

# The experiences of people with dementia and cognitive impairment during the COVID-19 pandemic: Analysis of the English Longitudinal Study of Ageing (ELSA)

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## Abstract

**Objective:** This project investigated the extent to which people with differing degrees of cognitive function had varied experiences during the COVID-19 pandemic in England. The key aim of our project was to understand the social and health impacts and inequalities among people with dementia and cognitive impairment during the COVID-19 pandemic.

**Data sources:** The work uses data from the English Longitudinal Study of Ageing (ELSA), which follows a representative sample of people aged 50+ across England. The analysis draws on two key sub-studies of ELSA. The Harmonised Cognitive Assessment Protocol (HCAP) from 2018 was used to classify ELSA respondents into one of three cognitive function groups (no impairment, mild impairment, or dementia), while the COVID-19 sub-study collected responses during the pandemic in June/July and November/December 2020.

**Methods:** The research examined four key thematic areas: shielding and isolation; access to health and care services; healthy lifestyle practices; and mental health and wellbeing. Various statistical techniques were applied, depending on the outcome measure, including logistic regression, latent class analysis, and growth curve modelling.

**Results:** The results from this project cover a wide range of outcomes within each thematic area. Key findings include:

- People with dementia were 2.4 times (95%CI: 1.13-5.03) more likely than those with no impairment to be self-isolating and staying at home in June/July 2020, but there was no difference in Nov/Dec.
- Importantly, there were no significant differences in access to health and care services according to cognitive function, once other characteristics like self-rated health were taken into consideration.
- The proportion of people with dementia reporting excellent/very good sleep quality declined from 25% to 16% between June/July and Nov/Dec 2020, with such changes not observed for other cognitive function groups. There was no link between cognitive function and the overall practices people engaged in.
- Quality of life declined from before the pandemic to Nov/Dec 2020, and it was significantly lower for those with dementia compared to those with no impairment at all time points. On other measures of mental health and wellbeing, including depression and life satisfaction, differences in predicted scores between those with dementia and no impairment observed before the pandemic largely disappeared by Nov/Dec 2020, suggesting a convergence in mental health and wellbeing.

**Conclusions:** Looking across our various outcomes and consulting our Patient and Public Involvement panel, lessons can be identified for policymakers and health and care practitioners. The role of wealth and education in generating certain social inequalities underscores the need for public health messaging that is delivered in clear language understood by all, which must also provide guidance that can be applied by people across the socioeconomic spectrum. People with cognitive impairment should continue to receive targeted support in certain areas, such as sleep. Moreover, as demand from those with no impairment rises for other support such as mental health, services must ensure that people with dementia maintain equal access and do not suffer the impact of supply-side constraints.

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## Key Abbreviations

95%CI: 95% Confidence Interval

BMI: Body mass index

CES-D: Center for Epidemiological Studies - Depression

CI: Cognitive impairment

ELSA: English Longitudinal Study of Ageing

GAD-7: Generalised anxiety disorder – 7

PPI: Public and Patient Involvement

## Plain English Summary

This research has examined how people with cognitive impairment and dementia experienced the COVID-19 differently to those aged 50+ without cognitive impairment. The research investigated experiences across shielding (staying at home or self-isolating), access to community health and care services, healthy behaviours and lifestyle practices, and mental health and wellbeing.

This project uses data from the English Longitudinal Study of Ageing (ELSA) COVID-19 sub-study, collected by telephone and online in June/July and November/December 2020. The key insights from our analysis include:

- People with dementia were more likely than those with no impairment to be self-isolating and staying at home in June/July 2020, but there was no difference in Nov/Dec.
- Importantly, there were no significant differences in access to health and care services according to cognitive function, once other characteristics like self-rated health were taken into consideration. However, those with dementia appear more likely to still be waiting for hospital cancellations to be rescheduled.
- People with dementia reported greater disruption to their sleep quality and less physical activity, even though all groups reported sitting more than before the pandemic. When looking at lifestyle practices together, there was no link between cognitive function and the practices people engaged in.
- Quality of life declined from before the pandemic over the course of it, staying significantly lower for those with dementia. On other measures of mental health and wellbeing, including depression and life satisfaction, the declines over the pandemic narrowed the gap between those with dementia and no impairment.

For policymakers and health care professionals, our work highlights the need for clear, easy-to-understand guidance and public messaging on health issues. It also underscores the need for vigilance to ensure equitable access to care and support services among those with dementia, particularly to support sleep, physical activity, and mental health.

## Scientific Summary

This project investigated the extent to which people with differing degrees of cognitive function had varied experiences during the COVID-19 pandemic in England. The key aim of our project was to understand the social and health impacts and inequalities among people with dementia and cognitive impairment during the COVID-19 pandemic.

This work is important because the number of people living with cognitive impairment is set to grow in the coming decades, and we need to understand the extent to which public services and other supports are adequately meeting their needs – or if more must be done to ensure this group receives equitable treatment and attention.

## Objectives

The project is organised according to four research questions that reflect distinct work packages, along with a fifth and sixth question that cuts across the others:

1. What are the experiences of shielding, self-isolation, and the development of and recovery from COVID-19 infection among people with cognitive impairment compared to those without?
2. How has COVID-19 affected receipt of care, access to health and social care, and treatment for non-COVID-19 health conditions?
3. What changes in lifestyle behaviours (sleep, alcohol consumption, smoking, physical activity, diet) occurred during and after the pandemic? How do these behaviours interact, i.e. are changes in one behaviour associated with changes in others? What are the characteristics associated with positive and negative changes in behaviours?
4. What are the short-, medium-, and long-term effects of the pandemic on individuals' mental health, well-being, psychological responses, and associated factors?
5. How are socioeconomic status, geographic location, and key comorbid conditions associated with all the above?
6. What are the policy implications of the findings from the above research questions for improving the outcomes of this high-risk group?

## Methods

Our project uses data collected before and throughout the COVID-19 pandemic as part of the English Longitudinal Study of Ageing (ELSA). ELSA has followed a representative sample of people aged 50+ across England since 2002, asking questions about topics including their health, wellbeing, finances, and social connections.

Our study additionally makes use of two sub-studies of ELSA completed in recent years. The Harmonised Cognitive Assessment Protocol (HCAP), conducted in 2018, captured a more nuanced measure of participants' cognitive function. This was used to develop a predictive algorithm to classify ELSA respondents into one of three cognitive function groups: no impairment, mild impairment, or dementia.

The second ELSA sub-study critical to this analysis was the COVID-19 sub-study conducted in 2020. A direct and rapid response to the pandemic, ELSA members and their partners provided responses to two special surveys conducted in June/July and Nov/Dec 2020, capturing a range of perspectives related to their experiences during the pandemic.

Understanding our findings and their implications has also been informed by engagement with a Public and Patient Involvement (PPI) panel. This participation was a particularly

important aspect of our work, and the panel's support helped us refine our research questions, findings, and the policy implications emerging from the work.

## Results

Below we summarise some of the key findings across the specific topics we investigated.

### Shielding and infection

- Those with dementia were 2.4 times more likely to be shielding – staying at home or self-isolating – than those with no cognitive impairment in June/July 2020. After accounting for cognitive function and other factors, being male, not living with a partner, having low education, being in paid work, and reporting excellent/very good health were associated with a lower likelihood of shielding at any time point (April, June/July, or Nov/Dec 2020).
- Around 7.4% of our sample were linked to probable infection with SARS-CoV-2 by June/July 2020. Adjusted estimates put 4.1% of people with dementia as infected compared to 7.7% and 7.8% of those with mild or no impairment, respectively. Respondents who received unpaid care also had around a 71% higher chance of probable infection than those not receiving unpaid care.
- People with mild impairment appeared less likely to shield than those with no impairment near the start of the pandemic, potentially supporting the idea that greater efforts are needed to ensure people with mild impairment receive support to avoid adverse outcomes.

### Disruption in access to health and care services

- Over a third of respondents with no cognitive impairment (35%) or mild cognitive impairment (38%) reported disruption in access to community health and care services by June/July 2020, compared to over 44% of people with dementia. Of those reporting disruption by June/July, around 29% reported ongoing disruption by Nov/Dec 2020. General practice and dentist services were the most frequently reported type of service to which access was disrupted by Nov/Dec. The likelihood of experiencing disruption was negatively associated with self-rated health status.
- A higher proportion of people with mild cognitive impairment reported having hospital-based operations and treatments cancelled compared to those with no impairment (23% versus 18% in June/July). 79% of people with dementia who had experienced a cancellation were still waiting for it to be rescheduled in Nov/Dec, compared to 42% of those with no impairment and 40% of those with mild impairment.
- Nearly all respondents in any cognitive function group had access to their regular medications during the pandemic. Polypharmacy was associated with disruption in access to community health and care services, as 29% of those taking zero medications reported disruption in June/July compared to 47% of those taking 10 or more medications.

### Changes in healthy lifestyle practices

- We identified some differences according to cognitive function group across lifestyle practices during the pandemic as well as changes compared to before the pandemic: particularly differences related to sleep, physical activity, diet, and weight:
  - Sleep quality among those with dementia declined between June/July and Nov/Dec, with the proportion reporting excellent/very good sleep quality

changing from 25% to 16%. Such changes were not observed for the other cognitive function groups. Also, nearly a quarter of people with dementia (24%) were sleeping more than usual in June/July compared to before the pandemic.

- People with dementia had lower levels of physical activity compared to other groups, with 44% classed as inactive in Nov/Dec compared to 18% of those with no impairment. All cognitive groups spent more time sitting down during the pandemic than before.
- While virtually all respondents had enough to eat during the pandemic, people with dementia were less likely than those with no impairment to get the food they wanted, with 19% reporting this in Nov/Dec compared to 7.0%. Also, 20% of people with dementia said they were eating less compared to before the pandemic, compared to 9.2% of those with no impairment. 7.6% (2.8-19.0) of people with dementia were classed as underweight compared to 1.7% (1.2-2.4) of those with no impairment in Nov/Dec.
- Lifestyle practices are often associated with each other, and we identified three distinct groups of practices among respondents. Group one includes people who drink and are overweight/obese, group two includes smokers who also drink alcohol, and group three covers people less linked to smoking or drinking but who experience poor sleep, are physically inactive, and are overweight/obese. A larger proportion of those with no impairment belong to the first group (68%) while 56% of people with dementia belong to the third group, but the association between cognitive function and group membership disappears when controlling for other factors.
- Lifestyle practices are influenced by cultural, economic, political, and social factors. While cognitive function (and impairment) is linked to similar determinants, the results here suggest that practices are more closely impacted by the factors that generate them than by any link to cognitive status. Modelling results clearly demonstrate the social stratification that links poorer socioeconomic status, worse health, and unhealthy lifestyles.

#### Changes in mental health and wellbeing

- Between 2018/19 and Nov/Dec 2020, quality of life declined for all three cognitive function groups, remaining significantly lower for those with dementia. On other measures, including depression, loneliness, life satisfaction, and happiness, differences apparent before the pandemic appeared to disappear by Nov/Dec 2020. This may suggest the pandemic had a more intense negative impact on those with no or mild impairment compared to those with dementia.
- With the potential convergence in mental health and wellbeing among the cognitive function groups during the pandemic, pressure on support services may be particularly intense as they seek to ensure accessibility and availability to those with no impairment and dementia alike.

#### Socioeconomic inequalities

- Significant inequalities based on region were identified with respect to shielding as well as disruption in access to community health and care services. People with impairment (mild or dementia) living in the North or Midlands were 1.6 times more likely to have reported disruption in Nov/Dec than those living there without impairment, but there was no difference in the likelihood of disruption based on

cognitive impairment status for those living in the East of England, London, or the South. People with impairment living the East/London/South were around half as likely as those with impairment in the North/Midlands and about 38% less likely as those with no impairment in the North/Midlands to report disruption in Nov/Dec.

- Wealth was linked to systematic inequalities with respect to lifestyle practices. People with cognitive impairment and in the top 2/3 of wealth were 1.7 times as likely to be in group three (those overweight/obese, physically inactive, with poor sleep) than group one (those overweight/obese who drink alcohol) compared to those with no impairment in the bottom third of wealth. People with no impairment in the top 2/3 of wealth were around 72% less likely than those with no impairment in the bottom third of wealth to be in group three rather than group one.
- Wealth and education generated inequalities in the mental health and wellbeing of people with cognitive impairment during the pandemic. The protective effect of wealth did not consistently apply to those with cognitive impairment; for quality of life and happiness, only the richest without cognitive impairment demonstrated better outcomes. Those with low education and cognitive impairment appeared to experience greater declines in mental health outcomes (depression and anxiety) compared to other groups.

## Conclusions

We summarise below the key conclusions from our findings and their implications for policy and practice across the four thematic areas our analyses covered.

### Shielding and self-isolation

- Public health messaging needs to be delivered in clear language that can be understood by all, including those with low level of cognitive function and those with low education. In some cases, messages may need to be tailored to ensure they resonate with groups who may be less engaged with health matters.
- Future efforts to encourage shielding – or otherwise deliver important public health messages – may need to consider engaging with organisations and social institutions beyond those directly linked to health, e.g. promoting health literacy across the life course within schools or workplaces.
- Adequate support for people whose socioeconomic position impacts their ability to follow public health guidance is needed, while there are lessons to learn from the experiences of those already engaged with the health system. Unpaid caregivers may be another group in need of special support to ensure they can provide quality care and are not negatively impacted by their caregiving role.

### Disruption in access to services

- Those who needed community health and care services and received them was much higher in Nov/Dec than in June/July, with around two-thirds of people in any cognitive function group reporting this. This may indicate that disruption in access was at least partly driven by stay-at-home orders and other restrictions on service availability early in the pandemic.
- Although hospital-based operations and treatment that were cancelled due to the pandemic will take time to be addressed, people with dementia were disproportionately waiting for cancellations to be rescheduled in Nov/Dec 2020. As further progress is made toward fulfilling the backlog of cancellations, people with

dementia may need extra support to ensure they have proper follow-up in getting the hospital-based services they need.

- Given that access to medications remained very high among respondents, this could highlight the role that local pharmacies can play in delivering key services in health and care through a crisis and beyond. Pharmacies are not appropriate for all services of course, but they may provide an opportunity to strengthen the delivery of health-related information and preventative interventions.

### Healthy lifestyle practices

- Many of the practices examined can be linked to an increased likelihood of developing cognitive impairment, just as they are linked to other significant morbidities like cardiovascular disease. For policymakers and practitioners, these results underscore the importance of early intervention to support healthy lifestyles.
- People with dementia reported sleeping more during the pandemic compared to before, but the quality of sleep declined. Sleep disturbances can impact both people with dementia and their caregivers, so greater attention may be needed to help manage sleep among those with cognitive impairment.
- Similarly, people with dementia had lower levels of physical activity and access to the food they wanted to eat during the pandemic. The conditions of lockdown during the pandemic may have exacerbated the challenges people with dementia face in remaining active and getting the nutrition they desire. Generally, however, policymakers, care practitioners, and public health professionals should consider strategies for ensuring people with cognitive impairment can be supported to pursue these key aspects of healthy ageing.

### Mental health and wellbeing

- On many of our measures, we find evidence suggesting a convergence in mental health and wellbeing among the cognitive function groups during the pandemic. The pressures on support services may be particularly intense as they need to respond to proportionately greater demand from those with no impairment than was the case before the pandemic.
- Worsening mental health and wellbeing outcomes for those with dementia may present particular challenges in delivering effective interventions and support. Such challenges likely relate to questions of accessibility and availability. Indeed, we found earlier that a larger proportion of people with dementia highlighted disruption in access to counselling for mental health. Policymakers and care practitioners will need to ensure that people with dementia have equal access to measures to support their mental health and wellbeing.
- Wealth and education, as expected, play a role in shaping the trajectories of outcomes over time. This further underscores the need to ensure that people at all levels of cognitive function are able to access the resources they need to support general wellbeing, including effective and easy-to-understand guidance. Alongside this, policymakers and care practitioners can draw on lessons learned to improve advanced planning and deploy simple interventions that do not require substantially higher resources.

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## Introduction

This project investigated the extent to which people with differing degrees of cognitive function had varied experiences during the COVID-19 pandemic in England. The key aim of our project was to understand the social and health impacts and inequalities among people with dementia and cognitive impairment during the COVID-19 pandemic.

The project was organised according to four research questions that reflect distinct work packages, along with a fifth and sixth question that cuts across the others:

7. What are the experiences of shielding, self-isolation, and the development of and recovery from COVID-19 infection among people with cognitive impairment compared to those without?
8. How has COVID-19 affected receipt of care, access to health and social care, and treatment for non-COVID-19 health conditions?
9. What changes in lifestyle behaviours (sleep, alcohol consumption, smoking, physical activity, diet) occurred during and after the pandemic? How do these behaviours interact, i.e. are changes in one behaviour associated with changes in others? What are the characteristics associated with positive and negative changes in behaviours?
10. What are the short-, medium-, and long-term effects of the pandemic on individuals' mental health, well-being, psychological responses, and associated factors?
11. How are socioeconomic status, geographic location, and key comorbid conditions associated with all the above?
12. What are the policy implications of the findings from the above research questions for improving the outcomes of this high-risk group?

This work is important because the number of people living with cognitive impairment is set to grow in the coming decades, and we need to understand the extent to which public services and other supports are adequately meeting their needs – or if more must be done to ensure this group receives equitable treatment and attention.

## Methods

Our project uses data collected before and throughout the COVID-19 pandemic as part of the English Longitudinal Study of Ageing (ELSA).<sup>1</sup> ELSA has followed a representative sample of people aged 50+ across England since 2002, asking questions about topics including their health, wellbeing, finances, and social connections.

Our study additionally makes use of two sub-studies of ELSA completed in recent years. The Harmonised Cognitive Assessment Protocol (HCAP) was conducted in 2018.<sup>2</sup> This took a more nuanced look at participants' cognitive function, applying a range of questionnaires and other evaluations used to assess cognition in clinical and non-clinical settings. From this work, we developed a predictive algorithm to classify ELSA respondents into one of three cognitive function groups: no impairment, mild impairment, or dementia.<sup>3</sup>

The second ELSA sub-study critical to this analysis was the COVID-19 sub-study conducted in 2020.<sup>4</sup> A direct and rapid response to the pandemic, ELSA members and their partners provided responses to two special surveys conducted in June/July and Nov/Dec 2020, capturing a range of perspectives related to their experiences during the pandemic. We asked ELSA members several questions related to their experiences related to infection, shielding, and other relevant topics. Retrospective data was also collected, e.g. about experiences in April 2020, providing three time points of data for most respondents on

some key questions. In some analyses, we compare outcomes during the pandemic to those before the pandemic, drawing on responses to Wave 9 of the main ELSA study collected in 2018/19.

Understanding our findings and their implications have been informed by engagement with a Public and Patient Involvement (PPI) panel. This participation was a particularly important aspect of our work, and the panel's support helped us refine our research questions, findings, and the policy implications emerging from the work, given their unique insights and perspectives.

This report presents our project findings in order of our research questions, with the fifth question on key inequalities incorporated into each section. Implications for policy and practice, reflecting our sixth research question, are included at the end.

### Sociodemographic characteristics and cognitive impairment

Before we examine the results from our specific research questions, we want to provide a snapshot of some of the key demographic, socioeconomic, and health-related characteristics of our sample. In Wave 1, 77.9% of our respondents reported no cognitive impairment, with 19.9% having mild impairment and 2.2% with dementia; when adjusted with sampling weights, these become 73.4%, 23.9%, and 2.8% respectively. Table 1 outlines the proportions of the COVID Wave 1 sample along several key indicators and adjusted for sampling weights.

We see unsurprising differences according to cognitive function along many of the demographic indicators. For example, those with dementia have an average age of 78.7 compared to an average age of 70.7 for those with no impairment; dementia is, after all, associated with age.

More noticeable are the trends in socioeconomic and health-related measures according to cognitive function. Whether it is education, labour market status, wealth, or income, we see similar distributions for those with dementia and mild impairment, which stand in contrast to those with no impairment:

- Nearly two-thirds of those with mild impairment or dementia have low education compared to less than one-third of those with no impairment.
- Around 90% of those with mild impairment or dementia were retired compared to 72.7% of those with no impairment.
- Those with no impairment were fairly evenly distributed across tertiles for wealth or income, while over half of those with mild impairment or with dementia were in the lowest (poorest) third.

When it comes to the health-related measures, some differences start to emerge between the mild impairment and dementia groups.

- Looking at self-reported health, the proportion of people with mild impairment who say their health is fair or poor (38.0%) sits in the middle of the proportions for those with no impairment or dementia (22.8% and 52.5% respectively).
- The average number of chronic conditions increases with greater impairment: 0.88 for no impairment, 1.32 for mild, and 2.05 for dementia.

- Multimorbidity – the presence of two or more chronic conditions – ranges from 22.9% of those with no impairment to 37.8% of those with mild impairment and 61.2% of those with dementia.

*Table 1: Descriptive characteristics of the ELSA COVID Study, Wave 1, by cognitive function status (% , unless specified as the mean)*

	No impairment (N=4,057)	Mild impairment (N=1,036)	Dementia (N=114)
Age ( <i>mean</i> )	70.65	79.85	78.66
Female	52.88	58.81	56.60
Ethnic minority background	3.22	6.43	10.93
Lives with a partner/spouse	68.77	50.32	56.82
Education (high)	22.54	5.19	9.18
(medium)	46.78	26.48	31.48
(low)	30.69	68.33	59.34
Employment status (in work)	21.60	4.58	2.63
(retired)	72.72	89.73	90.39
(other)	5.68	5.69	6.98
Net wealth (Poorest third)	35.61	51.37	53.65
(Middle third)	30.80	30.81	29.40
(Richest third)	33.59	17.82	16.95
Income (Poorest third)	33.12	52.45	54.57
(Middle third)	31.96	33.27	26.93
(Richest third)	34.92	14.29	18.50
Home tenure (Outright owner)	74.98	71.00	65.31
(Own w mortgage)	10.65	4.77	3.84
(Renter)	14.38	24.23	30.85
Rural residence	27.53	21.95	25.94
Region (The North)	28.33	30.33	26.73
(The Midlands)	19.82	18.51	22.61
(London & East)	22.53	23.40	28.51
(The South)	29.32	27.76	22.15
Self-rated health (Excellent or very good)	42.37	25.74	23.26
(Good)	34.87	36.31	24.20
(Fair or poor)	22.76	37.95	52.54
Number of chronic conditions ( <i>mean</i> )	0.88	1.32	2.05
Presence of 2+ chronic conditions	22.94	37.81	61.16

*Notes: Percentages and means are estimated using sampling weights.*

## Shielding, isolation, and infection

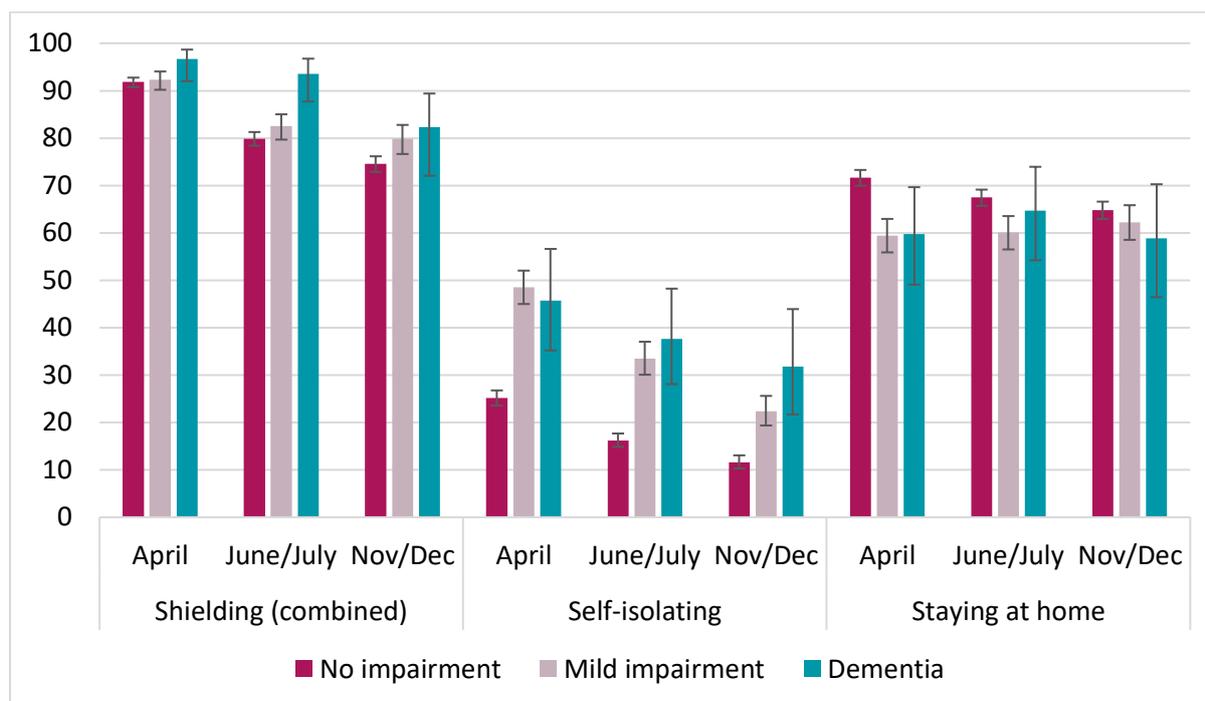
Turning directly to the question for WP1, we looked at the concept of shielding with respect to the three time points included in our two waves of data, exploring rates of shielding for these as well as overall trends across time.

We refer to our outcome of interest as shielding, though this does not reflect the clinical concept of shielding related to vulnerable people taking self-protective action. Nor does our use of shielding imply any evaluation of whether respondents received specific advice to shield from medical authorities. In our data, we have information related to two different questions that asked about self-isolation or staying at home. These differed primarily in that self-isolation was described as not leaving home at all, while staying at home allowed for short ventures out for necessary shopping, medical care, or exercise. There was a small degree of overlap of these, as 354 out of 5,207 respondents in Wave 1 mentioned both for April, so we have combined responses to these two items into our umbrella outcome of shielding.

### Shielding and isolation

Figure 1 illustrates the rates of shielding at the different time points for the different measures of shielding and level of cognitive function. Notable differences by cognitive function are most apparent when considering self-isolation, but the combined shielding measure shows that the great majority of people in any cognitive function group were shielding at all time points. Rates of shielding did decline over time, and this decline appears faster for those with no impairment than for people with dementia or mild impairment.

*Figure 1: Rates of shielding by time, cognitive function, and shielding measure*



Notes: April and June/July N=5,170; Nov/Dec N=4,968. Error bars reflect 95% confidence intervals.

The differences in shielding according to cognitive function in April were small and not statistically different, but the difference between those with no impairment and with dementia was distinct by June/July (79.9% and 93.6% respectively), as was the difference

between those with mild impairment (82.5%) and those with dementia. The proportion of people with dementia who were shielding in Nov/Dec fell to 82.4%, losing any statistically significant difference from the other groups. However, there was a statistically significant difference between the mild and no impairment groups for Nov/Dec, with shielding proportions of 79.9% and 74.6% respectively.

Looking at such differences in the proportions of people shielding tells us little about whether the different cognitive function groups were more likely to be shielding than others, as a range of other factors are assumed to be at play in shaping this likelihood. To explore this, we constructed logistic regression models to identify whether there was a significant link between shielding and cognitive function when controlling for other factors. Such covariates included demographics (age, gender, ethnicity, partnership), socioeconomics (education, wealth, and employment status), geography (urban/rural, English region), and health (self-rated health and the presence of multimorbidity). Charts illustrating the full results can be found in the Appendix 1.

For April, people with mild impairment were about 27% less likely as those with no impairment to be shielding (Odds Ratio (OR)=0.73, 95%CI 0.52-1.03). It is unclear why those with mild impairment were less likely to be shielding, but one possibility is that their lower level of cognitive function impacted their ability to interpret the public health messages around the need to shield to avoid the virus. Those with dementia, in contrast, were around 1.5 times more likely than those with no impairment to be shielding, a finding potentially linked to the need for those with underlying health conditions to take extra precautions against the spread of SARS-CoV-2, though there is a wide confidence interval in this estimate (95%CI 0.55-3.94).

April was of course just after the start of lockdown in England, when public and scientific understanding of the pandemic remained nascent. The importance of shielding was likely a message that resonated with most people, at least those in the social position to remain at home. The difference in the likelihood of shielding for the dementia group in June/July was considerably larger and statistically significant at conventional levels: people with dementia were 2.4 times more likely to be shielding than those with no impairment (95%CI 1.13-5.03).

By Nov/Dec, however, strong differences according to cognitive function essentially disappeared, although with some suggestion that the dementia group was 14% more likely to shielding than those with no impairment (OR=1.14, 95%CI 0.58-2.25). This may be due to the reimposition of lockdown in England around that time and fears associated with the second wave of the pandemic.

While we saw the above patterns related to the likelihood of shielding related to cognitive function, this likelihood was also driven by factors other than cognitive impairment. In other words, some of the other characteristics we included in our models demonstrated associations with shielding. Men were less likely to be shielding, as were those living with a partner or with low education (compared to high education). Being in work (compared to being retired) was unsurprisingly associated with a lower likelihood of shielding. Health was also a significant factor, with those reporting fair/poor health more likely to report shielding than those with excellent/very good health. In Nov/Dec, the presence of multimorbidity and reporting good health (compared to excellent/very good) were also linked to a higher likelihood of shielding.

## Inequalities in shielding

We were also interested in whether the relationship between shielding and cognitive function varied systematically across different social groups related to wealth, education, geography (English region), and the presence of multimorbidity. We tested this by looking at models with interactions, controlling for age and sex, finding evidence for significant impacts related to region along with some other inequalities around education and multimorbidity.

For example, this impact suggests that people with cognitive impairment (mild or dementia) living in the North or Midlands were just as likely to shield in April as those with no impairment living there or those with impairment living in the East of England, London, or the South. Among people with no impairment, those living in the East of England, London, or the South were about 50% more likely to shield in April as those living in the North or Midlands. Those with impairment in the East, London, or the South were about 50% less likely to shield in April than people with no impairment in the North or Midlands and 47% less likely than those with no impairment in the East, London, or the South.

In June/July, those with impairment in the East, London, or the South were about 34% less likely to be shielding than those with no impairment living in the North or Midlands. Although less statically significant, they were also found to be about 29% less likely to be shielding than those with impairment in the North or Midlands, and around 23% less likely as those with no impairment in the East, London, or the South. There were no systematic differences in the likelihood of shielding across region and cognitive impairment in Nov/Dec.

Some other inequalities in the experience of shielding were found related to education and multimorbidity. Among those with no impairment, people with high or medium education were about 35% more likely than those with low education to be shielding in April and 23% more likely in June/July. In April, those with cognitive impairment and without multimorbidity were around 36% less likely to be shielding than those without cognitive impairment or multimorbidity. In Nov/Dec, multimorbidity increased the likelihood of shielding by 61% among people without cognitive impairment.

## Probable infection with SARS-CoV-2

In the first wave of the ELSA COVID sub-study (collected in June/July 2020), respondents were asked about particular symptoms of illness that they had experienced. We used the three key symptoms associated with COVID-19 – a high temperature, a new continuous cough, and a loss of the sense of smell or taste – to create a measure of probable infection with SARS-CoV-2. Reports of these symptoms were combined with reports of a positive diagnosis or hospitalisation due to COVID-19 to assess probable infection.

Probable infection with SARS-CoV-2 was not highly prevalent in our sample, with only 382 out of 5,207 respondents classed as likely infected by June/July 2020. Looking at cognitive function groups and adjusting with sampling weights, about 4.1% of people with dementia had likely been infected compared to 7.7% of those with mild impairment and 7.8% of those with no impairment. Given the relatively small numbers involved here, the difference in these prevalence rates did not reach statistical significance.

Similarly for shielding, we constructed regression models to assess the link between cognitive function and having a probable infection. The results do provide some support for the idea that those with dementia may have had about half the chance of infection as those

with no impairment, albeit this is not statistically significant, probably due to the small number of infections observed in the dementia group (i.e. 6 out of 113).

A further question we explored in the context of infection was whether there was any link to the receipt of care. Drawing on measures in the survey related to the receipt of formal care services or unpaid care support, we supplemented our regression models with covariates for formal care, unpaid care, or any care (combining formal and unpaid). The results showed a strong association between the receipt of unpaid care and an increased likelihood of infection, with those who received unpaid care having nearly a 71% higher chance of contracting SARS-CoV-2 compared to the rest of the sample (which included those not receiving unpaid care and those receiving formal care only). It could be that unpaid care providers had less adherence to strict hygiene protocols that would protect against infection.

## Access to health and social care, treatments, and medicine

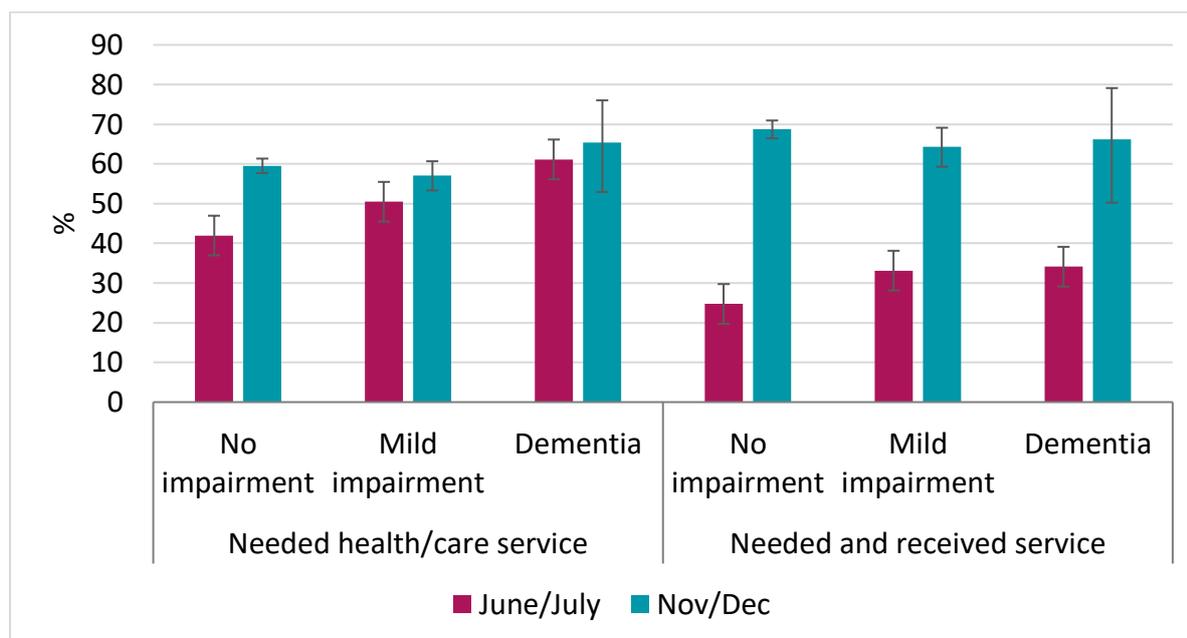
This section outlines results related to community health and social care services. At the first wave of the COVID survey, respondents were asked, “Since the coronavirus outbreak, have you been able to access the community health and social care services you need, for instance a dentist, podiatrist, nurse, counselling, or personal care?” A separate question asked if they had been able to see or talk to a general practitioner (GP).

At the second wave, the GP was explicitly mentioned as an example in the question on community health and social care services rather than asked about in a different question, so we have combined responses to the two questions from the first wave in June/July. Also, those who responded in June/July were asked about their experience since the previous interview, while new respondents were asked about experiences since the outbreak in February (in the UK). In addition to yes and no, response options included “did not attempt to contact” or “did not need to contact”. For our analyses, we have considered “did not attempt to contact” as implying need given that the respondents selecting this option chose it over “did not need to contact”.

### Access to community health and social care services

We first looked into the levels of need for such services alongside the extent to which that need was fulfilled. As shown in Figure 2, the need for community health and care services increased among those with no impairment from June/July to Nov/Dec. The proportion did not substantially change over the two periods for people with dementia, but this was already high in June/July at 61.2%.

Figure 2: Need for community health and care services



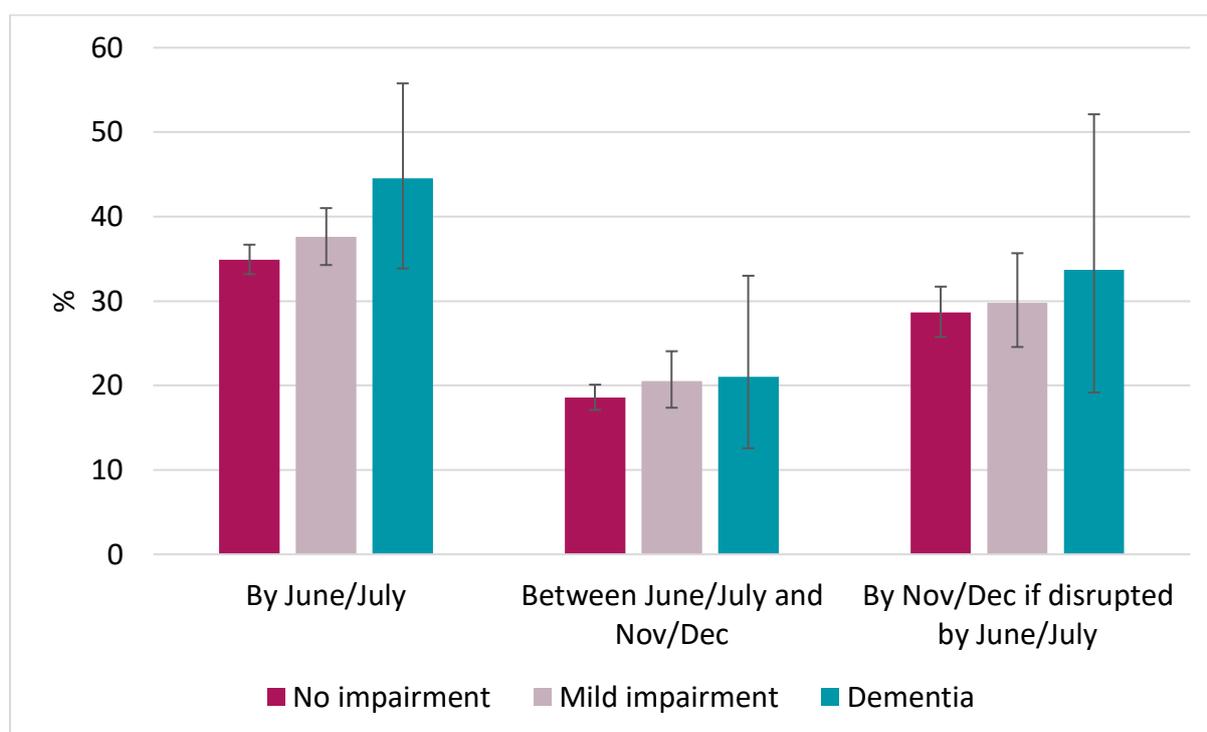
Notes: Needed: Wave 1 N=5,166, Wave 2 N=4,781; Needed and received: W1 N=2,261, W2 N=2,865  
Error bars reflect 95% confidence intervals.

The proportion of people who needed these services and received them was much higher by Nov/Dec across all cognitive function groups. In June/July, only around a quarter of people with no impairment (and around a third of those with either mild impairment or

dementia) who needed community services had received them, and this increased to around two-thirds by Nov/Dec.

There are different ways to look at the disruption to services based on the way that the questions were asked in the two waves. The first wave of data collection, which tells us about June/July, captured the experiences a few months after the start of the pandemic and around the time that the first lockdown restrictions were being eased. Although health services remained open, lockdown may have shaped people’s willingness to access them. Figure 3 shows that around a third (35.8%) of respondents reported disruption in June/July, with a suggestion that the level of disruption increased slightly with greater levels of cognitive impairment; 44.5% of those with dementia reported disruption, but the differences across cognitive function decreased over time.

*Figure 3: Disruption in access to community health services*



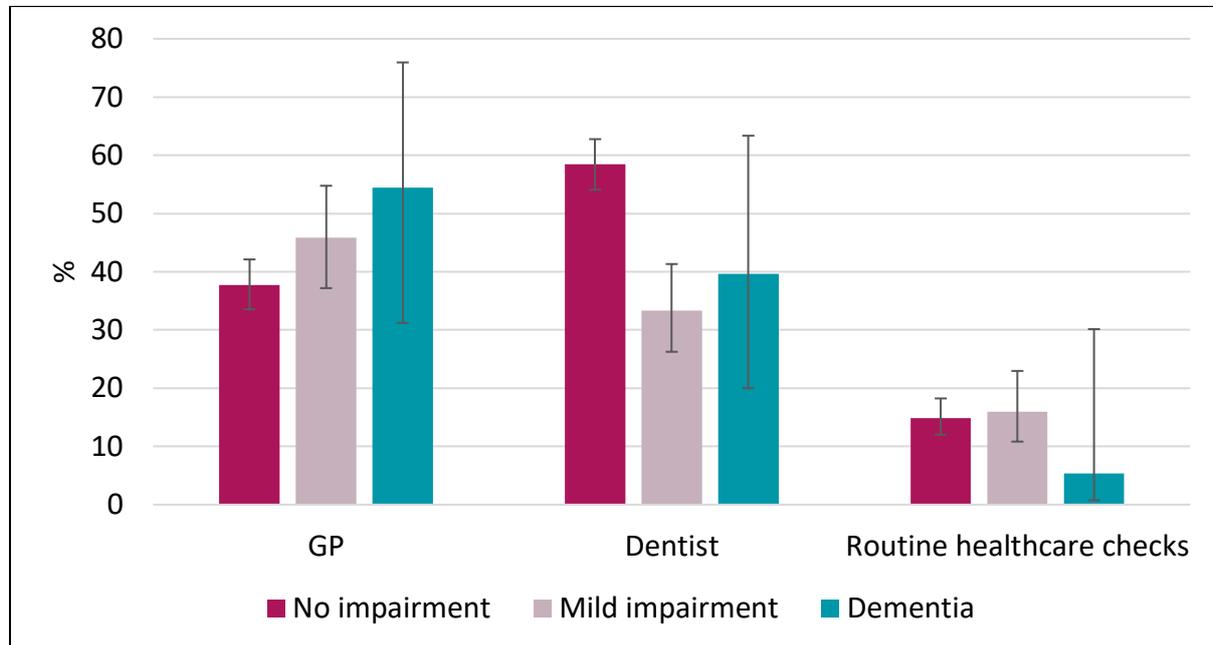
Notes: Sample sizes: 5,166 – 4,781 – 1,538; Nov/Dec estimates cover respondents present in both waves. Error bars reflect 95% confidence intervals.

At the second wave of data collection, participants who were present at the first wave were asked about any disruption they had experienced since their previous interview, which allows us to understand the pattern of disruption between June/July and Nov/Dec. Overall, disruption was less frequently reported in Nov/Dec than in June/July, with around 1 in 5 people present at both waves reporting disruption over the summer and autumn. When looking specifically at those who reported disruption at the first wave, the proportion of those who still (or again) experienced disruption was around 29.1%. A higher proportion of people with dementia reported this ongoing disruption (33.7%), but this is not statistically distinct from the other cognitive function groups.

For those who reported disruption, we also collected information on the type of services that were disrupted at Wave 2. We find that access to GP and dentist services were the

most frequently reported. Access to the dentist was also the only type to show statistically significant differences across cognitive function groups, as a much higher proportion of people with no impairment reported this compared to those with mild impairment (and to those with dementia, to a less significant extent). These results, along with a suggestion that those with dementia were less likely to have routine health checks disrupted, are illustrated in Figure 4.

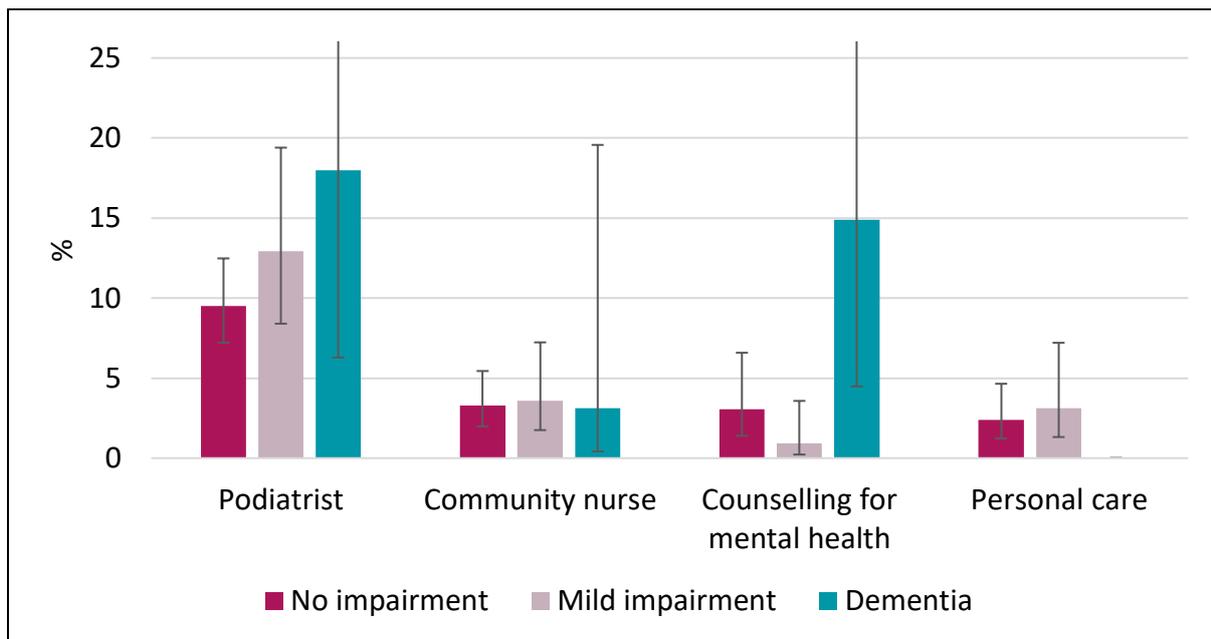
*Figure 4: Types of services disrupted more frequently*



Notes: Wave 2 (Nov/Dec) results; N=908. Error bars reflect 95% confidence intervals.

Similar to Figure 4, Figure 5 highlights results related to the types of services disrupted, focusing on those less frequently noted. We see that no respondents with dementia reported disruption to personal care services, but they were more likely to experience disruption to counselling for mental health than those with mild impairment (14.9% vs 0.9%). Although not statistically significant, findings also suggest disruption in access to a podiatrist increases with greater levels of cognitive impairment.

Figure 5: Types of services disrupted less frequently



Notes: Wave 2 (Nov/Dec) results; N=908. Error bars reflect 95% confidence intervals.

To understand whether the likelihood of disruption in access to community health services across different cognitive function groups was explained by other factors, we constructed a series of regression models. Our models controlled for demographics (age, gender, ethnicity, partnership), socioeconomic (education, wealth, and employment status), geography (urban/rural, English region), and health (self-rated health and the presence of multimorbidity). These models allow us to check whether any differences in our outcome of interest (e.g. disruption) across cognitive function groups remain when adjusted for other characteristics. They also help us identify whether these other characteristics are linked to our outcome of interest above and beyond cognitive function status.

After this adjustment, we found no statistically significant association between cognitive function group and disruption in access to community health services, suggesting that apparent differences in the prevalence reported above are linked to other factors. Furthermore, we found that, among other characteristics, self-rated health was strongly associated with disruption at both waves, after accounting for cognitive impairment and other variables. In particular, those reporting fair/poor health were over twice as likely to experience disruption than those with excellent/very good health in Nov/Dec and 2.5 times more likely in June/July. Those with good health were 67% more likely to report disruption than those with excellent/very good health in June/July and 39% more likely in Nov/Dec.

Age was also associated with the likelihood of disruption in Nov/Dec, with each additional year of age linked to just under a 2% reduction in likelihood, suggesting that older people were less likely to experience disruption on average. In addition, those living in the South of England were around 26% less likely to report disruption in Nov/Dec than those living in the North. Interestingly, people with high education were about 23% more likely to report disruption than those with low education.

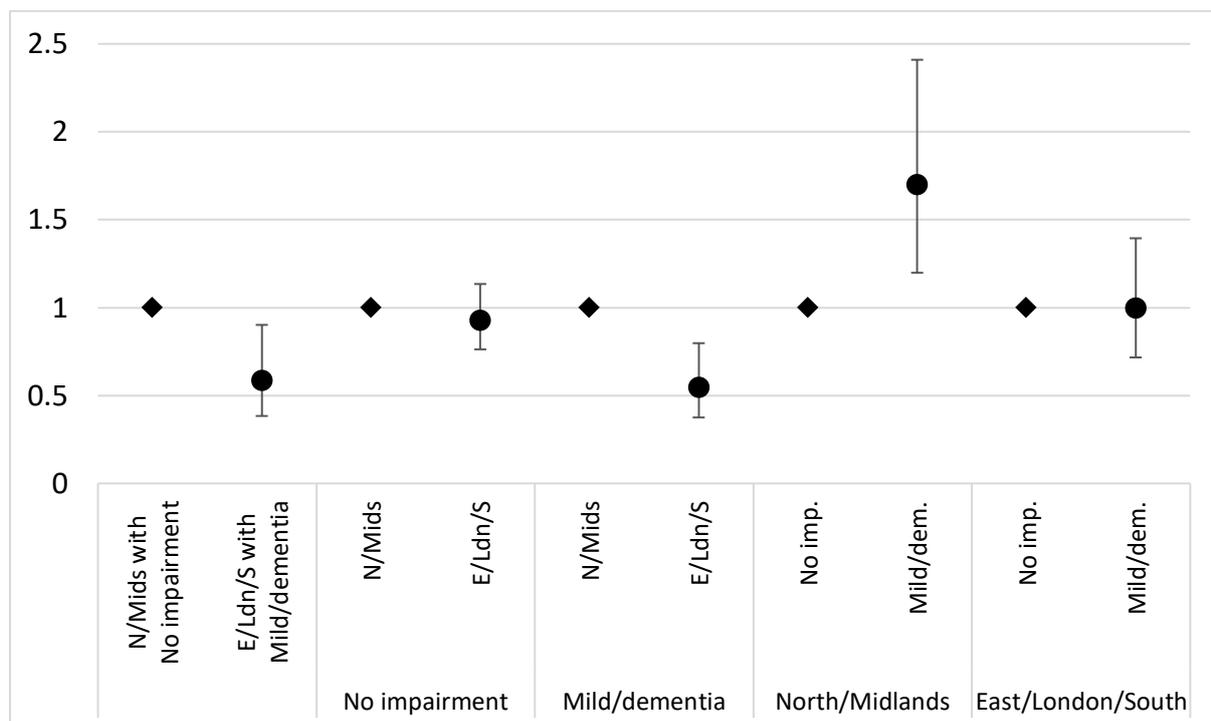
### Inequalities in experiencing disruption to access

The regression results related to regional and educational differences highlight the potential for systematic variations across cognitive function groups and disruption to access. We tested possible inequalities related to wealth, education, geographic region, and the presence of multimorbidity using models with interactions, controlling for age and sex.

No interactions were found regarding education or for responses in June/July. In terms of wealth, people with no impairment in the richest two-thirds of wealth groups were about 26% less likely to report disruption in Nov/Dec than those in the poorest third, but there was no difference among those with cognitive impairment. The presence of multimorbidity was associated with around 61% higher likelihood of reporting disruption in Nov/Dec among those with no impairment.

Greater inequalities were found related to region, and results are illustrated in Figure 6. People with impairment (mild or dementia) living in the North or Midlands were 1.6 times more likely to have reported disruption in Nov/Dec than those living there without impairment. There was not, however, any difference in the likelihood of disruption based on impairment status for those living in the East of England, London, or the South. People with no impairment in the East/London/South were 11% less likely to have reported disruption in Nov/Dec than those with no impairment living in the North/Midlands, although this is not statistically significant. People with impairment living the East/London/South were around 44% less likely as those living in the North/Midlands to report disruption in Nov/Dec. They were also about 38% less likely to report disruption in Nov/Dec as those with no impairment in the North/Midlands.

*Figure 6: Inequalities by region and cognitive function in disruption in access to community health services reported in Nov/Dec (Odds ratios with 95% confidence interval in pairwise comparisons with reference group (diamonds))*

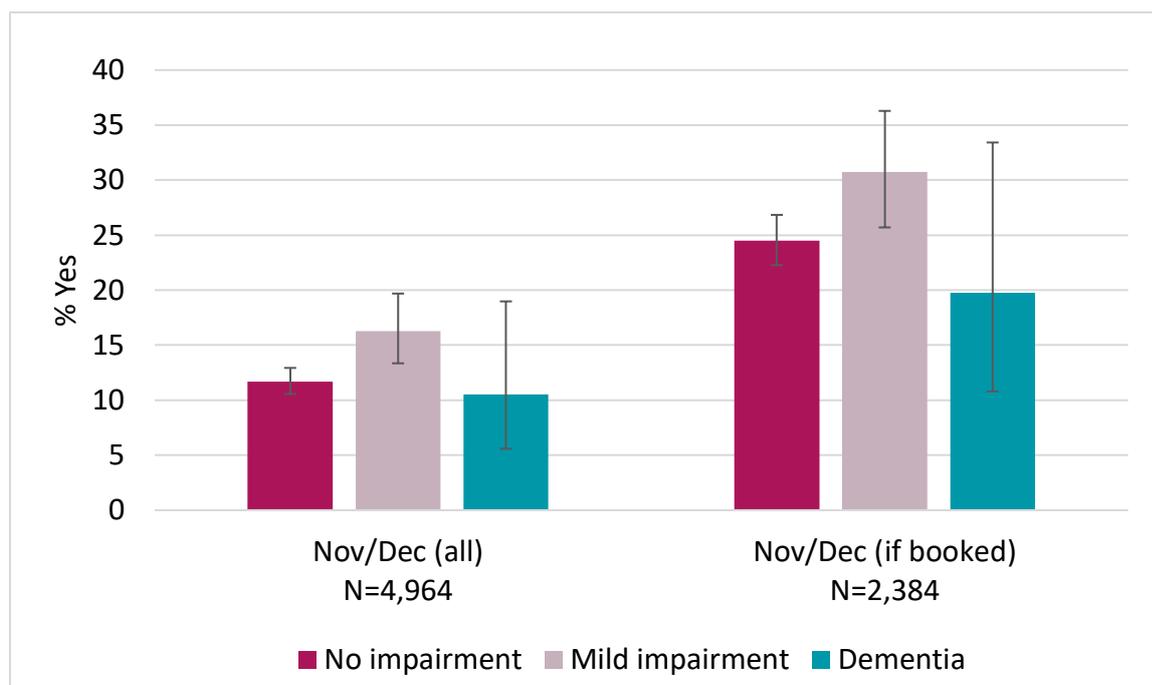


### Cancelled hospital operations and treatments

The finding reported above were focused on disruption to community-based health and care services (including GP visits). The survey also asked respondents about disruption to hospital-based operations and treatments.

Questions were asked at both waves, with slight differences in response options. More specifically, the question in Nov/Dec (Wave 2) asked about cancellations since the outbreak of the pandemic that included a response option of “I did not have a hospital operation or treatment booked”. As a result, we can look at responses in Nov/Dec in two distinct ways, as illustrated in Figure 7: measuring yes responses in contrast to all other respondents or where yes responses are contrasted only to those who did not have a cancellation but had an operation/treatment booked.

*Figure 7: Cancellations of hospital operations and/or treatments*



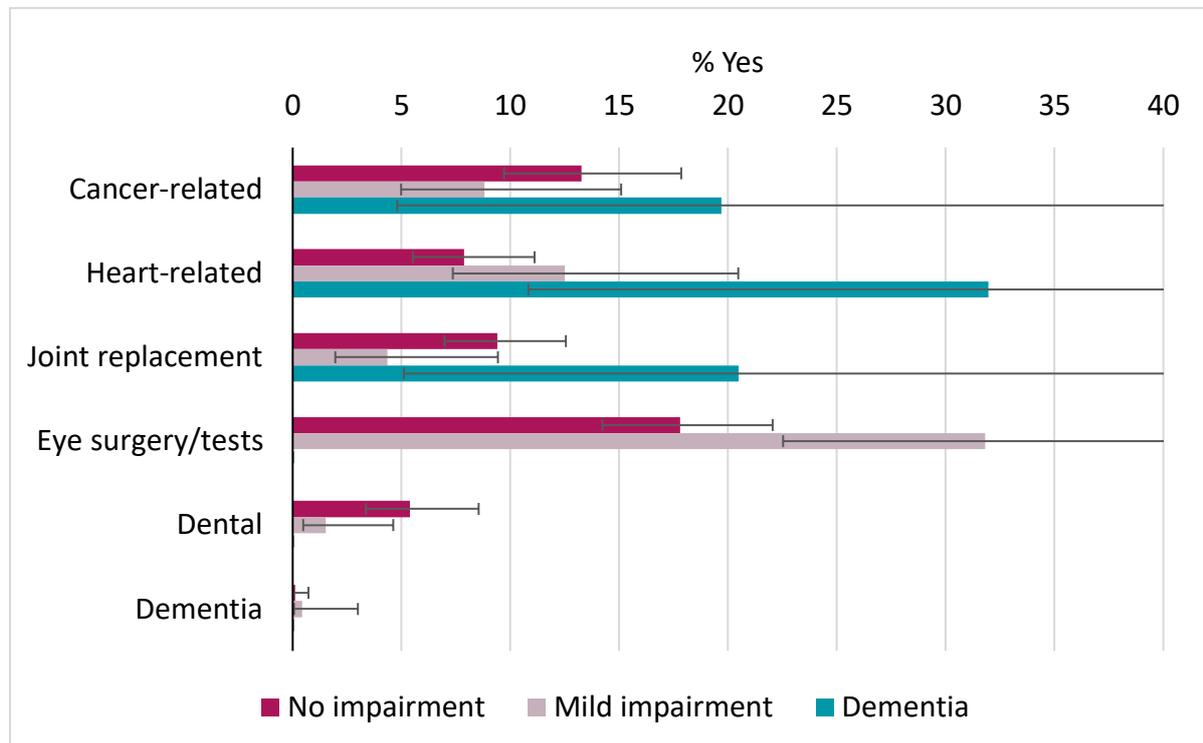
Notes: Error bars reflect 95% confidence intervals.

Looking at the results for Nov/Dec restricted to those who had operations and/or treatments booked, we find different estimates according to cognitive function groups, although with overlapping confidence intervals. The point estimates suggest that people with dementia who had hospital services booked may have experienced less disruption than the other groups, and those with mild impairment may have experienced greater disruption than those with no impairment. Indeed, looking at the results for Nov/Dec capturing all respondents, higher proportions of those with mild impairment did report cancellations compared to those with no impairment at a significant level.

In Nov/Dec, we also have information on the type of operations and treatments that were cancelled. There is some indication that people with dementia had cancer-, heart-, and joint-related operations and treatments cancelled more than those in the other cognitive groups, though confidence intervals are large given the small number of respondents reporting cancellations. Age could be a factor here, as those with dementia have a higher average age than those with no impairment; however, the average age of people with

dementia is similar to the average age of those with mild impairment in our sample. Those with mild impairment were more likely than those with no impairment to have eye/sight-related cancellations, while no respondents with dementia mentioned cancellations related to eye/sight-, dental-, or dementia-related treatments.

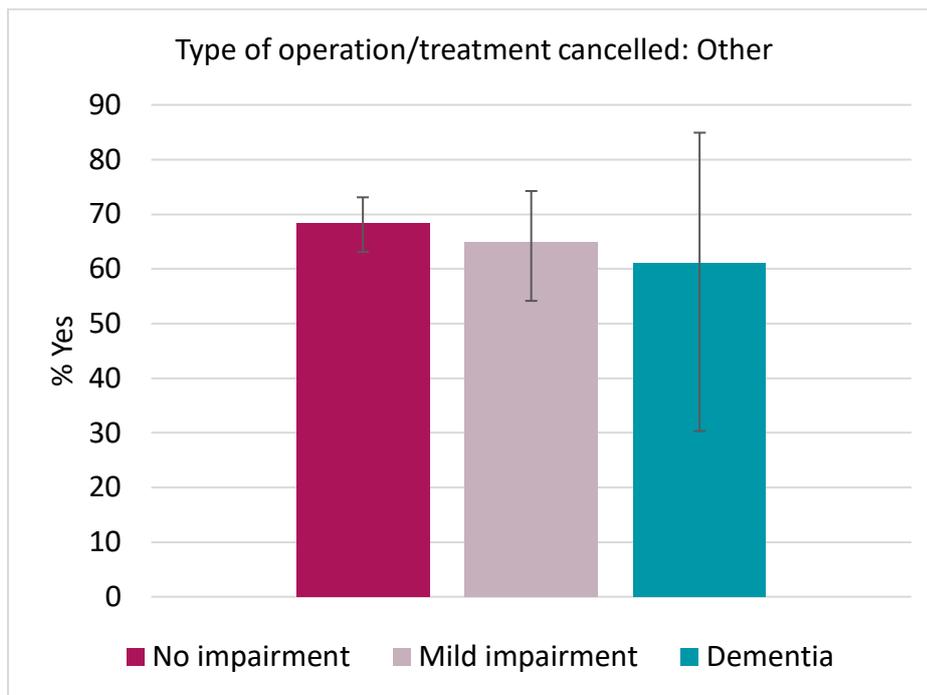
*Figure 8: Types of cancelled operations and treatments*



Notes: Wave 2 (Nov/Dec) results; N=582. Error bars reflect 95% confidence intervals.

The “other” category was by far the most frequently noted type of hospital operations and treatments that were cancelled. This was true for all cognitive groups, ranging from 61% to 68% of respondents, with no significant differences between groups.

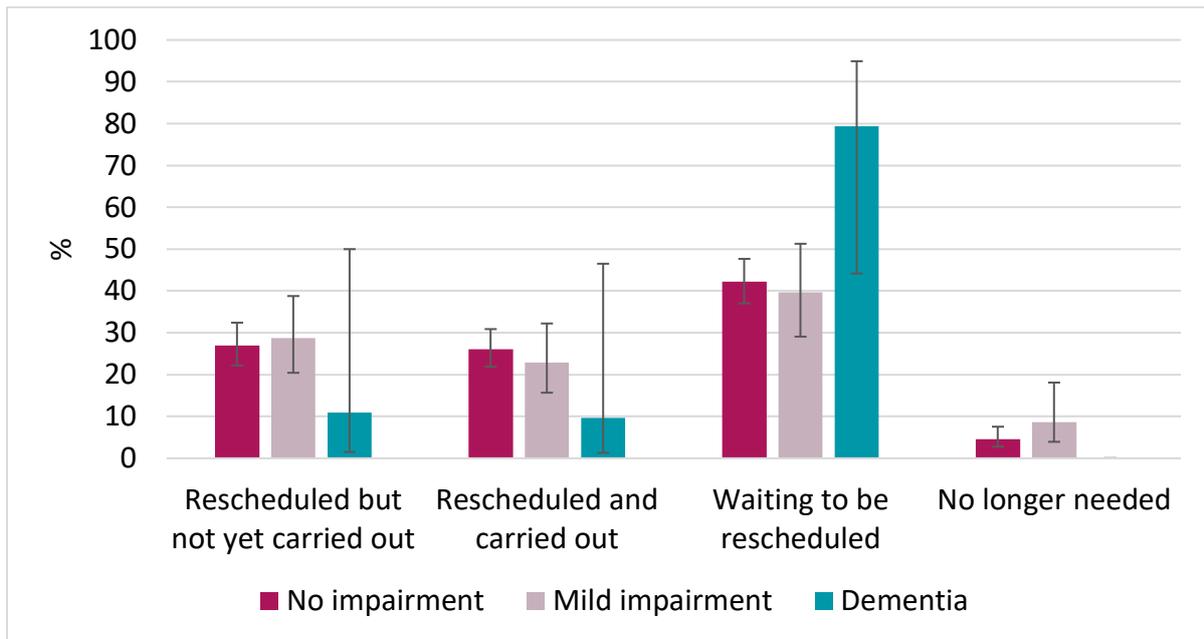
Figure 9: Cancellations of "Other" types of operations/treatments



Notes: Wave 2 (Nov/Dec) results; N=582. Error bars reflect 95% confidence intervals.

Respondents who reported a hospital-related cancellation were also asked about the status of the cancelled operation and/or treatment. The most commonly reported status was that they were still waiting for it to be rescheduled. This was true for all cognitive groups, but there was a strong suggestion that people with dementia were more likely to report this status, with around 79% reporting this compared to 42% of those with no impairment and 40% of those with mild impairment. No respondents with dementia said their cancelled operation and/or treatment was no longer needed. Around a quarter of those with no impairment or those with mild impairment said their cancellation had been rescheduled and already carried out.

Figure 10: Status of cancelled operations and treatments



Notes: Wave 2 (Nov/Dec) results; N=579. Error bars reflect 95% confidence intervals.

Like with community health disruptions, we created regression models to examine the likelihood of hospital-based cancellations by cognitive function group, accounting for other characteristics. Full results can be found in Appendix 2. By June/July, only health was strongly associated with the likelihood of a cancellation, as those with good health were 71% more likely than those with excellent/very good health to report a cancellation. Those with fair/poor health were over 2.8 times as likely to report a cancellation. Multimorbidity was also associated with cancellation, linked to a 45% increase in the likelihood of reporting a cancellation compared to those without multimorbidity.

Looking at responses in Nov/Dec, we compared those who reported a cancellation to those who reported no cancellation and, separately, to those who said they had no operation or treatment booked. Health-related variables remained the only factors linked to the likelihood of cancellation for both comparator groups. Unlike in June/July, there was no difference in those reporting good health compared to excellent/very good health. Yet those with fair/poor health were 46% less likely as those with excellent/very good health to say they did not have a cancellation and 65% less likely to say they did not have a booking compared to those with a cancellation. Those with multimorbidity were 34% less likely to say they did not have a cancellation and 47% less likely to say they did not have a booking. No interaction effects for region, wealth, or education were found related to cancellations among those who had bookings. The presence of multimorbidity did, however, show an association in our interaction model, as it was linked with an 87% higher likelihood of a cancellation among people with no impairment in June/July and 94% higher in Nov/Dec.

Looking at the current status of cancellations, we found the following when comparing those rescheduled but not carried out (pending) and those waiting for rescheduling:

- Those with mild impairment or with dementia were less likely to have been rescheduled and pending than those with no impairment (relative risk ratios (RRRs) 0.441 and <0.001, respectively).

- Older age slightly increased the likelihood of having been rescheduled and pending than to still be waiting for rescheduling, with an almost 8% increase in likelihood for each year of age.
- Those with medium education were about 56% less likely as those with low education to be pending, while those with high education were about 53% less likely as those with low education to be pending, although with weaker statistical significance ( $p=0.107$ ).
- Those with good health were over twice as likely than those with excellent/very good health to have been rescheduled and pending, while those with multimorbidity appeared less likely to have been rescheduled and pending rather than to still be waiting ( $p=0.087$ ).

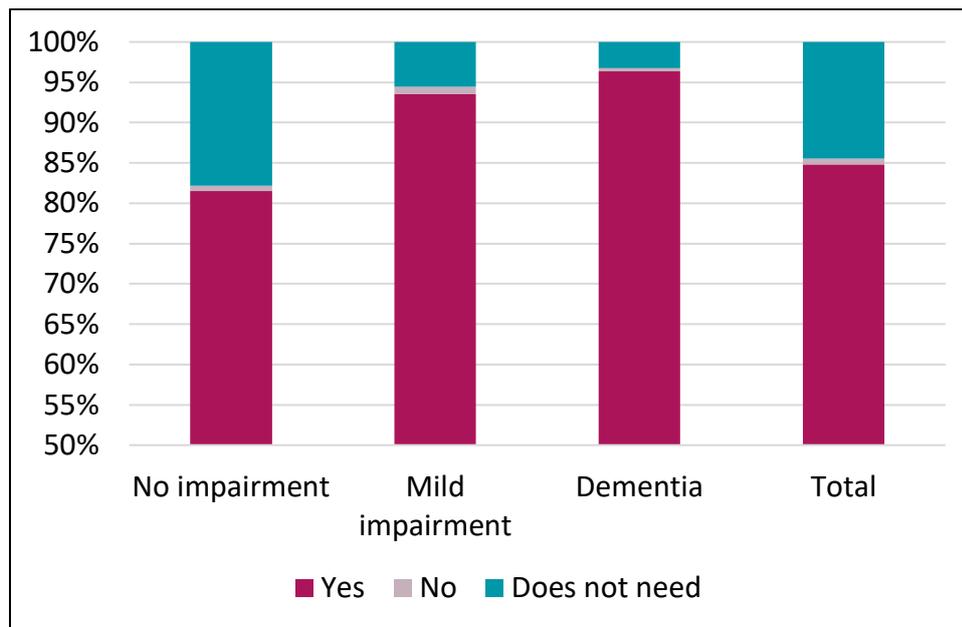
Comparing those still waiting to be rescheduled and those already rescheduled and carried out, only work status was linked, with those classed as “other” – a group that includes those unemployed, out of work due to sickness or disability, or looking after home and family – 84% less likely as those in paid work to have had their cancellation rescheduled and carried out rather than to still be waiting.

We also created models to look at specific types of cancellations, controlling for age, sex, household size, and whether living with a partner. Those with dementia were over five times more likely than those with no impairment to have a heart-related cancellation. Women were 2.7 times more likely than men to have joint-related operations cancelled, while higher ages and household sizes were linked to a greater likelihood of an eye/sight-related cancellation (with risk increased 6% and 63% for each increase in year of age or people in the household, respectively).

### Medications & polypharmacy

Another key aspect of health and care services that could have been disrupted during the pandemic is access to medications. Respondents were asked whether they had been able to access their regular medications at the first wave of data collection. Figure 11 shows responses among all respondents, illustrating that those with no impairment had a larger proportion not needing medication compared to those with mild impairment or dementia.

Figure 11: Whether respondents could access regular medication (Wave 1, N=5,170)



Restricting the view to only those needing medication, nearly all respondents in any cognitive group reported being able to access their medication: 99.2% with no impairment, 99.0% with mild impairment, and 99.6% with dementia.

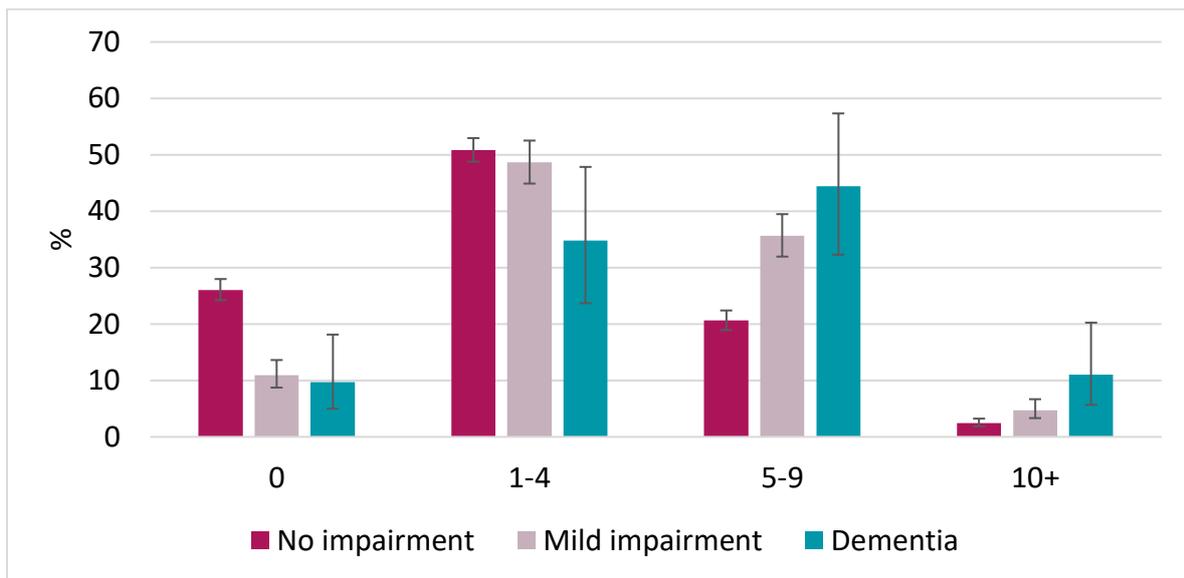
Understanding disruption in access to medications might be further informed by considering the number of medications taken by a given individual. Drawing on data from the most recent wave of the main ELSA survey (Wave 9, collected in 2018/2019), we were able to examine levels of polypharmacy among those in the COVID sub-study. Polypharmacy increases with higher levels of cognitive impairment; for example, the average number of medications was 2.7 among those with no impairment, 4.1 among those with mild impairment, and 5.2 among those with dementia. Average values were also higher when restricted to only those taking medications, as shown (with 95% confidence intervals) in Table 2.

Table 2: Average numbers of medications by cognitive function groups (COVID Wave 1)

	Mean (all)	95%CI	Mean (if taking meds)	95%CI
<b>No impairment</b>	2.7	2.6-2.8	3.7	3.6-3.8
<b>Mild impairment</b>	4.1	3.9-4.4	4.7	4.4-4.9
<b>Dementia</b>	5.2	4.5-6.0	5.8	5.1-6.5
<i>N</i>	4,121		3,187	

We also created groups to assess polypharmacy based on the number of medications taken, as shown in Figure 12. These groups more clearly show distinctions across cognitive groups, with a notably higher proportion of those with no impairment taking no medications than the other two groups. Higher proportions of those with either mild impairment or dementia were taking 5-9 medications or 10+ medications compared to those with no impairment.

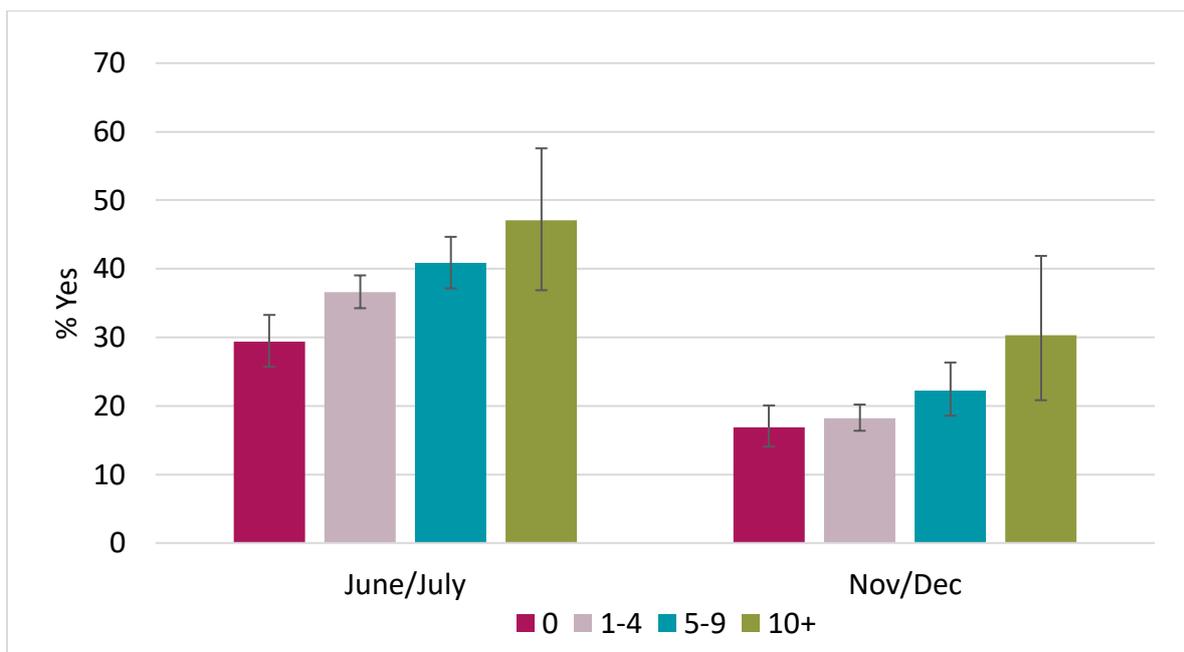
Figure 12: Polypharmacy level by cognitive function group



Notes: Wave 1 (June/July) results; N=4,151. Error bars reflect 95% confidence intervals.

Looking at the relationship between the polypharmacy groups and disruption in access to community health and care services, the trend shows that increasing proportions of people experienced disruption with increasing polypharmacy. Disruption was lower at Wave 2 than at Wave 1, but the underlying pattern by polypharmacy remains.

Figure 13: Disruption in access to community health and care services by polypharmacy



Notes: Wave 1 N=4,118; Wave 2 N=3,947. Error bars reflect 95% confidence intervals.

## Healthy lifestyle practices during the pandemic

This part of the research captures a snapshot of lifestyle practices during the pandemic and explores how they changed over time. When we mention lifestyle practices, we refer to the behaviours, activities, and experiences linked to healthy lifestyles. These include sleep, smoking, alcohol consumption, physical activity, and diet/nutrition. Extensive research has shown that these practices are linked to the risk of multiple illnesses, mortality, and overall adverse outcomes in the context of ageing.

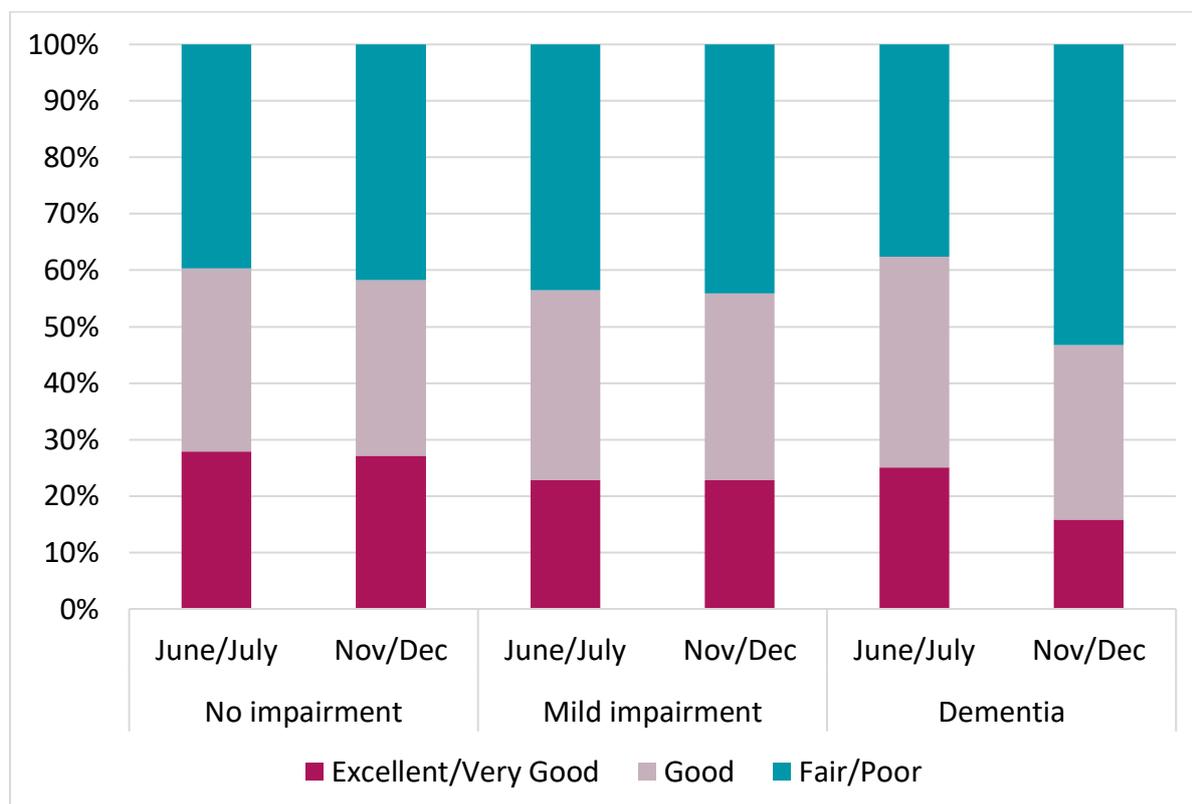
### Lifestyle practices during the pandemic

#### Sleep

Respondents were asked to rate the quality of their sleep in the month prior to their interview in June/July and Nov/Dec. In June/July, we find that similar proportions of people across cognitive function groups report their sleep quality as good, roughly around a third of people in each group. Similar proportions of those with dementia and no cognitive impairment also report either excellent/very good or fair/poor sleep. Those with mild impairment appear to have worse sleep than those with no impairment, with 22.8% classifying their sleep quality as excellent/very good and 43.5% as fair/poor compared to 27.9% and 39.7% as fair/poor.

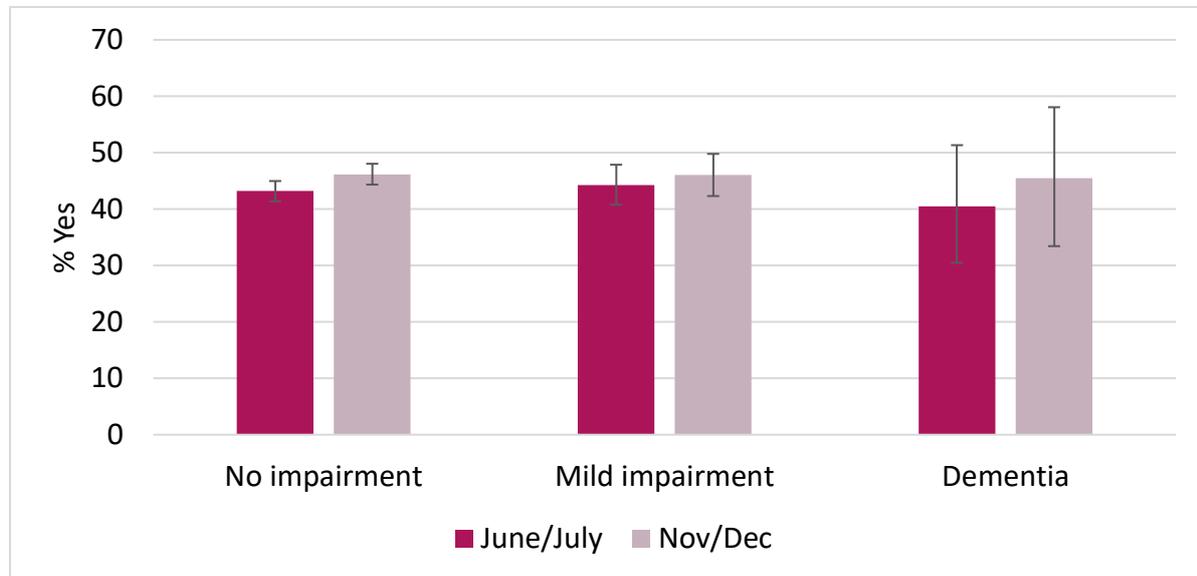
By Nov/Dec, the situation for people with dementia appears to have declined. Only 15.8% of those with dementia reported excellent/very good sleep compared to 27.2% of those with no impairment. Fair/poor quality sleep was reported by 53.3% of those with dementia compared to 41.7% of those with no impairment, with some overlap of 95% confidence intervals. Proportions for those with mild impairment fell between those for the other cognitive function groups.

Figure 14: Sleep quality by cognitive function status and time period



Another perspective on sleep was captured by asking if their sleep was mostly restless in the past week. A slightly smaller proportion of people responded that it was than not, at 43.4% versus 56.6% in June/July and 46.1% versus 53.9% in Nov/Dec. There were no significant differences across cognitive function groups.

*Figure 15: Mostly restless sleep in previous week by cognitive function status and time period (with 95% confidence intervals)*



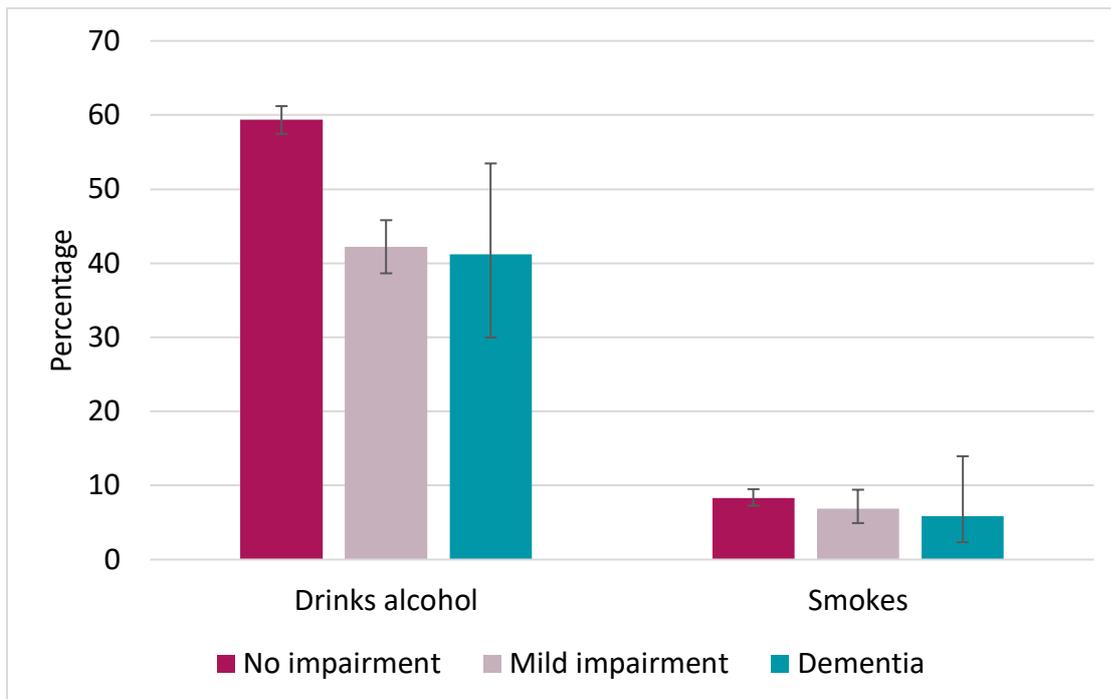
### *Smoking*

The vast majority of respondents were not smokers in June/July (91.9%) or Nov/Dec (92.1%). There were no significant differences according to cognitive function status.

### *Alcohol consumption*

In June/July, respondents were asked whether they were currently drinking alcohol. Lower proportions of those with either mild impairment (46.1%) or dementia (42.2%) were drinkers compared to those with no impairment (63.9%). In Nov/Dec, respondents reported the amount of alcohol they consumed in terms of pints of beer/cider, glasses of wine, and measures of spirits. There are issues around consistency, social desirability bias, and measurement error related to self-reported measures of alcohol consumption. This is likely to affect any attempts at comparison between individuals, particularly when included a dimension such as cognitive function status. As a consequence, we do not report those here; we will, however, return to them later when examining change over time, as the issues around bias and error should be reduced when comparing self-reports from the same individual.

Figure 16: Alcohol consumption and smoking by cognitive function status in June/July (with 95% confidence intervals)



### Physical activity

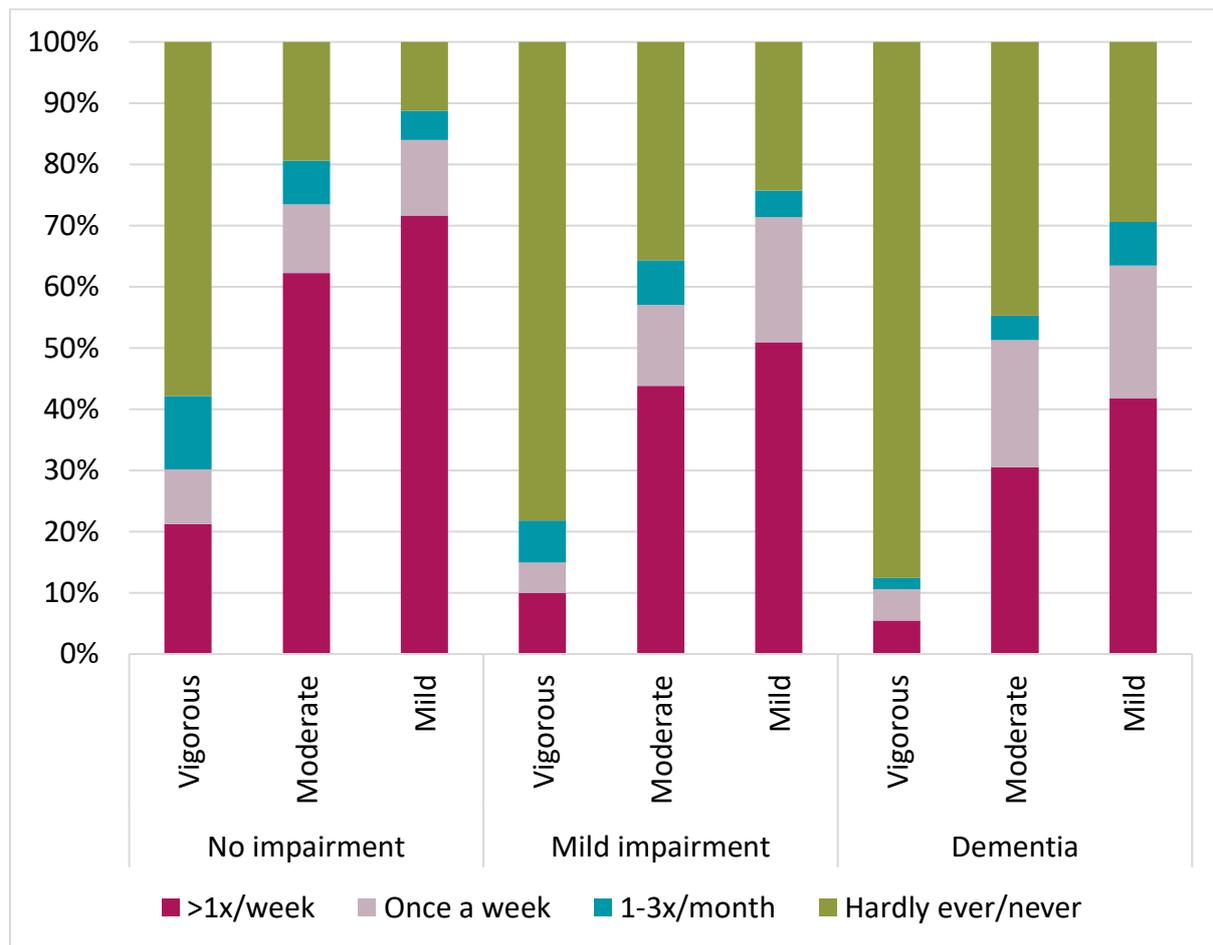
Self-reported levels of physical activity were collected in Nov/Dec. Respondents were asked about the frequency of taking part in sports or activities in three distinct questions, each focused on vigorous, moderately energetic, or mildly energetic activity. Each item had possible responses of “more than once a week”, “once a week”, “one to three times a month”, and “hardly ever or never”.

More intense physical activity was more prevalent among people with no impairment. For example, 21.2% of those with no impairment reported vigorous activity more than once a week compared to 10.0% of those with mild impairment and 5.4% of those with dementia. Hardly ever or never engaging in vigorous activity was reported by 57.8% of those with no impairment compared to 78.2% of those with mild impairment and 87.6% of those with dementia.

Moderately energetic activity was more common than vigorous activity among those with mild impairment or dementia, but it was still more common among those with no impairment. Moderately energetic activity more than once a week was reported by 62.2% of those with no impairment, 43.8% of those with mild impairment, and 30.6% of those with dementia. Rates for hardly ever or never engaging in moderately energetic activity were 19.4%, 35.7%, and 44.8%, respectively.

The majority of people in any cognitive group reported at least weekly mild activity, and just 11.2% of those with no impairment, 24.3% of those with mild impairment, and 29.4% of those with dementia reported hardly ever or never engaging in mildly energetic activity. Rates for more than once a week were 71.6%, 51.0%, and 41.8% respectively.

Figure 17: Frequency of physical activity by cognitive function status in Nov/Dec



Responses to these three items were combined to make an overall assessment of physical inactivity. Those who report hardly ever/never engaging in any type of activity or who only engage in mild activity are classed as physically inactive. This measure clearly captures the association between cognitive impairment and greater inactivity. Nearly 1 in 5 (18.1%) of those with no impairment are classified as physically inactive compared to 33.7% of those with mild impairment and 43.9% of those with dementia.

### Diet and nutrition

The questions included in the COVID sub-study related to diet and nutrition are limited to the access to food and concerns over having enough food. In June/July and Nov/Dec, respondents were asked about the situation related to the food eaten in their household. There were no significant differences across cognitive function groups with respect to responses in June/July, with 86.9% of those with no impairment, 86.3% of those with mild impairment, and 80.7% of those with dementia stating they always had enough of the kinds of food they wanted to eat. By Nov/Dec, there was some indication that those with dementia were not always able to get the kinds of food they wanted; 81.3% compared to 92.4% of those with no impairment. Indeed, 18.7% of those with dementia indicated that, while they had enough to eat, it was not always the food they wanted, in contrast to 7.0% of those with no impairment (and 8.0% of those with mild impairment, though there is an overlap in 95% confidence intervals). No respondents with dementia suggest they

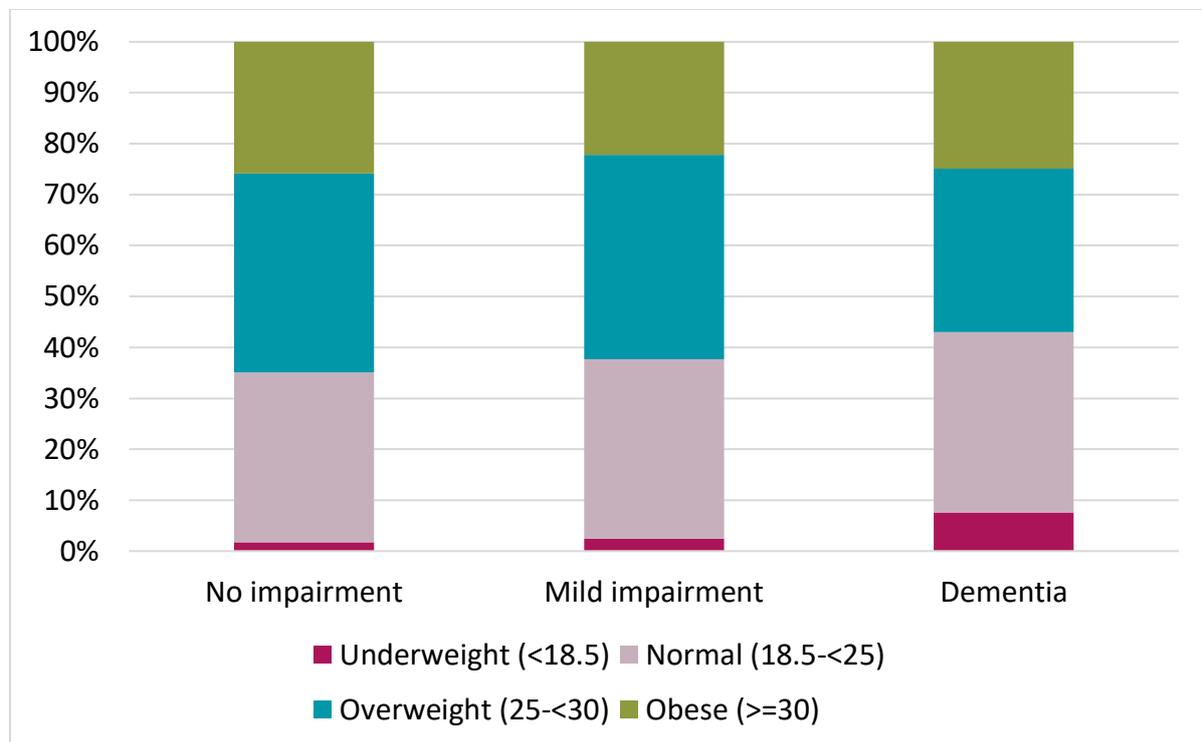
sometimes or often did not have enough to eat in Nov/Dec, while this was less than 1% of respondents in the other cognitive function groups.

### Weight and body mass index (BMI)

We also examined weight and body mass index (BMI) among respondents in Nov/Dec. Those with mild impairment or dementia had a significantly lower average weight than those with no impairment. The average weight for those with no impairment was 77.6 kg (76.9-78.3), while it was 72.8 kg (71.6-74.1) for those with mild impairment and 70.6 kg (66.1-75.1) for those with dementia.

Using height and weight, we calculated respondents' BMI and found no significant difference in the average BMI score by cognitive function status. The continuous score was categorised into underweight (<18.5), normal (18.5 to <25), overweight (25 to <30), and obese (>=30). There were similar proportions of people in each cognitive function group for the different categories of BMI except for the underweight group. Around 7.6% (2.8-19.0) of people with dementia were classed as underweight compared to 1.7% (1.2-2.4) of those with no impairment and 2.4% (1.5-3.8) of those with mild impairment.

Figure 18: BMI categories by cognitive function group in Nov/Dec



When grouping overweight and obese together, we find around two-thirds of the sample fall into this category. There is a smaller (though not statistically distinct) proportion of people with dementia classed as overweight/obese than the other groups: 57.0% (45.2-68.0) compared to 62.3% (58.6-65.9) of those with mild impairment and 64.9% (63.1-66.7) of those with no impairment.

### Changes in lifestyle practices during the pandemic

To examine changes in lifestyle practices during the pandemic, we can draw on self-reported changes as well as compare responses during the COVID sub-study to those given at earlier waves of the ELSA survey.

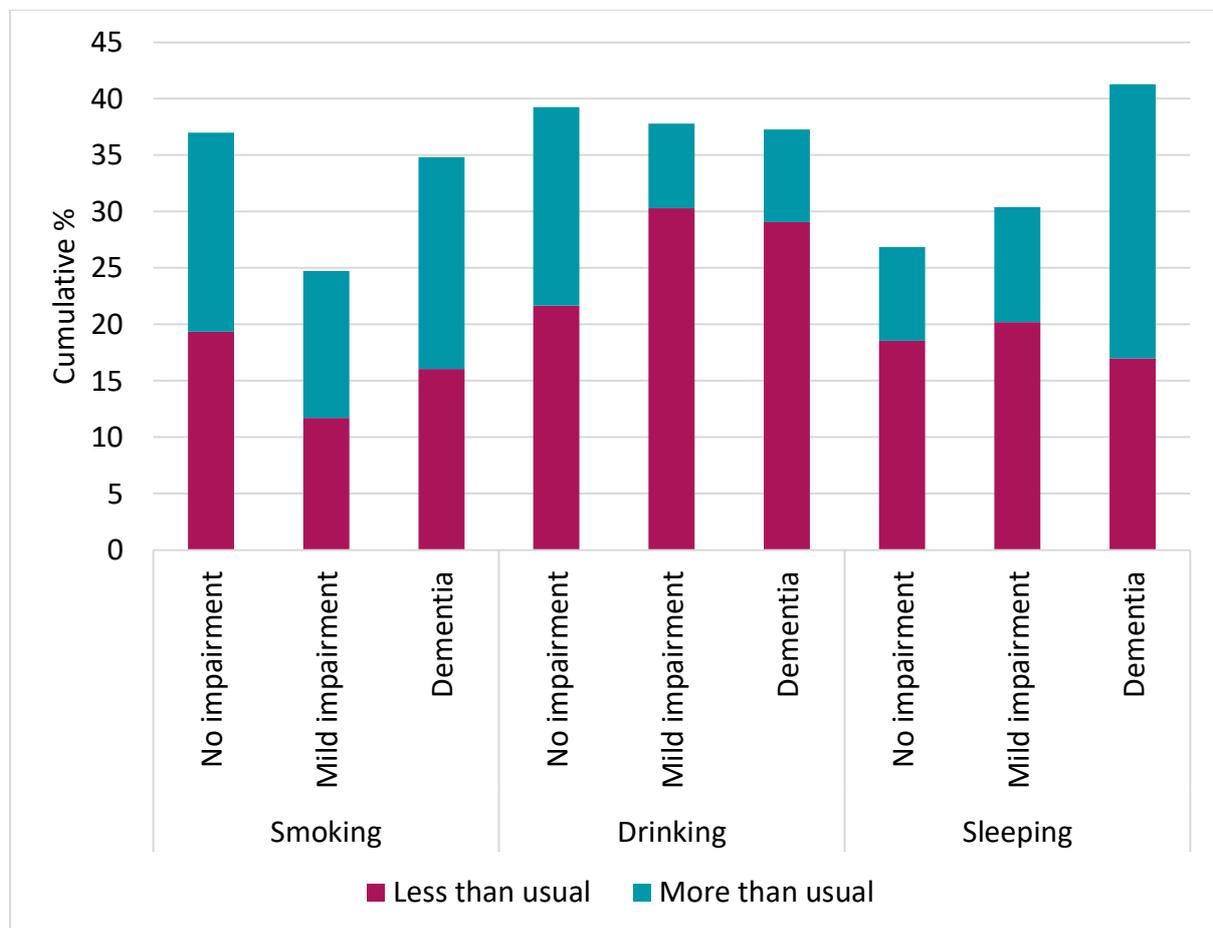
In June/July, respondents were asked whether they were doing various activities less than usual, about the same, or more than usual since the outbreak of the pandemic. Activities included sleeping, smoking, drinking alcohol, doing physical activity, sitting down, watching TV, and eating.

With such few smokers in the sample, the 95% confidence intervals involved are wide, reducing the strength of our estimates. Around 16.7% of respondents indicated they were smoking more, with a suggestion this proportion was lower for those with mild impairment (13.0%) compared to those with no impairment (17.6%) or with dementia (18.8%).

However, a lower proportion of those with mild impairment (7.5%) said they were drinking more alcohol than before compared to 17.6% of those with no impairment; this was 8.2% for those with dementia but with overlapping confidence intervals. Similarly, higher proportions of those with mild impairment (30.3%) or dementia (29.1%) were drinking less than those with no impairment (21.7%).

Similar proportions across cognitive function groups said they were sleeping less since the pandemic started (18.9% of the total). However, a significantly higher proportion of those with dementia (24.3%) were sleeping more than those with no impairment (8.3%) or with mild impairment (10.2%).

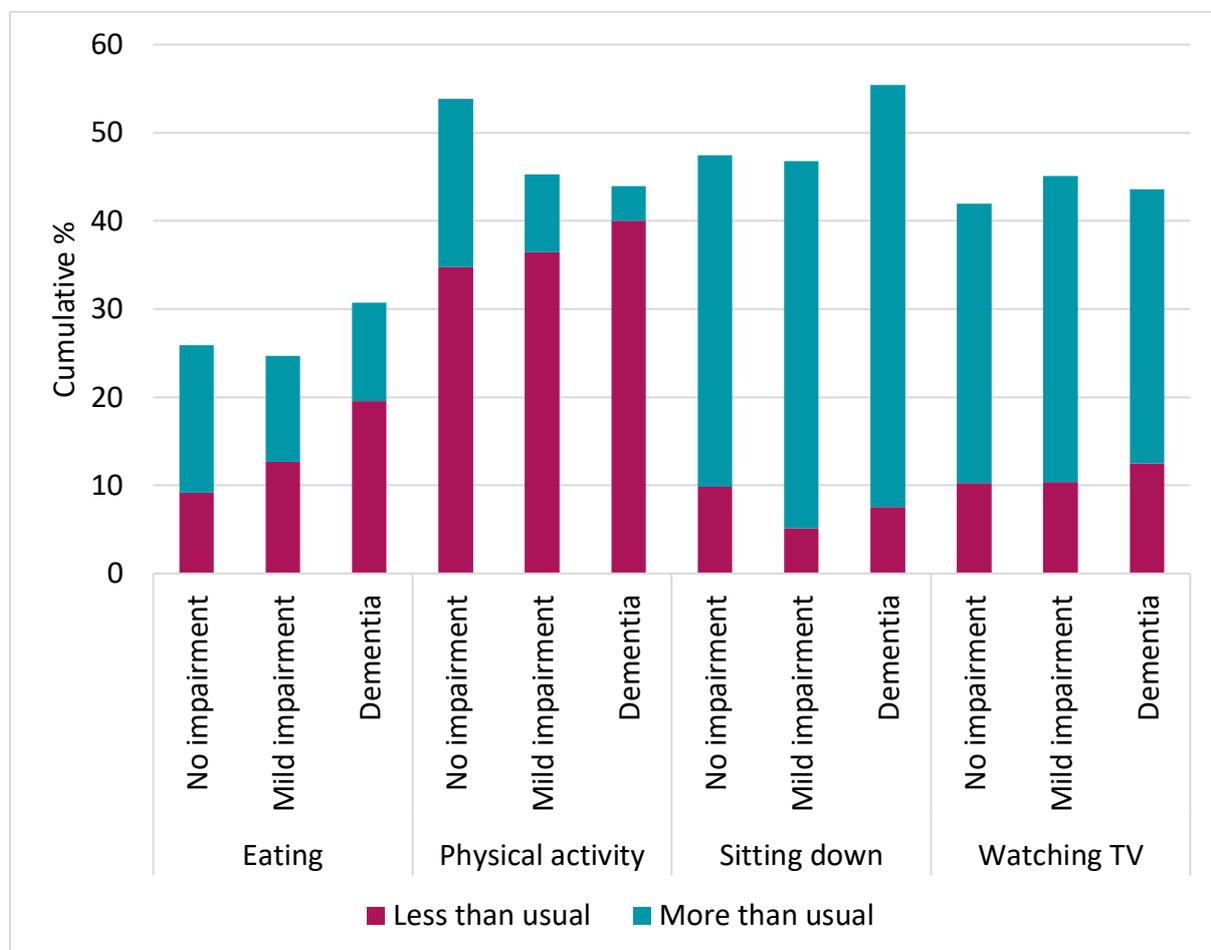
*Figure 19: Self-reported changes in activities (pre-pandemic to June/July) by cognitive function group (NB: No change is omitted but constitutes the remaining cumulative percentage to 100%.)*



Although we found no evidence that large proportions of respondents were unable to get enough to eat, we did find that a higher proportion of people with dementia (19.5%) were eating less compared to those with no impairment (9.2%) and those with mild impairment (12.7%, with overlapping confidence intervals). Lower proportions of those with dementia (11.2%) or mild impairment (12.0%) were eating more compared to those with no impairment (16.7%).

With respect to physical activity, there were no significant differences reporting less physical activity, but a significantly larger proportion of those with no impairment (19.1%) reported more physical activity than those with mild impairment (8.9%) or dementia (3.9%). This may partly be explained by more time spent sitting, reported by 37.6% of those with no impairment, 41.7% of those with mild impairment, and 47.8% of those with dementia. This is likely also linked to more time spent watching television, reported by around a third (32.4%) of all respondents, with no differences across cognitive function groups. Only around 8.7% and 10.4% of all respondents were sitting less and watching television less, respectively.

*Figure 20: Self-reported changes in activities (pre-pandemic to June/July) by cognitive function group (NB: No change is omitted but constitutes the remaining cumulative percentage to 100%.)*



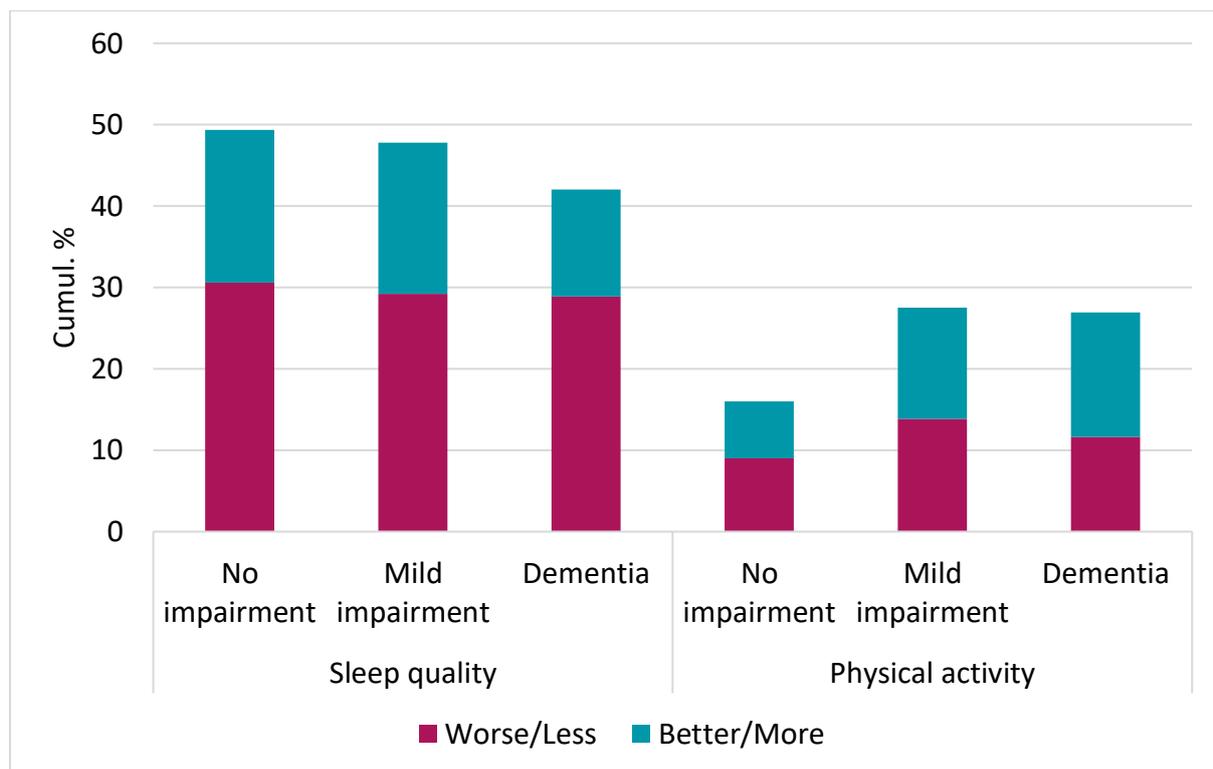
Of course, self-reported changes may not reflect reality, as people may misremember, be affected by the significant changes caused by the pandemic and lockdown, or be influenced by various forms of bias like social desirability. We consequently wanted to compare

responses to questions that were asked during both the COVID sub-study and waves of ELSA prior to the pandemic. We thus evaluated sleep quality, smoking status, physical inactivity, and levels of alcohol consumption in terms of whether respondents' situation was worse, same, or better after the start of the pandemic. Responses in Nov/Dec 2020 (COVID Wave 2) were compared to Wave 9 of ELSA, collected in 2018/19, with the exception of sleep quality, which used Wave 8 (2016/17).

Just over half of respondents had similar sleep quality before and after the pandemic (51.2%). Sleep quality improved after the start of the pandemic for 18.6% of all respondents, with a slightly lower proportion for those with dementia (13.2%) than those with no impairment (18.8%) or mild impairment (18.6%), although 95% confidence intervals overlap. Larger proportions were found to have experienced worsening sleep quality, approaching a third of all respondents (30.2%) with no significant differences according to cognitive function.

With respect to physical activity, a higher proportion of those with mild impairment (13.9%) were less active than those with no impairment (9.0%). A higher proportion (13.7%) were also more active (7.0%). Similar results were found for those with dementia compared to those with no impairment, with 11.7% less active and 15.3% more active (although the less active figure has overlapping confidence intervals). Based on self-reported physical activity, we have clear evidence that greater proportions of people with either mild cognitive impairment or dementia had increased their physical activity after the start of the pandemic compared to those with no impairment. However, as noted above, significantly higher proportions were classified as physically inactive after the start of the pandemic.

*Figure 21: Measured changes for sleep quality (2016/17 to Nov/Dec 2020) and physical activity (2018/19 to Nov/Dec 2020) by cognitive function group (NB: no change is omitted)*

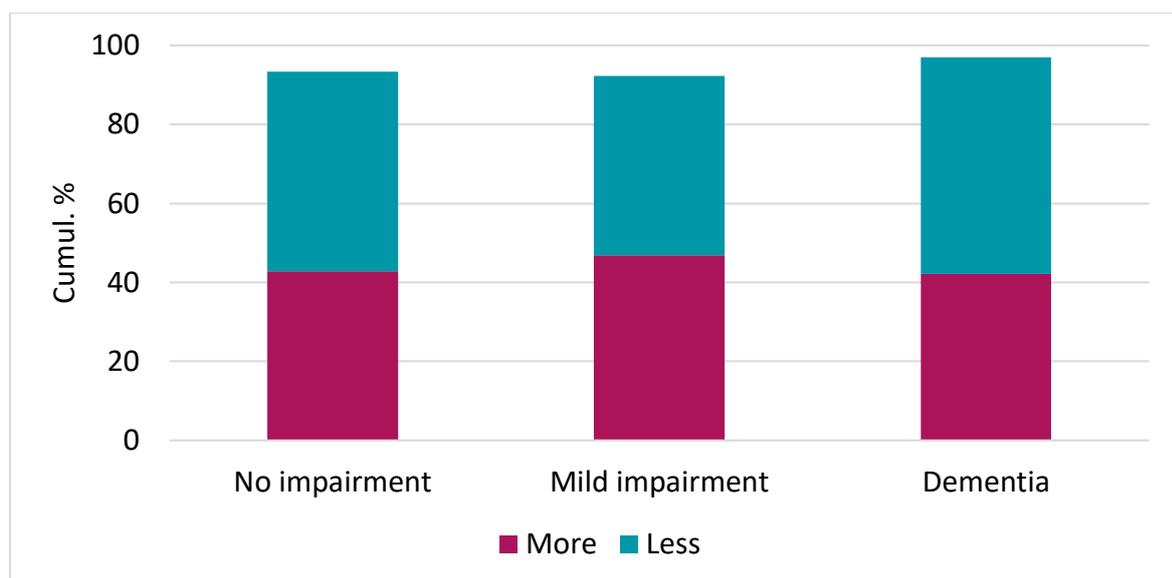


The vast majority of smokers (95.9%) were smoking at both ELSA Wave 9 and COVID Wave 2. A slightly larger proportion of those with no impairment had stopped smoking (3.7%) than had (re-)started (1.1%); the small number of smokers in some analytical strata do not allow confidence intervals to be calculated. There does appear to be greater change among those with dementia than the other cognitive function groups, although similar proportions stopped (4.2%) as (re-)started (4.3%).

To assess alcohol consumption, we draw on self-reports of the number of pints of beer/cider, glasses of wine, and single measures of spirits consumed in the previous week. We converted these estimates to standard units of alcohol, applying a multiplier of 2.5 to pints of beer/cider and to glasses of wine. This multiplier was applied to allow for variation in strength of beer/cider and sizes of glasses of wine; there are 2.3 units in a pint of 4% strength beer or a 175ml glass of 13% strength wine, for example.

When excluding non-drinkers, we find that only a small percentage of respondents report the same number of units consumed both before and after the start of the pandemic (6.8%). A similar proportion of people with mild impairment were drinking more as were drinking less (46.8% versus 45.4%), while a larger proportion of people with no impairment were drinking less than more (50.5% versus 42.8%). Similarly, a larger proportion of those with dementia were drinking less than more (54.8% versus 42.2%), albeit with overlapping confidence intervals.

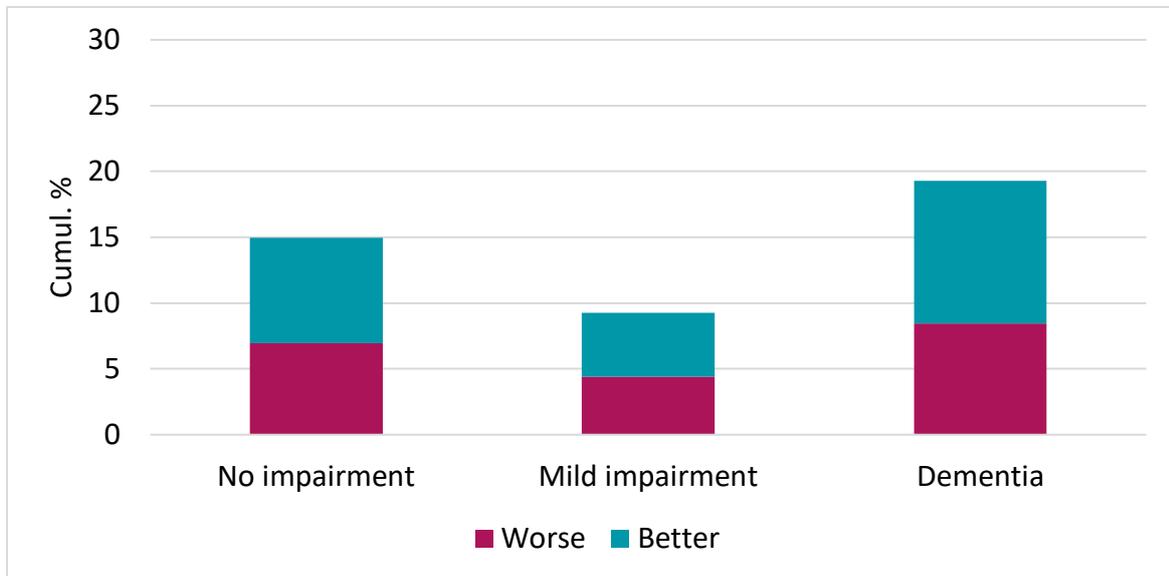
*Figure 22: Estimated change in consumption of alcohol units (2018/19 to Nov/Dec 2020) by cognitive function group (NB: no change is omitted)*



Given the low percentage of respondents with the exact same measure of alcohol unit consumption across the two time periods, we also looked at alcohol unit consumption with a cut-off of 14 units. Part of the public health guidance around alcohol consumption in the UK recommends individuals drink no more than 14 units in a week. Using this approach, we see the vast majority of respondents had no change between being over or under this limit. Where there was a shift to/from consuming more than 14 units, we see that a lower percentage of people with mild impairment shifted to drinking over this limit than people with no impairment; while the proportion for those with dementia was the highest, the confidence intervals overlap with the other two groups. At the same time, a lower

proportion of people with mild impairment was also found who shifted from over the recommended limit to under it compared to those with no impairment. Results for those with dementia again reflect the highest proportion but with overlapping confidence intervals.

*Figure 23: Estimated change in consumption of >14 units of alcohol per week by cognitive function group (NB: no change is omitted)*



### Associations among healthy lifestyle practices

Given that the risk for adverse outcomes increases with the number of unhealthy practices, we explored whether changes in individual lifestyle practices were linked to changes in others. We investigated this using latent class analysis in three parts, reflecting the different measures available at different times.

The first part looked at the seven self-reported changes in behaviours reported in June/July, covering smoking, drinking alcohol, physical activity, sitting, eating, sleeping, and watching television. The indicators created captured whether an increase was reported except for physical activity (which measured less physical activity) and sleep (where any reported change from “usual” was measured). Because of the low numbers of smokers, we attempted to fit models including and excluding smoking. We attempted to fit two- and three-class models, but results were difficult to interpret meaningfully (for two-class models) or the (three-class) models did not converge.

For the second approach, we created measures related to “worsening” lifestyle practices using measures from Wave 9 of the main ELSA study (Wave 8 for sleep) contrasted to responses in Nov/Dec 2020. We applied measures for smoking, alcohol consumption, sleep quality, and physical activity. Alcohol consumption was assessed in two ways: an absolute increase in reported units consumed and whether consumption went from under 14 units per week to over 14 units (as per current UK health recommendations). We again attempted to estimate two- and three-class models with no success, regardless of including/excluding smoking or using absolute versus 14-unit cut-off for alcohol consumption.

Our third approach looked at the self-reported measures collected in Nov/Dec assessing whether people reported fair or poor sleep quality, consumed alcohol, smoked, and were

physically inactive. We also used measures to calculate respondents' body mass index (BMI), allowing classifications of being overweight and/or obese.

In this instance, we were able to obtain interesting results from a three-class model; the marginal means are presented below. The three classes that emerge appear to reflect a group of people who drink and are overweight/obese, a group of smokers who also drink alcohol, and people less linked to smoking or drinking but who experience poor sleep, are physically inactive, and are overweight/obese.

*Table 3: Marginal means on 3-class estimation for lifestyle practices in Nov/Dec*

	Class 1	Class 2	Class 3
Poor quality sleep	0.3407	0.2878	0.5661
Current smoker	0.0022	0.9999	0.0883
Drinks alcohol	0.7090	0.5250	0.3818
Physically inactive	0.0360	0.1117	0.4830
Overweight/obese (BMI $\geq$ 25)	0.5780	0.3319	0.7670

After estimating the classes, we used posterior probabilities to assign individuals to one of the three classes in each analysis. Only a small proportion of respondents are linked to the second class (4%), reflecting the low proportion of smokers. Class membership was then used to examine associations with cognitive function. Bivariate results are shown in Table 4.

*Table 4: Estimated class membership by cognitive function status (Survey-adjusted % and 95% confidence intervals)*

	No impairment	Mild impairment	Dementia	Total
<b>Class 1</b>	68.04	55.3	40.77	64.34
	[66.21,69.81]	[51.5,59.04]	[29.67,52.9]	[62.67,65.99]
<b>Class 2</b>	4.767	2.964	3.699	4.312
	[4,5.671]	[1.914,4.565]	[1.123,11.49]	[3.667,5.063]
<b>Class 3</b>	27.19	41.73	55.53	31.34
	[25.49,28.96]	[38.01,45.56]	[43.17,67.23]	[29.74,33]

We see that a higher proportion of those with no cognitive impairment are classed in the first group than those with mild impairment or dementia. A higher proportion of those with dementia are classed in the third group compared to those with no impairment; the proportion among those with mild impairment falls between them, with confidence intervals that slightly overlap those for people with dementia. Similar proportions of people in any cognitive function group are grouped with the second class when taking confidence intervals into consideration.

### *Multinomial regression analysis of latent class membership*

The likelihood of class membership according to cognitive function status may be influenced by other characteristics, so we examined the association using multinomial logistic regression models and controlling for demographic, socioeconomic, geographic, and health-related variables.

As highlighted above, class groupings resulted in a small second class characterised most notably by current smoking status. Comparing this group to the first class (overweight/obese drinkers), cognitive function status is not associated with class membership. When looking at the third class (those physically inactive and overweight/obese with poor sleep quality) compared to the first class, cognitive function status also shows no association with class membership.

Fundamentally, the latent class analyses have estimated groups according to healthy behaviours and lifestyle practices, attempting to identify the patterns in how such practices are interrelated. Such behaviours are influenced by cultural, economic, and political factors, and as such reflect social embeddedness and therefore practices. While cognitive function (and impairment) is linked to similar factors, these results suggest that practices are more closely impacted by the factors that generate them than by any link to cognitive status.

Indeed, significant associations in the multinomial logistic models clearly demonstrate the social stratification that links poorer socioeconomic status, worse health, and unhealthy lifestyles. The first class reflected drinkers who are linked to being overweight or obese. Alcohol consumption and being somewhat overweight carries less social stigma among older people in England than other practices such as smoking or not being physically active. This may partially explain why membership in classes two and three – compared to class one – is (strongly) negatively associated with wealth and education.

Demographic features also demonstrated associations with the likelihood of being in the second or third class compared to the first class:

- Age was negatively associated with membership in the second class.
- Women were more likely to be grouped in class three than class one.
- Having a co-habiting partner was negatively associated with membership in class two or three (than class one).

Other covariates also demonstrated significant associations with class membership:

- People living in urban areas rather than rural areas were more likely to be in class three than class one.
- Self-rated health: Poorer health was linked to a higher likelihood of being in class three than in class one. Specifically, those reporting “good” or “fair/poor” health were more likely than those with “excellent/very good” health to be in class three than class one. There was also a link with class two, as those with “fair/poor” health were more likely than those with “excellent/very good” health to be in class two than class one.
- Multimorbidity: The presence of multimorbidity was also linked to class membership, increasing the likelihood of being in class three rather than class one.

The differences in class membership according to socioeconomic factors like wealth and education also point to potential inequalities that shape the relationship between cognitive function and lifestyle practice “type” (i.e. our latent classes). Controlling for sex and age, we explored interactions between an indicator for cognitive impairment (mild or dementia) and education, wealth, region, urban residence, and the presence of multimorbidity. With respect to the interact terms in these models, the only one to demonstrate significance was the one on wealth; people with cognitive impairment and in the top 2/3 of wealth were 1.7

times as likely to be in class three than class one compared to those with no impairment in the bottom third of wealth. People with no impairment in the top 2/3 of wealth were around 72% less likely than those with no impairment in the bottom third of wealth to be in class three rather than class one.

## Mental health & wellbeing during the pandemic

In this section, we report results from examining mental health and wellbeing as measured during the two periods of data collection during the pandemic, along with comparisons to measures collected prior to the pandemic in 2018/19. With respect to mental health, we specifically refer to measures of depression and anxiety. Regarding wellbeing, we have explored quality of life, loneliness, life satisfaction, and happiness.

### Mental health during the pandemic

In the COVID sub-study, depression and anxiety were measured using standardised scales, drawing on multiple questions to establish a score for depressive symptoms and generalised anxiety. Depression was measured using the 8-item Center for Epidemiological Studies Depression (CES-D) scale, a validated and reliable instrument for assessing depression among older adults. The scale draws on responses to eight yes/no questions to provide a continuous measure ranging 0-8 with higher scores reflecting greater levels of depressive symptoms. A binary measure was also constructed where scores of four or more were used to identify likely cases of clinical depression.

Anxiety was assessed using the 7-item Generalized Anxiety Disorder (GAD-7) scale, which has demonstrated validity and reliability for screening generalized anxiety disorder and assess its severity. Each item is measured on a 4-point scale ranging 0-3, providing GAD-7 scores ranging 0-21 with higher scores reflecting greater severity and association with higher levels of functional impairment. A binary measure to assess cases of generalized anxiety disorder was constructed using scores of 10 or more.

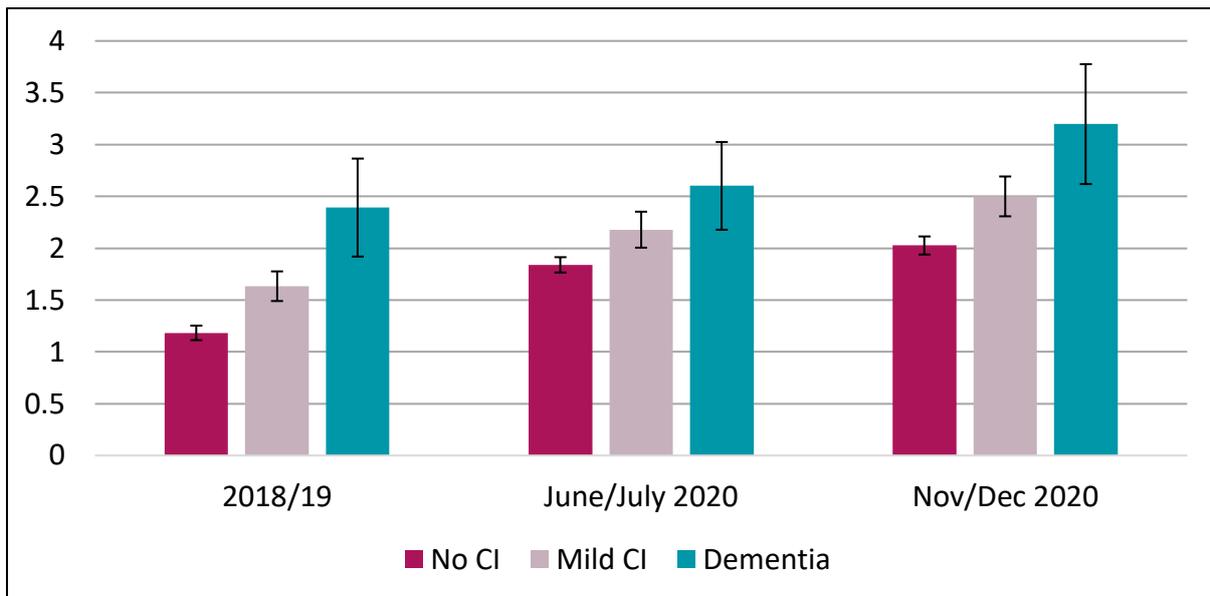
We can also compare average scores of depression to those from before the pandemic, drawing on CES-D responses in 2018/19 (Wave 9 of the main ELSA study). We do not have a similar pre-pandemic measure for anxiety, as GAD-7 was not collected before the COVID sub-study.

### *Depression*

We know there is a link between cognitive impairment and both depression and anxiety, so it is not surprising to see that the average score for both is higher among people with dementia.

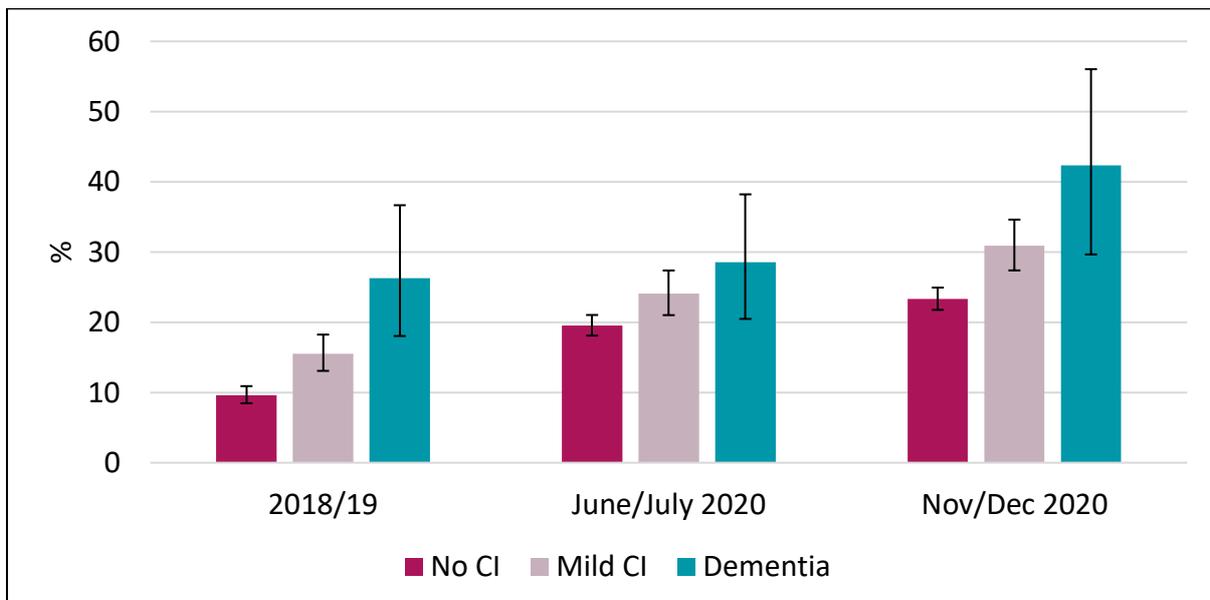
Looking at depression across the different time points, we see that average scores were higher across all cognitive function groups during the pandemic compared to measures from 2018/19. The 95% confidence intervals for those with dementia overlap, but the average score goes from 2.4 in 2018/19 to 3.2 in Nov/Dec 2020. For those with no impairment or mild impairment, the difference across time is starker and statistically significant, going from 1.2 to 2.0 and from 1.6 to 2.5, respectively.

Figure 24: Average depression score (CES-D) by cognitive function group and time period (with 95% confidence intervals)



When looking at likely cases of clinical depression as defined by CES-D scores greater than or equal to four, we see a similar pattern overall as we do with the average score. The proportion of people with no impairment with likely depression goes from 9.6% in 2018/19 to 23.3% in Nov/Dec 2020. For those with mild cognitive impairment, the figures are 15.5% and 30.9%, respectively. The confidence intervals for those with dementia overlap, but the estimates move from 26.3% to 42.3%.

Figure 25: Percentage of respondents with depression scores  $\geq 4$  by cognitive function group and time period (with 95% confidence intervals)

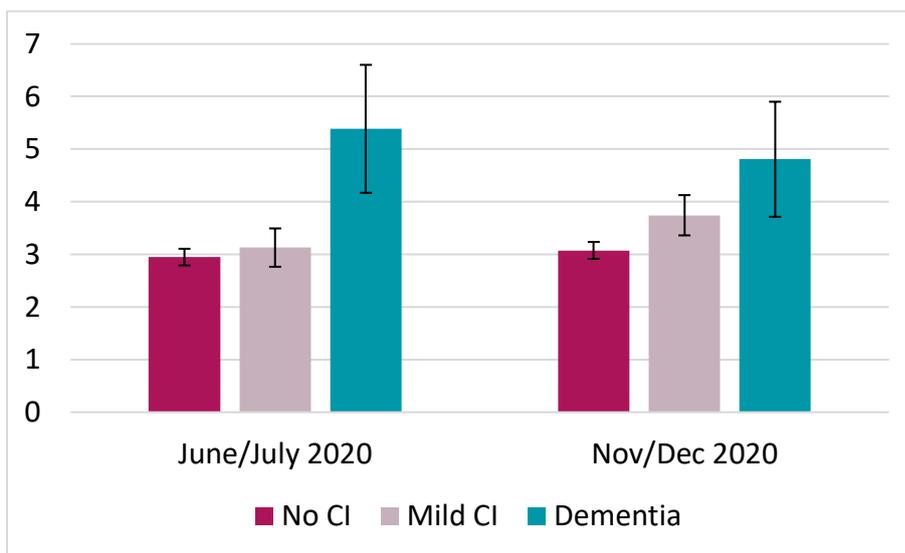


It is of particular note, with either measure of depression, that the estimates for those with no or mild impairment in Nov/Dec 2020 are somewhat similar to those for dementia before the pandemic.

## Anxiety

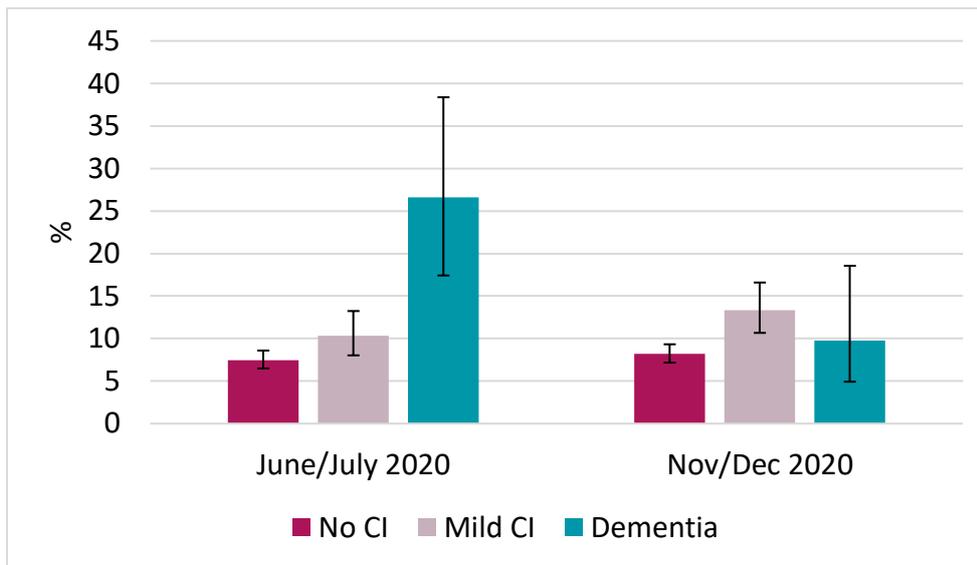
Again, given the known link between anxiety symptoms and cognitive impairment, it is not surprising to see that the average anxiety score is higher for people with dementia. Their average score was 5.4 in June/July 2020 compared to 2.9 and 3.1 for those with no impairment or mild cognitive impairment, respectively. In Nov/Dec 2020, the average score among those with dementia had declined to 4.8, though it was still higher than that among those with no impairment (3.1). The scores for those with mild impairment went from 3.1 to 3.7 over the same time; this increase was enough that, with the decline in the score for those with dementia, the two estimates had overlapping confidence intervals in Nov/Dec 2020.

*Figure 26: Average anxiety score (GAD-7) by cognitive function group and time period (with 95% confidence intervals)*



With the GAD-7 measure anxiety, scores greater than or equal to 10 indicate likely clinical cases of generalised anxiety disorder. On this measure, we see a higher prevalence of clinical anxiety among people with dementia in June/July 2020 compared to those with no or mild cognitive impairment: 26.6% versus 7.5% or 10.4%, respectively. By Nov/Dec 2020, however, the estimated prevalence among those with dementia had declined to 9.8%, with only small increases to 8.2% and 13.4% for those with no or mild impairment. There is a small overlap of 95% confidence intervals for the two estimates of those with dementia.

Figure 27: Percentage of respondents with anxiety scores  $\geq 10$  by cognitive function group and time period (with 95% confidence intervals)



### Wellbeing during the pandemic

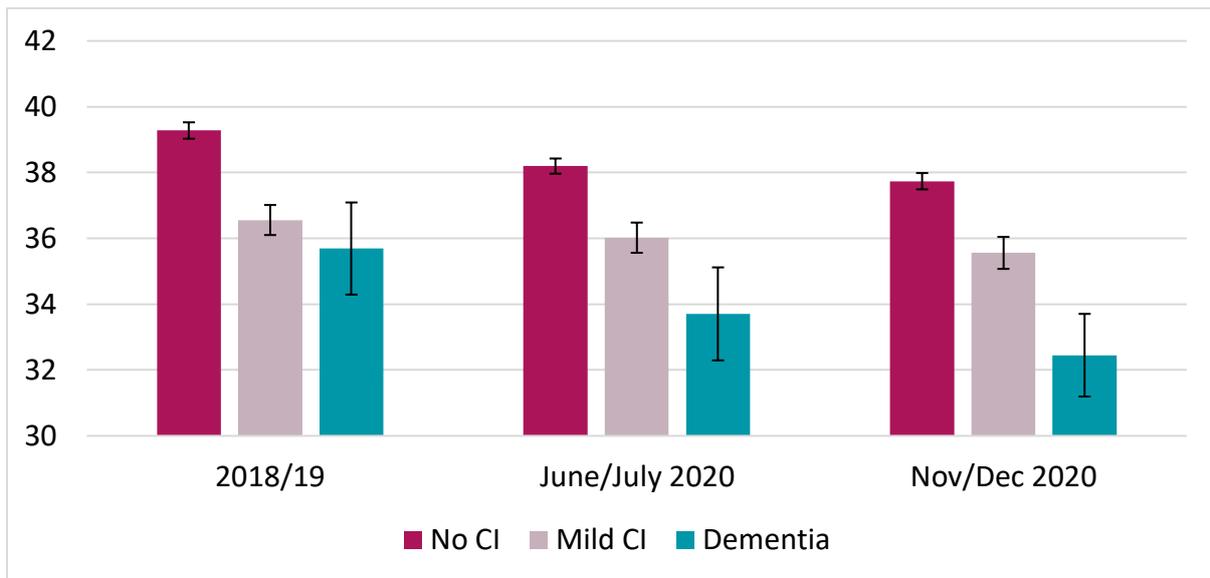
The COVID sub-study collected other measures related to psychosocial experiences among respondents that we have grouped under the concept of wellbeing. These include quality of life, loneliness, life satisfaction, and happiness.

### Quality of life

Quality of life was measured using the CASP-12 scale. This measure is a shorter version of the CASP-19 scale, which was designed specifically to assess older adults' quality of life in the domains of control, autonomy, self-realisation, and pleasure. The scale ranges from 12 to 48, with higher values indicated better quality of life.

The average scores show that quality of life was higher for those with no impairment (39.3) before the pandemic in comparison to those with mild impairment (36.6) or dementia (35.7). The scores for those with mild impairment and with dementia were not statistically different before the pandemic, but those with dementia experienced a sharper decline in average score during the pandemic. By Nov/Dec 2020, the average score among those with dementia was 32.5 compared to 35.6 and 37.7 for those with mild or no impairment.

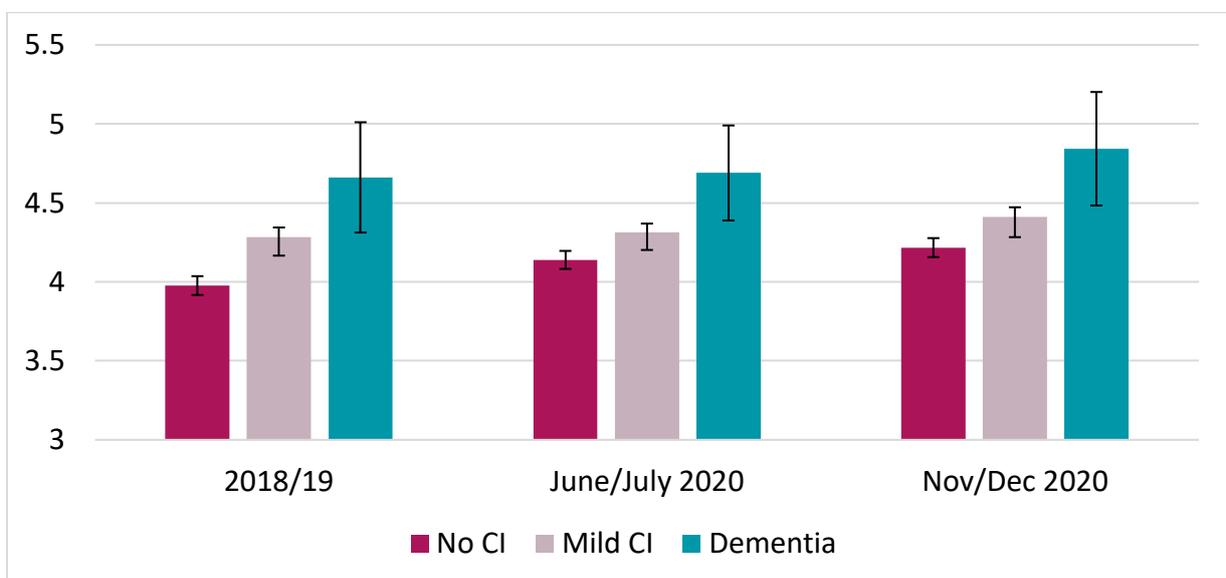
Figure 28: Average score of quality of life (CASP-12) by cognitive function group and time period (with 95% confidence intervals)



### Loneliness

The measure for loneliness draws on the 3-item form of the UCLA loneliness scale. It ranges from 3 to 9, with higher values reflecting higher levels of loneliness. Before the pandemic, the average score for loneliness among people with no impairment was lower (better) compared to those with mild impairment or dementia, at 4.0 compared to 4.3 and 4.7. Scores increased over the course of the pandemic for all groups. By Nov/Dec 2020, the average score among those with dementia was 4.8. While higher than that for other groups, the scores among those with dementia slightly overlapped with those for people with mild impairment.

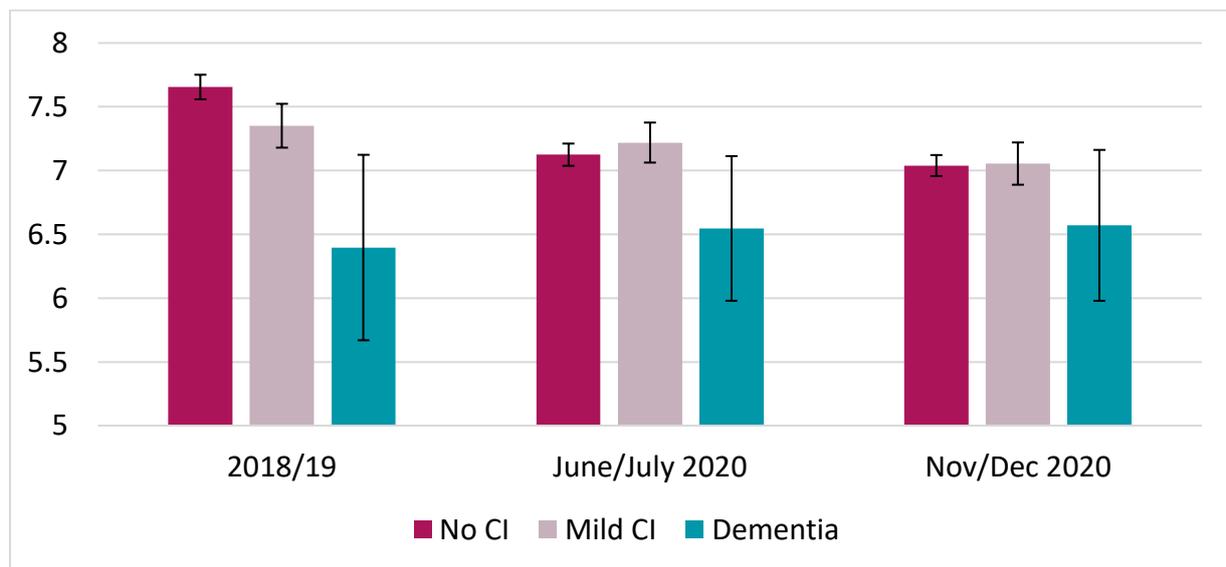
Figure 29: Average score of loneliness by cognitive function group and time period (with 95% confidence intervals)



### Life satisfaction

Life satisfaction was assessed using responses to the question, “On a scale of 0 to 10, where 0 is ‘not at all’ and 10 is ‘very’, how satisfied are you with your life nowadays?” There was relative stability in life satisfaction among people with dementia, ranging from 6.4 before the pandemic to 6.6 in Nov/Dec 2020. Larger changes were observed for those with no or mild impairment, declining from 7.7 to 7.0 among those with no impairment and from 7.4 to 7.1 for those with mild impairment. Considering confidence intervals, life satisfaction was significantly lower among those with dementia before the pandemic, but average ratings were statistically similar across groups by Nov/Dec 2020.

*Figure 30: Average rating of life satisfaction by cognitive function group and time period (with 95% confidence intervals)*



### Happiness

Similar to life satisfaction, happiness was rated using responses to the question, “On a scale of 0 to 10, where 0 is ‘not at all’ and 10 is ‘very’, how happy, overall, did you feel yesterday?” The pattern in average ratings across cognitive function groups and time is similar to that observed with life satisfaction. Ratings stayed relatively stable for people with dementia, at 6.7 both before the pandemic and in Nov/Dec 2020, and they were significantly lower than that for the other cognitive groups before the pandemic and in June/July 2020. Happiness ratings declined from 7.8 in 2018/19 to 7.3 in Nov/Dec 2020 among those with no impairment and from 7.5 to 7.1 for those with mild impairment.

### Mental health and wellbeing over time

In the previous part of this section, we have reported experiences of mental health and wellbeing across the three cognitive function groups as measured at three specific time points (two in the case of anxiety). These provide snapshots of the situation. However, we know that previous experiences are linked to later experiences, and other factors may be linked to the likelihood of them at a given time.

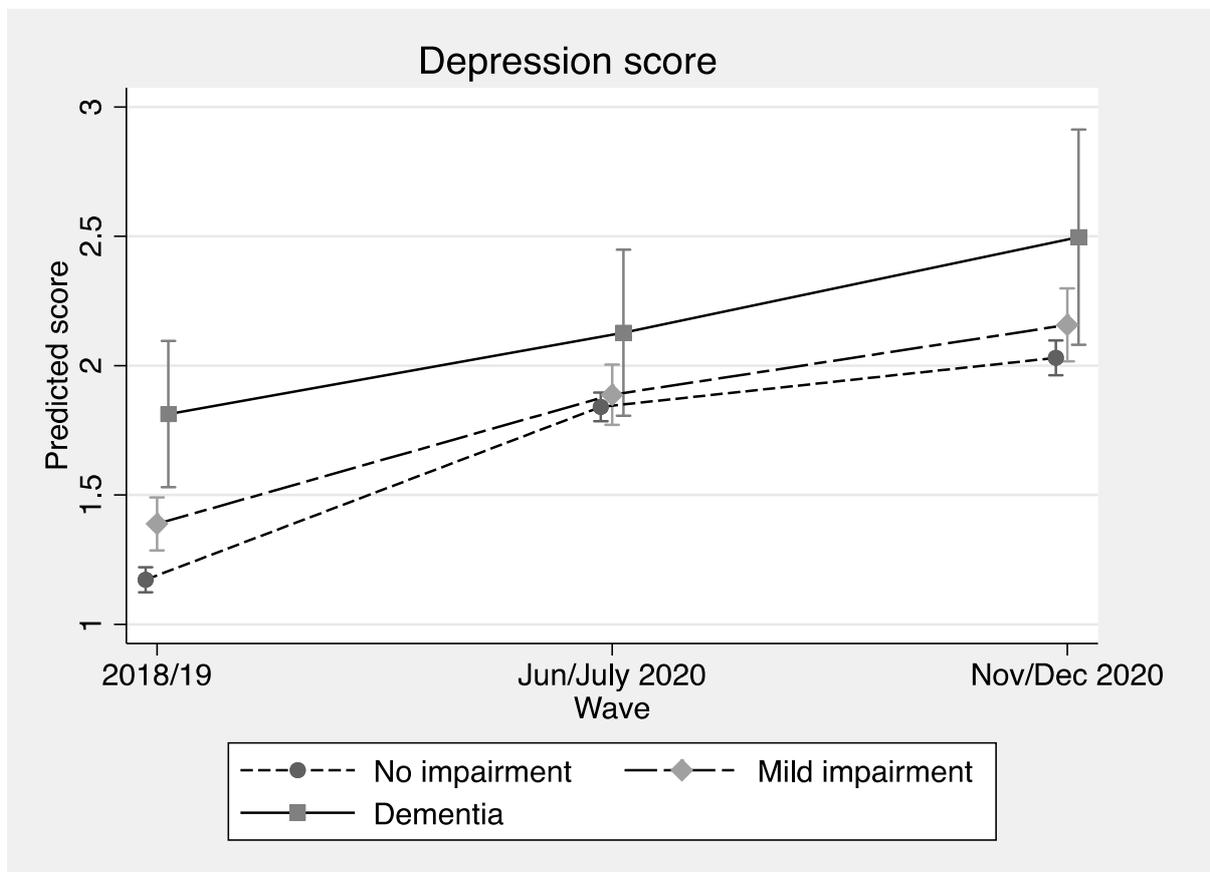
To account for this, we built models to predict scores and ratings across the available time periods to adjust for the correlation among individual respondents along with certain characteristics, including: demographics (age, gender, ethnicity, whether living with a

partner); socioeconomics (education, wealth, and employment status); geography (English region and whether urban or rural); and health (self-rated health and the presence of multimorbidity).

With these models, we can generate predicted scores for the average person in each cognitive function group at each measured time point. These average trajectories can then be plotted across time to examine the role of cognitive function in changes in mental health and wellbeing over time.

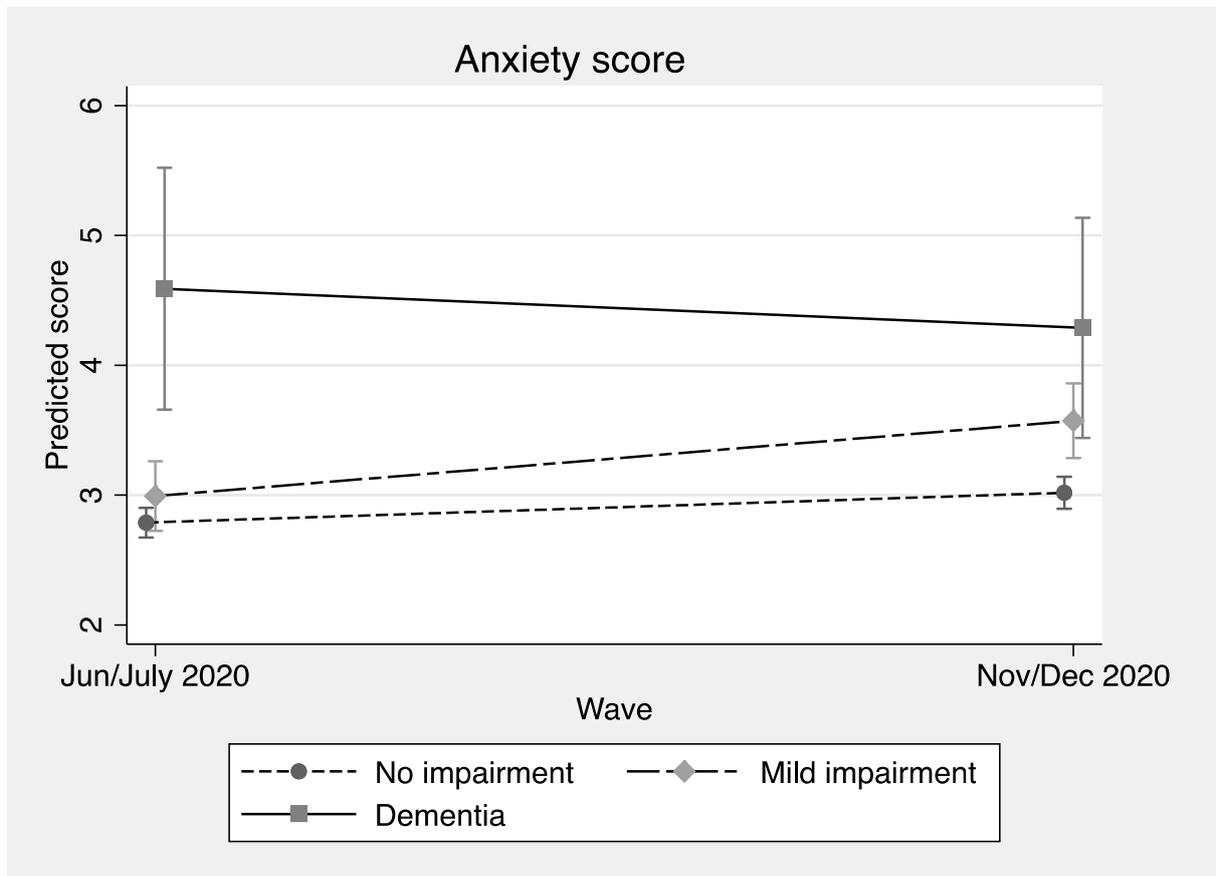
With depression, we see that the predicted scores are significantly different over the three cognitive function groups prior to the pandemic, with higher depression with increasing levels of cognitive impairment. These differences essentially disappear after the start of the pandemic (in June/July 2020), with depression score increasing at a faster rate for those with no impairment than for the other groups. The predicted scores change at a slower pace between June/July and Nov/Dec 2020 for those with no impairment than they do for those with dementia. By Nov/Dec, predicted values for the three cognitive function groups overlap.

*Figure 31: Predicted depression score over time by cognitive function group (with 95% confidence intervals)*



Over the course of the pandemic, predicted scores for anxiety increased between June/July and Nov/Dec 2020 for those with no impairment and with mild impairment. The predicted score for those with dementia was higher than the other two cognitive function groups in June/July. By Nov/Dec, the increase among those with mild impairment resulted in the predicted score approaching that of those with dementia, with scores for these two groups significantly higher than that for those with no impairment.

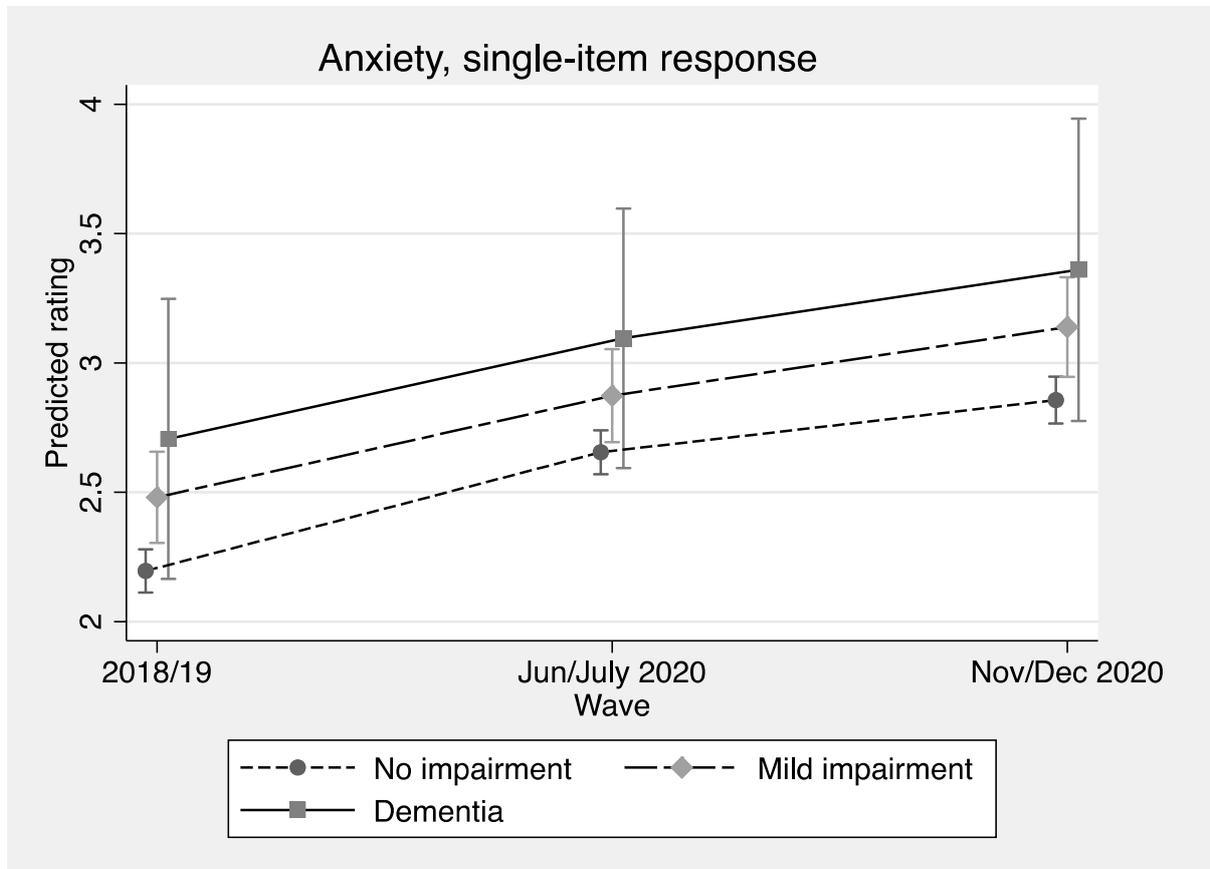
*Figure 32: Predicted anxiety score over time by cognitive function group (with 95% confidence intervals)*



Since we did not have the GAD-7 anxiety measure from before the pandemic, we looked at a single-item measure of anxiety consistent across our three time points to explore possible changes across the start of the pandemic. Similar to our measures for life satisfaction or happiness, this item draws on the question, “Overall, how anxious did you feel yesterday?”, with respondents answering on a scale of 0 (“not at all”) to 10 (“very”).

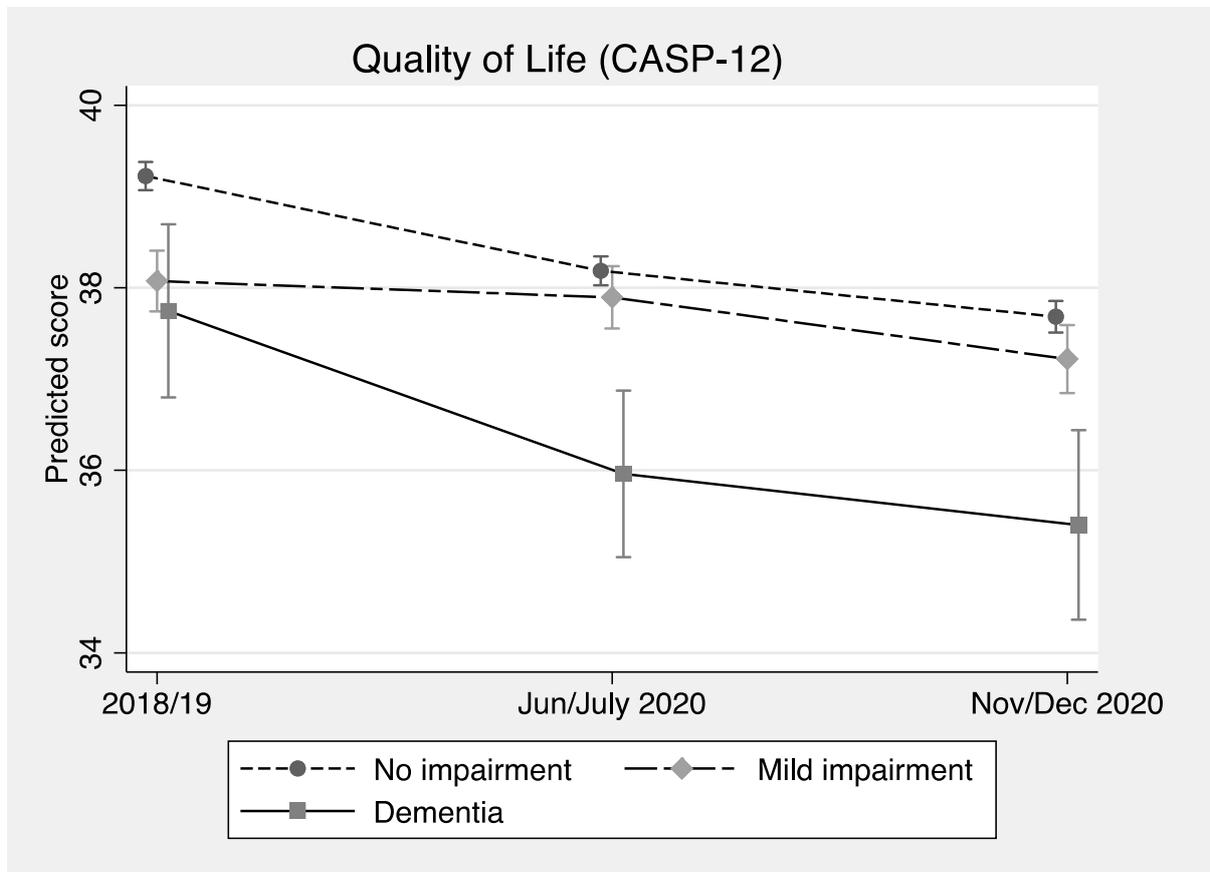
Predicted ratings for the average person in each of the three cognitive groups follow similar trajectories between the measured time points. Some scores are not statistically different; however, anxiety among those with no impairment was higher during the pandemic than before, as it was among those with mild impairment in Nov/Dec 2020 compared to before the pandemic.

*Figure 33: Predicted anxiety rating (using single-item measure) over time by cognitive function group (with 95% confidence intervals)*



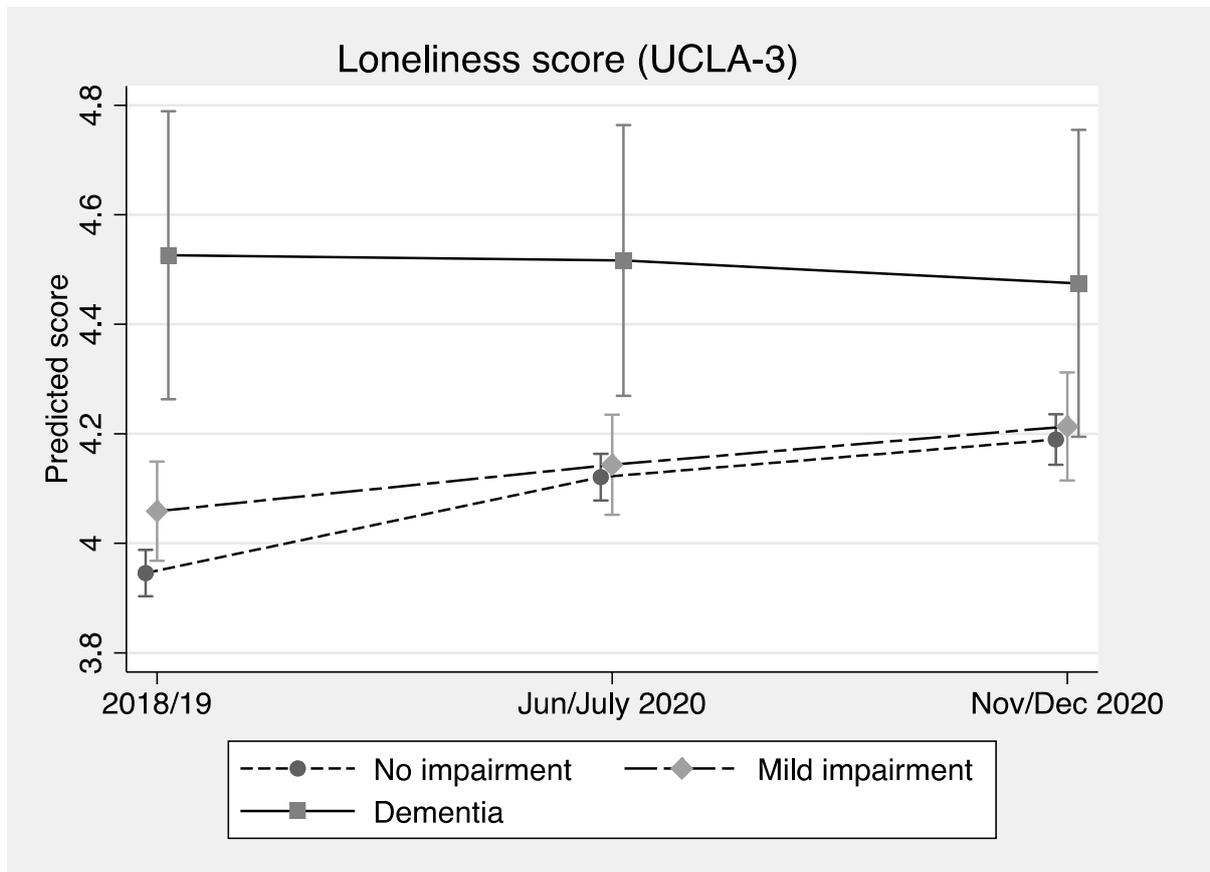
For all three cognitive function groups, there was a significant decline in quality of life from before the pandemic to Nov/Dec 2020. The decline up to June/July 2020 was greatest for those with dementia, although the confidence intervals for these two predicted scores overlap. The average person with no impairment experienced a significant decline by June/July; although the decline between June/July and Nov/Dec 2020 was smaller, it was still significant.

*Figure 34: Predicted quality of life score over time by cognitive function group (with 95% confidence intervals)*



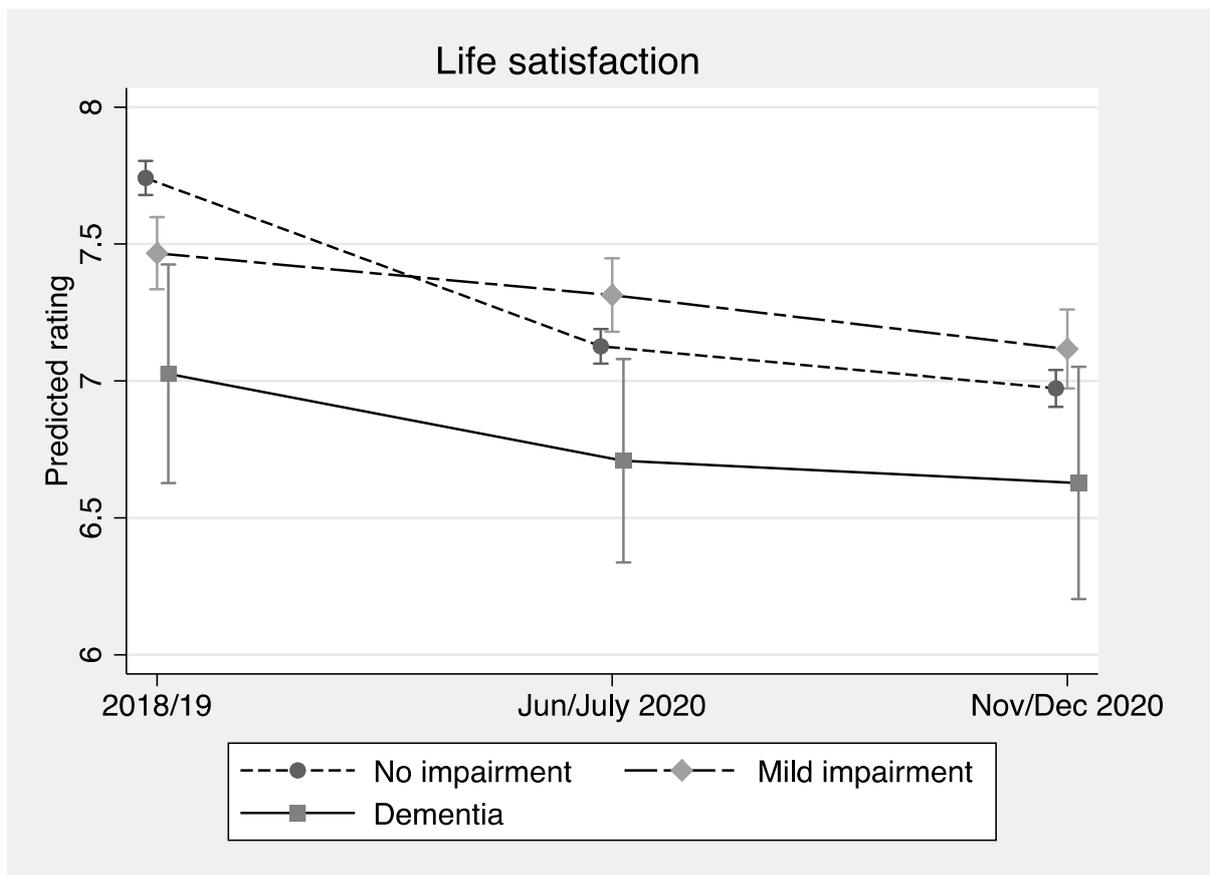
Before the pandemic, loneliness was significantly higher among those with dementia, but the predicted score changed little over the course of the pandemic. This contrasts with the situation for the average person with no impairment, who experienced a significant jump after the start of the pandemic and only increased slightly during it. The trajectory for the average person with mild impairment is upward, though predicted values are not statistically different.

Figure 35: Predicted loneliness score over time by cognitive function group (with 95% confidence intervals)



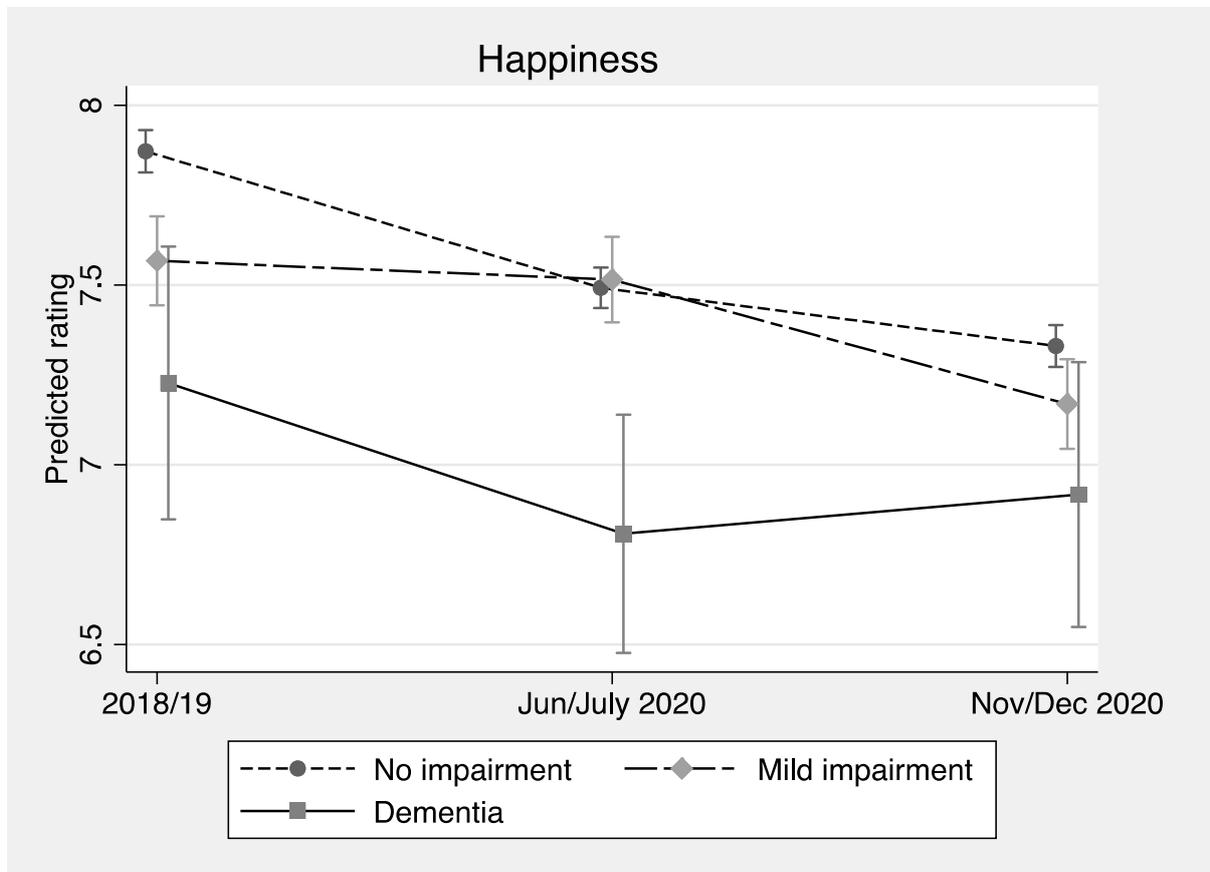
Changes in life satisfaction were most dramatic for those with no impairment, demonstrating a significant drop after the start of the pandemic. A more gradual decline over time was observed for those with mild impairment, although the predicted rating was significantly lower in Nov/Dec 2020 than before the pandemic. There was an apparent drop in life satisfaction after the start of the pandemic for those with dementia, but confidence intervals overlap to a great extent, although it was lower than for mild impairment in June/July. Moreover, while life satisfaction was significantly higher for the average person with no impairment compared to the other groups before the pandemic, confidence intervals overlap across the three groups in Nov/Dec.

*Figure 36: Predicted life satisfaction rating over time by cognitive function group (with 95% confidence intervals)*



The trajectories for happiness closely mirror those found for life satisfaction. There is little change from before the pandemic to June/July 2020 for mild cognitive impairment, but there is a significant drop by Nov/Dec 2020. For no impairment, happiness declined with each time point, ending lower in Nov/Dec than the predicted score for mild impairment before the pandemic. The predicted rating for dementia in June/July was significantly lower than the other two groups.

*Figure 37: Predicted happiness rating over time by cognitive function group (with 95% confidence intervals)*



Taking our results together, we find evidence for a number of differences in the trajectories of mental health and wellbeing across the pandemic among different cognitive function groups. The anxiety scores measured during the pandemic showed an increase for those with no or mild impairment, while the single-item measure suggests that anxiety also increased from before the pandemic for those with no impairment or mild cognitive impairment. Between 2018/19 and Nov/Dec 2020, quality of life declined for all groups, remaining significantly lower for those with dementia.

With respect to the other outcomes of interest, our estimates suggest a potential convergence among the cognitive function groups by Nov/Dec 2020. While point estimates suggest worse outcomes for those with dementia, the confidence intervals overlap; yet there are significant differences prior to the pandemic. While the mechanisms for these trends are unclear from our data, it is possible that the negative consequences of the pandemic, e.g. lockdowns, had a greater impact on the mental health and wellbeing of those with no or mild cognitive impairment than those with dementia.

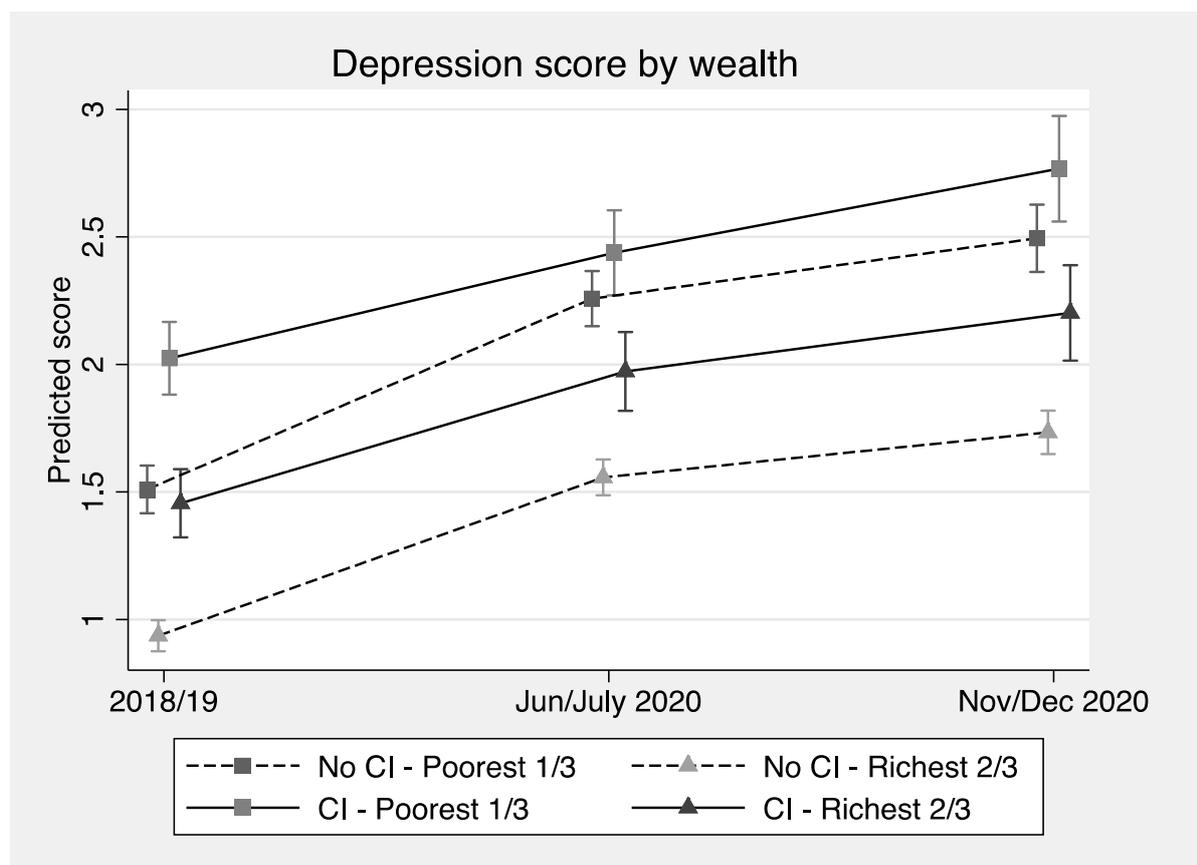
### Social inequalities in changes in mental health and wellbeing

So far, we have examined the relationship between cognitive function and various outcomes related to mental health and wellbeing over time. These estimates accounted for other factors such as wealth and education. To explore the potential for systematic inequalities, we built models with three-way interactions of time, cognitive impairment status, and the following characteristics: wealth, education, geographic region, and the presence of multimorbidity. These models controlled for age and sex.

We found no significant inequalities in the change in our outcomes of interest over time with respect to multimorbidity. In other words, the rate of change in a given outcome (e.g. depression score) between people with no impairment and those with mild cognitive impairment or dementia is not statistically different overall according to the presence of multimorbidity or being in the lowest third of wealth.

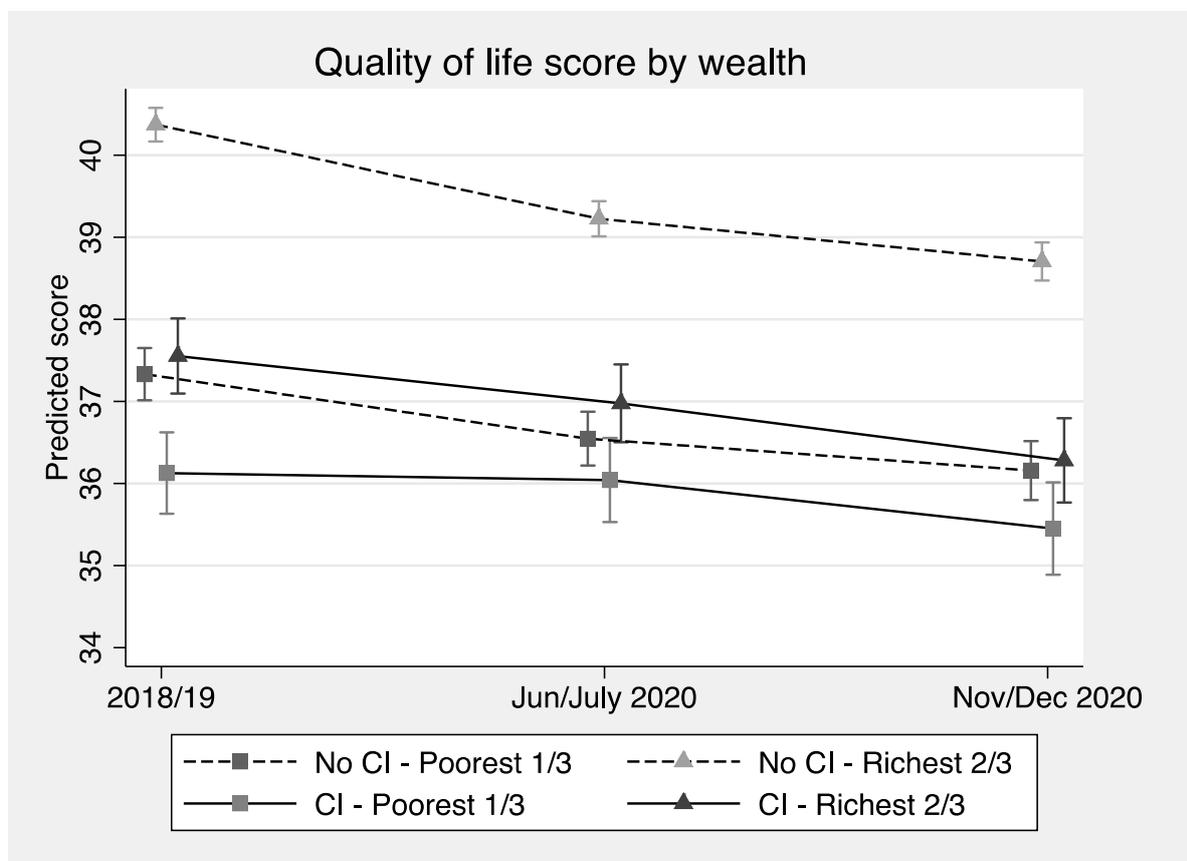
The interactions do provide some insights related to wealth, albeit not related to the rate of change for all groups. For example, those with no cognitive impairment in the poorest third of wealth had a similar predicted depression score before the pandemic as those with cognitive impairment (mild or dementia) in the richest two-thirds of wealth. By June/July 2020, the poorest third had worse scores than those in the richest two-thirds. There were no statistical differences in predicted depression score in Nov/Dec 2020 except among the richest with no cognitive impairment.

Figure 38: Depression score over time by cognitive impairment and wealth (with 95% confidence intervals)



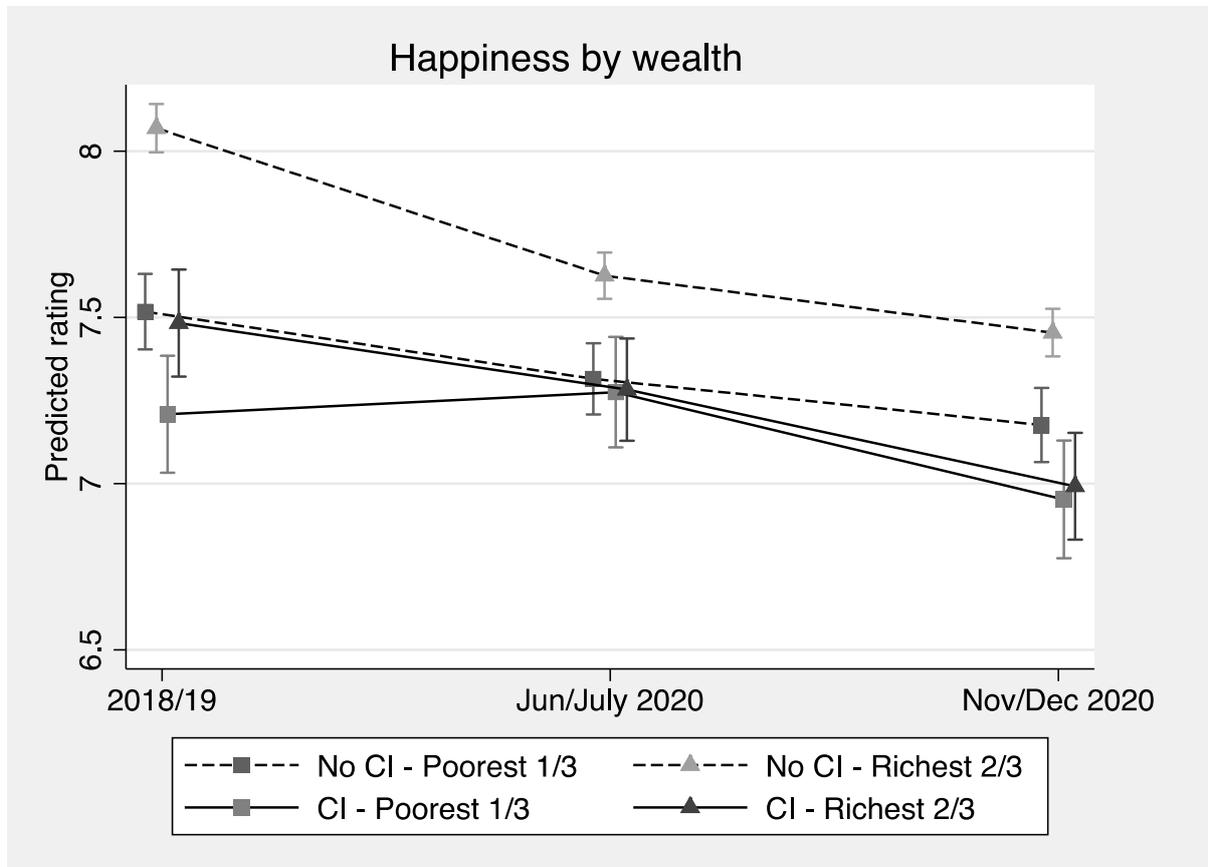
A similar pattern was found for the wealth interactions among other outcomes including quality of life, life satisfaction, and happiness, with small differences. With respect to quality of life, scores for all groups were similar at both times during the pandemic except for the richest with no impairment.

*Figure 39: Quality of life score over time by cognitive impairment and wealth (with 95% confidence intervals)*



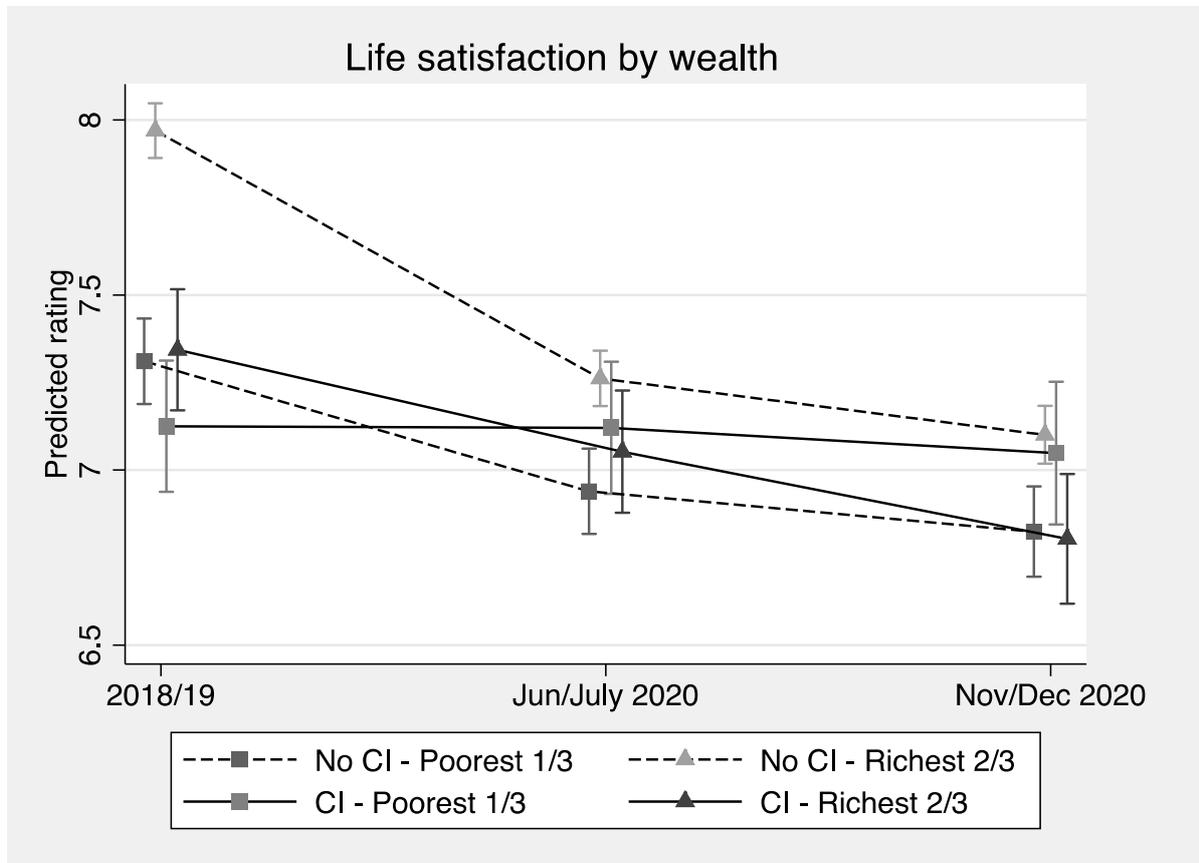
For happiness, ratings are similar for all groups during the pandemic except for the richest two-thirds with no cognitive impairment, who had higher happiness ratings at all time points. Among the poorest third, those with cognitive impairment had a lower happiness rating than those with no impairment before the pandemic, and they demonstrated little change by June/July.

*Figure 40: Happiness rating over time by cognitive impairment and wealth (with 95% confidence intervals)*



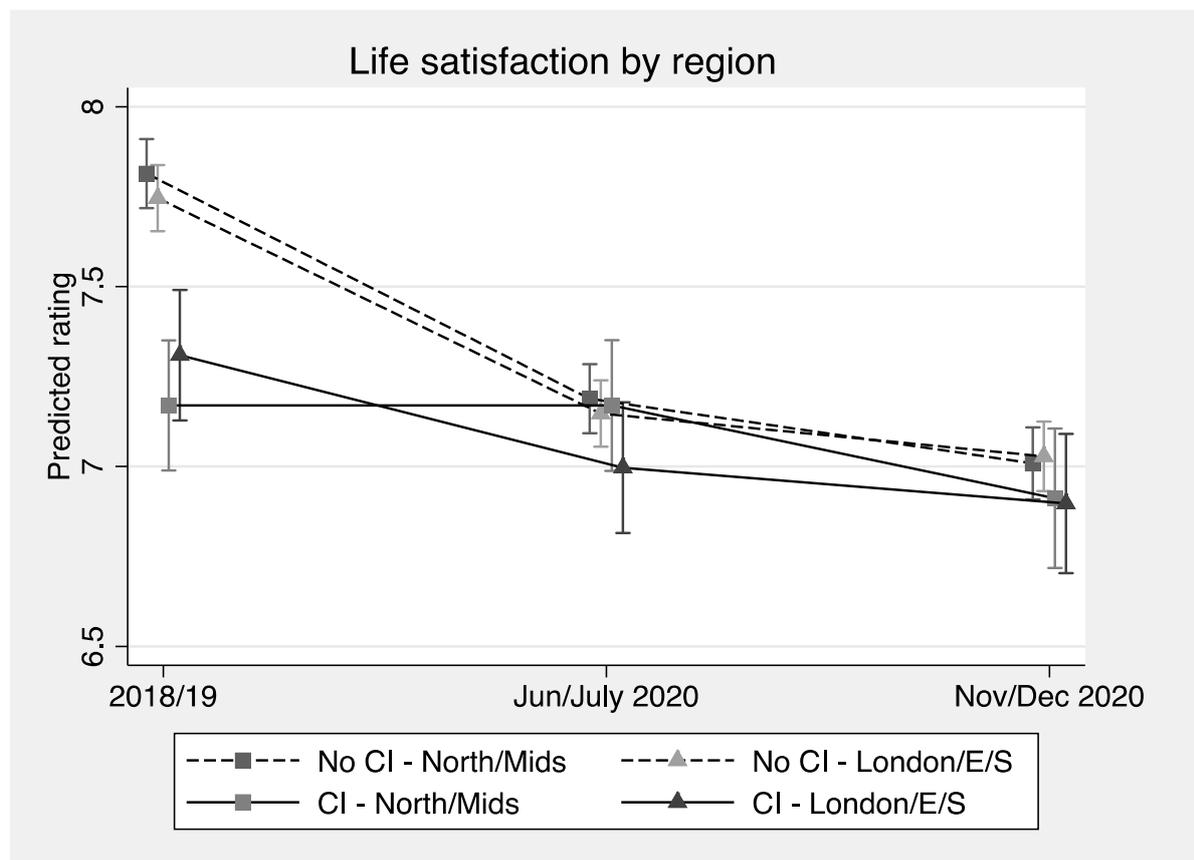
For life satisfaction, those with no impairment in the richest two-thirds of wealth had higher ratings before the pandemic; during the pandemic, ratings were similar across all groups. There is also evidence that life satisfaction remained stable over time for those with cognitive impairment in the poorest third of wealth, while other groups experienced declines.

Figure 41: Life satisfaction rating over time by cognitive impairment and wealth (with 95% confidence intervals)



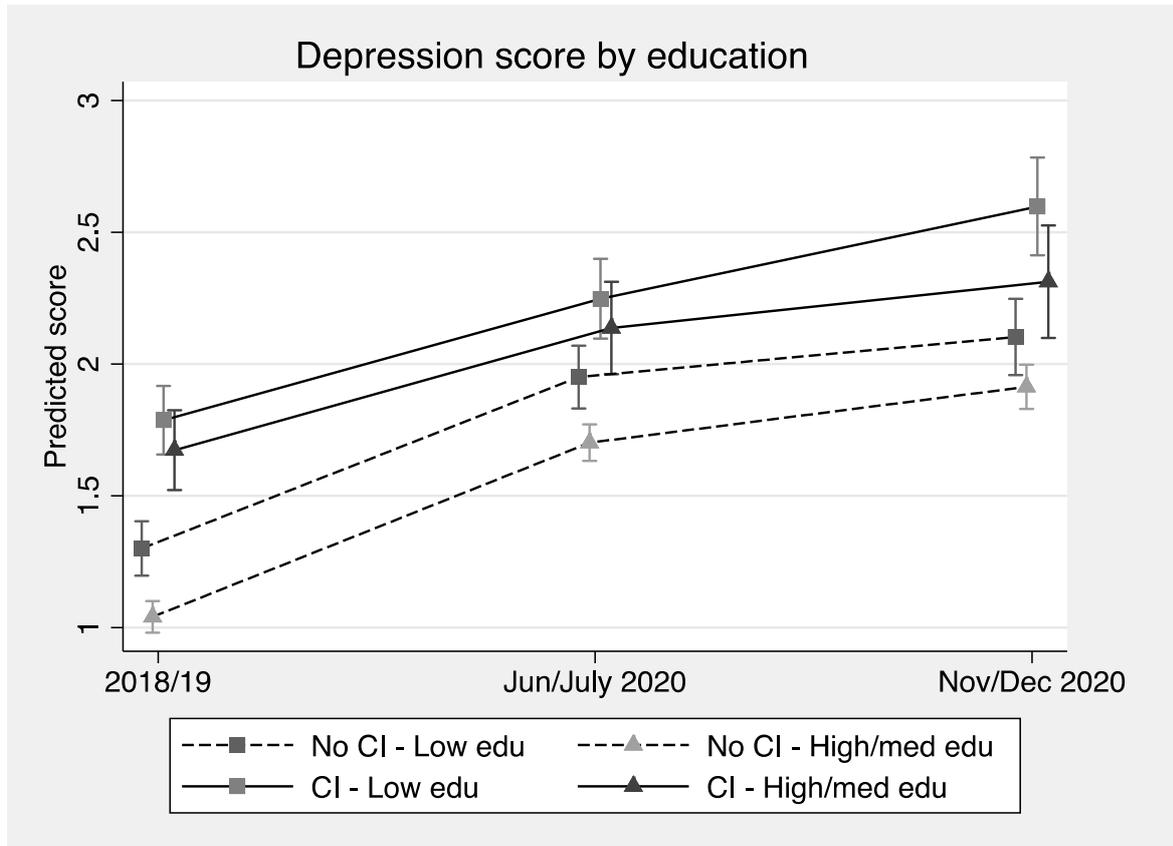
With life satisfaction, we also found a significant interaction for region with respect to the rate of change over time. People with cognitive impairment living in the North or the Midlands experienced relative stability in their rating of life satisfaction from before the pandemic to June/July 2020, while those with impairment living in London, East of England, or the South experienced a decline; for the latter, this decline was also at a similar rate as that seen for those with no impairment, regardless of where they lived. Moreover, those with no impairment in either geographic region experienced a sharper decline by June/July compared to those with impairment in the North/Midlands. Life satisfaction was lower before the pandemic for those with cognitive impairment, while during the pandemic, ratings were similar regardless of cognitive function or region.

*Figure 42: Life satisfaction rating over time by cognitive impairment and region (with 95% confidence intervals)*



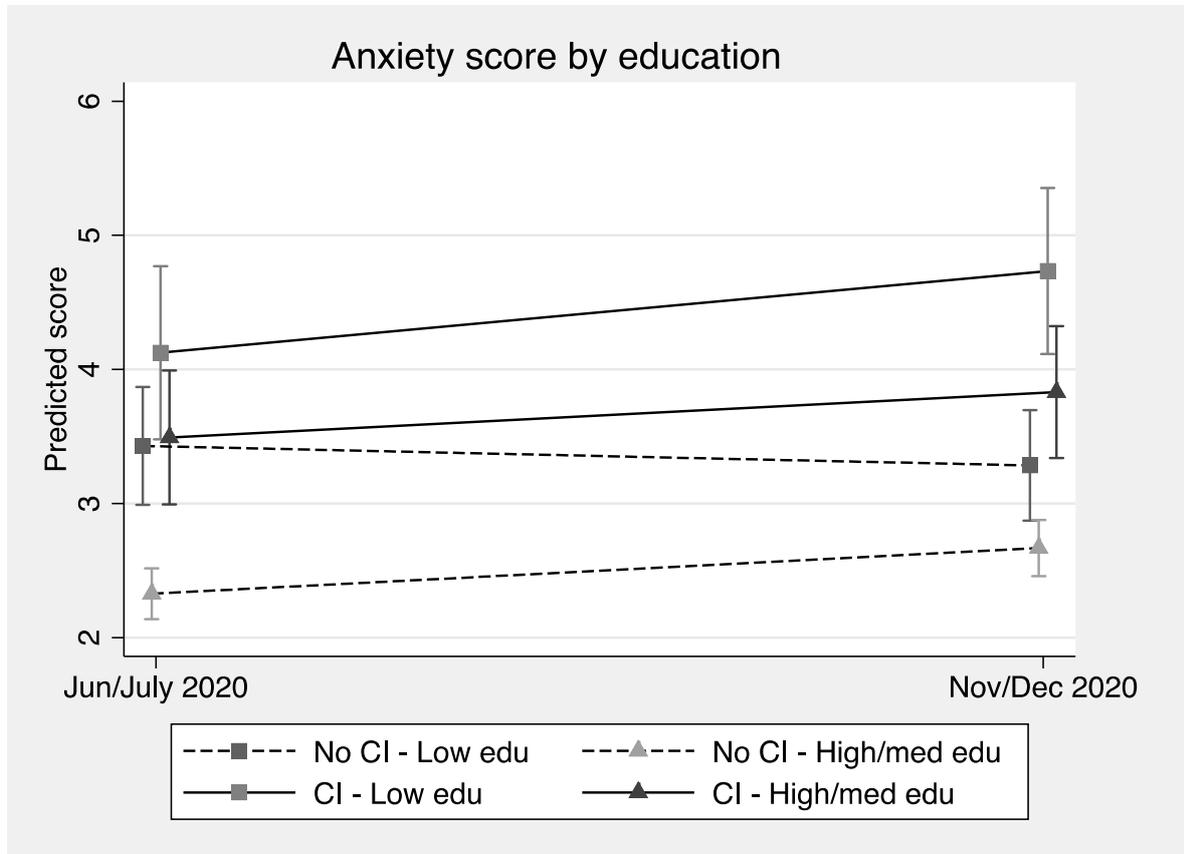
Significant inequalities in the change in mental health and happiness were also found according to education. Depression score increased at a faster rate between before the pandemic and June/July 2020 for those with no cognitive impairment than those with cognitive impairment, although those with no impairment and high/medium education were better off than the other groups at both time points. Depression score increased at a faster rate for those with cognitive impairment and low education during the pandemic than for those with no impairment.

*Figure 43: Depression score over time by cognitive impairment and education (with 95% confidence intervals)*

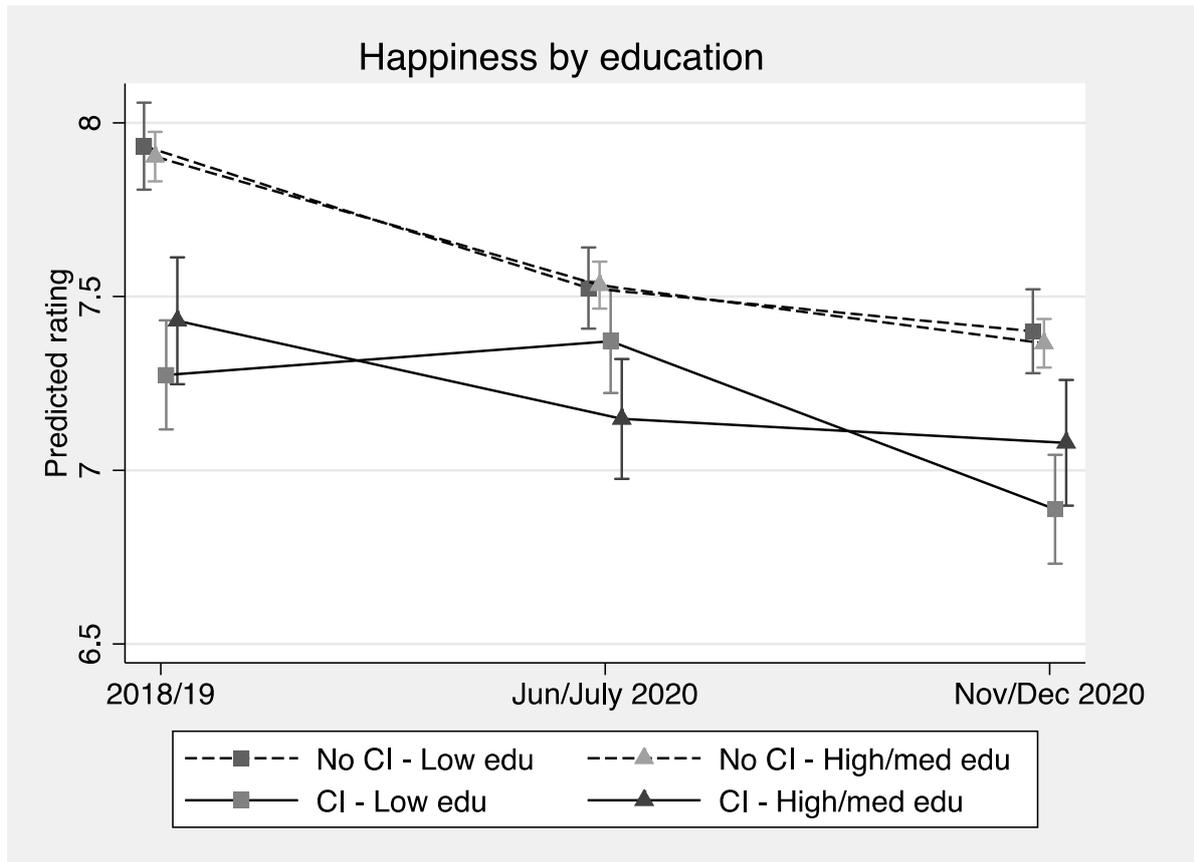


Among those with low education, anxiety score increased at a higher rate for those with cognitive impairment compared to those with no impairment. For those with high/medium education, anxiety was higher among those with cognitive impairment, but the rate of change was similar.

*Figure 44: Anxiety score over time by cognitive impairment and education (with 95% confidence intervals)*



With respect to happiness, those with cognitive impairment and low education displayed a different trajectory than the other groups. For them, happiness increased by June/July to approach levels found among those with no impairment. From June/July to Nov/Dec, however, the rating had declined significant compared to those with no impairment.



By looking at interaction effects in these models, we have identified some key social inequalities that shaped the mental health and wellbeing outcomes among people with cognitive impairment during the pandemic. While we know that wealth is a key determinant of health, we found that its protective effect does not consistently apply to those with cognitive impairment. For quality of life and happiness, only the richest without cognitive impairment demonstrated better outcomes. For life satisfaction, this was also true but only before the pandemic. This was not the case for depression, however, as scores were higher among the poorest during the pandemic – though outcomes were best for the richest with no impairment.

The only regional difference we found related to life satisfaction, but this reflected a stability in the change over the start of the pandemic for those with cognitive impairment in the North/Midlands, with other groups experiencing declines. Life satisfaction was higher for those with no impairment before the pandemic but was similar for all groups during the pandemic.

Finally, those with low education and cognitive impairment appeared to experience greater declines in mental health outcomes (depression and anxiety) compared to other groups. Interestingly, this group seemed to do better in terms of happiness rating.

## Implications for policy and practice

Our project has examined the impact of the COVID-19 pandemic on people with differing levels of cognitive impairment across a range of outcomes. We have looked at the trends around staying at home and how different factors, including cognitive function, were associated with these behaviours. We also explored access to different aspects of health and social care, including community services, hospital-based services, and medications. Healthy lifestyle behaviours were also examined, both in terms of how they changed over the course of the pandemic and how distinct practices grouped together. Our final area of investigation covered mental health and wellbeing. The nature of systemic social inequalities was also considered across these themes.

Based on our findings and discussions with our PPI panel, we have identified a number of implications for policy and practice.

### Shielding and infection

Encouraging people to take protective and preventive action with respect to their health is a key interest for public health bodies and related stakeholders. Observations of past behaviours like our analysis here can provide some insights into future directions for policy and practice to improve public health.

- Public health messaging needs to be delivered in clear language that can be understood by all, including those with low level of cognitive function and those with low education. Those with mild cognitive impairment were less likely to shield at the start of the pandemic than those with no impairment, while those with dementia were more likely to be shielding. These differences may possibly be explained by those with mild impairment experiencing challenges understanding the public health messaging around shielding. At the same time, the finding that men and those with low education were less likely to shield also underscores the importance of tailoring messages at times to ensure they resonate with groups who may be less engaged with health matters.
- Accounting for differences in cognitive function, we found that those in work were less likely to engage in shielding, while those with worse self-rated health or multimorbidity were more likely to shield. Future efforts to encourage shielding – or otherwise deliver important public health messages – may need to consider engaging with organisations and social institutions beyond those directly linked to health, e.g. promoting health literacy across the life course within schools or workplaces. Some groups may also have a reduced ability to shield – such as when working from home is not possible – underscoring the importance of adequate support for people whose socioeconomic position impacts their ability to follow public health guidance. On the other hand, those who could have been more vulnerable to complications from COVID-19 due to existing health factors were more likely to adhere to guidelines, possibly suggesting there are lessons to learn from the experiences of those already engaged with the health system.
- Our findings around care and probable infection may imply that those providing unpaid care were increasing the risk of exposure, which may point to a need for greater efforts to provide unpaid care providers with the kinds of essential knowledge and skills necessary to ensure quality care. It could also indicate that

unpaid caregivers face specific challenges that impact their own behaviour in the course of providing this unpaid care.

### Disruption in access to services

Assessing the performance of community- and hospital-based health and care services in terms of disrupted access during a crisis like the pandemic allows policy makers and practitioners to understand elements of robustness in the system. Estimating levels of disruption will also inform strategies to proactively adapt and plan to similar crises and respond to current and future need generated by delays or foregone treatments.

- Differences in access to community health and care services across cognitive function groups appeared to improve between June/July and Nov/Dec. Those who needed such services and received them was much higher in Nov/Dec than in June/July, with around two-thirds of people in any cognitive function group reporting this. This may indicate that such disruption was at least partly driven by stay-at-home orders and other restrictions on service availability early in the pandemic. One difference to note, however, was the larger proportion of people with dementia highlighting disruption in access to counselling for mental health. Mental health support may likely be needed for all people as we move into the post-pandemic era, but it may be that extra attention should be given to people with higher levels of cognitive impairment.
- It is understandable that hospital-based operations and treatment that were cancelled due to the pandemic will take time to be addressed; the pandemic has not completely gone away, and NHS services continue to be under high levels of pressure. Our analysis found that people with dementia were disproportionately waiting for cancellations to be rescheduled. As further progress is made toward fulfilling the backlog of cancellations, people with dementia may need extra support to ensure they have proper follow-up in getting the hospital-based services they need.
- Given that access to medications remained very high among respondents, this could highlight the role that local pharmacies can play in delivering key services in health and care through a crisis and beyond. Pharmacies are not appropriate for all services of course, but they may provide an opportunity to strengthen the delivery of health-related information and preventative interventions. A clear public health role for pharmacies has been argued elsewhere in relation to its function through the pandemic,<sup>5</sup> while UK policymakers had also highlighted this before COVID-19.<sup>6</sup>

### Healthy lifestyle practices

Although we found some variation on specific measures with respect to cognitive function, the overarching message from this analysis is that lifestyle practices are socially embedded and generated across the life course.

- Many of the practices examined can be linked to an increased likelihood of developing cognitive impairment, just as they are linked to other significant morbidities like cardiovascular disease. For policymakers and practitioners, these results underscore the importance of early intervention to support healthy lifestyles.
- There are three aspects that may be notable with respect to supporting people with cognitive impairment in the future and in particular periods of isolation such as the pandemic: sleep, nutrition, and physical activity. We found people with dementia

reported sleeping more during the pandemic compared to before, but the quality of sleep declined for them (while it remained relatively stable for the other cognitive function groups). Sleep disturbances can impact both people with dementia and their caregivers, so greater attention may be needed to help manage sleep among those with cognitive impairment.

- Similarly, people with dementia had lower levels of physical activity and access to the food they wanted to eat during the pandemic. The conditions of lockdown during the pandemic may have exacerbated the challenges people with dementia face in remaining active and getting the nutrition they desire. Generally, however, policymakers, care practitioners, and public health professionals should consider strategies for ensuring people with cognitive impairment can be supported to pursue these key aspects of healthy ageing.

### Mental health and wellbeing

Our research improves our understanding of the way that mental health and wellbeing changed due to the pandemic, along with the role that cognitive function played in shaping people's experiences. This work contributes to debates around how best to target support services to foster wellbeing and improve the mental health of people in later life.

- We have identified that mental health and wellbeing has generally been worse for people with increasing levels of cognitive impairment, which is unsurprising given existing research around the association of depression and anxiety with dementia, for example. However, on many of our measures, we find evidence suggesting a convergence in mental health and wellbeing among the cognitive function groups during the pandemic. This potentially means that the pressures on support services will be particularly intense as they need to respond to proportionately greater demand from those with no impairment than was the case before the pandemic.
- At the same time, worsening mental health and wellbeing outcomes for those with dementia may present particular challenges in delivering effective interventions and support. Such challenges are less likely to relate to the cognitive impairment itself but to questions of accessibility and availability, especially if the supply of support is diverted to those with no impairment. Policymakers and care practitioners will need to ensure that people with dementia have equal access to measures to support their mental health and wellbeing.
- We also identified that wealth and education, as expected, play a role in shaping the trajectories of outcomes over time. This further underscores the need to ensure that people at all levels of cognitive function are able to access the resources they need to support general wellbeing, including effective and easy-to-understand guidance. Alongside this, policymakers and care practitioners can draw on lessons learned to improve advanced planning and deploy simple interventions that do not require substantially higher resources.

### Equality, Diversity, and Inclusion

Our project focuses on the experiences of people with dementia and cognitive impairment, a group at greater risk of social exclusion. Our study design employed the analysis of secondary survey data collected as part of the ongoing English Longitudinal Study of Ageing. Consequently, aspects of diversity and representation in our study were limited to the

availability in the dataset. However, we did include gender and ethnic background in our multivariate analyses to account for differences according to these characteristics.

Future waves of data collection in ELSA will provide booster samples according to ethnic background. Such data will provide good opportunities to studies such as this one to examine the role that racial and ethnic differences play in shaping outcomes. This will be particularly important in the context of later life health and dementia.

Our Public and Patient Involvement panel also added some diverse perspectives to the research through their own input in PPI meetings. Panel members included people with lived experience of cognitive impairment, caregivers of people with dementia and cognitive impairment, and people from minoritised ethnic backgrounds.

## Public and Patient Involvement

We engaged with an experienced Public and Patient Involvement in Research Group (PPIRes) for this project, who gave advice on recruitment and the initial conception of the work, providing key comments and feedback. PPIRes also identified a lead member of the panel who contributed to the project during the proposal stage and beyond.

We held four meetings with our PPI panel during the course of the project, one meeting for each analytical stage of the project. Prior to each meeting, panel members were provided with a summary note of the key findings, which were then presented in more detail during each meeting. The first meeting also included more discussion on the key role of the panel and the overall project plan and research questions. A fifth meeting at the end of the project is planned to gather insights into further dissemination and messaging.

The PPI panel helped steer some of our exploration of the data and helped the research team understand the potential mechanisms for and mitigations against some of the key findings we identified. One key area in which the PPI benefited the project was in helping ensure clarity in the communications of results, strengthening the interpretation in a way to facilitate broader messaging and engagement.

Many of the insightful contributions from the PPI panel have featured in the report. To further highlight the value of this engagement, we also summarise them below:

- Receiving a formal diagnosis of dementia plays a key role in getting people connected to services or providing them with access to them. Getting a diagnosis is not always straightforward, and those without a formal diagnosis or with mild cognitive impairment may be at greater disadvantage from a service access perspective.
- Community support plays a key role in helping people access the services they need, not only by helping them understand what is available but also in facilitating connections between services and individuals.
- Complex health needs can impact the experience of burden with respect to accessing health and care services. Feeling burdened – even outside the context of dementia – may lead people into being passive with respect to taking action to access care.
- Lifestyle practices are intertwined with other health factors. Medications may impact sleep, while some people may take medication specifically for sleep. Smoking and/or

drinking alcohol may be aimed at relieving poor mental health (e.g. stress, depression). These interconnections place certain limitations on our analyses.

- With regards to physical activity, there will be notable differences in experiences between those living in the community (our sample) and those living in residential care homes and environments. Access to outdoor space likely played a role.
- Different aspects of mental health may be shaped by how easily accessible elements of treatment are. For example, if anxiety medications are available via one's GP.
- Findings related to mental health and wellbeing follow sensible trends, but the results focused on wealth suggest that people with higher wealth may have had further to fall in terms of losing access to more things. In contrast, greater wealth may have positioned people better in certain respects, such as having access to outdoor space and/or gardens.
- The findings highlight what has already happened, and they should be discussed further with respect to identifying lessons to improve responses in the future. Much of the learning likely relates to advance planning rather than the need for substantially higher resources. Improving outcomes for the future can be achieved without cost implications, drawing on simple interventions, between management of services, and training.

We are grateful to the six members of our PPI panel for their time and contributions.

## Acknowledgements

We want to thank the members of our Public and Patient Involvement panel for offering their time and valuable insights for the project: Richard Ballerend, David Caplin, Sheila Saunders, Shani Shamah, Deb Smith, and Penny Vicary. We are also grateful to Patience Renias-Zuva for helping organise the PPI panel and meetings.

## Contributions of Authors

Dr Brian Beach (Research Fellow, Epidemiology and Public Health) led on the analyses and manuscript composition. Prof Paola Zaninotto (Professor, Medical and Social Statistics) conceptualised and led the design of the main project, she supervised and supported the quantitative modelling and analysis. Prof Nick Steel (Clinical Professor, Public Health) and Prof Andrew Steptoe (Professor, Psychology and Epidemiology) contributed to the design of the project and provided feedback on content and analysis throughout the project.

## Data Sharing

This study uses data from the English Longitudinal Study of Ageing, which are freely available upon registration through the UK Data Service.

## Ethics Statement

As this study drew on existing secondary datasets, the project did not require ethical approval. Ethics review for the English Longitudinal Study of Ageing is carried out by the National Research Ethics Service for every wave of data collection.

## Information Governance Statement

The ELSA management team is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under Data Protection legislation NatCen Social Research is the Data Processor; while University College London, NatCen Social Research, Institute for Fiscal Studies, University of Manchester, and University of East Anglia act jointly as the Data Controller, and we process personal data in accordance with their instructions. You can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for NatCen's Data Protection Officer at <https://www.elsa-project.ac.uk/privacy-notice>.

## Department of Health Disclaimer

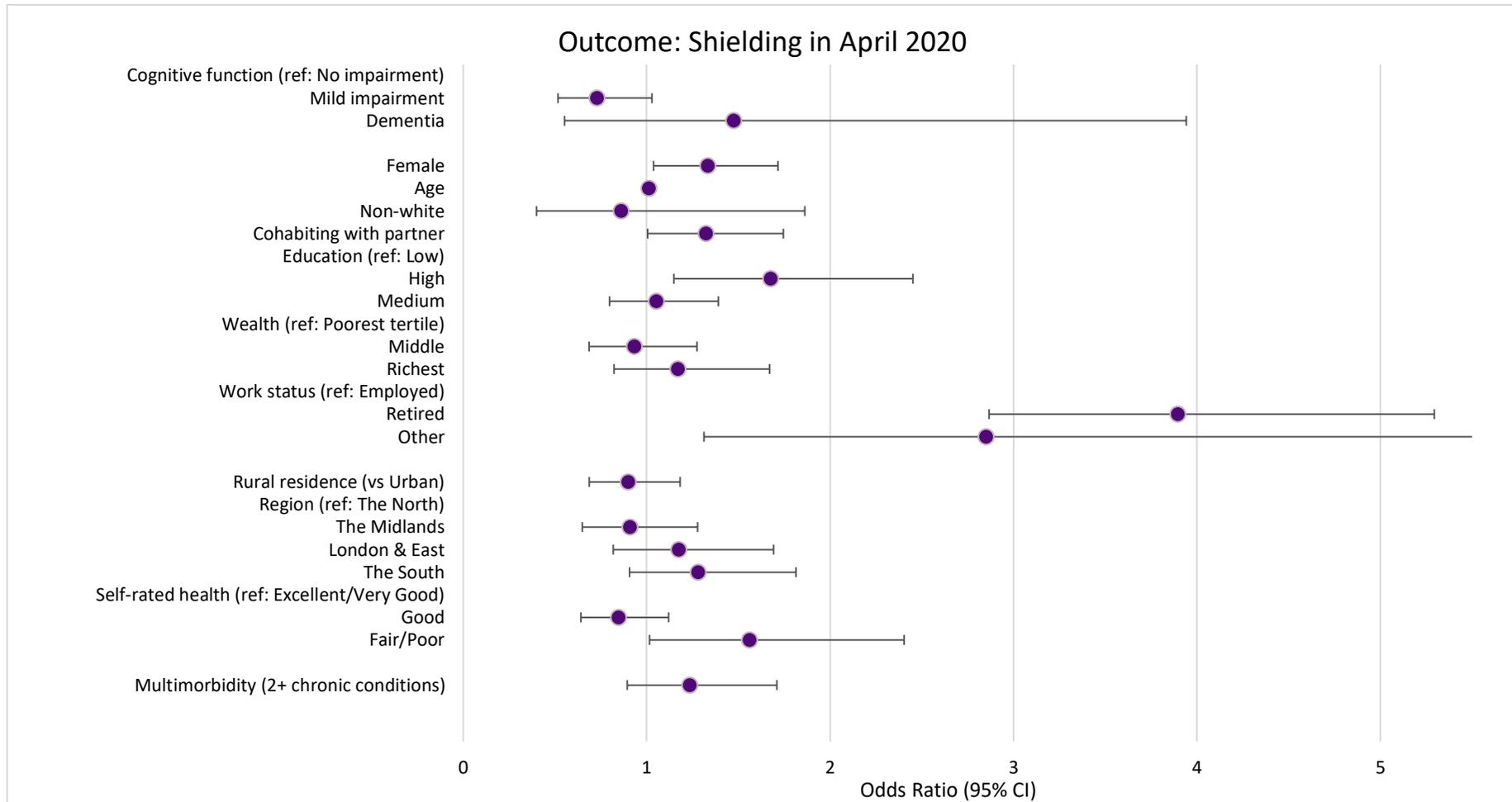
This report presents independent research commissioned by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, MRC, CCF, NETSCC, the Policy Research programme or the Department of Health and Social Care.

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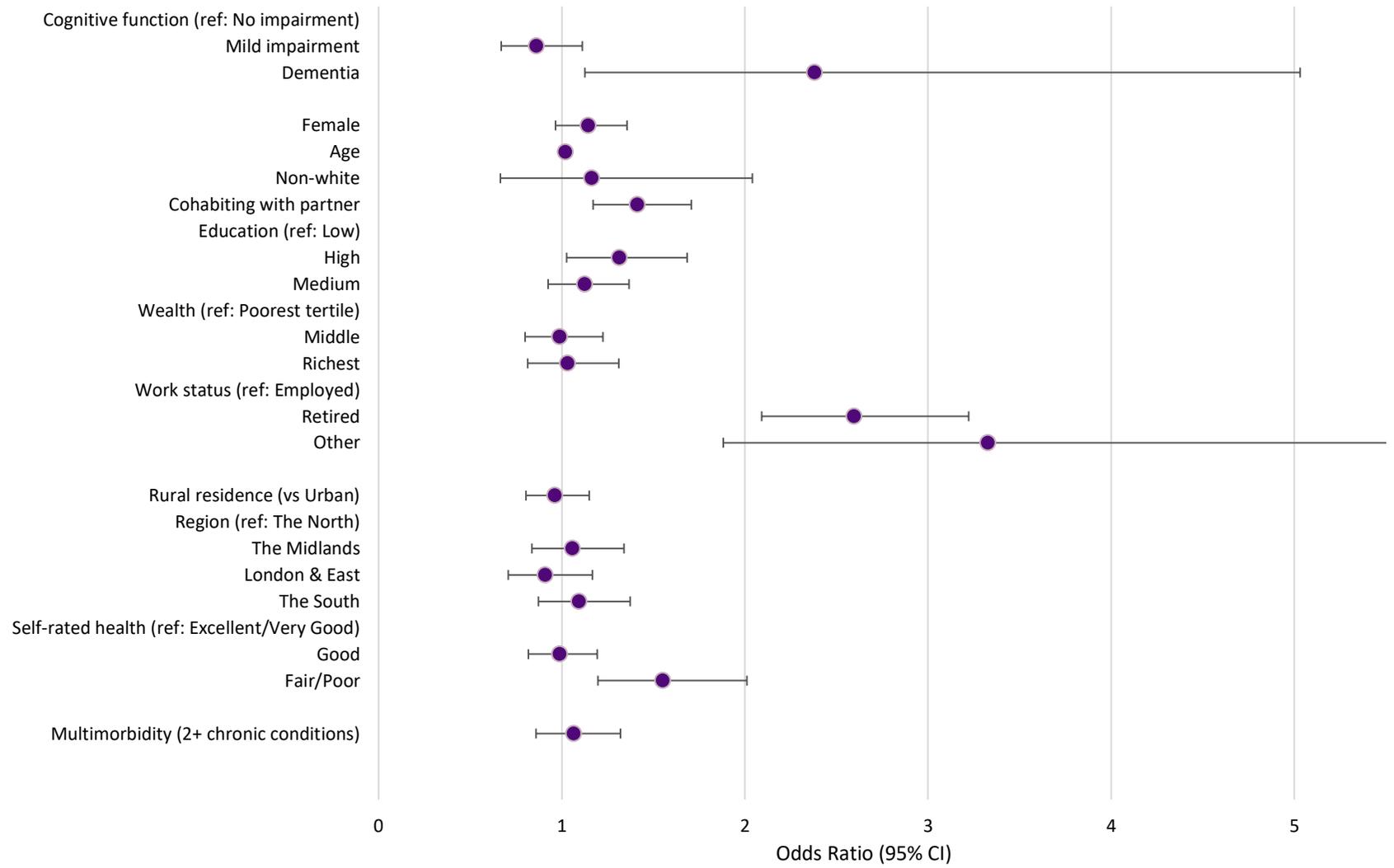
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## Appendix 1: Logistic regression results for shielding

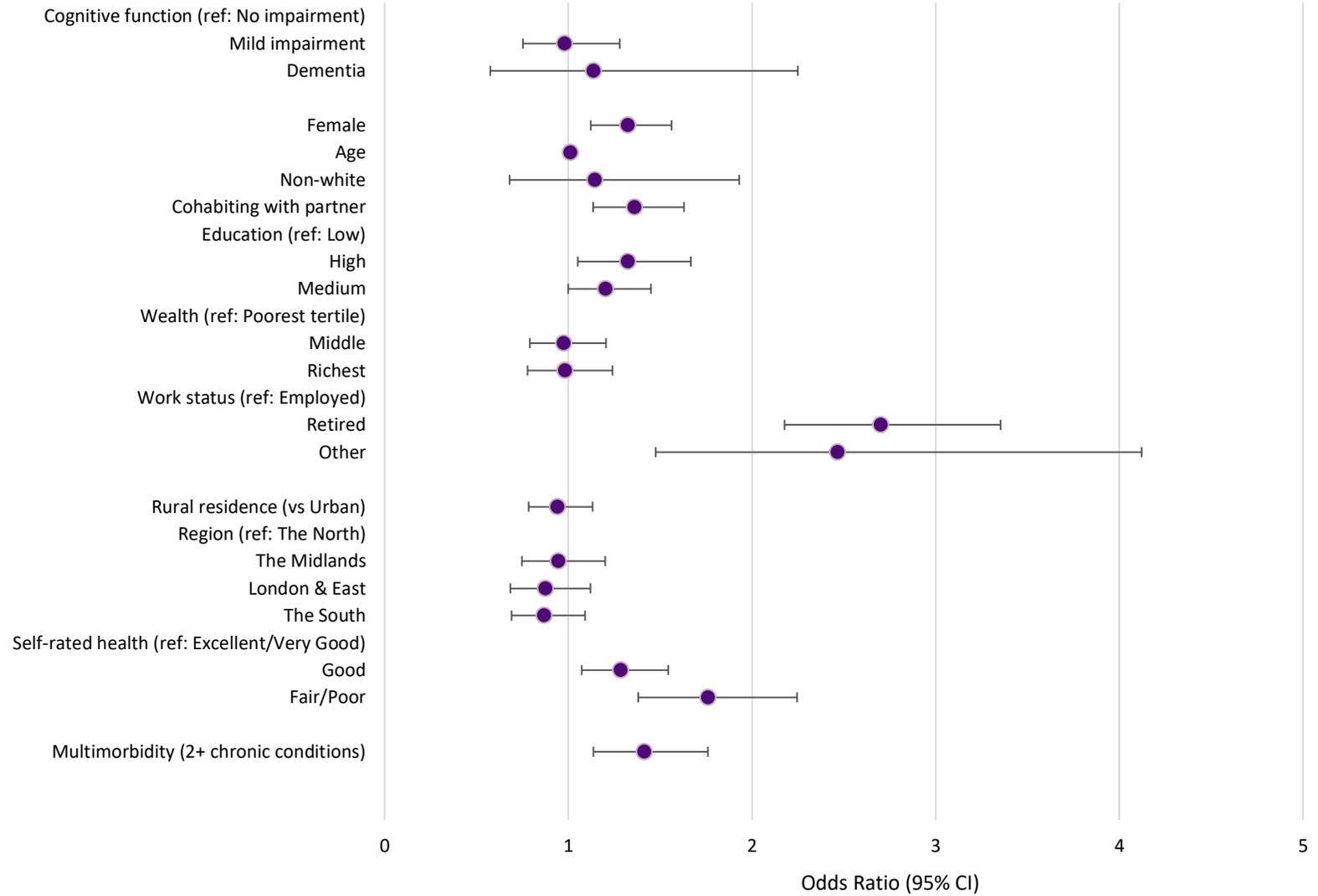
The following charts outline the results from our logistic regressions for whether people were shielding across each of the three time points in our data. They illustrate the Odds Ratios (ORs) as point estimates for each variable in the model along with the 95% Confidence Interval (CI); statistically significant associations are those that do **not** cross the OR value of 1.



### Outcome: Shielding in June/July 2020

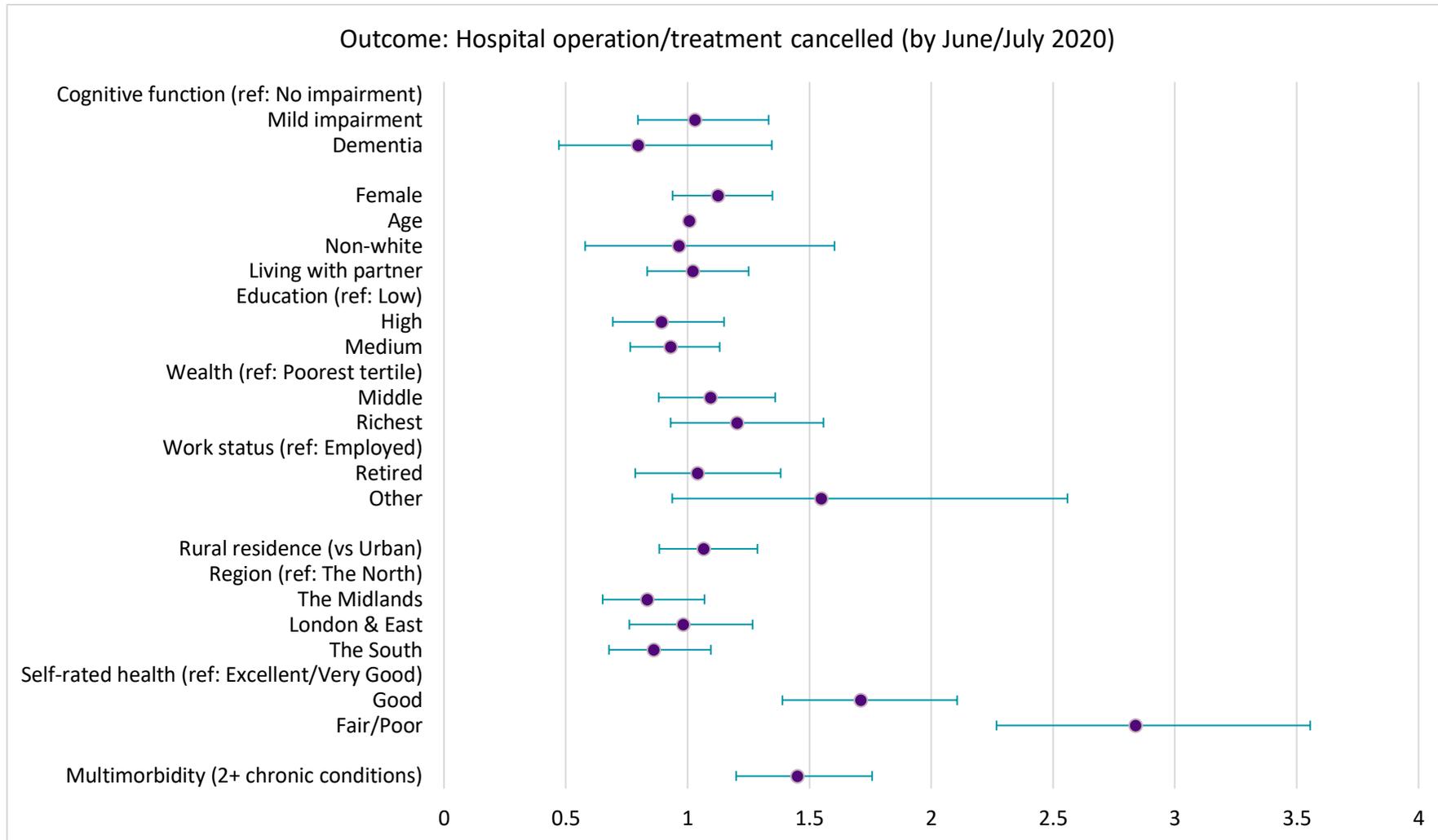


### Outcome: Shielding in Nov/Dec 2020

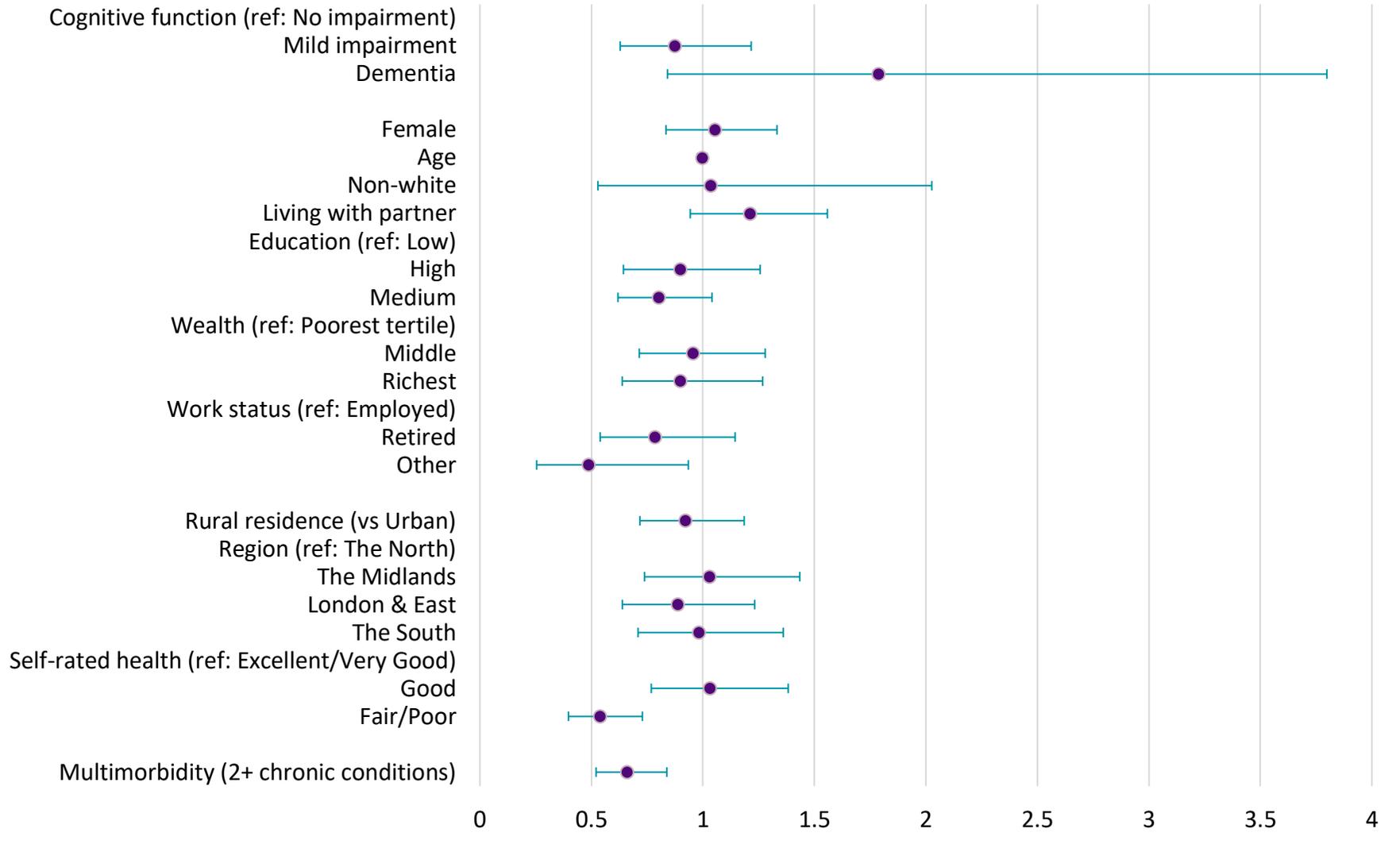


## Appendix 2: Logistic regression results for access to health services

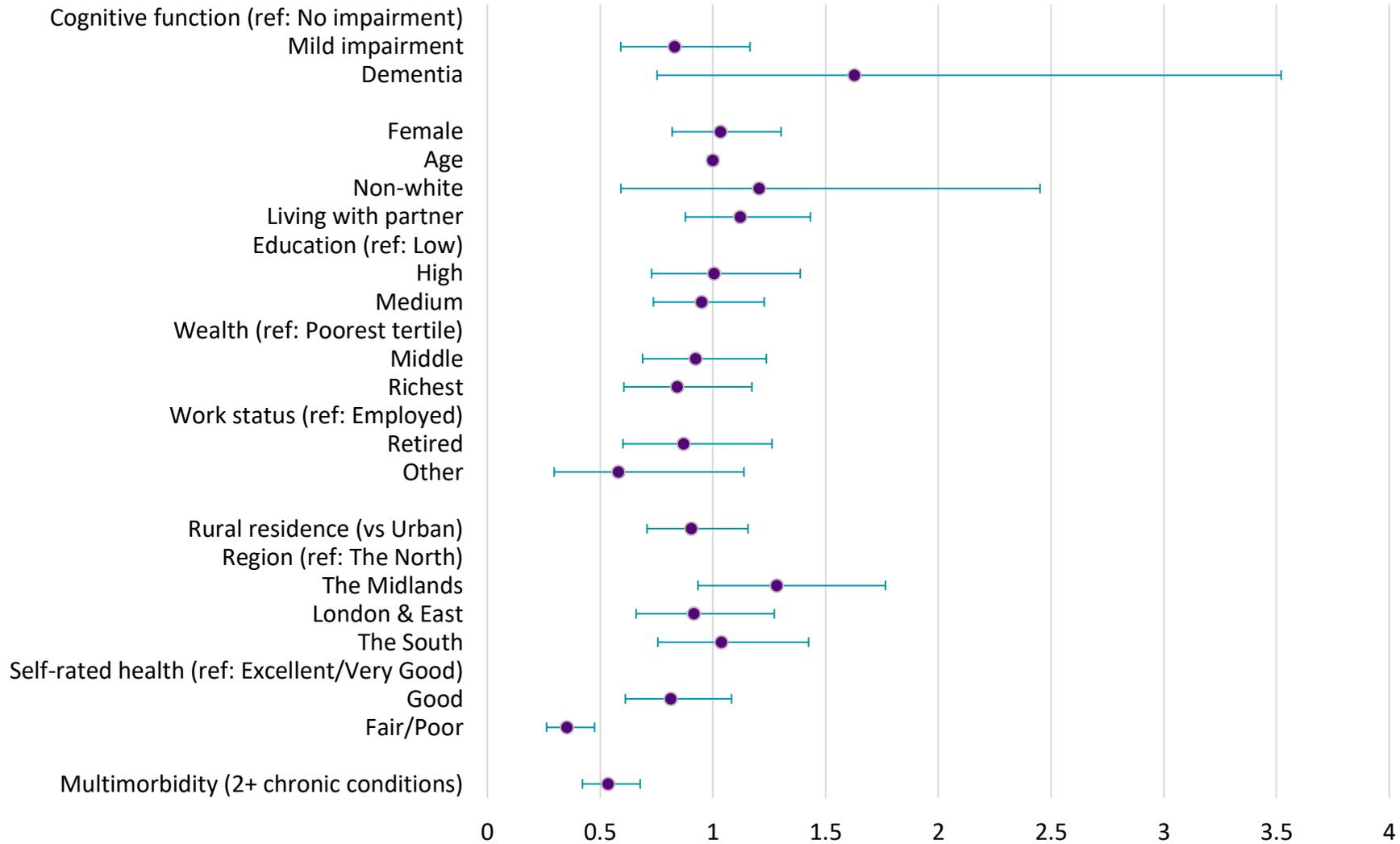
The following charts outline regression results across outcomes related to the access to various health services. Odds ratios (ORs) and Relative Risk Ratios (RRRs) are shown as point estimates with 95% Confidence Intervals. Statistically significant associations are those that do **not** cross the value of 1.



Outcome: Hospital operation/treatment booked and not cancelled (by Nov/Dec 2020)  
 compared to those cancelled



### Outcome: Hospital operation/treatment not booked (by Nov/Dec 2020) compared to those with cancellations



### Outcome: Hospital operation/treatment cancellation rescheduled but not yet carried out (by Nov/Dec 2020) compared to those not yet rescheduled

