Impact of COVID-19 on 'living well' with mild-to-moderate dementia in the community: findings from the IDEAL cohort

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Abstract

Background

Negative impacts of the COVID-19 pandemic on people with dementia have been widely-documented, but most studies have relied on carer reports and few have compared responses to information collected before the pandemic.

Objective

We aimed to explore the impact of the pandemic on community-dwelling individuals with mild-to-moderate dementia and compare responses with pre-pandemic data.

Methods

During the second wave of the pandemic we conducted structured telephone interviews with 173 people with dementia and 242 carers acting as informants, all of whom had previously participated in the IDEAL cohort. Where possible we benchmarked responses against pre-pandemic data.

Results

Significant perceived negative impacts were identified in cognitive and functional skills and ability to engage in self-care and manage everyday activities, along with increased levels of loneliness and discontinuity in sense of self and a decline in perceived capability to 'live well'. Compared to pre-pandemic data there were lower levels of pain, depression and anxiety, higher levels of optimism, and better satisfaction with family support. There was little impact on physical health, mood, social connections and relationships, or perceptions of neighbourhood characteristics.

Conclusion

Efforts to mitigate negative impacts of pandemic-related restrictions and restore quality of life could focus on reablement to address the effects on participation in everyday activities, creating opportunities for

social contact to reduce loneliness, and personalised planning to reconnect people with their pre-COVID selves. Such efforts may build on the resilience demonstrated by people with dementia and carers in coping with the pandemic.

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INTRODUCTION

Multiple factors are associated with the way in which people living with dementia perceive their own quality of life [1] and ability to 'live well' [2] with the condition. 'Living well' refers to the 'best achievable state of health that encompasses all dimensions of physical, mental and social well-being' [2]. It is reflected in perceived quality of life, well-being and satisfaction with life [3,4]. Grouping these multiple factors into life domains demonstrates two important points [3]. First, the life domains of psychological characteristics and health, social capitals, assets, and resources, social circumstances, physical fitness and health, and managing everyday life with dementia are all independently associated with perceived ability to 'live well' [4]. Second, when modelled together the psychological domain dominates. This suggests that experiences in multiple life domains are linked to perceived ability to 'live well' with the condition through their impact on psychological health, with varying combinations of factors explaining differences in individual outcomes [3].

These findings from the British IDEAL (Improving the experience of Dementia and Enhancing Active Life) cohort study offer an evidence-based framework for exploring the effects of the COVID-19 pandemic on people living with dementia in the community [4, 5]. The emergence of the pandemic in 2020 and resulting periods of lockdown, interspersed with periods of ongoing social restriction, in the UK necessitated rapid changes to individual lifestyles, social engagement, and health and social care delivery. These changes could potentially affect several life domains associated with 'living well' for people with dementia in the community. Physical distancing and self-isolation could have an impact on social, mental and physical health, and relationships. IDEAL data collected prior to the pandemic constitutes a unique benchmark against which to assess the extent of these effects among cohort participants.

Findings from a number of telephone or online surveys, mainly of informal carers, describe the perceived impact of the situation on people with dementia during the first wave of the pandemic. Carers reported declines in the cognitive, communication, and functional abilities of people with dementia in several surveys [6-9]. Where asked, people with dementia themselves were concerned about declining skills and abilities [10-14]. Increases in neuropsychiatric symptoms, behaviour problems, depression, anxiety, and loneliness were also reported by carers [11, 15-23], although some studies found only limited impacts in these areas [24, 25]. For example, Thyrian, et al. [24] observed rates of depression, anxiety, and loneliness that were comparable to or even lower than age-equivalent norms for the general population of older people recorded before the pandemic. This highlights the importance of benchmarking data against pre-pandemic information or relevant population norms. Reduced availability of health care and support services had an impact during the early stages of the pandemic [26] leading to feelings of abandonment for some [12], with those living alone particularly affected [27]. However, there was little evidence for an immediate worsening of physical health [28].

It was important to gather evidence promptly in the exceptional situation created by the early stages of the pandemic in order to highlight the particular challenges faced by people living with dementia. However, the resulting set of evidence has three key limitations. First, few studies directly questioned people with dementia, relying instead on informant responses made by carers. Where people with dementia were included, their responses were often amalgamated with informant responses from carers. The perspectives of people with dementia and their carers can differ considerably and should not be used interchangeably when evaluating aspects of well-being [29]. Furthermore, in some instances carers may underestimate the abilities of the person with dementia or overestimate difficulties, while the responses of the person with dementia are more accurate relative to objective measures [30]. The reports carers provide when acting as informants are known to be affected by stress [31, 32], and there is plenty of evidence to indicate that carers experienced elevated levels of stress during the pandemic [18, 33-38]. Second, only a handful of studies were able to offer any comparison with pre-pandemic measures and typically these reported on people participating in intervention trials, which tend to have highly selected samples, or those who had

recently attended a memory clinic for assessment. Only one study [24] related responses to pre-pandemic population norms. Third, many studies focused on clinical symptoms with little attempt to gather data about the impact of the pandemic on quality of life or capability to 'live well' with dementia.

The need for restrictive measures to be in place over a lengthy period as the COVID-19 pandemic progressed to a second wave in Britain allows for an evaluation of impact over a longer timescale, taking into account the potential for adjustment after the initial stages. In the study reported here we explored the impact of the pandemic on people with dementia who were part of the existing, well-documented IDEAL cohort, through interviews undertaken during the second wave of the pandemic. We aimed to address key limitations in the available evidence by: gathering and reporting information from both people with dementia and carers; comparing responses with pre-pandemic data; and evaluating a wide range of factors including effects on quality of life. Based on the available evidence, we anticipated that both people with dementia and carers acting as informants would describe a considerable degree of decline in cognitive and functional skills, and that benchmarking against data from pre-COVID assessments would demonstrate an impact on psychological health, ability to manage everyday activities, social engagement, and perceptions of capability to 'live well' with dementia.

METHOD

Design

We report a mixed-methods cross-sectional observational study embedded in, and forming a discrete component of, the ongoing longitudinal IDEAL cohort study. The present study, known as INCLUDE (Identifying and mitigating the individual and dyadic impact of COVID-19 and life under physical distancing on people with dementia and carers), focused on the experiences of people with dementia and carers from the IDEAL cohort during the pandemic. Participants living in England and Wales were interviewed between September 21st 2020 and April 30th 2021 using remote data collection methods.

Significant restrictions on social contact, mobility, retail, and services were in force throughout this time with long periods of full local or national lockdown, while the UK vaccination programme for older and clinically vulnerable individuals began in December 2020.

All participants completed a structured telephone or online interview designed specifically for this study, which yielded both quantitative data and responses to open-ended questions; separate versions were prepared for people with dementia and for carers. A sub-set of participants additionally completed a semi-structured interview yielding qualitative data. Informed consent was documented for all participants.

In this paper we report quantitative data about the experiences of participants with dementia from the structured interviews, elicited through self-report and through informant reports given by carers. Where feasible, we drew comparisons with information collected from the IDEAL cohort prior to the pandemic. We also included for comparison purposes a small number of questions used in the English Longitudinal Study of Ageing (ELSA) COVID-19 Sub-Study Wave 2, for which data were collected in November and December 2020; these data are available for download from the UK Data Service [39].

The following section provides background information about the IDEAL cohort study. IDEAL recruited a cohort of people with mild-to-moderate dementia in Great Britain (i.e., England, Scotland, and Wales) between 2014 and 2016 (Time 1, T1) who are being followed up at regular intervals; in many cases, a family member or close friend (here termed 'carer') participates alongside the person with dementia. Details of the study can be found in the published protocols [4, 5]. At baseline the cohort comprised 1,537 community-dwelling individuals with dementia along with 1,277 carers. Inclusion criteria for people with dementia were a previously-established clinical diagnosis of dementia and a current Mini-Mental Sate Examination [MMSE; 40] score of 15 or above (indicative of mild-to-moderate dementia) recorded as part of the study recruitment process. People with dementia and carers provided information during home visits by National Health Service (NHS) clinical research network staff. Both the distribution of dementia diagnoses, with Alzheimer's disease accounting for just over half of all diagnoses, and the small proportion of individuals from minority ethnic groups in the sample were consistent with available estimates of

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population values [41, 42]. From the original cohort, 1,183 people with dementia and 988 carers were interviewed again 12 months later (2015 – 2017; T2) and 851 people with dementia and 759 carers after a further 12 months (2016 – 2018; T3). The fourth wave of data collection (2018 – 2020; T4), intended to follow 24 months after T3, was disrupted by the COVID-19 pandemic and not all participants were seen; at T4 data were collected from 253 people with dementia and 306 carers. The fifth wave of data collection (T5, planned to take place 12 months after T4, in 2019 – 2021) had to be discontinued at an early stage because home visits were no longer feasible. All IDEAL participants seen at T4, and those seen at T3 who had not yet been approached for T4, were invited to take part in INCLUDE.

Alongside T4, prior to the start of the pandemic, an additional 204 people with dementia were recruited to enrich the original IDEAL cohort, together with 183 carers (the 'enrichment group'). Recruitment of people with dementia to the enrichment cohort was restricted to those with frontotemporal and Parkinsonian dementias, those with young-onset dementia of any type (<65 years), and the very old (90+ years) with dementia of any type; inclusion criteria were otherwise the same as for the original cohort. The intention when recruiting the enrichment group was to combine data collected at T4, T5 and T6 with data gathered from participants in the same sub-groups in the original cohort at T1, T2 and T3, where numbers were small, for statistical analysis purposes. All enrichment group participants were invited to take part in INCLUDE.

INCLUDE was approved by Wales Research Ethics Committee 5 as an amendment to IDEAL-2 for England and Wales (18/WS/0111 AM12). IDEAL was approved by Wales Research Ethics Committee 5 (reference 13/WA/0405) and IDEAL-2 by Wales Research Ethics Committee 5 (reference 18/WS/0111) and Scotland A Research Ethics Committee (reference 18/SS/0037). IDEAL and IDEAL-2 are registered with the UK Clinical Research Network (UKCRN), numbers 16593 and 37955, respectively.

Participants

People living with dementia and their carers living in England or Wales who had previously participated in the IDEAL cohort study were eligible for INCLUDE if they had either taken part at the most recent assessment point or indicated willingness to be contacted again at the next assessment point. People with dementia could take part regardless of whether they had a participating carer, and carers could take part even if the person with dementia whom they supported was not taking part. The only exclusion criterion was a lack of capacity to give informed consent on the part of the person with dementia. For the purposes of the analyses presented here, which focus on people with dementia living in the community, data from carers reporting on a person with dementia who had moved into residential care since joining the cohort were excluded. Where people could not be contacted by telephone or email, an invitation letter was sent to the last known address.

Measures

The structured interview was designed specifically for the study in order to gather as much relevant information as possible across the life domains covered in IDEAL while limiting the burden on participants. Versions were prepared for people with dementia and carers. Carers were asked to both provide informant reports and describe their own experiences; the latter will be reported separately. The interviews were programmed in Qualtrics to facilitate data capture and management. They included brief measures and items from validated scales used in the IDEAL study, as well as bespoke questions focusing on experiences during the pandemic; some additional open-ended questions offered opportunities to expand on specific responses. To enable some comparison of experiences during the pandemic against data from a wider sample of the older population, we also included 7 questions from the English Longitudinal Study of Ageing (ELSA) COVID-19 Sub-Study Wave 2. All questions reported in this paper are listed in full in Supplementary Tables 3 – 6, with references to the sources from which they were taken provided where applicable. The interviews began with questions about health and healthcare during the pandemic, and subsequent

sections covered perceptions of social connection and relationships, psychological health, ability to manage everyday life during this period, and overall perceptions of capability to 'live well'. To assess current cognitive function, we used the 5-minute Montreal Cognitive Assessment (MoCA) [43], which was designed to be suitable for telephone administration. In IDEAL, the MMSE was used on entry to the study and at each follow-up assessment, so for comparison purposes we converted MoCA total scores to their MMSE equivalents [44]. Demographic information was available from previously-collected data.

Procedure

Trained interviewers who were graduate or masters level psychologists contacted potential participants to discuss the study by telephone, email, or video call according to individual preferences. Where people could not be contacted by telephone or email, an invitation letter was sent to the last known address containing a reply slip and stamped addressed envelope as well as details of how to contact the team by telephone or email. In initial conversations with participants, interviewers provided information about the study and answered questions to ensure that participants could make an informed decision about whether or not to participate. Informed consent was taken in a follow-up call unless there was any indication that the participant lacked capacity to decide about participation. The structured interviews for people with dementia who consented to participate were then conducted over the telephone or online via platforms such as Zoom or Microsoft Teams according to participant preference. Carers were given the option of self-completing the survey online; half took this option while the remainder were interviewed over the telephone or online. Interviews could be undertaken in one single meeting or several shorter meetings depending on participants' wishes. Protocols were in place to ensure appropriate responses should a participant become distressed during the interview and appropriate action should significant concerns arise about a participant's welfare.

Data analysis

Quantitative data were analysed descriptively. Responses to questions or scales used previously in IDEAL were compared with data from the full cohort at T3, the most recent complete time-point, and non-parametric Chi-Square and Mann-Whitney U-tests were used to compare distributions across response categories or mean ratings to indicate where responses might differ pre- and post-COVID. The sample included both participants who had been in the cohort since the beginning and contributed data at T3 and participants who had joined the cohort as part of the enrichment group and who contributed data for the first time alongside the T4 round of data collection, and hence in relation to T3 data it comprised a mixture of paired and independent responses. Because of this partial overlap, we conducted sensitivity analyses using the 'PartiallyOverlapping' package in R which allows for a comparison of means using the partially overlapping t-test (for continuous and ordinal variables), and a comparison of proportions using the partially overlapping samples z-test (for dichotomous variables) [45-47]. In addition, differences for the paired sample only were examined using McNemar's tests and Friedman tests. These alternate methods have some limitations, with the PartiallyOverlapping package unable to handle categorical variables (these were treated as ordinal where appropriate), and McNemar's test unable to handle cells with low frequencies. Comparisons between INCLUDE and ELSA COVID-19 Wave 2 were conducted using Chi-Square and Mann-Whitney U-tests. ELSA COVID-19 Wave 2 cross-sectional weights for core members were applied (n = 5558).

RESULTS

Sample characteristics

We identified 625 people with dementia and 584 carers from available records as potentially-eligible for INCLUDE. We were able to contact 516 people with dementia and 496 carers, which included 445 dyads. The final sample reported here comprised 173 people with dementia (116 from the original cohort and 57

from the enrichment group), and 242 carers (166 from the original cohort and 76 from the enrichment group. There were 126 dyads, 47 people with dementia who had no participating carer, and 116 carers who provided information about a person with dementia who did not contribute directly. A flowchart summarising the recruitment process and reasons for withdrawal is provided in Supplementary Figure 1. Full details of the responses to all interview questions are provided for both the whole sample of people with dementia and carers and the subgroup of 126 dyads in Supplementary Tables 3 – 6. Sensitivity analyses (overlapping samples tests and paired samples tests) are reported in Supplementary Table 7. Here we focus on responses for the whole sample.

Characteristics of the participants with dementia and the carers contributing to the present analyses as informants are summarised in Table 1. Participants with dementia had a mean age of 74.33 years (range 50 – 98); 58.4% were male, 94.8% were white British, and 21.4% lived alone. The most common diagnosis was Alzheimer's disease (45.1%) and the mean 5-minute MoCA cognitive test score was 18.74 (range 1 – 30; MMSE equivalent score 24.14 ± 5.60). Overall, the MMSE equivalent score was higher for INCLUDE participants than the mean MMSE score at IDEAL T3 (IDEAL T3 20.54 ± 6.21, $p < 0.001$; Supplementary Table 7). However, considering only those INCLUDE participants who formed part of the original IDEAL cohort and were assessed at T3, the MMSE equivalent score was significantly lower in INCLUDE than at IDEAL T3 (23.99 ± 5.80 vs 25.18 ± 3.67, p=0.019; Supplementary Table 7). This is also demonstrated in Supplementary Figure 2, where the MMSE score from IDEAL T1-T3 is plotted for participants who were part of the original IDEAL cohort and hence had MMSE scores at those time-points, together with the MoCA-equivalent MMSE score from INCLUDE. This shows, at group level, a gradual decline in MMSE score over time with no indication of a steeper decline during the pandemic. Among the carers, 86.8% were spouses or partners of the person with dementia. Carers had a mean age of 70.92 years (range 32 – 93), and 68.2% were female. Characteristics of participants in IDEAL T3 and the ELSA COVID-19 Sub-Study Wave 2, the data from which were used in benchmarking, are shown in Supplementary Tables 1 and 2.

(((Table 1 near here)))

Health and healthcare during the pandemic

Details of responses to questions about health and healthcare are summarised in Table 2; full details can be found in Supplementary Table 3. According to carers, 5.9% of people with dementia had been infected with COVID-19 prior to the interview, a proportion which was in line with population data for over 50s in England as of 8th May 2021. Among the respondents with dementia, 3.5% reported having been infected with COVID-19 and 16.8% said someone close to them had been infected with the virus, which was lower than the 22.8% reported in the general older population in the ELSA COVID-19 Sub-Study Wave 2. Twenty-two percent of the participants with dementia said they had developed new health problems during the pandemic and a similar proportion (19.7%) said they had avoided seeking help because of COVID-19, although only 7.4% of carers thought there had been an avoidance of help-seeking. Within dyads, more people with dementia than carers reported avoiding seeking help (15.1% vs 10.3%). Despite this, for the participants with dementia, self-ratings of health in the past 4 weeks did not differ significantly from equivalent ratings at IDEAL T3 (11% vs 12.1% endorsing poor or very poor). While self-ratings of pain and mobility did not differ significantly from IDEAL T3, carer ratings indicated significantly fewer problems with pain (46.7% vs 55.3%). This was supported in the partially overlapping samples test, but not when looking at paired samples only (Supplementary Table 7).

About half of the participants with dementia (48%) thought their health care needs had been affected by the pandemic, for example through appointments being postponed or operations delayed, and within dyads perceptions were similar. Only 13.9% of people with dementia and 15.3% of carers reported that healthcare services people with dementia were already receiving had stopped due to the pandemic. Nearly one-quarter of the participants with dementia said they had seen a General Practitioner (GP) in person in the last 3 months, and over one-third said they had spoken to a GP on the telephone. Carer-reported contact with GPs reflected the shift to telephone consultations, with in person appointments significantly less frequent but telephone appointments significantly more frequent compared to IDEAL T3; these

findings were supported in the sensitivity analyses shown in Supplementary Table 7. The overall level of contact was somewhat lower than at IDEAL T3 (66.1% vs 77.5%). More carers s said they had a named health professional whom they could contact at any time than was the case in IDEAL T3 (62.0% vs 35.2%), and the named health professional was more often in place due to the dementia diagnosis rather than another health condition than at IDEAL T3 (50.8% vs 22.9%). These findings were supported in the paired samples tests (Supplementary Table 7).

(((Table 2 near here)))

Cognition, functioning and managing everyday activities

Responses to questions about cognition, functioning and managing everyday activities are summarised in Table 3; full details can be seen in Supplementary Tables 4 and 7. Considerable proportions of people with dementia had noticed a decline in their ability to remember everyday things (43.9%), remember recent events (45.1%), concentrate (49.1%), say what they wanted to say (42.8%), plan ahead (31.8%), and make decisions (30.6%), and increased confusion (47.4%). Higher proportions of carers reported a worsening in ability to remember everyday things (77.7%), remember recent events (73.1%), concentrate (70.2%), use language (63.2%), plan ahead (49.2%), and make decisions (55.0%), and increased confusion (77.3%), among people with dementia.

Self-ratings of day-to-day memory functioning were significantly different to those of the IDEAL T3 sample, with more endorsing 'poor' or 'very poor' (30.7% vs 23.4%) but also slightly more endorsing 'very good' or 'excellent' (13.3% vs 8.6%). This finding was supported in the tests for paired samples only (Supplementary Table 7). The majority of people with dementia (58.4%) perceived no problems in doing everyday activities, and about one-third (35.8%) thought they had 'some problems'; this did not differ significantly from responses at IDEAL T3 (Supplementary Table 4 and Supplementary Figure 2). Carers perceived significantly more difficulties, with nearly one-quarter saying that the person with dementia was unable to carry out

usual activities (23.6%), which was supported in the sensitivity analysis (Supplementary Table 7). This is also demonstrated in Supplementary Figure 2, where the score on this question from IDEAL T1-T3 is plotted for participants who were part of the original IDEAL cohort together with the equivalent score from INCLUDE. It shows carers reporting a gradual increase in difficulty with everyday activities over time, but the increase in the number of people with dementia said to be unable to carry out these activities at the time of the INCLUDE assessment might reflect a somewhat steeper decline than would otherwise be expected, although it is not possible to establish this with any certainty. Over two-thirds of people with dementia thought they had no difficulties with self-care (69.4%) and one-quarter (24.3%) thought they had 'some' problems; this differed significantly from IDEAL T3 where only 16.3% perceived some difficulties. Carers perceived significantly more difficulties in self-care, with just under one-fifth (18.2%) saying the person with dementia was unable to wash or dress independently, and this was supported in the sensitivity analysis.

Nearly three-quarters of participants with dementia (81.5%) felt it had been very or fairly easy to keep themselves occupied during the pandemic, and two-thirds of carers (65.3%) shared this view. Over two-thirds (68.8%) of people with dementia said they used the internet, compared to only 28.8% at IDEAL T3; informant reports suggested that fewer people with dementia were using the internet, although there was still an increase compared to IDEAL T3 (38.0% vs 24.3%). These findings were supported in the sensitivity analyses.

(((Table 3 near here)))

Social capitals, assets, and resources

Details of responses to questions about social capitals, assets, and resources are summarised in Table 4 and Supplementary Table 5. People with dementia tended to be more satisfied with the support they received from family compared to responses in IDEAL T3 (85.0% vs 80.2% very or slightly satisfied), and the average number of family members in contact was slightly higher. Sensitivity analyses support the findings that

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more family members were in contact since IDEAL T3, but not the finding that people with dementia tend to be more satisfied with support from family (Supplementary Table 7). Generally, the relationship with the primary carer was perceived positively by those with a carer participating in the study, with over three-quarters (76.2%) saying they got on 'very' or 'extremely' well, and carers also endorsed the perception of positive relationships (71.4%); there were no significant differences to the ratings made at IDEAL T3. The number of friends in regular contact did not differ significantly from IDEAL T3 for people with dementia; carer ratings suggested a small but statistically significant reduction compared to IDEAL T3, also supported in the paired samples only test (Supplementary Table 7). Although a higher proportion expressed satisfaction with support from friends (76.9% vs 63.5%) than at IDEAL T3, this did not differ significantly. Similarly, although higher proportions gave positive ratings of neighbourhood trust (74.6% vs 69.2%) and willingness to help (75.7% vs 71.5%), and satisfaction with the neighbourhood as a place to live (90.7% vs 84.7%), there were no significant differences to IDEAL T3.

With regard to practical concerns, the proportion of carers reporting worries about having enough food during the pandemic was slightly higher than for the ELSA sample (5.8% vs 8.1%) and there was a statistically-significant difference; the proportion of participants with dementia who said they had been worried about having enough food was the same as that in the ELSA sample (8.1%). In relation to their financial situation, significantly fewer people thought they were worse off compared to before the pandemic than was the case in ELSA.

(((Table 4 near here)))

Psychological well-being

Responses to questions about psychological well-being are summarised in Table 5, and additional details are given in Supplementary Table 6(a). Most people with dementia said they did not feel depressed or anxious. Rates of depression and anxiety were slightly lower than at IDEAL T3 (26.6% vs 31.2%) but did not

differ significantly, and anxiety levels the previous day were in line with the wider population surveyed in ELSA. Carers perceived significantly lower levels of depression and anxiety than was the case at IDEAL T3 (33.5% vs 47.6%) which was supported in the partially overlapping samples test (Supplementary Table 7). Nearly three-quarters of people with dementia said that in the last 2 weeks they had felt cheerful and in good spirits more than half of the time, most of the time or all the time, and although the proportion was lower than at IDEAL T3 (71.7% vs 77.5%), this did not differ significantly. Carers had a slightly less positive view, but this did not differ significantly from IDEAL T3 (62.0% vs 61.4%). Ratings of happiness the previous day did not differ significantly from the ratings obtained in ELSA. People with dementia were significantly more optimistic than was the case in IDEAL T3, with 71.1% vs 64.5% expecting more good things to happen to them than bad, which was again supported in the partially overlapping test. Nearly half (45.1%) of the participants with dementia, but only around one-fifth (22.3%) of carers, thought there had been some positive aspects or benefits of the COVID-19 pandemic. Most people with dementia thought they had coped fairly or very well during the pandemic, with nearly half (48.6%) endorsing 'very well' and only 6.9% saying they had not coped well; carers were somewhat less positive, with just over one-third (38.8%) endorsing 'very well' and 14.9% saying the person with dementia had not coped well.

In contrast to the generally positive picture with regard to perceptions of mood and coping, people with dementia reported significantly higher rates of loneliness compared to IDEAL T3 (38.7% vs 20.2%), and significantly more disagreed with the statement that they were 'still the same person' they had always been (29.5% vs 20.3%). Both of these findings were supported in sensitivity analyses (Supplementary Table 7).

 (((Table 5 near here)))

Capability to 'live well' with dementia

Responses to questions about capability to 'live well' are summarised in Table 5 with additional details in Supplementary Table 6(b). People with dementia reported significantly lower satisfaction with life, and less

of a sense that the things they do are worthwhile compared to IDEAL T3. When asked how they feel about their life as a whole, fewer endorsed 'good' or 'excellent' than was the case in IDEAL T3 (68.8% vs 79.4%). Carers, although having a less positive view overall, were slightly more likely to endorse 'good' or 'excellent' than at IDEAL T3 (50.8% vs 47.3%). All of these findings were supported in the sensitivity analyses (Supplementary Table 7).

DISCUSSION

Availability of the well-documented IDEAL cohort provided a unique opportunity to examine the perceived impact of the COVID-19 pandemic on people with dementia living in the community in Britain, with potential to compare responses with data collected before the pandemic. Mirroring the broad focus of the IDEAL programme, interviews undertaken during the second wave of the pandemic covered experiences in a range of life domains and perceived capability to 'live well' with dementia. Responses from the participants with dementia and from carers acting as informants suggested they perceived little negative impact on physical health, mood, social connections and relationships, or perceptions of neighbourhood characteristics. Indeed, compared to benchmark data, there were indications of lower levels of pain, depression and anxiety, higher levels of optimism, and better satisfaction with family support. As expected, negative impacts were perceived in relation to cognitive and functional skills, and ability to engage in self-care and manage everyday activities, along with increased levels of loneliness, a higher proportion feeling 'not the same person' as before, and an overall decline in perceptions of capability to 'live well' with dementia.

There was no evidence in our sample of even a modest perceived negative impact on physical health. This reflected indications gathered in the early stages of the pandemic [27, 28], and was observed despite perceptions that healthcare needs were affected by the pandemic and reports of developing new health problems. The lack of reports of any negative impact was reassuring given early concerns that negative consequences for physical health might not be detectable immediately but might become evident over a

longer time-period [48]. One factor that possibly mitigated against a negative impact on physical health in our sample was the availability of GP telephone consultations and an increase in the proportion having a named health professional as a key point of contact.

There was also no evidence of perceived negative impacts on social capitals, assets and resources, despite reduced availability of support services and usual activities during lockdown periods and the potential for increased tension on caregiving relationships due to lack of opportunity for respite. Our findings were consistent with other indications that social support was generally satisfactory and that people found alternative activities to engage in where usual activities were not available [24]. Although carers acting as informants were more likely to indicate concern over availability of food during the pandemic than the general population of over 50s, perceptions of neighbourhood characteristics were generally positive.

Evidence regarding psychological well-being was mixed. Importantly, we did see evidence of increased rates of feeling lonely relative to pre-COVID responses, consistent with reports of increased loneliness during the first wave of the pandemic [11, 15, 17-19, 23]. Other negative psychological impacts of the pandemic were suggested by the increased proportion of people with dementia feeling they were 'not the same person' as before; previous work with IDEAL cohort data identified this question as a sensitive indicator of poor psychological well-being [49]. However, reported levels of depression and anxiety did not differ significantly from benchmark except that carers were less likely to think that the person with dementia was depressed or anxious. Similarly, ratings of positive mood did not differ significantly from benchmark, except that people with dementia were significantly more optimistic. These findings appear to conflict with the numerous reports of increased levels of anxiety and depression in the first wave [11, 15, 17-19, 23], but may reflect changes in perspective as people adjusted to the pandemic, and reasons to feel optimistic once effective vaccines became available and vaccination programmes were introduced by the UK NHS.

As expected, there were responses suggesting strong perceptions of decline in cognitive and functional ability from both people with dementia and informants, and compared to benchmark data there were increased levels of perceived memory problems and difficulties with self-care. This was consistent with earlier studies primarily based on carer report that highlighted declines in cognitive [7, 8, 17, 22], functional [6, 8, 17], and communication [9] ability during the pandemic. Responses of people with dementia in our study were consistent with early reports indicating that people with dementia themselves were concerned about increased decline in abilities during lockdown [11, 13, 14]. While some decline would be expected over time, perceptions of accelerated cognitive decline are supported by studies of memory clinic samples that identified steeper trajectories of decline in MMSE scores during the pandemic [50, 51]. Perceived decline in cognitive and functional abilities over and above what would normally be expected could be attributable to the effects of pandemic-related restrictive measures, including more social isolation, reduction in usual activities and loss of routine as well as increased carer stress [51]. However, for those INCLUDE participants who contributed at IDEAL T1-T3, comparison with pre-pandemic data suggests that decline in cognitive ability was gradual over time, with no indication of a sudden steep drop during the pandemic; the situation is less clear with regard to carers' ratings of difficulty with everyday activities, where the increase in reports of people with dementia being unable to carry out these activities may possibly suggest a steeper decline than would otherwise be expected.

Also as expected, responses indicated significant perceived negative impacts of the pandemic on capability to 'live well' with dementia from the perspective of participants with dementia, although not from that of carers acting as informants. Given that multiple life domains, and individual factors within those domains, are associated with capability to 'live well' [3], these perceptions may be linked to perceived negative impacts of the pandemic in the domains of managing everyday life with dementia and psychological well-being. Having poorer functional ability, along with being lonely and feeling 'not the same person' have all been associated with poorer quality of life, satisfaction with life, and well-being in previous analyses of IDEAL cohort data [32, 49, 52].

The findings outlined above must be considered in the context of study limitations. While comparison with benchmark data is a useful indicator of pandemic-related effects, we needed to use the most recent complete dataset, rather than T4 which was interrupted by the start of the pandemic. IDEAL T3 data collection was completed 18 months prior to the outbreak of COVID-19, and hence other changes in the intervening time period may have influenced responses. For example, the higher proportion of carers saying the person with dementia had a named health professional as a main point of contact may reflect the emphasis on ensuring availability of a named health professional in updated practice guidance on management of dementia [53]. The differences observed are not necessarily caused by or attributable to the COVID-19 pandemic.

Additional recruitment to enrich the IDEAL cohort at T4 meant that the characteristics of the current sample, although similar in most respects, were different in some ways to the sample at IDEAL T3. The current sample had a higher proportion of people aged under 65 (17.3% vs 7.8%) and higher proportions with frontotemporal dementia (13.9% vs 3.7%), Parkinson's disease dementia (4.6% vs 2%), and dementia with Lewy bodies (8.1% vs 3.2%). Higher numbers of people with these rarer dementias where memory problems are less prominent in the early stages might account for the increased proportion reporting perceived 'good' or 'excellent' memory. A higher proportion of the enrichment group declined to participate in the current study than was the case among the original cohort members, and those participants from the original cohort who remain involved in the study after several years of participation may be a particularly resilient group with good physical health. The main reasons for attrition from IDEAL T1 to IDEAL T3 were increased health problems or death. It is possible therefore that our data underestimate the negative impact of the pandemic. Nevertheless, we did observe significant perceived negative effects in expected areas.

The significant results reported are intended to indicate variables which may show changes from pre-pandemic levels. The statistical tests used in the study assumed the current (INCLUDE) and IDEAL T3 samples were independent of each other, but they were partially overlapping and incorporated both paired

and unpaired samples. We therefore conducted sensitivity analyses using the partially overlapping t-test or z-test, and paired samples tests on paired data only. The partially overlapping tests are not able to handle categorical variables but since the categorical variables we tested were ordered, they were treated as ordinal, and the t-test was conducted as recommended by Derrick et al [47]. The tests for paired samples only also had limitations as the McNemar's test used to handle categorical variables fails when cells have zero or low numbers. When the partially overlapping samples tests or paired samples tests conducted for purposes of sensitivity analysis do not support the results of the main analyses, the main findings should be interpreted with caution, but in addition the limitations of these additional tests should be borne in mind. Finally, in designing the structured interviews we had to be mindful of the potential burden on participants and in order to cover the broad range of areas of interest and allow participants space to describe their experiences we opted to assess key constructs through single items rather than scales and had to take some difficult decisions about which topics to leave out.

Despite these limitations the study has a number of strengths. The sample is a sizeable one and conveys the perspectives of both people with dementia themselves and carers acting as informants, as well as allowing for benchmarking of responses. The data were collected over a seven-month period during the second wave of the pandemic, and may present a more realistic picture than that obtained amid the heightened emotion and anxiety of the first few weeks of restrictions, as there had been time for people to adjust. Because the study is embedded in the IDEAL programme, it will be possible to follow up the participants in a further round of data collection. This is important as the longer-term impact of the pandemic on people with dementia is as yet unknown.

While many participants with dementia felt they coped well during the pandemic, and some indicators were better than pre-pandemic levels, there were several important perceived negative impacts that could have significant long-term consequences. The main implications of these findings are three-fold. First, the findings are consistent with perceptions of a steeper than usual trajectory of decline in cognitive and functional ability, and hence ability to manage self-care and everyday activities, resulting from the

conditions experienced during periods of restriction due to the pandemic. Where there has been an accelerated decline, some lost ground might potentially be recoverable, but this would require appropriate support for reablement [54]; otherwise, more rapid and extensive decline is likely to result in increased needs for care and higher demands on family carers. Second, increased feelings of loneliness among people with dementia are a major cause for concern, especially given the established associations of loneliness with poor psychological well-being and quality of life [52] and hence the potential risks associated with experiencing loneliness. It may be that loneliness will reduce as restrictions ease and opportunities to resume social activities emerge, but here again, support may be needed to regain lost ground, especially where confidence has been lost or anxieties about contracting the virus remain high. Third, our findings demonstrate a negative impact on sense of self and on perceptions of quality of life and life satisfaction, and it is not clear whether this trend might reverse naturally; if not, additional support in the form of personalised planning might be needed to regain a better quality of life.

Conclusions

Examining the perceived impact of the restrictions imposed during the COVID-19 pandemic on people with dementia participating in the IDEAL cohort, as described through self-report and through informant reports from carers, has provided a unique opportunity to compare experiences during the pandemic with pre-pandemic data. The findings suggest that efforts to mitigate negative impacts of pandemic-related restrictions on people with dementia living in the community could focus primarily on reablement to address the effects of accelerated declines in ability to carry out and participate in everyday activities, on creating opportunities for meaningful social contact to reduce loneliness, and on personalised planning to reconnect people with their pre-COVID selves and restore pre-COVID levels of quality of life. Such efforts may build on the resilience demonstrated by people with dementia and their carers in coping with the pandemic and, in many cases, managing to maintain a generally positive outlook on life despite the extra challenges of living with dementia under these circumstances.

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Author contributions

Conception and design – LC, AM, CP, RC, LA, AB, AH, RL, CQ, FEM, CV

Acquisition, analysis and interpretation of data LC, AM, LDG, ED, AH, SP

Drafting the manuscript – LC

Critical appraisal and review of the manuscript – AM, LDG, CP, RC, ED, AH, SP, LA, AB, AH, RL, CQ, FEM, CV

Final approval of the manuscript – all

References

[1]   Martyr A, Nelis SM, Quinn C, Wu Y-T, Lamont RA, Henderson C, Clarke R, Hindle JV, Thom JM, Jones

         IR, Morris RG, Rusted JM, Victor CR, Clare L (2018) Living well with dementia: a systematic review

         and correlational meta-analysis of factors associated with quality of life, well-being and life

         satisfaction in people with dementia. *Psychological Medicine* **48**, 2130-2139.

[2]   Institute Of Medicine (2012) *Living Well with Chronic Illness: A Call for Public Health Action*,

         National Academies Press, Washington.

[3]   Clare L, Wu Y-T, Jones IR, Victor CR, Nelis SM, Martyr A, Quinn C, Litherland R, Pickett JA, Hindle JV,

         Jones RW, Knapp M, Kopelman MD, Morris RG, Rusted JM, Thom JM, Lamont RA, Henderson C,

         Rippon I, Hillman A, Matthews FE, On behalf of the IDEAL study team (2019) A comprehensive

         model of factors associated with subjective perceptions of "living well" with dementia: findings

         from the IDEAL study. *Alzheimer Disease & Associated Disorders* **33**, 36-41.

[4]   Clare L, Nelis SM, Quinn C, Martyr A, Henderson C, Hindle JV, Jones IR, Jones RW, Knapp M,

         Kopelman MD, Morris RG, Pickett JA, Rusted JM, Savitch NM, Thom JM, Victor CR (2014) Improving

         the experience of dementia and enhancing active life - living well with dementia: study protocol for

         the IDEAL study. *Health and Quality of Life Outcomes* **12**, 164.

[5]   Silarova B, Nelis SM, Ashworth RM, Ballard C, Bieńkiewicz M, Henderson C, Hillman A, Hindle JV,

         Hughes JC, Lamont RA, Litherland R, Jones IR, Jones RW, Knapp M, Kotting P, Martyr A, Matthews

         FE, Morris RG, Quinn C, Regan J, Rusted JM, van den Heuvel EA, Victor CR, Wu Y-T, Clare L (2018)

         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. *BMC Public Health* **18**, 1214.

[6]   Borges-Machado F, Barros D, Ribeiro O, Carvalho J (2020) The effects of COVID-19 home

         confinement in dementia care: physical and cognitive decline, severe neuropsychiatric symptoms

         and increased caregiving burden. *American Journal of Alzheimer's Disease & Other Dementias* **35**,

         1533317520976720.

[7]   Boutoleau-Bretonniere C, Pouclet-Courtemanche H, Gillet A, Bernard A, Deruet AL, Gouraud I, Mazoue A, Lamy E, Rocher L, Kapogiannis D, El Haj M (2020) The effects of confinement on neuropsychiatric symptoms in Alzheimer's disease during the COVID-19 crisis. *Journal of Alzheimer's Disease* **76**, 41-47.

[8]   Canevelli M, Valletta M, Toccaceli Blasi M, Remoli G, Sarti G, Nuti F, Sciancalepore F, Ruberti E, Cesari M, Bruno G (2020) Facing dementia during the COVID-19 outbreak. *Journal of the American Geriatrics Society* **68**, 1673-1676.

[9]   Tsapanou A, Papatriantafyllou JD, Yiannopoulou K, Sali D, Kalligerou F, Ntanasi E, Zoi P, Margioti E, Kamtsadeli V, Hatzopoulou M, Koustimpi M, Zagka A, Papageorgiou SG, Sakka P (2021) The impact of COVID-19 pandemic on people with mild cognitive impairment/dementia and on their caregivers. *International Journal of Geriatric Psychiatry* **36**, 583-587.

[10]   Bacsu JD, O'Connell ME, Cammer A, Azizi M, Grewal K, Poole L, Green S, Sivananthan S, Spiteri RJ (2021) Using Twitter to understand the COVID-19 experiences of people with dementia: infodemiology study. *Journal of Medical Internet Research* **23**, e26254.

[11]   Carlos AF, Poloni TE, Caridi M, Pozzolini M, Vaccaro R, Rolandi E, Cirrincione A, Pettinato L, Vitali SF, Tronconi L, Ceroni M, Guaita A (2021) Life during COVID-19 lockdown in Italy: the influence of cognitive state on psychosocial, behavioral and lifestyle profiles of older adults. *Aging & Mental Health*. doi: 10.1080/13607863.13602020.11870210

[12]   Roach P, Zwiers A, Cox E, Fischer K, Charlton A, Josephson CB, Patten SB, Seitz D, Ismail Z, Smith EE (2021) Understanding the impact of the COVID-19 pandemic on well-being and virtual care for people living with dementia and care partners living in the community. *Dementia* **20**, 2007-2023.

[13]   van Maurik IS, Bakker ED, van den Buuse S, Gillissen F, van de Beek M, Lemstra E, Mank A, van den Bosch KA, van Leeuwenstijn M, Bouwman FH, Scheltens P, van der Flier WM (2020) Psychosocial effects of corona measures on patients with dementia, mild cognitive impairment and subjective cognitive decline. *Frontiers in Psychiatry* **11**, 585686.

[14]   O'Rourke G, Pentecost C, Van den Heuvel EA, Victor C, Quinn C, Hillman A, Litherland R, Clare L (in

press) Living with dementia under COVID-19 restrictions: coping and support needs among people

with dementia and carers from the IDEAL cohort *Ageing & Society*.

[15]   Azevedo L, Calandri IL, Slachevsky A, Graviotto HG, Vieira MCS, Andrade CB, Rossetti AP, Generoso

AB, Carmona KC, Pinto LAC, Sorbara M, Pinto A, Guajardo T, Olavarria L, Thumala D, Crivelli L, Vivas

L, Allegri RF, Barbosa MT, Serrano CM, Miranda-Castillo C, Caramelli P (2021) Impact of social

isolation on people with dementia and their family caregivers. *Journal of Alzheimer's Disease* **81**,

607-617.

[16]   Barguilla A, Fernandez-Lebrero A, Estragues-Gazquez I, Garcia-Escobar G, Navalpotro-Gomez I,

Manero RM, Puente-Periz V, Roquer J, Puig-Pijoan A (2020) Effects of COVID-19 pandemic

confinement in patients with cognitive impairment. *Frontiers in Neurology* **11**, 589901.

[17]   Borelli WV, Augustin MC, de Oliveira PBF, Reggiani LC, Bandeira-de-Mello RG, Schumacher-Schuh

AF, Chaves MLF, Castilhos RM (2021) Neuropsychiatric symptoms in patients with dementia

associated with increased psychological distress in caregivers during the COVID-19 pandemic.

Journal of Alzheimer's Disease **80**, 1705-1712.

[18]   Cohen G, Russo MJ, Campos JA, Allegri RF (2020) COVID-19 epidemic in Argentina: worsening of

behavioral symptoms in elderly subjects with dementia living in the community. *Frontiers in

Psychiatry* **11**, 866.

[19]   Hanna K, Giebel C, Tetlow H, Ward K, Shenton J, Cannon J, Komuravelli A, Gaughan A, Eley R,

Rogers C, Rajagopal M, Limbert S, Callaghan S, Whittington R, Butchard S, Shaw L, Gabbay M (2021)

Emotional and mental wellbeing following COVID-19 public health measures on people living with

dementia and carers. *Journal of Geriatric Psychiatry and Neurology*. doi:

10.1177/0891988721996816

[20]   Panerai S, Prestianni G, Musso S, Muratore S, Tasca D, Catania V, Gelardi D, Ferri R (2020) The

impact of COVID-19 confinement on the neurobehavioral manifestations of people with Major

Neurocognitive Disorder and on the level of burden of their caregivers. *Life Span and Disability* **23**,

303-320.

[21]   Pongan E, Dorey JM, Borg C, Getenet JC, Bachelet R, Lourioux C, Laurent B, Group C, Rey R, Rouch I

(2021) COVID-19: association between increase of behavioral and psychological symptoms of

dementia during lockdown and caregivers' poor mental health. *Journal of Alzheimer's Disease* **80**,

1713-1721.

[22]   Rainero I, Bruni AC, Marra C, Cagnin A, Bonanni L, Cupidi C, Lagana V, Rubino E, Vacca A, Di Lorenzo

R, Provero P, Isella V, Vanacore N, Agosta F, Appollonio I, Caffarra P, Busse C, Sambati R, Quaranta

D, Guglielmi V, Logroscino G, Filippi M, Tedeschi G, Ferrarese C, Group SIC-S (2020) The impact of

COVID-19 quarantine on patients with dementia and family caregivers: a nation-wide survey.

Frontiers in Aging Neuroscience **12**, 625781.

[23]   Tam MT, Dosso JA, Robillard JM (2021) The impact of a global pandemic on people living with

dementia and their care partners: analysis of 417 lived experience reports. *Journal of Alzheimer's

Disease* **80**, 865-875.

[24]   Thyrian JR, Kracht F, Nikelski A, Boekholt M, Schumacher-Schonert F, Radke A, Michalowsky B,

Vollmar HC, Hoffmann W, Rodriguez FS, Kreisel SH (2020) The situation of elderly with cognitive

impairment living at home during lockdown in the Corona-pandemic in Germany. *BMC Geriatrics*

20, 540.

[25]   Manini A, Brambilla M, Maggiore L, Pomati S, Pantoni L (2021) The impact of lockdown during

SARS-CoV-2 outbreak on behavioral and psychological symptoms of dementia. *Neurological

Sciences* **42**, 825-833.

[26]   Giebel C, Cannon J, Hanna K, Butchard S, Eley R, Gaughan A, Komuravelli A, Shenton J, Callaghan S,

Tetlow H, Limbert S, Whittington R, Rogers C, Rajagopal M, Ward K, Shaw L, Corcoran R, Bennett K,

Gabbay M (2020) Impact of COVID-19 related social support service closures on people with

dementia and unpaid carers: a qualitative study. *Aging & Mental Health* **25**, 1281-1288.

[27]   Goodman-Casanova JM, Dura-Perez E, Guzman-Parra J, Cuesta-Vargas A, Mayoral-Cleries F, Durá-

Pérez E, Guzmán-Parra J, Mayoral-Cleries F (2020) Telehealth home support during COVID-19

confinement for community-dwelling older adults with mild cognitive impairment or mild

dementia: survey study. *Journal of Medical Internet Research* **22**, e19434.

[28]   Lara B, Carnes A, Dakterzada F, Benitez I, Piñol-Ripoll G (2020) Neuropsychiatric symptoms and quality of life in Spanish patients with Alzheimer's disease during the COVID-19 lockdown. *European Journal of Neurology* **27**, 1744-1747.

[29]   Wu Y-T, Nelis SM, Quinn C, Martyr A, Jones IR, Victor CR, Knapp M, Henderson C, Hindle JV, Jones RW, Kopelman MD, Morris RG, Pickett JA, Rusted JM, Thom JM, Litherland R, Matthews FE, Clare L, on behalf of the IDEAL Programme team (2020) Factors associated with self- and informant ratings of quality of life, well-being and life satisfaction in people with mild-to-moderate dementia: results from the Improving the experience of Dementia and Enhancing Active Life programme. *Age and Ageing* **49**, 446-452.

[30]   Martyr A, Clare L (2018) Awareness of functional ability in people with early-stage dementia. *International Journal of Geriatric Psychiatry* **32**, 31-38.

[31]   Martyr A, Nelis SM, Clare L (2014) Predictors of perceived functional ability in early-stage dementia: self-ratings, informant ratings and discrepancy scores. *International Journal of Geriatric Psychiatry* **29**, 852-862.

[32]   Martyr A, Nelis SM, Quinn C, Rusted JM, Morris RG, 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.

[33]   Altieri M, Santangelo G (2021) The Psychological Impact of COVID-19 Pandemic and Lockdown on Caregivers of People With Dementia. *The American Journal of Geriatric Psychiatry* **29**, 27-34.

[34]   Budnick A, Hering C, Eggert S, Teubner C, Suhr R, Kuhlmey A, Gellert P (2021) Informal caregivers during the COVID-19 pandemic perceive additional burden: findings from an ad-hoc survey in Germany. *BMC Health Services Research* **21**, 353.

[35]   Cagnin A, Di Lorenzo R, Marra C, Bonanni L, Cupidi C, Lagana V, Rubino E, Vacca A, Provero P, Isella V, Vanacore N, Agosta F, Appollonio I, Caffarra P, Pettenuzzo I, Sambati R, Quaranta D, Guglielmi V, Logroscino G, Filippi M, Tedeschi G, Ferrarese C, Rainero I, Bruni AC, Group SIC-S (2020) Behavioral

and psychological effects of coronavirus disease-19 quarantine in patients with dementia. *Frontiers in Psychiatry* **11**, 578015.

[36]   Carcavilla N, Pozo AS, Gonzalez B, Moral-Cuesta D, Roldan JJ, Erice V, Remirez AG (2021) Needs of dementia family caregivers in Spain during the COVID-19 pandemic. *Journal of Alzheimer's Disease* **80**, 533-537.

[37]   Koh ZY, Law F, Chew J, Ali N, Lim WS (2020) Impact of coronavirus disease on persons with dementia and their caregivers: an audit study. *Annals of Geriatric Medicine and Research* **24**, 316-320.

[38]   Savla J, Roberto KA, Blieszner R, McCann BR, Hoyt E, Knight AL (2021) Dementia caregiving during the "stay-at-home" phase of COVID-19 pandemic. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences* **76**, e241-e245.

[39]   Steptoe A, Addario G, Banks J, Batty GD, Coughlin K, Crawford R, Dangerfield P, Marmot M, Nazroo J, Oldfield Z, Pacchiotti B, Steel N, Wood M, Zaninotto P (2021) *English Longitudinal Study of Ageing COVID-19 Study, Waves 1-2, 2020. [data collection]*, UK Data Service. SN: 8688.

[40]   Folstein MF, Folstein SE, McHugh PR (1975) "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* **12**, 189-198.

[41]   All-Party Parliamentary Group on Dementia (2013) *Dementia does not discriminate: The experiences of black, Asian and minority ethnic communities*, House of Commons London.

[42]   Prince M, Knapp M, Guerchet M, McCrone P, Prina M, Comas-Herrera A, Wittenberg R, Adelaja B, Hu B, King D (2014) *Dementia UK: Second edition – Overview*, Alzheimer's Society, London.

[43]   Wong A, Xiong YY, Kwan PW, Chan AY, Lam WW, Wang K, Chu WC, Nyenhuis DL, Nasreddine Z, Wong LK, Mok VC (2009) The validity, reliability and clinical utility of the Hong Kong Montreal Cognitive Assessment (HK-MoCA) in patients with cerebral small vessel disease. *Dementia and Geriatric Cognitive Disorders* **28**, 81-87.

[44]   Wong A, Black SE, Yiu SYP, Au LWC, Lau AYL, Soo YOY, Chan AYY, Leung TWH, Wong LKS, Kwok TCY, Cheung TCK, Leung KT, Lam BYK, Kwan JSK, Mok VCT (2018) Converting MMSE to MoCA and MoCA

5-minute protocol in an educationally heterogeneous sample with stroke or transient ischemic attack. *International Journal of Geriatric Psychiatry* **33**, 729-734.

[45]   Derrick B, Russ B, Toher D, White P (2017) Test statistics for the comparison of means for two samples that include both paired and independent observations. *Journal of Modern Applied Statistical Methods* **16**, 137-157.

[46]   Derrick B, Dobson-Mckittrick A, Toher D, White P (2015) Test statistics for comparing two proportions with partially overlapping samples. *Journal of Applied Quantitative Methods* **10**, 1-14.

[47]   Derrick B, White P (2018) Methods for comparing the responses from a Likert question, with paired observations and independent observations in each of two samples. *International Journal of Mathematics and Statistics* **19**, 84-93.

[48]   Tuijt R, Rait G, Frost R, Wilcock J, Manthorpe J, Walters K (2021) Remote primary care consultations for people living with dementia during the COVID-19 pandemic: experiences of people living with dementia and their carers. *British Journal of General Practice* **71**, e574-e582.

[49]   Clare L, Martyr A, Morris RG, Tippett LJ (2020) Discontinuity in the subjective experience of self among people with mild-to-moderate dementia is associated with poorer psychological health: findings from the IDEAL cohort. *Journal of Alzheimer's Disease* **77**, 127-138.

[50]   Ismail, II, Kamel WA, Al-Hashel JY (2021) Association of COVID-19 pandemic and rate of cognitive decline in patients with dementia and mild cognitive impairment: a cross-sectional study. *Gerontology and Geriatric Medicine* **7**, 23337214211005223.

[51]   Tondo G, Sarasso B, Serra P, Tesser F, Comi C (2021) The impact of the COVID-19 pandemic on the cognition of people with dementia. *International Journal of Environmental Research and Public Health* **18**, 4285.

[52]   Victor CR, Rippon I, Quinn C, Martyr A, Clare L, on behalf of the IDEAL programme team (2021) The role of subjective social status in living well for carers of people with dementia: findings from the Improving the experience of Dementia and Enhancing Active Life programme. *International Journal of Care and Caring* **5**, 447-467.

[53]   National Institute for Health and Care Excellence (2018) *Dementia: assessment, management and support for people living with dementia and their carers*, National Institutre for Health and Care Excellence, London.

[54]   Clare L (2017) Rehabilitation for people living with dementia: a practical framework of positive support. *PLoS Medicine* **14**, e1002245.

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

Table 1. Characteristics of the participants with dementia and the carers who acted as informants

		People with dementia; N (%)	Carers; N (%)
Sex	Male	101 (58.4)	77 (31.8)
	Female	72 (41.6)	165 (68.2)
Age	<65	30 (17.3)	58 (24.0)
	65-69	25 (14.5)	45 (18.6)
	70-74	30 (17.3)	57 (23.6)
	75-79	32 (18.5)	31 (12.8)
	80+	56 (32.4)	51 (21.1)
	Mean (SD); range	74.33 (10.01); 50-98	70.92 (10.15); 32-93
Ethnicity	White British	164 (94.8)	226 (93.4)
	White Other	4 (2.3)	7 (2.9)
	Other	3 (1.7)	3 (1.2)
	Missing	2 (1.2)	6 (2.5)
Education	No qualifications	36 (20.8)	33 (13.6)
	school leaving certificate at age 16	32 (18.5)	55 (22.7)
	school leaving certificate at age 18	65 (37.6)	66 (27.3)
	University	38 (22.0)	75 (30.6)
	Missing	2 (1.1)	14 (5.8)
Socioeconomic Status	I Professionals	12 (6.9)	19 (7.9)
	II Managerial and technical	67 (38.7)	95 (39.3)
	III-NM Skilled occupations - non-manual	29 (16.8)	63 (26.0)
	III-M Skilled occupations - manual	32 (18.5)	26 (10.7)
	IV Partly skilled	20 (11.6)	13 (5.4)

	V Unskilled	3 (1.7)	4 (1.7)
	Armed forces	4 (2.3)	1 (0.4)
	N/A	2 (1.2)	7 (2.9)
	Missing	4 (2.3)	14 (5.8)
Current marital status	Single	7 (4.0)	6 (2.5)
	Married; first	88 (50.9)	156 (64.5)
	Remarried	29 (16.8)	50 (20.7)
	A civil partnership	2 (1.2)	2 (0.8)
	Legally separated	2 (1.2)	2 (0.8)
	Divorced	24 (13.9)	12 (5.0)
	Widowed	15 (8.7)	1 (0.4)
	Cohabiting	6 (3.5)	12 (5.0)
	Missing	-	1 (0.4)
Carer relationship	Spouse/partner		210 (86.8)
	Other family/friend		32 (13.2)
Living situation	Living alone	37 (21.4)	
	Live with spouse/partner	129 (74.6)	
	Live with other	7 (4.0)	
Diagnosis	Alzheimer's disease (AD)	78 (45.1)	
	Vascular dementia (VaD)	17 (9.8)	
	Mixed AD and VaD	26 (15.0)	
	Frontotemporal dementia (FTD)	24 (13.9)	
	Parkinson's disease dementia (PDD)	8 (4.6)	
	Dementia with Lewy bodies (DLB)	14 (8.1)	
	Unspecified/Other	6 (3.5)	
5-minute MoCA	Mean (SD); range	18.74 (7.28); 1-30	

| Estimated MMSE equivalent to MoCA score | Mean (SD); range | 24.14 (5.60); 9-30 | |

Note: Montreal Cognitive Assessment, MoCA; Mini-Mental State Examination, MMSE. ^ Socioeconomic status is categorised in accordance with the standard method used in the UK, which is based on occupational classification [55].

Table 2. Experiences of health and healthcare during the pandemic, and comparison with benchmark data (shown in brackets) where available

	INCLUDE		Benchmark for	Benchmark data	
	People with dementia	Carers (informants)	comparison where applicable	people with dementia	Carers (informants)
Direct experience of COVID-19:					
Had COVID-19	3.5%	2.5%	Population*	6.1%	6.1%
Treated in hospital for COVID-19	0.6%	0.8%	ELSA+	0.5%	0.5%
Someone close to you had COVID-19	16.8%	n/a	ELSA+	22.8%	
Health during the pandemic:					
Overall health poor or very poor	11.0%	12.0%	IDEAL T3	12.1%	
Experienced moderate or extreme pain	44.5%	**46.7%**	IDEAL T3	37.8%	**55.3%**
Developed new health problems	22.0%	n/a			
Avoided seeking help for health issues	19.7%	7.4%			
Healthcare needs affected by pandemic	48.0%	37.6%			
Healthcare services stopped due to pandemic	13.9%	15.3%			
Contact with health professionals and services:					
Seen GP in person in last 3 months	23.7%	**19.0%**	IDEAL T3		**58.5%**

Spoken to GP telephone in last 3 months	37.6%	**50.0%**	IDEAL T3		**16.1%**
Named health professional available	n/a	**62.0%**	IDEAL T3		**35.2%**
Health professional available due to dementia	n/a	**50.8%**	IDEAL T3		**22.9%**
Attended day centre (pre COVID-related closure)	12.1%	15.7%	IDEAL T3		19.2%
Day centre remains closed	8.1%	11.1%	IDEAL T3		

Note: English Longitudinal Study of Ageing, ELSA; Improving the experience of Dementia and Enhancing Active Life, IDEAL. Bold type indicates a statistically significant difference. ^Benchmark data are shown in brackets after the equivalent data for the current sample. *Population estimate for people aged 50+ in England as of 8th May 2021; source: https://coronavirus.data.gov.uk/details/download + English Longitudinal Study on Ageing COVID Sub-Study Wave 2 core members [39].

Table 3. Cognition, functioning and managing everyday activities during the pandemic, and comparison with benchmark data (shown in brackets) where available

	INCLUDE		Benchmark for	Benchmark data	
	People with dementia	Carers (informants)	comparison where applicable	people with dementia	Carers (informants)
Cognitive and functional ability:					
Memory poor or very poor	**30.7%**	n/a	IDEAL T3	**23.4%**	
Difficulty with everyday activities	39.3%	**69.1%**	IDEAL T3	36.4%	**76.6%**
Difficulty with self-care	**28.3%**	**54.6%**	IDEAL T3	**21.0%**	**49.9%**
Problems with mobility	44.5%	60.8%	IDEAL T3	42.2%	58.4%
Perceived impact of pandemic on cognition:	43.9%	77.7%			
Ability to remember everyday things declined	45.1%	73.1%			
Ability to remember recent events declined	49.1%	70.2%			
Ability to concentrate declined	42.8%	63.2%			
Ability to say what you want to say declined	31.8%	49.2%			
Ability to plan ahead declined	30.6%	55.0%			
Ability to make decisions declined	47.4%	77.3%			

Felt confused more often	43.9%	77.7%			
Occupation: Use internet	**68.8%**	**38.0%**	IDEAL T3	**28.8%**	**24.3%**
Fairly or very easy to keep oneself occupied	81.5%	65.3%			

Note: Improving the experience of Dementia and Enhancing Active Life, IDEAL. Bold type indicates a statistically significant difference. ^Benchmark data are shown

in brackets after the equivalent data for the current sample

Table 4. Social capitals, assets, and resources during the pandemic, and comparison with benchmark data where applicable

	INCLUDE		Benchmark for	Benchmark data	
	People with dementia	Carers (informants)	comparison where applicable	people with dementia	Carers (informants)
Practical concerns: Worried about having enough food	8.1%	**5.8%**	ELSA+	8.1%	**8.1%**
Financially worse off	**9.8%**	n/a	ELSA+	**18.9%**	
Family and friends: Get on very or extremely well with carer (dyads)	76.2%	71.4%	IDEAL T3	68.5%	65.6%
Number of relatives in contact at least monthly	**5.6 ±4.2**	5.0 ±3.5	IDEAL T3	**4.7 ±3.7**	4.8 ±3.6
Very/slightly satisfied with support from family	**85.0%**	n/a	IDEAL T3	**80.2%**	
Number of friends in contact at least monthly	5.1 ±6.1	**3.6 ±4.5**	IDEAL T3	5.2 ±7.3	**4.1 ±4.5**
Very/slightly satisfied with support from friends	76.9%	n/a	IDEAL T3	63.5%	
Neighbourhood:					
People in neighbourhood willing to help	75.7%	n/a	IDEAL T3	71.5%	
People in neighbourhood trustworthy	74.6%	n/a	IDEAL T3	69.2%	
Satisfied with neighbourhood	90.7%	n/a	IDEAL T3	84.7%	

Note: English Longitudinal Study of Ageing, ELSA; Improving the experience of Dementia and Enhancing Active Life, IDEAL. Bold type indicates a statistically significant difference. ^Benchmark data are shown in brackets after the equivalent data for the current sample. + English Longitudinal Study on Ageing COVID Sub-Study Wave 2 core members [39].

Table 5. Psychological well-being and quality of life during the pandemic, and comparison with benchmark data where applicable

	INCLUDE		Benchmark for	Benchmark data	
	People with dementia	Carers (informants)	comparison where applicable	People with dementia	Carers (informants)
Negative feelings: Moderately or extremely anxious or depressed	26.6%	**33.5%**	IDEAL T3	31.2%	**47.6%**
Anxiety the previous day (0 – 10 scale)	3.0 ±3.1	n/a	ELSA+	3.0 ±2.9	
Not the same person I have always been	**29.5%**	n/a	IDEAL T3	**20.3%**	
Feel lonely	**38.7%**	n/a	IDEAL T3	**20.2%**	
Positive feelings: Cheerful & in good spirits >50% of time last 2 wks	71.7%	62.0%	IDEAL T3	77.5%	61.4%
Happiness the previous day (0 – 10 scale)	**7.4 ±2.2**	n/a	ELSA+	**7.2 ±2.0**	
Expect more good things to happen than bad	**71.1%**	n/a	IDEAL T3	**64.5%**	
Coping with the pandemic: Pandemic had positive aspects or benefits	45.1%	22.3%			
Coped very or fairly well during the pandemic	91.4%	84.3%			
Quality of life: Satisfied with life (0 – 10 scale)	**7.0 ±2.2**	n/a	IDEAL T3	**7.7 ±2.1**	

Feel the things I do are worthwhile (0 – 10)	**7.2 ±2.2**	n/a	IDEAL T3	**7.8 ±2.0**	
Feel life as a whole is good or excellent	**68.8%**	**50.8%**	IDEAL T3	**79.4%**	**47.3%**

Note: English Longitudinal Study of Ageing, ELSA; Improving the experience of Dementia and Enhancing Active Life, IDEAL. Bold type indicates a statistically significant difference. ^Benchmark data are shown in brackets after the equivalent data for the current sample + English Longitudinal Study on Ageing COVID Sub-Study Wave 2 core members[39].

Supplementary material

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 (206)
	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) | |

Note: Improving the experience of Dementia and Enhancing Active Life, IDEAL; Mini-Mental State Examination, MMSE

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	2399	47.4%
	Female	3159	52.6%
Age	<65	1371	46.9%
	65-69	1153	14.4%
	70-74	1287	14.3%
	75-79	822	10.0%
	80+	925	14.6%
	Mean (SD); range		66.88 (10.44), 38-52
Ethnicity	White (any)	5331	92.0%
	Black, Asian and minority ethnic	227	8.0%
Education	No qualifications	836	17.0%
	school leaving certificate at age 16	1332	23.4%
	school leaving certificate at age 18	1399	23.5%
	University	1242	19.4%
	Other/foreign	473	9.7%
	Missing	276	7.0%
Current marital status	Single	293	6.6%
	Married	3556	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	1459	24.6%
	Lives with others	4078	75.0%
	Missing	21	0.4%
Dementia	Diagnosed	62	1.2%
	Not known to have a diagnosis	5496	98.8%

Note: English Longitudinal Study of Ageing, ELSA. ^ Socioeconomic status is based on self-reported information on main occupation and categorised based on the standard occupational classification for the UK.

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	Benchmarking data †	Statistical comparison
		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)	(where applicable)	(INCLUDE all carers vs benchmark)
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)	X^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)	X^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)			

Question	Response							
Did any healthcare services you were already receiving stop due to the coronavirus?	Yes	24 (13.9)	37 (15.3)	13 (10.3)	19 (15.1)			
	No	143 (82.7)	201 (83.1)	108 (85.7)	106 (84.1)			
	Missing/Unsure	6 (3.5)	4 (1.7)	5 (4.0)	1 (0.8)			
In the last 3 months have you seen your GP at the surgery?[5]	Yes	41 (23.7)	46 (19.0)	31 (24.6)	29 (23.0)	IDEAL T3 Carer Q179	444 (58.5)	X^2 (1) =, 128.01, p < 0.001
	No	126 (72.8)	193 (79.8)	90 (71.4)	96 (76.2)		275 (36.2)	
	Missing/Unsure	6 (3.5)	-	5 (4.0)	1 (0.8)		40 (5.3)	
In the last 3 months have you spoken to a GP on the telephone?[5]	Yes	65 (37.6)	121 (50.0)	43 (34.1)	63 (50.0)	IDEAL T3 Carer Q181	122 (16.1)	X^2 (1) = 110.50, p < 0.001
	No	102 (59.0)	118 (48.8)	78 (61.9)	62 (49.2)		616 (81.2)	
	Missing	6 (3.5)	3 (1.2)	5 (4.0)	1 (0.8)		21 (2.7)	
Is there a named health professional whom you can contact at any time?#	Yes		150 (62.0)		81 (64.3)	IDEAL T3 Carer Q98	267 (35.2)	X^2 (1) = 47.23, p < 0.001
	No		91 (37.6)		45 (35.7)		461 (60.7)	
	Missing/DK		1 (0.4)		-		31 (4.1)	
Is this named health professional in place to help specifically with the dementia?#	Yes		123 (50.8)		67 (53.2)	IDEAL T3 Carer Q99	174 (22.9)	X^2 (1) = 56.71, p < 0.001
	No		27 (11.2)		14 (11.1)		70 (9.2)	
	No previous Q		91 (37.6)		45 (35.7)		461 (64.8)	
	Missing/DK		1 (0.4)		-		54 (3.0)	
Before the coronavirus outbreak did you normally go to a day centre?[5]	Yes	21 (12.1)	38 (15.7)	14 (11.1)	11 (8.7)	IDEAL T3 Carer Q198	146 (19.2)	X^2 (1) = 1.34, p = 0.248
	No	147 (85.0)	202 (83.5)	108 (85.7)	115 (91.3)		605 (79.7)	
	Missing	5 (2.9)	2 (0.8)	4 (3.2)	-		8 (1.1)	
If yes, has this restarted?	Yes	7 (4.0)	9 (3.7)	6 (4.8)	4 (3.2)			
	No	14 (8.1)	28 (11.1)	8 (6.3)	7 (5.6)			
	Missing	-	2 (0.07)	-	-			
	NA	152 (87.9)	243 (84.4)	112 (88.9)	115 (91.3)			

*Note: English Longitudinal Study of Ageing, ELSA; Improving the experience of Dementia and Enhancing Active Life, IDEAL. *Population estimate for people aged 50+ in England as of 8th May 2021; source: https://coronavirus.data.gov.uk/details/download ^Comparison is INCLUDE carers (all) with IDEAL T3 carers +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.*

(b) Physical health

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

Note: Improving the experience of Dementia and Enhancing Active Life, IDEAL.

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	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)	(where applicable)	PwD	Carers	PwD all INCLUDE vs bench-mark	Carers all INCLUDE vs bench-mark
Compared to other people of your age, how would you describe your day-to-day memory?[8]	Very poor Poor Fair Good Very good Excellent Missing	15 (8.7) 38 (22.0) 56 (32.4) 35 (20.2) 18 (10.4) 5 (2.9) 6 (3.5)		10 (7.9) 29 (23.0) 40 (31.7) 26 (20.6) 14 (11.1) 2 (1.6) 5 (4.0)		IDEAL T3 PwD Q25	43 (5.1) 156 (18.3) 319 (37.5) 219 (25.7) 64 (7.5) 9 (1.1) 41 (4.8)		X^2 (5) = 11.99, p = 0.035	
Since the coronavirus outbreak have you noticed any changes in your ability to remember everyday things?∞	Better No change Worse Missing	3 (1.7) 86 (49.7) 76 (43.9) 8 (4.6)	2 (0.8) 50 (20.7) 188 (77.7) 2 (0.8)	2 (1.6) 67 (53.2) 51 (40.5) 6 (4.8)	1 (0.8) 28 (22.2) 97 (77.0) -					
Since the coronavirus outbreak have you noticed any changes in your ability to remember recent events?∞	Better No change Worse Missing	1 (0.6) 85 (49.1) 78 (45.1) 9 (5.2)	4 (1.7) 59 (24.4) 177 (73.1) 2 (0.8)	1 (0.8) 67 (53.2) 51 (40.5) 7 (5.6)	2 (1.6) 32 (25.4) 92 (73.0) -					
Since the coronavirus outbreak have you noticed any changes in your ability to concentrate?∞	Better No change Worse Missing	3 (1.7) 76 (43.9) 85 (49.1) 9 (5.2)	1 (0.4) 68 (28.1) 170 (70.2) 3 (1.2)	3 (2.4) 56 (44.4) 61 (48.4) 6 (4.8)	- 36 (28.6) 89 (70.6) 1 (0.8)					

Question	Response									
Since the coronavirus outbreak have you noticed any changes in your ability to say what you want to say?∞	Better No change Worse Missing	1 (0.6) 90 (52.0) 74 (42.8) 8 (4.6)	- 87 (36.0) 153 (63.2) 2 (0.8)	1 (0.8) 68 (54.0) 51 (40.5) 6 (4.8)	- 53 (42.1) 73 (57.9) -					
Since the coronavirus outbreak have you noticed any changes in your ability to plan ahead?∞	Better No change Worse Missing	2 (1.2) 106 (61.3) 55 (31.8) 10 (5.8)	1 (0.4) 120 (49.6) 119 (49.2) 2 (0.8)	2 (1.6) 75 (59.5) 41 (32.5) 8 (6.3)	1 (0.8) 69 (54.8) 56 (44.4) -					
Since the coronavirus outbreak have you noticed any changes in your ability to make decisions?∞	Better No change Worse Missing	2 (1.2) 110 (63.6) 53 (30.6) 8 (4.6)	- 107 (44.2) 133 (55.0) 2 (0.8)	2 (1.6) 81 (64.3) 37 (29.4) 6 (4.8)	- 62 (49.2) 64 (50.8) -					
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)	$X^2 (2) =$ 6.34, p = 0.042	$X^2 (2) =$ 5.97, p = 0.050

Question	Response					Source				
Which of these options best describes your ability to do your usual activities?[7]	1 no problems	101 (58.4)	73 (30.2)	74 (58.7)	56 (44.4)	IDEAL T3 PwD Q31	522 (61.3)	166 (21.9)	X^2 (2) = 4.60, p = 0.100	X^2 (2) = 6.73, p = 0.035
	2 some problems	62 (35.8)	110 (45.5)	43 (34.1)	54 (42.9)	IDEAL T3 Carer Q108	252 (29.6)	379 (49.9)		
	3 unable to perform usual activities	6 (3.5)	57 (23.6)	5 (4.0)	16 (12.7)		58 (6.8)	203 (26.7)		
	Missing	4 (2.3)	2 (0.8)	2 (3.2)	-		19 (2.2)	11 (1.4)		
Do you use the Internet?[9]	Yes	119 (68.8)	92 (38.0)	85 (67.5)	67 (53.2)	IDEAL T3 PwD Q250	245 (28.8)	185 (24.3)	X^2 (1) = 85.59, p < 0.001	X^2 (1) = 16.28, p < 0.001
	No	50 (28.9)	148 (61.2)	37 (29.4)	59 (46.8)	IDEAL T3 Carer Q138	526 (61.8)	566 (74.6)		
	Missing	4 (2.3)	2 (0.8)	4 (3.2)	.		80 (9.4)	8 (1.1)		
How easy was it to keep yourself occupied during the coronavirus outbreak?	Not very	30 (17.3)	82 (33.9)	20 (15.9)	32 (25.4)					
	Fairly easy	72 (41.6)	95 (39.3)	52 (41.3)	57 (45.2)					
	Very easy	69 (39.9)	63 (26.0)	52 (41.3)	36 (28.6)					
	Missing	2 (1.2)	2 (0.8)	2 (1.6)	1 (0.8)					
Overall how well do you feel you have coped since the coronavirus outbreak?	Not very	12 (6.9)	36 (14.9)	9 (7.1)	13 (10.3)					
	Fairly well	74 (42.8)	110 (45.5)	48 (38.1)	57 (45.2)					
	Very well	84 (48.6)	94 (38.8)	66 (52.4)	56 (44.4)					
	Missing	3 (1.7)	2 (0.8)	3 (2.4)	-					
Have there been any positive aspects or benefits of the coronavirus outbreak?	Yes	78 (45.1)	54 (22.3)	54 (42.9)	31 (24.6)					
	No	87 (50.3)	186 (76.9)	65 (51.6)	95 (75.4)					
	Missing	8 (4.6)	2 (0.8)	7 (5.6)	-					

Note: Improving the experience of Dementia and Enhancing Active Life, IDEAL. ∞ 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	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)	(where applicable)	PwD †	Carers	PwD all INCLUDE vs benchmark	Carers All INCLUDE vs 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 One Two Three Four Five Six Seven Eight Nine Ten More than 10 Mean (SD) Missing	2 (1.2) 15 (8.7) 19 (11.0) 27 (15.6) 19 (11.0) 22 (12.7) 16 (9.2) 9 (5.2) 6 (3.5) 5 (2.9) 9 (5.2) 18 (10.5) 5.6 (4.2) 6 (3.5)	7 (2.9) 16 (6.6) 32 (13.2) 35 (14.5) 36 (14.9) 31 (12.8) 23 (9.5) 12 (5.0) 14 (5.8) 10 (4.1) 11 (4.5) 13 (5.3) 5.0 (3.5) 2 (0.8)	1 (0.8) 5 (4.0) 15 (11.9) 24 (19.0) 14 (11.1) 14 (11.1) 13 (10.3) 7 (5.6) 3 (2.4) 4 (3.2) 7 (5.6) 14 (11.2) 5.7 (4.1) 5 (4.0)	2 (1.6) 8 (6.3) 13 (10.3) 21 (16.7) 22 (17.5) 15 (11.9) 9 (7.1) 7 (5.6) 8 (6.3) 5 (4.0) 7 (5.6) 9 (7.2) 5.4 (3.8) -	IDEAL T3 PwD Q99 IDEAL T3 Carer Q111	45 (5.3) 71 (8.3) 131 (15.4) 137 (16.1) 98 (11.5) 73 (8.6) 76 (8.9) 31 (3.6) 34 (4.0) 30 (3.5) 46 (5.4) 43 (5.1) 4.7 (3.7) 36 (4.2)	22 (2.9) 49 (6.5) 112 (14.8) 124 (16.3) 121 (15.9) 88 (11.6) 71 (9.4) 30 (4.0) 44 (5.8) 10 (1.3) 40 (5.3) 38 (5.0) 4.8 (3.6) 10 (1.3)	U = 76867, z = -2.66, p = 0.008	U = 93958, z = -1.07, p = 0.286
Has this changed since the coronavirus outbreak?	Yes No Missing	87 (50.3) 80 (46.2) 6 (3.5)	81 (33.5) 158 (65.3) 3 (1.2)	58 (46.0) 62 (49.2) 6 (4.8)	36 (28.6) 89 (70.6) 1 (0.8)					
How satisfied are you with the support you receive from family?#	Very dissatisfied Slightly dissatisfied Neither satisfied nor dissatisfied Slightly satisfied Very satisfied Don't know Missing	- 1 (0.6) 19 (11.0) 27 (15.6) 120 (69.4) 1 (0.6) 5 (2.9)		- 1 (0.8) 11 (8.7) 16 (12.7) 92 (73.0) 1 (0.8) 5 (4.0)		IDEAL T3 PwD Q105	16 (1.9) 18 (2.1) 44 (5.2) 78 (9.2) 604 (71.0) 9 (1.1) 82 (9.6)		X^2 (4) = 17.13, p = 0.002	

Question	Response					IDEAL ref				
Considering all your friends including those who live in your neighbourhood, how many friends do you see or hear from at least once a month?[11]	None	28 (16.2)	63 (26.0)	20 (15.9)	19 (15.1)	IDEAL T3 PwD Q102 IDEAL T3 Carer Q114	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)		73 (8.6)	82 (10.8)		
	Two	21 (12.1)	38 (15.7)	16 (12.7)	23 (18.3)		106 (12.5)	123 (16.2)		
	Three	23 (13.3)	27 (11.2)	20 (15.9)	16 (12.7)		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)		
	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 PwD Q106	18 (2.1)		X^2 (4) = 8.57, p= 0.073	
	Slightly dissatisfied	3 (1.7)		2 (1.6)			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 PwD Q111 IDEAL T3 Carer Q70	3 (0.4)	4 (0.5)	X^2 (5) = 9.23, p = 0.100**	X^2 (5) = 4.41, p = 0.491**
	Not too well			5 (4.0)	7 (5.6)		6 (0.7)	20 (2.6)		
	Quite well			7 (5.6)	10 (7.9)		34 (4.0)	80 (10.5)		
	Well			12 (9.5)	18 (14.3)		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 neighbourhood to what extent do you agree or disagree that people are willing to help their neighbours?[13]	Strongly disagree Slightly disagree Neither agree nor disagree Slightly agree Strongly agree Don't know Missing	8 (4.6) 8 (4.6) 19 (11.0) 45 (26.0) 86 (49.7) 2 (1.2) 5 (2.9)		4 (3.2) 8 (6.3) 12 (9.5) 32 (25.4) 64 (50.8) 2 (1.6) 4 (3.2)		IDEAL T3 P2_Q216_t3	31 (3.6) 22 (2.6) 70 (8.2) 191 (22.4) 418 (49.1) 35 (4.1) 84 (9.9)		X^2 (4) = 2.65, p = 0.618	
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 neighbourhood. How likely is it that it would be returned to you with nothing missing?[13]	Not at all likely Not very likely Quite likely Very likely Don't know Missing	10 (5.8) 16 (9.2) 60 (34.7) 69 (39.9) 13 (7.8) 5 (2.9)		5 (4.0) 13 (10.3) 42 (33.3) 52 (41.3) 10 (7.9) 4 (3.2)		IDEAL T3 P2_Q208_t3	40 (4.7) 80 (9.4) 276 (32.4) 313 (36.8) 66 (7.8) 76 (8.9)		X^2 (3) = 0.26, p = 0.968	
How satisfied are you with your neighbourhood as a place to live?[13]	Very satisfied Slightly satisfied Neither satisfied nor dissatisfied Fairly dissatisfied Very dissatisfied Don't know Missing	126 (72.8) 31 (17.9) 4 (2.3) 5 (2.9) 2 (1.2) - 5 (2.9)		93 (73.8) 20 (15.9) 3 (2.4) 4 (3.2) 2 (1.6) -		IDEAL T3 P2_Q207_t3	605 (71.1) 116 (13.6) 26 (3.1) 13 (1.5) 15 (1.8) 5 (0.6) 71 (8.3)		X^2 (4) = 3.30, p = 0.509	

Question	Response					Source				
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)		X^2 (4) = 7.20, p = 0.126	X^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)		X^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)			

Note: English Longitudinal Study of Ageing, ELSA; Improving the experience of Dementia and Enhancing Active Life, IDEAL. ** 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 vs benchmark	Carers all INCLUDE vs 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 PwD Q74 IDEAL T3 Carer Q19	9 (1.1)	26 (3.4)	X^2 (5) = 5.33, p = 0.377	X^2 (5) = 3.63, p = 0.604
	Some of the time	22 (12.7)	46 (19.0)	16 (12.7)	18 (14.3)		89 (10.5)	148 (19.5)		
	Less than half of the time	16 (9.2)	35 (14.5)	9 (7.1)	16 (12.7)		47 (5.5)	114 (15.0)		
	More than half of the time	28 (16.2)	60 (24.8)	21 (16.7)	35 (27.8)		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 PwD Q54	7 (0.8)		X^2 (4) = 25.86, p < 0.001	
	Disagree	12 (6.9)		8 (6.3)			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 PwD Q55	24 (2.8)		X^2 (4), = 43.20, p < 0.001	
	Disagree	32 (18.5)		24 (19.0)			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 PwD Q33	567 (66.6)	378 (49.8)	X^2 (2) = 1.59, p = 0.451	X^2 (2) = 16.79, p < 0.001
	2 moderately anxious or depressed	44 (25.4)	73 (30.2)	30 (23.8)	35 (27.8)	IDEAL T3 Carer Q109	249 (29.3)	337 (44.4)		
	3 extremely anxious or depressed	2 (1.2)	8 (3.3)	2 (1.6)	1 (0.8)		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 PwD Q51	658 (77.3)		X^2 (2) = 55.62, p < 0.001	
	More or less	54 (31.2)		35 (27.8)			86 (10.1)			
	Yes	13 (7.5)		7 (5.6)			86 (10.1)			
	Missing	6 (3.5)		5 (4.0)			21 (2.5)			

Note: English Longitudinal Study of Ageing, ELSA; Improving the experience of Dementia and Enhancing Active Life, IDEAL. † 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 vs benchmark	Carers all INCLUDE vs 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)	X^2 (3) = 13.57, p = 0.004	X^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]	Response									
	0 Not at all	3 (1.7)		2 (1.6)		IDEAL T3 PwD Q168b	5 (0.6)		U = 52733, z = -3.21, p= 0.001	
	1	-		-			-			
	2	3 (1.7)		2 (1.6)			6 (0.7)			
	3	5 (2.9)		2 (1.6)			12 (1.4)			
	4	6 (3.5)		4 (3.2)			16 (1.9)			
	5	17 (9.8)		10 (7.9)			79 (9.3)			
	6	20 (11.6)		15 (11.9)			49 (5.8)			
	7	27 (15.6)		19 (15.1)			105 (12.3)			
	8	39 (22.5)		28 (22.2)			185 (21.7)			
	9	14 (8.1)		11 (8.7)			102 (12.0)			
	10 Completely	32 (18.5)		26 (20.6)			194 (22.8)			
	Mean (SD)	7.2 (2.2)		7.4 (2.2)			7.8 (2.0)			
	Missing	7 (4.0)		7 (5.6)			98 (11.5)			

Note: Improving the experience of Dementia and Enhancing Active Life (IDEAL).

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.
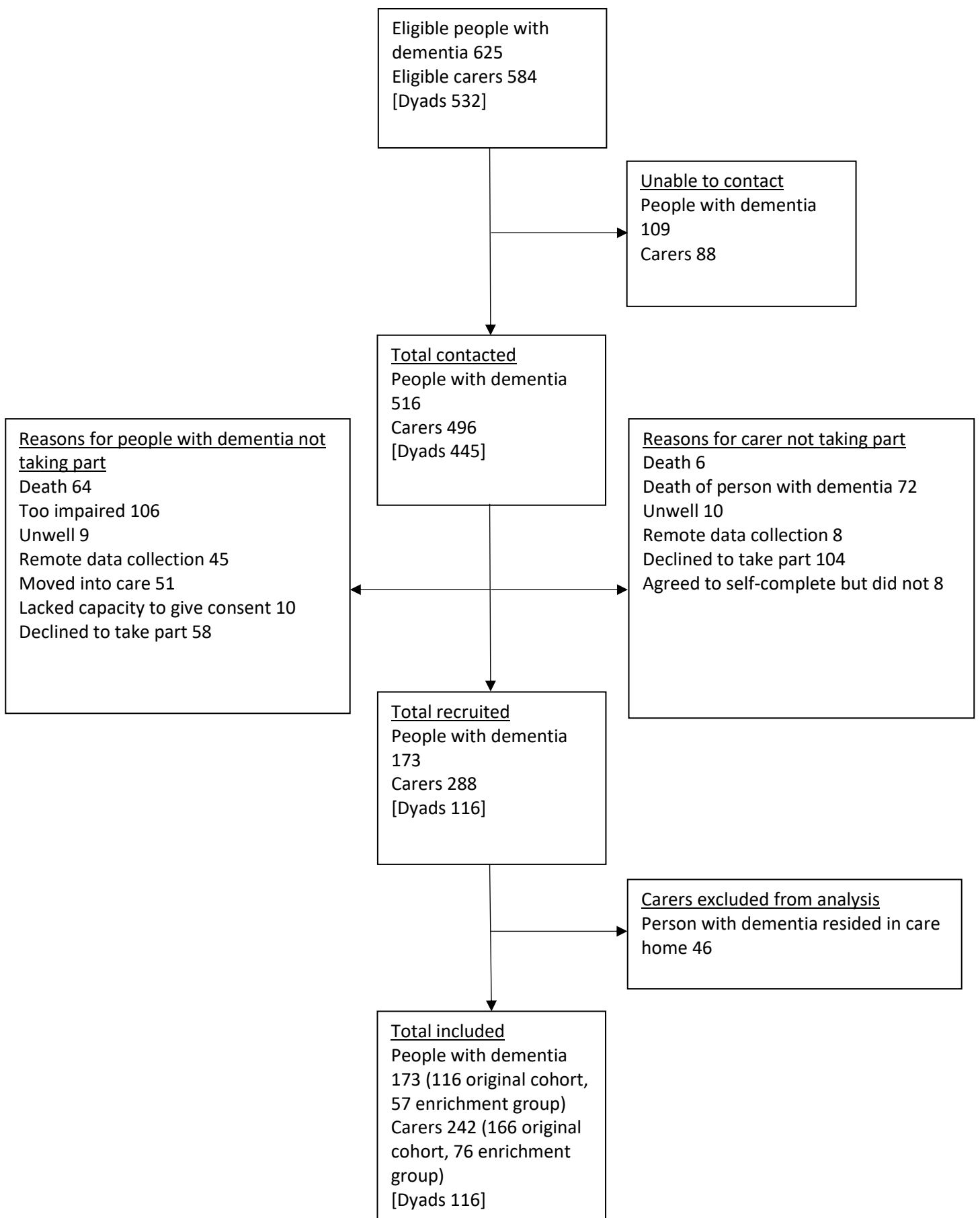
Measure	Original statistical test Chi-square test of independence or Mann-Whitney U Test	Overlapping samples tests: Partially overlapping samples t-test (comparison of means) or Partially overlapping samples z-test (comparison of proportions)	Paired samples tests: McNemar's Chi-squared test or Friedman test
Carer (informant) responses			
In the last 3 months have you seen your GP at the surgery?[5]	X^2 (1) = 128.01, p < 0.001	z = -9.71, p < 0.001	McNemar's test (n = 152): X^2 (1) = 55.14, p < 0.001
In the last 3 months have you spoken to a GP on the telephone?[5]	X^2 (1) = 110.50, p < 0.001	z = 3.29, p = 0.001	McNemar's test n = 153): X^2 (1) = 42.26, p < 0.001
Is there a named health professional whom you can contact at any time?#	X^2 (1) = 47.23, p < 0.001	z = 1.17, p = 0.240	McNemar's test (n = 151): X^2 (1) = 36.82, p < 0.001
Is this named health professional in place to help specifically with the dementia?#	X^2 (1) = 56.71, p < 0.001	z = 1.64, p = 0.101	McNemar's test (n = 145): X^2 (1) = 32.66, p < 0.001
Which of these options best describes your level of pain or discomfort today?[7]	X^2 (2) = 12.24, p = 0.002	t = -3.38, p = 0.001 †	McNemar's test (n = 151): X^2 (3) = 5.84, p = 0.120
Which of these options best describes your ability for self-care?[7]	X^2 (2) = 5.97, p = 0.050	t = 2.19, p = 0.029 †	McNemar's test (n = 153) X^2 (3), 47.16, p < 0.001
Which of these options best describes your ability to do your usual activities?[7]	X^2 (2) = 6.73, p = 0.035	t = -2.32, p = 0.021 †	McNemar's test (n = 155): X^2 (3), 11.85, p = 0.008
Do you use the internet[9]	X^2 (1) = 16.28, p < 0.001	z = 5.19, p < 0.001	McNemar's test (n=156): X^2 (1) = 10.24, p = 0.001
Considering all your friends including those who live in your neighbourhood, 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): X^2 (15), 52.37 p < 0.001
Which of these options best describes your mood today[7]	X^2 (2) = 16.79, p < 0.001	t = -3.78, p < 0.001 †	-
When you think about your life and everything together, how do you feel about your life?[18, 19]	X^2 (3) = 23.30, p < 0.001	z = 1.26, P = 0.207	Friedman Test (n = 154): X^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): X^2 (14) = 27.14, P=0.019
Compared to other people of your age, how would you describe your day-to-day memory?[8]	X^2 (5) = 11.99, p = 0.035	t = -0.64, p = 0.520	Friedman test (n = 110): X^2 (5) = 14.97, P=0.010
Which of these options best describes your ability for self-care?[7]	X^2 (2) = 6.34, p = 0.042	t = 1.58, p = 0.113 †	-
Do you use the internet[9]	X^2 (1) = 85.59, p < 0.001	z = -10.70, p < 0.001	McNemar's test (n = 109): X^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): X^2 (14) = 30.06, p = 0.007
How satisfied are you with the support you receive from family?#	X^2 (4) = 17.13, p=.002	t = -0.48, p = 0.629	Friedman test (n = 112) X^2 (4) = 8.81, p = 0.066
How satisfied are you with the support you receive from friends?#	X^2 (4) = 8.57, p = 0.073	t = 2.80, p = 0.005	Friedman test (n = 98): X^2 (4) = 10.47, p = 0.033
Overall, would you say you expect more good things to happen to you than bad?[15]	X^2 (4) = 25.86, p < 0.001	t = 3.00, p = 0.003	Friedman test (n = 113): X^2 (4) = 5.69, p = 0.223
Do you feel you are still the same person you have always been?[16]	X^2 (4) = 43.20, p < 0.001	t = -1.67, p = 0.094	Friedman test (n = 113): X^2 (4) = 10.19, p = 0.037
Do you feel lonely?#	X^2 (2) = 55.62, p < 0.001	t = -3.24, p = 0.001 †	McNemar's test (n = 111): X^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]	X^2 (3) = 13.57, p = 0.004	t = -2.45, p = 0.015	McNemar test (n = 113): X^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): X^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): X^2 (7) = 25.73, p = 0.001

Note: † 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 summarising the recruitment process and reasons for withdrawal

Eligible people with dementia 625
Eligible carers 584
[Dyads 532]

Unable to contact
People with dementia 109
Carers 88

Total contacted
People with dementia 516
Carers 496
[Dyads 445]

Reasons for people with dementia not taking part
Death 64
Too impaired 106
Unwell 9
Remote data collection 45
Moved into care 51
Lacked capacity to give consent 10
Declined to take part 58

Reasons for carer not taking part
Death 6
Death of person with dementia 72
Unwell 10
Remote data collection 8
Declined to take part 104
Agreed to self-complete but did not 8

Total recruited
People with dementia 173
Carers 288
[Dyads 116]

Carers excluded from analysis
Person with dementia resided in care home 46

Total included
People with dementia 173 (116 original cohort, 57 enrichment group)
Carers 242 (166 original cohort, 76 enrichment group)
[Dyads 116]

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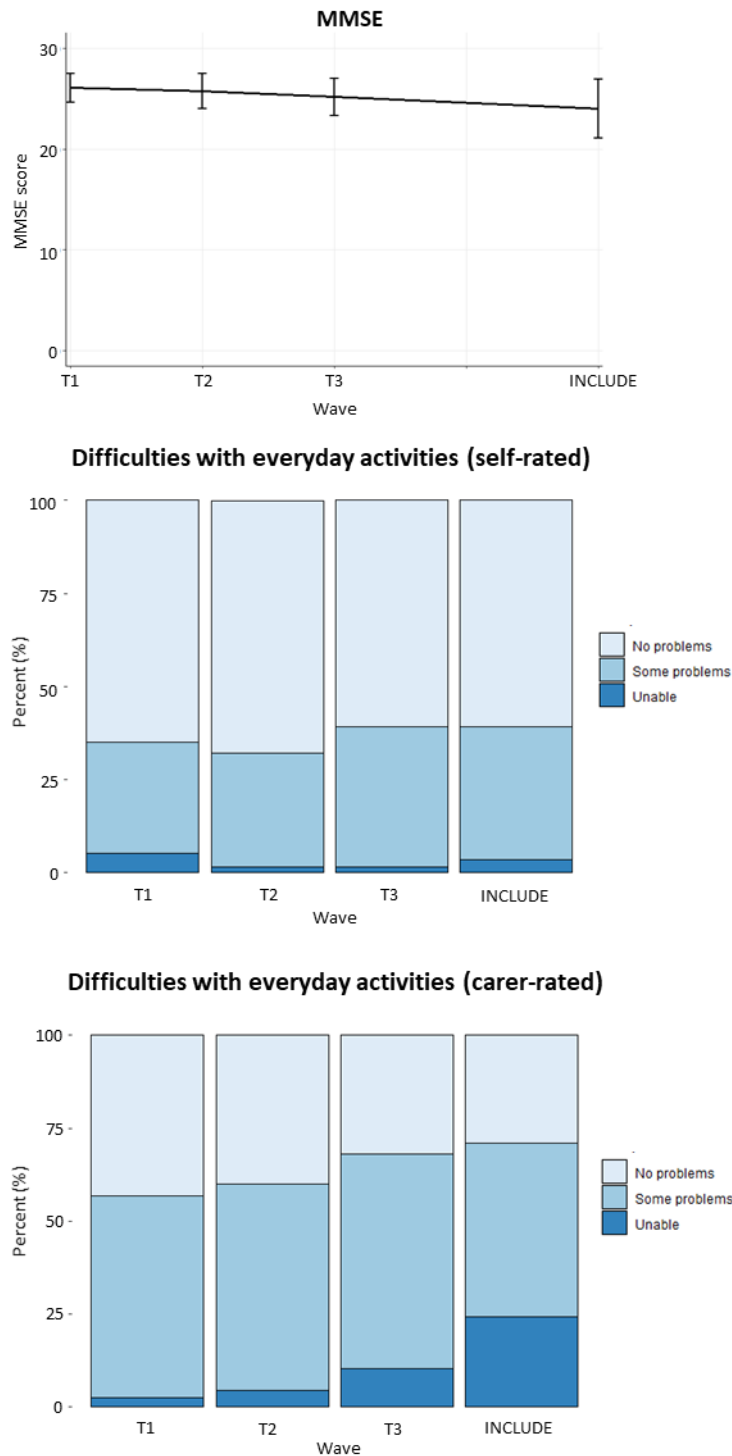
Note: There is approximately 1 year between IDEAL waves and approximately 2 years between T3 and INCLUDE. There were 116 people with dementia and 166 carers who took part in IDEAL T1-T3 and INCLUDE. *Ratings of functional ability were made in response to the item 'which of these options best describes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

References

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

[2]   Clare L, Martyr A, Henderson C, Gamble LD, Matthews FE, Quinn C, Nelis SM, Rusted J, Thom J, Knapp M, Hart N, Victor C (2020) Living alone with mild-to-moderate dementia: findings from the IDEAL cohort. *Journal of Alzheimer's Disease* **78**, 1207-1216.

[3]   Folstein MF, Folstein SE, McHugh PR (1975) "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* **12**, 189-198.

[4]   Steptoe A, Addario G, Banks J, Batty GD, Coughlin K, Crawford R, Dangerfield P, Marmot M, Nazroo J, Oldfield Z, Pacchiotti B, Steel N, Wood M, Zaninotto P (2021) UK Data Service.

[5]   Beecham J, Knapp M (2001) Costing psychiatric interventions In *Measuring mental health needs*, Thornicroft G, Brewin C, Wing J, eds. Gaskell, London, pp. 203-227.

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

[7]   The EuroQol Group (1990) EuroQol - a new facility for the measurement of health-related quality of life. *Health Policy* **16**, 199-208.

[8]   Opdebeeck C, Yates JA, Kudlicka A, Martyr A (2019) What are subjective cognitive difficulties and do they matter? *Age and Ageing* **48**, 122-127.

[9]   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.

[10]   Quinn C, Morris RG, 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.

[11]   Lubben J, Blozik E, Gillmann G, Iliffe S, von Renteln Kruse W, Beck JC, Stuck AE (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.

[12]   Bengtson VL, Schrader SS (1982) Parent-child relations In *Research instruments in social gerontology: Social roles and social participation*, Mangon DJ, Peterson WA, eds. University of Minnesota Press, Minnesota, pp. 115-185.

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

[14]   Bech P (2004) Measuring the dimension of psychological general well-being by the WHO-5. *Quality of Life Newsletter* **32**, 15-16.

[15]   Scheier MF, Carver CS, Bridges MW (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.

[16]   Clare L, Martyr A, Morris RG, Tippett LJ (2020) Discontinuity in the subjective experience of self among people with mild-to-moderate dementia is associated with poorer psychological health: findings from the IDEAL cohort. *Journal of Alzheimer's Disease* **77**, 127-138.

[17]   Office for National Statistics, Surveys using the 4 Office for National Statistics personal well-being questions, https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/methodologies/surveysusingthe4office fornationalstatisticspersonalwellbeingquestions, Accessed 18/01/2018.

[18]   Logsdon RG, Gibbons LE, McCurry SM, Teri L (1999) Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging* **5**, 21-32.

[19]   Logsdon RG, Gibbons LE, McCurry SM, Teri L (2000) Quality of life in Alzheimer's disease: patient and caregiver reports In *Assessing quality of life in dementia*, Albert SM, Logsdon RG, eds. Springer, New York, pp. 17-30.