3)		
	Ten	9 (5.2)	11 (4.5)	7 (5.6)	7 (5.6)		46 (5.4)	40 (5.3)		
	More than 10	18 (10.5)	13 (5.3)	14 (11.2)	9 (7.2)		43 (5.1)	38 (5.0)		
	Mean (SD)	5.6 (4.2)	5.0 (3.5)	5.7 (4.1)	5.4 (3.8)		4.7 (3.7)	4.8 (3.6)		
	Missing	6 (3.5)	2 (0.8)	5 (4.0)	-		36 (4.2)	10 (1.3)		
Has this changed since the coronavirus outbreak?	Yes	87 (50.3)	81 (33.5)	58 (46.0)	36 (28.6)					
	No	80 (46.2)	158 (65.3)	62 (49.2)	89 (70.6)					
	Missing	6 (3.5)	3 (1.2)	6 (4.8)	1 (0.8)					
How satisfied are you with the support you receive from family?#	Very dissatisfied	-		-		IDEAL T3	16 (1.9)		$\chi^2(4) = 17.13, p = 0.002$	
	Slightly dissatisfied	1 (0.6)		1 (0.8)		PwD Q105	18 (2.1)			
	Neither satisfied nor dissatisfied	19 (11.0)		11 (8.7)			44 (5.2)			
	Slightly satisfied	27 (15.6)		16 (12.7)			78 (9.2)			
	Very satisfied	120 (69.4)		92 (73.0)			604 (71.0)			
	Don't know	1 (0.6)		1 (0.8)			9 (1.1)			
	Missing	5 (2.9)		5 (4.0)			82 (9.6)			
Considering all your friends including those who live in your neighborhood, how many friends do you see or hear	None	28 (16.2)	63 (26.0)	20 (15.9)	19 (15.1)	IDEAL T3	138 (16.2)	131 (17.3)	U = 66473, z = -0.11, p = 0.916	U = 79220, z = -2.22, p < 0.027
	One	14 (8.1)	27 (11.2)	8 (6.3)	16 (12.7)	PwD Q102	73 (8.6)	82 (10.8)		
	Two	21 (12.1)	38 (15.7)	16 (12.7)	23 (18.3)	IDEAL T3	106 (12.5)	123 (16.2)		
	Three	23 (13.3)	27 (11.2)	20 (15.9)	16 (12.7)	Carer Q114	86 (10.1)	88 (11.6)		
	Four	18 (10.4)	24 (9.9)	12 (9.5)	10 (7.9)		87 (10.2)	93 (12.3)		
	Five	13 (7.5)	16 (6.6)	9 (7.1)	10 (7.9)		55 (6.5)	42 (5.5)		
	Six	14 (8.1)	8 (3.3)	10 (7.9)	7 (5.6)		59 (6.9)	58 (7.6)		

from at least once a month? [11]	Seven	3 (1.7)	2 (0.8)	3 (2.4)	1 (0.8)		25 (2.9)	12 (1.6)		
	Eight	4 (2.3)	4 (1.7)	1 (0.8)	2 (1.6)		27 (3.2)	26 (3.4)		
	Nine	1 (0.6)	5 (2.1)	1 (0.8)	-		9 (1.1)	8 (1.1)		
	Ten	11 (6.4)	14 (5.8)	10 (7.9)	10 (7.9)		50 (5.9)	32 (4.2)		
	More than 10	17 (9.9)	12 (4.9)	11 (8.8)	12 (9.6)		77 (9.0)	34 (4.5)		
	Mean (SD)	5.1 (6.1)	3.6 (4.5)	5.0 (5.9)	4.6 (5.3)		5.2 (7.3)	4.1 (4.5)		
	Missing	6 (3.5)	2 (0.8)	5 (4.0)	-		59 (6.9)	30 (3.9)		
Has this changed since the coronavirus outbreak?	Yes	87 (50.3)	147 (51.0)	63 (50.0)	65 (51.6)					
	No	80 (46.2)	139 (48.3)	57 (45.2)	61 (48.4)					
	Missing	6 (3.5)	2 (0.7)	6 (4.8)	-					
How satisfied are you with the support you receive from friends?#	Very dissatisfied	1 (0.6)		-		IDEAL T3	18 (2.1)		$\chi^2(4) = 8.57, p = 0.073$	
	Slightly dissatisfied	3 (1.7)		2 (1.6)		PwD Q106	18 (2.1)			
	Neither satisfied nor dissatisfied	17 (9.8)		11 (8.7)			134 (15.7)			
	Slightly satisfied	31 (17.9)		23 (18.3)			135 (15.9)			
	Very satisfied	102 (59.0)		76 (60.3)			405 (47.6)			
	Don't know	6 (3.5)		3 (2.4)			43 (5.1)			
	Missing	13 (7.5)		11 (8.7)			98 (11.5)			
Thinking of [carer] how well do you get along together? [12]	Not well at all			-	1 (0.8)	IDEAL T3	3 (0.4)	4 (0.5)	$\chi^2(5) = 9.23, p = 0.100^{**}$	$\chi^2(5) = 4.41, p = 0.491^{**}$
	Not too well			5 (4.0)	7 (5.6)	PwD Q111	6 (0.7)	20 (2.6)		
	Quite well			7 (5.6)	10 (7.9)	IDEAL T3	34 (4.0)	80 (10.5)		
	Well			12 (9.5)	18 (14.3)	Carer Q70	71 (8.3)	124 (16.3)		
	Very well			49 (38.9)	57 (45.2)		296 (34.7)	309 (40.7)		
	Extremely well			47 (37.3)	33 (26.2)		289 (33.8)	189 (24.9)		
	Missing			6 (4.8)	-		155 (18.1)***	33 (1.3)***		
In your neighborhood to what extent do you agree or disagree that people are willing to help their neighbors? [13]	Strongly disagree	8 (4.6)		4 (3.2)		IDEAL T3	31 (3.6)		$\chi^2(4) = 2.65, p = 0.618$	
	Slightly disagree	8 (4.6)		8 (6.3)		P2_Q216_t3	22 (2.6)			
	Neither agree nor disagree	19 (11.0)		12 (9.5)			70 (8.2)			
	Slightly agree	45 (26.0)		32 (25.4)			191 (22.4)			
	Strongly agree	86 (49.7)		64 (50.8)			418 (49.1)			
	Don't know	2 (1.2)		2 (1.6)			35 (4.1)			
	Missing	5 (2.9)		4 (3.2)			84 (9.9)			
Try to imagine a scenario where your purse or wallet containing your address details is lost, and is found in the street by someone living in your neighborhood.	Not at all likely	10 (5.8)		5 (4.0)		IDEAL T3	40 (4.7)		$\chi^2(3) = 0.26, p = 0.968$	
	Not very likely	16 (9.2)		13 (10.3)		P2_Q208_t3	80 (9.4)			
	Quite likely	60 (34.7)		42 (33.3)			276 (32.4)			
	Very likely	69 (39.9)		52 (41.3)			313 (36.8)			
	Don't know	13 (7.8)		10 (7.9)			66 (7.8)			
	Missing	5 (2.9)		4 (3.2)			76 (8.9)			

How likely is it that it would be returned to you with nothing missing? [13]										
How satisfied are you with your neighborhood as a place to live? [13]	Very satisfied	126 (72.8)		93 (73.8)		IDEAL T3	605 (71.1)		$\chi^2(4) = 3.30, p = 0.509$	
	Slightly satisfied	31 (17.9)		20 (15.9)		P2_Q207_t3	116 (13.6)			
	Neither satisfied nor dissatisfied	4 (2.3)		3 (2.4)			26 (3.1)			
	Fairly dissatisfied	5 (2.9)		4 (3.2)			13 (1.5)			
	Very dissatisfied	2 (1.2)		2 (1.6)			15 (1.8)			
	Don't know	-		-			5 (0.6)			
	Missing	5 (2.9)		-			71 (8.3)			
How worried, if at all, have you been about having enough food during the coronavirus outbreak? [4]	Not at all	133 (76.9)	206 (85.1)	100 (79.4)	110 (87.3)	ELSA	4321 (72.9)		$\chi^2(4) = 7.20, p = 0.126$	$\chi^2(4) = 20.76, p < 0.001 +$
	Not very	24 (13.9)	21 (8.7)	17 (13.5)	10 (7.9)		943 (19.0)			
	Somewhat	14 (8.1)	10 (4.1)	7 (5.6)	6 (4.8)		239 (6.1)			
	Very	-	4 (1.7)	-	-		39 (1.5)			
	Extremely	-	-	-	-		14 (0.5)			
	Missing/don't know	2 (1.2)	1 (0.4)	2 (1.6)	-		2 (0.0)			
How do you feel your financial situation now compares to before the outbreak? [4]	Much worse off	5 (2.9)		4 (3.2)		ELSA	175 (4.5)		$\chi^2(4) = 14.23, p = 0.007$	
	A little worse off	12 (6.9)		5 (4.0)			704 (14.4)			
	About the same	104 (60.1)		74 (58.7)			3573 (62.5)			
	A little better off	39 (22.5)		33 (26.2)			897 (15.1)			
	Much better off	6 (3.5)		3 (2.4)			202 (3.3)			
	Missing	7 (4.0)		7 (5.6)			7 (0.2)			

ELSA, English Longitudinal Study of Ageing; IDEAL, Improving the experience of Dementia and Enhancing Active Life. **dyadic data only. ***missing includes people with dementia participating without a carer and carers participating without a person with dementia. +Comparison is INCLUDE carers (all) with ELSA COVID Sub-Study Wave 2 [4].

†For ELSA COVID wave 2, percentages displayed are for weighted data. #Question taken from IDEAL survey.

Supplementary Table 6. Psychological well-being and capability to ‘live well’ with dementia during the pandemic, and comparison with benchmark where applicable

A) Psychological well-being

Item	Response key	Whole sample		Dyads only		Benchmark	Benchmarking data		Statistical comparison (where applicable)	
		PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)	PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)	(where applicable)	PwD [†]	Carers	PwD all INCLUDE versus benchmark	Carers all INCLUDE versus benchmark
In the last two weeks, how much of the time have you felt cheerful and in good spirits? [14]	At no time	1 (0.6)	8 (3.3)	-	1 (0.8)	IDEAL T3	9 (1.1)	26 (3.4)	$\chi^2 (5) = 5.33, p = 0.377$	$\chi^2 (5) = 3.63, p = 0.604$
	Some of the time	22 (12.7)	46 (19.0)	16 (12.7)	18 (14.3)	PwD Q74	89 (10.5)	148 (19.5)		
	Less than half of the time	16 (9.2)	35 (14.5)	9 (7.1)	16 (12.7)	IDEAL T3	47 (5.5)	114 (15.0)		
	More than half of the time	28 (16.2)	60 (24.8)	21 (16.7)	35 (27.8)	Carer Q19	146 (17.2)	207 (27.3)		
	Most of the time	77 (44.5)	78 (32.2)	54 (42.9)	50 (39.7)		426 (50.1)	239 (31.5)		
	All of the time	19 (11.0)	12 (5.0)	17 (13.5)	5 (4.0)		87 (10.2)	20 (2.6)		
	Missing	10 (5.8)	3 (1.2)	9 (7.1)	1 (0.8)		47 (5.5)	5 (0.7)		
Overall, would you say you expect more good things to happen to you than bad? [15]	Strongly disagree	1 (0.6)		-		IDEAL T3	7 (0.8)		$\chi^2 (4) = 25.86, p < 0.001$	
	Disagree	12 (6.9)		8 (6.3)		PwD Q54	84 (9.9)			
	Neutral	31 (17.9)		21 (16.7)			176 (20.7)			
	Agree	89 (51.4)		69 (54.8)			467 (54.9)			
	Strongly agree	34 (19.7)		23 (18.3)			82 (9.6)			
	Missing	6 (3.5)		5 (4.0)			35 (4.1)			
Do you feel you are still the same person you have always been? [16]	Strongly disagree	19 (11.0)		10 (7.9)		IDEAL T3	24 (2.8)		$\chi^2 (4) = 43.20, p < 0.001$	
	Disagree	32 (18.5)		24 (19.0)		PwD Q55	149 (17.5)			
	Neutral	14 (8.1)		12 (9.5)			77 (9.0)			
	Agree	62 (35.8)		46 (36.5)			458 (53.8)			
	Strongly agree	41 (23.7)		29 (23.0)			110 (12.9)			
	Missing	6 (3.5)		5 (4.0)			33 (3.9)			
On a scale of 0 - 10 how happy overall did you feel yesterday? [17]	0 Not at all	2 (1.2)		1 (0.8)		ELSA	53 (1.2)		U=508114, z-2.15, p = 0.031	
	1	2 (1.2)		2 (1.6)			27 (0.6)			
	2	3 (1.7)		3 (2.4)			70 (1.6)			
	3	4 (2.3)		3 (2.4)			104 (2.0)			
	4	5 (2.9)		3 (2.4)			175 (3.0)			
	5	15 (8.7)		9 (7.1)			616 (11.7)			
	6	12 (6.9)		7 (5.6)			531 (9.9)			
	7	30 (17.3)		20 (15.9)			959 (17.4)			
	8	36 (20.8)		28 (22.2)			1675 (29.2)			
	9	30 (17.3)		19 (15.1)			837 (13.7)			
	10 Completely	27 (15.6)		25 (19.8)			506 (9.6)			
Mean (SD)	7.38 (2.2)		7.51 (2.3)		7.15 (2.01)					

	Missing	7 (4.0)		6 (4.8)			5 (0.2)			
On a scale of 0 - 10 how anxious overall did you feel yesterday? [17]	0 Not at all	67 (38.7)		50 (39.7)		ELSA	1729 (30.3)		U = 436441, z-0.94, p = 0.345	
	1	6 (3.5)		4 (3.2)			515 (8.9)			
	2	15 (8.7)		11 (8.7)			700 (11.9)			
	3	12 (6.9)		10 (7.9)			486 (8.2)			
	4	7 (4.0)		6 (4.8)			394 (7.1)			
	5	18 (10.4)		10 (7.9)			560 (11.4)			
	6	13 (7.5)		9 (7.1)			312 (5.9)			
	7	10 (5.8)		5 (4.0)			339 (6.4)			
	8	6 (3.5)		5 (4.0)			300 (5.5)			
	9	7 (4.0)		6 (4.8)			122 (2.0)			
	10 Completely	4 (2.3)		3 (2.4)			971 (1.7)			
Mean (SD)	3.0 (3.1)		2.9 (3.2)		3.0 (2.9)					
Missing	8 (4.6)		7 (5.6)		30 (0.6)					
Do you feel sad or depressed?#	Yes	22 (12.7)		17 (13.5)						
	No	147 (85.0)		105 (83.3)						
	Missing	4 (2.3)		4 (3.2)						
Which of these options best describes your mood today? [7]	1 not anxious or depressed	123 (71.1)	157 (64.9)	90 (71.4)	89 (70.6)	IDEAL T3	567 (66.6)	378 (49.8)	$\chi^2 (2) = 1.59, p = 0.451$	$\chi^2 (2) = 16.79, p < 0.001$
	2 moderately anxious or depressed	44 (25.4)	73 (30.2)	30 (23.8)	35 (27.8)	PwD Q33	249 (29.3)	337 (44.4)		
	3 extremely anxious or depressed	2 (1.2)	8 (3.3)	2 (1.6)	1 (0.8)	IDEAL T3 Carer Q109	16 (1.9)	24 (3.2)		
	Missing	4 (2.3)	4 (1.7)	4 (3.2)	1 (0.8)		19 (2.2)	20 (2.6)		
Do you feel lonely?#	No	100 (57.8)		79 (62.7)		IDEAL T3	658 (77.3)		$\chi^2 (2) = 55.62, p < 0.001$	
	More or less	54 (31.2)		35 (27.8)		PwD Q51	86 (10.1)			
	Yes	13 (7.5)		7 (5.6)			86 (10.1)			
	Missing	6 (3.5)		5 (4.0)			21 (2.5)			

ELSA, English Longitudinal Study of Ageing; IDEAL, Improving the experience of Dementia and Enhancing Active Life. †For ELSA COVID wave 2, percentages and means displayed are for weighted data. #Question taken from IDEAL survey.

B) Capability to 'live well' with dementia

Item	Response key	All		Dyads only		Benchmark	Benchmarking data		Statistical comparison (where applicable)	
		PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)	PwD n (%) or mean (n, SD, range)	Carers (informants) n (%) or mean (n, SD, range)		PwD	Carers	PwD all INCLUDE versus benchmark	Carers all INCLUDE versus benchmark
QoL-AD item: When you think about your life and everything together, how do you feel about your life? [18, 19]	Poor Fair Good Excellent Missing	11 (6.4) 40 (23.1) 77 (44.5) 42 (24.3) 3 (1.7)	40 (16.5) 76 (31.4) 102 (42.1) 21 (8.7) 3 (1.2)	8 (6.3) 26 (20.6) 55 (43.7) 34 (27.0) 3 (2.4)	10 (7.9) 35 (27.8) 66 (52.4) 15 (11.9) -	IDEAL T3 PwD Q73 IDEAL T3 Carer Q18	23 (2.7) 134 (15.7) 472 (55.5) 203 (23.9) 19 (2.2)	100 (13.2) 295 (38.9) 340 (44.9) 18 (2.4) 6 (0.8)	$\chi^2 (3) = 13.57, p = 0.004$	$\chi^2 (3) = 23.30, p < 0.001$
On a scale of 0 – 10, how satisfied are you with your life nowadays? [17]	0 Not at all 1 2 3 4 5 6 7 8 9 10 Completely Mean (SD) Missing	2 (1.2) 2 (1.2) 2 (1.2) 7 (4.0) 4 (2.3) 30 (17.3) 11 (6.4) 33 (19.1) 36 (20.8) 15 (8.7) 27 (15.6) 7.0 (2.2) 4 (2.3)		1 (0.8) 2 (1.6) 1 (0.8) 4 (3.2) 3 (2.4) 19 (15.1) 4 (3.2) 24 (19.0) 27 (21.4) 13 (10.3) 24 (19.0) 7.3 (2.2) 4 (3.2)		IDEAL T3 PwD Q168a	4 (0.5) 6 (0.7) 11 (1.3) 8 (0.9) 20 (2.4) 85 (10.0) 52 (6.1) 114 (13.4) 184 (21.6) 90 (10.6) 195 (22.9) 7.7 (2.1) 82 (9.6)		U = 53082, z = -3.80, p < 0.001	
On a scale of 0 – 10, to what extent do you feel the things you do in your life are worthwhile? [17]	0 Not at all 1 2 3 4 5 6 7 8 9 10 Completely Mean (SD) Missing	3 (1.7) - 3 (1.7) 5 (2.9) 6 (3.5) 17 (9.8) 20 (11.6) 27 (15.6) 39 (22.5) 14 (8.1) 32 (18.5) 7.2 (2.2) 7 (4.0)		2 (1.6) - 2 (1.6) 2 (1.6) 4 (3.2) 10 (7.9) 15 (11.9) 19 (15.1) 28 (22.2) 11 (8.7) 26 (20.6) 7.4 (2.2) 7 (5.6)		IDEAL T3 PwD Q168b	5 (0.6) - 6 (0.7) 12 (1.4) 16 (1.9) 79 (9.3) 49 (5.8) 105 (12.3) 185 (21.7) 102 (12.0) 194 (22.8) 7.8 (2.0) 98 (11.5)		U = 52733, z = -3.21, p = 0.001	

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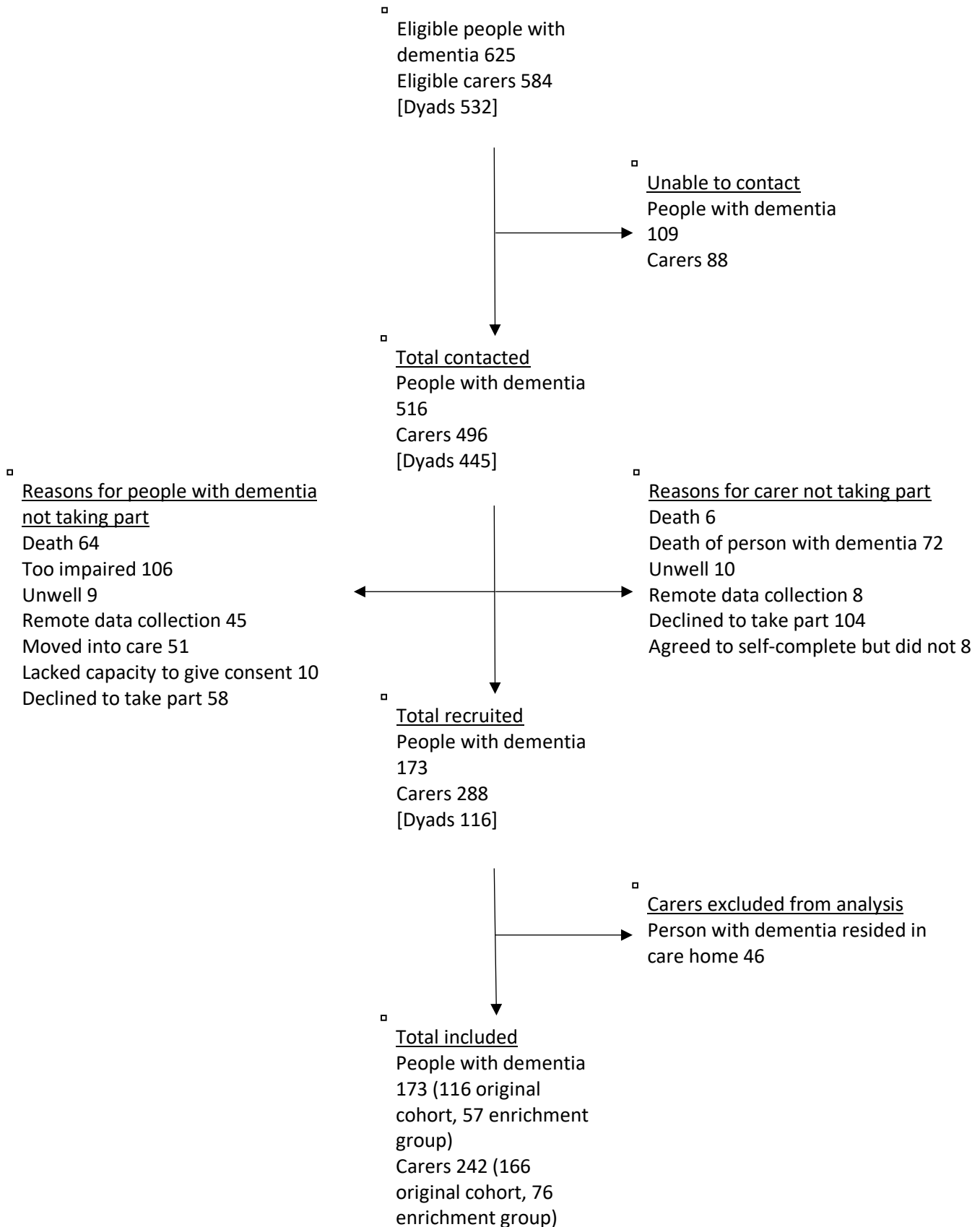
Supplementary Table 7. Sensitivity analysis for statistically significant tests from Supplementary Tables 3-6. The original statistical tests assume independence of samples when in reality the samples are partially overlapping. For these measures, overlapping samples t-tests for comparisons of means, or partially overlapping samples z-tests for comparisons of proportions are shown, as well as paired samples only tests.

Measure	Original statistical test Chi-square test of independence or Mann-Whitney U Test	Overlapping samples tests: Partially overlapping samples t-test (comparison of means) or Partially overlapping samples z-test (comparison of proportions)	Paired samples tests: McNemar's Chi-squared test or Friedman test
Carer (informant) responses			
In the last 3 months have you seen your GP at the surgery? [5]	$\chi^2(1) = 128.01, p < 0.001$	$z = -9.71, p < 0.001$	McNemar's test (n = 152): $\chi^2(1) = 55.14, p < 0.001$
In the last 3 months have you spoken to a GP on the telephone? [5]	$\chi^2(1) = 110.50, p < 0.001$	$z = 3.29, p = 0.001$	McNemar's test n = 153): $\chi^2(1) = 42.26, p < 0.001$
Is there a named health professional whom you can contact at any time?#	$\chi^2(1) = 47.23, p < 0.001$	$z = 1.17, p = 0.240$	McNemar's test (n = 151): $\chi^2(1) = 36.82, p < 0.001$
Is this named health professional in place to help specifically with the dementia?#	$\chi^2(1) = 56.71, p < 0.001$	$z = 1.64, p = 0.101$	McNemar's test (n = 145): $\chi^2(1) = 32.66, p < 0.001$
Which of these options best describes your level of pain or discomfort today? [7]	$\chi^2(2) = 12.24, p = 0.002$	$t = -3.38, p = 0.001^\dagger$	McNemar's test (n = 151): $\chi^2(3) = 5.84, p = 0.120$
Which of these options best describes your ability for self-care? [7]	$\chi^2(2) = 5.97, p = 0.050$	$t = 2.19, p = 0.029^\dagger$	McNemar's test (n = 153) $\chi^2(3), 47.16, p < 0.001$
Which of these options best describes your ability to do your usual activities? [7]	$\chi^2(2) = 6.73, p = 0.035$	$t = -2.32, p = 0.021^\dagger$	McNemar's test (n = 155): $\chi^2(3), 11.85, p = 0.008$
Do you use the internet [9]	$\chi^2(1) = 16.28, p < 0.001$	$z = 5.19, p < 0.001$	McNemar's test (n=156): $\chi^2(1) = 10.24, p = 0.001$
Considering all your friends including those who live in your neighborhood, how many friends do you see or hear from at least once a month? [11]	$U = 79220, z = -2.22, p = 0.027$	$t = -1.15, p = 0.251$	Friedman test (n=155): $\chi^2(15), 52.37 p < 0.001$
Which of these options best describes your mood today [7]	$\chi^2(2) = 16.79, p < 0.001$	$t = -3.78, p < 0.001^\dagger$	-
When you think about your life and everything together, how do you feel about your life? [18, 19]	$\chi^2(3) = 23.30, p < 0.001$	$z = 1.26, p = 0.207$	Friedman Test (n = 154): $\chi^2(3) = 9.9, p = 0.019$

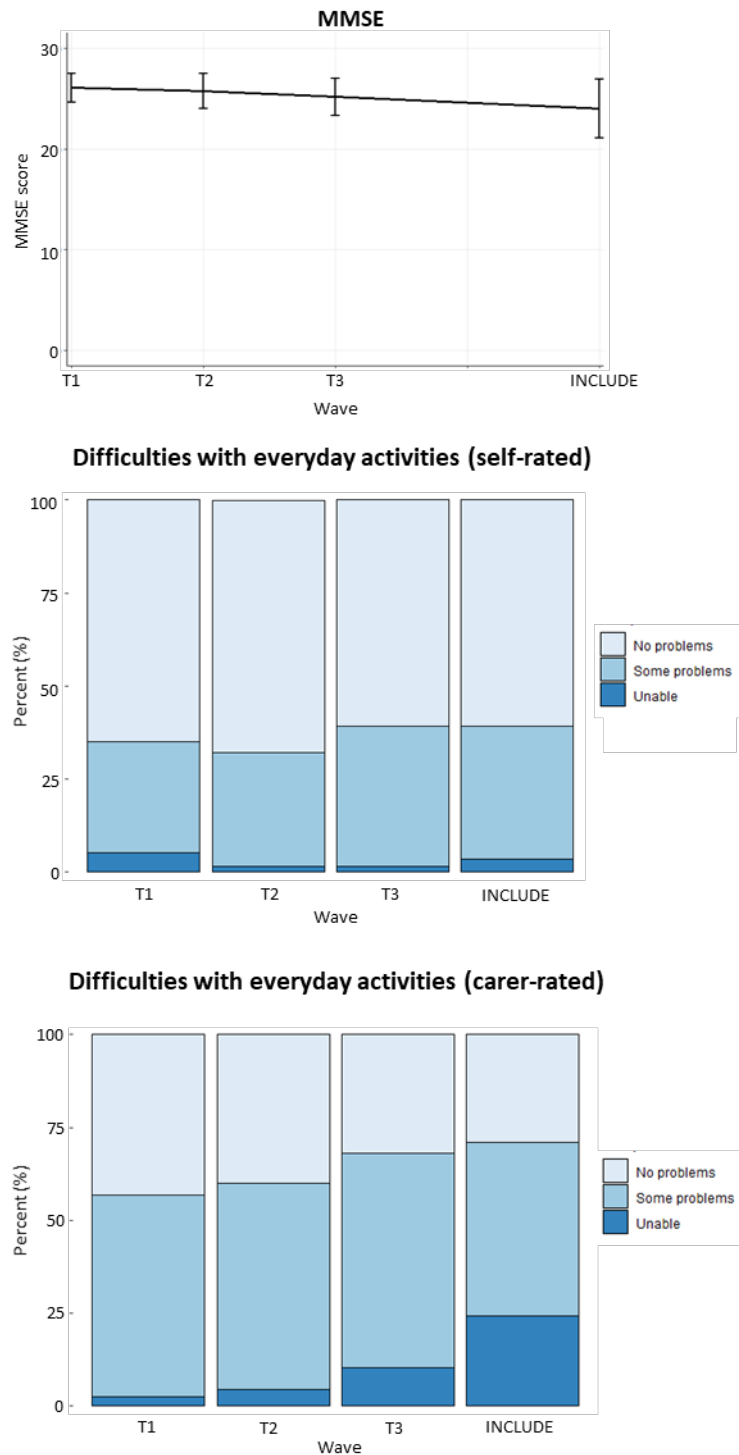
Person with dementia responses			
Estimated Mini-Mental State Examination score [^]	U = 95512, z = -7.43, p < 0.001	t = -7.5, p < 0.001	Friedman test (n = 112): χ^2 (14) = 27.14, p = 0.019
Compared to other people of your age, how would you describe your day-to-day memory? [8]	χ^2 (5) = 11.99, p = 0.035	t = -0.64, p = 0.520	Friedman test (n = 110): χ^2 (5) = 14.97, p = 0.010
Which of these options best describes your ability for self-care? [7]	χ^2 (2) = 6.34, p = 0.042	t = 1.58, p = 0.113 †	-
Do you use the internet [9]	χ^2 (1) = 85.59, p < 0.001	z = -10.70, p < 0.001	McNemar's test (n = 109): χ^2 (1) = 0.27, p = 0.606
Considering the people to whom you are related by birth, marriage or adoption, how many relatives do you see or hear from at least once a month? [11]	U = 76867, z = -2.66, p = 0.008	t = 2.97, p = 0.003	Friedman test (n = 111): χ^2 (14) = 30.06, p = 0.007
How satisfied are you with the support you receive from family? [#]	χ^2 (4) = 17.13, p = 0.002	t = -0.48, p = 0.629	Friedman test (n = 112) χ^2 (4) = 8.81, p = 0.066
How satisfied are you with the support you receive from friends? [#]	χ^2 (4) = 8.57, p = 0.073	t = 2.80, p = 0.005	Friedman test (n = 98): χ^2 (4) = 10.47, p = 0.033
Overall, would you say you expect more good things to happen to you than bad? [15]	χ^2 (4) = 25.86, p < 0.001	t = 3.00, p = 0.003	Friedman test (n = 113): χ^2 (4) = 5.69, p = 0.223
Do you feel you are still the same person you have always been? [16]	χ^2 (4) = 43.20, p < 0.001	t = -1.67, p = 0.094	Friedman test (n = 113): χ^2 (4) = 10.19, p = 0.037
Do you feel lonely? [#]	χ^2 (2) = 55.62, p < 0.001	t = -3.24, p = 0.001 [†]	McNemar's test (n = 111): χ^2 (3) = 25.00, p < 0.001
When you think about your life and everything together, how do you feel about your life? [18, 19]	χ^2 (3) = 13.57, p = 0.004	t = -2.45, p = 0.015	McNemar test (n = 113): χ^2 (10) = 21.09, p = 0.021
On a scale of 0 – 10, how satisfied are you with your life nowadays? [17]	U = 53082, z = -3.80, p < 0.001	t = -3.91, p = 0.001	Friedman test (n = 111): χ^2 (9) = 38.42, p < 0.001
On a scale of 0 – 10, to what extent do you feel the things you do in your life are worthwhile? [17]	U = 52733, z = -3.21, p = 0.001	t = -3.53, p = 0.001	Friedman test (n = 106): χ^2 (7) = 25.73, p = 0.001

[†]These are treated as ordinal for partially overlapping samples test and should be interpreted with caution as there are only 3 levels. [#]Question developed for IDEAL. [^]Estimated MMSE score is derived from 5-minute Montreal Cognitive Assessment (MoCA) scores collected as part of the INCLUDE assessment.

Supplementary Figure 1. Flowchart summarizing the recruitment process and reasons for withdrawal



Supplementary Figure 2. Trajectories of scores for cognition (MMSE and MoCA-equivalent MMSE) and functional ability* for participants with dementia from the original IDEAL cohort across the first three waves of IDEAL (T1-T3) and INCLUDE



There is approximately 1 year between IDEAL waves and approximately 2 years between T3 and INCLUDE. There were 116 people with dementia and 166 carers who took part in IDEAL T1-T3 and INCLUDE. *Ratings of functional ability were made in response to the item ‘which of these options best describes your (his/her) ability to do your (his/her) usual activities?’[7]

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